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ABSTRACT

This collection of articles and bibliographies provides a comprehensive guide to autism. Section 1 presents general information on autism such as characteristics, myths and facts about autism, factors associated with autism, and diagnostic criteria for autism and Asperger's disorder. Section 2, on the family, addresses such aspects as the diagnosis of autism, parent-professional collaboration, respite services, and supplemental security income. Section 3 provides extensive information on educational programming including inclusion, long range goals, planning for successful transition, peer support programs, integrated therapy, and building independence. Section 4, on adults with autism, covers lifestyle planning, supported living, vocational rehabilitation, and employment. Section 5, on behavior, addresses consequences, self-management, discrete trial training, movement differences, negation, relaxation, desensitization, managing challenging behavior, designing a behavior plan, analyzing the purpose of behavior, and positive behavior programming. Among the many topics discussed on communication (Section 6) are analysis of communicative behavior, communicating with people with autism, the role of the school speech language pathologist, facilitated communication, integration training, and augmentative communication. Section 7 addresses social and leisure aspects, including the value of movement activities, use of local community resources, and increasing social interaction. Section 8 is about self-help and medical concerns including medication, social/sexual training, and toilet training. The final section describes services and resources available through the Indiana Resource Center for Autism. (Contains over 200 references.) (DB)

Autism Training Sourcebook

IRCA

Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
The University Affiliated Program of Indiana
Indiana University
2853 East Tenth Street
Bloomington, Indiana 47408-2601
Phone: (812) 855-6508
Fax: (812) 855-9630
TDD: (812) 855-9396
http://www.isdd.indiana.edu

Donated by:
Indiana Resource Center for Autism
Institute for the Study of
Developmental Disabilities
The University Affiliated Program of Indiana
Indiana University

The Autism Training Sourcebook is a collection of articles and bibliographies written by staff from the Indiana Resource Center for Autism (IRCA). Information is presented on a diverse range of topics, including characteristics of autism, diagnosis and assessment, family support issues, education, supported living, supported employment, positive behavior supports, communication, recreation, social interactions, and medical and social issues. The final section contains information about services available through the Indiana Resource Center for Autism, and a selected bibliography of books which addresses various aspects of autism. If you require more information about autism or about our services, please feel free to contact the IRCA at:

Cleta Bowman/Marci Wheeler
Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
Indiana University
The University Affiliated Program of Indiana
2853 East Tenth Street
Bloomington, Indiana 47408-2601
Phone: 812-855-6508
FAX: 812-855-9630
E-Mail: prattc@isdd.isdd.indiana.edu
Internet: http://www.isdd.indiana.edu/~irca

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General Information on Autism

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Characteristics of People with Autism

People with autism, like all people, are different from one another. Each has individual strengths and weaknesses. Each has individual preferences and dislikes. However, all exhibit common global characteristics that may vary in intensity, degree, and amount. These characteristics include difficulties in the areas of social interaction, communication, sensory processing, and learning new tasks and activities. The specific manifestation of these characteristics will differ across individuals. The following list of characteristics associated with autism is loosely based on the Diagnostic and Statistical Manual of Mental Disorders (4th Edition). The checklist is NOT a diagnostic tool. It does not include all potential characteristics. The characteristics listed are not exclusive to autism, and may be found in individuals with other disabilities. Rather, the checklist is to be used in gaining a better understanding of the individual identified with autism, designing a program, and facilitating discussion. As people mature and learn, other characteristics may emerge. Therefore, it may be helpful to revisit the checklist at various times to gather new information about a specific individual.

Common Learning Characteristics

Although no two people with autism are alike, many demonstrate common learning characteristics. Those involved in working with the individual with autism will need basic information about these characteristics and how they impact learning.

- Individuals with autism typically perform unevenly within and across skill areas. Some demonstrate exceptional skills in specific areas.
- Individuals with autism often demonstrate exceptional rote memory skills and have greater difficulty with activities that require comprehension.
- Many individuals with autism have difficulty with changes in routine or environment. Transitions across activities, settings, or people may be difficult.
- Some may tune in to irrelevant cues or unrelated aspects of the environment or instruction.
- Each learns best when information is presented according to individual learning style. Many are better able to process information presented visually. Others may benefit from modeling the behaviors of others or via physical prompts. Most learn best with hands-on activities and concrete examples. Those who are blind may be strong tactile and auditory learners.
- Unstructured time or extensive waiting appears to be difficult for many.

- Individuals with autism may have difficulty generalizing learned skills from one setting to another, or they may overgeneralize behaviors. They may have difficulty discerning inappropriate versus appropriate behaviors across settings and situations.

- Individuals with autism may exhibit delays in initiating motor responses or in processing information. Some may actually experience a movement disturbance in which they have difficulty initiating, executing, or stopping actions.

Briefly describe the learning characteristics of the individual.

Social Difficulties

Difficulty in demonstrating appropriate social interactions is a defining characteristic of individuals with autism. Again, although each individual with autism has difficulty in this area, challenges may differ.

- Some individuals with autism show little or no interest in establishing friendships.

- Others may want to establish relationships but lack an understanding of the conventions of social interaction and how to nurture friendships.

- Some may engage in giggling or laughing which appears to be inappropriate to specific situations.

- Individuals may show a limited awareness of the physical presence or needs of others.

- Individuals with autism may have difficulty establishing relationships because of their limited ability to reciprocate emotionally and socially. Others may want to share incessantly. In other words, the ability to give and take in a relationship may be impaired.

- These individuals may lack spontaneity in their interactions with others and may seldom share unsolicited information about enjoyable experiences , interests, or achievements with others.
- People with autism may have difficulty using and understanding multiple nonverbal behaviors to regulate social interaction and communication (e.g., facial expressions, body postures, gestures).
- Some may have difficulty understanding the motives behind people's actions, or reading the intentions of others.
- Certain individuals may have difficulty understanding misunderstandings, or anticipating what others might think of one's actions.
- Some may have difficulty understanding how to deceive or discerning deception from others.

Briefly describe the social difficulties of the individual.

Communication Impairments

The communication difficulties of individuals with autism range from lack of spoken language to extremely verbal. Regardless of the verbal skills of these individuals, it is important to realize that all experience some level of difficulty in both receptive and expressive communication.

Those who are nonverbal may demonstrate the following:

- Delay in or lack of spoken language.
- Low rate of initiating communication or inappropriate initiations with others through non-verbal means.

Those who are verbal may demonstrate the following:

- Delayed or immediate echolalia as a means of conversation with others, for self management, or for self-stimulation. For example, dialogue from television programs or videos may be used in a somewhat appropriate context as a means of conversation.
- Abnormal use of pitch, intonation, rhythm, or stress. For example, speech may be monotone, or declarative sentences may end with a rising tone to signal the asking of a question.
- Grammatical structure which may appear immature (i.e., sentences may be short, word endings may be missing, pronouns may be inappropriately used).
- Stereotyped or repetitive use of non-echolalic language routines that serve various functions such as initiating or sustaining a conversation. The routines often are a series of questions asked of the communication partner; often there is little real interest in the response.
- Use of idiosyncratic speech. The intended meaning may not be readily apparent to others.
- Difficulty understanding the flow of conversation. For example, may not understand when it is time to talk, and may inadvertently interrupt.

In terms of receptive language or comprehension, the individuals with autism may have:

- Lack of realization that they are being spoken to as a member of the group.
- Difficulty perceiving the meaning of speech. Certain individuals with autism may hear spoken words as just one of many sounds.
- Difficulty understanding directions or simple questions.
- Difficulty understanding sarcasm, innuendos, and jokes. This may be due to the fact that many are quite literal in interpreting information.
- Difficulty understanding and interpreting long and complicated sentences.

Briefly describe the receptive and expressive communication characteristics of the individual.

The manner in which individuals with autism engage in simple imitation games or routines may not be typical. Spontaneous solitary or parallel play may be repetitive and/or idiosyncratic. Creative role playing or interactive make-believe play may be limited.

If the individual is a youngster, briefly describe his/her manner of play.

Restrictive Repetitive and Stereotyped Patterns of Behavior, Interests, and Activities

Although people with autism may enjoy the same activities as typical same-age peers, the intensity and focus of their interest may differ. This may be due to the fact that some have a limited repertoire of alternative behaviors, or that they prefer and feel comfortable repeatedly performing certain tasks. Behaviors under this category include:

- A fascination with activities, topics, or objects that is abnormal either in intensity or focus. For example, the individual may have a persistent preoccupation with parts of objects or with inanimate objects.
- Stereotyped, repetitive, or unusual motor mannerisms (e.g., hand flapping, whole body rocking, or walking on toes).
- Behaviors which seems compulsive, including an unreasonable insistence on following routines or ritual. Some rituals may serve no apparent function, but may in reality calm the person with autism.

Under this category, sensory processing difficulties may best be described. Individuals with autism have difficulty differentiating among, focusing on, attending to, processing, and integrating sensory stimuli, and using input in meaningful and relevant ways.

- Individuals may be under or over sensitive to certain sounds, tastes, visual input, textures, and other sensory input.
- Individuals with autism can be so under sensitive to particular types of stimuli that they register no awareness of the stimuli even though the stimulus is potently present for others in the environment. These individuals may not be able to appropriately perceive potentially dangerous situations.
- Some tune out sensory input as a coping strategy when overwhelmed with stimuli so that they become effectively insensitive to surroundings.

Briefly describe the restricted patterns of behavior exhibited by the individual.

Now discuss the sensory processing difficulties exhibited by the individual.

Additional Considerations

For some individuals with autism, additional conditions further impact their ability to successfully learn and live in society. These conditions include:

- Current or previous seizure activity.
- The use of medication for seizure activity, anxiety, obsessive-compulsive disorders, behaviors, or other conditions.
- Eating problems such as pica, overeating, and eating only particular foods.
- Current or previous sleeping or toileting problems.
- Allergies to environmental factors or food products.

Briefly describe related conditions of the individual.

Perhaps, the greatest challenge of those involved with individuals with autism is the existence of problem behavior. Difficult behavior can range from simple non-compliance to extreme acts of aggression or self-injury.

Briefly describe the behavior(s) of the individual.

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The University Affiliated Program of Indiana

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My Autism

I was born with autism. Almost everybody who has it is born with it. But usually parents don't know that. They think their baby is perfect. I looked terrific - and I was cute. But Mom now tells me that I was a difficult baby. I cried a lot and didn't sleep very much or very well. My friend, Josh, has autism and his mom says that he was a real good baby who never cried. So I guess people with autism aren't alike as babies.

As I began to grow my Mom and Dad and grandparents began to wonder why I did some of the things I did. I loved to watch certain things. Usually it would be things that moved like cars, wheels, balls, rolling words on TV or lights that blinked. Sometimes I made things move by rocking my body back and forth or flicking my fingers. I played with toys in my own way and liked things that could be put together and taken apart. Sometimes I wanted to play with other children, but I didn't know what to do. Sometimes when I tried to play I did the wrong thing and people told me, "No," "Stop," or "Go away."

I needed to know exactly what was going to happen and often got upset when things changed. Sometimes I yelled and screamed a lot since I couldn't explain what was bothering me. I had trouble understanding what people were doing and what they were saying. I didn't like to be around lots of people and some noises hurt my ears.

Now that I am older I want to know more about autism. I want to know why I have it. Sometimes I'm teased by other kids and this makes me mad. Sometimes people try to make me do things that I don't want to do and that don't make any sense to me. Sometimes people say I'm not trying or that I'm lazy or dumb. They just don't know how hard some things are for me.

I get in trouble for being too loud, too excited, too talkative, and too bossy. And I get in trouble for staying by myself too much, for playing Nintendo too much, and for watching TV too much. I don't have many friends to do things with. Sometimes I'm not sure what to do with friends. What I like isn't always what they like, or they don't want to do things the way I know to do them. I need to know more about how to get along with others. What makes me this way?

My mom and dad explained what the psychologists and doctors said. Your parents, grandparents, or teachers can talk to you about your autism. The brains of people with autism grow differently. We learn differently than most people. We can learn, but we need help to make sense from the things we hear, see, touch, smell, and taste. No one knows exactly why we learn differently, or exactly what parts of the brain make this happen.

Everyone with autism has problems communicating with other people. We have trouble understanding verbal and body language. We have trouble letting other people know our wants and thoughts. Sometimes it takes us longer to figure out what's going on. It's often easier to figure out math problems and how the VCR or computer works, than why people do what they do. People change too much.

People often get upset with kids with autism because we have so much trouble understanding and often refuse to do what other people want us to do. We often just need more time, more information, or more help. We don't even know why people are mad at us. We sometimes get upset just worrying about all this and we have trouble telling other people how we feel or what we need.

People with autism can do lots of things but we need extra special help sometimes. We need people who understand. And we need people to try and see what the world is like for us. We are trying. We want to learn. We want to have fun. We want to do well. We try to figure it all out, but sometimes we get mixed up and anxious. Sometimes our nervousness gets out of control and we do things that we're sorry about later. We often have trouble staying calm and relaxed.

I will learn more about autism later. But now I have lots to do. I'll work hard to figure things out and do my best; but I make mistakes like everyone does. I hope people will give me a chance and try their best to understand me, help explain things to me, and be patient with me.

Let's all work and learn together. And let's have fun, too.

Suggested use for My Autism:

This dialogue is based on conversations with people with autism. It was written on request from parents for something to read to their child with autism to better explain the disability. However, it is intended for anyone who is trying to understand autism from the perspective of those who struggle daily with its effects and with the frequent lack of understanding of those around them.

It can be read and discussed by any group, particularly students of any age who are learning to be more aware of autism and of ways they can interact with and understand their peers with autism. To enhance the discussion, the following videotape is suggested: Autism: Being Friends, Indiana University: Institute for the Study of Developmental Disabilities, Indiana Resource Center for Autism. It is available on loan from the ISDD Center for Dissemination and Information Referral, (812) 855-9396, or for purchase ($10.00 from the Indiana Resource Center for Autism or the Center for Dissemination and Information Referral). The 8-minute videotape shows school-age children and young adults with their peers at school, home, and in the community; a narration describes each of them and suggests ways to be friends with them. Learning to Live, a picture book published at ISDD, is also suggested for younger children.

My Autism can also be useful for people with autism to read and discuss as they come to terms with their own autism. Perhaps they can write down their differing and common perspectives to aid their self-understanding.

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The University Affiliated Program of Indiana

Nancy Dalrymple, June 1993

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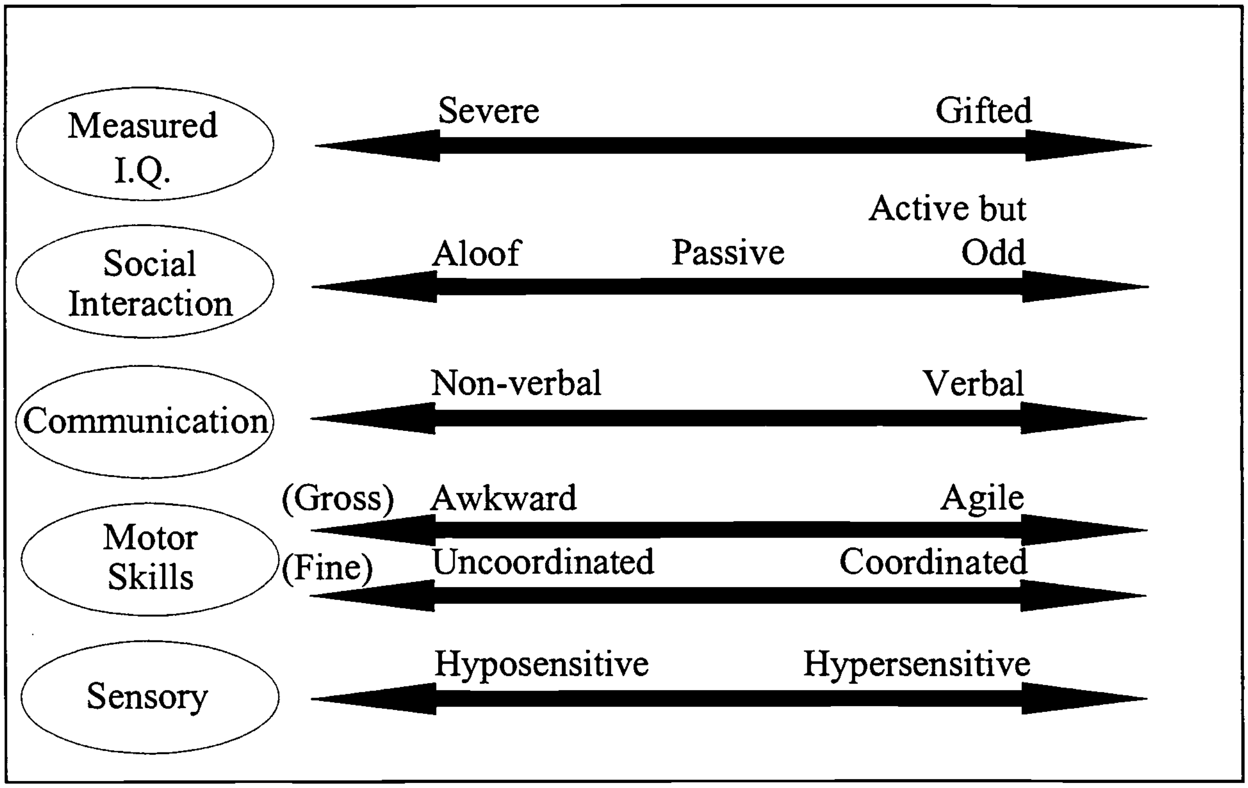
Autism Continuum

This chart, originally developed for the Instructional Modules on Autism (1993), is a visual representation designed to help people understand the variability of autism. While the core features of the disorder as presented in the Diagnostic and Statistical Manual, 4th edition, represent commonalities among individuals with autism, this chart illustrates that individuals vary from one another in the manifestation of the core characteristics.

Individuals with autism vary along a continuum. For example, an individual may be hyposensitive to some sensory stimuli and hypersensitive to other stimuli. Some individuals exhibit excellent fine motor manipulative skills and have difficulty with paper and pencil activities. These uneven patterns and variability across areas must be kept in mind as home, school, and community programs are developed for persons with autism.

Autism Defies Generalization!



Adapted from: Dalrymple, N., Porco, B., & Chung, J. (1993). *Instructional Modules on Autism*. Bloomington, IN: Indiana University, Institute for the Study of Developmental Disabilities.

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Myths and Facts About Autism

Myth: *Parents cause their son/daughter to have autism.*

Fact: This myth was cultivated by certain professionals who proposed that autism was caused by cold and aloof mothers, and little or no maternal bonding. In reality, there is no specific known cause for autism. It is now thought that multiple causes will eventually be identified. Current research suggests that the primary cause is some form of biological or neurophysiological dysfunction. Unfortunately, some families continue to feel responsible for their son/daughter's disability.

Myth: *All people with autism are alike.*

Fact: Current thinking depicts individuals with autism as demonstrating characteristics along a continuum. All individuals with autism do demonstrate difficulty in the areas of social awareness and interaction, communication, and sensory processing. All also exhibit a restrictive and repetitive repertoire of activities. However, specific characteristics are manifested quite differently in each individual.

Myth: *People can be cured of or outgrow autism.*

Fact: Autism is a lifelong disability. At present, there is no known cure. As an individual matures and learns coping strategies, the visible characteristics associated with autism may become less apparent. However, difficulties with communication, socialization, sensory processing, and related areas remain throughout a person's life.

Myth: *People with autism can turn their autism "on" and "off."*

Fact: Autism is a pervasive disability. This means that it affects all aspects of an individual's life. People do not have autism some times and not have it at other times. These remarks may be heard when professionals or family members feel they are being manipulated or controlled by the actions of someone with autism or when a person is doing something that does not seem typical of an individual with autism. Quite simply, individuals with autism always have autism. However, coping may be easier when the individual is not under stress or when dealing with conditions that are more easily understood or handled. Conversely, a young boy can have autism and exhibit behaviors that are typical of an eight year old youngster. This does not mean that he has stopped having autism. It means that he has learned or has the capacity to act like other eight year old boys who sometimes get in trouble and sometimes do very positive things.

Myth: *People with autism seldom make eye contact.*

Fact: People with autism may avoid eye contact or use it in atypical ways. They may stare for prolonged periods of time or avoid eye contact with people with whom they are having conversation. Some individuals use peripheral vision in ways that make it difficult to determine whether they are attending. Certain individuals with autism have difficulty responding to multiple sensory input. For example, an individual who is expected to make eye contact may not be able to listen to the speaker at the same time. Rather, allowing the individual to look away may result in their being better able to process verbal information.

Myth: *Students with autism must be in special "autism" programs, and participate in a curriculum designed for those with autism.*

Fact: Placement decisions must be determined on an individual basis. Placing all students with autism in a single class assumes that all students with autism have the same educational needs. Federal regulations show a clear preference for placing students with disabilities in their neighborhood school. If the student is not able to benefit from programming in their home school when the necessary supports and services are provided, then a more restrictive placement may be pursued. In addition, students with autism must have access to typical age-appropriate peers.

Likewise, adults with autism must be employed in a job, and live in a home which is individually determined. Not all individuals with autism have the same job and living preferences. Some individuals may prefer to live with others. Certain individuals may prefer to life alone. Placing all in a residential or work setting for individuals with autism may not be the most appropriate or match the individual's preferences or areas of strength. If individuals with autism are to participate, interact, and communicate in real world settings, they need to be in situations which present opportunities, and teach appropriate skills and behaviors.

A curriculum should be adopted which supports the achievement of individual goals. Utilizing a single curriculum to meet the needs of all students with autism is based on the assumption that all students with autism should have the same goals and hope to achieve the same educational outcomes. Clearly, each student is different and programming should be individually determined. There is no such thing as a "curriculum for people with autism" only.

Myth: *All that is needed for the child with autism to behave more normally is tender loving care, a firm "No!," and a good spanking now and then.*

Fact: Individuals with autism need to be taught behaviors that are appropriate to specific settings and situations. Telling a person not to do something and teaching negative rules provides no information about what the person is to do. Punishment results in confusion, low self-esteem, and escape/avoidance behaviors. Positive attitudes and strategies result in the greatest gains for individuals with autism.

Myth: *Individuals with autism are usually controlling and manipulative.*

Fact: Often times people with autism are accused of attempting to control or manipulate the behaviors of others or certain situations. It is important to realize that people with autism have difficulty reading social and contextual cues, and interpreting sensory information. As a result, certain situations which are not easily understood by the individual may create anxiety. These individuals may make every effort to maintain sameness as a way of coping with the demands of every day society. In addition, the manner in which we do things may not make sense for them. Try to evaluate and approach situations from the individual's perspective.

Myth: *People with autism prefer to be alone and without friends.*

Fact: Like all of us, people with autism have individual preferences about how they want to spend free time. Some prefer to be alone. Others want companionship, but may lack the skills to be able to easily interact with others. For some individuals with autism, the inability to form relationships can be a source of frustration and even lead to depression.

Myth: *Autism is such a severe and hopeless disability that little can be done with these individuals.*

Fact: Autism is a complex disorder, but all individuals with autism can learn skills that enable them to live, work, and recreate in the community. Early intervention, sound educational programming, and accurate information to all involved in the individual's life are critical in ensuring a successful future for these individuals. Networks of available family members and interested others need to be identified early and involved over the lifetime of the person with autism. Services need to be accessed to fill gaps and provide additional support. With appropriate education, acknowledgment of individual preferences, identified supports, and access to community opportunities, people with autism can live satisfying and productive lives.

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Factors Associated with Autism

There are no specific known causes for autism. Current research points to the primary cause as some form of biological or neurophysiological dysfunction. However, as research efforts continue, it appears that multiple factors may be associated with autism. The existence of multiple factors clarifies why autism is a spectrum disorder and potentially explains why individuals with autism exhibit behavior characteristics along a continuum.

Autism may be found in conjunction with other neurological conditions, including seizure disorders, attention deficit hyperactivity disorder, or mental illness. Individuals may exhibit extreme anxiety, depression, obsessive-compulsive disorders, multiple personalities, or other conditions. Occasionally, autism is found in conjunction with cerebral palsy, or Down Syndrome.

Approximately 75-80% of individuals with autism exhibit cognitive limitations (e.g., mental retardation). However, it is important to note that mental retardation is not part of the diagnostic criteria for autism. As professionals learn more about individuals with autism and are better able to tap their true intelligence, the percentage of individuals with normal or above normal intelligence may shift.

There seems to be a strong genetic component to the disorder. In some families, there appears to be a pattern of autism and/or associated problems of learning or language. In others, family members are extremely gifted or may have certain sensory difficulties. Autism has been linked to genetic factors such as Fragile X syndrome, tuberous sclerosis, and neurofibromatosis.

Other causal factors include viral infections during pregnancy (e.g., intrauterine rubella, cytomegalovirus), metabolic disorders (e.g., phenylketonuria, hyperlactocemia, purine enzyme errors), and birth complications (e.g., less then optimal pre and perinatal periods). Potential prenatal factors include alcohol or drug exposure during pregnancy and unusual occupational chemical exposure by either parent. Excessive alcohol exposure can lead to Fetal Alcohol Syndrome. A larger percentage of these individuals than expected have autism.

Postnatal factors which can cause individuals to demonstrate the behavioral characteristics of autism include strokes and viral infections (e.g., encephalitis). There is a growing group of individuals who are proposing that in certain cases, autism may be allergy induced.

Currently researchers are examining various structural abnormalities or biochemical disorders in the brain which may be associated with autism. Biochemical disorders have focused on levels of neurotransmitters, such as serotonin or oxytocin levels which may be either increased or decreased. Magnetic Resonance Imaging (MRI) studies show that the cerebellum may be either larger or smaller in some individuals. Autopsy studies show a loss of Purkinje cells ranging from 10% to 70%. There also appear to be changes in the limbic system, including the hippocampus and amygdala. These various structures and chemicals in the brain are responsible for behaviors such as compulsivity, attention shifting, memory, motor planning and execution, interpretation and modulation of emotions, and social phobia.

As the scientific community continues to unravel the mysteries surrounding autism, those who work, live, and recreate with these individuals can hope to gain new insights regarding the causes and nuances associated with this disability. In the end, a better understanding of autism can only lead to better programming and a brighter future.

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Disability Information for Someone Who Has Autism

You and over 25,000 other individuals in the United States have a developmental disability which is called "autism." Having this disability means that you are still like everyone else in most ways.

- You eat and sleep.
- You brush your teeth.
- You wear favorite clothes.
- You go places such as the grocery store.
- You visit your doctor for a check up.
- You enjoy special activities like listening to music or working on the computer.
- You learn to do new things.

Having the disability of autism, however, also means that your body and your brain sometimes work differently from that of other people. As a result, you may do or experience things differently from people who do not have autism.

- You may hear sounds that are louder or bothersome only to you.
- You may like to spend long periods of time watching unusual things such as the spinning of a fan or movements made with your fingers.
- You may rock your body to help yourself relax when you feel nervous.
- You may get quite upset when people talk too fast and you do not understand their message. (*You may forget that you could ask people to talk more slowly*.)
- You may like to make lists of unusual things that are of major importance to you. (*Over and over again you may make up or write these same lists*.)
- You may have a hard time making friends. (*Keeping or being a best friend for several years is even harder*.)

- You may have difficulty figuring out how other people feel and why they act a certain way. (*Others seem to interpret events and your behavior differently than you do.*)
- You may like to talk about topics that other people do not seem to find interesting. (*These topics might include things such as mileage between cities, or air conditioners.*)
- You may feel more comfortable when things always stay the same. (*Of course, things don't stay the same.*)

Colds and measles are diseases. Autism is different. Autism is a developmental disability and its effects will always be with you. People with autism live a normal life span. Hopefully, you will live to be 70 years old or more.

How did you become autistic?

No one knows exactly why your brain developed slightly differently. The differences probably occurred while your mom was still pregnant with you, that is, before you were born. She did not do anything wrong; neither did anyone else. The differences just happened. The differences in your brain influence the way you do and understand some things. People identify a certain set of behaviors as autism.

How can you help yourself?

You can be successful at home, school, or work. You may need to use schedules, rule books, communication boards, relaxation and exercise programs, or medication to help you cope or learn better. Many people care about you. They will be glad to help you become a happy person who just happens to have a developmental disability called autism.

Disability Information for Someone Who Has Autism was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

The University Affiliated Program of Indiana Beverly Vicker, 1994

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Comparison of Current Definitions of Autism

	World Health Organization ICD-10 (1987)	Autism Society of America (1987)	DSM-IV (1994)
Name of Disorder	Childhood Autism	Autism	Autistic Disorder (Pervasive Developmental Disorder)
Prevalence		15/10,000	10 to 15/10,000
Onset	Prior to age three.	Prior to age three.	Prior to age three.
Social	Qualitative impairments in social interaction.	Abnormal ways of relating to people, objects, and events.	Qualitative impairments in reciprocal social interaction.
Communication	Qualitative impairments in communication.	Speech and language is absent or delayed, while specific thinking capabilities may be present.	Qualitative impairments in communication.
Other	Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities.	Disturbances in the rate of appearance of physical, social, and language skills. Abnormal responses to sensations.	Restricted and stereotyped patterns of behavior, interests, and activities.
Related Disorders			Rett's Disorder Development of multiple specific deficits, e.g., deceleration of headgrowth (5-48 months), following a period of normal functioning after birth. Has been diagnosed only in females. Childhood Disintegrative Disorder Marked regression in multiple areas of functioning following at least 2 years of apparently normal development. Also termed Heller's Syndrome. Asperger's Disorder Severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests, and activities. No clinically significant delay in language or cognitive development. Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism) Impairments in the triad of Autistic Disorder but criteria are not met for a specific Pervasive Developmental Disorder.

References:

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Barbara Bailey Porco, 12/94

Historical Perspective: Definitions of the Autistic Disorder

	Kanner (1943)	**Rutter (1978)**	**NSAC (1978)**	**Wing & Gould (1979)**	**DSM III (1980)**	**DSM III-R (1987)**
Name	Extreme autistic aloneness	Autism	Autism	Early Childhood Autism	Infantile Autism (Pervasive Developmental Disorder)	Autistic Disorder (Pervasive Developmental Disorder)
Prevalence			5/10,000	21/10,000	2 to 4/10,000	4 to 5/10,000
Onset		Before 30 months	Before 30 months	Before 30 months	Before 30 months	During infancy or early childhood
Social	● Avoidance of eye contact. ● Lack of visual or auditory responses to others.	Impaired social development.	Disturbance of capacity to relate appropriately to people, events, and objects.	Abnormalities in social interaction.	Pervasive lack of responsiveness to other people.	Qualitative impairment in reciprocal social interaction.
Communication	● Non-initiation of sounds or gestures. ● Failure to use speech for purposes of communication.	Delayed and deviant language development.	Disturbance of speech, language, and cognitive capacities.	Abnormalities in verbal and nonverbal communication.	Gross deficit in language development.	Qualitative impairment in verbal and nonverbal communication and in imaginative activity.
Other	● Obsessive desires to maintain sameness. ● Abnormal mannerisms and movements. ● Cognitive potential masked by disorder; evidence of normal to superior intelligence.	Insistence on sameness.	● Disturbance of response to sensory stimuli. ● Disturbance of developmental rates and sequences.	Abnormalities in development of imaginative (symbolic play) activity.	Bizarre responses to various aspects of the environment.	Markedly restricted repertoire of activities and interests.

	Kanner (1943)	Rutter (1978)	NSAC (1978)	Wing & Gould (1979)	DSM III (1980)	DSM III-R (1987)
Related Disorders					Infantile Autism Residual State ● Once met all of above criteria. ● Currently shows signs such as oddities of communication and social awkwardness. Childhood onset pervasive developmental disorder: Similar to full syndrome but onset after 30 months and before 12 years.	Pervasive Developmental Disorder Not Otherwise Specified. (NOS)

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Pervasive Developmental Disorders

Autism is one of five developmental disorders classified as Pervasive Developmental Disorders (PDD). All of the disorders are referred to as syndromes. This means that diagnosis is based on a defined group of behaviors which combine to result in a disrupted pattern of development. The term "pervasive" was chosen for this group of disorders because people demonstrate difficulties in multiple, as opposed to specific, areas of development. Difficulties in one area of development (e.g., social) impact other areas of development (e.g., communication). The result is an extremely complex group of features and characteristics. The following grid contains the diagnostic criteria determined by the American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition (DSM IV) to differentiate the five Pervasive Developmental Disorders (PDD).

❦ DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER ❦

A. **A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):**
  - *(1) qualitative impairment in social interaction, as manifested by at least two of the following:*
    - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
    - b. failure to develop peer relationships appropriate to developmental level
    - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
    - d. lack of social or emotional reciprocity
  - *(2) qualitative impairments in communication as manifested by at least one of the following:*
    - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
    - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
    - c. stereotyped and repetitive use of language or idiosyncratic language
    - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
  - *(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:*
    - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
    - c. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    - d. persistent preoccupation with parts of objects

B. **Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communicate, or (3) symbolic or imaginative play.**

C. **The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.**

DIAGNOSTIC CRITERIA FOR ASPERGER'S DISORDER

(Generally noticed after age 3, often at 5, 6, or 7)

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
  (1) *marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction*
  (2) *failure to develop peer relationships appropriate to developmental level*
  (3) a *lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, brining, or pointing out objects of interest to other people)*
  (4) ***lack of social or emotional reciprocity***

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  (1) ***encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus***
  (2) ***apparently inflexible adherence to specific, nonfunctional routines or rituals***
  (3) ***stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)***
  (4) ***persistent preoccupation with parts of objects***

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiousity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

DIAGNOSTIC CRITERIA FOR CHILDHOOD DISINTEGRATIVE DISORDER

(Only 100 cases reported at time DSM IV criteria approved)

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
  (1) *expressive or receptive language*
  (2) *social skills or adaptive behavior*
  (3) *bowel or bladder control*
  (4) *play*
  (5) *motor skills*

C. Abnormalities of functioning in at least two of the following areas:
  (1) *qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)*
  (2) *qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)*
  (3) *restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes*

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

DIAGNOSTIC CRITERIA FOR RETT'S DISORDER

(Thus far, has been diagnosed only in girls)

A. All of the following:
  (1) *apparently normal prenatal and perinatal development*
  (2) *apparently normal psychomotor development through the first 5 months after birth*
  (3) *normal head circumference at birth*

B. Onset of all of the following after the period of normal development:
  (1) *deceleration of head growth between ages 5 and 48 months*
  (2) *loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)*
  (3) *loss of social engagement early in the course (although often social interaction develops later)*
  (4) *appearance of poorly coordinated gait or trunk movements*
  (5) *severely impaired expressive and receptive language development with severe psychomotor retardation*

PERVASIVE DEVELOPMENTAL DISORDER
Not Otherwise Specified (including atypical autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism"--presentations that do not meet the criteria for Autistic Disorder because of age at onset, atypical symtomatology, or subthreshold symptomatology, or all of these.

Source: American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
Luke Tsai (see source--1994 ASA conference presentation on DSM IV DX).

Diagnostic Criteria for Autistic Disorder

The following criterion are from the 1994 Revision of the Diagnostic and Statistical Manual, Fourth Edition (DSM IV). See the DSM IV manual for details and examples.

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) **Qualitative impairment in social interaction, as manifested by at least two of the following:**

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) **Qualitative impairments in communication as manifested by at least one of the following:**

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

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(3) **Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:**
   (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
   (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

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Diagnostic Criteria For Asperger's Disorder

The following criterion are from the 1994 Revision of the Diagnostic and Statistical Manual, Fourth Edition (DSM IV). See the DSM IV manual for details and examples. Note: Asperger's Disorder is one of five specific Pervasive Developmental Disorders listed in the DSM IV under the general heading of Pervasive Developmental Disorders.

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

- **(1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction**
- **(2) failure to develop peer relationships appropriate to developmental level**
- **(3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)**
- **(4) lack of social or emotional reciprocity**

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- **(1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus**
- **(2) apparently inflexible adherence to specific, nonfunctional routines or rituals**
- **(3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)**
- **(4) persistent preoccupation with parts of objects**

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Diagnostic Criteria for Asperger's Disorder was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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TITLE 511 INDIANA STATE BOARD OF EDUCATION
ARTICLE 7, RULES 3-16
SPECIAL EDUCATION RULES
EFFECTIVE DATE: MAY 26, 1995

RULE 11. ELIGIBILITY CRITERIA

511 IAC 7-11-1 Autism

Sec. 1. (a) Autism:

- (1) is a lifelong developmental disability;
- (2) is characterized by impairments in:
  - (A) communication,
  - (B) learning, and
  - (C) reciprocal social interaction; and
- (3) typically becomes evident in infancy or early childhood.

(b) Eligibility for special education shall be determined by the case conference committee based on, but not limited to, the following information:

- (1) An individual standardized multifactored test of learning capability that includes a nonverbal psychological measurement.
- (2) An assessment of academic strengths and weaknesses and present levels of academic functioning.
- (3) An adaptive behavior evaluation.
- (4) A communication evaluation by a licensed speech-language pathologist assessing receptive, expressive, and social communication skills.
- (5) A social history which includes family and cultural background information relevant to the suspected disability and the nature and extent of the student's learning difficulties.
- (6) A developmental history which includes communication, social interaction, play, sensory development, and physical milestones to determine onset during infancy or early childhood.
- (7) An evaluation of fine and gross motor skills.
- (8) A completed checklist of characteristics exhibited by students with autism as described in subsection (d).

(c) At least eight (8) of the sixteen (16) characteristics listed in subsection (d) must be exhibited by a student in order to be eligible for special education. The criterion is met only if the characteristic is abnormal for the student's developmental level. The term does not apply if a student's educational performance is adversely affected primarily because the student has an emotional handicap as defined in this rule.

(d) The following list of characteristics are referred to in subsection (c):

- (1) Qualitative impairment in reciprocal social interaction as manifested by at least two (2) of the following:
  - (A) Marked lack of awareness of the existence of feelings of others.
  - (B) Abnormal or no seeking of comfort at times of distress.
  - (C) Impaired or no imitation.
  - (D) Abnormal or no social play.
  - (E) Gross impairment in ability to make peer friendships.
- (2) Qualitative impairment in verbal and nonverbal communication and imaginative activity as manifested by at least one (1) of the following:
  - (A) No mode of communication.
  - (B) Markedly abnormal nonverbal communication.
  - (C) Absence of imaginative activity.
  - (D) Marked abnormalities in the production of speech.
  - (E) Marked abnormalities in form of content of speech including the following:
    - (I) Stereotyped and repetitive speech.
    - (ii) Pronominal reversal.
    - (iii) Idiosyncratic use of words or phrases.
    - (iv) Frequent irrelevant remarks.

- (3) Markedly restricted repertoire of activities and interests as manifested by at least one (1) of the following:
  - (A) Stereotyped body movements.
  - (B) Persistent occupation with an object or parts of objects.
  - (C) Persistent attachment to unusual objects.
  - (D) Marked distress over trivial changes.
  - (E) Unreasonable insistence on following routines.
  - (F) Marked restricted range of interests.

(e) Teachers and related services personnel serving students with autism shall receive specialized inservice training in this area.

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The Use of Developmental History Information in the Diagnosis of Autism

The proper diagnosis of autism requires that information be gathered from a variety of sources using formal and informal methods. One important source of diagnostic information is the parents' report of a child's developmental history. While information on a child's developmental milestones, such as the age of sitting, walking, and talking, are useful for determining if a general developmental delay is present, the diagnosis of autism relies on the observation of deviance from normal development. Several studies (see references below) have indicated that persons with autism have unique patterns of development that differentiate them from normally developing peers and from peers with mental retardation. The purpose of this paper is to report the developmental patterns often seen in autism and to provide suggestions on how to gather information useful for determining developmental deviance.

The types of developmental patterns reported by parents and summarized in this paper are derived from three separate studies. References for these studies are included. The three studies had both similarities and unique findings. Findings that are common to all three studies are included. Please refer to the individual studies if more detailed information about methods and procedures are desired.

Developmental history information should be considered in the context of current signs and symptoms of autism present in the individual. Information about an individual's current status should include behavioral observations, formal assessment across skill areas, informal assessment of learning and communication skills, and an analysis of opportunities for performance of functional skills. A multidisciplinary team including the parent and teacher is vital for compiling the information to determine if the individual meets the criteria for autism.

A semi-structured interview format is recommended for gathering information about early development. This format includes open-ended questions which are useful for encouraging parent discussion. When necessary, prompts can help in directing the parent to specific information. An open-ended interview is intended to build rapport with the parent and to determine the information that the parent believes to be important while information of interest to the interviewer is being gathered. Information on conducting an interview and the merits of open-ended questions are available from a variety of sources.

The interviewer's particular style of interaction and the parents' needs should determine how questions are asked. A list of suggested questions to use in gathering developmental history information is included in this paper. There are likely to be other important questions that emerge during the interview. Also, all of these questions may not be necessary to ask due to previous knowledge and information. The type of information that the questions are intended to elicit is noted in the section following the questions. These questions are organized around the areas of play, communication, social skills, and sensory behavior although there is some obvious overlap between areas. The intent of the questions is to gather information about the child's development across his or her lifespan so that patterns of development can be seen. Therefore the questions contain both past and present tenses which the interviewer should adapt as needed to fit the age of the child being evaluated.

Suggested Developmental History Questions

Play

1) Describe your child's play as a baby. What was it like to play peek-a-boo or patty cake with your child?

2) What things did your child like to play with and how did he/she play with them? What is play like now?

3) What are your child's interests? How does he/she spend leisure time? How have interests changed as your child has grown older?

4) What is/was your child like when playing with other children or with adults? How does your child do in group games?

Social

5) How did your child respond to you and other family members as an infant? How did that change as he/she grew older? What did your child like to do with each family member?

6) How did your child respond to strangers as an infant? How did your child respond to strangers as a young child? How does your child respond to people he/she sees occasionally? How does your child respond to persons he/she sees frequently?

7) Who were your child's friends growing up? What kind of things did they do together? Who are your child's friends now?

8) How has your child reacted to changes in normal routines, people, and in things around him/her?

Communication

9) What sounds did your child make as an infant?

10) What were your child's first words? How old was he/she? How did speech develop after that?

11) Were you ever concerned that your child might be deaf? What sounds did your child enjoy listening to?

12) What gestures did your child use to help say he/she wanted something? What kind of facial expressions were used?

13) How did/does your child get the attention of other children and adults?

14) Does it seem easy for your child to talk with other children and adults? Is it easy for others to talk with your child?

15) Does your child imitate things he/she hears? Does he/she imitate movements and gestures of others?

<u>Sensory</u>

16) As an infant and up until now, what things has your child been really interested in? What did he/she do with these objects or interests?

17) How did/does your child react when he/she was hurt?

18) How did/does he/she react to lights and sounds?

19) What things did your child like to look at? Was he/she interested in his/her own body parts?

20) How did/does your child react to different textures and temperatures?

21) What were your child's eating habits as an infant? What are they now?

22) How does your child explore new things?

<u>General</u>

23) What do you think is the most important thing for me to know about your child?

24) Was it difficult recalling how your child was as an infant and young child?

Developmental Patterns Often Reported in Autism

(Refer to Numbered Questions Above)

Play

1) Parents of children with autism often report that as an infant the child did not enjoy baby games such as peek-a-boo or patty cake. Their child did not show typical delight in or would resist this type of interaction.

2) Children with autism are frequently reported to have unusual play objects or extreme attachments to typical children's toys. Frequently a favorite object is chosen due to the child's interest in the visual, auditory, or tactile features of the object rather than for the toy's usefulness as a part of imaginary play. Play and leisure time may also involve unusual interests for a child's age, such as obsessions with commercials, brand names, musical jingles, calendars, or mechanical objects. As the child grows older, although play may not revolve around sensory features of toys and objects, play and leisure interests will likely remain restricted.

3) All children have areas of interest that occupy much of their time. Children with autism seem to be different in that they have a very narrow range of interests. The restricted range of interests may be more indicative of autism than an intense interest in a certain object or activity. Parents of children with autism often report that the child's interests changed with age but the restrictedness in leisure activities seemed to remain. Children with autism appear to be less likely to seek out parent help in structuring leisure time, possibly because they are content to play alone or they do not ask for help in structuring leisure time.

4) Parents often report that, as an infant and young child, the person with autism preferred to play alone. When interacting with others, adults or younger peers may be preferred to same-age children. Parents often report that when their child does play with others the peers are used as "mechanical aids" for the child's own interests and chosen activities. Parents frequently report that children with autism do poorly in group games. They may be able to kick and catch a ball, for example, but do not do well in a formal game of kickball.

Social

5) Parents often report that their child with autism did not show the normal development of a social smile. As an infant the child may not have shown an awareness of others, as indicated, for example, by not stretching out his or her arms in anticipation of being picked up or by not being responsive to a parent's coming and going from a room the child

is in. As the child with autism grows older, interactions increase but are still more restricted than same-age peers.

6) Frequently, children with autism show little fear or shyness toward strangers. Their interactions may be similar toward those they see every day and those they meet for the first time. They may avoid contact with others or, conversely, they may be overly friendly.

7) A lack of same-age peer interaction is frequently reported in children with autism. The child may not seem interested in others. He or she may interact more appropriately with others in structured play settings.

8) Parents often report that the child is distressed by seemingly minor changes in the child's physical setting and in normal routines.

Communication

9) Children with autism are often reported to be unusually quiet as an infant and to not babble and coo like other infants.

10) Parents frequently report unusual first words in children with autism or that speech developed normally until about 18 months when a loss of verbal skills occurred. Children with autism may exhibit echolalia or may use idiosyncratic language that only the parents understand.

11) Children with autism are often suspected of having hearing problems. Parents sometimes report that certain sounds attracted their attention while they appeared to not hear or to not attend to someone talking to them.

12) Children with autism often have trouble using nonverbal gestures and facial expressions to communicate. They may not point to things they want, as other young children do, when they want something that they are unable to vocally request. Facial expressions may not be appropriate for the messages the child is trying to convey.

13) The child with autism may have difficulty requesting help or initiating an interaction with another child or adult.

14) Communication problems are often apparent in the child's difficulty or lack of interest in communicating with others.

15) Children with autism may have echolalia. They either immediately or later repeat words or phrases that they hear. They often have difficulty, however, imitating nonverbal

communicative gestures and expressions or in imitating others in play activities as normally developing children usually do.

Sensory

16) Parents often report that their child was interested in objects that provide repetitive visual, auditory, or tactile stimulation. While all children are interested in this type of stimulation, children with autism persist in their attention to these objects beyond what normally developing children do, or may become upset if attempts are made to shift their attention to other objects. The type of play with these objects is often repetitive and persistent, while other children often play with these same toys in unique and different ways across time.

17) Parents frequently report that children with autism were either overly sensitive or seemingly insensitive to pain. They may react to pain in unusual ways, such as becoming aggressive rather than seeking comfort.

18) Children with autism may show extreme reactions to lights or sounds. Often certain types of sounds provoke a reaction. Conversely, a sound that upsets most children, such as a loud car engine, may not upset the individual with autism.

19) Again, children with autism may show an unusual interest in certain visual, auditory, or tactile features of objects that is extreme compared to other children their age. They may be particularly fascinated with, stare at, and twist their hands. Often the visual inspection of their hands or other objects is described as "bizarre."

20) The child may either be extremely interested in certain textures or show a great deal of aversion to certain textures or forms of physical contact. Sometimes parents report that the child did not seem to react to cold temperatures.

21) Children with autism may be picky eaters compared to other children their age. The child may have insisted on certain feeding routines, may have resisted new foods, been difficult to teach to feed him or herself, or may have an extreme dislike for certain food textures.

22) Parents often report that children with autism have extreme reactions to change and may be upset by new things. They may be upset by changes in a normal car route to the store or by a change in furniture in the house. They may be upset by changes in the usual daily schedules. They seldom explore a new environment in the usual cautious way of other young children.

General

23) It is useful to conclude with an opportunity for parents to put into perspective all the information they have provided. Parents may relate areas of great concern or may relate information that will be important in working with the family.

24) The ease or difficulty that the parent has in relating this information indicates the familiarity of the parent with typical developmental patterns. Also, the parent of a child with autism often has less difficulty relating instances of abnormal development than do parents of normally-developing peers.

References

Couteur, A. L., Rutter, M., Lord, C., Rios, P., Robersone, S., Holdgrafer, M., & McLennan, J. (1989). Autism Diagnostic Interview: A standardized investigator-based instrument. Journal of Autism and Developmental Disorder, 19, 363-388.

Dahlgren, S. O., & Gillberg, C. (1989). Symptoms in the first two years of life: A preliminary population study of infantile autism. European Archives of Psychiatry and Neurological Sciences, 238, 169-174.

Levy, S., Sears, L., & Kerns, M. (submitted). Developmental histories of children with autism: Diagnostic Implications. Indiana Resource Center for Autism, Bloomington, IN: Institute for the Study of Developmental Disabilities.

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Lonnie Sears, 8/91 Updated 12/93

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INDIANA RESOURCE CENTER FOR AUTISM

Information Regarding:
DIAGNOSIS AND ASSESSMENT OF AUTISM

If you are seeking a diagnosis or assessment for an infant or toddler who is at risk for or who has a developmental disability, an individual who is post-school age, or an individual seeking residential placement, contact:

Diagnostic and Evaluation Services
Indiana Family and Social Services Administration
Bureau of Developmental Disabilities
402 West Washington Street, Room W-453
Indiana Government Center South
Indianapolis, IN 46207-7083
(317) 232-7933

If you are seeking a diagnosis or assessment for an individual of school age, including ages birth-5, contact the local school system for information. Those persons of school age who are being considered for residential placement may be assessed by the Diagnostic and Evaluation (D & E) Teams.

If a family or agency wants a private or second evaluation, the following agencies and individuals have experience diagnosing and assessing autism. The Indiana Resource Center for Autism does not recommend a specific organization or person. Additional names and agencies will be added to the list as we become aware of them. Cost of private evaluations should be discussed at the time of the initial contact.

The Indiana Resource Center for Autism recommends a multidisciplinary assessment that includes a psychologist, educators, and family members. Since communication is always impaired in individuals with autism, it is important to include a communication assessment from a speech language pathologist. Other team members including a social worker, occupational therapist, recreation therapist, and health professional also might be involved.

Staff of the Indiana Resource Center for Autism at the Institute for the Study of Developmental Disabilities are available for consultation to assist in establishing programs for individuals with autism. For more information about available services, contact the Indiana Resource Center for Autism at (812) 855-6508.

RESOURCES for the DIAGNOSIS/ASSESSMENT of PERSONS with AUTISM

Indiana

Judith Campbell, M.D.
1525 North Ritter
Indianapolis, IN 46219
(317) 322-4087 ext 258
(Phone consultations -- children and adolescents)

Lezlie Blackford, Ph.D.
Patricia Gentile, M.D.
8101 Clearvista Pkwy. Suite 190
Indianapolis, IN 46256
(317) 841-0044

Carolyn Bryson, Ph.D., HSPP
9247 North Meridian Street, Suite 104
Indianapolis, IN 46260
(317) 575-9646
Fax: (317) 873-6630
(Children and adolescents)

Children's Resource Group and Developmental-Behavioral Pediatrics
Jennifer L. Horn, Ph.D.
Dennis Ray Kinder, Ph.D.
Nancy F. Slater, M.D.
Ernest E. Smith, M.D.
Julie T. Steck, Ph.D.
8802 North Meridian Street, Suite 230
Indianapolis, IN 46260
(317) 571-4460
Fax: (317) 571-4470

Indiana Child and Adolescent Psychiatry
Jerry H. Fletcher, M.D.
Danita Lively, M.D.
Kathleen Miller, M.D.
Beth Pfau, M.D.
8902 North Meridian, Suite 103
Indianapolis, IN 46260
(317) 844-0055

Mary M. (Peg) Maginn, Speech Language Pathologist
Beth Farny, Speech Language Pathologist
1424 East Goldspur Drive
Ft. Wayne, IN 46804-1339
(219) 432-2019

Kimberley A. Green, Ph.D., HSPP
1429 "J" Street Suite B
PO Box 213
Bedford, IN 47421
Private Practice
(812) 275-7765 (Answering service - leave a message)

Mercury Center
Mike Monahan, Ph.D., HSPP
125 Airport Pkwy., Suite 130
Greenwood, IN 46143
(317) 881-5050
747 East 86th Street
Indianapolis, IN 46240
(317) 726-1525

Robin R. Murphy, Ph.D., HSPP
2213 Queensway
Bloomington, IN 47401
(812) 333-1990
(Trained in use of the Autism Diagnostic Interview)

Dennis R. Olvera, Ph.D., P.C.
301 East Carmel Drive, Suite G 300-3
Carmel, IN 46032
(317) 581-8846

Robert Pearce, M.D.
Paul Stewart, M.D.
7250 Clearvista Drive, Suite 380
Indianapolis, IN 46256
(317) 576-9928
(children and adolescents)

Pediatric Behavioral and Developmental Associates
Mary Stuy, M.D., Behavior Pediatrician
14828 Greyhound Court, Suite 190
Carmel, IN 46032
(317) 582-9000

Susan J. Rautio-Dietz, Ph.D. HSPP
532 N. Walnut Street, Suite D
PO Box 5185
Bloomington, IN 47407-5185
(812) 332-7394
(Also sees adults)

The Rehabilitation Center
3701 Bellemeade Avenue
Evansville, IN 47714
(812) 479-1411

Riley Child Development Center
John D. Rau, M.D., Director
Morris Green, M.D.
Darlene Kardatzke, M.D.
Lynne Sturm, Ph.D.
Paula D. Sullivan, Ph.D.
Angela M. Tomlin, Ph.D.
Greg Wilson, M.D.
702 Barnhill, Room 5837
Indianapolis, IN 46202
(317) 274-8167

Riley Child Psychiatry Clinic
Matthew Galvin, M.D.
William Kronenberger, Ph.D.
Linn LaClave, Ph.D.
Gina Laite, M.D.
702 Barnhill
Indianapolis, IN 46202-5200
(317) 274-8162

Rick Robertson, M.D.
3600 North Prow Road
Bloomington, IN 47404
(812) 331-8000/(800) 972-4410
(treatment and management services for children and adults with autism)

Jeanine Roembach, M.D., FAACP
2510 Sandcrest Boulevard
Columbus, IN 47203
(812) 376-9371
(children and adolescents; assessment, medications)

Linda Ronald, Ph.D., HSPP
238 South Fifth Street
Richmond, IN 47374
(317) 962-2014
(Children and adolescents to age 18)

Southwestern Indiana Mental Health Center
Beth Stone, Ph.D.
Diplomate in Clinical Psychology, ABPP
1 North Barker Avenue
Evansville, IN 47712
(812) 423-4418

Rae Witvoet-Sieplinga, M.A.
3668 North Central #5
Indianapolis, IN 46205
317-926-2980

Out of State

University of Louisville
Child Evaluation Center
Attn: Allan S. Bloom, Ph.D.
Chief Psychologist
224 East Broadway
Louisville, KY 40292
(502) 588-5331

Developmental Disorders Clinic
Child & Adolescent Psychiatry
University of Michigan Medical Center
Luke Tsai, M.D., Professor/Director
3893 TC/0390
1500 E. Medical Center Drive
Ann Arbor, MI 48109-0390
(313) 764-7269

Rainbow Autism Center, Pediatric Neurology
Max Wiznitzer, M.D.
Rainbow Babies and Children's Hospital
11100 Euclid Avenue
Cleveland, OH 44106
(216) 844-7700

University Affiliated Cincinnati Center
for Developmental Disorders
Special Education Department
Pavilion Building
3300 Elland Avenue
Cincinnati, Ohio 45229
For information call: Dorothyann Feldis,
Ph.D.
(513) 559-4321
Intake: (513) 559-4648

University of Chicago
Developmental Disorders Clinic
Child and Adolescent Psychiatry
Edwin Cook, M.D.
Bennett Leventhal, M.D.
Catherine Lord, Ph.D.
Jane Nofer, Ph.D.
Marrea Winnega, Ph.D.
MC3077
5841 S. Maryland Avenue
Chicago, IL 60637
Information: (312) 702-9694
Intake: (312) 702-4453

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IRCA

Family

When Your Child Is Diagnosed with Autism

When a child receives a diagnosis of autism, parents and family members may experience a range of feelings. These feelings can include grief, denial, anger, fear, and confusion. If you are a parent, you may feel or have felt these emotions. It is important to know that you are not alone, and that many parents experience these same emotions. It is also important to recognize and work through these feelings as you begin to search for understanding, services, and support for your family and for your son or daughter with autism.

One of the first steps is to learn as much as you can about the diagnosis and how it affects your son or daughter. Unfortunately, there is still misinformation being circulated about the causes and impact of autism. The Indiana Resource Center for Autism (IRCA) at the Institute for the Study of Developmental Disabilities has prepared a bibliography of books that are current and relevant for families. Videos and print materials are available to help members of your immediate or extended family who are struggling to understand. As you learn more about autism, you will see that there are characteristics common to individuals with autism. Being aware of the characteristics that apply to your child will enable you to begin seeking supports and appropriate educational programs.

Throughout your child's life, you are going to be expected to make decisions for which most of us are not immediately prepared. These decisions are further complicated when faced with laws with numbers, therapies with abbreviations, government service agencies with acronyms, medical jargon, and an array of educational approaches. Making sense of the information can be overwhelming! It is nice to know that there are others who have been down this road and who can be of assistance in helping to untangle the web of agencies, services, and resources. There are national organizations, the Autism National Committee (AUTCOM) and the Autism Society of America (ASA), that exist as support and advocacy groups for persons with autism and their families. State and local ASA chapters exist in most states. The IRCA can provide residents of Indiana with the current contact person for the state organization and the chapter closest to your area. You may also find a support group in your area for families of children with other disabilities. These can assist in identifying the availability and type of local services. Support groups can help families find comfort, acceptance, and understanding of issues as the individual with autism goes through each stage of life. Whether or not you currently feel a need to actively belong to a support group, making an initial contact can provide valuable information.

Whatever the age of your child, one of the most important choices is going to be an appropriate educational placement. Children with autism can and do learn! Children of school age (3 to 21) identified with autism are served by the local educational agency. A good transdisciplinary educational evaluation is necessary to determine what needs to be taught. The Individuals with Disabilities Education Act (IDEA) provides for families to be actively involved in making decisions that impact their child's education. Learning your rights under this law will make it easier to participate in the important decisions surrounding your child's education. Information about accessing special education services can be obtained through your local school district. They can provide information as you begin to access your educational system.

Record keeping is another strategy that can help in your efforts. As your child matures, numerous professionals will need to know specific information about your son/daughter. A developmental history provides important diagnostic, evaluation, and programming information even into adulthood. No doubt you will have volumes of information by that time. Keeping information in an organized and concise manner will not only help you remember the information, but will be easier for busy professionals to access and utilize.

Identification of your child's and family's needs is very important. Each family is different and each child with autism is different. As a result, your needs will differ and shift as your son or daughter matures. Examples of services individuals with autism and their families may require include physical, occupational, and speech therapy, residential programs, medical and dental care, financial assistance programs, advocacy, legal information, respite care, sibling support and education, socialization, recreation, and vocational training. Accessing services can differ from community to community. The IRCA can assist families of persons with autism, in Indiana, to locate critical agencies, supports, and resources.

As a parent of a child with autism there are many new things to learn. At times it will be challenging to balance routines, schedules, and plans so that all family members feel accepted, supported, and valued. Establish time for all family members to revitalize and gain perspective. Maintain your sense of humor. Laugh together to relieve tension. You can and will have your ups and downs. Keeping things in perspective and taking time for yourself are vital in reducing the stress that is common when parenting any child, including your child with autism.

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Setting the Stage for Parent-Professional Collaboration

Supporting an individual with autism can present special challenges for both parents and professionals. When problem situations occur, it may be difficult for family members and professionals to work together. Clearly, effective communication is essential to ensure that all involved in the individual's life have accurate and important information. The following list presents helpful hints for maintaining effective, consistent, and honest communication.

- Reach an agreement about how often and in what format communication can best take place. Determine methods for maintaining ongoing communication, such as telephone calls, written journals, or other systems. Remember that the professional's primary responsibility during the school or work day is his or her students or employees.

- Frustration will naturally occur when two parties attempt to negotiate important issues. Therefore, keep communications as positive and free of blame as possible. Parents need to hear about successes, not just failures from teachers. Teachers need support and information from parents rather than angry phone calls. If tempers flare, postponing calls or meetings to allow a little cooling off time can be an effective beginning to problem resolution. It is always important for parents and professionals to thank each other when they do something positive, even if it does not work out perfectly.

- Honesty is vital. However, honesty does not preclude tact. Know when to be blunt and when to be diplomatic. Reserve judgement. There is always more to the story than one knows.

- Present information in a clear fashion and do not use jargon. Professional jargon can be both intimidating and confusing for family members.

- At the beginning of each partnership, it is important for parents and professionals to convey to each other what they realistically expect. When expectations change, the other party should be informed. Parents should be consistent in their expectations of professionals and the services desired. Professionals should never expect a parent to accept the argument that your service delivery system cannot afford what their child needs.

- Discuss problems as soon as they arise, rather than waiting for them to get out of control. If teachers do not have the answer to a problem, admit it and involve the parent in problem solving. Parents should not be afraid to ask questions about any aspect of their child's treatment or programming.

Working together takes commitment, time, and consideration by all involved. When parents and professionals cannot work together constructively, the child is the one who loses! But when good communication, mutual respect and sensitivity, and good faith efforts on everyone's part to resolve problems is the foundation of parent-professionals collaboration...all three are winners!

Dr. Cathy Pratt, Director, Indiana Resource Center for Autism
Susan Moreno, M.A., MAAP Services, Inc., PO Box 524, Crown Point, IN 46307

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Respite Services

All parents need time away from their children. This may be especially true for the family of an individual with a disability. Living with a family member who needs constant supervision and care can create continual stress. Respite services provide families with temporary relief from the sometimes 24 hour a day job of supervising and supporting a person with a disability. Respite is an option for any child, adolescent, or adult with disabilities. Depending upon programs in your area, respite may be available for several hours a week, overnight, or several days or weeks at a time. Respite services provide temporary relief and peace of mind by placing the family member with a disability in capable hands.

Respite services may provide the following:

- Individual care in the family home or in the provider's home on an as needed or on a regular hourly basis.
- A training companion to accompany the individual to community recreational activities.
- A short term placement in a group home, family home, or other residential setting.
- Assistance to attend camp or day programs in the summer.

Agencies providing respite operate under state guidelines and regulations, but individual agencies have flexibility in the design and implementation of programs. Respite workers are usually paid between $5.00-$7.00 an hour depending on the level of assistance required. Agencies providing respite services set fees according to a sliding fee scale based on a family's income. Agencies also can direct families to funding sources to defray costs. Respite providers should be contacted directly to clarify options, arrange services, and discuss cost.

To locate the respite care service agency or agencies in your area, call the local Arc (formerly known as the Association for Retarded Citizens), Integrated Field Services Office (sometimes referred to as the Bureau of Developmental Disabilities Case Management Field Offices), Autism Society of America Local Chapter, or other local groups who work with persons with disabilities and their families, such as United Cerebral Palsy and Mental Health Association. Many area respite contact people work only part time. Therefore, it may be hard to contact certain respite workers on the first phone call. However, once you leave a message, contact people are usually good about returning phone calls.

Many times, respite services are not used because parents are not aware of programs or because they feel guilty or anxious about using services. At times, respite care agencies lack personnel trained to deal with individuals with severe disabilities or with challenging behaviors. These are valid concerns, but hopefully will not prevent a family from seeking or receiving respite services. Agencies are required to train respite care staff. Most agencies try to provide advanced training to respite workers who are interested in and capable of working with persons with the most severe disabilities and/or challenging behaviors.

When using respite services, it is important for families to provide specific information about their family member with a disability to agency staff. Maintaining a notebook with information about the individual's method of communication, areas of concern, preferred activities, systems of reinforcement, medications, behaviors, suggestions for interactions, and a daily schedule can be helpful. Information about dressing, eating, bathroom use, and bedtime routines should be documented and readily available. Emergency numbers and emergency procedures should be clearly posted. Visual systems of support such as picture sequences, calendars, and checklists should be easy for the respite worker to access. Keeping updated information in one location will help the respite worker be successful, ease your peace of mind, and assist your son/daughter in adjusting to a new person.

Time for running errands, relaxing, pursuing other interests, and strengthening relationships with family members and friends is essential for all parents. Respite services can provide relief and can help all family members feel energized, including the person with a disability who spends time with trained people. Consider the benefits to the whole family. Be persistent in finding and working with an agency in developing respite services that meet your family's needs. Respite services can truly enhance the lives of all family members.

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Respite Services Directory
June 1996

The following list contains information about respite providers across Indiana. IRCA staff have not contacted individual agencies. Therefore, dissemination of this list does not reflect official endorsement of any organization. If you are in need of respite services, contact the nearest agency to gain specific information about cost, type of services, expertise of staff, and other considerations.

Administering Agency	Counties Served	Contact Person	Population Served
ARC of Allen County 2542 Thompson Avenue Ft. Wayne, IN 46807	Allen, Wells, Adams	Debbie Ainslie 219-456-4534	MI, DD
ADEC PO Box 398 Bristol, IN 46507	Elkhart	219-848-7451	MI, DD
Community Ventures in Living 401 South Earl Avenue Lafayette, IN 47904	Tippecanoe, Benton, Carroll, White, Jasper, Newton, Howard, Tipton	Karen Taylor 317-449-0784	MI, DD
Delaware County Mental Health Association 814 White River Blvd. Muncie, IN 47303	Delaware, Henry, Jay, Randolph, Wayne, Union, Fayette	Angie Divine 317-288-1924 Vicki Strahan	MI, DD
Developmental Services, Inc. PO Box 1023 Columbus, IN 47202	Bartholomew, Brown, Jackson, Jennings, Jefferson, Decatur, Franklin, Dearborn, Switzerland, Ripley, Ohio	Geraldine Reed Mary Burns 812-376-9404 800-745-7686	MI, DD
Southern Indiana Respite Services, Inc. PO Box 757 New Albany, IN 47151	Floyd, Scott, Clark, Harrison, Washington, Crawford, Orange, Perry, Spencer, Dubois	Muriel LaDuke 812-945-7470 812-945-6868	MI, DD
Grant-Blackford DS 2724 South Carey Street Marion, IN 46953	Grant, Blackford	Dan McDonough 317-668-8961	DD
Grant-Blackford Mental Health 505 Wabash Avenue Marion, IN 46953	Grant, Blackford	Jim Lundy 317-664-7792	MI

Administering Agency	Counties Served	Contact Person	Population Served
Visiting Nurse Services, Inc. 4701 Keystone Indianapolis, IN 46204	Marion, Hancock, Hamilton, Shelby	Cathy Boes 317-722-8200	MI, DD
Gateway Association 2120 Central Avenue Anderson, IN 46016	Madison	Joyce Reck 317-644-9233	DD
Home Health Services of Porter County 501 Marquette Street Valparaiso, IN 46383	Porter, LaPorte, Starke	Laurie Custer Pat Platt 219-462-5195	MI, DD
Logan Industries 3621 West Boland Drive South Bend, IN 46628	St. Joseph	Lynette Ladd Tonya Robinson 219-289-0385	DD, MI
Knox County ARC RR 3, Box 263A Vincennes, IN 47591	Knox, Daviess, Martin, Pike	Julie Carney 812-886-4882	MI, DD
MHA of Lake County 2450 169th Street Hammond, IN 46323	Lake	Cathy Corning 219-845-2720	MI
Noble Centers 7701 East 21st Street Indianapolis, IN 46219	Marion	Amy Holleran 317-375-4233	DD
Northeastern Center PO Box 817 Kendallville, IN 46755	LaGrange, Steuben, Noble, DeKalb	Karen Markward 219-347-4955	
Options for Better Living Box 1732 Bloomington, IN 47402 MHA of Monroe County 407 South Walnut Bloomington, IN 47401	Monroe, Owen, Green, Lawarence	Laurie Paarlberg 812-332-9615 Connie Baker 812-339-2803	DD MI
Passages, Inc. PO Box 1005 Columbia City, IN 46725	Kosciusco, Whitley, Huntington, Wabash, Marshall	Cheryl Eldridge 219-244-7688	MI, DD
Putnam County Comp. 630 Tennessee Street Greencastle, IN 46135	Putnam, Montgomery, Fountain, Warren, Clinton	Nancy Williams Judith Homler 317-653-9763	MI, DD
Res. Care Services, Inc. 6525 Columbia Avenue, Suite B Hammond, IN 46320	Lake	Doris Lee 219-931-8172	DD
Southern Hills Counseling Center PO Box 769 Jasper, IN 47546	Crawford, Dubois, Orange, Perry, Spencer	Bridget Dwyer 812-482-3020	MI

Administering Agency	Counties Served	Contact Person	Population Served
Southwestern Indiana 415 Mulberry Street Evansville, IN 47713	Posey, Vanderburg, Gibson, Warrick	Wanda Hay 812-424-7844	MI, DD
Sycamore Services 1001 Sycamore Danville, IN 46122	Hendricks, Boone, Morgan, Johnson	Duane Albertson 317-745-4715	MI, DD
ARC of Vigo County 89 Cherry Street Terre Haute, IN 47807	Vigo, Parke, Clay, Vermillion, Sullivan	Kent Sandschafer Susan Hendrichsen 812-232-4112	MI, DD
Woodlawn Center 1416 Woodlawn Avenue Logansport, IN 46947	Cass, Pulaski, Fulton, Miami	Dyan Elliot 219-753-4104	MI, DD

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Supplemental Security Income for Persons with Developmental Disabilities

Supplemental Security Income (SSI) is financial assistance, provided by the federal government, to eligible persons with disabilities. It is money in the form of a monthly check, that helps pay for basics such as food and shelter. It is available to people who are elderly, blind, or disabled (according to Social Security's *Listing of Impairments*), and who have little assets or income. Adults must document that the disability interferes with their capacity for self-support. Under recent Welfare Reform laws there is a new standard for childhood disability.

In determining medical eligibility for a child, the functional assessment must show that the child's condition, or combination of conditions is medically or functionally equal to Social Security's *Listing of Impairments*. The Social Security Administration has recently finished a review of more than 260,000 children who receive SSI to see if they still qualify under the new guidelines. The Disability Determination Bureau (DDB) in Indiana now looks at six areas of functioning in relation to a child's age. Limitations are assessed in the areas of cognition/ communication skills, motor skills, and social skills (how the child gets along with others is very important) in children birth to age 18. Children ages 3 to 18 also are assessed for self-care and focusing/concentration skills. For very young infants from birth to 12 months, responsiveness to stimuli is reviewed. The Social Security Administration must consider all options for qualifying a child. A specific form (SSA-538) must be completed before a decision is made. A Social Security worker can supply you with a copy of this form.

When applying for SSI it is important to supply as much information as possible from medical sources, school records, and others who know the child well, such as child care providers and close family friends. Complete information is not required to apply. What information you do not have the Social Security Office will obtain with your permission. A list of your child's medical, mental health, and educational providers will also be requested. Income information will need to be provided at the time of application. The determination process usually takes from 2 to 3 months, but benefits are retroactive back to the month of application. For an adult, the process should begin the month the person turns 18.

Once all documentation is obtained by the Social Security Administration, it is determined whether both financial and medical eligibility are met. Many adults with disabilities meet the income eligibility guidelines because they do not have full- or part-time employment that brings their income to the maximum allowed. Some people with developmental disabilities have too many assets in the form of bank accounts, life insurance, or trusts in their name, which cause them to be ineligible for SSI benefits.

In the case of too many assets, a lawyer or someone knowledgeable about the law can be consulted (the ARC of Indiana and Indiana Protection and Advocacy may provide help with this) for information on how to set aside funds for a person without jeopardizing eligibility for SSI and other benefits. If a person is turned down on the basis of proof of disability, an appeal can be filed. Instructions for the appeal process are provided, in writing, when the eligibility statement is received. It is very important, when appealing, that you follow the instructions that are provided on the back of your eligibility letter. Do not give up. There are four levels for appeals: reconsideration, hearing, Appeals Court review, and Federal Court action. During the appeal process you can provide new reports or information, such as medical or educational records that may have been overlooked and/or new test results provided by different doctors, educators, and professionals.

For more information about Social Security benefits there is a national toll free number: 1-800-722-1213 or TDD: 1-800-325-0778 from 7 a.m. to 7 p.m. on weekdays. It may be hard to get through but keep trying. The best time to get through is early or late in the day. You may be offered an automated service when a representative is not immediately available. The automated service allows you to request forms or pamphlets and hear recorded messages about various Social Security programs.

Contributor:
Marci Wheeler

The Indiana Resource Center for Autism (IRCA) is one of four of the Institute's seven centers with a cross-age focus in developmental disabilities (technology and technological adaptations, disability information, planning and policy studies, and autism). The three others focus on age-related issues (young children, school-age, and adults and seniors). The ISDD is dedicated to the promotion and maintenance of a seamless system of inclusionary services across the lifespan. Institute activities include interdisciplinary training, information dissemination and research, and community services.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

The University Affiliated Program of Indiana

Accessing Training Funds from the Indiana Governor's Planning Council for People with Disabilities

The Consumer Involvement Fund implemented by the Governor's Planning Council can help individuals with disabilities and family members with funding to participate in educational events. Educational activities include conferences, workshops, and other training formats as well as attendance at public forums, hearings, and task force meetings.

The Consumer Involvement Fund is designed and implemented to support the participation of persons with disabilities and/or their family members who do not otherwise have the organizational or financial support to attend. Individuals, or a sponsoring nonprofit agency or organization, can request the forms and complete the paperwork. The applicant must demonstrate how participation in the proposed event will benefit the consumer and how the funds will be used to increase participation of the consumer(s).

Most often assistance is provided as a reimbursement after the bills and receipts have been submitted as documentation. If this method is too burdensome, other arrangements sometimes can be made. Please contact Paul Shankland, Grants Manager for the Council, to obtain application forms and to gather additional information.

When a request is made, an application which includes several forms is promptly sent. A budget must be submitted. The budget must indicate any funds or ways in which the individual will reduce costs, such as sharing a hotel room or transportation. Funds can be tailored to address individual need and can cover the cost of registration, mileage, hotel room, meals, respite care, attendant care, or any other service that is needed for full participation, such as a communication device.

The Governor's Planning Council has the right to deny a request if the proposed activity is found to be inconsistent with the purpose of the Fund and/or with the mission of the Council. Occasionally allotted funds run out. Due to limited funds, out-of-state travel is restricted. Funds must be used specifically for those individuals identified in the grant. After the event, a report should be submitted by the consumer and/or sponsoring organization to the Council detailing the benefits of attendance by the consumer(s).

Applications can be requested at any time and should be submitted no more than three months prior to the event. Allow 4-6 weeks to process and authorize the application. Applications are accepted on a first come, first served basis. Requests can be made directly to the Indiana Governor's Planning Council for People with Disabilities. They are located in Indianapolis. The address and phone are as follows:

Harrison Building, Suite 404
143 West Market Street
Indianapolis, IN 46204
317-232-7770 Voice/TDD

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Selected State Resources for Information, Training, Advocacy, and Empowerment for Persons With Disabilities and Their Families

ARC of Indiana 22 East Washington Street, Suite 210 Indianapolis, IN 46204 317-632-4387 or 1-800-382-9100	State organization with local agencies in many counties across Indiana. Services may vary in each local agency but the general mission statewide and nationally is to protect the rights of persons with developmental disabilities and to help expand programs for them.
ATTAIN: Accessing Technology Through Awareness in Indiana 1815 North Meridian Street, Suite 200 Indianapolis, IN 46202 317-921-8766 or 1-800-5ATTAIN/1-800-528-8246	Statewide project to increase consumers' access to assistive technology services. Several sites across the state provide information, outreach, demonstration, training, and assistance to find equipment and funding.
COVOH: Council of Volunteers and Organizations for Hoosiers with Disabilities 445 North Pennsylvania Street Suite 414 Indianapolis, IN 46204 317-262-8632 or 1-800-262-8630	A not-for-profit coalition of many statewide, regional, and local organizations representing volunteers, advocates, providers, and consumers of programs for people with disabilities. Conducts "Partners in Policymaking" project in Indiana, a program to educate and empower consumers and family members in issues that impact the lives of persons with developmental disabilities.
DOE: Indiana Department of Education (Division of Special Education) Room 229, State House Indianapolis, IN 46204-2798 317-232-0587	Provides technical assistance to school corporations and assurance of implementation of laws that pertain to special education. Develops and provides materials on topics related to special education.
Indiana Advocacy Services (Indiana State Protection and Advocacy) 4701 North Keystone, Suite 222 Indianapolis, IN 46204 317-232-1150 or 1-800-622-4845	State agency staffed to respond to requests to protect the rights of persons with developmental disabilities through information, referral, and technical assistance.

Indiana Bureau of Child Development First Steps 402 West Washington Street PO Box 7083 Indianapolis, IN 46204-7083 317-232-1144 or 1-800-441-7837	First Steps early intervention services are available for children birth through two who are developmentally delayed or at risk of a developmental delay. STEP AHEAD is an Indiana Family and Social Services Administration statewide initiative that is carried out at the county level. Each county assesses, develops, and implements coordination of services to better serve local children and their families.
Indiana Family and Social Services Administration 402 West Washington Street Indianapolis, IN 46207- 7083 317-233-4454	Indiana Family and Social Services Administration was established by law in 1991. The state departments of Human Services, Public Welfare, and Mental Health were combined under one roof to form IFSSA.
Statewide agency with local offices. To locate/access information and services from the office nearest you, contact:	
A. Division of Disability Aging and Rehabilitative Services: 317-232-1147 or 1-800-545-7763	
Aging/In-Home Services Section: 317-232-7020 or 1-800-545-7763	Provides an array of home care services to the elderly and those with disabilities who are at risk of being institutionalized. Eligibility criteria need to be met to qualify for services.
Developmental Disabilities Section: 317-232-7933 or 1-800-545-7763	Provides diagnostic/evaluation services for preschoolers and adults with disabilities and those in need of residential services. Case management services are available.
Vocational Rehabilitation Section: 317-232-1410 or 1-800-688-6790	Assists persons with disabilities (after eligibility is determined) to prepare for, obtain, and/or retain employment.
B. Division of Family and Children Services: 317-232-4704	
C. Division of Mental Health Services: 317-232-7800	

Indiana Governor's Planning Council for People with Disabilities Harrison Building, Suite 404 143 West Market Street Indianapolis, IN 46204 317-232-7770 (V) or 317-232-7771 (TT)	Independent state agency disseminates federal funds to support planning, collaboration, research, and advocacy to empower individuals with developmental disabilities and their families. Free newsletter.
Indiana State Department of Health 1330 West Michigan Street PO Box 1964 Indianapolis, IN 46206 1-800-433-0746 (V/TT)	Indiana Family Helpline provides information on various programs including children with special health care needs, support groups, and Medicaid providers list. Assists with accessing health related programs and services.
Indianapolis Resource Center for Independent Living, Inc. (IRCIL) 8383 Craig Street, Suite 130 Indianapolis, IN 46250 317-596-6440 800-860-7181	A self-help, advocacy, and public education center for people with disabilities. Also provides Indiana American Disabilities Act training and referrals to other programs for assistance.
IN*SOURCE 809 North Michigan South Bend, IN 46601 219-234-7101 or 1-800-332-4433	Maintains Indiana's Family Involvement Fund which provides families with financial help to attend training events. Offers free parent training and information throughout the state of Indiana. Free newsletter. Maintains list of parent representatives in local communities.
IPIN: Indiana Parent Information Network 4755 Kingsway Drive, Suite 105 Indianapolis, IN 46205 317-257-8683 or 1-800-964-IPIN	Organization supporting families of persons with special needs with free information on disabilities, laws, education, social services, and resources throughout Indiana. Free newsletter.
ISDD: Institute for the Study of Developmental Disabilities 2853 East Tenth Street Bloomington, IN 47408-2601 812-855-6508 or 812-855-9396 (TT) Dial-IN (Disability Information Access Line for Indiana 1-800-437-7924)	Provides interdisciplinary training, information dissemination, research, and community services planning assistance for professionals, family members, and persons with developmental disabilities through its three core programs and four resource centers.

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Legislative Commission on Mental Retardation and Developmental Disabilities Legislative Services Agency 200 West Washington Street, Suite 302 Indianapolis, IN 46204-2789 317-232-9588	Legislative body made up of state senators, representatives, and lay members who meet to specifically review system needs and service issues, and to develop legislation.
TASH 29 West Susquehanna, Suite 210 Baltimore, MD 21204 1-800-482-TASH	Advocacy organization for persons with disabilities. (To locate information on contacting a representative from the Indiana State Chapter contact the National office.)

The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

INDIANA RESOURCE CENTER FOR AUTISM

Selected Bibliography for Families of People with Autism

The following books and articles provide a glimpse into the lives of people with autism and their families. The bibliography also contains resources for parents, siblings, and individuals with autism. Selected items may be available at your local library. Many may be borrowed by Indiana residents from the Library of the Institute for the Study of Developmental Disabilities, 2853 E. Tenth Street, Bloomington, IN 47408-2601, (800) 437-7924 (toll free in Indiana; voice/TT); (812) 855-9396 (Bloomington; voice/TT).

BOOKS FOR THE FAMILY

Anderson, W., Chitwood, S., & Hayden, D. (1990). *Negotiating the special education maze: A guide for parents and teachers*. Rockville, MD: Woodbine House.

Baker, B., & Brightman, A. (1988). *Steps to independence* (2nd ed.). Baltimore, MD: Paul H. Brookes Publishing Company.

Berkell, D. E. (Ed.). (1992). *Autism: Identification, education, and treatment*. Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.

Brill, M. T. (1994). *Keys to parenting the child with autism*. Hauppauge, NY: Barron's Educational Series, Inc.

Cutler, B. (1993). *You, your child and special education: A guide to making the system work*. Baltimore, MD: Paul H. Brookes Publishing Company.

Deschenes, C., Ebeling, D., & Sprague, J. (1994). *Adapting curriculum and instruction in inclusive classrooms: A teacher's desk reference*. Bloomington, IN: Indiana University, Institute for the Study of Developmental Disabilities.

Des Jardins, C. (Ed.). (1993). *How to get services by being assertive* (3rd ed.). Chicago, IL: Family Resource Center on Disabilities.

Dalrymple, N. J. (1992). *Helpful responses to some of the behaviors of individuals with autism*. Bloomington, IN: Indiana University, Institute for the Study of Developmental Disabilities.

Fewell, R., & Vadasy, P. (1986). *Families of handicapped children: Needs and supports across the lifespan*. Austin, TX: Pro-Ed.

Gray, C. (1996). *Social stories...All new stories teaching social skills*. Arlington, TX: Future Horizons, Inc.

Gray, C. (1996). *What's next?:...Preparing for the real world*. Arlington, TX: Future Horizons, Inc.

Hart, C. (1993). *A parents' guide to autism*. New York, NY: Pocket Books.

How they grow: A handbook for parents of young children with autism. (Revised 1991). Lansing, MI: Michigan Society for Autistic Citizens. Raleigh, NC: Autism Society of America.

Koegel, R., Schreibman, L., Good, A., Cerniglia, L., Murphy, C., & Koegel, L. (1989). *How to teach pivotal behaviors to children with autism.* Santa Barbara, CA: University of California.

Krahl, R. (1990). *Rebuilding your dream: Family life with a disabled child.* Iowa City, IA: University of Iowa, Publications Department.

Kushner, H. (1981). *When bad things happen to good people.* New York, NY: Schocker Books.

Miller, N. B. (1994). *Nobody's perfect: Living and growing with children who have special needs.* Baltimore, MD: Paul Brookes Publishing Company.

Moreno, S., & Donnellan, A.M. (1991). *High functioning individuals with autism: Advice and information for parents and others who care.* Crown Point, IN: MAAP Services, Inc.

Nisbet, J. (Ed.). (1992). *Natural supports in school, at work and in the community for people with severe disabilities.* Baltimore, MD: Paul H. Brookes Publishing Company.

Powers, M. (1989). *Children with autism: A parent's guide.* Rockville, MD: Woodbine House.

Quill, K. (Ed.). (1995). *Teaching children with autism: Strategies to enhance communication and socialization.* Albany, NY: Delmar Publishers.

Russell, L. (1983). *Alternatives: A family guide to legal and financial planning for the disabled.* Evanston, IL: First Publications.

Schopler, E., & Mesibov, G. (Eds.). (1983). *The effects of autism on the family.* New York, NY: Plenum Press.

Siegel, B. (1996). *The world of the autistic child: Understanding and treating autistic spectrum disorders.*New York, NY: Oxford University Press.

Smith, B., & Keeney, C. (1992). *Parents guide to facilitated communication.* Houston, TX: River Bend Publishing Company.

Smith, M.D., Belcher, R. G., & Juhrs, P. D. (1995). *A guide to successful employment for individuals with autism.* Baltimore, MD: Paul H. Brookes Publishing Company.

Turnbull, A., Patterson, J., Behr, S., Murphy, D., Marquis, J., & Blue-Banning, M. (1993). *Cognitive coping, families, and disability.* Baltimore, MD: Paul H. Brookes Publishing Company.

Wing, L. (1985). *Autistic children: A guide for parents* (2nd ed.). New York, NY: Brunner/Mazel.

Individual and/or Family Accounts of Living with Autism

Barron, J., & Barron, S. (1992). *There's a boy in here*. New York, NY: Simon and Schuster.

Christopher, W. (1989). *Mixed blessings*. Nashville, TN: Abington Press.

Dillon, K. (1995). *Living with autism: The parent's stories*. Boone, NC: Parkway Publishers, Inc.

Eastham, M. (1990). *Silent words: The story of David Eastham*. Ottowa, Ontario: Oliver-Pate.

Grandin, T. (1995). *Thinking in pictures and other reports from my life with autism*. New York, NY: Doubleday.

Grandin, T., & Scariano, M. (1986). *Emergence: Labeled autistic*. Nowato, CA: Arena Press.

Hart, C. (1989). *Without reason: A family copes with two generations of autism*. New York, NY: Harper and Row.

McDonnell, J. T. (1993). *News from the border: A mother's memoir of her autistic son*. New York, NY: Ticknor and Fields.

McKean, T. A. (1994). *Soon will come the light: A view from inside the autism puzzle*. Arlington, TX: Future Horizons, Inc.

Maurice, C. (1993). *Let me hear your voice*. New York, NY: Alfred A. Knopf.

Park, C. C. (1982). *The siege: The first eight years of an autistic child with an epilogue, fifteen years later*. Boston, MA: Little, Brown, and Company.

Schopler, E. (Ed.). (1995). *Parent survival manual: A guide to crisis resolution in autism and related developmental disorders*. New York, NY: Plenum Press.

Williams, D. (1992). *Nobody nowhere*. New York, NY: Times Books.

Williams, D. (1994). *Somebody somewhere*. New York, NY: Times Books.

Williams, D. (1995). *Not just anything*. Arlington, TX: Future Horizons, Inc.

Williams, D. (1996). *Autism: An inside-out approach*. Bristol, PA: Jessica Kingsley Publishers, Ltd.

Williams, D. (1996). *Like color to the blind*. New York, NY: Times Books.

Selected Resources for Families

1. The Advocate Newsletter
Autism Society of America, Inc. (ASA)
7910 Woodmont Avenue, Suite 650
Bethesda, MD 20814
1-800-328-8476
(Subscription is by membership to Autism Society of America, Inc.: $20.00 subscription for individuals. Also provides various packets of information relating to autism.)

2. The Autism National Committee -- The Communicator
c/o Rena Gans, Membership Chair
249 Hampshire Drive
Plainsboro, NJ 08536
Barbara Domingue, Information and Referral
508-677-9239
(Membership for individuals is $20.00 per year which includes receiving a newsletter)

3. Autism Network International (ANI)
P.O. Box 448
Syracuse, NY 13210-0448
($15.00 membership to ANI includes subscription to the newsletter *Our Voice*.)

4. Autism Research Review International (ARI)
Autism Research Institute
4182 Adams Ave.
San Diego, CA 92116
($16.00 subscription for individuals)
619-281-7165

5. Autism Society of North Carolina
3300 Women's Club Drive
Raleigh, NC 27612-4811
(Operates an extensive mail order service for books on autism.)
919-571-8555

6. Exceptional Parent Magazine
Post Office Box 3000, Dept. EP
Denville, NJ 07834-9919
($18.00 subscription for individuals)
800-247-8080

7. Families and Disability Newsletter
Beach Center on Families and Disabilities
3111 Haworth Hall
The University of Kansas
Lawrence, KS 66045-7516
913-864-7600

8. Focus on Autism and Other Developmental Disabilities
PRO-ED, Inc.
8700 Shoal Creek
Austin, TX 78758
($39.00 newsletter subscription for individuals: quarterly publication.)
512-451-3246

9. The MAAP Newsletter (More Advanced Autistic Persons)
MAAP Services, Inc.
P.O. Box 524
Crown Point, IN 46307
($20.00 subscription for individuals in U.S.)
219-662-1311

10. The Morning News
c/o Carol Gray
2140 Bauer Road
Jenison, Michigan 49428
(Quarterly newsletter: subscription $8.00 for U.S., $10.00 Canada and Mexico in U.S. funds.)
616-457-8955

11. National Information Center for Children and Youth with Handicaps (NICHCY)
Post Office Box 1492
Washington, DC 20013
(Newsletter subscription is free of charge.)
800-695-0285

12. Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
2853 E. 10th Street
Bloomington, IN 47408-2601
(Newsletter free to Indiana residents; $15.00 for outside of Indiana. Staff generated materials on autism disseminated worldwide.)
812-855-6508

Selected Resources by and for Siblings

1. Family Resource Associates, Inc.
   35 Haddon Avenue
   Shrewsbury, NJ 07701
   (908) 747-5310

   Quarterly newsletters: *For Siblings Only* (ages 4-9) and *Sibling Forum* (ages 10 & up).

2. The Sibling Information Network
   A.J. Pappanikou Center
   1776 Ellington Road
   South Windsor, CT 06074
   (203) 648-1205

   Quarterly newsletter subscription.

3. The Sibling Support Project
   Children's Hospital and Medical Center
   4800 Sand Point Way, N.E.
   Seattle, WA 98105
   206-368-4911

   The *NASP Newsletter*.

Videos:

1. Just Call Him Matthew. (1992). VHS format; 26 minutes. Produced by Mountain Productions, New Mexico; 505-291-9284. Young brothers and sisters of children with autism speak openly about their feelings and experiences.

2. Brothers and Sisters on Siblings with Developmental Disabilities. (198?). VHS format; 20 minutes. Produced by YARC Sibling Support, Waisman Center, Madison, Wisconsin. Older siblings discuss their experiences, joys, and disappointments concerning their brothers and sisters with disabilities.

Booklets:

1. Brothers and Sisters Talk with PACER. (1987). Produced by Parent Advocacy Coalition for Education Rights (PACER), Minneapolis, MN; 612-827-2966. Cost is $4.00. Booklet with accounts based on interviews conducted with siblings of children and young adults with disabilities.

2. The Sibling. By Barbara Azrialy. (1992). Produced by Azrialy Publishing, Encino, CA; 818-344-8011. Cost is $11.00. Booklet with stories of people who grew up as the brother or sister of a child with a disability. The author is a sibling and a special education teacher.

Selected Resources for Understanding and Supporting Siblings

Autism . . . a family affair. (1985). Minneapolis, MN: Minneapolis Children's Medical Center.

Celiberti, D. R., & Harris, S. L. (1993). Behavioral intervention for siblings of children with autism: A focus on skills to enhance play. *Behavior Therapy, 24*(4), 573-599.

Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders, 23*(1), 147-163.

Harris, S. (1994). *Siblings of children with autism: A guide for families.* Bethesda, MD: Woodbine House.

Howlin, P. (1988). Living with impairment: The effects on children of having an autistic sibling. *Child: Care, Health and Development, 14*, 395-408.

Lobato, D. (1990). *Brothers, sisters and special needs.* Baltimore, MD: Paul H. Brookes Publishing Company.

Lobato, D. (1983). Siblings of handicapped children: A review. *Journal of Autism and Developmental Disorders, 13*(4), 347-364.

Lobato, D. (1985). Brief report: Preschool siblings of handicapped children: Impact of peer support and training. *Journal of Autism and Developmental Disorders, 15*(3), 345-350.

Mates, T. (1990). Siblings of autistic children: Their adjustment and performance at home and in school. *Journal of Autism and Developmental Disorders, 20*(4), 545-553.

McHale, S., Sloan, J., & Simonson, R. (1986). Sibling relationships of children with autistic, mentally retarded and non-handicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16*(4), 399-413.

Meyer, D., Vadasy, P., & Fewell, R. (1985). *Sibshops: A handbook for implementing workshops for siblings of children with special needs.* Seattle, WA: University of Washington Press.

Powell, T., & Gallagher, P. (1993). *Brothers and sisters: A special part of exceptional families* (2nd ed.). Baltimore, MD: Paul H. Brookes Publishing Company.

Rodrigue, J. R., Geffken, G. R., & Morgan, S. B. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders, 23*(4), 665-674.

Stewart, D., Benson, G., & Lindsey, J. (1987). A unit plan for siblings of handicapped children. *Teaching Exceptional Children, 19*(3), 24-28.

Stoneman, L., & Berman P. (1993). *The effects of mental retardation, disability and illness on sibling relationships.* Baltimore, MD: Paul H. Brookes Publishing Company.

Books for Siblings (Specific to Autism)

Amenta, C. (1992). *Russell is extra special: A book about autism for children.* New York, NY: Magination Press.

Bodenheimer, C. (1979). *Everybody is a person: A book for brothers and sisters of autistic kids.* Syracuse, NY: Jowonio: The Learning Place.

Dalrymple, N. (1979). *Learning together.* Bloomington, IN: Indiana University, Institute for the Study of Developmental Disabilities.

Katz, I., & Ritvo, E. (1993). *Joey and Sam.* Northridge, CA: Real Life Storybooks.

Gold, P. (1975). *Please don't say hello.* New York, NY: Human Services Press.

Martin, A. (1990). *The babysitters club: Kristy and the secret of Susan.* New York, NY: Scholastic Inc.

Martin, A. (1984). *Inside out.* New York, NY: Scholastic Inc.

Messner, A. W. (1995). *Captain Tommy.* Stratham, NH: Potential Unlimited Publishing.

Nolette, C. (1986). *Having a brother like David.* Minneapolis, MN: Minneapolis Children's Medical Center Program for Autism and Other Exceptional Children.

Thompson, M. (1992). *My brother, Matthew.* Bethesda, MD: Woodbine House.

Thompson, M. (1996). *Andy and his yellow Frisbee.* Bethesda, MD: Woodbine House.

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For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

The University Affiliated Program of Indiana

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Educational Programming

There is No Place Called *Inclusion*

It is not unusual to hear professionals discuss inclusion in terms of inclusive students, inclusive classrooms, or inclusive schools. Unfortunately, these terms lend to the confusion surrounding inclusion. Inclusion is not a student, a classroom, or a school. Rather, inclusion is a belief that ALL students, regardless of labels, should be members of the general education community. As members of the general education community, students with and without disabilities should have access to the full range of curriculum options. This means, for example, that students without disabilities should be able to utilize resource rooms without receiving a label first. It also means that students with disabilities should have access to typical homerooms, general education classrooms and courses, and school clubs. Those who support inclusion acknowledge that students have diverse learning needs and that the traditional model of education increasingly, is not able to accommodate all students. The philosophy of inclusion encourages the elimination of the dual special and general education systems, and the creation of a merged system that is responsive to the realities of the student population.

Today, the controversy over the appropriateness of inclusion for students with autism continues. Much of this controversy is based on diverse interpretations of the law and of current thinking. However, several basic premises behind the concept of inclusion are often overlooked in these discussions. First, students with and without disabilities do not fall into neat categories of educational need. Stating that a student has autism does not paint an exact picture of the supports or services needed. It was never the intent of either federal law (Individuals with Disabilities Education Act) or state regulations to base curriculum and placement decisions on categorical labels. The law clearly states that programming and placement must be individually determined. Second, the least restrictive environment mandate shows a clear preference for educating students with autism and other disabilities in general education settings. The law articulates that students must receive needed supports and services within the context of the regular classroom. When these accommodations are insufficient to insure educational success, then students can be placed in more restrictive settings. However, the responsibility is placed on the school to show that sufficient and appropriate resources were accessed and were unsuccessful in supporting a student's education in a regular classroom setting. Finally, the law states that students must have the opportunity to interact with nondisabled peers. Clearly, segregated settings do not promote these opportunities and place teachers in the position of having to create artificial options.

Unfortunately, the debate about the benefits of inclusion versus segregation misses one critical point. Neither general education nor special education settings are inherently good. Placement in a general education setting does not mean that a student is learning valuable information. And segregation does not equal quality programming. The failure of students with autism in general education settings can be attributed to strategies and classroom structures that make learning difficult for all students. It is clearly time to get past the arguments surrounding inclusion and focus our efforts on teaching students what they need to know and in a manner that is effective. Interestingly, these are the same concerns expressed by the general education community. In reality, inclusion is not a special education issue. For schools to successfully support students with diverse learning needs, special education reform must be viewed within the broader context of school restructuring. Schools which are focused on improving outcomes and on preparing students without disabilities for meaningful and productive lives are in a better position to address the needs of students with disabilities. In other words, good schools are good schools for all. And good teachers are good teachers for any student. It is within the context of global school restructuring activities that educators can better focus their efforts on supporting students with autism in gaining maximum educational benefit from the general education setting. Below are a few recommendations to guide these efforts.

First, educators need training. Too often, teachers are presented with students for whom they are unprepared to teach. Information is important since individuals with autism can seem a paradox of strengths and weaknesses, and many develop false perceptions of these individuals. At a very basic level, teachers will need to know the primary characteristics associated with autism. While it is important to ensure that information is not stigmatizing to the student, teachers need to know about any areas of difficulty, special talents, and other important information. In addition to receiving up-front information, the instructional team needs time to meet to problem solve strategies and to address concerns. When teachers do not receive information and support, both students and teachers are set up for failure.

Decisions to consider all students as members of the school community must be made by the entire school community with support from key administrators. When administrators are not supportive of students' participation in the school community and the changes this requires, teachers are placed in the position of bargaining for every bit of assistance. In addition, parents must spend time each year working aggressively with the school to ensure continued success. Schools which systematically accept and support all students are better prepared to support students with autism.

When choosing courses in which to involve students, consider areas of interest and situational demands (e.g., open spaces, lighting). When building a schedule, it may be helpful to intersperse easy and difficult coursework, or allow students to spend certain parts of the school day in a smaller classroom area. In all cases, make sure students experience some successes during the school day. If the demands of the school day become too intense, it may be necessary to provide the student with a safe area in which to escape. Some may learn best when exercise or physical activity are available throughout the day.

The trend toward educating students with autism in local neighborhood schools requires the adoption of innovative and flexible instructional strategies to ensure that educational objectives are met and that students are supported across a diverse array of educational settings. Innovative strategies such as multi-age grouping, cooperative learning, authentic assessment, instruction which acknowledges the concept of multiple intelligences, thematic approaches, whole language instruction, and other innovations found in the general education community present a positive framework for teaching students with autism.

Peer support programs are another innovation used to ensure that students get the maximum benefit from their school day. Peers are a natural and readily available resource for supporting students with learning difficulties in general education settings. Research and practical experience indicate that students learn best from each other. Students will often get together in a study group. Students who are doing well in a subject area often help friends who are struggling to prepare for an exam. Some schools have building-wide programs in which tutoring and cooperative learning are established practice, and students change roles between tutor and tutee as the situations demands. Clearly peer support programs can serve as a critical resource for any student who is challenged by some aspect of the school curriculum.

Students must receive an adequate level of support during the school day. While peer support programs provide one mechanism for support, instructional assistants provide another. Assigned assistants will need information on providing instruction in a manner that is easily understood by students. It is helpful if instructional assistants are not always closely positioned next to the student. Rotating assistants and positioning assistants away from the student are important strategies for avoiding cue dependency. While different assistants can be used, adopted strategies must be consistent. Allow instructional assistants time with the team to discuss approaches that work and those that do not.

The general education setting can be less stressful if students are provided with information about expectations and rules. In most cases, this information should be presented in a written format so that the student can rehearse at his or her own pace, and refer to it as needed or when under added stress. Provide students with visual supports to assist with following a daily schedule, identifying classmates, completing homework assignments, getting to class prepared, and using self-control.

Many voice a concern about whether inclusion can work. Success stories from around the country provide testimony that students with autism can learn in general education settings if students' time is wisely used, sufficient support is provided, all are informed, and proven methods of instruction are used. If all these factors are addressed, implementing an educational program which reflects the philosophy of inclusion can prepare young people with autism to be members of a place called *community*.

Contributor:
Cathy Pratt, Ph.D.
Director
Indiana Resource Center for Autism

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Establishing Long Range Goals with Family Members

Family members are the primary advocates, educators, and support systems for individuals with autism. As such, it is important to involve them early in a discussion of long range goals in the areas of work, residential, and leisure activities. Identifying long range goals early will assist in establishing educational goals and services for students with autism. The following questions can be used to consult with family members about their vision for their son or daughter with autism.

Where will he or she live? What activities will he or she need to perform?

> Examples of skills needed in residential settings include: self-care skills such as shaving and showering; domestic skills such as doing laundry, cooking, completing yard work, and shopping; interpersonal skills such as sharing space and chores with roommates; and making choices about leisure activities.

Where will he or she work? What skills will be needed?

> Jobs should reflect the preferences and skills of the individual with autism. Regardless of the job, being flexible, communicating, displaying appropriate social skills, working within the prescribed rate and accuracy, following directions and rules, and dealing with changes will need to be taught.

What leisure activities will he or she do with others? What skills will be needed?

> Leisure skills must be taught early and may include: playing board or card games with a friend, attending sports or musical events, and engaging in physical fitness activities such as jogging, swimming and biking.

What general community survival skills will he or she need?

> Preparing individuals to safely participate in community activities involves teaching them about the dangers of the community, self-protection, distinguishing friends from strangers, and basic concepts of appropriate social interactions.

What will he or she do during free or unstructured time?

> Personal free time interests and activities must be taught and expanded from an early age. Examples include: listening to music, reading, using a computer, pursuing hobbies, drawing, and writing stories.

What self-management skills will he or she need to learn?

> As the person gains independence, they must learn to monitor their own behavior. Examples of self-management skills include: learning how to relax when stressed, seeking information when confused or fearful, managing money, and moving about the community.

By answering these questions and others, family members and support personnel can begin to identify desired outcomes for the person with autism. Long range planning assists family members and agencies in designing a meaningful educational program for each individual. Thoughtful planning is key to future success.

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Teaching Students Who Are *Low-Functioning*: Who Are They and What Should We Teach?

During recent years, interest in individuals with autism who are high-functioning has grown as increasing numbers of students who fit that description have been identified. During the same period, those who advocate on behalf of students with severe cognitive disabilities have continued their search for information on teaching, working, and living with individuals perceived as belonging to this *more challenging* group. Before discussing programming issues, it seems important to first attempt to clarify who these individuals are who are referred to as *low-functioning.*

The most common tool for identifying this population of students are standardized test scores. It is commonly believed that 75-80% of students with autism also have cognitive disabilities. However, we need to be careful when using formal instruments to determine levels of cognitive functioning. During the past several years, professionals and family members have become keenly aware that traditional methods for measuring true intelligence, such as standardized tests, are often flawed in ways that can reap highly unreliable results. Although information gained through the process of testing can provide us with valuable information about how a person learns and about areas of difficulty, standardized tests are virtually never a true predictor of future success. Many adults who were considered severely disabled as students, are now able to secure jobs, live in a variety of residential arrangements, and are able to become members of their community when appropriate supports are in place and when taught necessary skills. Labeling a person as *low functioning* may in effect serve to limit the person's potential by limiting our vision for that person.

Clearly, students with autism who have severe cognitive limitations can be challenging to educators. However, as professionals and family members review the literature on autism, beware of the dichotomy between low- and high-functioning. These two groups often are referred to as if they are two discrete and separate categories of individuals. Realize that there are individuals with autism who may be gifted in certain areas but who are extremely challenged in others. Conversely, students with the label of severe disabilities can possess exceptional talents. In other words, students labeled as high-functioning may be severely disabled by their autism. And those who are labeled as *low-functioning* may be less affected by the characteristics associated with autism.

Generally, those who are labeled as having a severe cognitive impairment are individuals who have greater difficulty with social skills, and academic performance. They often have few readily recognized and/or socially appropriate means for communicating with others. It should not be surprising, then, that these individuals may more readily exhibit challenging behaviors, such as self-injury and aggression. This may be because they simply have not learned a better way to act or to cope with the demands of daily stressors, or may have no better means for communicating with others. These individuals may also engage in more sensory-related activities such as hand flapping, spinning, or rocking.

When designing educational programs for students with autism labeled as severely disabled, professionals and family members are cautioned to remember that programs for specific students are to be individually determined through the individualized education program (IEP) process. There is no IEP for people who are low-functioning versus people who are high-functioning. There are only IEPs for each student. Individualized programs must describe strategies for providing the student with acceptable and understandable ways of communication, teaching situation-appropriate social behaviors, and providing experiences that satisfy sensory needs by promoting desensitization or reducing sensory overload in specific settings and situations.

If a student has greater difficulty learning, it seems that the valuable school years should be spent teaching him/her to participate in important or functional activities. A functional curriculum is comprised of activities the person will need in order to live, work, and recreate in his/her community. Activities such as balancing a check book, recreating at the neighborhood YMCA, eating at a restaurant, maintaining a job, and shopping are targeted. Note that the program a student is engaged in is not a categorical decision. The mandate for an individualized education program is misapplied when one set of goals or a category-driven placement is adopted for all students with a given disability or a perceived level of functioning. Typically, when such practices prevail, the IEP neither guides instruction nor results in acquisition of life skills that are relevant to the student's present or future. No *canned* curriculum fits all students with autism; no *canned* curriculum or label-specific placement fits all students who are perceived as functioning on similar levels. It is a simple truth that not all students who have more severe cognitive limitations will choose the same path in adulthood. What students learn in school should reflect this diversity of preferences.

By definition, individuals with autism have a restricted repertoire of skills. For those who have difficulty learning, this repertoire may seem further restricted. A good place to begin the discussion about what to teach a student, is to work with the family and the individual him/herself to identify daily life activities in which the individual will be expected to engage. For example, the family and student may desire participation in grocery shopping. The job of the instructional team is to identify all the skills the student will need for grocery shopping. Possible options include:

- Cutting Coupons
- Making a Grocery List
- Identifying Food Labels
- Pushing the Cart Appropriately
- Saying *Hello* to Friends or Acquaintances
- Initiating a Request for Help in Locating an Item
- Ordering Food from the Deli Counter
- Matching Coupons to Selected Food Items
- Paying for Groceries

As a classroom teacher, the challenge is to teach community life skills in the context of the school setting. An elementary or middle school teacher, could write the following goals to ensure that students with severe disabilities learn these skills in the general education setting:

- During lunch time in the school cafeteria, Susie will request two specific food items using a communication board during 4 out of 5 days.
- During art class, Jimmy will cut coupons from the local newspaper for 15 minutes once a week.
- During math class, Jill will identify the amount needed for 10 specific food items using the next dollar strategy with 90% accuracy.
- During break time, Mark will greet two classmates in the hallway each week by pointing to *Hello, how are you?* on his communication board.
- During writing class, Scott will trace 5 words which represent grocery items 2 times each week.

When the student reaches high school, instruction should increasingly occur in real world settings. If grocery shopping is the desired activity, then the student should learn in a grocery store. Teaching students to shop for groceries in a mock classroom grocery store rarely prepares them for shopping in a real grocery store. Students with autism tend to learn cues which occur in specific context, and they cannot easily generalize learned skills across significantly different settings. They also may become dependent on adult coaches whom they come to perceive as part of the learned tasks, on sequences of events which characterize mock situations, and on other factors that frustrate their efforts to generalize skills from contrived to real-life circumstances. Recruiting peers who can model appropriate behaviors and coach individuals with autism in learning skills appropriate to natural settings is often useful in reducing dependancy and in fostering self-initiation, self-confidence and greater flexibility as new challenges are met.

For students who may have greater difficulty learning, the following suggestions may be helpful to consider:

- Train staff! In addition to workshops, conferences or other training events, there is a wealth of information on autism. Information about what and how to teach students who are severely disabled is also useful. Books written by those who have autism can provide valuable insight into those who have greater difficulty communicating.
- Work closely with parents so that skills practiced in the school setting, can be practiced in the community with family members.
- Use a team approach to make sure that the communication and sensory needs of these students are being addressed in ways that are natural to environments frequented by the student.
- Take time to teach each skill. Students may need repeated opportunities to learn and to practice a skill. Even when a skill seems mastered, students need to practice from time to time. It is also important that significantly more emphasis is placed on what a student is to do, rather than on what he/she is not to do. Accentuate the positive; remember that success begets success. A focus on failure reaps futility and future avoidance.
- Identify the type of supports individuals will need, and do not remove supports when a task is mastered. If a student needs visual cues to learn a task, he/she may always need visual cues associated with the task. If the students need a visual sequence board for the activity, do not take it away once the activity is mastered.

- It may be difficult to engage students for prolonged periods of time. Be prepared to shift activities, and to provide both easy and difficult tasks so that the student will be challenged while experiencing success. A typical day should include significantly more opportunities to perform easy tasks which promote security, than to engage in new and challenging tasks.
- Provide students with clear information about the beginning and ending times of an activity, and about the expectations of the task. Avoid taking apart and/or redoing a task that the student perceives as finished. If additional practice is needed, intersperse it throughout the day rather than requiring sequential trial repetitions.
- Embed communication into all aspects of the school day. Make sure students who are nonverbal have augmentative communication systems that are readily available throughout the day. Communication devices must also contain relevant messages for students. For example, the picture for *toilet* is probably not as motivating as a picture that depicts a student's need for time alone.
- If a student is engaging in difficult behavior, conduct a thorough assessment to determine why the behavior is occurring. Utilize positive behavior approaches which focus on teaching students alternative ways of responding to difficult situations.
- Take time to teach essential skills in places and at times when skills are needed. For example, take time to teach students to put their coats on when it is time to go outside. Have them learn to *take out* and *put away* during natural activity sequences. Avoid the tendency to do essential life tasks for students while rushing to get to less essential tasks. Generally, avoid doing for the student what he/she can be taught to do for him/herself.

All students can learn. As educators and as family members, it is our job to ensure that an environment conducive to learning is provided and that student's valuable time is used wisely. This is true regardless of the functioning level of the student.

Contributors:
Cathy Pratt & Rozella Stewart

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Including Students with Autism in Typical School Settings

Students with autism increasingly are being included in typical school settings and curriculum. Unfortunately, there remains great philosophical debate about inclusion and about what constitutes an effective inclusive program. What is clear is that we must move past the philosophical discussion if inclusion is to be successful. The following article highlights strategies to support students with autism in general education settings within the context of identified outcomes for inclusion (Sprague, Wilcox, & Pratt, in process).

Students with disabilities are equal members of the school community. This means that students should have access to the full range of curricular options, including school, after-school, and extracurricular activities. Unfortunately, many students with autism remain segregated because of behaviors or the existence of "autism" classrooms. In all cases, the first consideration when making placement decisions should be where the student lives. This strategy helps to ensure that students with autism are not clustered or unduly segregated. If students are removed because of challenging behaviors, positive programming should focus on strategies to facilitate reentry into typical settings.

Students have equal access to instructional opportunities throughout the school day. Students with autism should have the opportunity to eat lunch, play at recess, attend general education classes, and participate in school clubs with their nondisabled peers. Individuals with autism often are placed first in less structured activities. For students with autism, the level of auditory and visual input may be too intense in these settings. Unfortunately, success in unstructured activities such as gym, lunch, music, and art is used to determine eligibility for more academic-oriented classes. Instead, it may be more appropriate to place the student with autism in more structured settings that are not as chaotic and noisy. It is important to remember that student participation in general education should not be based on a readiness mindset. Students only become proficient at being in a setting by being in a setting with proper support.

Once in the general education setting, the curricular goals for students with autism may be different than those for typical students. Most important goal areas may relate to socialization, communication, and behavior.

Direct student support is coordinated by certified special education personnel. In the state of Indiana, there is no certificate for educating students with autism. Typically, staff hold a license in working with individuals with moderate or severe disabilities. As students are included in the general education setting, it becomes necessary to train general and special education staff in the areas of autism, infusing therapies in natural settings, collaboration models, augmentative communication, positive behavior supports, social skills training, and curriculum modification and adaptation.

Once in the general education setting, certified special education personnel need to be available to collaborate with staff, to problem solve programming strategies, to provide ongoing support to students and staff, to develop curriculum modifications and adaptations, to team or co-teach with general educators, and to supervise instructional assistants and peer tutors.

Students have equal opportunities for developing and enhancing meaningful social relationships. The lack of appropriate social behaviors is a defining characteristic of individuals with autism. This means that social skill development will need special attention. One strategy involves providing students with a written social protocol of how to act in specific situations. Students with autism may need to rehearse strategies. Another approach to nurturing friendships involves peer buddy or peer tutor programs. Peer programs can serve many functions. The type of program chosen will depend on the desired outcomes and the grade level.

Each student has a personal schedule that reflects identified learning and social goals. The personal schedule for each student should reflect goals identified on the IEP and curriculum options within the general education setting. Once the schedule is established, it is important to help students develop useful self-management strategies to assist them in understanding the expectations of the day and transitions. Picture or written schedules can provide students with critical information.

Effective instruction is planned and delivered. This outcome refers to the need to structure classroom instruction so that it reflects a student's learning style and uses the student's time in an efficient and effective manner. The following are possible strategies to be used in inclusive settings.

Students with autism do not easily tolerate excessive transition or down time. For example, individuals with autism often have difficulty transitioning to new activities or settings. Therefore, strategies should be in place to help the person cope with these stressful situations. Teaching relaxation techniques, desensitizing to new situations, and providing a "safe spot" in which to temporarily escape have been highly successful with many individuals with autism.

Extended periods of unstructured time provide many individuals the opportunity to fall back on inappropriate behaviors or activities. Students also may need to be taught waiting strategies to help with down time or transitions. Most importantly, professionals should ensure that the schedule provides students with a diverse range of opportunities that keep the student actively engaged in learning.

Students with autism have problems with abstract ideas and conceptual thinking. Most learn best using concrete examples and hands-on activities. One suggestion is to use manipulatives that represent real-life activities (e.g., money).

In all cases, identify the manner in which the individual learns best (e.g., modeling, visual cues, physical prompts). Individuals with autism often learn best using visual cues. This means that staff should not depend on verbal directions, but instead should use visual means to assist the student to understand what is expected of him/her. A common example of a visual cue needed by these students is written rules to help them understand classroom and behavior expectations. Having the rules written or presented in picture format can help students define the expectations of the setting and clarify their participation. Finally, if the student does not seem able to learn a task, break it down into smaller steps or present the task in various ways.

Typically individuals with autism have difficulty generalizing what has been learned from one setting to another. Therefore, teach across settings in which skills will be used.

Curriculum and instruction is adapted to meet the needs of all students. Students with autism may participate in the same activity with the same objectives or in the same activity with adapted objectives. There are many frameworks available for identifying curriculum modifications and adaptations. One system that has been used successfully in Indiana was developed by Deschenes, Ebeling, and Sprague (1994). Again, remember that goals for the individual with autism may differ from those for others. For example, while other students are working on multiplication skills, the student with autism may be focusing on identifying numbers, exhibiting appropriate classroom behavior, and initiating requests for assistance.

There is active family participation in the life of the school. Parents need to be part of an ongoing team that helps in setting goals and developing programs. Staff should develop strategies for making family members feel comfortable in school (e.g., regular reporting, parent visitations) and define potential opportunities for participation.

In all cases, programs for students with autism in inclusive settings must be individually designed. However, it is clear that individuals with autism can be highly successful if appropriate program supports and strategies are in place. These are a few suggestions that should help in your efforts to include students with autism.

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Written by: Dr. Cathy Pratt, Director, IRCA and Susan J. Moreno, MAAP Services, Inc., Crown Point, IN

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Motivating Students Who Have Autism

Motivating individuals who have autism is an essential but often difficult challenge. It is essential because, by definition, they have restricted repertoires of interests and skills needed for community living and coping. Without planned, positive experiences, these individuals often become increasingly victimized by their autism as they age. With successful experiences, each can become a victor who lives, works, and plays in the community. It is difficult, at least in part, because people who have autism are particularly vulnerable to key factors which impact motivation.

An individual's motivation is strongly influenced by: learning history; learning styles; internal and external incentives to engage in tasks; expectations of success or failure with a particular task; meaningfulness and purposefulness of the task from the perspective of the learner; and task-surrounding environmental variables which affect attention and achievement.

In general, tasks and activities which learners associate with past success tend to stimulate interest. Success begets success! Challenges which trigger memories of past anxieties and failures tend to stimulate avoidance reactions and self-preservation responses. Although occasional failure is often seen as a challenge by learners who are highly motivated to learn through problem solving, repeated failure fosters feelings of futility and frustration in fragile learners who lack self-confidence and may lack competencies for task-related problem solving.

When diligently applied, proactive strategies often prove successful in eventually eliciting positive, productive responses and pride in personal accomplishment. The following are just a few success-oriented strategies that support motivation for individuals who have autism:

Know the individual.

- Maintain a current list of the individual's strengths and interests. Include preoccupations and fascinations that may be considered "bizarre" or strange. Use these strengths and interests as the foundation for gradually expanding the individual's repertoire of skills and interests.
- Note tasks or activities which create frustration and heightened anxiety for the individual. Attention to these factors can result in avoiding episodes which perpetuate insecurity, erode confidence, foster distrust in the environment, and generally result in avoidance behaviors.
- Pay attention to processing and pacing issues which may be linked to cognitive and/or motor difficulties inherent to the individual's autism. Give the individual time to respond. Vary types of cues given when movement disturbances are suspected.

Structure a supportive environment. Both the social and physical milieu should encourage and support successful task performance.

- Teach in natural environments that contain the cues and reinforcement which prompt and maintain learned behaviors whenever possible.
- Be sure that everyone involved encourages and supports independent effort whenever possible. Willingness to try to perform independently as opposed to remaining dependent on others results when the individual attributes successful performance to his own efforts rather than to external factors.

- Plan optimally stimulating (neither too stimulating nor too nonstimulating) tasks and activities. Plan ways to decrease the impact of environmental distractors that interfere with task initiation and completion.

Use instructional strategies which support successful outcomes.

- Assemble materials, or teach the learner to assemble materials, in task-appropriate sequences.
- Teach new tasks by providing examples or modeling so the learner has a clear vision of task sequences and expected outcomes.
- Incorporate learning tasks into preferred topics and activities.
- Plan tasks and activities that result in meaningful outcomes from the perspective of the learner.
- Vary tasks and activities frequently as opposed to requiring boring repetition. Conversely, capture opportunities to expand learning when interest is high.
- Plan and present tasks and activities at an appropriate level of difficulty for the individual involved.
- Provide instructions or information visually as opposed to verbally to decrease distraction and to make information more user friendly for the person.
- Introduce unfamiliar tasks in a secure environment so that later learned familiarity will capture the individual's attention in more challenging environments. For example, if science class is going to discuss the stars during class time, parents might observe a night sky with their son/daughter. This provides a familiar link to subsequent school experiences. This familiarization process is sometimes referred to as "teaching pivotal behaviors." Learned behaviors become pivotal in motivating the individual to attend to tasks in a variety of situations.
- Assign specific models for the individual to observe and imitate when in group activities such as circle time or group exercises. When in more fluid group situations, assign or help the individual to select a specific role which he or she can perform. Teach the individual how to perform selected roles.
- Plan for successful outcomes that can be achieved "here and now" rather than at some more distant time. Reinforce all goal-directed attempts at first rather than pushing for a perfect response.
- Structure motivating event sequences in which the less familiar, less preferred activity is followed by the familiar, preferred experience. (First _____, then _____.) Structure short, successful experiences with less preferred activities and longer, equilibrium restoring experiences with more preferred, easier-to-tolerate activities. This strategy works particularly well for very hesitant learners who have extremely restricted repertoires of interests.
- For learners with broader repertoires of interests and skills, build motivational momentum by beginning with highly preferred, success-guaranteed tasks and alternating such tasks and activities with less preferred, more challenging tasks throughout the day. This strategy also works for individuals who are so highly aroused by anticipated preferred events that they can not focus on other tasks until the highly stimulating need has been addressed.
- Focus on errorless learning. Teach (perhaps by modeling or having a peer model) the person to do the task right the first time.
- Avoid having the learner undo or disassemble products which he or she perceives as finished. Erasing work or taking apart finished products often makes no sense to the learner and may result in a "Why do it?" response mode. Plan ways to correct or repeat work that do not involve undoing what has been done.

- Offer attention-getting choices which stimulate personal involvement.

In general, accentuate the positive; disempower the negative.

Finally, remember that failure, sarcasm, ridicule, and apparent lack of confidence on the part of those who live and work with people with autism decrease motivation and perpetuate cycles of learned helplessness. Increased motivation results from experiences which teach people how to interact with both social and physical environments in ways that result in positive outcomes. While always most secure with the familiar, resistance to the unfamiliar decrease and inclinations to try gradually increase as people with autism learn that they will be okay and that they might even enjoy a new experience.

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The University Affiliated Program of Indiana *Contributor: Rozella Stewart* 5/96
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IEP: MODIFICATIONS ADDENDUM/SUPPORTS CHECKLIST

STUDENT______________________DOB ____-____-____ DATE ____-____-____

Modifications needed for this student to assure participation in regular and supportive programs including participation in extracurricular activities are specified below.

Pacing

____ Extend time requirements
____ Vary activity often
____ Allow breaks
____ Omit assignments requiring copy in timed situation
____ School texts sent home for summer preview
____ Home set of texts/materials for preview/review
____ Other:______________________

Environment

____ Preferential seating
____ Planned seating: ____Bus ____Classroom
 ____Lunchroom ____Auditorium
____ Alter physical room arrangement
____ Define areas concretely
____ Reduce/minimize distractions:
 ____Visual ____Auditory
 ____Spatial ____Movement
____ Teach positive rules for use of space
____ Other:______________________

Presentation of Subject Matter

____ Teach to student's learning style
 ____Visual ____Auditory ____Model
 ____Tactile ____Multi ____Experiential learning
____ Individual/small group instruction
____ Utilize specialized curriculum
____ Tape lectures/discussion for replay
____ Provide notes
____ Functional application of academic skills
____ Present demonstrations (model)
____ Utilize manipulatives
____ Emphasize critical information
____ Pre-teach vocabulary
____ Make/use vocabulary files
____ Reduce language level or reading level of assignment
____ Use total communication
____ Use facilitated communication
____ Share activities
____ Use visual sequences
____ Other:______________________

Materials

____ Arrangement of material on page
____ Taped texts and/or other class materials
____ Highlighted texts/study guides
____ Use supplementary materials
____ Notetaking assistance: carbonless or xerox copy of notes of regular student
____ Type teacher material
____ Large print
____ Special Equipment:______________
 ____Electric typewriter ____AAC device
 ____Calculator ____electronic
 ____homemade
 ____Computer ____Telephone adaptations
 ____Video recorder
 ____Other:____________

Assignments

____ Give directions in small, distinct steps (written/picture/verbal)
____ Use written backup for oral directions
____ Lower difficulty level
____ Shorten assignment
____ Reduce paper and pencil tasks
____ Read or tape record directions to student
____ Give extra cues or prompts
____ Allow student to record or type assignment
____ Adapt worksheets, packets
____ Utilize compensatory procedures by providing alternate assignment/strategy when demands of class conflict with student capabilities
____ Avoid penalizing for spelling errors/sloppy papers/penmanship
____ Other:______________________

Self Management/Follow Through

____ Visual daily schedule
____ Calendars
____ Check often for understanding/review
____ Request parent reinforcement
____ Have student repeat directions
____ Teach study skills
____ Use study sheets to organize material
____ Design/write/use long term assignment timelines
____ Review and practice in real situations
____ Plan for generalization
____ Teach skill in several settings/environment
____ Other:______________________

Testing Adaptations

____ Oral
____ Taped
____ Read test to student
____ Preview language of test questions
____Short Answer
____Multiple Choice
____Modify format
____ Shorten length
____Application in real setting
____ Test administered by resource person
____ Extend time frame
____ Other:______________________

Social Interaction Supports

____ Peer advocacy
____ Peer tutoring
____ Structure activities to create opportunities of social interaction
____ Focus on social process rather than activity/end product
____ Structured, shared experiences in school, extracurricular
____ Partial participation
____ Cooperative learning groups
____ Use multiple/rotating peers
____ Teach friendship skills/sharing/negotiation
____ Teach social communication skills
 ____Greetings ____Conversation turntaking
 ____Sharing ____Negotiation
____ Other:______________________

Motivation and Reinforcement

____ Verbal
____ Non-verbal
____ Positive reinforcement
____ Concrete reinforcement, e.g., ____________
____ Planned motivating sequences of activities
____ Reinforce initiation
____ Offer choice
____ Use strengths/interests often
____ Other:______________________

* *Adapted form North East Independent School District of San Antonio, Texas, by IRCA 10/92.*

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Behavioral Issues and the Use of Social Stories

A frequent positive programming recommendation for an individual with autism is that the family or the staff of an agency develop one or more "social stories" to present particular information or to address specific situations. Such a recommendation may reflect either a proactive or reactive programming stance. Regardless of its purpose, the development and use of social stories is often a task that is underestimated in terms of its complexity, or one that may simply be misunderstood. This article will attempt to identify some of the issues that should be considered when using this intervention tool.

"Social stories" have become a popular programming buzzword. Trainings about the development and use of social stories can be quite varied experiences on the inservice market. This may occur because "social stories" is both a program-specific term and a generic term. The program-specific term was initially used by Carol Gray as a descriptor for her intervention strategies. *(Gray has presented her information at many conferences and has published various print resources regarding the programming and materials developed and piloted within her school district. Her materials are presently available from Future Horizons and are identified under the rubric of Social Stories Unlimited™, although most people simply use the term "social stories.")*

"Social stories" as a generic term currently refers to print- or text-supported picture material that presents information or scripting. The informal intervention concept pre-dates the program introduced by Gray. The informal "stories" may or may not be stories in the sense of having a plot or a narrative form. Rather, they may be descriptive of a situation, or may outline the steps in a sequence or process. Some forms might be called "social scripts." People who talk about social stories in this generic sense may or may not be utilizing any of the guidelines of Gray's program. These "stories/scripts," however, can also represent a legitimate means of providing visual information and support for a person with a social/language-processing disability.

Whether one chooses to follow Gray's program or not, much can be learned by looking at her program and at the considerations regarding its implementation. The development of social stories, as defined by Gray, places a central focus on writing the stories in a positive tone. A given story may have an impact on the reduction of a specific behavior because of the information and insight it provides for the person with autism. The stories are not meant to be judgmental or to be strongly directive. In order to avoid the latter tone, Gray developed her published guidelines regarding the ratio of sentence types for each social story. The stories try to help the person with autism have a better understanding of the parameters of a problem situation and to have some idea of how to cope, manage, or operate within that situation.

Social stories usually are not a unilateral means of changing behavior or the performance of the person with autism, however. More typically, social stories may represent only **one** intervention strategy out of several that may be needed in order to impact or reverse a given situation. For example, if John experiences much frustration in the classroom and he releases some of his tension by hitting other students on the playground, his positive program might involve many components. It might include a *social story* about being a good friend and sharing, but it may also include a reassessment of his academic skills and the subsequent addition of extra academic support, the adaptation of work assignments, inservice training for support staff to increase daily instances of positive interaction, general instruction regarding social skills, and specific teaching of playground games and rules in order to facilitate successful outdoor play. The social story might not be effective enough by itself to modify a complex situation such as John's frustration and aggression, but it might have a powerful impact when combined with other tailored strategies.

Factors to consider when writing a social story for an individual include the following:

- Know that social stories will not work with everyone. For some individuals, they may be inappropriate; for others, they may be especially inadequate, if used as a **sole** intervention tool.

- Know Gray's guidelines and the literature regarding the writing of good social stories, even if you choose not to use her approach.

- Gather appropriate information about the complexities of the situation before attempting to write a social story.

- Consider doing a positive programming behavior analysis with the **key** people involved in a situation before writing a social story.

    - Identify the cluster of strategies needed for circumventing or managing a certain situation. The development of a social story could be a high or low priority, depending on the individual situation. One or more stories may be needed when the strategy is appropriate.

    - A story should only be written if one has some idea of WHY, that is, for what purpose(s) the individual is engaging in a specific behavior. A story may have a totally inappropriate focus or present an irrelevant set of information if the person is engaging in a behavior for a different reason than what is covered in the social story.

    - A behavior analysis would also identify the frequency of a behavior and if it is specific to a given setting or person. Sometimes ignoring a specific behavior is a better positive programming strategy than making an effort to call attention to it.

- View the social stories in the books available from Future Horizons only as examples of how to write a positive story. It is important to remember that each story should be written for a specific child. The child or student's behavior may have different factors that need to be considered or addressed than what appear in the example story. Many of the sample stories were written, under Gray's supervision, by high school students in psychology classes. Family members and adult staff, who have broader experiences and more personal knowledge of the person for whom the stories are intended, may incorporate some different insights and information into their narratives.

- Have other people review the story before presenting it to the person with autism. Consider involving a speech language pathologist in the review process since language comprehension is frequently an issue. The reviewer will want to consider:

    - *The agenda or purpose of the story.*

      Is the story written with the objective of promoting self management, positive self esteem, a better understanding of the seemingly confusing world around the individual, and with recognition of what is difficult for people with autism?

    - *The level of language used in the story.*

      Does the child know the vocabulary? Is the grammar too complex or are sentences too detailed? Conversely, is the text level too simple for someone with more sophisticated language skills?

    - *The processing demands of the story.*

      Are some steps or any information missing? Does the individual have to make inferences that he or she cannot easily make? Is the story line brief but too complex? Is the individual missing some prior experiences or basic understanding that will make comprehension more difficult? Is it clear how the individual might handle a situation in a positive manner in the future?

    - *A positive message.*

      Is the story more of a "Thou shalt not . . ." commandment than a positive source of information? Does the thrust of the story depend on the individual being empathetic and understanding of the feelings of others (*something that is difficult for the person with autism*)? Does the story try to foster a feeling of guilt or shame, for example, "Don't do X so Mommy will be proud of you"?

    - *The plan for the use of social stories.*

      Has a plan been devised about who will introduce the social story, who will supervise use, and who will monitor and revise the plan or story, as needed?

Just as social stories may be one piece of a behavior or positive programming plan, it is also important to remember that social stories represent one strategy when attempting to teach social skills. Multiple strategies are usually needed in this area as well. Numerous books, articles, and materials are available as resources for developing and implementing a social skills training program.

Resources Regarding Social Stories:

Monographs:

Jenison Public School publications: *New Social Stories, Taming the Recess Jungle,* and *Comic Strip Conversations*
Available from: Future Horizons, 720 North Fielder, Arlington, TX 7601, Phone: 800-489-0727, Fax: 817-277-2270

Articles and Book Chapters:

Gray, C. (1993). Social stories: Improving responses of students with autism with accurate social information. *Focus on Autistic Behavior, 8*, 1-10.

Gray, C. (1996). Teaching children with autism to "read" social situations. In K. Quill (Ed.), *Teaching students with autism: Methods to enhance learning, communication, and socialization* (pp. 219-242). New York, NY: Delmar Publishers.

Gray, C. (1996). Social assistance. In A. Fullerton (Ed.), *Higher functioning adolescents and young people with autism* (pp. 71-89). Austin, TX: Pro Ed Inc.

Newsletter:

Morning News, c/o Carol Gray, Jenison Public Schools, 2140 Bauer Road, Jenison, MI 49428

Resources Regarding Positive Programming and Positive Behavior Support Components:

Books:

Carr, E. G., Levin, L., McConnachie, G., Carlson, J. I., Kemp, D. C., & Smith, C. E. (1994). *Communication-based intervention for problem behavior: A user's guide for producing positive change*. Baltimore, MD: Paul H. Brookes Publishing Company.

Demchak, M. A., & Bossert, K. W. (1996). *Assessing problem behaviors*. Washington, DC: American Association for Mental Retardation.

Koegel, L. K., Koegel, R. L., & Dunlap, G. (1996). *Positive behavioral support: Including people with difficult behavior in the community*. Baltimore, MD: Paul H. Brookes Publishing Company.

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The University Affiliated Program of Indiana *Beverly Vicker, 6/97*

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A Young Adult's Guide to Deep Breathing as a Relaxation Technique

(written in social story format)

◆

Developed by:
Beverly Vicker
Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
The University Affiliated Program of Indiana
Indiana University

I get nervous or tense sometimes when I am at work. Everybody gets nervous or tense sometimes.

When I am home and I get nervous, I can go to my room and relax. I might lay on my bed or turn on some soothing music. Other people might listen to relaxation tapes. Some like tapes with the sound of the ocean surf.

When I am at work, I can't lay down or put on a tape. I will have to use other ways to calm myself.

If there is a "big" problem at work, I may need to talk to my supervisor or job coach. He or she can help me find ways to solve the problem.

Some problems, however, are "little" problems. I solve them by myself. I can deal with "little" problems by helping to relax myself. When I am tense, I can't think well. I think better when I am calm.

There are many things that people can do to get rid of tension. Many of them cannot be done at work. Many of them would draw attention to me even if I could do them at work.

One strategy for "little" problems is called Deep Breathing. It is a safe and easy thing to do, if I follow the rules. It also is something that I can do without other people knowing that I am tense and am trying to relax. I want to take responsibility for myself as much as I can because I am an adult. Deep Breathing is an important strategy for me to know.

I need to practice Deep Breathing when I am not nervous or tense. When I can do it easily and correctly many times in practice, then I can try it in a real situation.

* * *

Before I begin to practice, I need to know something about me.

- **I need to know what it feels like to breathe normally and how deep breathing is different. First, I will want to watch my stomach and my chest to see how much they move away from my body when I do normal breathing. Then I want to watch my stomach and my chest when I am taking in more air or oxygen. I will want to close my eyes and think about how each way of breathing FEELS DIFFERENT.**

- I need to know how many times I normally breathe per minute. Most people, when they breathe normally, breathe somewhere from 12-20 times per minute. My Mom or someone else can help me time myself. Knowing what is normal for me is very important. When I deep breathe, it should be less than normal. If it is not, I'm doing the deep breathing too fast and I may not relax.

* * *

These are the things I need to do to practice:

- I need to take in a little more air through my nose than normal breathing. I can use my imagination to help me relax. I can pretend that the breath is coming up to my chest through Swiss Cheese holes in my feet. I can still tell myself to "calm down" while doing the breathing.

- Then I need to hold my breath for about 5 -10 seconds. A respiratory therapist said this step is important.

- I need to let the air SLOWLY escape from between my lips. My lips can be open just a little so no one knows what I am doing. It should take 3-5 seconds to let the air out.

Maybe Mom or my job coach can help me decide when I am ready to use Deep Breathing in a real situation.

Deep Breathing won't help me fix all of my problems. But, it is nice to know a strategy that may help me some of the time. Adults like me need to know many strategies for helping ourselves in a world that is often busy and confusing. I like to feel relaxed as often as I can.

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The University Affiliated Program of Indiana

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Planning for Successful Transitions Across Grade Levels

Transition is a natural part of all educational programs. Students with and without disabilities are expected to adjust to changes in teachers, classmates, schedules, buildings, and routines. The transition from one grade to the next can be especially challenging for the student with autism. However, it is clear that these students can make this shift if careful planning and preparation occurs. Below are suggestions for facilitating a smooth transition:

- Preparation for transition should begin early in the spring. Whether a student is moving to a new classroom or to a new building, it is helpful to identify the homeroom teacher or general educator who will have primary responsibility for the student.
- Once the receiving teacher is identified, involve this person in the annual case conference process so that they may gain information about the student's current level of functioning and can provide input into projected goals.
- Written transition plans may facilitate the student's successful movement. A meeting should be conducted to allow key participants to exchange relevant information. Responsibilities and timelines for individuals involved in the transition should be clearly stated.
- Either during the annual case conference or at the transition planning meeting, information should be exchanged about effective instructional strategies, needed modifications and adaptations, positive behavior support strategies, and methods of communication. The receiving teacher should learn about the strategies that have worked in the past so that precious time is not lost at the beginning of the new school year.
- The receiving teacher may find it helpful to observe the student in his/her current classroom or school setting. This will provide important insight into the student's learning style.
- Instructional assistants who will be involved in the student's daily education should be identified, educated, and informed about their role in the student's education.
- Many teachers may not have previous experience with students with autism. Therefore, they will need basic information about autism and about how autism impacts the student with whom they will be working. Student-specific information about learning styles, communication systems, and behavior supports is also critical. Remember to include cafeteria workers, custodians, bus drivers, the school secretary, and the school nurse in the training. Classmates of the new student also may need

information. This should be provided in a respectful manner and without stigmatizing the student with autism.

- Before entering a new school, work to alleviate any anxieties the student with autism may have about the new setting. Preparation for this move can be facilitated by providing the student with a map of the school, a copy of his/her schedule for the fall, a copy of the student handbook and rules, and a list of clubs/extracurricular activities.
- Develop a videotape about the new school and provide written information about specific situations so that the student can learn and rehearse for the change at his/her own pace.
- Visitations should be conducted to allow the student and his/her family to meet relevant school staff, to locate the student's locker, and to become familiar with the school culture.
- Identify for the student key people she/he can contact if she/he is having a difficult time adjusting or understanding a certain situation. It may also be helpful to find a location where the student can go to relax and to regroup.
- Parents should receive information about bus schedules, parent-teacher organizations, and available resources (e.g., counselors, social workers, nurses).
- Prior to the new school year, it will be helpful to establish methods and a schedule for communicating between home and school. Suggestions for maintaining ongoing communication include journals, daily progress notes, mid-term grades, scheduled appointments or phone calls, informal meetings, report cards, or parent-teacher conferences.
- Once in the new school, ask for peers who are willing to help the student with the transition and acclimation to the new school. By gaining the support of a friend without a disability, the student with autism may have greater access to social opportunities during and after school.

The ultimate goal is to promote a successful experience for both the student and the rest of the school community. By systematically addressing the transition process, students with autism can be prepared to participate in their new school experience.

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Peer Support Programs

As the school year begins, special and general education teachers must consider how the educational needs of students with autism will be met across a variety of instructional settings. Questions arise about who will support the student during classroom instruction, in the resource room, at lunch time, and during special activities. In addition, involvement of students with autism in extracurricular and after school activities becomes a primary concern. One strategy that has been successful in the state of Indiana and elsewhere is the use of peers. Regardless of the grade level or the area of need, peers have been crucial in helping students with autism to succeed in typical school and community activities. Here are some suggestions for using peer supports in your school:

- Involve students with autism in cooperative play and shared learning arrangements during the early childhood and elementary school years.
- Pair elementary age students with autism with buddies while walking down the hall, when playing on the playground, and during other unstructured times of the day. To prevent dependence on one child, vary buddies across time and activities.
- Build cross-age peer/buddy supports by assigning older students to assist a student with autism with classroom activities. For example, fifth graders can be used to help first graders.
- Assign peers to help the student become acclimated to their new setting when a student with autism transitions to a new school.
- Assign peers at the middle and high school level to instruct students with autism in classroom activities. The peer can be seated next to the student with autism and assist with keeping him/her on task and with completing assigned work.
- Provide individualized instruction through peer support in a resource area of the school.
- Pair students with autism with peers while attending special school events such as school assemblies and clubs.
- Facilitate students' involvement in after-school or extracurricular activities, such as school dances and athletic events by using peers. These arrangements can serve as the basis for a real friendship.
- Recruit peers to assist students with autism in completing homework assignments. Peers can be recruited by fancily members to further tutor students at home.

- Assist students with autism to support their classmates. Utilize the strengths of specific individuals with autism to build relationships with peers. For example, a student with autism who excels in computers can teach his/her classmates how to use a computer.

Peer support can serve a variety of functions for students with autism in the school community. With the ever expanding needs of students and diminishing resources, peer support programs become a necessary strategy to ensure that all students gain maximum benefit from the school day.

Contributed by:
Dr. Cathy Pratt, Director

The Indiana Resource Center for Autism (IRCA) is one of four of the Institute's seven centers with a cross-age focus in developmental disabilities (technology and technological adaptations, disability information, planning and policy studies, and autism). The three others focus on age-related issues (young children, school-age, and adults and seniors). The ISDD is dedicated to the promotion and maintenance of a seamless system of inclusionary services across the lifespan. Institute activities include interdisciplinary training, information dissemination and research, and community services.

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Advice for Peer Tutors
By Susan J. Moreno, M.A. and Cathy Pratt, Ph.D.

When you do not know how to help, ask a teacher, a program assistant, the parents or a sibling of the student with autism, or another peer tutor who has known the person longer. Know to whom you may turn for help or advice for your classmate with autism before you start working with him/her.

Treat classmates with autism like people first. People with autism are just that: people who happen to have the disability of autism. Please avoid references to "the autistic" or "the disabled." Rather say, "the person with autism." These individuals have the same feelings and personalities as you. They just cannot always show it as clearly.

Be consistent in how you refer to your classmate with autism. Use whatever name he/she prefers. Avoid calling him/her by their given name one time and by a nickname like "pal" or "buddy" the next.

Be specific when discussing plans or directions. For example, do not say, "I'll meet you near the room after class." Instead say, "I'll meet you at locker number 220 at 12:05 p.m."

DO NOT BE LATE! Many people with autism have a hard time understanding the concepts of time and waiting. Therefore, when you are late, they are not able to figure out on their own that an emergency or some other event may have delayed you. The result is that they may feel confused, upset, and insulted. If necessary, plan to be early and wait for him/her.

Remember that taking a little extra time or trouble to include the person with autism in your social plans could be very important to him or her. They need and want friends and social opportunities, and do not always know how to show that need to others.

Do not tease or be sarcastic with the person with autism. In order to understand the humor in teasing or sarcasm, people must be able to detect double-meanings. The person with autism may not have that knowledge. Teasing has probably already been a very unpleasant part of that person's life.

If you see others teasing, laughing at, or making fun of a person with autism, try explaining a little about the person to them. They may only be laughing because they do not understand the person or the disability.

Do not make promises that you cannot keep. Avoid phrases like, "maybe we'll go to the show together someday." This may be interpreted as a promise. They seldom process all of the qualifiers, such as "maybe" or "someday."

Do not borrow things from the person with autism. Having others borrow items can be frustrating for any person—mainly because people seldom return what they have borrowed on time and/or in the same condition that it was before it was borrowed. The person with autism already handles too many frustrations in daily life. This is one frustration which easily can be avoided.

Remember that you can play an important role and make a wonderful difference in the life of a person with autism.

For more information contact: Susan Moreno, MAAP Services, Inc., P.O. Box 524, Crown Point, IN 46307.

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Integrated Therapy

Many students with autism benefit greatly from the services provided by therapists. By utilizing the expertise of speech language pathologists, students with autism learn to respond to questions, to initiate requests for assistance, and to relay other important messages. Occupational therapists assist students with developing fine motor skills for eating, writing, and typing. Some occupational therapists can guide students through sensory integration activities. While it is clear that therapists serve a valuable service, controversy remains over where these services should be provided to be most effective.

Traditionally, therapy services were provided in isolated settings. For example, students with autism worked with the speech language pathologist in a room away from the classroom and removed from classmates. Today there is a shift in the service delivery model used by therapists. Many are realizing that infusing therapy services into the activities of the school community can have the greatest impact. This is true for two reasons. First, students with autism have great difficulty generalizing learned skills from one setting to another. It is not unusual for the speech language pathologist to report the student as having a skill that is not demonstrated at home or in the classroom. Second, students with autism learn skills within a specific context. They cue into various pieces of information in the environment which prompt them to perform a skill or activity. For example, a student with autism may need to learn to respond to a greeting while walking down the hall between class periods. By practicing this skill in the hallway, the context for greeting is presented, and classmates are readily available to model greeting.

Providing therapy services in classroom settings presents a new challenge for both the therapists and classroom teacher. Both must shift from being the sole professional in charge of teaching specific skills to sharing classroom space, instructional time, and goals. This shift in service delivery also requires that the individualized education program (IEP) goals be collaboratively determined. No longer does it make sense to write goals such as:

- Susan will correctly respond to "wh" questions.
- Jimmy will demonstrate a pincer grasp.

In reality, communication, and fine and gross motor skills are not used in isolation from other activities. In both instances, a more effective strategy is to embed related service goals within the context of other instructional objectives. For example:

- Upon arrival to the school cafeteria, Sally will point to the desired food items on her communication board once daily during a 7-week observation.
- During a 9-week gym class, Bobby will complete 10 minutes of an exercise routine with classmates each day.

This method of providing services may also require a shift in scheduling for the therapist Instead of developing a schedule whereby students are seen every 30 minutes twice a week, the therapist may spend extended time in each setting for a few days each week. For example, a speech language pathologist may spend the afternoon in a classroom which contains several students who are receiving services. The therapist may work with one student to encourage the use of a communication board to request assistance or to respond to questions. He or she may work with another student to frame responses in complete sentences. The therapist may also spend this time assessing communication systems to determine whether changes need to be made or to collect data to determine progress.

By being in more natural settings, therapists can remind professionals and family members of strategies that will help the student be more successful in real life settings. For example, the speech clinician can work with the classroom teacher to help the student with initiating requests for assistance or responding to questions. In the community, therapists can teach students how to request food from a fast food restaurant respond to requests for payment, and initiate conversation with a familiar acquaintance. As the student prepares for community employment therapists can spend time in the community ensuring that the skills learned during the school years generalize to job situations. For example, the speech language pathologist can help the student with autism learn how to communicate the need for assistance or for a break. The occupational therapist can assist with organizing a job setting so that students can perform to the maximum extent possible.

By being creative in our approach to working with students with autism, everyone benefits. By infusing therapy services into the instructional day of students, classmates learn how to support the interaction and instruction of their friends with autism. The presence of therapists in the classroom can provide teachers with colleagues with whom to brainstorm ideas and strategies. And most important the likelihood that students will be able to learn and practice skills in natural settings is increased.

Contributed by:
Dr. Cathy Pratt, Director

The Indiana Resource Center for Autism (IRCA) is one of four of the Institute's seven centers with a cross-age focus in developmental disabilities (technology and technological adaptations, disability information, planning and policy studies, and autism). The three others focus on age-related issues (young children, school-age, and adults and seniors). The ISDD is dedicated to the promotion and maintenance of a seamless system of inclusionary services across the lifespan. Institute activities include interdisciplinary training, information dissemination and research, and community services.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

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Transition: Preparing for a Lifetime

Each year, multitudes of students prepare to leave school in search of the perfect job, place to live, relationships, and lifestyle. For a person without a disability, this dramatic change from the secure world of school to the uncertainty of adulthood can be stressful and challenging. For a person with autism, this shift can seem even more complex and demanding. Across the nation, a strategy called "transition planning" is being used to ease the move from school to adulthood for students with autism. Faced with similar fears and building on the experience of the special education system, the general education community has adopted the school to work movement. Unfortunately, despite years of mandated transition planning and a continued interest in preparing students for real life, many continue to experience high drop-out rates, high unemployment, low wages, few job choices, limited relationships, and restricted living options. In addition, some leave school unprepared to handle simple daily routines such as paying bills, balancing a budget, and maintaining an orderly living environment. This bleak outlook requires that those who are involved in the education of students with autism begin to systematically and seriously pursue effective transition planning.

So what exactly is transition planning? According to federal regulations, students who are beneficiaries of individualized education programs (IEPs) must have transition services outlined beginning at the age of 16. According to Osborn and Wilcox (1992), transition planning serves several important functions:

- Introduces the family to the adult service system;
- Determines support required by the student to live, work, and recreate in the community as an adult;
- Identifies adult service system gaps and inadequacies, enabling transition team members to advocate more appropriate services;
- Provides information to adult service providers about individual needs so that providers will not assume all people with disabilities have identical needs when planning services and implementing programs; and
- Provides information critical to determining appropriate IEP goals. Through the IEP, parents and educators can target skill development necessary for a smooth transition.

In many states, individual transition plans (ITPs) are used as the mechanism to guide activities related to transition. Interestingly, the general education community has developed a parallel format, referred to as Individual Career Plans, which focuses on helping students without disabilities move from school to work. In some states, school districts write both Career Plans and ITPs for students with disabilities. The Career Plan focuses solely on work, while the ITP document becomes the mechanism to begin to discuss the following issues:

- Work/Post-School Options
- Income Support/Insurance
- Residential Options
- Transportation Needs
- Medical Needs
- Community Recreation and Leisure Options
- Maintenance of Family/Friend Relationships
- Advocacy/Guardianship
- Trusts/Wills and Long-Term Planning
- Graduation or School Exit Date

Quite simply, the ITP should address a job, a home, friends, family, leisure and recreation opportunities, and long term life planning. The desired outcome is that young adults with autism will enjoy a good quality life. However, how one defines a quality life is subject to individual interpretation. To avoid determining a life which does not reflect the individual's goals, the most important participant in the planning process is the person with autism. Each person should have the opportunity to choose leisure activities, job opportunities, personal schedules, living arrangements, and so on. Involving the person with autism in his/her own transition planning is called self-determination. Self-determination refers to the obvious step of making one's own life choices, setting personal goals, and initiating a plan of action. As simple as this seems, determining one's future requires certain skills including the ability to:

- Communicate preferences;
- Set achievable goals;
- Make choices;
- Manage one's time;
- Identify and solve problems;
- Learn how to access resources; and
- Self-advocate (Wehmeyer, 1993/94).

A method for assisting in designing a vision and plan of action with the individual is referred to as person-centered planning. This process sometimes provides the person's support network with the opportunity to articulate a future vision with the person, and to clearly develop a plan of action for achieving this vision. Once all involved have a common understanding of the person's desired path toward adulthood, it is time to begin the formal process of planning and programming for the shift to adulthood. The individual transition plan (ITP) should focus on current and future goals, identify strategies for achieving identified goals, present a time line for follow-up, identify responsible persons or agencies for each objective, and clarify how various roles will be coordinated. Vocational goals and objectives must be further articulated on the IEP. To promote the movement of students from school to post-school options, vocational rehabilitation (VR) counselors in Indiana receive student information beginning the freshman year of high school. This practice differs across states.

While the ITP document provides the format for careful planning and program development, there is still much to consider when preparing a person with autism for adulthood. Below are a few considerations:

- When choosing a curriculum or course of study, encourage the person to make choices which both peak their interest and lead to a real job. Many times, areas of interest may not lead to feasible job options. In these cases, people are being prepared for a lifetime of dependency on social services or jobs which are not good matches.

- During the school years, there are skills which can be taught within the context of the school curriculum which will promote future success. Competencies such as being organized, being prepared, completing assigned tasks, following directions, and interacting with others are important work skills.

- Involve the person in curriculum options which will teach other important life skills, such as cooking, repairing items, and handling personal finances.

- Encourage the involvement of students with autism in extracurricular activities, school clubs, and other social events in hopes of building a network of support for the person that can assist in accessing employment later.

- During the school years, pursue apprenticeship programs, volunteer positions, or other options that will allow the person to gain experience in a real work environment.

- Begin to build a resume for the individual. These can be done in various formats by using video, computer, or portfolios that portray competencies.

- Gradually prepare the individual for the nuances and social demands of the work place. Some behaviors are clearly against the rules of most work environments. Other behaviors will serve to annoy co-workers and may result in termination. Teach behaviors appropriate to specific work sites while in the natural setting.

- Begin to teach the individual appropriate hygiene and dress for specific work settings.

- It may be important to teach the person a menu of social interchanges around appropriate topics that can be used to assist with office small talk and during job-related discussions.

- Initial preparation of the job site can avoid unnecessary difficulties and promote long-term success. Present information in a manner that is respectful of the individual with autism and of his/her co-workers.

- Although co-workers will serve as the most efficient and effective method of long-term support, a job coach or other support personnel may need to be available to problem-solve difficult decisions and to assist the individual in adjusting to his/her work environment. Once on the job, it may be helpful to identify a mentor whom the person can readily turn to for assistance and advice.

- When examining job options, consider safe and efficient means of transportation. If public transportation is preferred, supply the person with routes, schedules, and other relevant information. If not, creative options such as hiring drivers, arranging taxi service, or sharing travel expenses with co-workers in exchange for transportation can be pursued.

People with autism can make an important contribution to society. Unfortunately this contribution is not capitalized on when the person is not prepared or supported. As family members and professionals, our job is to guide the person in determining a future which is both meaningful and realistic. With careful planning, people can leave school prepared for a lifetime of struggles and successes.

Contributor:
Cathy Pratt, Ph.D.
Director
Indiana Resource Center for Autism

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The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

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LOVAAS REVISITED: SHOULD WE HAVE EVER LEFT?

Images of people with autism are among the most striking many of us will ever encounter. Sometimes these images are of individuals engaging in intense, violent, and often self-destructive behaviors. Other times these images are powerful because of the amazing skills and accomplishments of individuals who face such difficult challenges in doing things many people consider routine. Regardless of the image we hold of people with autism, our common ground lies in our desire to help such individuals to lead more fulfilling and productive lives. How we accomplish this--as family, friends, and professionals--remains both the obstacle and the challenge.

The past thirty years have seen a myriad of interventions targeted at people with autism. The interventions have typically fallen into one of three "camps"--medical, psychological, or behavioral. All of these types of interventions have had their respective proponents and detractors. All have been thoroughly documented and disseminated, but only a few have been empirically validated as to their effectiveness within the scientific community. One such category of intervention is behavior modification.

Though the application of behavioral principles to the education and "treatment" of people with disabilities is hardly new, the publication of the 1993 book, *Let Me Hear Your Voice*, has pushed behavior modification, specifically early intensive behavioral therapy, once again to the forefront in the education and treatment of people with autism. The question that comes to mind for many is, "Should it have ever left the forefront?" It is clear that the publication of *Let Me Hear Your Voice* has been the catalyst for a new wave of excitement, hope, and controversy surrounding the application of "behavior modification" techniques to young children with autism.

The controversy surrounding *Let Me Hear Your Voice* centers on the concept of "recovery from autism," something which is foreign (and contradictory) to many involved in the lives of people with autism. *Let Me Hear Your Voice* tells the story of the Maurice family and their attempts to find treatments which will cure their two children of autism. The Maurice family's hopes for the treatment of their children center around their discovery of the 1987 article, "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children," published by Ivar Lovaas, a UCLA researcher, in the *Journal of Consulting and Clinical Psychology*. The article describes the outcomes of intensive behavioral interventions for a pre-school aged group of children with autism. In this article and subsequent writings, Lovaas has described three distinct groups as emerging following intensive early intervention: (1) a recoverable group of individuals who, following intervention, no longer demonstrate the characteristics of autism; (2) an intermediate group who make substantial progress but who still demonstrate characteristic autistic behaviors; and (3) a small group of individuals who benefit little from the intervention. The Maurice family focused on "the 47% of subjects (nine out of nineteen)" in the 1987 study, who were described as having recovered from their autistic deficits, and established an intensive home-based therapy program which featured behavior modification therapy based on the principles set forth in Ivar Lovaas's 1981 book *Teaching Developmentally Disabled Children: The Me Book*. The Maurice's report achieving a similar state of recovery for both children.

The Me Book

Teaching Developmentally Disabled Children: The Me Book, published in 1981 by Ivar Lovaas, is the primary source for the application of intensive behavioral therapy for children with autism. The book is a training manual which sets forth in considerable detail the principles of behavior therapy. The manual consists of seven units: (1) Basic information; (2) Getting ready to learn; (3) Imitation, matching and early language; (4) Basic self-help skills; (5) Intermediate language; (6) Advanced language; and (7) Expanding your child's world. Five videotapes supplement the manual.

The Me Book offers "low inference" teaching procedures. That is, the books lays out very specific teaching situations (in instructional task analysis format), including providing information on how to position a child for instruction; how to present stimuli in a basic teaching sequence; how to prompt a response; and how to fade a response prompt. There is an emphasis on preparing the individual for learning (i.e., focusing attention and setting the stage for instruction), building on earlier training sessions, and ensuring maintenance and generalization of skills to new settings.

Home-Based Therapy

Lovaas has a well established home-based treatment approach for children with autism. Generally, the training consists of between 30 to 40 hours a week of therapy beginning (most often) before a child reaches the age of 3 and 1/2 years. Therapy usually consists of 4-6 hours per day of 1:1 training 5-7 days a week for two years. All of these parameters may change based on individual need and even family preference. Typical teaching sessions reportedly last about 2-3 hours (including breaks). Specific instructional tasks last 2-5 minutes followed by short breaks of 1-2 minutes. At the end of each instructional hour, a child is typically given a 15-20 minute break for snacks, free play, and other activities. This allows children the opportunity to practice new skills across non-trained routines and activities.

The Lovaas method is based on operant conditioning. A discrete trial teaching format encompasses the model and consists of three basic parts: (1) presentation of a discriminative stimulus (i.e., a request or command); (2) a response (what the individual does following the request or command); and (3) presentation of a reinforcing stimulus, defined in this program as a reward if correct, saying "no" if incorrect. All teaching situations follow this three step model and attempt to build simple behaviors into more complex chains of behavior.

A description of a lesson for teaching students to "match to sample" may be helpful for those unfamiliar with this approach. To teach matching one object with an identical object, the teacher places a cup on a table in front of the child. The teacher then hands the child a second identical cup and instructs the child to "put with the same." If the child responds correctly by placing the cup with its match, the child is reinforced by the teacher. Reinforcement can include food, praise, a hug, or a combination of these. If the child does not respond to the prompt he is physically assisted to make the response and then is reinforced. The physical prompt is removed (faded) over a series of trials until the child responds consistently to the verbal command. Upon mastery of this task, a second pair of objects (e.g., two spoons) is introduced into the situation. The child is then requested to match objects in the presence of a second item on the table, thus beginning to learn to discriminate between the two sets of objects. The same type of response prompting, fading, and reinforcement is utilized until the child consistently discriminates between two sets of items. As the child masters this skill, new objects are introduced. Objects are randomly presented so that the child learns to discriminate between objects and is not inadvertently guided (or misguided) by instructor cues. Matching training continues until the child learns to discriminate among the many potential features of objects (e.g., color, size, shape). Teaching follows in this step-wise manner across 12 different "programs" such as receptive and expressive language, nonverbal imitation, social language, play, and self-help skills.

Providing intensive behavioral therapy generally requires the establishment of a "treatment team." Recommended treatment teams consist of at least three persons who are available for a total of 30-40 hours weekly. The Clinic for Behavioral Treatment of Children at UCLA uses a "pyramid-like" staffing structure where undergraduate students form the base of the pyramid and provide direct therapy experiences. They are supervised by more experienced therapists and graduate students in the Department of Psychology. Therapy experiences occur in the student's homes and include weekly team meetings and a strict focus on data collection and measurement for the purpose of making treatment decisions.

For individuals not receiving services directly from UCLA, the Lovaas training has been made available to families through a network of consultants trained in the Lovaas method. Families receiving these consultation services are expected to arrange and in most cases lead the treatment team's efforts with consultation support. Families generally rely on recruiting college students on both a paid and volunteer basis. One underlying premise of the Lovaas method is that motivated and dependable individuals can be successfully trained to implement treatment programs with ongoing supervision.

Lovaas notes that treatment is offered to children at such early ages with the goals of reducing maladaptive behaviors (before they become well established) and teaching the child basic language and social play skills. It is a philosophy of this program to first begin intensive therapy at the individual level before expanding treatment into group environments that are typical of school experiences. Lovaas's work consistently suggests that building skills early is critical for successful integration of children with their non-disabled peers. Early treatment is believed to reduce the likelihood the child will require separate educational programs.

Lovaas's work has spanned more than three decades. During this time his approach to behavioral treatment has evolved in the following ways: (1) treatment has moved from clinical to home settings; (2) interventions have begun at an earlier age--preferably before the age of three and as young as eighteen months; (3) the focus has shifted to an emphasis on developing language and social skills which allow for and enhance effective peer integration; and (4) the primary target of the application of behavioral principles is for learning new and adaptive behaviors as a means of replacing maladaptive behaviors (rather than only for purposes of behavior management).

Controversy surrounding behavioral therapy

Given that the behavioral procedures described in *The Me Book* are grounded in behavioral science and have a substantial body of research to support them, then why the controversy?

Several aspects of intensive behavioral therapy have emerged as controversial, both in the method of delivery and in the outcomes documented in Lovaas's studies. First, the primary controversy over the application of intensive behavioral therapy lies in the use of aversive techniques to reduce maladaptive behaviors. Lovaas has discussed at length in his writings his position regarding the role of aversive stimuli in behavioral therapy. *The Me Book* notes that punishment may be used to establish control both to open a window of opportunity for teaching a child alternative behaviors and as a means to exaggerate correct from incorrect responses. Most often "aversives" take the form of corrective verbal feedback, for example a loud "No," though other examples include a spanking or a slap. Though defending the use of physically aversive techniques in situations where a child engages in self-injurious or self-stimulatory behaviors which prevent a child from attending to instruction, Lovaas has contended that aversives constitute no more than 1% of the typical interactions in his therapy programs. The aversives generally are not required after the first few weeks. Interestingly, the Maurice family emphasized that aversive therapy in the form of physical punishment was never used (or even considered) with their children, despite adhering to most other basic tenants of the Lovaas method.

Another controversial aspect of intensive behavior therapy is the extent to which children are "shaped" into robot-like responders, incapable of fluid interactions, who never seem to generalize beyond the specific responses taught. This is indeed a problematic situation for people with autism, regardless of the therapy or educational experiences provided. It does not seem to be specific to the "Lovaas Method." Lovaas has addressed response specificity extensively in his work and the failure of researchers to identify a set of "pivotal behaviors," which, when mastered, open the door to individuals with autism generalizing and expanding their skills. Lovaas notes that many individuals with autism must be taught what they need to know in each environment they encounter, as they often will not generalize without such situation specific instruction.

The final debate is over the issue of recovery from autism. When autism is viewed as a lifelong disability with an organic basis, then "recovery from autism" becomes a contradictory statement. However, if autism is viewed as a set of behaviors which can be ameliorated to one degree or another, then recovery from autism is possible. That is, by examining individuals on a case by case basis, judgment can be made about whether the behaviors which constitute autism are no longer present, thereby removing the need for the label of autism. Judgment as to what constitutes recovery is controversial and has varied across individuals attempting to make this claim, both in their personal judgment and in what measures they claim are useful or acceptable for supporting the claim of recovery. In addition, those who question the possibility of recovery from autism often claim that individuals reportedly recovered were in fact misdiagnosed originally.

Making sense of it all

Regardless of whether one supports or disputes Lovaas's claim regarding the validity of his studies, there is a continual need to scrutinize educational services and "treatments" for people with autism.

One issue to consider is whether there has been an inordinate amount of attention paid to the variable of "recovery from autism," to the extent that it masks and overshadows the utility of behavioral treatment in general. Certainly, there is the possibility of creating false hopes for families, something which has almost become a trademark among interventions applied to people with autism. However, no one has questioned whether the studies conducted by Ivar Lovaas (either the 1987 study or the 1993 follow up study on the same subjects) resulted in substantial positive behavior change. The focus of controversy has been on challenging two specific aspects of the study, specifically the concept of recovery from autism and the means by which subjects were assigned to the experimental treatment and control groups. Assignment to groups was not completely random but instead quasi-random based on the availability of therapists to conduct the extensive behavioral therapy. This quasi-random assignment of subjects has resulted in some researchers claiming that the two groups were not properly matched and that the experimental group contained individuals destined to achieve better outcomes. Lovaas has discussed at length the assignment of subjects to each group and his attempts to minimize the impact of not being able to randomly assign subjects. Both of these aspects of Lovaas's work have been subjected to considerable professional peer review. Though neither question has been answered to the satisfaction of all, there are several points upon which researchers appear to agree. First, the best outcomes for the experimental group were significant and remained so on follow-up several years later. Second, there is considerable agreement that the results obtained in the study were in fact the result of the intensive behavioral intervention. Third, there continues to be a need for replication and extension of this body of information, especially to the individuals who were not among those achieving the best outcomes.

There is emerging information from other research and educational programs documenting substantial behavior change using similar (if not identical) behavioral practices. One important variable emerging from these programs is that younger children, (generally under the age of five) make substantially more progress than older children. This phenomenon has lead researchers to hypothesize that intensive early intervention may actually alter the neurological structure of the brain in the first years of life.

Implications of Behavior Modification for Parents and Educators

The use of behavioral techniques is not limited to the "Lovaas Method." Applied behavior analysis offers parents and educators a wealth of educative strategies to address problematic behavior as well as to teach appropriate alternative behaviors. Interestingly, advocates of intensive behavioral therapy often note that typical home and educational settings are sufficiently "diluted" and thus are ineffective environments for people with autism. In many settings this is undoubtedly true, especially if parents and teachers who "manage" the environment are not sufficiently attentive to the increased need for structured teaching (and the skills to implement structured teaching) for students with autism. Parents and teachers should be vigilant about ensuring that learning opportunities for child with autism are sufficiently structured and individualized, regardless of whether these students are in general or special education settings. Structured teaching situations are not inherently found in either special education or general education. Systematic learning environments can be developed in any educational, community, or home setting. Parents, educators, and advocates of people with autism would be remiss if they did not acknowledge that early behavioral interventions for children with autism are effective and achieve significant results when consistent with principles of learning and when applied by sufficiently trained individuals.

The goal of parents is to choose services for their children that they can be confident will maximize their child's learning and hopes for a productive future. At this point in time there is no question that behavioral interventions offer the best chance for young children with autism to learn and grow to the greatest extent. Also, at this point in time Lovaas has put forth some of the most impressive results among behavioral interventions focused on young children with autism. Whether the work of Lovaas is replicated by other research projects to the satisfaction of the scientific community remains to be seen.

There is a great deal of information available regarding intensive behavioral intervention for young children with autism which cannot be fully addressed in this article. In addition, there are multiple perspectives on behavioral interventions applied to people with autism. The intent of this article was to provide an overview about early intensive behavioral intervention based on the work of Ivar Lovaas. Future issues of the IRCA Newsletter will explore other perspectives on this topic. The bibliography and resource list which follows will allow interested persons to further access information to learn more about intensive behavioral intervention and how it might benefit individuals they support. Additional information on this topic is available through the Indiana Resource Center for Autism (IRCA).

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Reports result from a study at the Princeton Child Development Institute program. The study indicated superior outcomes for students entering the program before age five compared to those entering after age five.

Harris, S. L. Handleman, R. G., Gordan, R., Kristoff, B., & Fuentes, F. (1991). *Journal of Autism and Developmental Disorders*, *21*(3), 281-290.

Reports findings from a one year intensive education program for preschoolers with autism. Results of the study indicated substantial gains in IQ and language test scores following the intervention.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, *55*, 3-9.

Lovaas's study which documented that 47% (nine of 19) children with autism achieved "normal levels of functioning" by first grade following two years of intensive (40 hours per week) individual treatment. The control group performed poorly compared to the experimental group, with only 2% achieving "normal levels of functioning."

Lovaas, O. I., Ackerman, A. B., Alexander, D., Firestone, P., Perkins, J., & Young, D. (1981). *Teaching Developmentally Disabled Children: The Me Book*. Austin, TX: Pro-Ed.

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Lovaas and his colleagues reply to criticism of his 1993 follow-up study of students who were reported on in the 1987 article.

Maurice, C. (1993). *Let Me Hear Your Voice*. New York, NY: Alfred A. Knopf, Inc.

Documents the Maurice family's use of the Lovaas Method for their two children with autism.

McCeachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, *97*, 359-372.

Lovaas and his colleagues report follow up data on the subjects from their 1987 study, which indicated that individuals receiving intensive intervention maintained their gains over time. Following this article are six independent commentaries on the study by respected researchers.

Perry, R., Cohen, I., & DeCarlo, R. (1995). Case Study: deterioration, autism, and recovery in two siblings. *Journal of the American Academy of Child and Adolescent Psychiatry, 34(2), February.*

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Schopler, E., Short, A., & Mesibov, G. (1989). Relation of behavioral treatment to normal educational functioning: Comment on Lovaas. *Journal of Consulting and Clinical Psychology, 57,* 162-164.

Schopler and his colleagues criticism of the 1987 Lovaas study.

Further information regarding early intensive behavioral treatment can be obtained from the following sources:

Ivar Lovaas, Director
Clinic for the Behavioral Treatment of Children
UCLA Department of Psychology
405 Hilgard Avenue
Los Angeles, CA 90024-1563
Phone: 310-825-2319
Fax: 310-206-6380

John J. McEachin, Ph.D.
Ronald B. Leaf, Ph.D.
Services for Autistic Children
3346 Olive St.
Signal Hill, CA 90807
(310) 424-9293 ext. 314 or 306

Bancroft Young Autism Project
Hopkins Lane
Haddonfield, New Jersey 08033
Phone: 609-429-0010
Fax: 609-429-1613

Contributed by:
Steve Buckmann

The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

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The University Affiliated Program of Indiana

TIPS FOR TEACHING HIGH-FUNCTIONING PEOPLE WITH AUTISM

Written by Susan Moreno and Carol O'Neal

(1) People with autism have **trouble with organizational skills**, regardless of their intelligence and/or age. Even a "straight A" student with autism who has a photographic memory can be incapable of remembering to bring a pencil to class or of remembering a deadline for an assignment. In such cases, aid should be provided in the least restrictive way possible. Strategies could include having the student put a picture of a pencil on the cover of his notebook or maintaining a list of assignments to be completed at home. Always praise the student when he remembers something he has previously forgotten. Never denigrate or "harp" at him when he fails. A lecture on the subject will not only NOT help, it will often make the problem worse. He may begin to believe he can not remember to do or bring these things.

These students seem to have either the neatest or the messiest desks or lockers in the school. The one with the messiest desk will need your help in frequent cleanups of the desk or locker so that he can find things. Simply remember that he is probably not making a conscious choice to be messy. He is most likely incapable of this organizational task without specific training. Attempt to train him in organizational skills using small, specific steps.

(2) People with autism have **problems with abstract and conceptual thinking**. Some may eventually acquire abstract skills, but others never will. When abstract concepts must be used, use visual cues, such as drawings or written words, to augment the abstract idea. **Be as concrete as possible in all your interactions with these students.** Avoid asking vague questions such as, "Why did you do that?" Instead, say, "I did not like it when you slammed your book down when I said it was time for gym. Next time put the book down gently and tell me you are angry. Were you showing me that you did not want to go to gym, or that you did not want to stop reading?" Avoid asking essay-type questions. **Be as concrete as possible** in all your interactions with these students.

(3) **An increase in unusual or difficult behaviors probably indicates an increase in stress.** Sometimes stress is caused by feeling a loss of control. Many times the stress will only be alleviated when the student physically removes himself from the stressful event or situation. If this occurs, a program should be set up to assist the student in re-entering and/or staying in the stressful situation. When this occurs, a "safe place" or "safe person" may come in handy.

(4) **Do not take misbehavior personally**. The high-functioning person with autism is not a manipulative, scheming person who is trying to make life difficult. They are seldom, if ever, capable of being manipulative. Usually misbehavior is the result of efforts to survive experiences which may be confusing, disorienting, or frightening. People with autism are, by virtue of their disability, egocentric. Most have extreme difficulty reading the reactions of others.

(5) Most high-functioning people with autism **use and interpret speech literally**. Until you know the capabilities of the individual, you should avoid:

- idioms (e.g., save your breath, jump the gun, second thoughts);
- double meanings (most jokes have double meanings);
- sarcasm (e.g., saying, "Great!" after he has just spilled a bottle of ketchup on the table);
- nicknames; and
- "cute" names (e.g., Pal, Buddy, Wise Guy).

(6) **Remember that facial expressions and other social cues may not work.** Most individuals with autism have difficulty reading facial expressions and interpreting "body language."

(7) If the student does not seem to be learning a task, **break it down into smaller steps** or present the task in several ways (e.g., visually, verbally, physically).

(8) **Avoid verbal overload**. Be clear. Use shorter sentences if you perceive that the student is not fully understanding you. Although he probably has no hearing problem and may be paying attention, he may have difficulty understanding your main point and identifying important information.

(9) **Prepare the student for all environmental and/or changes in routine**, such as assembly, substitute teacher, and rescheduling. Use a written or visual schedule to prepare him for change.

(10) Behavior management works, but if incorrectly used, it can encourage robot-like behavior, provide only a short term behavior change, or result in some form of aggression. **Use positive and chronologically age-appropriate behavior procedures.**

(11) **Consistent treatment** and expectations from **everyone** is vital.

(12) Be aware that normal **levels of auditory and visual input can be perceived by the student as too much or too little.** For example, the hum of fluorescent lighting is extremely distracting for some people with autism. Consider environmental changes such as removing "visual clutter" from the room or seating changes if the student seems distracted or upset by his classroom environment.

(13) If your high-functioning student with autism uses **repetitive verbal arguments** and/or repetitive verbal questions, you need to interrupt what can become a continuing, repetitive litany. **Continually responding in a logical manner or arguing back seldom stops this behavior.** The subject of the argument or question is not always the subject which has upset him. More often the individual is communicating a feeling of loss of control or uncertainty about someone or something in the environment.

Try requesting that he write down the question or argumentative statement. Then write down your reply. This usually begins to calm him down and stops the repetitive activity. If that does not work, write down his repetitive question or argument and ask him to write down a logical reply (perhaps one he thinks you would make). This distracts from the escalating verbal aspect of the situation and may give him a more socially acceptable way of expressing his frustration or anxiety. Another alternative is role-playing the repetitive argument or question with you taking his part and having him answer you as he thinks you might.

(14) Since these individuals experience various communication difficulties, **do not rely on students with autism to relay important messages** to their parents about school events, assignments, school rules, etc. unless you try it on an experimental basis with follow-up, or unless you are already <u>certain</u> that the student has mastered this skill. Even sending home a note for his parent may not work. The student may not remember to deliver the note or may lose it before reaching home. Phone calls to parents work best until the skill can be developed. **Frequent and accurate communication between the teacher and parent (or primary care-giver) is very important.**

(15) If your class involves **pairing off** or choosing partners, either draw numbers or use some other arbitrary means of pairing. Or ask an especially kind student if he or she would agree to choose the individual with autism as a partner before the pairing takes place. The student with autism is most often the individual left with no partner. This is unfortunate since **these students could benefit most from having a partner.**

(16) **Assume nothing** when assessing skills. For example, the individual with autism may be a "math whiz" in Algebra, but not be able to make simple change at a cash register. Or, he may have an incredible memory about books he has read, speeches he has heard, or sports statistics, but still may not **be able** to remember to bring a pencil to class. Uneven skills development is a hallmark of autism.

For more information, contact: MAAP Services, Inc., C/O Susan J. Moreno, P.O. Box 524, Crown Point, IN 46307.

The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities ac ross the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

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INTERPRETING EARLY DEVELOPMENTAL SKILL LEVELS INTO FUNCTIONAL LIFELONG ACTIVITIES

A hierarchy of child development skills provides a framework for tracing the normal growth and progress of children. These developmental skills also can provide a framework for educational programs for young children. However, for individuals with autism, using these developmental milestones for educational purposes may be inappropriate. For example, a 24 year old with autism may be evaluated as performing at a 36 month level. If this framework were used for designing an educational program, s/he would be working on matching shapes or primary colors. Instead, a functional program for that same individual targets skills such as sorting, washing, and putting away clothes.

The following chart (1) lists common developmental skills achieved by children at 18 and 36 months, and (2) translates these into functional skills that impact a person's quality of life, level of independence, and rate of success in the areas of cognition, fine motor, gross motor, self-care, communication, personal management, and social-emotional growth.

COGNITION

18 month level skills	36 month level skills
Matches identical objects	Matches shapes, primary colors
Matches pictures to identical objects	Identifies pictures by function
Uses another object to obtain a toy	Uses sound, touch, shape cues
Attempts to activate mechanical toy	Understands "more" (36 - 48)
Demonstrates some sense of time	Identifies colors (36-48)

This means that an individual can:

Turn on a TV, microwave, tape recorder, etc.
Stock shelves
Sort and wash clothes
Stock pop machines
Select and pay for items
Follow simple recipes
Identify his/her name
Pull easily identifiable weeds

FINE MOTOR

18 month level skills	36 month level skills
Fills up cups/cans with small items	Stacks tower of 7 blocks
Dumps items from bottle/jar	Opens doors
Turns pages two or three at a time	Combines blocks into complex structures
Imitates strokes with crayon	Shapes clay into complex forms
Builds tower of three small blocks	Creates scribbles
Puts cover on box	Draws simple designs (36 - 48)
Places pegs in holes	
Turns door knobs	
Fits boxes and cups inside each other	

This means that an individual can:

Turn pages of a book
Set and clear the table
Wash and put away dishes
Load dishwasher
Print personal information with a stamp
Play board games
Load a computer and touch keys
Turn on lights and other switches
Use vending machines
Assemble and carry equipment

GROSS MOTOR

<u>18 month level skills</u>
Trots about well
Stoops to pick up something
Climbs into a chair
Walks backward
Climbs stairs, up and down
Jumps slightly with both feet off floor

<u>36 month level skills</u>
Walks upstairs, alternating forward foot
Jumps from height of 30 cm.
Walks tiptoe for 3 meters
Walks on a line
Stands on one foot alone
Rides tricycle

This means that an individual can:

Jump on trampoline
Jog and walk on a track
Swim
Cross country ski
Bowl
Ride a stationary bike
Do exercises either aerobic or on machines
Ride a horse

SELF-CARE

<u>18 month level skills</u>
Partially feeds self
Drinks from a cup
Uses spoon to feed self
Pulls off socks and shoes
Indicates when wet or soiled
Sits on potty chair

<u>36 month level skills</u>
Feeds self
Uses napkin
Uses straw when drinking
Pours liquid from smaller pitcher to glass
Undresses independently
Puts on jacket, shirt, cap, pants
Puts on shoes
Unsnaps clothes
Indicates toilet needs
Completes toileting and attempts to wipe
Toilets independently (36 - 48)
Brushes teeth
Avoids hot stove, electrical outlets, etc.
Distinguishes between things that should and should not be eaten

This means an individual can:

Eat in restaurants/cafeterias or elsewhere with others
Undress self
Use the bathroom with reminders
Follow basic safety rules
Follow basic grooming routines

COMMUNICATION

18 month level skills
- Points to pictures
- Names a few familiar objects
- Uses words consistently
- Uses two-word combinations (20 - 24)
- Responds to names of familiar objects when not in view
- Responds to two-word instruction

36 month level skills
- Recognizes familiar pictures
- Knows items by names
- Talks about past and future
- Tells how old s/he is
- Uses multi-word combinations to describe events
- Uses pronouns
- Uses prepositions in, on, under, out
- Understands pronouns my, your
- Understands concepts big, little

This means an individual can:

Use a communication book/board
Verbalize in short sentences, if verbal
Make choices of objects, foods, activities
Respond to familiar instructions
Understand concepts of in, on, under, and out in context
Understand concept of "my"

PERSONAL

18 month level skills
- Shows accomplishments to adults
- Refers to self by name
- Waits for needs to be met
- Responds to name
- Uses simple play schemes
- Acts out familiar events (18 - 24)
- Shows affection

36 month level skills
- Knows own sex
- Cooperates with adult requests
- Identifies self in mirror
- Identifies own possessions
- Shows independence
- Takes on familiar roles
- Imagines and acts out events

This means an individual can:

Exchange greetings
Attend movies and community recreation activities
Go to dances, parties, and musical events
Cruise the mall with friends
Care for own belongings
Perform familiar activities independently if taught and supports are in place
Wait if strategies are in place

SOCIAL/EMOTIONAL

Understanding the social/emotional characteristics of typical children during their first three years can help in understanding the social/emotional behaviors of older children and adults with autism. Understanding can lead to planning appropriate strategies rather than to reacting negatively to behaviors thought to be "inappropriate for his/her age."

First three years

Separation anxiety seen in the form of clinging, anxiety, resisting contact, and seeking proximity.
Wariness to new objects and to strangers.
Anger may be expressed by hitting, kicking, pinching, biting or other forms of aggression when thwarted or restrained.
Interference with choice-making may lead to anger.
Overstimulation may trigger aggression in the form of hurting others or breaking items.
Aggressive behavior towards the child often results in his or her aggressive behavior to others.
Very strict external control prevents exploration and may stifle internal control.
Fears develop in overly demanding social situations, and when the child feels that s/he is doing something wrong or being bad.
Anxiety can develop if fears become widespread and/or unfocused.
Humor is an intellectual process that helps the young children laugh after s/he experiences feelings of tension. The child responds to what s/he perceives to be funny but also may laugh in other situations when s/he is unsure how to react.

Strategies and procedures effective in helping young children and older persons with autism cope with and move beyond the social/emotional characteristics listed above include:

Providing positive praise while learning.
Providing information about what the person does right or well.
Planning gradual transitions; preparing the person for change.
Keeping the person with familiar people, places, and objects at times of crisis.
Teaching techniques for coping with difficult situations.
Using modeling.
Using desensitization procedures for new experiences and contingencies such as "First do _____, then do _______."
Rehearsing strategies (e.g., "First we go to the store, then to get the car washed, then we stop for ice cream.")
Providing many experiences in which the person learns to make choices.
Keeping the level of stimulation within the person's ability to cope.
Refraining from restraining the person whenever possible.
Refraining from aversive techniques.
Planning for adequate exploration and familiarity of environments.
Establishing routines, schedules, and waiting strategies that permit everyone to live more harmoniously.
Speaking clearly, slowly, and pausing often.
Using visual supports, including pictures, objects, and written information.
Teaching social skills such as how to have fun but not to "make fun of."
Teaching and modeling relaxation strategies and diversions to reduce anxiety.

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Restricted Repertoires In Autism and What We Can Do About It

This is a summary of a presentation by Tony Attwood, Ph.D., from Brisbane, Australia. Dr. Attwood described the developmental sequence followed by typical children. Children with autism follow the same developmental sequence, but in an exaggerated fashion. For example, children with autism may collect the same type of objects as other children, but to a point of excess. Another example is the intense need for symmetry, or for information on a certain subject. These exaggerated behaviors are identified as a restricted repertoire of activities and interests.

Many individuals with autism engage in simple, repetitive actions such as rocking or spinning objects. What to do about repetitive actions depends on the reason the individual is performing the activity or the function of the behavior. The following are possible reasons for repetitive actions and programming ideas specific to these reasons.

Reason: Exploration for sensation.

Programming: Try to find a more acceptable alternative and provide a variety of sensory activities which fulfill the same sensory needs. Divert the person's attention to some other activity.

Reason: The desire to screen out excessive stimulation. The individual may be hypersensitive or have a disturbance in perception of sound, vision, touch, taste, or smell.

Programming: Use ear plugs, blue tack in the ears, sunglasses, or a visor to help the individual filter stimuli. Change the environment. Desensitize the person to the sensation. Screen out the distressing sensation, perhaps by listening to music on a walkman. Teach the individual to relax and calm down when input level is high.

Reason: Enjoyment of a sensation, such as rocking.

Programming: Try to find a more acceptable alternative and provide a variety of sensory activities which appeal to the same sense. Divert the person's attention to some other activity. Negotiate with the person when and where such actions are acceptable.

Reason: The need for life to be predictable and secure. These individuals need to create order out of chaos.

Programming: Make a portable visual schedule for the person. Changing environments may allow you to stop an elaborate routine that is interfering with programming. Try to stop the sequence of behaviors from beginning. Encourage tolerance for change early in the person's life.

Reason: Communication of thoughts or feelings, such as happiness, anger, or "I need help."

Programming: Teach a more appropriate way of communicating "I need help" or "I am frustrated." Accept that emotions can be communicated by body language. Teach when and where to show various emotions.

Reason: Compulsive behaviors. For example, an act starts as pleasurable, but the need to continue is irresistible or the person is unable to switch to another activity on his/her own. The thought occurs and the individual cannot prevent him/ herself from carrying out the action.

Programming: This behavior may be related to obsessive-compulsive disorder and to high levels of anxiety. Avoid the initial stimuli that may set the stage for this behavior. Ask if the person wants to be finished with the repetitive activity or would like to switch to another activity, and help him/her do so. Reduce the person's level of stress. Use distractions, such as music.

Reason: The inability to start or change actions or emotions. This may be related to transitions between activities or environments. The person who has a movement disorder such as akinesia or bradykinesia sometimes uses a short repetitive action to get his/her body into gear with the brain.

Programming: Develop a picture schedule to help the individual move from one setting to another.

Repetitive behaviors cannot and should not be eliminated completely from a person's behavioral repertoire. You may wish to reduce the time spent performing the repetitive behavior or to identify a more acceptable alternative with similar sensory input. Consider the following:

- Teach the person an alternative behavior.
- Provide a variety of sensory experiences during a person's day.
- When the behavior is happening, try to divert the person's attention to another activity.
- Negotiate with the individual when and where repetitive actions are acceptable. Controlled access to the behavior will reduce the person's level of desperation to do the behavior. This controlled access should not be contingent on good behavior. The person's visual schedule should note the appropriate time to engage in the repetitive behavior.
- Gradually reduce the amount of time allotted for the repetitive behavior. Increase the amount of time between scheduled access to repetitive behaviors.
- Use freedom to indulge in repetitive behaviors as a reward if the person has few motivators.
- Use the level of repetitive behavior to assess the person's level of stress. Institute other stress reduction measures when repetitive behavior rates increase.
- Promote success in other areas. The behavior will reduce itself when the person achieves success in other areas and has a low level of distracting sensory stimuli.
- Allow the person to engage in the repetitive behavior in an emergency situation to calm him/herself.

Repetitive behaviors are very resistant to reward or discouragement programs, so if you can live with them, leave them alone. Remember, repetitive behaviors will come and go. However, if one behavior is suppressed, another will replace it. The replacement behavior is always dictated by the individual and may be worse than the one it replaced.

Restricted Repertoires in Autism and What We Can Do About It was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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Building Independence
Through the Use of Adaptations and Enablers

Individuals with autism or other developmental disabilities often show limitations in independence in their homes, communities, and the work world. People with severe developmental disabilities are often eliminated from community programs and competitive employment because of interpersonal behavior problems brought about by impairment in their ability to communicate and to understand social interactions. Developing teaching strategies to enhance one's strengths and limit the reliance on one's deficits is essential to an individual's programming.

Teaching strategies and methods that use enablers, adaptations, supports, or prosthetics are vital to success. Enablers are created to help cope with an environment. They regulate stimuli, adapt materials to meet individual needs, modify sequences, and provide information in understandable ways. Enablers are as important to someone with autism as eyeglasses are to people with a visual impairment. They are essential for developing independence in an individual who has severe disabilities.

The following are enablers this paper will discuss:

Consistent Routines/Schedules
Knowledge of Expectations
Desensitization Processes
Rehearsal Strategies
Stimulus Cues
Environmental Adaptations
Augmentative Communication
Peer Advocates
Motivational Procedures

Consistent Routines/Schedule

Consistent routines and schedules are necessary to provide the best learning situation for an individual with autism. Also, because most individuals with autism are concrete, visual learners, providing visual materials in the form of wall calendars, written schedules, picture boards to denote events, written steps of a task, or rules stated clearly and visually will aid in the individual's understanding of his or her routines. Other suggestions are:

- A morning routine as shown by a schedule board: get up, wash face and brush teeth, make bed, eat breakfast, pack lunch, go to work.

- Schedule the same activities at the same time each day (or week) and place the pictures, in order, on the schedule board to provide the knowledge and security that persons with autism require. For example, 15 minutes of exercise everyday just before leaving for home, or eating out every Friday night.

- All staff/family know all cue words and become familiar with needed visuals for particular routines. This ensures that all routines are directed consistently.

- Review schedule boards with the individual each morning, or each half day, so s/he knows what will be happening.

- Explain changes in routines through the use of the schedule boards. Actually remove one activity and help the learner put on the new activity.

Consistency in programming provides the structure that is often needed for someone with autism. The success of programs for individuals with autism often depend on how consistent these programs are and how they are presented to each individual. Frustration occurs when the individual does not understand the plans and expectations for the day. Independent behaviors can be increased by using consistent teaching methods that include clearly defined visual materials.

Knowledge of Expectations

While teaching individuals with autism, giving clear instructions or directions is crucial to their understanding of what to expect in their day. Unnecessary words or sentences containing abstract thoughts, such as "in a little while," "just a moment," "just a little bit," etc., often confuse or frustrate someone with autism. Most people with autism are concrete, visual learners. S/he needs to know exactly when an event will occur ("we leave in 5 minutes or when the timer goes off"), and strategies to cope with waiting until the event begins.

Support staff often assume that someone with autism will automatically understand when they are finished with a project or job, that they are to work faster because they will earn more money, or how long 10 minutes lasts. Often, staff or teachers need to clearly state when a project is finished ("You do 15 problems and then you are finished," or "Fill the template two times and then it's break time"). Also, since time itself is an abstract concept, use of timers can clearly define the passage of time and can be used to help someone know when one event stops and another begins.

Other examples are:

- Visual templates specifying the steps to be performed in a set routine.
- A check off list or a sheet of paper marked into squares telling a worker that s/he must put one assembled unit in each box, then s/he is finished.
- A simple chart with a box to mark each step completed and a picture of the reinforcer at the end, telling the worker exactly what is to be done and the reason for working.
- Using the "First __________, then __________" strategy tells exactly what is expected of the person. Examples are "First use the bathroom, then wash your hands," "First go shopping, then we get ice cream," "First set the table, them make the salad."

These strategies tell the individual everything s/he needs to know about that particular order of events or routine. Many times the directive expressed in these terms is enough for the person to understand what s/he is to do. However, supplementing the verbal with a pictured or written sequence is often necessary and facilitates independence in routines.

Desensitization Procedures and Rehearsal Strategies

In many instances, the learner with autism may have unusual anxiety and fears surrounding new or unusual situations, people, places, or routines. Often these interfere or disrupt the successful accomplishment of a task or event. Examples of some fears and anxieties include doors that are open, certain types of medical or dental procedures, loud noises, passing trucks, rain, animals, or other objects, events, or people.

Other examples are:

- Strong obsessions with needing certain objects to be in certain places.
- Particular people being only in particular environments.
- The need to perform a certain ritual such as straightening all the chairs in the room before leaving, or checking the sink drain every time s/he passes the kitchen.
- Not allowing a vending machine door to be opened for servicing.

If an obsession or ritual interferes with programming, a desensitization procedure may be necessary. A desensitization procedure is the gradual introduction or exposure to the particular object or event. During this exposure, the individual is reinforced for remaining calm while the object is near or the event is occurring. The process starts with a short exposure to the object or event, with a gradual increase as the person becomes less anxious. Reinforcement for remaining calm is an important component of the process, keeping in mind the individual preferences of the person.

Many fears/anxieties can be eliminated entirely by prior planning and preparation. If staff or family know that an individual is fearful of new situations or transitions, then before s/he moves to a group home, for example, short visits can take place to introduce the situation gradually. Preparation for next year's class could include desensitization in the spring to the new teacher, new room, and new materials; then, only a shorter introduction is needed in the fall. Careful planning is always needed.

Many individuals with autism are burdened with unusual concerns that prevent them from enjoying aspects of their lives and programs. With carefully planned and executed desensitization procedures, these same individuals can improve and enhance their lives.

Rehearsal strategies, like desensitization practices, also help the learner with autism feel comfortable with a particular situation. Many individuals with autism do not need the intense desensitization procedures, but do benefit by short rehearsal strategies. Examples of when such strategies are useful are rehearsing the ordering sequence at a restaurant, practicing a banking sequence, practicing a signature before cashing a check, writing down the grocery list and finding the aisle numbers, and rehearsing an already familiar dental routine.

Rehearsing familiar events and routines before they occur can give the individual with autism the added comfort of knowing that s/he can function in the situation comfortably. Many times that is all the preparation needed to be successful.

Stimulus Cues

Because learners with autism have difficulty processing verbal instructions, they often need to rely on environmental cues. Many times the individual understands what is going to happen by observing what is happening around him/her. Staff or family members can plan for stimulus cues (or programmed environmental cues) to eliminate confusion and the necessity of relying on verbal instructions.

Examples of stimulus cues are:

- Having the same event at the end of every day's program. This would tell the learner when it is time to gather his/her things and get ready to go home.

- Performing the same routine before going out, such as turning off all the lights, checking the locks on the door, and turning on the answering machine. When the learner sees the parent or staff member performing these duties, s/he knows that it's time to leave.
- Using the same object to perform the same task each day: a certain bucket is used only for cleaning tables or a certain pillow is kept only for a particular relaxation routine. When the bucket is taken out of the closet, then it is time to start work; when s/he is given the pillow, it's time for the relaxation routine.
- Setting only enough chairs or placements as needed at the table to show where to put the plates and silverware.
- Bringing out everyone's raincoats to let the learners know it is raining and they will need to wear them.
- Mom picking up her purse to indicate it is time to leave. (Remember, sometimes there are miscues. The learner may expect to go with Mom everytime she picks up her purse.)

Stimulus cues can be a valuable, verbal or non-verbal method to increase the learner's independence in his/her everyday activities.

Environmental Adaptations

Adapting the environment and materials to an individual's needs often creates a more successful learning situation. Eliminating objects or routines that might confuse, disorient, or upset a learner with autism can make the difference between him/her feeling comfortable with his/her surroundings or feeling frustrated and anxious. Eliminating loud noises, bright light, messy shelves or materials, or decreasing the number of people in a group can help to decrease this anxiety.

One example of adapting the environment is providing a relaxation area to direct an anxious child or adult to until s/he learns to initiate relaxing. This gives the individual the opportunity and the knowledge of a place to which to withdraw from an upsetting situation. It also provides the person a place to calm down. This may be as simple as having a bean bag chair in a corner of the room or a particular shelf with the person's favorite toy or object. When anxiety or frustration occurs, the person can independently choose to calm down in this area or can be directed there by the parent or staff.

Teachers or staff often need to analyze materials for particular jobs or tasks to determine if adaptations need to be made for an individual. Once the task has been taught, additional adaptations may be needed if the learner has difficulty with a particular step of the job. Many times, simple adaptations can mean the difference between dependence on staff and individual independence. Adaptations on the job can open up new possibilities for learners by offering them opportunities for competitive employment. Teachers and support staff often utilize creative methods to analyze the best way to meet these needs and offer increased opportunities.

Augmentative Communication

Half of all people with autism are non-verbal, and more are minimally verbal. People with autism often rely on means other than speaking to communicate their wants and needs. The use of sign language, communication boards, or electronic devices can enable learners to better communicate wants or needs in their daily lives. Consistency in the use of the augmentative system will be a major key to its success. The system must be used across all settings and environments; all staff must be used across all settings and environments; all staff must be familiar with and help initiate its use; and, the system must be functional for the individual.

Individuals with autism are often low initiators of communication. In the beginning, responsibility for the use and maintenance of a system must fall to family or staff. The services of a speech and language pathologist can guide family member's or relevant staff in the use of the augmentative system and ensure that the system or format is functional for the individual.

Augmentative communication systems can be quite simple or complex. They can be as small as an index card with a specific order for a specific restaurant or as large as a book with hundreds of labeled pictures. Other examples include small communication books that have been made specifically for a job routine, morning exercise workout, or community outing.

Having an augmentative communication system means that the individual has a better way to communicate wants and needs which otherwise might be exhibited as inappropriate behavior. Increased independence and self-esteem is often a result of improved communication.

Peer Advocates

Peer advocacy programs are used in many school systems and some work sites, pairing a person with a handicap with someone who does not have a handicap. Peer advocates can open the door to many social and instructional events which teachers cannot. Peers can teach activities and social gestures and nuances so the learner can successfully interact with a wider group. Some examples of activities that peers could teach are after school games, sports skills, home living skills, community recreation or outings, shopping, and leisure skills. The skills gained through peers often help the individual with autism understand social rules, help to integrate the individual into larger peer groups and may enhance self-esteem. Peer advocates are a valuable resource for teachers, parents, staff, and the individual with autism.

Motivational Procedures

Many learners with autism are not motivated by the common reinforcers of most people. Often, it is assumed that the individual with autism should be motivated by a monthly paycheck, verbal praise, social groupings such as parties or get togethers, or competition. Staff or teachers are often puzzled when the individual with autism does not respond in the same manner or enthusiasm as others. S/he can be perceived as unmotivated, lazy, or uncaring when responses are not like others. However, with careful analysis of individual likes and preferences, motivators can be found and used effectively.

Examples of motivators for an individual with autism include time spent alone, time to talk to a favorite staff member or teacher, trips to the cafeteria, an exercise routine, a favorite object, music, playing in the water, set amounts of money for a specific treat, getting to perform a favorite routine, sensory objects, sitting at the window, or another favorite activity or object. Each person will need to be assessed periodical for motivators. What motivates a person one week may not motivate him/her the next week. Motivators will change occasionally to reflect new or different interests. Motivation can often be a determining factor in the success of teaching strategies and programs.

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S. Wagner 8/89, Revised N. Dalrymple 9/91

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Building Accurate Information Through Structured Learning

Information is power. Information permits control. Information relieves anxiety. Information encourages growth of independence and problem solving. How can information be transmitted to people with autism in a way that enables them to translate the sensory input they receive into meaningful action?

Because people with autism have difficulty processing information so that it can be organized and used in multiple situations, it is necessary for their teachers to provide structured learning opportunities. Learning activities must be presented in an orderly, sequential, organized way that accounts for the individual needs of each student. Structure is a word that means something different to each teacher. However, structure really must be interpreted from the point of view of each student.

Some specific sensory considerations are reviewed followed by a brief discussion of teaching ideas.

SENSORY CONSIDERATIONS

* Consider distracters - light, movement, reflection, background, patterns.

* Consider cues - layout of materials, right to left or up and down movement, storage of materials, pictured or written schedules that can be marked off or have parts removed.

* Consider position - location of the teacher in relation to the student, relation of the student to the other students and models.

* Consider the eye level of student.

* Consider the time required to shift attention.

* Consider vistas/spatial issues - reaction to space, to looking down, to looking out the window or at the chalkboard, to moving.

AUDITORY

* Consider distracters - fans, loud speakers, people yelling or crying, fire alarms, several people talking at once, air conditioners, bells, dogs barking, furniture scraping, etc.

* Consider level - voices and other noises.

* Consider predictability and repetitiveness of sounds.

* Consider comprehension of verbal information and time required to process and shift attention.

TACTILE

- Consider temperature.
- Consider texture.
- Consider the need to explore through touch and yet avoid being touched.
- Consider ability/defensiveness in use of objects.
- Consider all visual motor needs.

VESTIBULAR

- Consider need to move/exercise.
- Consider reactions to movement, i.e., spinning, jumping.
- Consider all visual motor needs.

TASTE

- Consider preferences/dislikes.
- Consider texture and temperature of foods.
- Consider (need to use and explore) the environment.

Some Teaching Ideas:

- Visual supports can be used to supplement auditory whenever possible. Written and pictured information are references long after the spoken word is gone. Usually modeling provides a visual step-by-step sequence better than sentences. Gestures and environmental cues often provide information more clearly than words.
- Consistent rules and routines that are visually presented and that teach the student what to do to provide a secure base from which to operate.
- Defined, clear expectations; activities and rules with specific beginnings and endings need to be in place and taught. Abstract concepts such as, "Finish your paper, work neatly, do more," must be concretely defined so the student knows what degree of accuracy is required.
- Prepare the student for changes, new situations, new expectations, and people. Individual calendars, by the day, week, month, or appointment books help the student have his/her own reference. Picture sequences or pictures to encourage discussion and practice future experiences provide information about future events.

Many people with autism do not "feel" or grasp the relationship of time or time passing; therefore, individualized pacing and teaching about time as it relates to the student is necessary.

Structured learning can occur when structured teaching is planned in an individualized way for students with autism. These students are not able to organize and access pieces of information into useful activities without help; therefore, the teacher becomes a key factor in promoting learning through structure.

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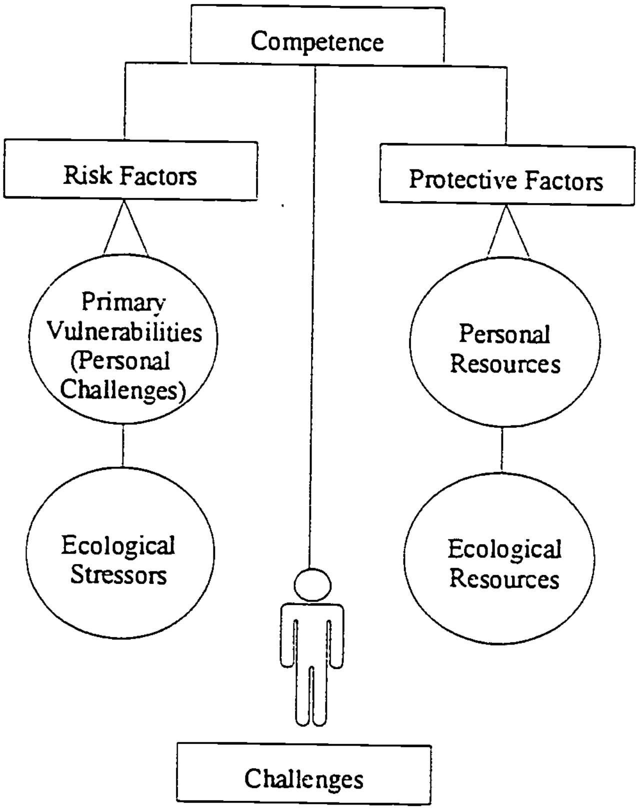
MODEL FOR COMPETENCE ENHANCEMENT IN PERSONS WITH AUTISM

Challenges are a part of everyday life. Depending on your present *niche* in life, activities requiring vocational, academic, social communication, or leisure skills present unique challenges. We often fail to consider these daily challenges because we have developed the skills to master them. In fact, we often master them so well that we develop a sense of competency in our skills leading to personal well-being and an acceptable quality of life for ourselves. Individuals who lack skills in meeting daily challenges also fail to develop self-competence.

AUTISM COMPETENCY MODEL



Adapted from Minnesota Competency Enhancement (1990)

Competence looks different across the lifespan of the individual. The competent infant has a complex range of behaviors for meeting daily challenges. Crying, smiling, cooing, and eye contact all serve to help the infant meet daily challenges via the effects of these behaviors on caretakers. Early social and communicative behaviors are built upon by the toddler as demonstrated in the use of language and interactive play patterns. Increasing motor skills and cognitive abilities are evidenced in displays of independence as the young child begins to negotiate challenges directly rather than by influencing the behavior of others. Young children also face challenges in the demands for interactive play requiring that they be able to better control their emotions and understand more complex social behavior such as sharing.

School provides a unique set of challenges in the development of competence. The child must adjust to being away from home and must adapt to the increased challenges of *academic* learning. The school setting requires that the child exhibit self-control, social, communication, and emotional competencies. Play skills take the form of organized sports or may require that the child be able to interact in peer-organized activities such as during recess. Changes in routines also become more pronounced as children are expected to make many new transitions both at school and home. Challenges during early school years expand significantly as the child moves to adolescence and faces new and more complex demands for competency skills.

Transition to adulthood brings with it vocational decisions as well as demands for more independent living skills. The individual no longer is faced with the school routine but must now develop social and leisure activities on her own initiative. The social, communication, self-control, and emotional competencies continue to be refined and utilized throughout adult life. Childrearing adds new challenges to these skills. In older adults challenges include transitions from work to retirement. Sometimes older adults are presented with challenges of having to adapt their lifestyle to changes in skills brought on as a part of the aging process. The ability to cope with challenges at this stage in life is aided by the acquisition of competency skills early in life. Competence in facing challenges is a developmental task with early success supporting the personal competence in adulthood.

Individuals with autism often lack the necessary competency skills to meet these daily challenges occurring across the lifespan. The competence of a person with autism can be enhanced, however, by understanding how vulnerabilities interact with one's environment when challenges are faced. The model presented in the accompanying figure illustrates how competency enhancement can occur from this perspective. The model is adapted from the Minnesota Competence Enhancement Program (e.g., August, Anderson & Bloomquist, 1992).

The competency model suggests that a balance exists between risk and protective factors. The greater the risk factors for an individual the more the balance is weighted toward failure in meeting challenges. A competent outcome to challenges depends on the balance being *tipped* in favor of protective factors.

Risk factors leading to poor competency include the individual's primary vulnerabilities (personal challenges) and ecological stressors. Factors that protect the individual from poor competence include personal and ecological resources which produce skills to meet challenges.

Primary vulnerabilities include biological predispositions that increase risks. Neurobiological research indicates that brain function is altered in autism leading to differences in the way information from the environment is processed. The information processing difficulties are apparent in the social and communication problems of persons with autism as well as in the narrow range of interests and unusual sensory and motor behaviors. These vulnerabilities are apparent early in life producing difficulties for the infant in responding competently to the social and communicative demands of the environment. The vulnerabilities lead to further problems as the challenges increase with age. Comprehensive, multi-disciplinary evaluations are important in identifying the primary vulnerabilities in autism.

Adding to the risk factors are ecological stressors. These are environmental stressors that impede competence development. Some possible stressors include misunderstandings about the individual's needs, placement in isolated settings, confusing environments, and punitive behavioral programs. A lack of trained professionals can produce additional stress as well as failure to plan for the life transitions of persons with autism. Inadequate supports for communication, social, leisure, and sensory needs also contribute to failure. Family stressors may also lead to further risk of poor competency development.

While it is important to assess the vulnerabilities and ecological stressors of persons with autism, competence enhancement focuses on the increase of protective factors. Protective factors must balance risk factors to develop competency. During various periods throughout a person's life the need for protective factors will wax and wane; however, individuals with autism will always need help to build their personal resources. They also need a variety of ecological resources and supports to meet their needs.

Personal resources are the strengths and interests that can produce competent responses to challenges. Individual strengths and preferences must be built, then used to enhance other skills. These strengths and preferences also become the motivators and building blocks for the development of functional life skills. Interests will change and expand as the person grows. Relative strengths tend to remain stable, but must be enhanced. Sometimes the interests of individuals with autism are narrow. However it's important to begin with current interests, gradually widening and adding. Music, puzzles and manipulative items, books and magazines, specific TV shows like *Jeopardy*, *Wheel of Fortune* or *World Class Wrestling*, water, specific foods, riding in a car, rocking, spinning things, routines, sequences, patterns, numbers and letters, and moving - running, pacing, jumping - are some of the preferences of individuals with autism.

An interest in music can be expanded by introducing similar music to the current repertoire. Slowly add to the repertoire by adding varied beats, vocals, and instruments. Expand experiences with recorded tapes to include line music, singing, playing a keyboard, tapping rhythms, and dancing. Music can then be used as a vehicle to share interests with others, to relax and calm down, and for reinforcement after work. Similarly, a liking for water can be used within many activities that help meet sensory needs. Bathing, showering, washing and rinsing dishes, watering or spraying plants, hosing, washing windows or tables, and swimming are some possible *water* activities. Looking at water in falls, creeks, oceans, fountains, bottles, toilets, and puddles can be exciting or soothing. Pouring, drinking, sipping, spraying, swirling, swishing, and splashing are a few actions to do with water. Experiencing water by being in a shallow pool, deep pool, indoor pool, lake, or ocean broadens the concept of *swimming*.

Strengths are assets on which to build a strong foundation for competency. These must be discovered and enhanced. Sometimes the same attribute can be interpreted as a liability by some and a strength by others. Interpretation and the viewpoint of the observer set the stage for competency or failure. For instance, stamina could be listed as a strength or could be seen as a challenging behavior if called hyperactivity. Strengths might include visual and auditory memory, visual/spatial skills, desire to please, word and number recognition, gross motor skills, desire for order, self-care, and perseverance. These strengths and interests lead to competent behavior in particular areas. A person with autism, for example, may be highly competent at completing a complex puzzle. Unfortunately, puzzle competency does not produce the social and communication competencies needed to meet the challenges of daily activities. By utilizing protective factors in the environment, however, unique competencies of persons with autism can be used to develop functional skills for daily life.

Ecological resources are positive environmental supports. They do not remove challenges from the lives of persons with autism, but rather provide the balance on which to build competency. Ecological resources must be community-based, system-wide, and individualized to meet each person's needs. Consistency and stability through a continuum of services as well as individual and family supports are essential. If we are going to be successful in supporting children and adults with autism to be competent, we must collaborate across people, agencies, and governments.

Some of these positive environmental supports are:

- Family supports that include respite, recreational opportunities, networks, positive inclusion, access to information and resources, and meaningful programs and employment.

- Trained and knowledgeable personnel.
- Longitudinal/futures planning that includes transition plans, interagency collaboration, choices, community access and inclusion, stability and consistency, and promotion of choices and independence.
- Proactive, positive program components that include supports for inclusion; functional, meaningful assessments; continuum of services; individual supports; and home/school collaboration. A proactive, rather than reactive, approach teaches rather than punishes.
- Positive, individualized programs focus on using individual learning styles with visual supports, meaningful activities, appropriate pacing, and meeting sensory needs. Other components include teaching functional communication and social interaction skills across settings and people and teaching community skill development in collaboration with families and friends. Planning and developing vocational and job skills and social supports and networks are also part of positive programs.
- Positive Behavior Supports focus on self management strategies such as choice, exercise, relaxation, and self advocacy; means to communicate and people who reciprocate; development and inclusion of strengths, preferences, and interests; sociable, interactive peer relationships; and organization and structure. Supports that enhance problem-solving, negotiating, independence, and making current and future events predictable and meaningful are put in place.

The competence enhancement approach is currently being used by the IRCA as a training model for addressing the needs of persons with autism. It is useful in describing and understanding the behaviors of people with autism and their relationship to individual needs and the environmental impact. More important, however, is that the model provides a structure for problem-solving about the needs of individuals with autism, leading to the development of competency-enhancing environments. Two examples of how the model is applied are provided below.

Program Plan - Measurable goals and objectives are designed from this model. Too often, the current program plan is written to address weaknesses, rather than looking at all the needs of the individual along with the stressors, challenges, and resources.

An example for a young child with autism - Health/Self Care

Goal: To use the toilet when needed

Personal Challenges:
- Has difficulty sitting and waiting
- Doesn't understand time frames
- Self stims with water

Personal Resources
- Follows learned routines
- Likes set schedules
- Likes books, shiny objects, and water play

Ecological Stressors:
- Being in small, enclosed spaces
- Having to transition from one activity to another

Ecological Resources:
- Visual schedule that includes picture of the toilet
- Visual timer designating sitting time
- Rehearsal following a set pattern
- Special books, pictures, or objects to use while sitting
- Reinforcement of flushing the toilet after sitting

An example for a young adult with autism - Recreation & Leisure

Goal: To become a Y Center member and participate with others

Personal Challenges:
- Dependence on others
- Low initiator
- Loner
- Difficulty sorting out which cues to follow
- Sensitivity to lots of movement

Personal Resources
- Likes water
- Likes to run
- Can model/imitate
- Follows routines

Ecological Stressors:
- Lack of transportation
- Lack of peers/friends
- Lots of people and movement

Ecological Resources:

- Teach through routine, rehearsal, and visuals how to use theY
- Provide consistent people to accompany
- Desensitization to number of people and movement
- Identify place to *take a break* and relax

August, G.J., Anderson, D. & Bloomquist, M.L. (1992). Competence enhancement training for children: An integrated child, parent and school approach. In S. Christenson & J.C. Conoley (Eds.), Home-school collaboration: Building a fundamental educational resource. Silver Springs, MD: National Association of School Psychologists.

Contributed by:

Lonnie Sears,
Psychologist, Child Evaluation Center, Louisville, Kentucky

Nancy Dalrymple,
Director, Indiana Resource Center for Autism

Barbara Porco,
Education Consultant, Indiana Resource Center for Autism

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IRCA

Adult

THE PUZZLE OF LIFESTYLE PLANNING

Everyone makes choices daily that impact life. For example, people decide where they will work, with whom they will live, and in what extracurricular activities they will engage. For individuals with disabilities these decisions are often made by others and without the person's input. Lifestyle planning allows people to explore possibilities, brainstorm strategies, and identify outcomes that are typically beyond what is offered by traditional services. Quite simply, lifestyle planning is a method for supporting individuals with disabilities in making choices which reflect preferences, areas of strength, and their own visions.

The individual with a disability is supported by friends, family members, and professionals to construct a map for his/her life. Below are questions that can facilitate decisions about:

EDUCATION

1. Would the person be interested in taking classes at the post-secondary level?
2. Would the person be interested in taking classes at a local vocational training school?
3. Would the individual be interested in taking classes through the YMCA or YWCA?
4. Would the individual be interested in taking an adult education class through the community schools or local library?

EMPLOYMENT

1. Does the person want to be employed part-time or full-time?
2. Does the person want to work at one job or two jobs?
3. Would the person be interested in volunteering instead of working?
4. Would the person be interested in working and volunteering?
5. Is the wage important to the person?
6. What is the minimum amount of money that s/he is willing to accept?
7. Would the person be interested in being self-employed?
8. Does the person want to sample a number of different jobs to determine what s/he likes?

COMMUNICATION

1. What means of communication does the individual want to use?
2. Should different means of communication be used at different times?
3. How do the people who surround the person support the individual's communication?
4. Does the person want to be able to use the telephone?
5. How can the person maintain correspondence with people (e.g., telephone, visits, letters)?
6. What are the best ways for the person to receive information (e.g., reading, listening, seeing, or a combination of methods)?

TRANSPORTATION

1. How does the person get to his/her job?
2. Is car pooling possible?
3. How does the person get to the grocery store?
4. How does the person want to travel to school?
5. Are some methods of traveling better than others depending upon the time of day?
6. Does the person feel comfortable traveling in a crowded bus?
7. What means of transportation make sense now and what are the person's goals for the future?
8. Does the person want to hire a driver to get to and from work?
9. Is the person eligible for support money for transportation through Supplemental Security Income (SSI), e.g., Individual Work Related Expense (IWRE), Plan for Achieving Self Support (PASS plans)?
10. What transportation is available if the person wishes to take part in social gatherings in the evening?

RESIDENTIAL

1. Does the person want to live in a group home?
2. Does the person want to live in a supported apartment?
3. Does the person want to rent or own?
4. Would the person rather live in a house, an apartment, or a duplex?
5. Does the person want to have a roommate? If so, how many?
6. Does the person want to live alone?
7. Does the person want to live in a foster family situation?
8. Does the person want to live with someone in particular?
9. Where does the person want to live?
10. Does s/he want to live in the city or on the outskirts of town?
11. Does the person want to rent an apartment that is within someone else's home?
12. Does the person want to live in a dorm?
13. How much does the individual feel s/he can spend on rent?
14. Does the person want to rent something that is furnished or unfurnished?

TRAVEL

1. Does the person want to go to a camp?
2. Does the person want to go on vacation with his/her family?
3. Does the person want to vacation with a good friend?
4. Does the person want to go to the city, the mountains, or the beach?
5. How does the person finance the vacation?
6. What is the person's dream vacation?

7. What are other vacations that interest the person?
8. Are there any groups that offer scholarships for vacations?
9. What does the person want to gain from the vacation (e.g., adventure, excitement, relaxation, socializing, education)?
10. What time of year does the person want to travel?
11. How long is the person interested in vacationing?
12. How long can the person afford to vacation?
13. Does the person want to take a vacation? (This might change from year to year.)

RELATIONSHIPS

1. Who does the person want to spend time with?
2. Where does the person want to go to make new friends?
3. Does the person like spending time with many people or few people?
4. What are the person's interests?
5. Does the person want a pet?
6. Does the person want to join a club or organization that reflects his/her interests?
7. Does the person want to get together with individuals his/her own age?
8. Is the individual interested in dating?
9. What support is needed to continue friendships? Can the person use the telephone? Can the person invite a friend to his/her home? Are friends introduced to the individual's communication system?
10. Is it helpful if people support the person by asking if s/he would like to get in touch with someone?
11. Does the person have a choice about whom they are introduced to and with whom they spend time?
12. How can the person communicate to others that there is an individual that s/he wishes to get to know?
13. What is the person's support system doing to assist the individual with learning about relationships and the dynamics they bring?

COMMUNITY PERCEPTION

1. Does the person want to make all his/her own decisions?
2. Does the individual want others to make decisions?
3. Does the individual want the decision making process to be a cooperative effort? If so, between whom?
4. Does the person want to have times when there is no staff present?
5. How does the person feel about socializing with individuals with disabilities?
6. Does the individual want to take part in age appropriate activities? What kind of books are available to the person? What movies does the person want to see? Does the person want to go to night clubs? Does the person want to go to concerts?
7. How does the person communicate in the community?

8. Do support staff talk to local merchants or does the person?
9. How can the person's support system support the individual to be perceived by the community in the way the individual wishes to be perceived?

SUPPORTS

1. How much and what type of support does the person want?
2. How much and what type of support does the person need within the home?
3. How much and what type of support does the person need when using transportation?
4. How much and what type of support does the person need in the community? For example, could a grocery store offer assistance to the individual when s/he is doing the shopping?
5. How much and what type of support does the person need at work?
6. Can coworkers offer any of the supports that are needed?
7. How much and what type of support does the person need to take classes? Can the teacher offer support? Can a friend offer support?
8. Is the person interested in getting a canine companion?
9. How does the individual want the support person to describe himself/herself?
10. What supports can be offered to an individual who does not self-medicate so that the individual feels as if s/he is respected?
11. How do the people who surround the person support the individual's decisions?
12. How do the people who are in the individual's life support the person to try something new?

By answering these and other questions, individuals with disabilities and the people who support them can begin to chart a course for a fulfilling and productive life.

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Nancy Kalina, 6/95

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Supported Living: It's a New Direction

Our understanding of what it means to support individuals with autism and other developmental disabilities to live in the community changes over time. Since the beginning of the deinstitutionalization movement in the 1970s, we have seen the development of increasingly smaller residential facilities, with group homes becoming popular in the 1980s. This trend continues across the country. In fact, a majority of people receiving Mental Retardation/ Developmental Disability residential services live in homes of 6 or fewer people now; many of them live in homes of 3 or less (Prouty & Lakin, 1996).

A critique of the current service system, however, is that people considered to have the most severe disabilities, and often people with autism, tend to remain in the largest and most restrictive settings (Prouty & Lakin, 1995). Furthermore, from the perspective of people with disabilities, even a small group home can be similar to living in an institution (Bercovici, 1983; Kennedy, 1994). People continue to be segregated and have limited control over their lives.

Since the mid 1980s, there has been a movement to support individuals to live in their own homes, become members of their communities, and to have greater control over their lives and the assistance they receive, regardless of their disability. This approach is referred to as supported living and is based on the philosophy that even though people may have needs specific to their disability, these needs should not interfere with the opportunity for basic life experiences such as physical and social integration, choice, and respect (O'Brien, 1987). Increasing numbers of individuals and their families are requesting supported living services and several agencies around the state of Indiana have recently adopted the approach.

This approach is particularly responsive to the many individuals with autism who have difficulty with unpredictability, inconsistency, commotion, and communication. The opportunity to live in their own home and to choose who they live with, who provides their support, and what activities and routines to follow has led to significant improvements in people's behavior and sense of satisfaction (Hulgin, 1996). As successful situations are developed, our vision of what people need and what is possible is expanding.

Moving toward this vision will require a great deal of change. Policies, funding, and practices are designed to provide services in institutions and other congregate settings. This is evident by the fact that an overwhelming majority of individuals with autism in Indiana currently live in settings of 6 or more people (see Table on page 4). The opportunity for individuals to live in their own homes will depend upon the following changes.

- Individuals with autism and their families need the opportunity to learn about supported living as an alternative approach to congregate services. It is not enough to simply ask an individual where they want to live. Many individuals need experience, the opportunity to explore their preferences, and input from people who know them well to make such decisions. Families also need the opportunity to learn. They often have concerns and even fears that their family member will not receive the support they need if they live in a home of their own. They have come to believe that it is only appropriate or possible for those who acquire the skills to live independently. Individuals and families can learn from situations in which others have been successfully supported to live in their own homes.

  - ervice agencies will need to make fundamental changes in the way they are organized to provide supported living services. This approach requires an organization to be personal, flexible, and innovative. It requires change in organizational structures and staff roles and responsibilities. Such change is difficult to implement in agencies that are heavily invested in providing congregate services and will take a great deal of commitment and time.
- As individuals, their families, and service providers figure out what it takes to support people to live in their own homes, they are identifying barriers within the current system. Several changes in policy and funding are essential to the development of supported living such as:
  - expanding our state's utilization of the Medicaid Home and Community Based Waiver;
  - removing state imposed limitations on the cost of services for individuals as opposed to the use of an average; and
  - redirecting resources from institutional and congregate services.

Though the development of community services has been associated with the move toward smaller group settings, supported living represents a radically new direction. As the opportunity to live in one's own home and become a valuable member of the community is becoming the expectation of a growing number of individuals and their families, we will all be challenged to make significant changes.

Contributed by:
Kathy Hulgin

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What You Should Know About Vocational Rehabilitation

Welcome to the world of adult services! It is important to realize that adult services function very differently than services for children. This is due to the fact that The Individuals with Disabilities Education Act (IDEA) provides for a free appropriate public education for all children. Unfortunately, there is not a similar law that entitles adults to services. This makes it particularly important to be knowledgeable about adult services to support each individual's effort to lead a successful adult life. Vocational Rehabilitation is one resource that can assist in many ways. It is worth exploring the services available when your son/daughter is approaching the transition from high school to adulthood, or for an adult who can benefit from vocational rehabilitation services.

Your application and eligibility to participate in the Vocational Rehabilitation program is based on federal requirements. You are eligible if:

- You have a physical or mental impairment which is a substantial impediment to employment, and
- You require vocational rehabilitation services (VRS) to prepare for, to enter, to engage in, or to retain employment.

Services provided through Vocational Rehabilitation can include, but are not limited to:

- An assessment to determine eligibility and vocational rehabilitation needs, including, if appropriate, an assessment by personnel skilled in rehabilitation technology;
- Counseling and guidance;
- Work-related placement services, including job search assistance, placement assistance, job retention services, personal assistance services, and follow-up or follow-along services;
- Post employment services, if, due to your disability you need services to maintain, regain, or advance in employment;
- Vocational or other training services, including personal and vocational adjustment, books or other training materials, and services to family members if necessary for rehabilitation;
- Physical and mental restoration services, including corrective surgery or therapy for conditions which are stable or slowly progressive, related hospitalization, artificial limbs or braces, prescribed eyeglasses, hearing aids and similar devices, special services necessary for the treatment of end-stage renal disease, and diagnosis and treatment for mental and emotional disorders;

- Maintenance for additional basic living costs which result from program participation;
- Interpreter services for persons who are deaf;
- Recruitment and training services to provide new employment opportunities in the fields of rehabilitation, health, welfare, public safety, law enforcement, and other appropriate service employment;
- Reader services, rehabilitation teaching services, and orientation and mobility services for people who are blind;
- Occupational licenses, tools, equipment, and initial stocks and supplies;
- Transportation in connection with receiving any vocational rehabilitation service;
- Telecommunications, sensory, and other technological aids and devices;
- Rehabilitation technology services;
- Referral to other programs and service providers;
- Transition services to help make the transition from school to work. The formal application for VR services usually is made during a student's next to last school year;
- On-the-job or other related personal assistance services provided while vocational rehabilitation services are being received; and
- Supported employment services.

(from Indiana Family & Social Services Administration)

For more information about these services, contact Vocational Rehabilitation Services at (317) 232-6467.

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Nancy Kalina, 5/95

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Vocational Rehabilitation Office Locations

Anderson 46016
1010 West 8th Street
317-643-7413

Bloomington 47403-2492
302 West 2nd Street
812-332-7331
TDD: 332-9372

Clarksville 47131-2517
1452 Vaxter Avenue
PO Box 2517
812-288-8261

Columbus 47201-3726
2320 Midway Street, Suite 1
812-376-9935

Elkhart 46517-1825
347 West Lusher Avenue
219-293-2771

Evansville 47712-5289
2305 West Michigan
812-425-1367

Fort Wayne 46802-3678
219 West Wayne Street
219-424-1595

Gary 46402-1921
504 Broadway, Suite 444
219-881-6746

Highland 46322-2049
3445 Ridge Road
219-838-0083
TDD: 923-3029

Huntington 46750-9719
2835-B Guilford Street
219-356-1284

Indianapolis - Central 46208-4392
3737 North Meridian Street
Suite 302
317-921-3825

Indianapolis-Northeast 46205-1542
2506 Willowbrook Parkway
Suite 320
317-354-6700
TDD: 254-6706

Indianapolis-South 46227-1379
933 East Hanna Avenue
317-781-3745
TDD: 317-781-3755

Indianapolis-West 46222-2556
3607 West 16th Street, #B1
317-232-1571
TDD: 317-232-1572

Jasper 47546-2620
611 Bartley Street
812-482-4648

Kendallville 46755-1735
119 West Mitchell Street, Suite 3
812-347-4555
TDD: 347-4777

Kokomo 46901-4670
State Building
105 West Sycamore, Suite 406
317-459-8871

Lafayette 47901-1315
323 Columbia Street, Suite 2A
317-423-2276

Logansport 46947-3103
Logans Square
300 East Broadway, Suite 502
219-753-0102
219-722-1777

Marion 46953-2095
415 South Branson Street
317-662-9961

Muncie 47305-2435
201 East Charles Street, Suite 130
317-282-9863

Richmond 47374-4212
50 South 2nd Street
317-966-0932
TDD: 317-966-4394

Seymour 47274-0930
202 East Third Street
812-522-4585

South Bend 46601-2198
221 West Wayne Street
219-232-4861

Terre Haute 47802-0062
30 North 8th Street (4th floor)
PO Box 2062
812-232-7864
TDD: 812-232-8149

Valparaiso 46383-5674
57 South Michigan Avenue
219-462-0521

Vincennes 47591-1304
307 North Second Street
812-882-7208

INDIANA RESOURCE CENTER FOR AUTISM

Selected Employment Bibliography

This bibliography contains resources for individuals with autism, parents, and professionals who support people with autism who work in the community. Selected items may be available to Indiana residents at your local library. Many may be borrowed from the Library of the Institute for the Study of Developmental Disabilities, 2853 E. Tenth Street, Bloomington, IN 47408-2601, (800) 437-7924 (toll free in Indiana; voice/TT); (812) 855-9396 (Bloomington; voice/TT).

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INDIANA RESOURCE CENTER FOR AUTISM

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Nancy Kalina, 7/95

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IRCA

Behavior

Positive Behavior Programming:

Concerning Consequences:
What do I do when . . .?

Any discussion about teaching students with autism in school settings will invariably turn to a discussion about the role of consequences in managing inappropriate behavior. Usually this discussion takes the form of this question: What do I do when "Johnny" does . . .?

Few educators would contest that consequence interventions have long dominated the lion's share of our behavior management efforts. The result is that consequences have become narrowly linked with managing inappropriate behavior, and it is the misguided use of consequences for inappropriate behavior that is of concern. Fortunately, as our efforts shift toward *prevention* of challenging behavior, questions about consequences should no longer monopolize our efforts and energies. Nonetheless, for the present, it represents a valid question which warrants discussion and some ideas about direction. The discussion begins by addressing the purpose of consequences, followed by an examination of ways consequences are misused, and, finally, some ways to use them more effectively.

What is the purpose of consequences?

Consequences have three purposes when used to manage student behavior: (1) reinforcement to strengthen behavior; (2) punishment to weaken undesirable behavior; and (3) neutralization of behavior in a crisis. Too often our focus lies on the second of these three purposes, using consequences solely to eliminate behavior.

Why do negative consequence interventions still dominate our efforts?

Negative consequences meant to punish (i.e., decrease) behavior are a familiar entity. Responses to problem behavior, such as verbal reprimands, time out, and response costs (to name only a few), have a long history in school settings. And they often achieve results. For most students, negative consequences work exceedingly well, at least on the surface. They are the behavior management version of a quick fix because they generally require low effort and produce a quick change. Unfortunately, for many individuals, and especially those with autism, the fix is short lived, overly simplistic, and tends to suggest that what is needed in the future is merely a stronger negative consequence. It also fosters an elusive and never ending search for the perfect consequence.

How are consequences misused?

Below are some ways consequences for inappropriate behavior are commonly misused in school settings, followed by suggestions for more effective use:

- Consequences are applied continuously and for long periods of time, **even when ineffective**.

  Although negative consequences represent tangible evidence to others (e.g., the principal, other staff, parents, the student) that something is being done about inappropriate behavior, too often they are applied reflexively, without much consideration for their individual effectiveness or how the person perceives them. For many students with autism, repeated use of negative consequences quickly loses effectiveness as the student becomes immune to their use. For others, consequences simply serve to heighten anxiety levels when the student is doing what is logical to him or her. They also send the message that the people and activities in the settings are worth avoiding.

- Consequences are predetermined by school policy **without regard to individual student needs.**

  The first and foremost job of schools is to establish safe and effective environments conducive to learning for all students. The second job is to be responsive to individual student needs. Unfortunately, students with autism are often locked into school-wide discipline practices incongruent with their needs—especially when such practices focus on exclusion, suspension, or expulsion instead of instruction and inclusion. The assumption that tough discipline is effective discipline often supersedes the necessary individualization of responses to problem behavior.

- Certain consequences are assumed to be universally punishing (e.g., reprimands).

  The effect that a consequence has on future behavior determines whether we label it as punishment or reinforcement. If a behavior increases in frequency or strength we say it has been reinforced, and the consequence we applied is therefore a reinforcer. If a behavior decreases in frequency or strength we say it has been punished, and the consequence we applied is therefore a punisher. It is important to remember that these terms are merely descriptive ones which indicate whether behavior is strengthened or weakened. Also important to remember is that consequences are perceived differently across individuals. A punisher for one individual is a reinforcer for another. Unfortunately, when addressing behavioral consequences there is a strong tendency to assume the effect in advance. For example, we assume that praise and other social interactions are reinforcing to everyone when in fact they can be quite aversive—especially to individuals uncomfortable with social interaction. Likewise, scolding is generally considered punishment when in fact it may actually be reinforcing—especially in situations where an individual desires attention but cannot gain it except through problem behavior.

- Consequences are used without regard to what the student is trying to achieve through the behavior (i.e., function).

Of particular importance when examining consequences is to determine the purpose or function the behavior serves for the individual. Knowing the purpose has direct relevance for determining how to respond to the behavior. For example, a student with autism who experiences general difficulty with academic tasks may become aggressive out of frustration, confusion, or boredom. Removing the individual as punishment "for being bad" may not actually be punishment at all, but rather reinforcement. In order to know the effect of the consequence of removal, we must look to see the effect over time. If the student continues aggression during academic tasks, we can assume that removing the student is reinforcing. If the student stops being aggressive we can say the behavior was punished.

- Consequences are often assumed to elicit desirable behaviors which the student may in reality not know how to perform.

  Simply stated, **a student may not know what to do when only told what not to do**. Many individuals with autism will require more explicit instruction on performing alternative behaviors before they can be expected to replace inappropriate ones. Although it is true that consequences can suppress behavior by literally trampling over its function, it is not true that they can teach the individual something they do not know how to do.

How can consequences be used more effectively?

The following questions and considerations are meant to promote a more effective use of consequences:

- Determine consequences by individual need and situation. The initial consideration is: Does the behavior require a consequence? If so, what effect will the consequence have now and over time?

- Consider that predetermined consequences may be ineffective and incompatible with behavioral functions. A lot of energy is spent on creating environmental and staff consistency for students with autism. Though this is sound instructional advice, when addressing problem behavior it is also logical to consider whether consistent responses may prove problematic when they don't meet the function of the behavior at any given moment.

- When possible, ignore the problem behavior while establishing future instructional situations to teach the alternative behavior. Then provide immediate, powerful, and consistent reinforcement for performing the alternative. Remember that if the alternative behavior is not sufficiently effective and efficient in achieving desired outcomes, then the individual will be likely to re-engage in the problem behavior.

- Consider whether the consequence is instructive or only suppressive. Does the consequence actually help the person to learn an alternative behavior for the next time the same or a similar situation arises?

- Do not assume ineffective consequences will become effective if used long enough or if strengthened. If individual needs are not met, the behavior will likely continue.

- Finally, gather ongoing functional assessment information to understand the conditions under which behavior occurs and does not occur. Understanding the conditions under which behavior occurs can help shift the focus to prevention and instruction and reduce the need for consequences which serve as punishment.

Shifting away from reliance on negative consequences to addressing problem behavior is difficult. On a broad level it will require ongoing examination of some well-established educational practices. On a personal level it will require individual reflection on our own behavior. Both can result in a more appropriate use of consequences to build skills with long-term utility for students with autism.

Contributor:
Steve Buckmann

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The Indiana Resource Center for Autism (IRCA) is one of four of the Institute's seven centers with a cross-age focus in developmental disabilities (technology and technological adaptations, disability information, planning and policy studies, and autism). The three others focus on age-related issues (young children, school-age, and adults and seniors). The ISDD is dedicated to the promotion and maintenance of a seamless system of inclusionary services across the lifespan. Institute activities include interdisciplinary training, information dissemination and research, and community services.

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Don't Forget about Self-Management!

A primary goal of education is to assist individuals to become more independent in managing their own behavior. For most people, this is a gradual process which extends well into adulthood! For many individuals with autism, moving towards increased independence is difficult without systematic, long term instruction. Though support persons strive to assist individuals with autism in reaching greater heights of independence and autonomy, many of our efforts actually result in teaching individuals to be heavily reliant on outside influences and controls.

Typically, instruction for individuals with autism has focused on teaching ALL of the skills and behaviors needed in EACH instructional setting, since individuals with autism may experience difficulty generalizing behaviors and skills across settings. Unfortunately, this becomes an overwhelming prospect as well as an inefficient strategy. Instead, it would seem more logical and efficient to teach behaviors that have the potential to transfer across settings and to benefit the individual in multiple settings. Self-management is such a behavior.

What is self-management?

Self-management is a *procedure in which people are taught to discriminate their own target behavior and record the occurrence or absence of that target behavior* (Koegel, Koegel, & Parks, 1995). Self-management is a useful technique to assist individuals with disabilities, including autism, to achieve greater levels of independence in vocational, social, academic and recreational activities. By learning self-management techniques individuals can become more self-directed and less dependent on continuous supervision. Instead of teaching situation specific behaviors, self-management teaches a general skill that can be used in an unlimited number of environments. Self-management techniques have also been useful in reducing or eliminating such behaviors as stereotypic responding. The procedure has broad applications for individuals with and without disabilities and can be adapted in some manner to benefit a variety of learners.

How do you teach self-management?

Koegel, Koegel and Parks (1995) have outlined five general steps to teach self-management. These are: (1) operationally define the target behavior; (2) identify functional reinforcers; (3) design or choose a self-management method or device; (4) teach the individual to use the self-management device; and (5) teach self-management independence. Each of these steps are explained below.

1. *Operationally define the target behavior.*

   First, it is essential that the target behavior(s) be described so that the individual who is learning to self-monitor as well as all who support him/her can identify and agree upon the occurrence or non-occurrence of a behavior. For example, a description such as *behaving in the lunchroom* is vague and open to interpretation. Instead, *staying in the lunch line, not touching other students, remaining seated until finished eating* provides a description of the behavior that is observable, measurable, and can result in agreement across observers.

When first instructing an individual in self-management, the target behavior should be simple enough to be performed fairly quickly and easily so the student can gain access to a reward. As the individual experiences success, more behaviors can be added to the procedure.

2. *Identify functional reinforcers.*

Reinforcers, by definition, increase the behaviors they follow. What is reinforcing varies across people. The best way to select a meaningful reinforcer is to let the individual select it. However, sometimes it is difficult to identify reinforcers. In these instances, several strategies may be helpful. First, observe the individual to see what they like to do. Second, look at the possible function of behavior. This may provide a direct link to a functional reinforcer. For example, for an individual who exhibits challenging behavior to escape a boring or difficult task, access to free time may be the logical (and preferred) reinforcer.

It is important (at least initially) that reinforcement for performing the target behavior and for self-monitoring the occurrence of the behavior be given each time. In addition, students can be encouraged to access their own reinforcer.

3. *Design or choose a self-management method or device.*

The purpose of the self-management method or device is to provide the individual with a clear means to record the occurrence of behavior. This could entail making check marks on paper, placing stickers in a notebook, using a tape recorder with pre-recorded signals at pre-set intervals, or using a wrist counter. Considerations for choosing a method/device include: the present ability level of the individual, ease of use and portability (so that self-monitoring can be expanded to many settings), age-appropriateness, and the behavior(s) to be targeted. For example, a large cumbersome device probably would not work well during gym class.

4. *Teach the individual to use the self-management device.*

In this step the individual is taught (generally through modeling by a facilitator) to accurately recognize and record the occurrence or nonoccurrence of target behaviors and receive reinforcement for accurate recording. Then the individual is instructed to perform the target behavior and self-record the occurrence of the behavior. To ensure that problem behaviors are not strongly reinforced, the facilitator should provide more reinforcement for recording the occurrence of desired behaviors, and less reinforcement for monitoring the occurrence of undesirable ones. Again, the time to teach self-monitoring will vary considerably across individuals. However, it is important that the facilitator ensure that individuals learn to self-monitor in the individual's *real world*.

Interestingly, individuals do not always have to record with complete accuracy to achieve the desired effect, though it will be important for facilitators to ensure two things:

- That the individual understands the procedure; and

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- That the individual is not simply cheating to gain a reward. Careful monitoring by the facilitator will reduce the effect of either of these factors.

5. *Teach self-management independence.*

This is the stage at which the facilitator fades himself out of the picture and allows the individual to self-monitor and self-reinforce. The following outcomes should be addressed at this stage:

- Prompts to self-manage behavior should be reduced.
- The amount of time the individual spends self-managing should be increased.
- The number of self-recording responses expected before reinforcement should be increased.
- The schedule of reinforcement should be reduced by increasing the duration between times when self-recording is expected.
- The individual should be taught to access their own reinforcement for successful self-recording.

Example: Adam is a nine year old with a diagnosis of autism and severe mental retardation. He is extremely active and moves about his fourth grade classroom continuously. It was estimated that Adam would stay seated (at best) for about three minutes at a time. His parents and teachers were concerned that if this pattern continued it would compromise his chances to learn and be included in typical educational activities. They wanted to consider educational interventions before investigating medications to address this hyperactivity. It was decided to teach Adam a self-management procedure. Each step is described below.

Step 1. Operationally define the target behavior.

Initially, only one behavior was targeted: staying in seat. Since the duration of a typical group lesson in Adam's class was about 20 minutes, remaining seated for this period of time became a *long-term* goal for Adam. The target behavior was communicated to Adam with a photograph of him seated at his work table with three other students.

Step 2. Identify functional reinforcers.

Observations of Adam quickly showed that his preferred reinforcer was simply to move about the classroom freely. Since Adam did not disturb the classroom environment in any way when he walked around, it was agreed that Adam could earn free time to walk about the room.

Step 3. Design or choose a self-management system.

Adam was familiar with typical kitchen timers. His parents had used them successfully at home to indicate transition times. It was agreed that a kitchen timer would indicate intervals at which to self-monitor. In addition, Adam greatly enjoyed cartoons. Stickers of cartoon characters would be used to record the appropriate target behavior of staying in seat.

Step 4. Teach the individual to use the self-management device.

Initially the teacher used one of Adam's peers to model in and out of seat behavior and prompted Adam to record his peer's behavior (placing a cartoon sticker under the *in-seat* picture if his peer was seated). When Adam responded correctly to 8 out of 10 trials, his teacher began to use the timer.

Initially, to teach the procedure, the timer was set at two minute intervals (about a minute less than he typically stayed seated) during his regular instruction. No physical or verbal prompts were used to keep Adam seated during instruction. At the end of each interval, Adam was asked, *Were you seated?* If he was seated and correctly identified that he was seated, he was given a sticker. If he answered incorrectly, he was told, *Yes, you WERE seated, you earned a sticker.* He placed the sticker on a monitoring card and was then told, *You earned free time* and was allowed to walk around the room for a minute.

When Adam was out of his seat at the end of the interval, he was brought back to his desk, but not seated. He was asked, *Were you seated?* If he correctly identified that he was not seated, he was praised and asked to sit down and begin working. Adam was then instructed to remain seated until the bell and his assistant resumed instruction.

Step 5. Teach self-management independence.

Over time Adam was able to stay in his seat for continuously longer periods. The length of the timed intervals has gradually increased until after 6 weeks he was remaining in his seat consistently for 10 minutes at a time and at times for up to 15 minutes! The amount of instruction Adam is receiving has greatly increased.

On-going efforts will be made to increase self-management independence (as outlined in Step 5). Though Adam still requires his teacher or assistant to *prompt* him through the procedure when the timer rings, Adam is beginning to more accurately identify his behavior.

Discussion

Self-management is a procedure with broad applications. Though there is a general series of steps to follow, individualization is critical to increase the likelihood of success. It is also important that self-management procedures not be used as a substitute for a well developed and individualized curriculum. Activities and curriculum for all individuals should be developed so that they are interesting and result in meaningful outcomes. Self-managment is not a tool to simply teach individuals to be compliant.

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Contributor: Steve Buckmann 5/96

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A Brief Explanation of Discrete Trial Training

Given the increasing interest in early behavioral interventions for children with autism, it is not surprising that the Indiana Resource Center for Autism receives almost daily requests for information about such interventions. Two frequent questions asked by individuals requesting information are, "What is discrete trial training?" and "What is the difference between discrete trial training and the Lovaas Method?" The following is a brief explanation of discrete trial training and a basic contrast of the two.

Discrete trial training (DTT) is a method of providing intervention. According to Anderson et al. (1996), the discrete trial method has four distinct parts: (1) the trainer's presentation, (2) the child's response, (3) the consequence, and (4) a short pause between the consequence and the next instruction (between interval trials). For some readers, these four parts are perhaps more familiar when presented in the following model:

SD →	**R** →	**C**	
(Discriminative Stimulus) A cue to perform some behavior that leads to a reward	(Response) Child's action as a result of the cue	(Consequence) What happens following the response (i.e., a reward for correct responding)	(Pause)

This model is the basic framework used fairly consistently across DTT programs. The primary difference among discrete trial training programs is found in what they teach, rather than how they teach. For example, the UCLA Young Autism Project (aka *Lovaas* Method) is one treatment program directed mainly at pre-school aged children with autism. It uses discrete trials as its main instructional method and follows a fairly set progression of instructional programs beginning with early receptive language and "terminating" with programs focused on achieving skills in self help, community and school situations. Not all programs using DTT follow the same program sequences or curriculum as the UCLA project.

Many readers may also be asking the question, "Don't ALL educational programs involve some use of the discrete trial method?" The answer is yes—at least to a limited degree. Instructional situations and interactions can generally be described in terms of this basic teaching model. However, there is often confusion between an informal or periodic use of this teaching model and "doing discrete trial training." What distinguishes DTT programs is the intensity and duration of the training and the primary role of the discrete trial method for instruction. DTT programs generally involve several hours of direct 1:1 instruction per day (including high rates of discrete trials) over many months or years.

Though the basic model for DTT appears relatively straightforward, applying the model effectively is not. A casual understanding of applied behavior analysis is insufficient for applying DTT programs. Given the high stakes of early intervention, the controversy surrounding discrete trial training programs, and the effort and knowledge required to effectively deliver DTT, parents, administrators and teachers must invest the time and energy to understand all aspects of discrete trial training programs. This includes not only understanding how to implement such a program, but having the ability to evaluate the effectiveness and appropriateness for each child. The following resources can assist this effort.

Contributor:
Steve Buckmann

Reference

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Movement Differences Among Some People with Autism: An Impetus to Re-Examine Behavioral Issues

Background

Beliefs, attitudes, and old information about autism appear to need constant re-examination as new concepts, information, and treatment approaches continuously become available. In recent years professionals and parents have reflected about concepts such as *inclusion* and *theory of mind* and interventions ranging from holding therapy to manual signing. *Movement differences* has become a contemporary topic in the area of autism in the 1990's, although the neurobehavioral construct itself is referenced in pre-1990's medical chronicals. Present discussion of the topic with regard to individuals with autism represents a broadening of application and reflection beyond the original documented disability groups. The significant questions and possibilities presented by the topic of movement differences compel people with an interest in autism to engage in some personal re-assessment. This paper presents some basic information regarding the nature of movement differences and provides suggestions as to its functional application. Readers are urged to read full text discussions by Donnellan & Leary (1995), and Leary & Hill (1996), and to remember that movement difference is a construct and not a new disability category.

Recent widespread awareness of selected aspects of movement differences began with the publications and trainings of Rosemary Crossley (1980) and Doug Biklen (1990) on the technique of facilitated communication. The need for an assisted movement/emotional support technique (i.e., facilitated communication) arose from supposition. Later, direct confirmation occurred when selective nonverbal individuals indicated that they did indeed have difficulty initiating or sustaining independent coordinated motor movements. Controversy still surrounds the use of the facilitated communication technique in terms of consistent authentic authorship of messages. As part of the controversy, there has been speculation that many nonverbal individuals who were introduced to the facilitated technique may not have had a movement difference or a disturbance of the magnitude that prevented them from using more conventional and independently accessed augmentative means of communication (e.g., Liberator™, DynaVox®, non-commercial manual communication boards). There is no significant data to support or refute the prediction about prevalence. In comparison to dialogues and disagreements about facilitation as a technique, discussion about the more broadly defined construct of movement ability or difference has been less provocative. If anything, the new information has encouraged others to notice potential movement differences in individuals with autism that had been previously overlooked and to engage in pondering about new interpretations of human behavior.

The reframing of observations that derived from the facilitated communication movement, however, proved to be just the tip of the iceberg in the topic area of movement differences. Many neurologically based disorders such as Parkinson's and Tourette's appear to share symptoms that are also found in some individuals with autism. The neurobiological basis for autism per se, however, is not considered to be the causal agent for the movement difference symptoms that have been noted but there does seem to be some relationship. Selective examples of shared characteristics or symptoms include the following: repetitive movements, abnormal gait, abnormalities in muscle tone, lack of imitation, self injurious behavior, echolalia, and difficulty initiating, stopping or switching actions (Donnellan & Leary, 1995).

On a semantic basis one would guess that movement differences literally referred to observable motor movement patterns. Instead, movement differences, as described by Donnellan and Leary, and others, has a more figurative meaning. While the construct does include movement patterns or actions, it also encompasses posture, speech, perception, thought, attention, consciousness, motivation, memories, and emotion. Overlaid on each of these is the issue of volitional or voluntary control (Donnellan & Leary, 1995; Leary & Hill, 1996). The more figurative or metaphorical nature is evidenced by discussions of someone's internal mobility to *cease* thinking about a particular thought, to *switch* a perceptual focus, or to *combine* memories with new thoughts. Both Leary and Donnellan define movement differences through visual information displays and examples rather than through an exact dictionary-type of definition.

Recognizing Possible Instances of Movement Differences

Recognition of movement differences as a factor in observed behavior certainly will force rethinking in the area of behavioral analysis. It will no longer be possible to only hypothesize about the probable purpose or motivation for a given behavior. Since specific actions may not be under the individual's volitional control, there may be a mismatch between personal motivation and the action observable by others. There also may be a mismatch between a service provider's hypothesis about the intent or benefit of an action and the actual intent of the person with a movement difference. The mismatches can best be illustrated by some common examples. Movement differences may be a co-occurring factor *or* the sole factor behind the observed behavior in any of the illustrations and the hypothesized intent of the behaviors.

Examples of Real Situations

Situation One: John paces the perimeter of the kitchen in an intense manner; he ignores directives to find something else to do.

Possible function of the behavior: John is anxious about an upcoming event or he has the need to relieve built up tension.

Possible movement difference: John has difficulty ceasing the motor behavior, switching his thoughts to an internal activities option menu, and initiating body movement to begin the selected activity.

Situation Two: Brian is told to get ready for gym class; he begins screaming.

Possible function of the behavior: Brian is sound sensitive and he is avoiding the transition to a noisy environment.

Possible movement difference: Brian is unable to execute all of the motor steps or sequence involved in getting ready for gym class, (i.e., putting away his pencil, returning a book to the library shelf, getting his jacket, lining up with his classmates to transition to another building for gym). Shifting his thoughts regarding what he must do with his body at each step may be difficult. The movement difficulties may be instigated or compounded by the challenge of transitioning to an environment that is adversive to a sound sensitive individual.

Situation Three: Sarah enjoys assembling puzzles. She reaches to insert a puzzle piece but appears to stop for a minute before moving on to insert the piece.

Possible function of the behavior: Sarah was waiting for a verbal cue to continue the action which also would have resulted in a brief social interchange with her favorite staff member. Second, she could have been distracted by the shininess of the table upon which she was assembling the puzzle. As a third option, Sarah could have had a seizure.

Possible movement difference: Sarah experienced a freezing or blockage in her ability to smoothly execute a volitional motor plan.

Situation Four: Gary periodically bites his hand and makes sounds as he tries to manipulate his shirt buttons while dressing in the morning.

Possible function of the behavior: Gary is expressing his frustration with the difficulty level of the task.

Possible movement difference: Gary is unable to execute the complex movements involved in buttoning his shirt. He finds it difficult to shift his thoughts from memories of past difficulties and frustration with the present episode.

Situation Five: Tim takes a long time to think of what he wants to say. By then the relevant moment for a response is gone. Usually his second grade teacher and classmates are talking about a different aspect of the topic when he contributes what appears to be an off task comment. He gets angry when the other students laugh at what appear to be non sequitur comments.

Possible function of the behavior: Tim is protesting that the other students laughed at his contribution to the class discussion. He has experienced an affront to his dignity.

Possible movement difference: Tim is unable to quickly move from thought to thought, to sift the important aspects, and then combine those thoughts while executing a motor movement plan.

Implications Emanating From the Construct of Movement Difference

If people with autism are having difficulty with performance in given environments, such as in the situations above, then specific adaptations or accommodations may be implemented. Although the latter two terms, "adaptation" and "accommodation" are frequently used as synonyms, the terms seem to have different connotations in the movement differences literature. The term "adaptations" refers to how or what the environment or other people may change or do to circumvent a specific problem. Adaptations are a natural component of positive behavior supports, and usually reflect strategies suggested and implemented by others. For example, the use of a schedule to aid Brian make transitions in situation two and the use of a button hook to aid Gary to independently button his shirt in situation four represent external adaptations. However, adaptations do not always need to be something material. With Jeff, a child who finds it difficult to halt his forward fast-walk movement, his classmates may employ a touch cue to stop him, or they simply may get out of his way. In situation three, if Sarah's recovery time from the freeze blockage had lasted longer, someone might have used a touch cue at the shoulder to enable her to resume the forward motion toward the puzzle. In contrast to accommodations, adaptations are devised by others and may or may not reflect input from the individual with movement differences.

Donnellan and Leary (1995) use the term *accommodation* when they are referring to strategies that directly help the person with a movement difference adjust or work through his or her problem. This assumes that the expert resource about movement differences or difficulties is the individual. Without direct information and feedback, everyone is only guessing about the existence of a difference, whether the person already has some strategies to deal with the situation, and how the person is emotionally coping with his or her challenges. Unfortunately, while just asking may be a first strategy for the caregiver, the situation may not be quite that simple. The explicitness of the information obtainable may depend on the person's ability to self-analyze, a meta-cognitive skill, and the individual's ability to communicate in a verbal or augmentative medium. With reference to self-analysis, can the person objectively think about his thoughts or his motor movement patterns? Can he identify what is difficult, and when or how he works through a movement difficulty? Has he or she had many opportunities to develop or practice using this type of thinking? It is from recent autobiographies and biographies such as Donna Williams' books (1992, 1994) and *There's a Boy in There* (Barron and Barron, 1992) that care providers are developing more understanding of what it might be like to experience movement difficulties (Leary & Hill, 1996). Some individuals may be very aware of their differences and may have highly effective personal strategies for overcoming periodic challenges. Specific strategies, however, may or may not be considered effective or socially acceptable by the person's peers or care givers. For example, Jeff, the child who had difficulty stopping his forward movement, might use the strategy of heading to a wall to stop himself. He most likely found this strategy to be effective in some situations and not in others (i.e., when no wall is available). He may need acceptance and encouragement to use his personal strategy, but also assistance in defining a plan to accommodate more open space conditions.

In addition to meta-cognitive or self-analysis skills, the individual with movement differences also needs an adequate means of communication for interactive discussion. Even if a person appears to be quite verbal, he or she still may need print displays with specific vocabulary or phrases to provide him or her with support during what could be very emotional discussions about a difficult and personal topic. Augmentative means, with or without facilitation, can be considered as another alternative to enable more effective expressive output.

In summary, this brief orientation suggests that some individuals with autism may share movement difference characteristics with people who have other disabilities. It appears that what care givers observe and interpret may not always reflect an accurate guess or hypothesis about specific situations. Many instances of movement differences may not be initially obvious and they may reflect internal movement problems. Since differences vary along a continuum and may be influenced by emotional state, circumstances, effective strategies, and such, variability in performance may be the norm for some individuals. In some situations, the person with autism may be receptive to suggestions or training to develop effective strategies to overcome a given situation. In other instances, professionals and families may need to put aside their attitudes or beliefs and respectfully allow or encourage the individual to use his or her preferred way of managing or coping with the movement difference. Much has yet to be explored and developed in this new area of interest; much will need to be scrutinized as the flow of information in the area of autism continues.

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Contributor: Beverly Vicker 5/96
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Using Negation with Students with Autism

Adults don't typically tell other adults "No" except as a direct request, i.e., "Can you go to lunch tomorrow?" Usually even this question gets a qualified "No," such as "I'm busy, what about Friday?" Yet we continue to use "No" frequently with people with autism. Usually they hear this word when they are trying to comply with specific demands or requests from others. The word "No" gives them the information that someone is mad, or that they have done something wrong or "bad." For some, the word "No" may even create anxiety. Unfortunately, the word "No" does not tell an individual what is desired or requested behavior.

Many people with communication impairments do not understand negation in a sentence. Therefore, they do not hear or process "No" and "Don't" in a sentence. For example, when someone says, "Don't go outside," the child may run to the door. He is responding to "go outside" rather than being non-compliant. It may be better to teach responses to specific directives, rather than using the broad spectrum of "No." "Stay in the family room" is a better direction. Use "No" sparingly and only when there is not a better phrase to use.

In expressing a choice: "Do you want to eat some ice cream?", "No" may be the most appropriate response. Used in this context, the word "No" does not reflect wrong doing, it only states a preference or choice. Teaching choice is vital to independent functioning, and therefore, learning to say "No" as a choice is important. This can be learned through practice and modeling.

So what do you use when you want to stop a behavior? Don't say "No." Try REDIRECTION! For example, a student is biting his hand. Redirect him to do something requiring the use of his hands. Another student is hitting her head. Redirect her to an activity, such as exercising. In both cases you want to figure out what is causing the behavior. Analyze the purpose of the behavior, then teach a better way to reach that purpose. Maybe the individual needs to learn through modeling to express frustration or to say, "I need a break." Saying "No" may stop the behavior for the moment, but it gives no information for correction. It may raise anxiety and cause more problem behavior later. Saying "No" doesn't teach a person what to do.

We need to practice creative teaching rather than resorting to "No" on a regular basis. Use proactive strategies, rather than constant correction to teach individuals with autism about the world and how to interact successfully.

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Adapted from N. Dalrymple, 1/94

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Relaxation for the Person with Autism

While often overlooked, relaxation is a skill of great value to both individuals with autism and staff. For an individual to be able to relax on cue or, better yet, without a cue, means that he/she has a coping mechanism to use in a stressful or exciting situation. Variables such as functioning level, effect, communication skills, and general activity level will need to be taken into account when developing an individual relaxation program. However, several concepts can be generalized:

A. Spontaneous Relaxation

Situations where the individual is already somewhat relaxed present a good opportunity for reinforcement and to make him/her aware of what being relaxed feels like. Emphasize the word "relax" while giving back rubs and massaging the shoulders. Generally reinforce "good relaxing" in a smooth, low tone of voice. This can happen during freetime, at a regular time (though should never be forced), and if and when the learner requests this at any other appropriate time. *Relaxing may become associated with a certain musical theme, a particular place, person, or object. These associations and, in fact, the whole process are best developed at any early age.

B. Teaching Relaxation

Teaching relaxation is more structured and a little more abstract in that the person should (ideally) imitate what staff is modeling. However, an individual can be guided through the procedure until it is learned. Begin with relaxation of body parts, e.g., arms. Have person sit in a chair facing you. Demonstrate the position of holding your arm straight making a fist and tightening own arm and feeling parts that are tight. This will more than likely take many tries to coordinate; don't get discouraged and always reinforce! You should then "relax" your arm, let it drop and have the individual do the same with you modeling by keeping your arm limp. The individual's relaxation can then be "tested" by lifting his/her arm up and letting it drop. This may take weeks for the person to perform at will. You may want to start by having the individual push against a table with his/her elbow if he/she seems to have trouble keeping his/her arm straight while making a fist. If making a fist is a problem, try having the person squeeze two of your fingers (or a squeezable rubber ball). Another effective exercise is to practice bending at the waist with the head down. This works well in conjunction with breathing exercises.

Like everyone else, people with autism may have subtle flexion/extension problems; therefore, you may need to help straighten legs or arms and flex feet/wrists to create tension in the muscles. You can then let the person naturally relax the body part and see how it feels.

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*Massages should always move <u>**toward**</u> the heart, e.g., stroke <u>**up**</u> the back, <u>**up**</u> the arm. It sounds trivial, but a vigorous massage any other way may affect the blood pressure.

It is important to note that for many people with autism, even accepting a back rub that's been offered may pose a challenge. This may be overcome by desensitizing the client: first, to your presence (i.e., just being in the same room), then gradually lessening the distance and increasing the time spent with the person. A few seconds of physical contact may exceed the limit of what the individual will tolerate initially. It will take pacing and patience to become truly "spontaneous."

1. Use of objects to help relax body parts. These can be incorporated to emphasize tense/relaxed states of specific body parts. Good examples: hand grips, foam rubber balls (or any foam rubber object), any soft squeezable object, weights to be moved with either arms or legs, or old clothes to be twisted/untwisted. Vibrators or vibrating pillows on the back of the neck are excellent relaxation inducers.

*2. **Breathing exercise.*** Demonstrate deep breathing slowly. "breath in - relax - breath out"-- very slowly. Individuals will often inhale and exhale on cue, but controlling the pace is the problem. This is why practicing when the client is at his/her most relaxed (e.g., after a meal, before bed) is essential. Breathing in can be paired with shoulders up, breathing out can be paired with shoulders down.

Blowing is also a good means of controlled breathing. This can be coupled with bending at the waist, and putting the head down for each blow exhaled. Again, start slowly. Each blow outward should be followed by a deep inhalation to avoid hyperventilation.

This is also a first line of action in a potential crisis. Breathing exercises can be done anywhere at any time and having practiced while the learner is calm is essential in order to induce a relaxation response in a tense situation. Only the learner who understands relaxation (through practice) will be able to initiate such a response.

C. A Sample Relaxation Routine

Prior to starting a relaxation routine, several questions must be answered: Where? When? With whom? For how long? These all depend on the individual and what his/her environment will allow. Does he/she have a favorite place? A favorite staff member that seems to act as a calming influence? What can staff reasonablely expect from this person's attention span? If relaxation is to work, it must be individualized to meet the needs of the individual.

Practice several times a day. Model or, in a gentle way, physically assist at first. Give verbal praise during and reward afterwards. Set a limit: number of minutes, number of repetitions (whatever the individual responds to!). Try to fade the cues from the routine in order to focus mainly on breathing.

Cue: Time to sit and relax
[What kind of cues/stimuli will the learner respond to best? Does he/she have a communication board that can incorporate relaxation?]

Bend at waist
Head down
Blow out
Breathe in
(Repeat 3X)

Sit up
Raise hands
Wiggle fingers
Bend at waist
(Repeat)

Cue: Sit and relax
Sit in comfortable chair or on carpet
Squeeze (e.g., nerf ball, wash rag, or shirt)
[Count for each repetition, e.g., one one-thousand...]
Relax
Squeeze
Relax
Squeeze
Relax
Breathe in slowly
Breathe out
(Repeat as many times as needed)

Of course this should be modified based on what works best with each individual. Each step and the whole routine should be repeated followed by praise for "nice relaxing." Visual cues may help as well as appropriate music. Pictures, whether on a communication board or standing alone, may be of great help both to cue the person to what is about to happen as well as during the routine. In addition, visual cues may allow staff to teach relaxation at a distance that's comfortable for the individual. As the person becomes desensitized to staff presence and the routine itself, the distance may be decreased.

Any stimulus cues may be used in combination. Be aware, however, that things like music, rocking devices, or favorite chairs may not always be available (e.g., in community settings). Staff may be well advised to not depend too heavily on these accompanying stimuli.

Spontaneous relaxation (i.e., independent relaxation) is a goal that will be reached when the individual is able to rely on his/her internal cues. Therefore, after practicing for a substantial length of time with stimulus cues, try gradually fading them out. A good reinforcement plan should allow this to take place, even in the absence of music, pictures, or objects. The learner should ultimately be able to initiate relaxation on his/her own.

After the routine has been learned, the next step is to employ it when staff detect antecedents to the learner possibly getting upset. It is therefore very important to become familiar with any common behaviors that precede anxiety. Relaxation works best **before** the fact rather than after a behavioral incident is in progress. Staff must be able to facilitate relaxation across settings.

1993 Addendum

Additional materials on relaxation:

Book:

Cautela, J., & Groden, J. (1978). Relaxation: A comprehensive manual for adults, children, and children with special needs. Champaign, IL: Research Press. $14.95.

Videotape:

Groden, J., Cautela, J., & Groden, G. (1992). Relaxation techniques for people with special needs. Champaign, IL: Research Press. $195.00. (includes the manual listed above).

Also available for $195.00 from Research Press is the 1992 videotape, Imagery procedures for people with special needs.

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Misha Angrist, 1988
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Desensitization

Desensitization: To make less sensitive to a situation or object.

A strategy for step-by-step reduction of anxiety associated with changes in routine, introduction of new stimuli/new people, or changes in environment for individuals with autism.

Teachers, service providers, and parents wanting to broaden the repertoire of activities and interests of their clients/students must plan a systematic strategy to reduce the anxiety that may result in interfering behaviors that may block success.

The time needed to desensitize an individual with autism to a new situation or activity depends on:

- the person's previous history with that particular situation
- the person's previous history with similar situations
- the person's general temperament
- the person's level of trust in the accompanying parent or staff
- the integrity of the desensitization routine

A desensitization plan can be implemented either over a few weeks, once or twice a day or every other day, or over several months, practicing once or twice a week. Individualizing the plan may call for increases or decreases in frequency. The client/student should progress step by step, remaining on each step until he or she is comfortable.

Examples of the Desensitization Process

Activity: Eating at McDonald's

Step ①: Talk about McDonald's and drive by.
Step ②: Talk about McDonald's, drive there, and get out of car.
Step ③: Go inside and watch for three minutes.
Step ④: Stand at counter while staff places order. Go to table, leave immediately.
Step ⑤: Order placed by staff. Sit down and stay three to five minutes.
Step ⑥: Student places own order using written cue card and sits to eat or drink.
Step ⑦: Student orders, sits to eat, and cleans up.

Activity: Group Participation

Step ①: Select a small group activity (2-3 clients/students) that is scheduled in the daily routine. If possible, select a group activity that may be potentially motivating for the student. The group may be art, music, story listening, snack, exercise, or similar activities that do not require much waiting, response, or reciprocal interaction.

Step ②: Desensitize the client/student to the environment and new people. Then begin to desensitize him or her to being part of the group activity. Tell the client/student before hand, "Tomorrow you will watch the music group." Talk to the student about this several times prior to the group time.

Step ③: Follow steps which gradually draw the student into the group. Steps include:

A. Watching the group. Student is in the same room or area as the group.

B. Sitting in a chair, six feet away from the group. Gradually move the chair closer by one or two feet each time; use a tape mark on the floor to indicate where the chair goes.

C. Sitting with the group for two minutes. Gradually increase to five, ten, and then fifteen minutes.

Step ④: When the client/student's anxiety lessens, increase the expectations for his or her participation in the group activity.

Activity: Using a vacuum cleaner

Step ①: Parent/staff talks about vacuum cleaner and shows picture.

Step ②: Open door to storage closet and look at vacuum for 30 seconds.

Step ③: Parent/staff gets vacuum out and student stays in same room with vacuum for 1-3 minutes.

Step ④: Student helps get vacuum out of closet and put it in the room, and stays in room for 3-5 minutes.

Step ⑤: Student gets vacuum out, parent/staff turns vacuum on, and student stays some where in room with it for 1 minute.

Step ⑥: Student gets vacuum out and stays in room while parent/staff uses vacuum for 3-5 minutes.

Step ⑦: Student gets vacuum out and uses it for 1-3 minutes.

Step ⑧: Student gets vacuum out, uses it, and puts it away.

Activity: **Dental Exam**

Step ①: Visit Dr. Smith's office every Thursday at 3:00 p.m. for four weeks.
- A. Sit in dental chair-gradually increase time until tolerates sitting for ten minutes.
- B. Become familiar with instruments-mirror, "tooth checker," suction, water, and air.
- C. Practice opening mouth and keeping it open on command.

Step ②: Dental practice (10 minutes) at home twice weekly for same four weeks.
- A. Read book on dentist visit to learner.
- B. Practice opening mouth on command.
- C. Put mirror in mouth, no biting.
- D. Talk about visit using pictures of office and Dr. Smith.

Step ③: Dental practice (10 minutes) in classroom twice weekly for same four weeks.
- A. Read book about going to dentist.
- B. Color pictures.
- C. Practice opening mouth on command.
- D. Talk about visit using felt board pictures.

Assessment and Generalization

In assessing student's progress through the desensitization process, data should show increasing time tolerating the situation and decreasing anxiety.

Desensitization can be generalized to other similar situations. Once desensitization to a particular activity or place has taken place, parents/teachers/staff should introduce the person to other similar activities or places to help the student generalize and extend new skills. Desensitization to similar activities or places will usually require less time and fewer steps.

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AUTISM:
MANAGING CHALLENGING BEHAVIOR

Flapping, echoing, spinning, pacing, biting... Not sleeping, eating, toileting, sitting, complying, producing, socializing, talking... These are some of the challenging or problem behaviors that are often attributed to people with autism. One of the main objectives of education and of parents is to teach students to be social, independent, productive members of society. People often experience frustration and failure when teaching individuals with autism because these students don't always respond to usual teaching and discipline methods and require so much planning and individualization. Persons with autism have problems differentiating, organizing, and effectively using stimuli and cues, and they need carefully planned approaches to help them understand their worlds and communicate their wants and needs. Too often they experience failure and negatives from the people around them and do not know how to correct the situation. Therefore, behavior must be managed through a comprehensive analysis and program, not by a reactive or punitive approach.

ASSESSMENT. Much background information must be known about the individual to help that person successfully learn to manage his/her own behavior. Some questions to ask include:

About the person:

- What does he like/not like?
- What frustrates/frightens him?
- What does he do in unstructured time?
- What are his habits?
- How does he communicate?
- What environmental stimuli does he react to?
- What are his strengths?
- What are his medical needs?
- What are his sensory needs?
- How does he socially interact with others?

About the behavior:

- When/how often does it occur?
- Where does it occur?
- What is the purpose of the behavior for the individual?
- Is there a chain of behaviors?

About other people's reactions:

- What do they do when the behavior occurs?
- Does it work? For whom?
- Is there consistency?
- Is it judgmental and negative?

PURPOSE OF BEHAVIOR. It is vital to gather accurate information and compile it so that interventions can be planned that address all the necessary parts. Too often, the approach that is taken is to "fix the problem" without identifying what the problem is. Discovering the purpose of a behavior is like sleuthing in a detective story and is necessary to "solving" the mystery. Challenging behavior may either be communicating a message or relieving tension and anxiety. Messages may range through refusals, negations, emotions, desires, and basic needs, while self-stimulatory and repetitive behaviors may be strategies used to self-regulate and monitor emotions. Knowing what purpose(s) a behavior plays is the first step in deciding what new behaviors to teach. A person can be taught other ways to express the same message and other methods to relieve tension and anxiety.

Examples.

Behavior: Throwing materials.
Purpose: Wanting to be finished.
New Behavior: Sign, say, or point to "finished" or "all done."
Reinforce: Praise and acknowledge by use of sign or words permitting student to be finished.

Behavior: Pacing.
Purpose: Anxious about next activity.
New Behavior: Plan a jogging/exercise program and teach a more appropriate "waiting" strategy.
Reinforce: Reinforce the new skills and behaviors.

ENVIRONMENTAL CHANGES. Often the easiest, quickest, and most effective intervention to use is a rearrangement and adaptation of the environment. Distracting stimuli can be eliminated, screened, or cut down. Space, arrangement of furniture and materials, crowding and time of activities can be varied. Schedules and routines can be established and conveyed clearly. Adaptation of materials and environments can be designed and implemented.

POSITIVE PROGRAMMING. Without an appropriate positive program, a person with autism becomes unable to learn and confused, often leading to frustration, anxiety, and challenging behaviors. The emphasis is on developing a solid, positive approach with all the necessary program ingredients to assure that the person with autism can be a successful learner. The need to use behaviors to express frustration, basic needs, or anxiety is lessened. Some necessary components of a positive program for individuals with autism follow.

Communication. Every person needs a functional, reliable way to communicate. The means of communication must be understandable to the persons who need to receive the messages. For people with autism this usually means a combination of modes that are taught in the settings and with people who socially interact with the person. Because individuals with autism often are not initiators of social communication, they are often thought incapable of being communicators. They need instruction and guidance with communication throughout their lives and in all settings. Without a means to communicate and to understand what is communicated to them, people with autism become frustrated and anxious and use behavior as a means of communication. It is often quite effective and efficient and so often gets the attention of adults much better than more conventional means. Therefore, developing reciprocal communication is vital to all programs for students with autism regardless of age or functioning level.

Cues. Because people with autism rely on order, structure, and routines to help them organize the stimuli around them, the methods of cuing that are used in instruction are important variables. Often the person with autism needs visual cues to supplement verbal/auditory cues. These may be in the form of environmental cues such as laying out the cookbook when getting ready to cook, posting a daily schedule, or having a towel in place after showering. When the environment is ordered and predictable it is much easier for the individual to rely on the cues and be successful. Sometimes physical prompts and assists are needed, but the individual should know when these are going to be offered, and these physical cues need to be faded, when possible. Verbal cues often become so much a part of the routine that the person becomes cue dependent. Therefore, it is important to think about the types of cues that lead toward independence before instruction begins.

Choice. Teaching a person with autism to make choices and honoring those choices helps increase independence and decision making. Providing some choice in one's life also helps to eliminate unnecessary battles. Encouraging the person to say "NO" when she means it can eliminate the need to use more forceful means to demonstrate refusal. Choosing whether to have potatoes or not, what candy bar or soda pop to buy, what restaurant to go to, whether to swim at the lake or the pool, what toppings to have on pizza, and what clothes to wear takes much practice and help at first. However, individuals with autism have opinions and like to have ways to appropriately express them and have others listen. Learning the concept of choice helps one learn to be more flexible and gives a person control over his world.

Desensitization and Rehearsal Strategies. New places, procedures, people, and things are often difficult for people with autism to get used to. They may have had a previous bad experience or may just be afraid of the unknown and of change. Although it takes previous planning to carry through with a desensitization plan, it is always worth the work. Implementation necessitates a slow introduction until the person becomes comfortable with the situation. An example would be visiting the dentist. Practice with instruments and procedures can be done at home or school and short visits can be made to the dentist's office until the student is familiar with the situation and comfortable enough to go through an exam or dental work. This eliminates fear and ensures treatment in the future.

Relaxation Training/Exercise and Fitness. People with autism are often anxious from trying to cope with a confusing world. They develop ways to manage, such as pacing or flapping their hands. Some of their methods can be shaped into specific routines to follow to relax while new methods are incorporated. Having a specific relaxation strategy to access, when needed, is a major benefit for people with autism.

Social Interaction. Individuals with autism need information, predictability, instruction accompanied with opportunity, and supportive people. Social scripts, rehearsal, awareness, and feedback across people, activities, and environments are needed.

REINFORCEMENT. Reinforcement is part of everyone's life. We receive some reward for doing what we do. It may be a cup of coffee because we got up. It may be a long, hot bath after a hard day's work. It may be going out to eat or buying a new toy or article of clothing. It may be the pay check each week or it may be a star on the paper, a smile from the boss, or a picture in the newspaper. It may be feeling good about the tree we planted, the yard we mowed, or the floor we mopped because the results make us happy. Control over our reinforcers helps make them stronger, such as saving to buy the boat, planning to eat the apple pie, or deciding where and what movie to go to. Motivators are expanded through social interactions.

People with autism require reinforcement also. Sometimes their strongest reinforcements are sensory in nature. They may not have learned to enjoy other social reinforcers. They may like food, spinning objects, music, water, pacing, rocking, or pats on the back. They may need reinforcement often and immediately for a long time. However, students with autism gradually learn a larger repertoire of motivators as they learn a larger repertoire of enjoyable activities and to delay the reinforcer. They must have reinforcement systems designed to meet their individual needs, and these systems must change as their needs and interests change.

Most people with autism are not competitive and are not rewarded by doing more of something or by being quicker or better than someone else. They may model others and pace their rate according to others, but are seldom interested in "winning." Therefore, their reinforcement plans have to be designed to have meaning for them. Money may not have much meaning, because they do not know what they can buy with it or they don't desire much. Working to earn more money as a reinforcer requires that many other concepts and experiences be taught and opportunities provided.

There are many methods of reinforcement and much information available to help in designing plans. The reinforcement plan often is the weakest part of the total behavior plan. Teachers and staff members are often reluctant to provide a comprehensive, meaningful system and want to get rid of it before they even start. Many people with autism fail because of this reaction, and their rights are overlooked. Experts in the field argue that a person with behavior problems may require a reinforcement system forever, just as someone else requires a hearing aid or a wheelchair. The reinforcement plan helps people with autism understand that they are succeeding in the world, and therefore they are able to live in it as more productive members.

REACTIVE PLAN. The interfering behavior will probably continue to occur for a while even when all plans are in place. Often it is necessary to see if there is a usual chain of behaviors so that an early behavior may be targeted for change, thereby breaking the first links.

However, everyone must be ready with a consistent way to react to challenging behavior. This is an area where there is much debate and much written information. It is vital to emphasize at this point that all the preceding components must be in place to be successful at changing behavior. When the interfering behavior does occur, consistency is vital. Some of the techniques that are useful for various behaviors are ignoring the behavior, redirection, and removal from reinforcement. Deciding what plan to use depends on the person, the history of the behavior, the situation, and the severity. Calmness and quick action are needed to preserve the dignity and self-esteem of the person with autism and protect others if needed. All too often people only react to behavior after it occurs. Negative consequences and punishment are reactive.

DESIGN A BEHAVIOR PLAN. A behavior plan for each targeted behavior is necessary so that everyone involved, including the student, knows what to expect. A contract with the student might be drawn up in a visual mode so that he/she sees the expectations and the progress. A sample follows:

Sample Behavior Plan

Targeted Behaviors

Perseverates on saying he's upset.
Pulls own hair.
Pinches self.

Purpose(s):

To refuse or avoid something.
To express frustration to being denied attention or something else he wants.

Environmental Plans

* Establish a consistent schedule.
* Avoid noisy, stimulating environments.
* Provide a quiet place to relax.

Positive Program Strategies

* Pictured and written schedules.

- Practice relaxation techniques.
- Prepare and rehearse before activities — Use words/pictures.
- Have set times for "special talk time," such as five minutes per hour to talk about any subject s/he wishes.
- Talk about emotions/feelings at times he or others are demonstrating them.
- Desensitize to new people and places.
- Provide an exercise program.

Reinforcement

- Teach to say, "I need a break." Reinforce by giving a break.
- Encourage choice making and input into activities and jobs.
- Use scheduling to build in favored activities throughout the day.

Reactive Plan

- Redirect to "Tell me you need a break," or redirect to "Take a break." Student returns when calm.
- Redirect to sit and relax.
- Ignore pulling hair and pinching self, but not another person.

Site Specific Strategies:

Fast Food Restaurant: If he says "I need a break," direct him to the car to go through relaxation routine, then return. Rules for reinforcement are specific, and picture cards for ordering are specific to each restaurant.

SUMMARY. In conclusion, people with autism who have challenging behaviors have a great need for a comprehensive program. Excluding them from community activities or participation in programs until they get their behavior under control is dooming them to a life of restriction and loss of the ability to learn and grow into a productive person. The world is a very complicated place in which to live, work, and enjoy; but given carefully designed program plans that are implemented in increments according to individual needs and growth, the person with autism will succeed.

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Nancy Dalrymple

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DESIGNING A BEHAVIOR PLAN

TARGETED BEHAVIOR Aggression: hitting, biting, shoving

Rate Per Day .05 **Average Duration** 2 minutes

NAME

Purpose	Environmental Needs	Positive Programming	Reinforcement Plans	Reactive Plans
Expression of frustration, refusal, protest, wanting to stop	Specific teaching procedures designed Routines established: • laundry • trash Own space to work Community recreation Community work experience Limit clothing selection Consider what "Finished" means	Communication training through board, few signs Explanations of changes and schedules through pictures in sequence Choices provided and work on global point Use minimal verbal cuing Use models, gestures, and environmental cues Discrete trial training for compliance/compulsions Use rehearsal strategies using sequenced pictures Relaxation Training Teach and encourage refusal with "Not" sign Regular exercise program Make diet more fun	Eliminate antecedents when possible, i.e., stop verbal cuing Drop schedule	Relax in chair Sit on floor, couch, chair, or in car when cued Leave area Only hold or restrain as very last resort

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DESIGNING A BEHAVIOR PLAN

RGETED BEHAVIOR

Rate Per Day **Average Duration**

NAME

Purpose	Environmental Needs	Positive Programming	Reinforcement Plans	Reactive Plans

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Analyzing the Purpose of Behavior

When/Where/With Whom Does Behavior Occur?	Targeted Behavior	Reinforcement after Behavior Occurs	Purpose of Behavior	New Skill(s)/ Behavior(s) to Learn	Reinforcement for New Skill(s) Behavior(s)
X too close transition from place to place	Biting	People move away; gets away	To escape	Gesture "Go away," "More," "No"; (I need space, I need information)	People move away, acknowledge, praise
X playing in water in bathroom	Whining/pushing	Gets staff attention	Get X to stop	Sign "Stop"	X stops, praise
Not knowing schedule or wanting schedule	Agitation	Gets help and attention	To let people know he needs help to "Cope"	Cope through relaxation routine	Use primary reinforcer and praise until the new response is learned
Being in small room with lots of people	Throwing chairs	Gets out	Gets out of situation	Gestures or uses words, "Want to go"	Gets out quickly and always at first
When working in groups	Wets pants	Gets out of situation	Attention; gets out of situation	Asks to use "Toilet"	Reinforce; give attention primary reinforcer if needed

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Analyzing the Purpose of Behavior

When/Where/With Whom Does Behavior Occur?	Targeted Behavior	Reinforcement after Behavior Occurs	Purpose of Behavior	New Skill(s)/ Behavior(s) to Learn	Reinforcement for New Skill(s) Behavior(s)

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POSITIVE BEHAVIOR PROGRAMMING

TEACH RATHER THAN PUNISH

by Nancy Dalrymple

Too often individuals with interfering behaviors are punished instead of taught and reinforced for new, appropriate behaviors. People with autism often fail because they have difficulty understanding verbal language and attending to social cues or because the environment is too stimulating. In such situations they become confused and anxious, and may exhibit a number of interfering behaviors.

Physical punishment should never be an option for dealing with inappropriate behavior. Individuals with autism often do not react to pain or exhibit emotions the way other people do. They are vulnerable for abuse and cannot defend themselves by talking about it, by understanding what is happening, or by developing appropriate social behavior unless they are specifically taught what to do. Other kinds of punishment such as yelling or removal of preferred items, can also be detrimental.

Some results of punishment may be:

* Social disruption - the person moves away from the punisher or punishing environment, lowering the possibility of developing trust and positive social interaction.

* Lack of teaching - the person only learns that s/he has done wrong, but is not taught and does not know what to do that is correct.

* Lack of functionality - the consequence is usually not related to the function or purpose of the behavior. Punishment is just something that happens and in the mind of the learner may not have any connection with the behavior that provoked it.

* Lack of generalization - the problematic behavior, if changed at all, is only changed in <u>one</u> setting, only in the presence of the punisher, and only for a limited period of time.

* Lack of self-management - the person relies on the punisher to regulate behavior rather than learning self regulation.

* Recurrence - the behavior usually comes back when the punisher or punishment is not there.

* Creation of increased anxiety - often causes out of control behavior; the body's defense responses become mobilized.

- Generation of aggression - the body is mobilized and the person aggresses in an effort to protect him/herself; then the individual experiences more anger from others, failure, low self esteem, and the cycle repeats itself.

- Suppression of positive behavior - may instead create severe anxiety, fear, anger, avoidance behaviors, and inability to learn. Punishment doesn't teach the person what s/he is to do!

Teaching appropriate behavior to individuals with autism is a challenge. However, it is most important that we teach them to trust people, to trust their environments, and to develop a positive image of themselves. This can be done by everyone working together to develop positive, consistent longterm plans. Concerns about the necessity of discipline and knowing the consequences of one's actions can also be addressed, but in a manner that is effective, non-punitive, and considers the learning needs of the person with autism. We must implement strategies for teaching them WHAT TO DO as opposed to punishing them for what they do wrong.

SETTING THE STAGE FOR APPROPRIATE BEHAVIOR

by Cathy Pratt

Assessment and program development for people who exhibit challenging behaviors should include an ongoing analysis of the environmental variables which influence performance. An environmental assessment provides information about circumstances in an individual's school, work, leisure, or residential setting which may increase the occurrence of undesirable behavior.

For example, the presence of a particular person, extreme temperatures, high noise levels, bright lights, clutter, certain instructional materials, boring tasks, and unstructured or high demand situations may increase the likelihood that a person will engage in an inappropriate behavior.

Professionals can identify those situations that have a high probability for setting the occasion for a behavioral episode. They are able then to design an intervention which maximizes learning and can develop plans to desensitize students to aversive environmental factors.

Traditional integration strategies target gym, recess, music, art, and lunch as primary settings in which to promote interactions with peers who are nondisabled. Integration plans for students who are unable to cope with unstructured environments should acknowledge the student's learning style. Arranging activities with peers that involve computer games, or cooperative learning groups during highly structured or traditional academic periods, may be more conducive to positive behaviors.

By rearranging furniture, reassigning seating placements, introducing interesting instructional materials, providing a clear schedule, or reducing distracting environmental stimuli, staff can accommodate individual learning styles and provide clear cues about desired activities. Ultimately, through these procedures staff can learn to quickly modify new environments and help students exhibit appropriate behavior across a variety of settings.

THE IMPORTANCE OF DATA COLLECTION

by Valerie DePalma

Everyone collects data. Clerks in stores collect data for inventory purposes, waiters and waitresses to record orders, and scorekeeping even occurs in a leisurely card game with friends. Teachers typically collect data to evaluate initial performance in the form of a pretest and then document changes of performance after instruction in the form of a post test. Therefore, one can conclude that there is value in collecting data.

Often subjective means are used for documentation of problem behaviors. These should be based on the observation of the behavior over time. For example, the statement, "Joe has greatly improved. He is not screaming as much as he was last month" doesn't tell us much. It would be more helpful to state, "Joe's screaming decreased from 22 times in May to 8 times in June." If you are able to see, hear, feel, or smell a behavior, you can count or measure it.

A behavioral assessment is based on detailed observations of how the current behavior of the individual interacts with the environment. A behavioral assessment seeks to discover critical factors which might influence the targeted behavior of a person.

For example, a targeted behavior for Joe may be screaming, quickly followed by biting his hand. A behavioral assessment shows these behaviors occur when Joe is presented with a difficult task. A new, appropriate behavior to teach Joe is to ask for help in situations where the task is too difficult. If the initial data were accurate you should then expect the screaming and biting behavior to decrease, as the asking for help behavior increases. By continuing to take data you find out whether the initial hypothesis and the behavioral intervention is working.

An ongoing behavioral analysis process will provide data which can be used to evaluate both the effectiveness of any intervention program, as well as the progress of the person with autism. For example, data over time showed Joe was asking for help when needed. Screaming and biting were exhibited twice over a four week period and when no one was available to immediately help Joe. Data clearly demonstrated the effectiveness of the intervention program for Joe.

There are a number of strategies for collecting data that can produce helpful information when evaluating behavioral intervention plans. Permanent products are tangible items or environmental effects which result from a behavior. Examples of permanent products are graded tests, work created when "on task," bruises, scratches, or pictures painted.

The recording or tally method provides an exact record or count of how often the behavior occurred. The behaviors counted should have an obvious beginning and an obvious end. Because

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it is difficult, however, to keep an accurate tally on behaviors with high frequency, use this method with lower frequency behaviors.

Interval recording or time sampling provide data to determine what proportion of a specified time period the behavior encompasses. The observation period is divided into equal intervals, and only one observation is recorded in each interval. Interval recording notes + or - as to whether or not the behavior occurred or did not occur any time during the interval and is especially appropriate for continuous behavior. Time sampling notes a + or - when the person is observed at the end of the interval.

Duration recording is used when the concern is the length of time the person engages in a particular behavior. This is appropriate for behaviors with an identifiable beginning and ending and when each incident of behavior is longer than 5 minutes.

Latency recording is used when the primary concern is how long a person takes to begin performing a behavior once its performance has been requested.

Anecdotal reports are written reports to provide a complete description in a particular environmental setting or during an instructional period.

In conclusion, accountability issues requiring proof of progress or attempts at progress have made data collection almost mandatory. Behavioral assessments, functional analysis, and various data collection strategies provide valuable information to help analyze which factors are effective and why, as well as which need changing and why. Therefore, there is great value in collecting and organizing data so that it can be effectively utilized to help people with autism reach their greatest potential.

FUNCTIONAL ANALYSIS OF BEHAVIOR

by Rozella Stewart

Functional analysis of behavior is based on the assumption that all behavior serves some purpose for individuals engaging in it. The process is particularly critical when planning for people with autism who invariably have limited means for obtaining desired responses from people and things around them.

Behavior--often inappropriate behavior--may be the only means people with autism have for accomplishing particular purposes or for exerting some control in their environments. Without specific teaching, they may resort to whatever works for them in specific settings and with particular people. For people with autism, behavior often proves to be the most efficient way to:

* **obtain reinforcement**--to get responses and/or feedback that satisfies a need or is pleasurable for the person engaging in the behavior, i.e., for getting attention; help;

needed information; gaining access to food; objects or activities and/or for getting the respondent to act.

- **escape/avoid situations/tasks/activities** that the person experiences as displeasurable or painful. Behavior may be used as means for communicating negative feelings/inclinations, and/or for protesting and refusing.

- **make declarations or comments** about some person, place, thing or event and/or about their feelings or personal state.

To plan successful programs for persons with autism, it is necessary to determine purposes that existing behaviors accomplish. People who interact with the individual must ask, "What functions do observed behaviors serve for the individual engaging in them? What particular purposes do exhibited behaviors accomplish in specific settings? What purposes do specific behaviors accomplish when exhibited in the presence of others?"

To answer these questions, we must identify circumstances that prompt and/or maintain targeted behaviors. We need to gather descriptive, unbiased data about:

- antecedents--i.e., What is happening before the behavior occurs?

- setting events--In what setting/situational contexts does the behavior occur? Identify physical, sensory, and social aspects of the setting that may prompt or be responsive to certain behaviors.

- consequences--What do particular individuals accomplish through specific behaviors? How do the people in the environment respond to the behavior?

Functional analysis of behavior usually reveals that people with autism engage in behaviors that prove useful for accomplishing purposes that have meaning to them. Analysis may also reveal situations in which people with autism resist behaving according to what is expected of them. They may refuse tasks and activities that, from their perspectives serve no function or are purposeless, or they may resist because they are anxious or confused.

Information gained through functional analysis of behavior provides a foundation for designing positive, individualized programs. Once we know what functions or purpose behaviors serve for specific individuals, we ask, "What more appropriate behaviors do we need to teach to enable individuals to accomplish their purposes in efficient, but acceptable ways? What environmental changes, if any, are needed to enable individuals to accomplish purposes effectively?" We then teach them what they need to do to accomplish specific purposes. We teach them how to achieve desired ends in appropriate ways.

USE OF STRENGTHS FOR PROGRAMMING

by Kim Davis

It is important to consider a person's strengths when planning an educational program. Incorporating these strengths into activities can lead to a decrease and/or elimination of disruptive behaviors. Think of this in a personal sense; if we are instructed to do an activity, one we may not enjoy or one that may be tedious for us, we tend to become agitated, frustrated, and ready to take our anger out on anything or anyone. The need to do activities that are pleasurable is the same for all people. When planning lessons or activities for individuals with autism, it is important to use their strengths throughout the activities.

Frequently, individuals with autism like to move and do gross motor (large muscle) activities. They need to move and like to be involved with movement activity. When they are asked to stop or change activities, often disruptive behaviors can occur. By planning to utilize the individual's strengths and by giving that person time to perform his/her skills on a regularly scheduled basis, behavioral episodes diminish. If a child likes to and completes work lying on the floor, but screams every time s/he has to sit at a table, wouldn't a positive approach be to allow the child to complete the work on the floor? Does it really matter where s/he does the activity in this instance?

Activities that people do should be enjoyable and not a chore. They should simultaneously allow a release of energy and yet be energizing. This release can help deter negative behaviors through naturally occurring motor activities, rather than turning tables over or throwing chairs. We take care to program ourselves to utilize our strengths or best points and take care to avoid or put off those activities that are difficult or mundane to us. When working with individuals with autism, we should respect this need within them. Plan for the use of strengths in their activities. This will reduce struggles, ease frustration, decrease disruptive behaviors, increase cooperation, and interactions can be more positive.

THE USE OF ADAPTATIONS AND ENABLERS IN POSITIVE PROGRAMMING

by Chris Ivanick

Individuals with autism often exhibit difficulties with independence in their homes, schools, communities, and at work due to their challenges in understanding expectations and in expressing their individual wants and needs. Teaching strategies that incorporate adaptations and enablers are an important component for promoting longterm independence and success. The following strategies are crucial to consider when providing programming for persons with autism. Each of these strategies works to enhance the person's understanding of expectations. Then, they feel more secure, are able to focus on the task better, experience success more frequently, and so grow and learn more thoroughly and independently.

Routines

Consistency in how a task is presented and in one's overall day (i.e., schedules which represent sequences of activities, such as bath, snack, brushing teeth, then bed) is a valuable tool or promoting skill development.

Visual Supports

Persons with autism usually learn best when information is presented through objects, pictures and/or written words since understanding spoken language is more difficult for them. Visually presenting daily schedules and steps in tasks also provides clear information about expectations and the beginning and ending of activities.

Desensitization and Rehearsal

Careful preplanning and gradual step by step introduction to new places and activities will help them to be successful and expand their world. These strategies help persons with autism relieve anxiety in new situations when they are not sure what will happen or what to do.

Stimulus Cues

Because learners with autism often have difficulty processing verbal instructions, they can better understand what is going on by observing what is happening. Examples of stimulus cues include setting out the needed supplies for a specific task, seeing peers line up at the door to indicate that it is time to go out, and putting out a specific number of place mats to show where to put plates and silverware.

Augmentative Communication

Many individuals with autism need additional strategies to help them to communicate effectively and reliably with a wide audience of people. The use of sign language, communication books, or electronic devices can help enhance communication for people in their daily lives. The system should be used across all settings and staff. Of primary importance is that the system includes what learners want to communicate about so that using it has meaning for them.

MOTIVATION - WHAT MAKES US LIKE TO DO WHAT WE DO?

by Nancy Dalrymple

Though reward and reinforcement can take many forms, they most often stem from the preferences and strengths of an individual. Motivation comes from having some control over one's environment through being able to exert choice and experience success. How do we apply this principle to individuals with autism who so often seem to do what they are not supposed to do and who so often seem to fail?

First, we must know the individual well and build a positive program based on strengths and preferences. Activities can most effectively serve as reinforcement when they are useful and meaningful to the individual, shared rather than simply directed, and meet the needs of the individual involved. Learners with autism often do well working alongside others who model and pace the task or activity. They often do well when movement and action are built into the day or into the work activity. They may do well working with background music, and they may do well with a computer to help them focus attention and overcome perceptual motor difficulties. These are only a few ways to build motivation into activities through utilizing learning styles and strengths, rather than penalizing a person for deficits.

Naturally occurring reinforcers should be used in teaching whenever possible. For example, when a person needs to put on shoes in order to go outside, to order food in a restaurant in order to get the food, to put the coins in the vending machine in order to get the item, or to turn on the water in order to get a drink, the motivation to perform the more difficult behavior is reinforced by the naturally occurring event that follows, if that event is desirable.

Natural self-initiative should also be encouraged so the person with autism learns to be an initiator rather than a person who is dependent on cues. Once self-initiative presents itself, it is important to reinforce and shape that initiative rather than extinguish it. If a person goes to the refrigerator for food, let him/her have some food, then gradually shape that behavior to appropriate times so that the initiative behavior remains intact. If the person goes to the door to go out, encourage the complimentary behavior of asking to go out rather than just stopping the person.

Use reinforcement to vary activities and to teach contingency. For example, teach an individual that when all tables are cleared he may empty the trash; when the groceries on the list are in the cart, then she may choose one item for herself; or after going to the dentist he may have an ice cream cone. By sequencing activities in this way, we are timing reinforcement to benefit learning. This can be extended into contracts that visually represent the agreement between the teacher and the learner, so that all conditions are understood and agreed upon ahead of time. This type of reinforcement sequencing governs all aspects of our lives.

Reinforcement strengthens behavior. Positive reinforcement encourages success and builds a positive self-image. Care should be taken to refrain from using the preferences of individuals against them, or they may refuse to divulge their preferences, likes, and dislikes. Give them as much control over their lives as possible by pairing their positive behavior with reinforcers and by giving them as much choice among reinforcers as possible.

REACTIVE PLAN

by Susan Gray

A reactive plan is the final step of the behavior plan; dictating action that will be taken to control the situation and prevent harm to the learner(s), other learner(s), or staff after the challenging behavior has happened. A reactive plan will not prevent the interfering behaviors from occurring or recurring. A reactive plan is designed to keep the situation safe and under control in spite of the challenging behaviors on the part of the consumer, allowing time to teach the individual a better method of communicating his needs or wants.

Teachers intervene early by trying to anticipate when the interfering behavior may arise or recognize early steps in a chain of behavior before escalation. Interrupt the behavior chain early; then elicit the new skill or functionally equivalent communication behavior that you may be teaching. Prompt the new communication behavior, and then reinforce the person's behavior, by giving him the desired outcome. If the learner is asking for escape, allow him to be finished with the activity for now. If he wants an object, give it to him. This is not "giving in to" or "bribing" the person. The individual has been using the challenging behavior to obtain his want, and it has been working. The new behavior must work even better for him, or he will not use it. After the new communicative skill is well established, you can teach the student to wait briefly for his reward.

The components of a reactive plan depend on the philosophy of the agency, the characteristics of the consumer, and what the behavior looks like. Often ignoral or extinction (withholding the reinforcer which has been maintaining the behavior, like not giving attention to swearing) is used. The interfering behavior is ignored, and expression of the new, functionally equivalent behavior is rewarded. Ignoral often works well with attention getting and escape behaviors, but typically will not work with self-stimulatory behaviors. If a staff person decides to use ignoral, the behavior may increase for a few days before beginning to decrease. This increase should not cause one to stop ignoring the behavior; it is a sign that ignoral is working. The person, finding that a behavior which previously obtained results is no longer working, will tend to increase the frequency of the behavior in an attempt to get it to work again. Finding that the old behavior no longer works, but that a new behavior which is being taught does work, the individual should then replace the old behavior with the new.

Another frequently used technique to deal with challenging behavior is time-out from positive reinforcement. A quick-sit can be used when the direction has been repeated; for example, given the direction "Stand here by me," the consumer runs around the room. The person is helped to sit right where he is and given no attention. After 20-30 seconds when the individual is calm again, the direction is repeated. Sit-out might be used if the person is throwing materials or hitting. The individual is removed to a chair across the room and in 2-3 minutes is asked to return to the activity. These techniques should not be used as punishment, but merely to help the consumer to gain control. The staff person's voice is calm and neutral rather than critical. An example of a positive use of sit-out would be to direct the learner to a beanbag chair and say, "You need to sit in the beanbag chair and relax," or "Sit in the beanbag for 5 minutes by the timer," whichever is more appropriate.

A relaxation/calming routine may be employed while the person is sitting out, such as deep breathing, counting, or relaxing muscle groups in sequence. This type of relaxation plan needs to be tailored to the individual and be taught several times a day when the person is calm. This will allow him to learn the routine, so that it will come automatically when he is upset. The ultimate aim of a relaxation routine is for the person to become self regulating and be able to calm himself when he starts to become anxious before the interfering behavior begins.

If the individual's challenging behavior is dangerous to himself or others, some form of time-out may have to be used. Time-out or isolation is a technique where the person is directed to a separate room away from all attention, until he can return to the group. When calm, he can return to the same activity he was engaged in before. Isolation should be continued only if a documented decrease in behaviors is occurring, since time in isolation is time lost from teaching more appropriate behaviors. If time-out is being used, the consumer must have a positive, interesting program so that time in isolation is not more rewarding than programming time.

Positive Behavior Programming was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, technical assistance, reference information, and applied research.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

The University Affiliated Program of Indiana

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AUTISM: REFUSAL

HOW? WHY? WHAT TO DO?

HOW IS REFUSAL SHOWN?

Verbally, e.g., saying, "No," "I don't want to," or swearing
Going limp
Tuning out/looking away, avoiding looking
Hiding under furniture or behind objects
Throwing objects
Not moving
Not answering
Not conforming
Not trying
Taking too long
Falling to the floor
Tearing things
Screaming, making noises
Self-stim behaviors: e.g., rocking, flapping, flicking something
Hitting, kicking, pinching, biting
Any other means that gets the message across

WHY DO PEOPLE WITH AUTISM REFUSE?

Generally there is a belief that children should do as they are told. As children grow up, control is expected to be transferred to them; however, people with autism often haven't been taught or haven't assumed self control. Furthermore, because they often seem to be "out-of-control," "non-compliant," and "negative," an increase of "external control" strategies are often used by teachers or caregivers. This response leads to a spiraling cycle. How can we put more effective strategies in place that encourage positive interactions without inviting refusal?

First, we have to understand what the refusal of a person with autism may mean. We cannot interpret these refusal behaviors solely as interactions towards people. We cannot attribute our own experiences and interpretations to them. We must understand these behaviors from the perspective of the person with autism.

People with autism refuse for many reasons. The situation, the people, and their own internal state all influence responses. We do know that the way people with autism interpret the world is a factor. The age of the person, the circumstance, the supports around them, their own anxiety, and their ability to communicate their wants and needs are some of the contributing environmental factors. Refusal may be a protection of self.

People with autism may refuse because they:

- don't understand what to do next
- are mixed up or anxious about time frames
- are anxious about a new situation
- have steps in a sequence out of order
- have received directions or cues that are not understood
- have received directions or cues that are different
- know rules but can't carry through with the application (recitation of rules and statements about what not to do are quite different from knowing what to do)
- are afraid of making mistakes and want to follow the rule of doing one's best; therefore, it's safest not to try
- may be overwhelmed by stimulation in the environment
    * new environments where self-in-space, directions, depth perception, visual stimuli, noise, and expectations are confusing and upsetting
    * familiar environments that overwhelm the sensory systems cause over - and under- reactions
    * demands and directions that are unrealistic, e.g., pace is too fast, there is too much to do, learning style is not considered, conformity is expected, there is more emphasis on weaknesses than strengths, and social expectations are too demanding.
- are in need of more time
    * to respond
    * to observe
    * to stop present activity
    * to finish
- are afraid of or don't understand change
    * have no reference in experience to understand the change
    * may have fears from past experiences

- aren't able to ask for information or help
- have different meaning for completing an activity (may need to "finish" from their perspective) before transitioning, or may believe they are finished
- need to see what to do, rather than be verbally told
- have past experiences that reinforce a certain way of dealing with situations
- want/need control
- are trying to establish autonomy and independence and need to learn to be able to:
    - make choices
    - express negation and have it accepted
    - understand the difference between yes and no
    - understand questions or have choices offered without a question format
- may not know the differences between when choices are an option and when they are not

WHAT TO DO WHEN A PERSON WITH AUTISM REFUSES

To know what to do when a person with autism refuses, you must first recognize the behavior as refusal without extra interpretations and labels. A person saying "No" or "I won't" is often understood, but often interpreted as defiant, non-compliant, stubborn, or disrespectful of authority. Each of these labels suggests direct interaction with people, something that few people with autism do well.

A behavior that accompanies a "No" adds power to the refusal, but is given even stronger interpretation such as "belligerent," "out-of-control," or "behavior disordered."

The purpose of the behavior must be discovered by neutral observers accurately collecting data, rather than labeling a person. Once the reason(s) for the refusal is understood, skills to teach, stimuli to desensitize to, supports to provide, and choices to encourage can then be planned and implemented.

Reacting to refusal with additional control, punishment, or anger often accelerates the situation. Self-control is not accomplished. Future refusal is guaranteed.

While you are assessing the purpose of the refusal so that positive teaching strategies can be put in place, there are some reactive strategies that are more likely to defuse the situation:

- Give the person space and time, if possible.

- Provide visual information instead of constant verbal correction and information.

- Provide support and help in a calm, non-threatening manner, and offer to do the activity with the person. This will provide an opportunity to learn more about the problems the person may be encountering.

- Suggest a quiet place to get away to and ways to calm down. Provide information about what TO DO, instead of what not to do. Reinforce the person for small steps towards trying.

People with autism are often anxious. Providing supportive teaching strategies, environments, and teachers often lowers anxiety, thus permitting them to participate more and refuse less.

Nancy Dalrymple 4/93

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Communication

THE MESSAGES OF BEHAVIOR*

AUTISM AND BEHAVIOR

Over the past few years, millions of people around the world have seen the movie *Rain Man*, starring Dustin Hoffman and Tom Cruise. For many people, the movie provided them with their first glimpse into the world of someone with the disability of autism. Perhaps this was also your introduction to autism.

Even now, when you hear the word "autism," are images of scenes from that unforgettable movie evoked inside your head? Many of us still can picture Raymond learning how to dance, getting his first kiss, and counting cards and toothpicks. But *Rain Man* was not just about positive or exceptional events in the life of a person with autism. This movie was also about the evolution of relationships and the harsh reality of the stresses related to having this disability. We saw Raymond get upset when he thought he might miss seeing Judge Wapner in *People's Court*. We saw him rocking when he was distressed. We also heard his screams when the smoke detector was suddenly activated while he was cooking in his brother's kitchen. These latter less positive images are also a part of autism.

Some of us know people who have autism and we can see additional mental images that emerge from our real life experiences. Maybe you have similar images swirling inside your head. Perhaps you can picture the following scenarios:

Scene #1

A young adult paces the living room of his home. He repeatedly slaps himself in the face. Periodically, he vigorously bangs his head against the wall.

Scene #2

A middle aged man in a workshop for people with disabilities sits working at an assembly task. Suddenly, he angrily begins to throw the assembly parts around the room.

Scene #3

An elementary school child sits in a classroom with 30 other children. After sitting passively for 10 minutes, he deliberately puts his head down on his desk. He steadfastly refuses to begin his schoolwork.

Regardless of whether we personally know someone who has autism or if our knowledge is limited to our exposure to *Rain Man*, our minds will seek to attach a label or a word to describe or classify such images. Chances are the word "behavior" with a negative connotation will be one of the associated words. It is less likely that we would use the notion or idea of a communication problem to describe these mental pictures.

In the movies and in reality, autism, communication, and behavior problems can intertwine. We are not accustomed to thinking that a person may have a communication disability when we see him or her engaged in what we might call "negative behaviors." Not only are we not used to thinking of communication and behavior as related, but we may not be able to see any messages hidden within the behavior. We may need to learn how to look for the masked messages. We may also need to learn how to interpret the messages and how to respond to them. This may take time and training. We can begin, however, by understanding the connection between communication and behavior. Let us use our three previous negative behavior scenes to explore this concept.

THE MESSAGES OF BEHAVIOR

The three negative behaviors described above are examples of potential communicative messages. The exact meaning of any one of them would depend upon the circumstances surrounding each real situation. Sometimes a behavior such as screaming may represent two different messages in what seem like identical circumstances. To help you understand the idea of messages hidden in behavior, let's re-examine the three scenes.

Scene #1

In the self-injury situation, the person might have been protesting an unexpected change in his daily activity schedule. He was expecting to go out to eat. No one remembered to tell him in advance that the activity was postponed until tomorrow. To put it mildly, he is upset and disappointed.

Scene #2

In the throwing of materials situation, the person might be communicating: (a) boredom with the task at hand, and (b) the need for a break. Because of an inability to talk, this man cannot tell anyone in a direct fashion how bored he is with doing the same task day after day. He needs a break, but, more importantly, he needs a greater variety of challenging tasks to fill his day.

Scene #3

In the non-compliance situation, the child might be confused about the assignment and needs help or an explanation. He may have been unable to process all of the spoken instructions when they were given to the class ten minutes ago. Now he does not know what to do and feels he is a failure.

WHY USE NEGATIVE BEHAVIOR?

A reasonable question to ask is "If someone really wants to communicate a message, why would he or she use a negative behavior?" The reason is that some people with autism have difficulty producing conventional communication. You and I may have skills that the person with autism may not have. You and I would know what to do in each situation. You could tell someone that you needed a break. I could seek a reason for the schedule change. We both would raise our hands and ask for additional directions. Some individuals with autism may be unable to do any of these things unless someone actively teaches them better communication skills. Other individuals may need reminders before they will use the more positive communication strategies.

Many people with autism can not speak. Others: (a) may have some ability to talk, but may have limited skills (remember Raymond in *Rain Man*?); (b) may become inarticulate and not be able to use their skills when they are in a distressing situation; or (c) may freeze and not be able to find or retrieve the right words to clearly express their message when they are under stress. Instead, people with autism often use a means of communicating that is immediate and effective, i.e., negative behaviors.

A negative behavior almost certainly will get someone's attention. It also may quickly achieve the desired intent. The person with autism may have learned the effectiveness of a given negative behavior when more subtle communicative messages were ignored. For example, in the wanting-a-break situation (scene #2), the following may have occurred:

> His wiggling around in a chair was too subtle of a message. No one had a clue that he needed a break and they overlooked or ignored the wiggling.

His standing up was not an effective cue either. The person with autism was told to sit down.

His throwing of materials, however, communicated a clear message. The excitement broke the boredom. The person got to leave the task. As punishment, he was sent to a time out area. He may not have perceived time out as a punishment. He may have seen it as a welcome relief from his dreary assigned task.

A BEHAVIOR PLAN THAT ADDRESSES COMMUNICATION SKILLS

A major component of any behavior plan involves teaching the person with autism a socially acceptable way of communicating a message. This means giving the person the **power** to communicate in a better way. Punishment will not teach positive skills. Instead, punishment may insure that the behavior occurs again. For example, the next time the person wants a break, he may immediately throw materials. Why shouldn't he do this? After all, the negative behavior previously got him the desired outcome. We all tend to use behaviors that work effectively.

Whenever you think of a person with autism, remember that behavior and communication go hand in hand. Whenever you have opportunities for interacting with people with autism, resist your impulse to get angry when a negative behavior occurs. Resist your impulse to punish. Think about the link between behavior and communication problems.

Ask yourself these questions after a behavioral incident:

- What might the person <u>really</u> be communicating?
- What other means could the person have used to give you the same message?
- Would a communication board or picture message board have helped?
- How could you become involved in teaching him/her better ways to communicate?

We can influence the behavior of a person with autism if we learn strategies which foster good communication skills development. It makes sense to help each individual become a better communicator. As a result, he or she should become less dependent on using negative behaviors to communicate. With improved communication skills, the person with autism may have a better relationship with you and with other people. Better relationships and lifelong friendships don't occur just in the movies. They also can occur in our own personal *Rain Man* experiences with people who have autism. We, however, may need to play an active role in fostering these types of positive outcomes.

See the following publication for more information:

Reichle, J., & Wacker, D. (1993). Communicative alternatives to challenging behaviors: Integrating functional assessment and intervention strategies. Baltimore, MD: Paul H. Brookes Publishing Company.

Also see the following IRCA handouts for additional information:

Sampling Communicative Behavior

Communicative Functions

* The emphasis upon negative behavior in this publication represents a strategy designed to draw attention to the link between communication skills and behavior. The staff of the IRCA clearly recognize and value the positive qualities and talents of individual s with autism. No offense to people with autism is intended.

The Messages of Behavior was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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Beverly Vicker, 7/94

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INDIANA RESOURCE CENTER FOR AUTISM

Analysis of Communicative Behavior *

Name of Person ______________________________ DOB ___________ Age _______

CurrentPlacement ____

Directions: During the Consultation Meeting all persons will discuss the communication skills and needs of the individual. Please look at each category of "Basic Messages" on the attached sheet. Briefly state your observations regarding how the individual communicates his/her wants or needs in these areas. The examples below may be helpful in identifying possible means of communicating.

For example, an individual might:

- Use verbal intelligible responses
- Use unintelligible speech
- Point or use gestures
- Take individual to desired location
- Cry/scream
- Leave the situation
- Shake head yes/no
- Stand by person or object
- Take person to location
- Use aided communication, e.g., picture board/book
- Use sign language
- Grab object/person
- Exhibit agitation
- Exhibit aggression
- Engage in self-stimulation
- Engage in self-injurious behavior

* See also the **Procedural Manual for Review of Effectiveness of Communicative Behavior** which was designed to help interpret this Analysis form

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Analysis of Communicative Behavior

Basic Messages	Means: How? Where? With Whom?
Requests	
Food	
Objects	
Activities	
Toilet	
Attention	
Want to be finished	
Need help	
Refusals	
No	
I don't want to	
Go away	

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Basic Messages	Means: How? Where? With Whom?
I don't know	
Other Messages	
Angry/mad	
Frustrated	
Confused	
Yes	
Happy/excited	
Tired	
Hurt/sick	
Personal identification	

Additional comments:

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Adpted from M. Winner, 1/94

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COMMUNICATIVE FUNCTIONS

Everyone engages in communicative acts every day. Some acts are more easily noticed or understood than others. This handout provides examples of several classes of communication messages, shows a variety of ways or means of communicating a message, and supplies examples of messages that are not always consciously signaled by the child/adult with disabilities. These ideas are usually identified by specific terms which are defined below.

> **Means of Communication:** Regular speech, echolalia, vocalizations, gestures, signs from manual sign language, communication boards, electronic communication devices, handwriting, typing, or pulling someone to a location are some of the different means by which messages are conveyed.
>
> **Communicative Function:** All messages have a basic underlying purpose such as the seeking of an object or information, refusal, provision of information, indication of agreement, or social engagement.
>
> **Communicative Intent:** Not all messages are deliberately signaled to a communication partner. Sometimes the partner has to notice the behavior of the other person and then assign meaning or intent to it. For example, a person could intentionally tell someone, "No, I don't want to fold the towels." The same message might be surmised from a behavior such as someone tipping the basket contents onto the floor and then defiantly walking away.

Recognizing the diversity of communicative functions that might be expressed (whether intentional or not) and having an awareness of the multiple means by which messages can be expressed are central to understanding the communication of individuals with expressive communication disabilities and to building a positive communication program for them.

Function	Example of situation and communication means used
I. Requests	
A. Wants tangible object	1. Says "drink" to teacher. 2. Takes person to refrigerator. 3. Points to picture of popcorn on communication board. 4.** Says "trick or treat" anytime candy is wanted.

Function	Example of situation and communication means used
B. Wants an action, event, or activity to occur.	1. Says "go Target." 2. Points to phrase "scratch my back, please" on communication board. 3. Spells "watch basketball" on a spelling board via the aid of a facilitator. 4.* Rubs eyes and looks tired. (Parent directs child to get ready for bed.)
C. Wants attention.	1. Signs "help." 2. Says "Mom" repeatedly until she comes. 3.* Goes to block area, picks up some blocks, and randomly begins to throw them. (Adult will automatically come over and show child how to constructively play with blocks.)
D. Seeks permission or direction.	1. Turns and looks to see if adult indicates that it's ok to open the cabinet to get a cracker for snack. 2. Holds crotch and says "teacher" until told that it is ok to proceed to the bathroom.
E. Wants or needs information.	1. Looks at adult with puzzled expression when told to go to the office. 2.* Begins to throw things and screams when told that Mom will be late for pick up today. ("Lateness" is abstract concept. Child does not know when Mom <u>is</u> coming to get him.) 3. Asks "home?" (Rising inflection indicates that the child wants to know whether it is time to go home.)

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Function	Example of situation and communication means used
II. Negative assertion or disagreement	
A. Refuse, reject, or protest a directive, action, activity, or object.	1. Says "no." 2. Pushes work materials away. 3.* Hits self in face after being told to go to X. 4.* Screams when favorite toy is not in its usual place on the shelf.
B. Denial.	1. Shakes head when told it is his turn to water the plants. (Indicates that it is actually someone else's turn.) 2. Says "no John" when someone mistakenly calls him "John."
III. Comments	
A. Names or comments on objects, people, or activities.	1. Says "Mickey Mouse" as he sees the words in advertising for Disneyland. 2. Says "charge" as he hears the charge sound on TV during a ball game. 3. Signs "dirty" with regard to Kool Aid on peer's shirt. 4. Points to "home" on communication board as he recognizes a toy on shelf. Does not try to take toy. (Message indicates he has same toy at home.)
B. Comments on self or expresses feelings.	1. Points to ear and "hurt" on communication board. 2. Signs "sleep" and puts head down. 3. Spells "I'm frustrated" on computer with a facilitator providing support at the wrist. 4.* Jumps up and down with excitement.

Function	Example of situation and communication means used
C. Agreement or affirmation.	1. Nods head "yes". 2.* When asked if he wants a cookie, he reaches out and takes it. 3.** Mother asks, "Do you want some juice?" as she pours juice into a glass. The child repeats her question and grabs the juice.
IV. **Social Routines**	
A. Initiates interaction.	1. Says "what's your name?" and may continue with a routine of other questions. 2. Walks up and touches the hair of a familiar adult.
B. Selected examples of social functions.	1. Says "thank you" with communication device. 2. Signs "sorry" when he steps on someone else's foot. 3. Waves "bye" with a facilitator providing support at the elbow.
* Represents non-intentional communicative behavior. ** Represents purposeful or functional echolalia.	

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*A Communication Bill of Rights**

All persons, regardless of the extent or severity of their disabilities, have a basic right to affect, through communication, the conditions of their own existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. These basic communication rights are as follows:

1. The right to request desired objects, actions, events, and persons, and to express personal preferences, or feelings.

2. The right to be offered choices and alternatives.

3. The right to reject or refuse undesired objects, events, or actions, including the right to decline or reject all proffered choices.

4. The right to request, and be given, attention from and interaction with another person.

5. The right to request feedback or information about a state, an object, a person, or an event of interest.

6. The right to active treatment and intervention efforts to enable people with severe disabilities to communicate messages in whatever modes and as effectively and efficiently as their specific abilities will allow.

7. The right to have communicative acts acknowledged and responded to, even when the intent of these acts cannot be fulfilled by the responder.

8. The right to have access at all times to any needed augmentative and alternative communication devices and other assistive devices, and to have those devices in good working order.

9. The right to environmental contexts, interactions, and opportunities that expect and encourage persons with disabilities to participate as full communicative partners with other people, including peers.

10. The right to be informed about the people, things, and events in one's immediate environment.

11. The right to be communicated with in a manner that recognizes and acknowledges the inherent dignity of the person being addressed, including the right to be part of communication exchanges about individuals that are conducted in his or her presence.

12. The right to be communicated with in ways that are meaningful, understandable, and culturally and linguistically appropriate.

* Excerpt from National Joint Committee for the Communication Needs of Persons with Severe Disabilities.** (1992). Guidelines for meeting the communication needs of persons with severe disabilities. ASHA, 34(March, Supp. 7), 1-8.
Permission to excerpt granted to the Indiana Resource Center for Autism by the American Speech-Language-Hearing Association. (ASHA Help-line 1-800-638-8255).

** Joint Committee members who prepared this statement include the following: American-Speech-Language-Hearing Association (ASHA) - James McLean (chair), Patricia Porter, and Diane Paul-Brown, ex officio; American Association on Mental Retardation - Mary Ann Romski; American Occupational Therapy Association - Barbara Chandler and Jane Rourk; American Physical Therapy Association - Claire McCarthy; Council for Exceptional Children, Division for Children with Communication Disorders - Lee Snyder-McLean; The Association for Persons with Severe Handicaps -Philippa Campbell, Joseph Reichle, and Kathleen Stremel; United States Society for Augmentative and Alternative Communication - Patricia Mirenda and David Yoder.

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Selective Characteristics of Verbal Children and Adults with High Functioning Autism

Communication Characteristics

The list of common characteristics includes many which are present in younger individuals both with and without autism. With increasing age and increasing communication competency, most of these characteristics lessen or disappear for those who do not have autism. It is the frequency and persistence of these characteristics from childhood into adulthood that exemplifies the syndrome of high functioning autism:

In general, high functioning verbal individuals with autism:

- Usually can participate in a conversation that involves some degree of turn taking, *if* the communication partner assumes a directive or dominant role.

- May have a restricted conceptualization regarding social/conversational interaction as manifested by:

    - not knowing strategies for keeping a conversation going.

    - having difficulties providing sufficient clarification of statements so that the communication partner understands the message. (*May get angry and/or blame communication partner for the communication breakdown.*)

    - having difficulties asking for clarification of someone else's message. (*May not recognize a need to check his/her comprehension of the message.*)

    - having difficulties understanding the perspective of the person to whom he/she is talking, e.g., understanding that the listener was not present during an event experienced by the person with autism.

    - having difficulty understanding the significance of another person's role and the implications for one's social communicative behavior, e.g., the more formal manner or style needed when addressing an "authority" figure or a stranger.

- May have restricted conversational competency or fluency when the topics are limited to the ones with which the person with autism feels comfortable or to those topics that he/she has chosen.

- May sound as if he/she has a good vocabulary and has a sophisticated command of the language. *(In some instances the impression is valid, but in others, the sophisticated language may reflect repetition of bits of dialogue heard on television or in the conversation of others. This mitigated echolalia may or may not be used in appropriate contexts.)*

- May mask the true degree of language comprehension difficulty experienced in everyday communication situations, by creating an inflated positive image through the use of pseudo-sophisticated language.

- May exhibit good recall for past events, people, and facts, but the knowledge may be superficial.

- On occasion may replace more appropriate verbal social communication with old communication or behavior patterns. When under stress he/she:

    - may engage in self stimulation or self abusive behavior.

    - may resort to other nonverbal means of communication such as aggression, passive gaze, or physical activity.

    - may become echolalic.

- May talk about unusual topics which he/she finds fascinating, e.g., talks about fans and air conditioners. (*In contrast to people with schizophrenia, unusual interests have been present since early childhood.*)

- May be perseverative and appear bothersome on limited topics. May ask repetitive questions on some topics.

- May talk about inappropriate topics with unfamiliar people or at inappropriate times, e.g., tells a stranger about hemorrhoids.

- Desires social interaction, but has difficulty knowing how to initiate and maintain a friendship. (*May have no real friends.*)

- Probably misses nonverbal cues and nuances in social situations unless taught these skills. (*Processes concrete information better than abstract or subtle information.*)

- Lacks a repertoire of strategies or has difficulty selecting/applying the appropriate strategy for a given situation. (*Feels more comfortable with a concrete set of rules to guide his/her behavior in specific situations.*)
- May have difficulty recognizing and identifying various states of emotion.
- Has some awareness of the basic feelings of others but has more difficulty recognizing, labeling, and/or responding to more subtle expressions of feelings or emotions.
- May have impaired ability to make predictions and inferences and to impute motivation to others.
- May not understand everyday humor in television programs, magazine and newspaper cartoons, or in conversation.

Other Characteristics of Autism That May Be Present:

- May engage in repetitive activities.
- May be resistive to changes in routine or environment.
- May have splinter skills, e.g., unusual abilities in music, math.
- May exhibit clinical anxiety or varying degrees of depression.
- May express thoughts about suicide.
- May exhibit clinical obsessive-compulsive disorder.
- May exhibit seizures.
- May exhibit some bizarre behaviors.
- May be physically as well as socially awkward.
- May have difficulty with fine motor skills, especially handwriting.
- May not perform well when under pressure or stress.
- May have some difficulty with reading comprehension.

- May need some degree of supervision, support, and/or advocacy to be employable or to live independently in the community.
- May be very naive and vulnerable to social/sexual abuse.
- May become more socially isolated as his/her negative experiences in social situations increases.

Selective Characteristics of High Functioning Verbal Children/Adults with Autism was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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Beverly Vicker, Revised 7/94

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Communicating with People with Autism

Communication problems are central to autism. Therefore, special care must be taken to know what each person understands and how to best give messages.

Our messages to people are conveyed through tone of voice, gestures, body language, and choice of words. It's important to create a relationship through which everyone can feel respected. Consider using visual means to convey information whenever possible. Visual information is more concrete and enduring.

The following general techniques are helpful:

1. Be as positive as possible. Praise often and honestly. Notice the good things. Ignore things that don't matter. Many individuals are conditioned to react negatively to "no" or "don't." These words may only trigger a signal that someone is mad or something is wrong but give no information about how to correct it. Use these words sparingly and only when you must have immediate compliance. Be specific when praising. "You did a good job. You washed your hands," is better than "You are a good boy."

2. Teach individuals to listen. Many repetitions of directions teach people not to listen to the words and thus should be avoided. Instead, follow a set procedure such as: "Wayne, come to the table" accompanied by a picture and/or gesture. Wait and give time for processing and moving. Repeat using the picture and/or gesture either with or without the verbal "Wayne, come to the table." If he does not come, move toward the person and gently assist him to the table. In this way, Wayne will learn to listen and follow directions. If you give a direction, make sure you have the individual's attention and that it is followed. Learners learn that they do not need to comply when adults do not consistently require them to do what is asked.

3. Know what you want the person to do. Be very clear in your own mind what you want learners to do and why. Be sure you are making a reasonable request and one which they are capable of doing.

    a. Example: "We will go to lunch when you show me you are ready" is too vague. "Ready" must be defined. "Shut the computer off, then we will go to lunch" gives more information.

    b. Example: "Dust all the furniture" tells the person what to do, but does not set any standard for quality. Instead picture each piece of furniture in order and use a light spray to indicate space. Now you have made the expectations clear.

4. Give adequate information. Tell learners in advance what is going to happen next. If there are changes, inform them and involve them with plans. Let the learners know what will happen and what behavior is expected. Use language, pictures, and gestures they understand. Daily schedule boards and sequence routines made with velcro or check-off sheets and picture wallets are concrete ways to provide information.

5. Use language that is as simple, clear, and as concise as possible. People with autism usually can only comprehend a limited amount of language directed at them. It is best to be concise. Loading too many directions and explanations creates frustration and confusion. Individuals can be taught to listen and follow two and three step directions if the language is kept specific and concise. Usually they need individual direction rather than group directions.

   a. Example: "Pick up your paints, wash your hands, and go to music."

Some people may not be able to follow all of this and may give up or become confused. When several steps are required, break the directions up to allow the receiver to complete one step before a second direction is given.

   b. Example:
      . "It is time for music. Put the paints in the box."
      . When the person is finished, say "Wash your hands."
      . Then, "Go sit on the rug for music."

Often refraining from verbal cuing helps build independence. Use gestures and objects to provide information. Draw attention to others who can be modeled. Some of this information could be provided by sequenced pictures.

6. Tell the learners what to do and avoid telling them what not to do, whenever this is practical.

   a. Example: Person throws food on the floor. Say, "Pick it up and put it in the sink." (The two-part direction may need to be broken up into two one-part directions.) "Don't throw food" only tells him what he just did.

   b. Example: Person finds some food on the floor and picks it up with the intention of eating it. Say, "Put it in the trash can," or offer your outstretched hand and say, "Give it to me." "Don't put that in your mouth," probably will invite just that action.

   c. Example: Person grabs an object from another person. Say, "Ask Jennifer if you can see her magazine," or "Give the bell back to Gary." Avoid, "You must not grab the magazine."

These statements give information that will help learners know what behavior is acceptable. The negative statements only tell them what is unacceptable and do not provide needed information to learn what to do differently and more appropriately.

7. Be as neutral as possible when giving directions. The tone of voice, a facial expression, or the difference of a word can change the meaning of a question, direction, or statement. When giving a direction, state what needs to be done and avoid challenges. Individuals tend to become defensive or upset and try to avoid or do the opposite of what is asked when directions are given in a threatening manner.

   a. Example: Say, "It's time to go to the library." Avoid, "You must go to the library right now."

b. Example: Asking questions, "Where are you supposed to be?" or "What are you supposed to be doing?" can help the person correct his behavior if said in a neutral tone. However, an entirely different message can be conveyed by the tone of voice. Sometimes students become dependent on these verbal cues instead of self-initiating.

Although many individuals with autism cannot answer questions, they can learn set questions as a cue to stop and think, then return to a place or activity on their own.

8. Avoid asking questions with a choice unless the person really has a choice. Directions are given to be followed or to provide information. Do not ask a person if he wants to do something unless you are prepared to accept "No." Clear statements provide information needed to carry out the request. Pictures may be substituted for words, especially in helping the person know sequential happenings. Gestures to objects and environmental cues are sometimes better than words.

   a. Example: Say, "Jim, come to the P.E. room" or "Jim, P.E." or point to picture. Avoid, "Are you ready for P.E.?"

   b. Example: Say, "Come to the table for dinner," or point to picture of table or tap the table. Avoid, "Let's come to the table, O.K.?"

   c. Example: Say, "Write your name on the top of the paper" or provide an example. Avoid, "Can you write your name on the top of the paper?"

9. Teach people to respond immediately to learned words, phrases, gestures, environmental cues, or questions. These help set expectations and permit the person to function more appropriately in a variety of settings. They may also serve as safety devices. Occasionally the person may have been conditioned negatively to a word, so another word will have to be found to convey the meaning. Use concrete cues and words.

   Examples: "Wait," or a "Out of bounds," "Stop," "Find something to do," "What do you do next?" or a fire alarm, an object to use while waiting, an "Out of bounds" sign such as ⊘.

10. Label feelings. Individuals with autism have great difficulty recognizing feelings of others and expressing their own feelings. Labeling expressions of feeling in natural situations help them gain information if accompanied by the reason for the feelings.

    a. Example: "I'm mad. You broke my necklace." "I'm happy. You shared your popcorn with me."

    b. Example: "You are mad that you have to come in." "Going swimming makes you happy." "John hit you, it makes you sad."

11. Avoid labeling people. Usually people know when they have done something "bad." Criticizing or attaching negative labels to people only reduces their self-esteem and self-confidence. Statements that clearly define the expectations, but do not attack the self-image, help people gain a positive picture of themselves.

   a. Examples: "Go change your pants" is better than "You are a mess." "Keep your hands to yourself" is better than "You are a bad boy. You hit Sally." You are using the moment to teach.

12. Avoid reprimands. Use set rules that are consistent and neutral. Reprimands are for the benefit of the adult, not the learner. They have little meaning to most individuals with autism and will not change behavior.

   a. Example: Avoid saying, "You know better than that," or "I've told you not to go in the street a hundred times." Use: "The rule is, ride bikes on the sidewalk."

13. Avoid threats. Threats are negative ways to give consequences. They often provide a negative response.

   a. Example: Say, "Get your money. Then we'll go to McDonalds." Avoid saying, "If you don't get your money, then you can't go to McDonalds."

   b. Example: Say, "Be quiet, then we'll go to recess." Avoid saying, "If you aren't quiet, you'll miss recess."

   c. Example: "If you throw the block at Jim again, you may not play with the toys anymore." This statement is vague and, therefore may act as a challenge and probably cannot be enforced. What does throwing the block mean? What does the person need to learn about playing or cleaning up?

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The University Affiliated Program of Indiana

From *Helping People with Autism Manage Their Behavior*, N. Dalrymple

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Understanding and Supporting People with Autism Who Are Able to Interact Verbally

Individuals with autism who can converse and verbally interact with others are often misunderstood. It is difficult to realize that they too have a communication impairment that affects all their interactions. It is imperative that they have positive support and experiences with people, as well as success using their skills in functional, useful, valued ways. These experiences give them an opportunity to build a positive self-image. For these individuals, the environments in which they must interact can seem both confusing and hostile. The following is a discussion of some of the areas of difficulty, examples of how they are manifested, and some suggestions of ways to help.

AREAS OF DIFFICULTY

RECEPTIVE COMMUNICATION PROBLEMS

1. Interpreting what is said literally or assigning very narrow meanings based upon a specific past experience. Misinterpreting idioms and sarcasm.

   "Smoking is glamorous. It causes heart disease, cancer, and emphysema." (after seeing an anti-smoking poster which sarcastically stated "smoking is glamorous")

   "People who lay down the law get in serious trouble. They steal, break in, rob people."

   "The sign says 30 miles an hour, so I drive exactly 30 miles an hour."

   A person with autism was anxious to get to his destination and continuously asked "when." He was told, "Just hold your breath, we'll be there." He literally did just that.

2. Difficulty understanding subtle nonverbal messages.

   "Other people give messages with their eyes and I don't know what they are saying."

   "What is moody? How do I know if she is moody?"

EXPRESSIVE COMMUNICATION PROBLEMS

1. Perseveration on topics/themes/words/particular concerns.

   Monologues about orchids, history, health food, the environment, maps, geography, or any other topic of interest at the moment.

Often there is a lack of understanding that others may not be as interested and that the conversation is primarily one-sided.

Using long quotes from TV shows, movies, or written material repeatedly in conversations.

Using a word or phrase repeatedly because it is new and they enjoy the sensation of producing it or the sound of it (e.g. "allergy," "Mississippi," "embarrassed").

2. Difficulty in initiating and sustaining conversations.

   Starting conversations the same way and responding with a few pat phrases.

   Repeatedly asking questions or responding to questions with a question. This may be an attempt to compensate for difficulties by controlling the conversation. It also gives the individual more time to organize or retrieve a response. E.g., "What's your name?" (Margaret) "Why did your mother name you Margaret?" (I guess she liked that name.) "Why did she like that name?"

3. Unusual vocal quality

   The individual may speak too loudly or too softly for a particular context. He may not understand to vary how loud or soft he is depending on where he is when he is talking.

   The person with autism may speak in a monotone voice.

   The rate with which he speaks may be too rapid or too slow.

UNDERSTANDING SUBTLE SOCIAL MESSAGES AND RULES

1. Difficulty understanding and interpreting the behaviors of others.

   "What is wrong with her? She won't talk or write to me or talk to me on the phone."

   "The people I used to sit with in the cafeteria left, now no one likes me and I don't want to eat."

   When out with a peer tutor the student with autism put his arm around the female tutor. She responded with, "My boyfriend won't like this. Please put your arm down." The person with autism responded, "No one likes me. I do everything wrong."

   "When I walk away people get mad, but I don't know if they are finished talking or not."

2. May request a concrete rule when one doesn't exist.

   "When can you hit on the playground?" The rule is no hitting on the playground. However, the child with autism just observed children hitting.

3. Knowing what is appropriate social behavior

A young man approaches several different people in a mall and asks them for the name of their dentist.

4. Understanding humor

A girl with autism spit a mouthful of pool water at the opposing team's swim coach. When asked for an explanation, she said she was bored and wanted to do something funny.

THE NEED FOR ORDER AND PREDICTABILITY

1. He/she may lack the ability to deal with change and accept uncertainties.

May need to know exactly when a friend will come pick him/her up, where they are going, and when they will be returning before he/she is able to agree to go.

On the first day of April, the student with autism begins to ask about going roller skating. Last April 26 her class went roller skating.

When going to the mall, a person with autism may expect to do exactly what he/she usually does there and in the same order.

Receiving the answer, "I don't know" or "Maybe" can cause increasing anxiety. The need for a definitive answer may drive him/her to repeatedly ask until he/she gets one.

2. May rigidly adhere to rules and expect others to do so.

"Why are you drinking coffee? Caffeine is bad for you. You should drink milk for health and strong bones. It contains calcium."

A school rule was to play on the blacktop if it had rained. The home rule was not to bounce the ball on the blacktop since it got your clothes dirty. One wet day, the student with autism went onto the grass to play ball and was sent to the office. He could not explain why. His Mom explained that when faced with conflicting rules, he always chose the home rule.

A six year old had toileted independently at home and at the homes of family members. After having been taught to ask permission to use the bathroom in school, he insisted on asking permission everywhere.

3. May establish own rules, routines, and rituals

"I allow myself to daydream only while I am walking. I cue myself to wait until I can walk to daydream."

"When I enter a new motel I use my credit card to check my messages, put the suitcase on the bureau, and use the bathroom."

"If a class is canceled, I just sit in the room for that time period, then I can go on with my day."

MORE EASILY OVERWHELMED, OVERSTIMULATED, OVERLOADED

1. May become extremely anxious when there is an overload.

   "Sometimes I just sit alone at night and I start to scream."

   "When my heart starts beating very fast I get scared."

   "It took all I could do to come here today."

   "I just want to go home now."

2. May close down when there is an overload.

   May sit in the car rather then go in the store with others.

   May sit with eyes closed or stare off into space for a period of time.

   May go to his/her room right after school or work, line things up, lie or bounce on the bed, pace or play music.

   "I just have to leave sometimes."

3. When overwhelmed, may employ compensation strategies that seem odd to others.

   Increased pacing or putting hands up to ears.

   Getting a book and sitting in a corner to read.

   Carrying something of value around with him/her.

   Talking to him/herself aloud.

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HOW WE CAN HELP

The desire to have friends and do what others do is often strong for people with autism who are verbal communicators. This desire often grows as they grow older. Sometimes their experiences have taught them to be very cautious and they turn inward. Sometimes they appear to be very assertive and almost aggressive in stating their point of view. Often it is impossible for them to understand another person's needs. Therefore, it becomes necessary to teach the social skills that will help them be better at socially interacting with peers, friends, family members, and the community at large.

WHAT TO TEACH

1. Complimenting

   "You have a pretty house."

   "That's a neat VCR."

   "I like going out to dinner with you."

2. Agreeing

   Teaching the person with autism to accept the initiations of others. E.g. "Do you want to see my pictures?," "Do you want to go to the game with me?" (Care will have to be taken to help him/her decide where and with whom to go. Strategies can be developed for this.)

3. Making pleasant comments.

   "I like it that Joe came with us."

   "I had a good time with you."

   Learning to look at others and smiling from time to time.

4. What to say when there is a pause.

   "Wow," "Sure," "I know," "uh huh"

5. Teach specific rules for certain situations.

   Tell people when you are leaving rather than just walking away.

   Respond when you are thanked.

   Thank people when they give you something.

6. Teach ways to get more information

   Asking what words mean

   Saying, "I don't know"

7. Teach negotiation

   It's okay to state a preference, but also ask others what they want.

   Writing down possible choices and learning choosing, negotiating, and taking turns.

8. Teach to initiate sharing

   Concrete ways to share can be taught. Having a bag of candy with many small pieces can more easily be shared. He/she can learn to ask, "Would you like some?" "Do you want to try a _____?"

9. Teach greeting

   Students can be taught to say "hello" or shake hands when seeing someone or being introduced.

10. Teach the person with autism to look at what others are doing. This can give him/her information on what he/she can be doing.

11. Teach ways to deal with unpredictable responses and rejection.

    Teach what can be done when he/she is angry or frustrated.

    Teach what can be said to a peer who has rejected him/her.

    Teach ways to recognize early signs of anger and frustration so the person with autism can act sooner.

12. Teach specific skills that can then foster friendship by promoting social interaction through the use of that skill. E.g., chess, running,etc.

13. Teach social/sexual rules and how they apply to the individual with autism and to the interactions and environments in which the person lives, works, and plays.

SOME SPECIFIC SUGGESTIONS

1. Some successes have been found with music, spectator sports, and clubs like computer and chess. Active individual sports such as hiking, jogging, walking, swimming, biking, exercise routines, and aerobics have been successful.

2. Turn-taking activities in which each turn provides a model for the routine are often enjoyed. These include bowling, computer games, and some board games.

3. The establishment of a peer program so the individual can learn from peers in social contexts. There may need to be several different peers, so one individual is not expected to do too much. There may need to be a reinforcement system for the peer, such as school credit, being tutored by the person with autism in a subject area, or other rewards. The peer will also need feedback from others since he will not get the typical feedback from the person with autism.

GENERAL NEEDS

1. The need for a mentor or advisor who will help with problem solving any time, any place, about anything.
2. The need for enablers such as written rules, calendars, lists, or appointment books to fall back on as needed.
3. The need for positive, patient people who take a genuine interest in the individual with autism.
4. The need for real social experiences in school and in the community (e.g., member of a swim team, going to the local YMCA, part of boy/girl scouts).
5. Consider real-life experiences taught and practiced often, such as banking, talking on the phone, and holding part-time jobs.

Understanding and Supporting People with Autism Who Are Able to Interact Verbally was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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Nancy Dalrymple, Annamaria Mecca

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Long and Short Term Strategies for Reducing Specific Repetitive Questions

Repetitive questions may serve a variety of functions for the person with autism. There may be several functions operating simultaneously or the functions may be different in what appears to be similar situations. Which strategy to implement in a given situation may depend upon the communication partner's familiarity with the person with autism and knowledge about his/her repertoire of social and repetitive behaviors. The communication partner's ability to assess the situation also may influence which strategies is chosen. Below are examples of several functions or reasons and some possible strategies.

Possible functions or reasons for repetitive questioning:

1. Inability or difficulty with adequately communicating other ideas via oral speech.
2. Difficulty knowing how to initiate or maintain a conversation.
3. Lack of other strategies for gaining attention in a positive way.
4. Need for information.
5. Need for reassurance.
6. Need to escape a situation that is boring or unpleasant.
7. Need to avoid transitioning to a new situation.
8. Desire to be social.
9. Need to be in control of situation and/or attempt to keep the social interaction within their level of understanding.
10. Fascination with predictable answers.
11. Desire to demonstrate knowledge or competency by content of questions.

Possible Strategies to Teach Adaptive Skills

Long Term Strategies

a. Introduce an augmentative means of communication that may be more efficient either as a primary or backup system. Options include facilitated communication, and backup communication boards or card sets.

b. Use a scripted format to teach better conversational strategies; review, as needed.

c. Use a topic notebook to suggest other subjects to discuss with various people.

d. Provide visual information that may reduce anxiety (e.g., schedule boards, activity charts).

e. If questioning reflects task avoidance, analyze the environment and the person's schedule and change accordingly.

f. Provide positive alternative situations for the person with autism to use his special knowledge. For someone with extensive knowledge about cars, help him develop a book that could be shown to other people.

Short Term Strategies

a. Ask the person if they would like to be facilitated (if the person uses facilitated communication).

b. Redirect the person to augmentative communication materials or topic notebook.

c. Remind the person using a visual or verbal cue of what has been learned in a scripted situation.

d. Set a limit on the number of questions or the amount of time for the interaction before it is terminated and share this information with the person with autism. Let the person know when you will be free to talk or have it built into his/her schedule.

e. Reverse the question to see if the person already knows the answer to his/her own question.

f. Suggest an alternative activity so the opportunity for interaction is maintained but the focus shifts from the attempt at conversation to something more visual.

g. Use a checklist so that if the questions reflect anxiety, the person with autism can independently check off events until the target activity occurs.

_____ get in van at 6:30

_____ drive for 30 minutes to shopping mall

_____ buy CD

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Beverly Vicker, 7/94

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Guidelines for Interaction with Students and Clients Who Have a Severe Communication Disability

Many adaptations may be needed to assist someone with autism and a communication disability. The guidelines below represent some general strategies to consider. The staff or consultant speech language pathologist can be of assistance in the identification and implementation of specific individual strategies.

Aiding students/clients who have difficulty understanding your message

Talk more slowly than normal. (Think of Mr. Rogers as a model.)

- Say your words more slowly and be reasonably distinct, but don't over articulate.
- Have a slight pause between words. Pauses help each word seem more distinct from the others.
- Pause much longer than normal between sentences. This will allow better processing time for the student/client.

Talk at a sentence level appropriate to each student/client's comprehension capabilities.

- For some students/clients, 2-4 word sentences may be appropriate.
- For these same students/clients, put your most important information word at the end of the sentence frame. These individuals may focus more on the last word that they hear.
- Do not judge a person's comprehension capability, however, by his/her inability to use oral speech. Some individuals with autism will have near-average comprehension ability and should be communicated with on an age appropriate level.

  The above guideline may need to be violated when a fairly capable person with autism is in a stressful state. He/she then may process information better if the syntax level is simplified and presented at a slower rate.

Monitor your choice of words.

- Use words that are familiar or those that are in that student/client's vocabulary repertoire.

- Be consistent with your choice of words. If you notice others using different words for the same thing, discuss this at a staffing. Some students/clients are ready to learn that more than one word can refer to the same thing; others would become confused.

- Use specific concrete words rather than abstract or vague words when possible.

Repeat or restate your sentence as needed to help the processing of your message.

- After a pause, repeat your statement.

- Alter your initial statement to emphasize the same or new key words, or to add new information. For example, "Time to eat dinner. Eat. Time to eat. (Student/client still hasn't come.) Dinner. Time for dinner. Time to eat dinner."

Use visual input to aid comprehension of oral speech.

- Use a total communication approach. For example, use sign language, a communication board, printed words, or pictures as a supplementary input source. First, present the verbal message, pause, and then repeat with the aid of the visual backup. When sign language is used, sign 1-2 key words rather than the whole message.

- Use demonstration to nonverbally indicate what the student/client should do or to focus his/her attention. For example, use a pointing gesture to direct attention to a given object or location. Touching or tapping the target object could also help.

Encouraging communicative interaction with the student/client who has a severe expressive communication disability

Accept restricted verbal behavior, unconventional verbal behavior, and nonverbal behavior as communicative.

- Forcing a student/client to use a long verbal sentence, such as "I want coke, please," may neither increase frequency of verbal output nor increase joint attention or interest in social interactions and spontaneous communication. Saying "Coke" or "Want Coke" can communicate intent as well as the longer sentence.

- Recognize requests for information from the student/client even though the requests are not phrased in conventional question forms such as "What is...?" or "Are we...?" Some questions will be presented in statement form but you will hear a rising inflection at the end of the sentence (e.g., "Go home?").

- Observe that echolalia is often communicative. Because of this, echolalia should not be extinguished, but reshaped, if possible, into something that more clearly expresses that student/client's communicative intent. The individual's intent, however, must first be recognized and responded to. The person can then be shown an alternative way of communicating the same message (e.g., putting someone's hand on the desired object, pointing to a picture on a choice board).

  Sometimes a student/client's echolalia is non-interactive and is communication to him/herself. This echolalia is different from self stimulation. It may serve the purpose of helping the person with autism to process or organize information, or to provide self direction.

- Recognize nonverbal behavior as communicative. For example, moving next to someone and standing by him may be that person's way of requesting attention or interaction. More explicit communicative behaviors, however, may need to be taught.

Encourage the student/clients to use their augmentative means of communication to supplement their oral speech or to minimize other communication problems.

- For some student/clients, oral speech should be encouraged as their primary means of communication. Other systems which help make oral communicative messages more easily understood can be used as back up systems. When messages are incomplete, repetitive, contradictory, and difficult to interpret:

  - The caregiver can suggest that the person use the supplementary system. The caregiver may need to direct the person to his/her communication equipment or actually go and get it for him/her.

  - If the person uses facilitation, the caregiver will need to ask if he/she wishes to be facilitated.

- For some individuals, the use of a communication board or topic cards facilitates the circumvention of word retrieval or oral language formulation problems. This person may be able to speak his/her message quite adequately after access to the visual display material. The person may need to be reminded to use his/her supplementary communication material.

- Other individuals may need to consistently rely on their augmentative communication equipment to meet most of their communication needs. He/she should be encouraged to be responsible for his/her own equipment. The caregiver, however, needs to assume that responsibility if the student/client is reluctant to do so. The student/client will place more value on the augmentative communication display if he/she is successful with using the material and if he/she is given numerous opportunities and support throughout the day to engage in communicative exchanges.

- Customized backup displays can be designed for various situations or environments so the individual has more opportunities for active participation in an activity (e.g., a display for going to K-Mart). Going places without such communication support is the equivalent of each caretaker taking the student or client on an outing without taking along that individual's tongue and larynx.

- In order to effectively encourage use of any augmentative system, the caregiver needs to know the potential usage capabilities of that system, the vocabulary related to that student/client's system, and, in the case of facilitation, the site and degree of physical and emotional assistance needed. Information transfer between staff is essential.

Encourage informal as well as formal communicative social exchanges during the course of the day.

- Regardless of what means of communication the student/client uses, avoid asking him/her questions about things he/she knows you already know. For example, if you went swimming with Tom today, it serves no communicative purpose (i.e., it provides no new information to the social interchange) to ask him if he went swimming today. Even though Tom may not be able to express it, he may very well know that you were there and resent your efforts to try to make him communicate.

  Try to promote natural social interchanges. Use self talk, multiple choice, and acceptance of that individual as a person (including his/her decision sometimes to be silent) during a social interchange. Forcing him/her to talk puts you into an authoritarian position and may increase his/her resistance to communicate.

  As an example of self talk or commenting behavior, the following could have taken place. The caregiver says, "Swimming was fun today. I like swimming, (pantomimes swimming motion). First I swam this way and then I swam that way (changes directions and pretends to swim). I like swimming. Swimming makes me feel good. Do you like swimming?" No verbal response is emitted by the student/client but he/she smiles. (The smile is communicative that swimming is something positive for that student.) "Great." (Caretaker pats student's knee.) "You like swimming. I like swimming." Not much information was exchanged during this social interaction, but it was a positive communicative situation upon which to build a social relationship.

- Remember that the very passive person who has autism may also have important messages that he/she wishes to communicate. He or she may have a movement disorder and engage in limited initiation behavior. Periodically ask if he/she needs or wishes to talk about something so that his/her concerns or topics can be addressed. Offer to facilitate, if this is needed, or offer to get the communication display for the user.

- Use the communication equipment yourself while engaging in a reciprocal interchange. By seeing you use the display, the person can see that you value it as a communication tool. From your demonstration he/she can learn other ways of using the display. This type of activity can also alert caregivers to vocabulary or phrases that need to be added to a display in order for positive, informative exchanges to take place.

Also see the following IRCA handouts

- Facilitated Communication
- Communicative Functions
- Selective Characteristics of High Functioning Verbal Children and Adults with Autism

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Beverly Vicker, 7/94

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The High Functioning Articulate Person with Autism Who Also Has a Communication Problem

How can parents explain to relatives, neighbors, teachers, or service agency personnel that their son or daughter with autism has a significant communication problem? People often hear the high-functioning individual using good articulation, speaking in sentences, and engaging in turn-taking conversation on selective topics. The parents may be asked, "How can there be a communication problem?" Parents explaining their son or daughter's disability face a dilemma. Should the parent explain using the jargon terms of the speech language pathologist (e.g., the child or young adult has problems with pragmatics and with the comprehension of the subtleties of daily communication discourse)? Probably not. Such descriptions do not explain to people how to interact with a person with autism. Parents really want people to feel comfortable about communicating with their son or daughter with autism and want to make the interaction more mutually successful. Parents may find that people will better understand the situation if information is presented within a familiar frame of reference. Thus, an analogy might help someone understand whereas a presentation of facts may not.

Suppose parents describe their son or daughter's problem as very similar to that of a person from a foreign country studying English in the United States. Upon arrival to the United States, a tourist would find that he does not understand some of the cultural and linguistic aspects of our daily lives. He may not understand the colorful and sometimes questionable slang used by our teenagers. He could be confused, for instance, by slang such as "awesome." He might want to talk about subjects on which he is very knowledgeable. Unfortunately people would talk about topics he does not understand or about which he does not have a point of reference. Conversing about the New Hampshire primary, the Yuppies, or the 1960's would be difficult for him, and he would probably find these topics somewhat uninteresting. Until he had a better command of the language, he might avoid situations which required engaging in chit-chat or small talk.

In many ways the high-functioning articulate person with autism is just like this tourist. He does not quite understand the language and is unaware of some of the cultural information implicit in our daily communication. But, unlike the tourist, the person with autism <u>may not know</u> that he does not understand or <u>may not realize</u> the extent to which he is missing common information. The tourist may ask questions or develop hypotheses about what he thinks people are talking about. He may check his hunches with a familiar communication partner. In many cases, however, the person with autism <u>probably would not</u> engage in these activities.

So what can parents tell people to help them understand their child with autism and to help them be more successful in daily interactions with him/her? Parents can simply advise them to do what they would do with tourists:

- Talk a little slower.
- Explain things that they think s/he may not understand or find familiar.
- When possible, use pictures or objects to add clarification to a verbal message.
- Watch for body language and conversational content that may suggest difficulty with processing a message. (This is not a fail-safe strategy.)
- Allow the individual with autism sufficient time to process the message and respond.

The challenge will be to use these suggestions and at the same time engage in a natural interaction. Parents, through their own interactions with their sons and daughters, may need to discreetly model appropriate interactions so that relatives, neighbors, or friends can more easily understand what s/he needs to do.

As a nation with an increasing multicultural heritage, our citizenry may need periodic reminders to help appreciate, understand, and cope with the cultural and linguistic diversity of visitors as well as with the growing immigrant and native born populations. People just need to remember that these same strategies can be used with the articulate high-functioning person with autism.

* For real-life examples of communication problems experienced by a high-functioning articulate person, see the book <u>There's a Boy in Here</u> by Judy and Shawn Barron.

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Beverly Vicker, Revised 3/94

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The Role of the School Speech Language Pathologist and the Student with Autism

Speech language pathologists (SLPs) sometimes wonder what role they should perform when asked to provide services for a student with autism. Parents may equally wonder what types of services they should request or approve for their son or daughter. Since individuals with autism vary across the many dimensions of communication, such as ability to talk, to communicate basic needs, or to engage in conversation, a single answer is not possible. Instead, it is feasible to review a menu of options and related ideas that may impact the selection of a delivery of services to meet individual needs.

QUALITATIVE COMMUNICATION IMPAIRMENT—BY DEFINITION

As a starting point, it may be appropriate to begin with a set of questions:

- Does the student with autism have a communication problem?
- Does he or she need the services of a school speech language pathologist?
- Does this need for special services also apply to the student who is high functioning, i.e., a student who has average or above average cognitive abilities?

The answer to all three questions is an unequivocal "yes." The degree of certainty emanates from what is known about the disability itself. A qualitative impairment in communication skills is considered to be a characteristic of autism. Typically the services of the speech language pathologist are needed by the student with autism and by his or her educational team, including the school staff and the family.

SERVICES MAY BE NECESSARY BUT DIRECT SERVICES ARE NOT ALWAYS MANDATORY

Having a qualitative communication impairment does not mean that each individual with autism automatically requires direct or personally administered service by a speech language pathologist (SLP). Instead, it should mean that the SLP is familiar with each student and that the SLP works with each family and the school staff to plan and to customize a communication program which meets each student's needs.

OPTIONS FOR INDIVIDUALIZING A PROGRAM

There are several options or models for the provision of communication services to the student with autism. This publication presents brief information about direct service, consultation, and collaboration, and discusses other intensive roles that might be performed by the SLP. Following the discussion of models and roles, hypothetical case studies will illustrate how customized programs might be developed for individuals with differing needs.

The following is an overview of the options or models for providing services:

Direct Service Model

- Services are provided to a student by the SLP or by a speech/communication assistant, a paraprofessional under the supervision of the SLP.
- Services may take place in a separate room in the school, in the classroom, in the community, or in a combination of settings. With very young students or students with severe medical conditions, services may occur within the home environment.
- Services may be one-on-one, in a group setting, or both.
- Services might include assessment (testing) and the instruction, practice, and generalization of communication skills training. Examples of the many services include:
    - observing in various environments in order to obtain functional assessment information;
    - observing in the classroom to check for generalization of skills;
    - testing vocabulary comprehension and use through formal and informal means;
    - teaching someone to speak louder;
    - teaching someone acceptable ways of requesting attention;
    - teaching someone to understand a question format that requires a time-related response;
    - teaching someone to signal when he or she wants to change topics during a conversation;
    - teaching someone how to use a communication device; and
    - teaching a student who is having difficulty learning to read about phonological or sound awareness.

- Generalization of skills is always a concern when using this model, especially for services that only take place in a therapy room. That does not mean, however, that pull out services (i.e., services in a therapy room) should never be provided on a short- or long-term basis. Instead, it means selecting the best option for a specific situation.

Consultation Model

- Consultation can include a variety of activities. A team discussion with clarification of roles and expectations regarding the consultant's services might be necessary before an Individualized Education Program (IEP) is completed.

- Sometimes consultation services have a major collaborative or partnership component.

- In some situations, a consultant uses an expert service delivery model.

    - Someone has a problem and the SLP is requested to observe, evaluate the student, and provide suggestions to the teacher.

    - Consultation also can be used in a proactive manner. For example, an SLP may observe the effectiveness of a teacher's discourse or oral communication with a class during group instruction. The SLP might make suggestions that could improve the attending behavior or verbal comprehension of the student with autism.

- Consultation services also may represent a means of monitoring a student's generalization of skills into everyday situations.

- SLP consultation services may be combined on the IEP with other service delivery options or roles, or instructional goals.

Collaboration Model

- Collaboration involves team planning and team implementation of a communication plan. The SLP, classroom teachers, and teaching assistants meet to plan specific activities. The SLP may or may not be in the classroom or community when activities occur.

- Collaboration may also vary and need definition as it pertains to a particular student.

- Collaborative planning allows communication goals to be practiced throughout the school day. Potentially, more practice will occur each day than would occur if only a pull out model (services in a therapy room) were used to teach a given skill. Data keeping is needed to insure that sufficient communication teaching or practice occurs during activities each day.

- A collaborative model has the potential to insure that communication is learned in functional or daily situations. Collaborative planning also must include adequate training and support of all persons who implement daily or weekly instruction.

In addition to direct service, consultation, and collaboration, the SLP may perform other roles such as the support or management of the augmentative communication program for an individual with autism, the provision of training to others, and advocacy for the student. Just as the various service delivery models or options could be used in combination, so too may the various roles be combined with each other and with the various service delivery options. Example duties are listed for each role.

Augmentative Communication (AAC) Support/Management Role

- Communication board development can consume much time. In order for students to participate in specific daily activities, mini-communication boards or specific overlays for activities need to be designed. The SLP may recruit or supervise volunteers to aid in the construction of materials.

- Electronic communication devices have become very sophisticated. Many hours of specific training and practice are usually needed before an SLP is able to program a specific student's electronic communication device. Often the SLP must be familiar with several different devices.

- Updates of vocabulary and specific messages are always needed for both electronic and nonelectronic communication devices. A student's desire to share some information may wane, if he or she does not have the means for communicating that message.

- School staff and family need instruction on programming a device. It is advisable that more than one person know how to program a specific student's communication equipment. Training will need to occur when staff and family members can be available.

- Some staff and family also may need instruction in order to learn a core vocabulary of manual signs that may be used for short, quick communicative messages to the person who has autism. Signing may supplement the use of a communication board or device.

Training Role

- Training may be provided to classroom and specialty areas teachers (music, art, P.E.), the student's classmates, family members, instructional assistants, administrators, bus drivers, and others.

- Training may be a specific concentrated event such as a workshop that focuses on the use of visual backups to supplement verbal directions.

- Training also may be ongoing and occur in a more informal manner. In this type of training, the trainee may only be given small, manageable chunks of information on any given day.

Advocacy Role

- Advocacy might be needed in order to gain support for an intervention method such as AAC, to identify additional opportunities for the student to contribute to the classroom discussion, or to achieve better staff understanding of a student's special needs. For example, the SLP might help other staff understand that acting out behavior will continue unless the use of better communication skills is taught and supported.

- Advocacy could take the form of soliciting funding for an electronic communication device.

- Advocacy also could involve the solicitation of a specific service for a student (e.g., an occupational therapy evaluation because the student has difficulty producing written communication).

HYPOTHETICAL CASE STUDIES

A student's needs and opportunities for learning and practicing communication skills may change over the course of a school year. Parents, teachers, and SLPs may consider writing the IEP so that it specifies goals and the amount of time that will be spent by the SLP on a given student's case or needs during the course of a week (e.g., 1 hour of service per week). This is in contrast to the typical restrictive specifications which appear on many IEPs, i.e., both time **and** method of service delivery are specified, such as two 30-minute **direct** therapy sessions per week.

A student's needs may be more adequately met if a **combination** of service delivery methods is considered. A time-only specification on the IEP allows the SLP the flexibility of adapting to best meet the student's diverse needs on both a short-term or weekly basis, and on a long-term or school year basis. The time specification assures parents that a specific amount of time will be allocated for their son or daughter. The records kept by the SLP will document how time (e.g., one hour) was allocated each week. This documentation also verifies that the student received the total amount of service specified in the IEP. The concepts of time allocation and various service delivery options are illustrated by the following case scenarios. Without the flexibility to use service time as needed, some important activities might not occur.

Case #1, Joshua

Joshua has autism. He attends third grade. He performs in most areas at grade level. He is able to use speech in a fluent manner.

Direct service:

The SLP teaches him social skills as part of a small peer group activity.

Consultation:

Periodically the SLP observes during various classroom situations and on the playground. He meets with the classroom teacher and the resource teacher on a monthly basis to discuss Joshua's ongoing difficulties in social situations. Social skills training priorities for small group therapy sessions may be identified during these meetings.

Training:

The SLP provides a workshop on social skills training to the school staff. This has the effect of training both his present teacher and his future teachers.

Advocacy:

The SLP combines several roles in working with Joshua's family. The main goal is to help his family be supportive when he engages in socially inappropriate behavior. His family members must view themselves as important partners in helping him to develop better skills. The SLP develops video tapes which discuss and demonstrate how the family can help. The tapes are supplemented by phone calls and periodic meetings.

Case #2, Eric

Eric has autism. He attends a first grade general education classroom and a resource room. He is nonverbal but uses a communication board and a few manual signs to communicate messages. His parents have purchased a Liberator for him to use at home and school. (The Liberator is a sophisticated electronic communication device that can retrieve messages based on a coding system; it produces voiced output.)

Direct Service/Augmentative Communication Support:

The SLP works with Eric to develop a personalized system of messages for the Liberator that will meet his social and academic needs.

The SLP helps Eric become efficient at retrieving messages from his device.

The SLP teaches Eric strategies for managing conversations. Through field trips and planned activities with others, Eric practices his skills with a variety of people, including his parents.

Training:

The SLP teaches parents, teachers, and volunteer staff how to program the device. She also teaches them to use software to design communication device overlays that correspond to various activities.

Collaboration:

The SLP meets weekly with his classroom teacher and special education resource teacher to plan key lessons for the week and to discuss how to increase opportunities for Eric to engage in various activities. His SLP also participates in selective activities to monitor, teach, and model communicative behavior for Eric and for the school staff.

Frequently SLPs find it difficult to provide the variety of services outlined above. They may have a large caseload of students and be unable to customize to the degree that they or the parents desire. This situation represents an administrative problem. Restricted budgets may make it difficult to hire more SLPs. There is also a nationwide shortage of qualified SLPs, so that some school districts are unable to recruit needed personnel, particularly if caseloads are high. A parent will need to be knowledgeable about the status of SLP services within his or her student's school district. Parent group advocacy may be needed before creative solutions to budgetary or recruitment constraints will occur.

In conclusion, a qualitative impairment in the communication area is a characteristic of autism. An SLP's involvement in the educational program of a student with autism represents a logical affiliation. The SLP's unique training makes him or her an educator with different skills than the classroom teacher. Together, this educational duo has the potential to make a significant difference in the life of the student with autism.

Also see the IRCA training papers:

- Diagnostic Criteria for Autistic Disorder
- Communicative Functions
- Selective Characteristics of High Functioning Verbal Children/Adults with Autism
- Guidelines for Interaction with Students and Clients Who Have a Severe Communication Disability

The Role of the School Speech Language Pathologist and the Student with Autism was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

The University Affiliated Program of Indiana

Beverly Vicker, 1/95

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FACILITATED COMMUNICATION REVISITED

In its brief time in the public eye, facilitated communication (FC) has generated an incredible amount of publicity and controversy. In one sense, the controversy is surprising since the techniques used in facilitated communication are similar to the techniques used by parents, teachers, and therapists for many years. On the other hand, the controversy is very understandable, since facilitated communication challenges how we view the individual whom we are attempting to support.

As we embark on the summer of 1995, it seems like a good time to take a step back and think about the actual application of facilitated communication. Let's begin by defining the word facilitation. Facilitation is a *strategy* that can be used to assist people to make voluntary movements, whether it is to use a spoon, to make a selection from a supermarket shelf, to use scissors, to kick a ball, or to write. In other words, facilitation is a tool to assist a person in accomplishing an act. Building on this notion, facilitated communication could be defined as a technique to assist an individual to communicate his/her thoughts. More specifically, facilitated communication involves physical, emotional, verbal, and conversational support which assists the person to make selections on a keyboard that spell out his/her individualized message.

PHYSICAL SUPPORT

The physical support generally involves backward pressure applied to the hand, wrist, or arm. This pressure creates a resistance that the person who is typing must push against to make a selection on the keyboard. Physical support is not limited to supporting the individual's hand or arm. Support also includes positioning the person while typing, positioning of the keyboard to the person, and selecting and/or adapting the augmentative communication device.

EMOTIONAL SUPPORT

Emotional support is more involved and harder to describe. It involves two general areas. The first is treating the individual as a competent, intelligent person who has important messages to contribute.

The second facet of emotional support is providing verbal encouragement, reassurance, and a safety net. It has been described by many people who facilitate that it is a tremendous risk to communicate not knowing if you will be listened to or taken seriously. It is the facilitator's responsibility to create an atmosphere of safety upon which the person can rely. Creating a safe environment includes:

- Listening to what the person has to say.
- Not judging what the individual has to say.
- Responding, both verbally and behaviorally to the person.
- Telling the person that what he/she has to say is of value and is important to be shared.

- Not talking and being patient while the individual collects his or her thoughts and types them out.
- Supporting the person while he/she determines what works for him/her. For example, a person may need to decide what is the most effective way of communicating once he/she is already upset.
- Allowing the individual to have private conversations.
- Informing the person that his or her information will not be shared with anyone unless he/she gives approval.
- Displaying reciprocal behavior. For example, people need to learn the expectations of a reciprocal conversation. Hence, facilitators need to model reciprocal behavior. This involves listening, sharing experiences, apologizing for being late, asking typical conversational questions, and coordinating schedules with the individual.
- Expressing confidence in the person's abilities.
- Not talking in front of the person as if he/she is not there.
- Sharing information on a sophisticated level. In other words, paying attention to how the information is communicated as well as to what information is communicated. This pertains to the messages one presents when altering the tone, style, pitch, and manner of one's voice.

VERBAL SUPPORT

Facilitators need to be aware of the questions they ask so they can assist an FC speaker to develop communication. It has been noted that it is more difficult to reply to an open ended question than it is to a yes/no question. Therefore, verbal support involves structuring questions to enhance verbal interactions. In addition, verbal support refers to asking a person to clarify what s/he has typed. This is done when the actual message is unclear to the reader.

CONVERSATIONAL SUPPORT

The role of the facilitator is more than physically assisting the person to facilitate. Rather, the facilitator is responsible for assisting the person to engage in conversation with others by helping them to access the board, by helping them to access individuals with whom to converse, and by promoting their involvement in interactions. For example, a support person may need to encourage an FC speaker to become involved in a conversation. In addition, the support person may need to encourage others (e.g., staff, local merchants, principal, clergy, family members) to speak directly to the person and to acknowledge the FC speaker's comments that are presented through facilitated communication.

Individuals should be encouraged to engage in conversation despite their initial level of facilitation. For example, if the person's initial ability with facilitation is limited to yes/no or single word statements, it is important to include that person's communication whenever naturally occurring turn-taking would allow. By encouraging typical conversation the individual learns that facilitation is an effective method of relaying their messages.

The facilitator must assume that people would take part in conversation if they could. Therefore, it becomes the responsibility of the facilitator to ask the individual if s/he has anything to contribute to the conversation. This status might change throughout the conversation. For example, if a person has nothing to add at one point, it is important to ask again as the conversation continues and takes on new form.

It is important to realize that providing the combination of supports mentioned above does not guarantee that an individual will facilitate. Training is still found to be of utmost importance for the novice as well as for the experienced.

Finally, it is important to note that all people use many forms of communication throughout a day. Anything from speaking to writing to faxing to gesturing to silence are accepted means of communication. The difference between these forms and many others is that no single method is effective in all situations. Likewise, people who utilize facilitated communication need to expand their competency for communicating across home, school, work, and community settings. Below are suggestions for promoting communication across settings:

- Each FC speaker should be encouraged to have multiple facilitators.
- Discuss with the FC speaker where facilitated communication works well and where it is difficult.
- Identify communication options of what to do when there isn't a trained facilitator present and the FC speaker wishes to express him/herself. The person may decide to work on independent typing, signing, picture boards, or verbalization as options to utilize when facilitated communication is not feasible.
- Encourage people to problem-solve how to facilitate with more people and how to make facilitation more accessible across settings.
- Encourage people to incorporate all forms of communication (e.g., gesturing, leading, helping oneself, signing, verbalizing, using communication boards). Regardless of the method chosen, the FC speaker should be involved in determining what other forms of communication will be used to complement facilitated communication.

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Nancy Kalina

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Auditory Integration Training: Issues and Questions To Consider

Consumer empowerment involves access to information that in turn influences a consumer's decision to purchase or not purchase specific goods or services. Auditory Integration Training (AIT) is a relatively new intervention that is currently available for individuals with autism or other disabilities. No intervention is without risk. Interventions that work with 100% of individuals treated are rare. Parents and other care providers face the difficult task of securing and sifting through diverse information and then deciding what is right for their child or client. The following material can assist in deciding whether or not to purchase AIT services, and in selecting a reputable agency.

AIT is still an experimental procedure. The published literature on AIT contains numerous personal accounts but few articles or studies by individuals who are not personally invested in providing AIT services. Selective references are listed on an Indiana Resource Center for Autism training paper entitled *Auditory Integration Training Bibliography*. Anyone considering AIT may also want to consult this resource and an IRCA fact sheet.

In addition, the Indiana Resource Center for Autism (IRCA) can assist Indiana parents who desire a parent-parent exchange of information. The IRCA has permission from several Indiana parents to release their names and phone numbers; each parent has had AIT intervention one or more times for his or her child. Contact information can be obtained from Marci Wheeler, the IRCA social worker, by calling 812-855-6508.

The content for the following sections evolved from IRCA surveys, from the stories parents have shared, and from a common knowledge about best clinical practices.

EXPECTED OUTCOME OF AIT:
Documenting a Reduction in Sensitivity to Sound

A consideration of need and expected outcome can be a first step in the decision process regarding AIT. If you are considering AIT intervention because your child is sensitive to some sounds, then you will want to assess your child's current behaviors before you reach a final decision. Through observation and discussion with other family members, decide the following:

- What sounds appear to be bothersome?
- Are these sounds bothersome 100% of the time?
- Has there been a lessening of the reaction over time?

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- Has there been a reduction in the number of things that are bothersome as your child increases in age?
- Under what conditions are offending sounds **not** bothersome?

What formal or informal interventions or strategies have been used to assist your child in adapting to sounds that he or she finds offensive?

- Have any of the strategies been more successful than others?
- How often are the strategies used by you and other family members?
- Does your child self-implement any of the strategies listed below or has he or she devised any others?

Have your intervention strategies included any of the following:

- Giving advance information about the occurrence of a predictable event (e.g., a fire drill, concert)?
- Using a social story to give information about unpredictable events such as sirens, laughter, or babies crying?
- Encouraging your child to think about something else (i.e., shift his attention until the offending noise has ceased)?
- Redirecting your child to another activity?
- Having your child wear earphones or a Walkman to mask the offending sound(s) with music or some other pleasurable auditory stimuli?
- Having your child wear ear plugs to reduce the intensity level of the offending sound(s)?
- Building up endurance to the offending sound by frequent exposures while allowing small incremental increases of time or duration?
- Noting improvements as a consequence of his or her medication (e.g., Mellaril, Risperal)?
- Using sensory integration techniques during times of offensive sounds?
- Giving your child control of desensitizing him or herself (e.g., child controls Play and Volume buttons as he or she listens to a tape of the offending sound)?

EXPECTED OUTCOME OF AIT:
Selecting a Pre-AIT Benchmark for Marking Improvement in Social/Communication or Processing Skills

If your expected outcome from AIT is an improvement in social, communication, or processing skills, then you will want to first gather information about your child's current skills. You will want to define what you hope will improve and gather information over several weeks of time. Taking data on your child's performance only one time before and after AIT could give you a false impression of change.

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You will also need to consider other changes occurring in your child's life that may have a positive or negative impact on these areas. For example, programming in a regular education classroom might impact social and communication development.

Consider whether your child's current status in the social/communication area may be a reflection of the programming *(or lack thereof)* that he or she has received. Is your child in a classroom with children who are all nonverbal? Does your child have appropriately designed communication materials that allow him or her to participate in all classroom activities? What visual supports are being used to assist your child in improving his or her processing of auditory information? Another possibility to consider is that your child may have an underlying language or learning disability that is only exacerbated by also having autism.

Unless a change is immediate and quite dramatic following AIT, it may be difficult to exclusively attribute change to the procedure. The longer the time span between intervention and noted change, the less likely, in this complex world, that AIT is exclusively responsible for the change. Prior language testing would seem to be helpful in tracking post-AIT change. Even a slight post-AIT change in test scores, however, will not be conclusive evidence of improvement, since a score is reflective of a range of possible scores rather than an absolute. *(If you took the same test several times, it is unlikely that you would score the same each time. Instead, your scores would randomly increase or decrease within a specific range each time the test was administered.)*

OTHER POSSIBLE OUTCOMES OF AIT: Expectations of the Good and the Bad

Every parent is hopeful that, for his or her child, some intervention will greatly improve the quality of life for the child and for the family. The risks are always the same: the child improves, remains unchanged, or gets worse. The following questions identify some of the worst outcomes. Parents have sufficient dreams and hopes to provide their own balance of what is the best possible outcome.

In making a decision about AIT you will want to ask the following questions; consult with others about how to minimize any effects.

- Are there any emotional risks for your child from participation in AIT? *(There have been a few reports of depression.)*
  Will your child be able to understand what is expected if he or she is scheduled to participate in AIT?
  Will he or she be a willing participant in the process?
  Will he or she be uncooperative or upset if he or she is not in control of the AIT situation?
  Will he or she feel fearful with the invasion of his/her personal space?

Will he or she find the sensory aspects of the experience uncomfortable (e.g., disliking the earphones exerting pressure on his\her head)?
If your child experiences disorientation, how easily can he or she be assisted in coping with the situation?

- Are there any physical risks to your child from participation in AIT?
Is there any permanent or temporary risk to his or her ears or hearing ability? *(There have been a few reports of perforated eardrums and exposure to loudness levels of over 90 decibels.) (See questions to ask of an agency; if loudness levels are adequately controlled and the ears are checked for infection, physical risk to the child should be minimal.)*

- Are there physical risks for you if you must hold your child during the procedure because he or she will not sit independently?

- Could behavioral problems, including aggressiveness or self injurious behavior increase? *(Talk with various parents; an increase has been reported for some individuals.)*

- Will your child be unable to listen to music or taped stories via headphones following AIT? If not, what will this mean for him or her in terms of recreation or school? *(There seems to be differences of opinion on the extensiveness of a restriction post-AIT.)*

- Will anyone be angry with you, criticize you, etc., if the expected outcome is not achieved?

- Can your child emotionally cope with the outcome, if there is no major improvement? Can you and other family members cope?

SEEKING AN AGENCY TO PROVIDE AIT SERVICES:
Qualifications & Reputation

When you have made a decision to proceed with exploration of AIT, it may be important to talk to several agencies before selecting one. Not all agencies are the same in philosophy, staffing, and cost. As you screen agencies, remember that AIT should not be viewed as a procedure that is "done to your child." Instead, your child should be an active learner during the process.

It is also important to know that whatever changes occur, the effects are not always permanent. Numerous individuals have had auditory training several times. No one really knows what happens when a person experiences AIT.

Consider the following questions to guide your interview of an agency regarding the qualifications of their staff and the agency's reputation:

- Who will be involved as part of the AIT team?
  What is each person's specific role?
  When will each person be involved and for how long?
  Who will control the AIT equipment?
  Will the audiological (hearing) testing be done by an audiologist? *(It should be.)* If not, why not?

- What are the qualifications of the people who will be involved in providing the treatment sessions?
  Where did they receive their training in AIT?
  How long ago did their training occur?
  How long was their training program?
  What was the content of the training program?
  Have they had any subsequent training in AIT?
  What experience do they have working in a **positive** manner with persons with autism?
  What is the professional background of the team (e.g., audiologist, speech-language pathologist, psychologist, teacher)?
  How is their professional background related to the provision of AIT?
  Do they hold professional state licenses and in what area(s)?
  Are they certified to practice in your state?
  Are they nationally certified and in what area(s)? Are they governed by a professional Code of Ethics?
  Do any staff belong to an AIT organization such as the Society for Auditory Integration Training (SAIT)? Who are they and do they hold SAIT certification?

- How many individuals have received AIT by the agency?
  How is "success" defined and what is their reported success rate?
  Is the agency willing to give a prognosis? *(Prognosis is difficult; data is still limited as the procedure is experimental. Be weary of agencies who promise too much).*
  Are there any common characteristics found in those cases where outcome was "successful" vs. "nonsuccessful"?
  Can the agency provide client references (i.e., the names and phone numbers of families who are willing to talk about their experiences with AIT and this agency)?
  Can the agency provide professional references (i.e., the names and phone numbers of other professionals or service providers who are willing to share their opinion of AIT and that agency)?

- How many individuals have had to repeat AIT? What is the explanation for needing to repeat the procedure? How soon did this occur after completion of the first training?

- Can you observe a training session before making a decision?

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- How long has the agency been in existence and is it likely to still be operating six months from now if you have new questions?
  Does the agency have a satisfactory reputation that is built on the provision of services other than AIT?
  Has the Better Business Bureau, the Attorney General's Office or the American Speech, Language and Hearing Association received any complaints about the agency?
  Is the agency operating in a professional manner consistent with the provision of clinical services to clients? *(There have been reports of discounts offered if parents can recruit other parents as customers; such practices might be acceptable for businesses such as long distance telephone companies but are not common practice in the human services sector.)*

- What forms must you complete? What forms must you sign? Must you sign any liability waivers? *(Be sure you are comfortable with agreeing to any waivers.)*

The Procedures Used by an AIT Agency

Consider the following to guide your interview regarding an agency's procedures and after care.

- What are the exact procedures used for the training?
  Will the publicized "10-day treatment (20 sessions)" approach be used or are the sessions individualized for your child?
  Will your child be allowed or encouraged to do something during the training sessions (e.g., work puzzles, look at books)? (*Some professionals believe that the child should not be using his/her hands or engaging in self-stimulation; others may disagree.)*
  What levels of cooperation, alertness, and attention are expected from your child? *(There have been a few isolated reports of children being allowed to sleep during AIT.)*
  If your child becomes upset during the training, must you ignore his/her protests regardless of what you feel your child is trying to communicate?
  Will you be expected to restrain your child until a session is completed?
  Will your child be left unattended at any time? If so, are you comfortable with that?
  Will other children be receiving the training at the same time as your child? Will they be in the same room?

- What music will be used for the training?
  If the music is familiar to your child, will he/she be upset if it sounds distorted?
  If your child does not like the type of music used, will other music or other types of materials be used?
  What is the relationship between the filtering of the music's frequencies and your child's audiogram?
  At what decibel level (i.e., loudness level) will the music be presented? How is the decibel level chosen? How long will the music be played at this level?

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- Where is the training done?
  Is the area soundproof or relatively quiet?
  Will your child and you be allowed to see the room ahead of time?

- What AIT equipment is used for the training?
  Is the equipment working to specifications? Is it calibrated?
  How often is the equipment checked or calibrated? By whom?

- Under what conditions would the training be stopped either temporarily or permanently?
  If terminated permanently, would you receive at least a partial refund?

- How will your child be prepared for the AIT experience?
  Will you be expected to desensitize your child to earphones prior to beginning the training?
  Will you be given instructions on how to desensitize your child to the use of earphones?
  If your child will not tolerate earphones, will the training be done in sound field (i.e., via speakers)?
  Will your child be given a written/picture schedule of events?
  Will your child be instructed about the AIT experience?
  What else is done or must be done to prepare your child for the AIT experience?

- How will you be prepared for the AIT experience?
  What exactly will be your role?
  Will you be given written instructions about the procedures?
  Will you be given literature to read about AIT?
  Will you be given the names and telephone numbers of other families whose children have received AIT at this agency?
  Will you be given the names and telephone numbers of other professionals, not affiliated with this agency, who have experience with AIT?
  Are there any inservices or other educational-type sessions that you can attend to learn more about AIT?
  Are there any videotapes or other audiovisual materials (including television programs) that you can watch to learn more about AIT? *(There was a report on AIT on the TV program "20/20.")*
  Is there anything else you must do to prepare for the AIT experience?

- What audiological testing is done before the training?
  Is the hearing test done by an audiologist? If not, why not?
  What type of signal will be used during the hearing test (e.g., pure tones or complex auditory signals)?
  Will tympanometry be done to check your child's ears for middle ear infection before the training starts? If not, will your child's ears be checked for middle ear infection in some other way (e.g., an otoscopic inspection by a physician)?

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What is the time interval between hearing testing and training? Could your child develop an ear infection during that interval?
Will he or she be periodically checked for ear infections over the course of the 20 training sessions?

- What other testing is done before and after the training (e.g., tolerance to sounds, language, cognition, behavior)? *(If you expect any change in language, behavior, etc., after the training, these areas should be assessed both before and after the training.)*

FOLLOWUP AFTER AIT

- What types of post-AIT services are available?
  Will you receive a written report summarizing the AIT training and your child's responses?
  May you call at any time to ask additional questions?
  Will anyone from the agency contact you after the training? When?

- What counseling is available to help your child and family deal with the effects of the training?
  Will the counseling be strictly informational, for example, print materials to read on your own?
  May you or your child receive other counseling (e.g., psychological support) if needed or requested?
  Is there a network of other families who have participated in AIT with whom you could interact?

- Will your child's training or results be part of any research project, now or in the future? *(Participating in research projects is vital for increased understanding of AIT and its effects.)*
  Will you need to keep data or complete questionnaires after AIT? How many and for how long?

TRAVEL/TIME/EXPENSE CONSIDERATIONS

- What is the cost of the training?
  Is there a sliding scale?
  Does the training qualify for any third-party or insurance payment? If so, will the agency file the necessary paperwork?
  Do you need to pay the full amount and then your insurance company will reimburse you?
  Does the fee need to be paid in one installment prior to training or can it be paid over time?
  Does the agency accept credit cards?

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- If the training needs to be repeated in the future, is the cost the same?
  Is there a refund if you or the agency decides to terminate treatment before the training is completed?
  Is there a refund if you are not satisfied with the outcome of the training or with the way AIT was conducted?

- What commitment (travel/time/expenses) are you willing to make for your child to receive AIT?
  How far away is the agency from where you live?
  How much travel time is required?
  Are transportation or transportation costs a problem for you?
  Do you have any concerns about preparing your child for the travel time?
  What food/lodging accommodations are available?
  Will food/lodging costs be a problem?
  How long will you need to be away from home and other family members?
  Will child care for other siblings be a problem?
  Can you be away from work or from your office for the required amount of time (e.g., do you have enough vacation/sick/personal days to cover the time)?

- Do you have the financial resources to pay for the training?
  Will you need to take out a loan?
  Will the training costs result in financial sacrifices in other areas (e.g., vacation/entertainment budgets)?

This training paper was developed by:

Beverly Vicker
Speech Language Consultant
Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
Indiana University - Bloomington

Victoria Keetay
Assistant Professor & Coordinator of Audiology
Department of Communication Disorders
Indiana State University - Terre Haute

Dianne Gray
Parent of a child with autism
Autism Society of America - Central Indiana Chapter

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A Brief Overview of the Current Status of Auditory Integration Training

Research, parent observation, and personal reports by people with autism suggest that some individuals with autism perceive and manage auditory stimuli and information in a different manner than individuals who do not have autism. For example, some persons with autism appear to have hyperacute hearing. They may hear a sound such as the noise of an approaching train before peers or parents hear it. Others experience everyday noises such as crowd noise, traffic, sirens, vacuums cleaners, and motorcycles as painful sounds. A few people with autism have even reported that they were three years of age or older before they realized that the sounds humans uttered were words that had meaning. Difficulties with perception and the processing of language often persist into adulthood.

One of the interventions proposed to assist individuals who are extrasensitive to sound or who have difficulty processing auditory information or language is called Auditory Integration Training or AIT. People in the USA first became aware of this intervention technique with the publication of the book entitled *A Sound of a Miracle: A Child's Triumph over Autism* (Stehli, 1991) and the earlier condensed version which appeared in *Reader's Digest*. Additional public awareness was raised when a segment of the TV news program *20/20* focused on the procedure.

An audiogram usually precedes the initiation of AIT. With many of the younger children, especially those under the age of six, however, it is not possible for an audiologist to get an accurate audiogram. This usually does not mean that a child will not be accepted for AIT. Some agencies will ask parents to desensitize their child to earphones prior to the audiological testing or the beginning of AIT. Other agencies will not recommend or require prior desensitization. They have found that younger children quickly adapt to the use of earphones if the orientation is done at the first AIT session by a professional who has experience with challenging young children.

AIT consists of 20 training sessions of 30 minutes each. These sessions occur twice a day for a two week period. During each session the individual listens to attenuated or modulated music; the

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music is at a loud decibel level. Auditory Integration Training services are offered by various agencies in many states. The cost can range from $1200 to over $2000 for a two week program; expenses for travel, meals, and lodging and such would increase the total cost.

At the present time, the devices used for the provision of sound for the training have been classified by the Food and Drug Administration (FDA) as Class III medical devices. This means that substantial clinical research using protocols approved by the FDA will be needed before the devices and subsequent treatment are reclassified. During the approval process, service providers can continue to provide AIT unless local state laws prohibit the use of non-FDA approved equipment. The devices under the current Class III designation include the AudioKinetron, AudioScion, and Audio Effects Generator. Practitioners have been advised via the Society for Auditory Training Integration newsletter, *The Sound Connection* (1995), to avoid making claims about the value of AIT in treating any specific condition until FDA approval is received.

At the present time, according to the Society for Auditory Integration Training (SAIT), there is no scientifically proven explanation for how AIT works. There also is no definitive information about who is a good candidate for AIT; the training seems to produce changes for some individuals and not for others. The training program is still viewed as "experimental" by the majority of the professional community as well as the FDA. With this designation, insurance companies are less likely to cover the costs of the training, although the Indiana Resource Center for Autism staff have heard second hand reports of occasional payments by Medicaid and certain insurance carriers. FDA approval would most likely change the status of 3rd party payment. In the educational realm, case conference committees have the option of writing AIT training into an Individualized Education Program (IEP) as a consensus educational need but it is not mandated that the school do so simply because of parent request.

This summary presents a very limited set of information. Anyone interested in the topic is encouraged to see the listing of additional resources. At the present time accessing AIT for an individual with autism remains a personal family decision.

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Sources of additional information:

The Georgiana Organization
P.O. Box 2607
Westport, CT 06880
Phone: 203-454-1221; Fax: 203-454-3788

The Society for Auditory Integration Training
1040 Commercial St. S.E., Suite 306
Salem, OR 97302

The Internet can also provide information by searching under the term "Auditory Integration Training"

See Additional IRCA training papers:

- Auditory Integration Training: Issues and Questions to Consider
- Auditory Integration Training Selective Bibliography
- Auditory Processing and Autism Bibliography

The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

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Visual Resources for Enhancing Communication for Persons with Autism or Other Disabilities

Probably no single set of visual materials will meet the needs of all individuals who require augmentative communication or visual materials to aid their comprehension. In order to make good choices, service providers might want to:

1. Review the book: *Visual Strategies for Improving Communication (Vol. 1): Practical Supports for School and Home* by J. Hodgdon for general ideas. (Available from Imaginart Communication Products listed below.)

2. Review the article: Beukelman, D., McGinnis, J., & Morrow, D. (1991). Vocabulary Selection in Augmentative and Alternative Communication. *AAC: Augmentative and Alternative Communication, 7*(3), 171-185.

3. Call or write for various catalogs.

4. Call companies for additional information if it is unclear about the type of vocabulary and pictures included in any given set of materials.

5. Order various sets of material for a closer review. Most companies will allow a preview and will refund the purchase if the materials are returned within 30 days.

Company Name	Company Address	Materials Available
Attainment Company, Inc.	504 Commerce Parkway Verona, WI 53593 800-327-4269	Various picture materials for choice boards, sequence boards, recipes, etc.
Blissymbolics Communication International	1630 Lawrence Ave. W., Suite #104 Toronto, Ontario, Canada M6L 1C5 416-242-9114 Fax: 416-244-6543	All Blissymbolics materials
The Capper Foundation	Speech Language Pathology Department 3500 West 10th Street Topeka, Kansas 66604 913-272-4060	Capper Foundation Communication Pictures
Crestwood Company	6625 N. Sidney Place Milwaukee, WI 53209 414-352-5678	Talking Pictures, Passport series

Company Name	Company Address	Materials Available
Imaginart Communication Products	307 Arizona Street Bisbee, AZ 85603 800-828-1376	Pick N' Stick, Touch N' Talk Hodgdon book
Don Johnston Developmental Equipment	PO Box 639 1000 Rand Road, Building #115 Wauconda, IL 60084 800-999-4660	Core Picture Vocabulary, Picture Communication Symbols, Book I, II, III, Pick N' Stick, and Ke:nx icon galleries
Mayer-Johnson	PO Box 1579 Solana Beach, CA 92075-1579 619-481-2489	Picture Communication Symbols or PCS, Book I, II & III, other material for schedule boards, etc.
Poppin and Company Communication Materials	PO Box 5439 Arlington, VA 22205 Fax: 703-533-1080	DynaSyms Cut & Paste

Although pictures of manual signs are static representations of movement patterns, some depictions can be readily recognized after minimal training. The following are three resources that contain visual depiction of ASL concepts and signed English vocabulary.

Company Name	Company Address	Materials Available
Gallaudet University Press	800 Florida Avenue NE Washington, DC 20002-3695 800-451-1073	*The Comprehensive Signed English Dictionary*, *American Sign Language Dictionary*, *The Signed English Starter*

Visual Resources for Enhancing Communication for Persons with Autism or Other Disabilities was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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Communication Issues Across the Diversity of Individuals with Autism: A Selected Bibliography

No single book or article will provide complete assistance to the professional or student in training regarding the complexity of the communication disability experienced by various individuals with autism. This bibliography lists materials that may provide both overview and more specific information to support both verbal and nonverbal individuals. References that are specific to augmentative communication programming or specific techniques such as facilitated communication are listed on separate IRCA bibliographies. (See notation regarding additional resources at the end of the bibliography.) Although some of the materials may be available from the library at the Institute for the Study of Developmental Disabilities, others will need to be borrowed through local interlibrary loan programs.

An asterisk (*) denotes material available from the Institute for the Study of Developmental Disabilities, CeDIR (Center for Disability Information and Referral); at (812) 855-9396 (voice/TT). Materials are only available for checkout by Indiana residents.

AUTISM SPECIFIC BOOKS OR TOPICAL ISSUES:

Barron, J., & Barron, S. (1992). *There's a boy in here.* New York, NY: Simon & Schuster. (Provides personal insight into the learning and use of language.)

Duchan, J. F. (Ed.). (1982). Communication problems of autistic children: The role of context [Topical issue]. *Topics in Language Disorders, 3*(1). *

Grandin, T. (1995). *Thinking in pictures and other reports from my life with autism.* New York, NY: Doubleday.
(Provides personal insight into the learning and use of language.)

Layton, T. (1987). *Language and treatment of autistic and developmentally disordered children.* Springfield, IL: Charles C. Thomas. *

Miller, P. S. (Ed.). (1988). Autism: Ecological issues in intervention [Topical issue]. *Topics in Language Disorders, 9*(1). *

Prizant, B. (Ed.). (1983). Communication problems in autism [Topical issue]. *Seminars in Speech and Language, 4*(1). *

Quill, K. A. (1995). *Teaching children with autism: Strategies to enhance communication and socialization.* New York, NY: Delmar Publishers, Inc.

Schopler, E., & Mesibov, G. (1985). *Communication problems in autism.* New York, NY: Plenum Press. *

Watson, L., Lord, C., Schaffer, B., & Schopler, E. (1989). *Teaching spontaneous communication to autistic and developmentally handicapped children.* New York, NY: Irvington Publishers, Inc. *

COMMUNICATION/AUTISM SPECIFIC ARTICLES AND BOOK CHAPTERS:

Boucher, J. (1988). Word fluency in high-functioning autistic children. *Journal of Autism and Developmental Disorders, 18*(4), 637-645.

Cromer, R. F. (1981). Developmental language disorders: Cognitive processes, semantics, pragmatics, phonology, and syntax. *Journal of Autism and Developmental Disorders, 11*(1), 57-74.

Fay, W. H. (1982). The development of yes and no answers in autistic children. *Topics in Language Disorders, 3*(1), 24-32.

Frea, W. D. (1995). Social-communication skills in higher-functioning children with autism. In R. E. Koegel & L. K. Koegel (Eds.), *Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities* (pp. 53-66). Baltimore, MD: Paul H. Brookes Publishing Company.

Hurtig, R., Ensrud, S., & Tomblin, J. B. (1982). The communicative function of question production in autistic children. *Journal of Autism and Developmental Disorders, 12*(1), 57-69.

Jarrold, C., Boucher, J., & Smith, P. (1993). Symbolic play in autism: A review. *Journal of Autism and Developmental Disorders, 23*(2), 281-307.

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Landry, S. H., & Loveland, K. A. (1989). The effect of social context on the functional communication skills of autistic children. *Journal of Autism and Developmental Disorders, 19*(2), 283-299.

Mundy, P., Sigman, M., & Kasari, C. (1990). A longitudinal study of joint attention and language development in autistic children. *Journal of Autism and Developmental Disorders, 20*(1), 115-128.

Prizant, B. M. (1982). Speech language pathologists and autistic children: What is our role? Part I. Assessment and intervention considerations. *Asha, 24*, 463-468.

Prizant, B. M. (1982). Speech-language pathologists and autistic children: What is our role? Part II. Working with parents and professionals. *Asha, 24*, 531-537.

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Prizant, B. M., & Rydell, P. (1984). An analysis of the functions of delayed echolalia in autistic children. *Journal of Speech and Hearing Research, 27*, 183-192.

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Beaty, J. J. (1995). *Converting conflicts in preschool*. Philadelphia, PA: Harcourt Brace College Publishers.*

Brinton, B., & Fujiki, M. (Eds.). (1993). Adults with mental retardation. Maximizing communicative competence [Topical issue]. *Topics in Language Disorders, 13*(3).

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Bunce, B. H. (1995). *Building a language-focused curriculum for the pre-school classroom: A planning guide* (Vol. II). Baltimore, MD: Paul H. Brookes Publishing Co.

Butler, K. G. (Ed.). (1994). *Best practices I: The classroom as an assessment area.* Gaithersburg, MD: Aspen Publishers.

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Calculator, S. N., & Bedrosian, J. L. (Eds.). (1988). *Communication assessment and intervention for adults with mental retardation.* Boston, MA: Little-Brown and Company.

Calculator, S. N., & Jorgensen, C. M. (1994). *Including students with severe disabilities in schools: Fostering communication, interaction, and participation.* San Diego, CA: Singular Publishing Group.

Carr, E. G., Levin, L., McConnachie, G., Carlson, J. I., Kemp, D. C., & Smith, C. E. (1994). *Communication-based intervention for problem behavior.* Baltimore, MD: Paul H. Brookes Publishing Company.

Crary, M. A. (1993). *Developmental motor speech disorders.* San Diego, CA: Singular Publishing Group.

Duchan, J. F. (1995). *Supporting language learning in everyday life.* San Diego, CA: Singular Publishing Group.

Duchan, J., Hewitt, L., & Sonnemeier, R. (1993). *Pragmatics: From theory to practice.* Englewood Cliffs, NJ: Prentice Hall.

Fey, M. E., Windsor, J., & Warren, S. F. (Eds.). (1995). *Language intervention: Preschool through the elementary years.* Baltimore, MD: Paul H. Brookes Publishing Company.*

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Speidel, G. E., & Nelson, K. E. (Eds.). (1989). *The many faces of imitation in language learning.* New York, NY: Springer-Verlag.

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Warren, S. F., & Rogers-Warren, A. K. (Eds.). (1985). *Teaching functional language: Generalization and maintenance of language skills.* Baltimore, MD: University Park Press. *

Wiig, E. H. (1989). *Steps to language competence: Developing metalinguistic strategies.* San Antonio, TX: The Psychological Corporation. *

Yoder, D., & Koppenhauer, D. (Eds.). (1993). Literacy learning and persons with severe speech impairments [Topical issue]. *Topics in Language Disorders, 13*(2).

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American Speech-Language-Hearing Association. (1993). Guidelines for caseload size and speech-language service delivery in the schools. *American Speech and Hearing Association, 35*(Suppl. 10), 33-39.

Berg, F. S., Blair, J. C., & Benson, P. V. (1996). Classroom acoustics: The problem, impact, and solution. *Language, Speech & Hearing Services in Schools, 27*(1), 16-20.

Blischak, D. M. (1994). Phonological awareness: Implications for individuals with little or no functional speech. *AAC: Augmentative and Alternative Communication, 10*(4), 245-254.

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Kim, Y. T., & Lombardino, L. J. (1991). The efficacy of script contexts in language comprehension intervention with children who have mental retardation. *Journal of Speech and Hearing Research, 34,* 845-857.

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Reichle, J., York, J., & Eynon, D. (1989). Influence of indicating preferences for initiating, maintaining, and terminating interaction. In F. Brown & D. H. Lehr (Eds.), *Persons with profound disabilities: Issues and practices* (pp. 191-211). Baltimore, MD: Paul H. Brookes Publishing Company.

Rowland, C., & Stremel-Campbell, K. (1987). Share and share alike: Conventional gestures to emergent language for learners with sensory impairments. In L. Goetz, D. Guess & K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairment* (pp. 49-76). Baltimore, MD: Paul H. Brookes Publishing Company. *

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VIDEOTAPES (NOT SPECIFIC TO AUTISM):

Cooley, E. (1987). *Getting in touch: Communicating with a child who is deaf-blind* [Video recording]. Champaign, IL: Research Press. *

Kupperman, P., Bligh, S., & Barouski, K. (1988). *Hyperlexia* [Video recording]. Elmhurt, IL: Center for Speech and Language Disorders. *

McLean, J., Sack, S., McLean, L., O'Connor, A., & Simmons, S. (1990). *Developing communicative interactions* [training videos and manuals]. Parsons, KS: University of Kansas, Bureau of Child Research.*

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Gajewski, N., & Mayo, P. (1989). *S. S. S.: Social skills strategies, Book A.* Eau Claire, WI: Thinking Publications.

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Goldstein, A., Sprafkin, R. P., Gershaw, N. J., & Klein, P. (1980). *Skillstreaming the adolescent: A structured learning approach to teaching prosocial skills.* Champaign, IL: Research Press.

Gray, C. G. (1994). *The social story book 1994.* Arlington, TX: Future Education.

Hodgdon, J. (1995). *Visual strategies for improving communication (Vol. I): Practical supports for school and home.* Troy, MI: QuickRoberts Publishing.

McGinnis, E., & Goldstein, A. (1984). *Skillstreaming the elementary school child: A guide for teaching prosocial skills.* Champaign, IL: Research Press Company.*

McGinnis, E., & Goldstein, A. (1990). *Skillstreaming in early childhood: Teaching prosocial skills to the preschool and kindergarten child.* Champaign, IL: Research Press.*

Also see the following IRCA handouts for additional information:

1. Augmentative Communication: A Selective Bibliography
2. Communication Characteristics of High Functioning Persons with Autism
3. Facilitated Communication
4. Topic Packet Bibliographies for Specific Communication Subjects

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Augmentative Communication
A Selected Bibliography

The following bibliography presents an array of possible sources of information and ideas. Although some of the materials may be available from the Institute for the Study of Developmental Disabilities, others may need to be borrowed through local interlibrary loan.

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If you are unable to obtain the articles through your local library system, you may be able to obtain a copy through the Indiana Resource Center for Autism. Articles are available at a cost of 10 cents per page. Call 812-855-6508 for further information.

Books, Monographs, and Topical Issues of Journals

Baumgart, D., Johnson, J., & Helmstetter, E. (1990). *Augmentative and alternative communication systems for persons with moderate and severe disabilities*. Baltimore, MD: Paul H. Brookes Publishing Company.*

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Elder, P., & Goossens', C. (1994). *Engineering training environments for interactive, augmentative communication: Strategies for adolescents and adults who are moderately/severely developmentally delayed.* Birmingham, AL: Southeast Augmentative Communication Conference Publications.

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Also see the following IRCA handouts for additional information:

- Communication Issues Across the Diversity of Individuals with Autism (a bibliography that focuses on communication materials)
- Facilitated Communication
- Visual Resources for Enhancing Communication for Persons with Autism or Other Disabilities

The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

The University Affiliated Program of Indiana

Beverly Vicker, 9/96

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Auditory Integration Training Selective Bibliography

Auditory Integration Training or AIT is one of two primary approaches to auditory retraining. The other approach, the Tomatis method, will be described in future Indiana Resource Center for Autism publications. The following bibliography only contains references to the AIT procedure.

Auditory Integration Training is still considered to be an experimental procedure according to the American Academy of Audiology. The bibliography, therefore, contains references to published material that either question or support the AIT intervention. The most extensive pro-con discussion was published in a specific issue of the *American Journal of Speech Language Pathology*. A family or agency may be able to borrow this issue 3(2), 1994 from a local speech language pathologist. Some of the books and the video may be available through the local public library interlibrary loan program or from a chapter of the Autism Society of America.

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Section 7

IRCA

Social/Leisure

The Value of Movement Activities for Young Children

Movement is one of the most important aspects of a young child's life. Most early interactions involve movement. This is true for all children, including children with autism and other disabilities. It is true that all children progress through developmental motor sequences, however some may move at a slower, more awkward or uneven rate. It is important for adults who are beginning to instruct a child who moves more slowly or awkwardly to understand the child's abilities. Children with disabilities, who may move differently, are more similar to normally developing children than different.

> Both groups are children, often of the same chronological age.
> Both groups move during their lives. Sometimes the movements aren't the same, but they all move to some degree and at some level of proficiency.
> Both groups process information.
> Both groups have self concepts that need to be enhanced through movement experience.
> Both groups have feelings.
> Both groups need attention.
> Both groups have common movement goals, that is, to improve their motor proficiency.
> Both groups need to feel wanted and loved.
> Both groups include children who vary in their individual motor ability.
>
> G.S. Don Morris, Burgess Press 1980
> *How to Change the Games Children Play*

Keeping abilities in mind and considering how vital motor skills are for the continued development of children, rethinking the motor program for all young children is an excellent idea. Motor activities are a valuable component of early childhood education programs. Parents, teachers, or even friends should initiate play at the level which will enable the child to participate safely and successfully. As the child becomes more comfortable and competent with the activity, the expectations can be changed to allow for more challenges. Since all children like to succeed and to feel competent, careful attention to skill level and ability would help ensure a positive motor experience. It is not fun for anyone to fail.

Movement can help children develop, not only motorically but emotionally and socially as well. Their well-being can be greatly enhanced if they are given simple foundations in all areas during their early years. These foundations will carry through as they continue to develop and learn at home and at school. In physical education (motor) programs as previously mentioned, the social, communication, emotional, and cognitive skills of children are "exercised" as well as their motor skills. Playing interactive games develops social interaction and communication skills while working on motor development. Problem-solving or cognitive skills such as counting, identifying colors, or learning body parts, are stimulated during games. Participation in motor activities with peers who are accepting influences friendships and the social and emotional growth of all children.

Children with autism and other disabilities can improve their motor skills, just as typically developing children do. The most effective way to improve the motor skills is to practice and utilize motor skills. The development of a gross motor program that includes all children doing a variety of skills and activities is an important aspect of a young child's life. Although adaptations to equipment or rules may be needed, what children with disabilities need most is challenge, encouragement to try, reinforcement for their success, and involvement in the decision making process about what they want to do.

Young children can benefit from many different motor activities. Broad categories of possible activity areas include physical fitness, basic motor skills, dance and music, individual and group activities, and cooperative games. Within each category, activities can be simple, short, and promote success for all children involved. Physical fitness may involve simple stretching, bending, twisting, and other body movements. Some imaginative activities such as bear walking or other animal walks can encourage movements created by the child.

Basic motor skills include activities such as walking, running, jumping, climbing and ball skills to name a few. A simple way to include a variety of basic motor skills is to create an obstacle course. The children can go through, in, over and under obstacles; throw balls at a target, and jump over a rope or crawl under a rope (if they are in a wheel chair). Some equipment to use for basic motor skills are air mattresses, cones, mobiles, balance beams, balloons, balls, bean bags, hoops, mirrors, rattles, ropes, targets, tires, and tunnels. When practicing basic motor skills, the emphasis should be on attempting the activity, rather than on the correctness of the movement.

Dance and music can be done by listening to the radio or children's music. Public libraries often have a children's music section. Encourage children to move in whatever manner they want as the music plays, either individually or in groups. The adults should also participate by moving with the music so children have a model. This will help them believe that moving/dancing is good to do.

Cooperative games and activities help children learn how to work and play together rather than always compete. One example of a game is "Beach Ball Balance" in which two or more children hold the beach ball between them without using their hands. They hold it back to back, head to head, head to shoulder, etc. An excellent resource book for cooperative games is *Cooperative Sports and Games Book* by Terry Orlick.

Adapting the motor program when needed, can benefit all children. All children may need basic motor skills, games, or movement activities broken down into manageable components. Games and skills should be modified to make activities safe and successful. Children can practice adapted components of balance, locomotor, and manipulative skills during a motor program. This is important because each of these skills contributes to children's performance in other types of activities. Activities should be geared to the abilities of the children rather than the children having to adapt to the game or activity. Adaptations are often necessary when planning a motor activity. Some suggested adaptations are reducing the playing areas, using larger equipment, changing rules, shortening the duration of the activity, providing frequent rest periods, using lighter equipment, simplifying the activity, and slowing the pace of the activity. In other words, the entire environment should be geared to safety and success.

Expectations or materials may need to be adapted as well. This may mean removing the competitive aspects, decreasing the number of repetitions, slowing the tempos on musical activities, decreasing the emphasis on accuracy, and using motivators during the activity.

Young children do not have the need for highly complicated motor or play activities. They are learning at the very basic and fundamental level, and activities can be very simple and singular in nature. There is not the need for competition or highly organized games. Less organized, slower paced, and more exploratory activities are very appropriate for young children.

Children need opportunities to practice motor skills and to have interested adults and other children participate with them. Simple activities can help achieve long reaching skills that can assist a child in later life. It is important to remember that during movement activities, the whole child benefits, not simply the arms, legs, and lungs. Therefore including children with autism and other disabilities in movement activities can be a starting point for further development in many other areas.

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The attached material was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

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Kim Davis, 4/97

Local Community Resources to Enhance Activities

Communities offer an array of opportunities for all of us to become involved in recreational activities and to develop relationships with others. Families of people with disabilities may need to fully investigate as many options as possible for recreational outlets. The first step is to identify the interests of the person you are supporting. From there, begin to explore the community for various organizations or associations which match that interest and begin to attend their meetings. Some of these resources may not be typically associated with people with disabilities.

The following lists will hopefully trigger creative thinking regarding ways in which to access and utilize community resources. The lists are by no means complete, but present some ideas about where to go to connect with your community regarding the varied interests of the individuals you are supporting.

Groups:	**Organizations:**
Business:	Chamber of Commerce, Neighborhood business associations, Trade groups
Charitable:	Red Cross, Cancer Society, United Way, Big Brothers, Big Sisters
Church:	Prayer groups, Acolytes, Youth groups, Bible study, Choirs
Collectors:	Stamp collectors, Coin collectors, Flower dryers, Antique collectors
Community:	"Friends of the Library," Volunteers at hospitals and nursing homes
Elderly:	Senior Citizens, Golden Diners Club
Ethnic:	Sons of Norway, Black Heritage Club, Hiberians
Interests:	Antique cars owners, Dog clubs, Ceramics classes
Neighborhood:	Crime watch, Beautification, Christmas decorations
Outdoors:	Garden clubs, Audubon Society, Conservation clubs, Sierra Club

Groups:	**Organizations:**
Political:	Democrats, Republicans, Green party
Recreation:	Parks and Recreation, Young Mens' Christian Association (YMCA), Boys Clubs, Girls Clubs
School:	Printing club, Parent/Teacher Association, Child care
Self-help:	Alcoholics Anonymous, Epilepsy Self Help, Single Parents
Service:	Kiwanis, Rotary, Lions, American Association of University Women
Social Cause:	Civil rights, Environmental, Peace
Sports:	Bowling, Swimming, Baseball, Volleyball
Study:	Literary clubs, Bible Study groups
Veterans:	American Legion, Veterans of Foreign Wars (VFW)
Youth:	4H, Future Farmers, Future Homemakers, Boy Scouts, YMCA, Girl Scouts

For school-age children, some of these organizations and activities may be very appropriate. However, these organizations are not the only source for fulfilling recreational needs. School can also provide students with a variety of options for leisure and recreational activities. During the case conference process, family members and professionals can identify potential leisure opportunities and pinpoint skills which need to be taught to facilitate involvement in an array of community and school activities.

Prior to the case conference meeting, it may be helpful to provide family members with a list of leisure activities which are available in their school and local community. The Elementary Activities List on page 7 was developed for elementary students (Wilcox & Bellamy, 1987). This list offers a variety of ideas, but is by no means meant to be the final list of available choices. It can be used as a starting point to begin thinking of all the options that are available. Remember that the list will vary depending on where the student lives. For example, opportunities available in a rural setting will differ from those available in a large city. The goal of providing this list to family members is to acknowledge family and individual preferences, and to begin to prepare students for involvement as adults in their home community. Parents should be encouraged to come to the annual case conference with potential options highlighted.

Finally, additional information regarding transportation, funding, ways to advocate for your family member, and available systems of support can be obtained from the following groups:

American Red Cross
ARC of Indiana
Child Guidance Clinics
Community Mental Health Centers/Clinics
IN*Source
Department of Public Welfare (Medicaid benefits)
Family Service Agencies
Indiana Vocational Rehabilitation
Indiana Protection and Advocacy for Developmental Disabilities
Local Parent Support or Resource Groups
Social Security Administration (SSI Benefits)

Be creative and inquisitive within your community. There are many avenues which can be explored. Ask for help from those you know or from those you contact. In most instances, people are willing to share information and problem solve. The community is there for all to use and enjoy.

Contributor: Kim Davis

The Indiana Resource Center for Autism (IRCA) is one of four of the Institute's seven centers with a cross-age focus in developmental disabilities (technology and technological adaptations, disability information, planning and policy studies, and autism). The three others focus on age-related issues (young children, school-age, and adults and seniors). The ISDD is dedicated to the promotion and maintenance of a seamless system of inclusionary services across the lifespan. Institute activities include interdisciplinary training, information dissemination and research, and community services.

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Elementary Activities List
Leisure/Recreation Domain

Exercise	*Games/Crafts/ Hobbies*	*Events*	*Media*	*Other*
Team sports (YMCA, Parks & Recreation) Riding a bike Jumping rope Participating in school intramurals Playground play Gymnastics class Roller-skating Roller-blading Ice-skating Sledding Skiing Walking Playing catch/ frisbee Swimming Hiking Games using balls (e.g., keep away) Horseback riding Skateboarding Little League Softball Soccer Basketball Throwing & catching a football Dancing lesson	Playing video games Playing target games Playing table games Coloring/painting Jigsaw puzzles Collecting (coins, stamps, baseball cards) Playing an instrument Singing Photography Activity books Computer games Art projects Playing card games Making a scrapbook Playing marbles Flying kites Fishing Bubble play	Movies Attending school events Going to the library Attending club meetings Attending Boy/ Girl Scouts Going out to eat Spend night with a friend Attend concerts Local festivals Shopping with family or friends Attending or having parties Attending local sporting events (volleyball, hockey, baseball, basketball)	Play records Watching T.V. Listening to radio/stereo Using cassette player Listening to/ following along with books on tape Reading books, magazines Watching home movies Using a VCR Renting a movie	Camping Going to zoo Going to museum Visiting the Botanical Garden Going to the park Going to the library Visiting relatives Attending picnics Spending time with friends Writing letters Attending church Playing miniature golf Going bowling Sand play Water play

Adapted from:
Wilcox, B., & Bellamy, G.T. (1987). *The activities catalog: An alternative curriculum for youth and adults with severe disabilities.* Baltimore, MD: Paul H. Brookes Publishing Co.

LOOKING AT THE LEISURE DOMAIN OF INDIVIDUALS WITH AUTISM

THE ISSUE

Given the nature of deficits in communication, impairment in reciprocal social interaction, and the restricted repertoire of activities and interests associated with autism, individuals with this developmental disability are likely to be left out of recreational planning for leisure time. This common statement is made: "It is just too difficult to program for ____, and I'm not sure s/he enjoys doing this anyway."

THE PHILOSOPHY

Individuals with autism have a right to leisure time choices that are similar to those available to all people. Individuals with autism are able persons first.

Program planning in the leisure domain must be:

1. Individualized to meet the client's particular needs and interests with special attention given to the right to fitness, growth of independence, and maintenance through on-going opportunities for participation.

2. Diversified to offer a variety of opportunities and experiences, which will add breadth to acquired skills in leisure activities and appropriate behaviors in social interaction. A longitudinal perspective is essential, as appropriateness of activities will change over time. A holistic perspective is equally crucial as objectives will be adjusted for the vocational setting and how much time an individual will be working; as well as the residential setting and how much time an individual will be alone, in groups, or share home responsibilities.

3. Creatively organized for realistic planning incorporating knowledge and understanding of the individual community resources, recreation skill instruction needed, availability of adjunct personnel, and budget guidelines.

THE STRATEGIES

Identifying strategies for planning and implementing leisure programs for individuals with autism can be facilitated by addressing three key topics:

- Motivation
- Free time
- Independence

The following discussion addresses each of these.

IS MOTIVATION MY RESPONSIBILITY?

Ideally, we would like individuals to be self-motivated by activities in the social/leisure domain. Inherent in our concept of leisure and recreational activities are opportunities for free choice and independence. Individuals with autism may not be able to initiate or make choices that indicate self-motivation. The comparison below challenges our general assumptions about motivation.

Individuals who are developing normally	Individuals with severe handicaps
Have intrinsic incentive	May require external incentive
Recognize short and long term rewards	May require immediate rewards or reliance on routines
Benefit immediately from feeling good about doing the activity	May benefit at the end of an activity being finished and/or earning the reinforcer
Often tire of sameness	Enjoy routines, structure, sameness

Realistically, then, the teacher/service provider/parent will most often become the initial facilitators of motivation in clients by utilizing the following process:

1) Identify whatever motivation is already in place for the client through family interview, observation, and data collection. Record anything that the client initiates, without judgment as to its appropriateness, goals or benefit. Look for information on ways the client reinforces her/himself. If the client initiates an activity, assume it is motivating; use it as a reinforcer.[1]

2) Develop and implement a plan for increasing independence based on an understanding of the hierarchy of cuing, i.e., which cues are more easily faded and which cues offer more independence. The guide which follows, on page 5 of this handout, further explains levels of cuing from most restrictive to least.

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[1] What is reinforcing to an individual today may be replaced by something new over time. This happens with or without intervention. Find reinforcers that work and reevaluate their effectiveness often. The following have been found successful in motivating some individuals with autism:

adult attention
tactile stimulation
electronic toys
community outings
verbal praise
spectator sports
time alone
back rubs
exercise
food
swings
music
mirrors
balls
string
sewing

FREE TIME - A TASK TO BE TAUGHT

What is leisure time? What does it mean to you and how were your interests for leisure activities sparked?

Leisure time, free time, break time are often used to mean the same thing; that time of day to be with friends, to rest, to have fun, or to engage in cooperative games or sports. Usually free time provides opportunities within unstructured time when we can choose to do whatever it is that makes us comfortable.

What about the person who cannot make a choice? What about the person who relies on verbal cues and prompts to get involved in an activity? What about someone who cannot relax and who cannot think abstractly about what is fun?

* "People with autism do not learn to be sociable, to communicate socially, or to use their leisure time well when left to their own devices" (Henning, Dalrymple, et al, 1982).

A person with autism who works well during structured time may exhibit self-stimulation and escalating agitation when break time and free time occur. S/he may not have any idea what to do with this time. Free time skills must be taught with the same diligence, focus, and preparation as any workshop or academic task. Service providers sometimes meet resistance from clients as they are instructed in an activity that should be <u>fun</u>. Learning a new activity may not be fun at first. Changes in routine, introduction of new stimuli, and transitions between people, places and things are all difficulties for most people with autism. We must push past the early interfering resistance, whether in ourselves or the individuals we are attempting to teach. This is our responsibility. Even under these constraints, service providers at school, at home, and in the vocational environment can initiate and maintain a successful program. Strategies for facilitating free time programming can be categorized in three areas.

COMMUNICATING

Utilizing visual, tactile, environmental, and verbal modes.

Identifying clear, concrete expectations, including when the activity begins and when it ends.

TRANSITIONING

Developing, discussing and posting schedules (written words, pictures).

Allowing processing time for new information ("In five minutes, we will go to the gym.")

Utilizing environmental cues to prepare individuals for change without direct contact with the service provider (bells, timers).

TEACHING

Accepting the fact that teaching free time skills must be during the free time itself.

Understanding that initial time involvement on the one-to-one will be lengthy, but can be reduced as skills are acquired and independence achieved.

Planning to teach the skills first, then the concept of choices. Building the repertoire of activities for the client will facilitate realistic choice-making.

Utilizing reinforcements that are client specific and initially establish value for participation right from the start.

THE INTERDISCIPLINARY TEAM APPROACH

The actual implementation of these strategies, like any skill being taught to a person with severe handicaps, will work best when planned and implemented by a team. This may present agencies with several challenges.

1. Interdisciplinary "role release" - professionals training each others.
2. Physical Therapists, Occupational Therapists, Speech-Language Pathologists, Therapeutic Recreation Specialists, and Physical Educators who deliver their services in the teaching environments of the classrooms, the home setting and the community.
3. Interdisciplinary representatives training parents, paraprofessionals, and agencies involved in the next placement.

THE INDIVIDUAL PLAN

Goals and objectives must be longitudinal, integrated, age appropriate, and community referenced. Most of all, goals must be realistic for the individual. To best identify specific objectives, a complete situational assessment must be done.

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The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, technical assistance, reference information, and applied research.

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Jill McLaughlin and Robin Smith, 7/88

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EXERCISE

Considerations When Programming for a Person with Autism

Exercise is a vital component to the health and maintenance of wellness for everyone. Some of the benefits of an exercise program include weight maintenance, relaxation, reduction in excess behavior, improved cardiovascular condition, strength and flexibility, and better sleep.

Specific components of an exercise program include a variety of factors including frequency, duration, and intensity. It is important that a person routinely engage in activity that gets the heart pumping and the person breathing more rapidly for a sustained period. It is somewhat more important to engage in activity than it is to achieve specific levels of intensity. Thirty (30) minutes of sustained activity on a daily basis is sufficient.

The feelings or experience of exertion may be distressing for some individuals. Therefore, a desensitization program to help the person become gradually accustomed to the sensations of exertion may be an important part of the initial exercise program.

It has been useful to provide individuals with information about their level of exertion. This has been accomplished with the use of heart rate monitors which are now generally available to the public. Heart rate monitors typically emit an auditory signal when the heart rate is above or below the exercise range, negative information. It has been demonstrated that providing positive information is a more effective strategy to help someone sustain their activity level. This can be accomplished by wiring the heart rate monitor so that it emits the auditory signal when the heart is pumping within the exercise range. Most heart rate monitors provide a visual display of the heart rate as well. This may be sufficient information for some people to see that they are exercising at a specific level.

Exercising the larger muscles of the body tends to result in greater reduction or displacement of anxiety. Therefore activities which include movements using the larger muscle groups are important. These include the leg and torso muscles. Some exercise activities that include the use of these muscles are:

- jogging
- trampoline
- bicycling
- jumping rope
- walking
- skating
- swimming
- skiing
- exercise machines (e.g., treadmill, weight, stair stepper, rowing, and cross country ski)
- playing structured modified games like soccer or basketball
- classes (e.g., aerobics, aquaerobics, and exercise/jazzercise)
- videotape exercise routines

These are all examples of lifetime skills that people with autism need to learn to have fulfilling, healthy lifestyles.

Supports

It is vital that the exercise experience be a positive one. The key component of enjoyment is an individual's perception of competence. Thus, providing information to the individual so that he or she knows what to do and how to do it is essential. Some ideas to consider to provide this information include:

- facilitators/trainers knowing the individual, activity, and possibly equipment to develop a match and make appropriate adaptations or modifications needed for the individual to experience success
- set routines for engaging in the activity (e.g., walk the same route, follow someone on a bicycle, follow the route marked on the road, count laps by moving bands from one wrist to the other, using a clicking counter, or picking up a nickel each lap)
- visual timers to indicate length of time to participate in the activity
- sequence charts, flip cards, and checklists can be used to provide the individual with information about what to do now and what to do next
- models or someone to do the activity with

Motivation and Reinforcement

People with autism probably will not understand the abstract nature of being more healthy as a result of participating in routine vigorous physical activity. Therefore, it may be necessary to incorporate various motivation and reinforcement techniques into the individual plan for exercise. Some ideas to consider include:

- matching the exercise to individual preferences and strengths
- pairing the exercise with something else that is in itself motivating or reinforcing for the individual (e.g., time with a particular person, music, different types of movement, and various sensory aspects of activity such as water and swimming)
- follow or embed rewards into the activity (e.g., get a juice after exercising, go someplace to do or get something under human power by biking, jogging, or skating)
- valuing and accepting the idea that participation in the activity need not be perfect - engaging in activity for better health is the goal

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Philip Cooper, 8/93

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SOME SOCIAL BEHAVIORS THAT STUDENTS WITH AUTISM NEED HELP TO LEARN AND APPLY IN EVERYDAY SITUATIONS

* WAITING

- Waiting for the bus to come.
- Waiting for dinner.
- Waiting for someone else to take a turn.
- Waiting in line.
- Waiting for someone else to answer.
- Waiting until someone else is finished.
- Waiting for events to occur or group activities to start.
- Waiting for help with a problem.

Interventions: Teach specific strategies for waiting to make waiting less abstract and more specific to the situation. Use visual means such as objects, pictures, and written words to give concrete information. Some of these strategies might be:

- Establish concrete rules such as: "Stand on the porch until the bus stops."
- Sequence activities to give information about when dinner will happen. These might be eating celery, setting the table, looking at a book, then ringing a bell.
- Use visual cues and specific rules to explain what a turn is and what rotation the turn takes. Use a visual check off system to cross off turns.
- Learn to wait in short lines first and give the person something to hold. Use some environmental marker to show movement towards a goal. Establish a clear reason for waiting in line.
- Establish rules for answering and have them visually displayed. These could be: answer every fourth time; answer after someone else has had a try; answer after a certain cue. The person may have to have something else to do instead of calling out the answer, such as writing it down on a card. Raising a hand may be a way to get attention, but may not deter the student from calling out the answer.
- Finishing is abstract and the person with autism may only be aware of "finish" as it relates to himself. Establish the cue(s) that mean finish in each situation. For example, does to be finished with a meal mean all food needs to be eaten, everyone at the table must be finished, the plate needs to be taken away, or Mom gets up?
- While waiting for events, the person may learn to engage himself in one or two favorite activities such as looking at magazines, playing with a calculator, or using an etch-a-sketch. Timers may be used to demonstrate the passage of time.
- Build in reinforcement for doing these very difficult behaviors for even short periods of time. Reinforce attempts.

* **TAKING TURNS AT BEING FIRST**

- Being first in line.
- Being first to answer.
- Being first at finishing the game, which is usually reaching a goal first, whether that be a number, a place, or a prize.

Many individuals with autism are not competitive. However, as they become more socially aware, they seem to understand that being first or having the most is highly valued. Therefore, they become upset when they do not win. Being fastest in a race or playing a team sport appear to be different and usually are not successful activities for most people with autism.

Interventions: Planned strategies help. A visual chart that states who is first in line is usually enough. Rules that apply to answering were discussed above. Stress the process with all individuals involved rather than emphasizing competition and winning. However, for most people with autism the "game" may be a vehicle for social interaction, but the end product becomes quite important. Possibly charting who wins over time would give visual information about reality. Having games continue so that all players can finish helps with the concept of completion, and establishing clear rules of behavior upon winning may be useful for all.

* **TRANSITIONING BEFORE COMPLETING SOMETHING**

- Completion of a computer game or art activity.
- Completion of a workbook page.
- Clearing the table.
- Putting everything away.
- Straightening chairs.
- Completing work before break.

Some people with autism insist on completion before they can move on to the next activity or before they can leave. This sometimes causes problems for schedules and groups. Completion may be defined quite individually.

Interventions: If having activities completed or in order before moving on is a need of an individual, it is wise to understand the need and build time to make transitions in a smooth way. Write or picture the sequences to be finished by certain times. Give 5 and 2 minute warnings for transition. Teaching flexibility for some changes through desensitization methods, in order to lessen compulsion and rigidity, may be required if other people are being inconvenienced by the person with autism.

* **NEGOTIATING**

- Where to go to eat?
- What movie to see?
- What kind of pizza to buy?
- Where to shop?
- What TV show to watch?
- When to do an activity?

Many people with autism are not able to listen to another person's point of view and persist in expressing their own desires, expecting others to do as they wish. This lack of ability to compromise causes friends and relatives to stay away from them at times.

Interventions: Presenting choices visually, either in writing or with pictures, will help. It may also be necessary to write people's names under each possibility and then go through a specific strategy to reach a decision. The person with autism can then decide whether to go with the group decision or not. With a highly verbal person it may be possible to teach a sequence of conversational exchanges. Example: Ask where a friend wants to go. State where you want to go. Ask the friend if that is ok. If friend says, "No," then do X. This would take much practice. It might also be possible to teach the person to use a strategy using visual means, so he or she becomes the negotiator.

* CHANGING TOPICS

- Asking questions about what is going to happen.
- Talking about favorite topics endlessly.
- Making outrageous statements repeatedly.
- Repeating feelings of remorse or that others do not like him.

In most situations concrete visual rules established and rehearsed ahead of time help a person remember how to behave in times of stress. However, the reason behind the perseveration must be investigated. Is the person anxious about what is going to happen? Does the person know anything else to talk about? Does the person need more attention and a better strategy for getting it? Is the person really feeling unsuccessful?

Interventions:

- Use a topic wallet to remind the person of topics to discuss; give a choice.
- Set time limits such as 3 minutes on a topic.
- Set a place and time to engage in talk on the person's own topics with someone.
- Establish a rule about questions such as, answer them 2 times, then say "You know the answer" or "What is the answer?" Write the answer down for future reference.
- Recognize all attempts at expression of feelings and attempt to understand from the individual's point of view.
- Acknowledge feelings and plan how to change things with concrete rules.

* FINISHING

- Finishing dinner or lunch.
- Finishing a work paper.
- Finishing mopping the floor.
- Finishing a bath.
- Finishing dressing.
- Finishing watching the movie or baseball game.

For many people with autism, to be finished is an abstract, situation specific concept. Each situation has to be defined in specific, concrete ways. The person with autism has learned some kind of environmental cue or waits for a cue to tell him when something is finished. Past experience partially defines the concept of finished.

Interventions:

- Finishing dinner or lunch could be defined by everything being gone from the plate, pushing the tray or place away and getting up, taking the tray to the counter, handing the plate to someone, saying "Excuse me," signing "Finished," when mom or someone else gets up, or by a bell or buzzer. Remember that there are so many stimuli for the person with autism to tune into and that there may not be consistency from day to day or place to place, so the person is often guessing. Teach what cue to use.
- Finishing a work paper may mean putting something in every blank space, getting to the bottom of the paper, etc. If the paper must be turned over this may present a problem.
- Finishing mopping will have to be defined by spatial boundaries and an exact method taught to cover the entire area.
- Finishing a bath may be defined by a timer going off, by another person appearing, by completing a sequence, or by being handed the towel. Whatever it is, it should be consistent and clear to the person with autism.
- Finishing dressing could be defined by checking in the mirror and touching each outer article of clothing or going through the sequence. Reinforce completion.
- Finishing watching a movie or sports events will require careful planning for each person. Initially a person may only stay for 10 or 15 minutes, so finishing is defined individually and perhaps by a watch beeper. Marking innings, keeping score, a pop near the end, or crowd cues are all possibilities.
- Finishing a conversation or even knowing when a person has finished talking is something that must be taught. Pauses, movements, or looking away may be perceived as being finished.

Probably it will be necessary to teach the person to ask for information about being finished or look and listen for specific cues.

* **INITIATING**

- Approaching others.
- Asking for something.
- Getting into a game.
- Saying hello.
- Leaving the situation if upset.

Interventions:

Whatever the person is required to initiate and by whatever means, it will be necessary to teach a situation specific strategy. Teach the person to follow set rules and provide written or pictured rules that they can carry with them at first. Spell everything out as concretely and specifically as possible.

* **BEING FLEXIBLE**

- TV shows are canceled or daylight savings time causes them to come an hour earlier.
- The dishwasher is broken; we must wash dishes by hand.
- The swimming pool is closed tonight.
- The teacher is sick.
- The car won't start.
- The blue shirt is in the laundry.

Obviously, learning to accept last minute changes and being flexible causes an increase in anxiety for many people. However, most people employ past experiences to construct an alternative course of action. People with autism often can't do this. They may become anxious and behave quite inappropriately when unexpected changes occur.

Interventions:

- Use visual systems to explain changes in a concrete way.
- If there is a sequenced, pictured routine, cross the planned activity out, remove it and put in another, or provide other choices from two or more.
- It is usually easiest to change a whole activity rather than a step within an activity.
- The teacher being absent can be handled the same way, by putting another name by the teacher's name.
- For things being broken or not starting, it is important to supply an alternative. Don't dwell on the problem. The concept of broken may be difficult for the person with autism to understand.
- Use authorities like newspaper listings of TV schedules to show changes.
- Whenever possible explain the change ahead of time so the person has time to accept it and rehearse it with you. How far ahead to rehearse will depend on the person; sometimes knowing too far ahead creates more anxiety.

* **BEING QUIET**

- Being quiet while working.
- Being quiet while others are talking.
- Being quiet when others are being quiet.
- Talking quietly or in an appropriate voice for the occasion.

Many people with autism who are verbal rehearse or think aloud. They may become quite oblivious to others around them. They also may hum or make repetitive sounds as a monitoring or habitual behavior.

Interventions:

- Teach a specific, concrete way to "be quiet."
  Does this mean making no sounds for a specific period of time? Teaching may start with raising the person's awareness level through audio or video tape; then reinforcing minutes of "being quiet."
- Provide and teach specific rules for specific situations. Practice and teach in context, through real activities.

- Teach social interaction strategies, especially how to get the attention of others and how to engage in exchanges.
- Teach specific strategies in specific situations.

* **MODULATING BEHAVIOR IN EXCITING PLACES/SITUATIONS**

- Learning when to stop clapping — often when a person with autism imitates s/he starts later and stops later.
- Learning when to stop yelling or what is appropriate to yell at a sports event.
- Learning when and where to run, jump, and talk loudly.

Intervention:

- Teach specific rules, practice, rehearse, and sharpen imitation strategies.

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Structuring Positive Social Experiences

In order for persons with autism to be successfully included in the variety of community settings in which they live, work, play, and go to school, it has become increasingly important to engage in the complex and challenging task of providing effective programming to help these people build social skills. The realization that adults with autism are often removed or excluded from job opportunities and community participation when inappropriate social interactions persist can only emphasize the importance of building social skills.

The following considerations and programming strategies are not meant to be an exhaustive list. Rather, they represent some underlying issues that need to be thoroughly discussed and planned for when designing individualized programs to encourage social skill development and interactive participation for persons with autism.

Currently, the person with autism receives frequent negative feedback as teachers, family, and peers try to teach him/her better social skills. While our ultimate goal is to teach appropriate alternatives, this current strategy inadvertently undermines the person's confidence and feelings of self-worth. Therefore, the following prerequisites to teaching need careful consideration:

1. **Trust** - The person must first feel secure in his/her environment before attempting to engage in this difficult skill area.

2. **Positive Self Concept** - Regardless of the current lack of skill or the presence of inappropriate behaviors, the person needs to be valued for who s/he is and have his/her personal interests and abilities respected.

3. **Initial Success** - As the person attempts to learn new skills, s/he must feel successful in his/her attempts in order to provide the person with continuing motivation to keep trying. Waiting to reinforce through praise or reward until more thorough skill development occurs is often unsuccessful.

4. **Motivation** - Individual preferences and interests need to be the basis of a person's program in order to provide pleasurable experiences within which the person can learn new skills.

5. **Assessment** - It is essential to objectively analyze the person's current skill levels, to determine his/her specific strengths, likes, and frustrators, and to identify the purpose of any inappropriate behavior and the important environmental factors that maintain that behavior. Only after such careful assessment can an individualized social skills building program be planned.

Once the individual plan is developed, guidelines for teaching in a structured manner must be considered. Since persons with autism have difficulty learning social interaction skills through informal mechanisms, systematic teaching becomes an important necessity for skill development to occur. Some teaching strategies found to be useful in this area follow:

1. **Routine**. Having a consistent and reliable routine to follow provides a concrete structure within which the person with autism can practice skills, and promotes overall success of the skill development program.

2. **Functional Activities**. Useful and meaningful activities provide the person with a motivation for social interaction. Teach skills that are part of <u>specific</u> activities such as playing board games, swimming at the YMCA, or going to the local library. More global expectations for interaction often create confusion and decrease the likelihood of success. Teaching through activities also helps

the person participate in group activities and be included socially, even when that person is less able to communicate verbally.

3. **Clear Expectations**. Provide concrete information that tells the person which specific actions are expected. For example, the instruction "You can shake hands." rather than "No hurting." provides specific information which promotes successful interaction.

4. **Work for Success**. Set up programming that starts where the person can be successful. Desensitization, rehearsal, partial participation, visual supports such as picture sequences or lists for comprehension, motivating activities, and specific reinforcement for interaction are some of the methods which have proven successful.

5. **Communication**. This is an essential component for long term success and needs to be a central part of programming for both verbal and nonverbal individuals, since persons who are highly verbal also have significant deficits in reciprocal communication skills. Communication skills and related activities must always be practiced in the settings in which they will be used. Additional supports to consider for individuals who have difficulty interacting verbally include alternative/augmentative devices, visual cue cards, and planned conversational sequences.

These are a few of the considerations to be addressed in this challenging area. Learning social communication and interaction skills is a lifelong process that entails continual expansion and refinement. It is an area that challenges us to be creative and to develop knowledge and skills in a realm of human development that has a relatively short history of close examination. While we will continue to need to make adjustments along the way, we can assist persons with autism to more fully and successfully participate in their unique social worlds.

See also:

Odom, S. L. & McConnel, S. R. (1993). Play Time/Social Time: Organizing Your Classroom to Build Interaction Skills. Communication Skill Builders: Tucson, AZ.

McGinnis, E. & Goldstein, A. P. (1984). Skillstreaming the Elementary School Child: A Guide for Teaching Prosocial Skills. Research Press Company: Champaign, IL.

Additional References can be found on the IRCA Selected List of Books and in the book, Bibliographies of Topics on Autism (1993) edited by Rimstidt, S. and available from the IRCA or ISDD Library.

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The University Affiliated Program of Indiana

Chris Ivanick, 10/90, Revised 8/93

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Increasing Social Interaction

Increasingly, people responsible for providing services for persons with autism are recognizing the importance of structuring social experiences into programs implemented at home, at school, and in the community. Indiana parents, school people, and residential and community programmers are responding to the challenge to **teach** situation-appropriate social skills that will enable persons with autism to function in natural settings. Programmers are also recognizing the need to structure social relationships that foster inclusion and participation.

Just as programming for persons who are blind requires compensation for that blindness, viable programs for persons with autism include supports and strategies that enable them to compensate for an impairment that might be described as "social blindness." Wise programmers must recognize the existence of this not-so-visible condition; sound programming must facilitate social inclusion and participation. Successful social experiences for people with autism are based on an understanding of relatively invisible, but innate and currently incurable, impairments.

Impaired social functioning has been recognized to be a primary component of the autistic syndrome since the disorder was first described. Almost half a century ago, Kanner asserted, "...these children have come into the world with innate inability to form the usual biologically provided contact with people."

Recent writers such as Fein et al. have reflected continuing concern with the importance of affective impairments. Hobson (1989) asserts that persons with autism are profoundly impaired in their relations, and **these impairments are probably unique to autism**. It is crucial to understand that impaired functioning is inherent to the disorder and does not result from willful ignoring of social cues and conventions.

McCarthy et al. conclude that affected individuals do not have the ability to discern and interpret subtle signals provided by others in their environments. McCarthy et al. further explain that people with autism rarely spontaneously initiate participation in reciprocal social interaction; when they do, their behaviors are likely to be awkwardly out-of-sync with contextual expectations.

Behaviorally, individuals with autism appear to lack either neurological mechanisms or biologically based internal programming that facilitate social cognition and adjustment. They appear to lack neurological facilities for mental processing of social information.

Dodge observes at least five steps involved in the social information processing of normally developing children. Thinking about these steps may further our understanding of just a few of the adaptive tasks that people with autism are unable to do. The steps include:

1. Decoding social cues.

This is the ability to focus on relevant cues, to extract the cues that are important and attend to them while tuning out the stimuli that will not be needed. The need to do this is evident in one-to-one situations, but most evident in group situations. On a playground, in a cafeteria, or at a party a person with autism is often confused and unable to focus on social cues, and therefore may retreat to familiar patterns or become quite anxious.

2. Interpreting social cues.

Once attention is focused, the person derives meaning from the cues by understanding the intent of the other person. For instance, it is easy to teach that the out-stretched hand means to shake it, because one cue always means one response. However, when a person pauses in a conversation, it may mean she is finished, she is waiting for a verbal or non-verbal response, she is tired, she is thinking, or she is mad. If the person with autism walks away, because a pause means finished to him, he will be correct only a small percentage of the time.

3. Response search.

The search for a proper response involves the ability to solve problems, generalize, and hold internal images. Varied experiences must also be available, from which the individual chooses responses that might be applicable. The person with autism appears usually to work from a set script and to select an entire situation and routine rather than select a response for one particular social interaction.

For instance, if plans are changed and there is a wait or a need to substitute an alternative, a person with autism usually focuses on one known strategy that is applicable to herself, without being able to apply variance to the situation or to the needs of others.

4. Selecting an appropriate response.

After the repertoire of behaviors are searched, the best one must be identified. This requires understanding the setting, the circumstance, and possible consequences from each response. For the person with autism this means being able to do abstract thinking about how the other person might react or feel. We know that this is extremely difficult, if not impossible, for most people with autism.

5. Enacting the selected response.

With the appropriate response selected, the person now initiates carrying it out through motor movements and/or vocalizations. Persons with autism have difficulties initiating. This inability may demonstrate that the social information processing has failed to work effectively; therefore, the person has nothing to initiate.

Although Wing (1983) discusses the various degrees of severity that appear to exist, all individuals with autism evidence impaired capacities for social adjustment. Affected persons have problems with social information processing and adjustment regardless of their levels of intellectual functioning. Indeed, people with autism have come into the world--and are often introduced into "integrated" environments--equipped with innate inabilities and with seemingly innate social inhibitions.

We are faced with the challenge of enabling people with autism to break through social barriers that result, at least partially, from biological causes. We **can offer no cures** for innate characteristics of autism; we **can** offer support and instruction that teaches people with autism precise setting/situation appropriate behaviors. **We can** structure social environments and relationships that facilitate social inclusion and promote participation.

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For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

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Rozella Stewart, 10/90

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IRCA

Self Help/Medical

Implementing a Desensitization Plan for Health Care Visits

Many people with autism become anxious in unfamiliar situations where they do not understand what is happening or what is expected of them. Each person with autism expresses his/her anxiety in a different way. Some anxious behaviors may interfere with obtaining health care. Previous methods of coping with the anxious behaviors, such as restraint or punishment by parents, staff, or health care providers, may have increased fright and anxiety, and led to the need for even stronger methods of behavior control. Desensitization is a way to break this cycle of anxiety or prevent it from occurring in the first place. Desensitization is the strategy of exposing an individual to the anxiety provoking situation for short periods of time using mini-rehearsals. Expectations are gradually increased until the individual's anxiety is decreased enough for him/her to tolerate the situation with minimal expression of interfering behaviors.

General Recommendations:

Design a desensitization plan with input from all persons involved with the individual's program. Assign one or two staff members, teachers, or parents to carry out the plan for desensitizing to each situation to increase the consistency of implementation. The plan should be carried out frequently, and if possible, daily. Increases in expectations should be gradual to avoid major anxiety. It is best to introduce only one new object or activity at a time, although each individual differs in the amount of change s/he can cope with before becoming anxious. Length of time at any one setting should be short enough that the individual's attention does not lag. Each session should end on a positive note. If the individual is having anxiety over a new object or activity, end the session with an activity s/he already is very familiar with and can do successfully. Good communication among staff is essential. Share the individual's progress and the methods of working with him/her that were successful.

Communication:

Communication problems are central to individuals with autism. Therefore, special care must be taken to ensure that the individual understands what will happen in each session and what behavior is expected in return. Use short sentences and give the individual enough time to process the request and comply before repeating. Phrase behavioral expectations in a positive manner, such as "Open your mouth. Keep your hands down." Sequenced pictures may be used to explain what will happen during a session. Instruments such as the light, mirror, and stethoscope can be labeled. The doctor, dentist, or optometrist can be named and his/her picture shown. Sometimes modeling other people as they practice the activity may work well.

Reinforcement:

The individual with autism should be reinforced during each step in the desensitization process. Establish clear expectations for both the person and staff about the behaviors s/he is to exhibit. For example, the staff member approaches the individual's face with a light while the individual keeps his/her hands down. One tooth is touched with the dental pick while the individual keeps his/her hands down. The individual is told to be quiet for one minute while stethoscope remains on his/her chest. When expectations are met, reinforcement is given.

Staff, teachers, and parents can identify each person's particular reinforcers. Small successes during the session can be rewarded. For example, sitting in a waiting room for one minute is rewarded with a carrot stick. A reinforcer also can be given for overall completion of the session. For example, Mom looks in Dave's eyes with a flashlight until the timer goes off, then Dave is allowed to play video games.

Implementing the Plan:

Discuss the desensitization plan with the health care provider (doctor, dentist, or optometrist) and find out the exam procedure and routines that the individual must be able to cooperate with and tolerate. For example, what charts does the optometrist use to check near and distant vision? Will the doctor check the individual's reflexes? Will the dentist floss the individual's teeth? Obtain the instruments which will be used, either from the health care provider or from a medical supply company, or use an available substitute such as a flashlight or other household item.

Check the individual's history for possible anxiety provoking stimuli during medical procedures, such as white coats, strange looking instruments, or long waits. Ask the health care provider if s/he would wear street clothes while examining the individual, clear the office of unnecessary equipment, and schedule the appointment to minimize waiting.

Decide when and where to begin desensitization procedures. Choose a time of day and a place that is relaxing to the individual, such as in the evening on the family room couch or after lunch in a quiet corner of the classroom. Plan to keep distractions to a minimum.

When visits to the medical office begin, keep them short. Very little progress may be seen in the beginning visits; patiently reinforce small successes. Gradually the individual should feel more comfortable in the new environment and be able to tolerate longer time periods. Begin practicing some exam procedures in the office as well as at home or in the classroom.

If the individual has a history of traumatic visits for health care, staff, teachers, and parents should expect his/her anxiety level to be high during the desensitization routine. Therefore, each step of the plan should be repeated for several sessions until s/he is able to complete that step comfortably. Anxiety should be controlled before moving to the next step. The time frame may be increased or decreased according to the individual's anxiety level.

Maintenance and Generalization:

As the individual progresses through the plan, the earlier skills s/he learned can be incorporated into the later steps. For instance, when the individual starts visiting the office, s/he can also practice keeping his/her mouth open or matching eye chart pictures back at the residence, school, or home before or after the visit.

After the individual's successful health care exam, desensitization sessions can be practiced once every 1 or 2 months. When the next checkup approaches, the practice should occur more frequently. Before each subsequent appointment, steps can be grouped together for practice. Fewer practice sessions may be needed. The staff, teacher, or parent's clue to the amount of time needed for each step will be the individual's anxiety level.

The individual's desensitization to one type of health care can be generalized to other medical care visits with some modifications. Desensitization to the second type of health care often goes more quickly and easily. Also consider desensitizing the individual to emergency rooms and other medical situations which s/he might encounter, such as ambulances, and police. Desensitization to various medical tests and procedures can also be done, such as blood tests, EEGs, and gynecological exams, using the same principles.

Suggested Steps for a Medical Desensitization Plan:

1. Begin practicing the necessary exam procedures in a comfortable environment, probably the home or classroom. Show the individual the instruments and allow him/her to handle and feel them. Reinforce the individual for proper behavior.

    a. Chest: practice with the stethoscope. First place the stethoscope on one spot of the chest and then increase the placement to several spots both on the front and back of the chest. At first the stethoscope may have to be placed up under the shirt (or perhaps on top of the shirt), but later the individual should be able to pull up his/her shirt and tolerate the stethoscope. Vocalizations should decrease as the procedure becomes more familiar, but the staff can also communicate that the individual should be quiet.

    b. Mouth: have the individual practice opening his/her mouth on command. Work towards increasing the time s/he will keep it open. Modeling another individual, staff, teacher, or parent may help. Introduce a tongue blade into the individual's mouth. S/he might watch while another individual or staff does it first. Increase the time that the tongue blade remains in the mouth, then add the flashlight for looking into the throat. Reinforce attempts and small steps.

    c. Ears: begin to practice looking in the individual's ears with the otoscope (ear instrument). Watching while it is done to another individual or adult may help. Allow the instrument to touch the ear as a first step, then actually insert it. The staff, teacher, or parent then should look into the ear. Hold the individual's ear while practicing so that s/he will not jerk away suddenly and scratch his/her ear. Some individuals are interested in the light in the otoscope. Allowing a brief (1 minute) play period with the lighted instrument if the individual permits insertion of the instrument may be rewarding. Supervise so as not to damage the instrument.

    d. Abdomen: practice palpating (feeling) the individual's stomach. The top button of the individual's jeans should be undone while the individual lies on the couch. The staff, teacher, or parent should press gently but firmly in several places on the abdomen.

2. Visit the doctors office.

    a. Begin visiting by driving by and labeling, e.g., "This is Dr. Bob's office" for one session. Progress to entering the waiting room for one session, and then to sitting down in the waiting room for one visit, if necessary. Use sequenced pictures to let the individual know what is scheduled. The pictures may have written explanations under each, even if the individual cannot read, to promote consistency in what staff say each time.

    b. Visit the exam room at the doctor's office. Encourage the individual to look around but do not require him/her to sit on the table. Consider taking another individual along and have this individual sit on the table. Have the doctor and assistants greet the individual and talk to him/her briefly.

   c. Have the individual sit on the exam table while the staff, teacher, or parent does one short exam procedure (the exam procedure the individual cooperates with the best).

   d. Incorporate the doctor's other exam procedures into the individual's practice at the office setting. These may include getting weighed on the scales, having blood pressure measured, and having reflexes tested with the rubber hammer.

   e. Continue to practice in the home or classroom while the desensitization visits to the office continue.

3. When the individual goes for the actual appointment, watch his/her anxiety level. During the procedure, reinforce with praise and frequently remind about the reward when the exam is finished. S/he may need to get up from the table, walk around for a couple of minutes, and then sit down again. Allow this, but say, "Two minutes to walk, then sit on table again." If the individual's anxiety will not allow the exam to be completed, stop before physical restraint is needed, and schedule another appointment for later. Be sure to leave on a note of success and give him/her the reward even if the entire exam was not completed.

Suggested Steps for an Optometry Desensitization Plan:

1. Begin practicing the necessary exam procedures in a comfortable environment, such as at home or in the classroom. Show the individual the instruments and allow him/her to handle and feel them.

   a. Have the individual look straight ahead while the flashlight is shown in his/her eyes. Work towards increasing the time s/he will tolerate the light and the adult's face close to his/hers. Have him/her watch while the procedure is done to another staff, teacher, parent, or other individual. Perhaps set a timer and have the individual tolerate the procedure until the timer rings. Reinforce attempts and small steps.

   b. Introduce other instruments such as prisms, lenses, etc. Have the individual practice looking straight at the staff, teacher, or parent while the prism or lenses are moved around in front of his/her eyes. S/he might watch while another individual or staff does it first. Begin with a short time period and gradually lengthen the session.

2. Evaluate the chart that the optometrist uses. Can the individual read letters? Can s/he label pictures? Or can s/he match the pictures on the chart by pointing to or handing the staff, teacher, or parent a smaller card containing the same picture? If the individual can match or label but is not interested in the drawings, staff might find 2 or 3 line drawings that the individual is interested in and reduce or enlarge the drawing size on a Xerox machine to approximate sizes on the chart. The optometrist can then use these pictures to evaluate the individual's near and far vision. If the individual cannot label or match abstract line drawings, staff may have to modify the task still further by having the individual identify actual objects at various distances.

3. Visit the optometrist's office.

   a. Begin by driving by for one session, entering the waiting room for the next session, and if necessary, sitting down in the waiting room for the following visit. Use sequenced pictures to let the individual know what is scheduled. The pictures may have written explanations under each, even if the individual does not read, for consistency in what is said by staff, teacher, or parent each time.

b. Visit the exam room at the optometrist's office. Allow the individual to look but do not require him/her to sit in the chair. Perhaps take another individual along and have this individual sit in the chair. Have the optometrist and assistants greet the individual and talk to him/her briefly.

c. Have the individual sit in the optometrist's chair and look at the eye chart.

d. While the individual is sitting in the chair, introduce the ophthalmoscope (light).

e. Have the optometrist turn off the lights and practice with the ophthalmoscope in the dark.

f. Incorporate the optometrist's other exam procedures into the individual's practice at the office setting.

g. Continue to practice in the home or at school while desensitization visits to the office continue.

4. When the individual goes for the actual appointment, watch his/her anxiety level. During the procedure, reinforce with praise and constantly remind the individual what the reward will be when the exam is finished. S/he may need to get out of the chair, walk around for a couple of minutes, and then sit down again. Allow this, but say, "Two minutes to walk, then sit in chair again." If the individual's anxiety will not allow the exam to be completed, stop before physical restraint is needed, and schedule another appointment. Be sure to leave on a note of success and give him/her the reward even if the entire exam was not completed.

Desensitization to Wearing Glasses:

If the optometrist prescribes glasses, the individual may need to be desensitized to wearing them. Some individuals may be particularly sensitive to having objects on or near their face.

Again, clearly articulate expectations. The individual will wear his/her glasses for 5 minutes during a particular activity. Choose an activity where wearing the glasses will improve the individual's ability to do the activity, such as a table task if the glasses are to correct near vision, or a community outing if the glasses are for far vision.

Begin with a set of empty frames (the optometrist may be able to supply some old or used frames). Have several spare pairs of empty frames, so that they can be replaced right away if the individual breaks them. Place the glasses on the individual and say, "Dave wears his glasses during sorting," or "Dave wears his glasses during the walk." Staff should remove the glasses at the end of the period, or direct the individual in the exact method of removal and putting away. If the individual takes off the glasses, replace them, and repeat directions.

When the individual can tolerate the empty frames for 5 to 20 minutes without damaging them, begin with the real glasses. Have the individual wear them during the same activity and for the length of time that the frames were tolerated. Extend wearing the glasses to several activities and for increasing amounts of time.

Usually the individual will realize that the glasses improve the performance or enjoyment of the activity, and his/her toleration of the glasses will increase rapidly.

Suggested Steps for a Dental Desensitization Plan:

1. Begin practicing the necessary exam procedures in a comfortable environment, such as at home or in the classroom. Show the individual the instruments and allow him/her to handle and feel them.

    a. Have the individual open his/her mouth on command. Work towards increasing the time s/he will keep his/her mouth open. Have him/her model the staff, teacher, or parent. Sometimes modeling another individual may work better. Possibly use a mirror to show the individual how to open his/her mouth. Perhaps set a timer and have the individual keep his/her mouth open until the timer rings.

    b. Introduce the instruments into the individual's mouth. S/he might watch while another individual or staff does it first. Begin by tapping the individual's front teeth with the pick. Slowly increase the amount of time that instruments remain in the mouth. Place the instruments further towards the back teeth and stretch the cheek out a bit. Reinforce attempts and small steps.

    c. Add a practice session with cotton wads in the mouth. Staff, teachers, or parents should wear gloves if these are part of the dentist's exam routine.

2. To prepare the individual for visiting the dentist's office, begin by driving by for one session. During the next session enter the waiting room. If necessary, during the next visit sit down in the waiting room. Use sequenced pictures to let the individual know what is scheduled. The pictures may have written explanations under each, even if the individual cannot read, for consistency of what is said by staff each time.

    a. Visit the exam room at the dentist's office. Allow the individual to look but do not require him/her to sit in the chair. Perhaps take another individual along and have this individual sit in the chair. Have the dentist and assistants greet the individual and talk to him/her briefly.

    b. Have the individual sit in the dental chair and open his/her mouth.

    c. While the individual is sitting in the dental chair, introduce the mirror and pick into the mouth.

    d. Incorporate the dentist's other exam procedures into the individual's practice at the office setting.

    e. Have the dentist turn on some of the equipment, so that the individual can become accustomed to the noise and the sensation (e.g., water and air squirters, drill, suction).

    Have the individual first feel the air squirter on his/her hand, later on his/her face, and finally in his/her mouth.

f. Continue to practice procedures at home or school while desensitization visits to the office continue.

3. When the individual goes for the actual appointment, watch his/her anxiety level. During the procedure, reinforce with praise and constantly remind the individual what the reward will be when the exam is finished. S/he may need to get up out of the chair, walk around for a couple of minutes, and then sit down again. Allow this, but say, "Two minutes to walk, then sit in the chair again." If the individual's anxiety will not allow the exam to be completed, stop part way through, (definitely before physical restraint is needed), and schedule another appointment. Be sure to leave on a note of success and give him/her the reward even if the entire exam was not completed.

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The University Affiliated Program of Indiana

Susan K. Gray, 1/94

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MEDICATION ISSUES in AUTISM

Everyone who works or lives with a person who has autism knows that there is no medication which will cure autism. There is no medical intervention which can reverse or undo the underlying neurophysiological basis of the disorder. Educational, vocational, and habilitative programming are the most important factors in improving the quality of life for a person with autism. However, self injury, aggressive behavior, hyperactivity, seizures, depression, or extreme anxiety can interfere with a person with autism's ability to learn and cope with the world. Rational use of medications may be able to decrease a challenging behavior, may control seizures or anxiety, and can create an opportunity for the person to learn new skills.

Medications are not a substitute for an individual plan of positive behavioral supports for the person with autism. The plan should include environmental changes, positive programming, a communication system, direct intervention by reinforcing a more appropriate behavior which serves the same function, and a reactive plan.

DATA KEEPING

Data keeping is essential for both the behavior plan and any medication trials. The interfering behavior must be defined clearly, so that everyone's data is consistent. Knowing when, where, and with whom the behavior occurs and possible triggering factors will give clues about needed environmental changes and hypotheses of the purpose of the behavior. The reason for the medication should also be stated in clearly defined behavioral terms, so that the data collection is designed to reflect the desired outcome. Continued data keeping assesses whether the behavior plan and medication are working. Adjustments in programming and medication can be made as indicated, but only one aspect of the plan should be changed or adjusted at any one time. Also sufficient time (two or three weeks) should be allowed after each change before deciding on its effectiveness or ineffectiveness.

If a challenging behavior suddenly appears or suddenly increases, a medical problem may be the cause. Pain or illness can cause behavioral outbursts. Some individuals can point or indicate where it hurts when asked, but do not initiate complaining about pain. For others, family and service providers need to be alert to symptoms such as a runny nose, frequent toileting, rubbing or holding part of the body, unusual posture, or a limp. Cycles of behavior may be related to the menstrual cycle, sinus headaches from weather changes, migraine headaches, or seasonal allergies. Changes in current day or residential programming can cause confusion, indicated by behavior problems, and should be evaluated before deciding to start or increase a behavior modifying medication.

INTERDISCIPLINARY COMMUNICATION

In autism, medications are usually prescribed symptomatically and are aimed at reducing seizures or undesirable behaviors. Good communication between the doctor, parents, school personnel, and other service providers is essential. Although anticonvulsant and psychopharmacological drugs are not inherently dangerous if managed correctly, serious problems may arise if excessive doses are administered, if treatment is not monitored, if medications are not integrated into the overall program, or if several drugs are used at once without careful monitoring of possible interactions.

Doctors are usually not specialists in behavior management. Parents, teachers, and service providers should take the lead to analyze the data before asking for a medication change. Medication adjustment is usually a trial and error technique. A certain class of medication is suggested according to the type of behavior needing control. However several different medications in the class may have to be tried before finding a suitable one or before ruling out that class. Usually medication is started at a relatively low dose and increased slowly until the behavioral symptoms are controlled or a maximum dose is reached. This is known as titration. Before starting a medication, a plan should be discussed and agreed upon as to how quickly the dose will be increased and to identify the maximum level. A system of analyzing the data changes and communicating between home, school or work, and the doctor should be set up.

If a medication reduces the behavior, but does not control it sufficiently, another medication may be tried or a second medication of a different class known to complement the first medication might be added. However prescribing two medications from the same class at once is generally considered poor practice (except in the case of seizures). A larger dose of one or a medication from a different pharmacological class should be tried instead.

DRUG CLASSIFICATIONS

Classes of medications commonly used with individuals with autism are the antipsychotics, the anticonvulsants, the anti-anxiety drugs, and the stimulants. Opiate blockers, beta blockers, and vitamins also are used.

Antipsychotics:

This class of medication is used for psychiatric illnesses such as schizophrenia or severe Tourette Syndrome. They may be prescribed for an individual with autism who also has hyperactivity, aggression, self injury, severe disorganization, agitation, or insomnia.

Antipsychotic use should be reserved for severe problems in which reasonable alternative treatments have failed. Short term success with antipsychotics does not necessarily mean these medications will be needed on a long term basis. Careful evaluating of the therapeutic benefits and monitoring for side effects are essential. Haldol has been used with both children and adults with good results. Other medications from this class include Mellaril, Stelazine, Navane, Orap, and Thorazine.

The lowest effective dose should be determined, and an attempt to taper maintenance doses should be made at regular intervals. The parent or guardian needs to be aware of possible side effects and make a rational decision as to whether the benefits outweigh the risks. Sleepiness is another common side effect; it often wears off after 2-3 weeks. Tremors, stiffness, and muscle spasms may also occur. The most serious side effect is tardive dyskinesia, an involuntary muscular twitching which might become permanent and often starts in the facial muscles.

Anticonvulsants:

Children with autism are particularly vulnerable to the development of seizure disorders. Seizures may begin in infancy, early childhood, or in adolescence. Seizures in individuals with autism usually require long term anticonvulsant medication. People with developmental disabilities who have limited intellectual capacity and a tendency for behavior problems are especially vulnerable to negative cognitive and behavioral effects of anticonvulsants. Dilantin, Phenobarbital, and Clonopin can have negative intellectual effects. Tegretol and Depakote generally have fewer sedative effects, although they too can have side effects. The physician who prescribes the anticonvulsant regime should be attentive to the possibility of negative cognitive or behavioral side effects. The occurrence of an occasional seizure may be an acceptable price to pay to maintain the quality of day to day life. Complete seizure control may not necessarily be worth the price of severe intellectual blunting as long as the individual's safety can be assured.

Tegretol has been used also to control explosive aggression in individuals with developmental disabilities including autism without identified seizures. It seems to be most effective in persons with abnormal EEG tracings.

Anti-anxiety:

These drugs are sometimes prescribed when a person seems anxious or upset by a change of routine and are sometimes used on an as needed basis. Often anti-anxiety medications such as Ativan may help for a time. The effect seems to wear off and an increased dose is needed to achieve the same effect. This limits the drugs usefulness for longstanding, chronic anxiety. Sometimes antianxiety drugs such as Valium and Librium cause increased behaviors because the individual loses what little impulse control s/he had.

For some individuals with autism, medications such as Tofranil or Elavil, although technically in the antidepressant category, act as antianxiety agents. These medications can be taken for long periods of time without losing their effectiveness or needing dosage increases. They usually have minimal side effects. This makes them a good choice for a trial in a person with autism who suffers from chronic anxiety.

Antidepression-Antimania:

Individuals with autism may also have superimposed psychiatric disorders such as depression, mania, compulsive behaviors, anxiety, or panic disorder. These may be difficult to diagnose in nonverbal or minimally verbal individuals, but close observation can give clues. If the individual's mood, appetite, sleep, and behaviors seem to increase for a period and then return to a more normal level, the person may be experiencing recurring depression or a bipolar (mania-depression) cycle. Information on appetite (weight gain or loss), hours of sleep per night, mood (indicated by enjoyment of activities/reinforcers), activity level, and any verbalizations indicating depression or euphoria are important data to collect and share with the doctor.

Lithium and Depakote are both good medications for bipolar disorder in persons with autism. Many antidepressants are effective for individuals with autism who are depressed. Several antidepressants may have to be tried to find the one most effective. Most antidepressants take 2-3 weeks to become effective, so a longer trial period is indicated for these medications.

Compulsive behavior can be a problem for people with autism. If the compulsions interfere greatly with programming or other people's rights, and cannot be controlled by environmental or programmatic means, they may need to be addressed through medication. Several anticompulsive medications have been tried in individuals with autism. Anafranil and Prozac are the most common. A few people have done well on these medications, some have been helped slightly, and others have had behavioral side effects. Low doses are often effective for compulsive behaviors associated with autism; high doses or rapid increases of dose seem to be associated with more side effects.

Sedatives:

Sedative or sleeping medications may be prescribed if a person with autism does not sleep, and may allow the frazzled parents or caregivers to get some needed sleep. Sleeping medications are best used to help set a sleeping pattern along with a bedtime routine. After the routine becomes set and the person is sleeping in a normal pattern, the medication can be gradually withdrawn. This may take several months to accomplish. Medications which have been used include Chloral Hydrate/Noctec and Benedryl. In some individuals these medications can cause paradoxical excitation and sleeplessness in which case another medication can be tried.

Stimulants:

Ritalin has recently been reappraised for use in children with autism who are hyperactive and have problems focusing their attention on a task long enough to learn. Some children with autism seem to benefit from Ritalin, Dexedrine, or Cylert showing increased attention span, concentration, and appropriate on-task behavior. Ritalin and Dexedrine are typically given during the school day to improve the child's learning in school. Ritalin/Dexedrine often decrease a child's appetite. Weight and height gains need to be monitored to make sure the child is getting sufficient calories for normal growth. Some parents report that sadness and temper tantrums increase. Some children have "rebound" hyperactivity in the late afternoon when the medication effect wears off. Others have mild insomnia for the first few days.

If Ritalin or Dexedrine is going to be effective for a particular child, the teacher should be able to document a lengthened attention span and increased ability to concentrate by the end of one to two weeks. Cylert may take a week or two longer to show results. These medications have relatively mild side effects and thus may have an advantage over other medications that might be prescribed to control hyperactivity.

Ritalin is used by some adults with high-functioning autism to decrease distractibility and to help themselves focus.

Opiate Blockers:

Naltrexone/Trexan is a medication which blocks the brain's receptors for opiate drugs (such as Morphine). It may be useful for individuals who have biologically induced self-injurious behavior. One theory about self-injurious behavior hypothesizes that the injury causes the brain to produce its own opium-like chemicals (endorphins) and that this opiate *high* is addicting. Therefore the individual repeats the injurious behavior to continue feeling *high*. Another hypothesis is that individuals with autism have an inborn high level of endorphins and do not feel the pain of injuries, including self-inflicted ones. If an individual with autism is engaging in self-injurious behavior for either of these reasons, Naltrexone/Trexan will cause him/her to feel the pain of the injuries and block any *high* that s/he might feel. The behavior will then diminish quickly. However, if the purpose of the self-injury is to communicate frustration, the wish to escape from tasks, or to obtain attention, then Naltrexone may not be effective.

There are also some studies which indicate that low doses of Naltrexone may improve socialization, attention span, and eye contact and decrease self-stimulatory behaviors and hyperactivity in some young children with autism.

Beta Blockers

This class of medications is generally used to reduce high blood pressure. They can also help individuals who have challenging behaviors, such as aggression, caused by a sudden rush of adrenalin. Adrenalin is the natural body hormone which causes the *flight or fight* reaction. It is released when an individual is startled or frightened. Some individuals seem to release a large amount of adrenalin to what seems to be a small stimulus and are unable to control their actions while the adrenalin is flooding their system. Beta blocker medications, such as Inderal, prevent this adrenalin *rush* and gives the individual more control of his/her impulsive reactions. Another blood pressure medication, Clonidine/Catapres, also reduces adrenalin by a slightly different mechanism, and has been used to control aggressive outbursts and hyperactivity in children and adults with autism who have not responded to other medications.

Vitamins

Some parents report that large doses of the B vitamins, particularly B-6, plus magnesium, reduce tantrums and hyperactivity and increase attentiveness and interest in communicating. It is important that all the B vitamins be taken in increased amounts because merely taking large doses of B-6 can cause a relative deficiency of the other B vitamins. Magnesium intake also needs to be increased at the same time. Generally vitamin B-complex and C are safe, even in high doses. Sometimes a skin rash can occur with high doses of the B vitamins. Other side effects may be vitamin deficiency symptoms of other vitamin groups.

Not all children will be helped and data need to be kept on the child's behaviors. A two month test period on the vitamins is recommended before deciding whether or not they have been helpful. When stopping high doses of vitamins, they should be tapered off since stopping abruptly may cause vitamin deficiency symptoms as the body has become used to the high dose.

In children with autism who also have Fragile X Syndrome, Folic acid, one of the B vitamins, has produced behavioral improvement according to some studies.

Summary

Medications are not the only answer to behavior problems, but used in conjunction with a positive educational program and necessary environmental adaptations, they can sometimes help the individual with autism participate more fully. When parents, teachers, and physicians all work together, follow an agreed upon plan, and communicate honestly and factually with each other, medication use can be assessed individually for each person and the best quality of life can be achieved.

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For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

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Social/Sexual Training

The following are examples of concepts which could be included in social/sexual training:

1. Learning About Growth and Development
   a. Changes in body
   b. Caring for menstruation
   c. Understanding ejaculation
   d. Breast development
   e. Hair growth

2. Modesty
   a. Where to undress
   b. Where to be nude
   c. Who sees you nude

3. Public and Private
   a. What places are private?
   b. What behaviors are private?
   c. Private behaviors are done in private places

4. Respect of privacy

5. Differentiating between friends, family, acquaintances and strangers.
   a. What to do when meeting a stranger.
   b. Demonstrate appropriate greetings and responses. These should be role-played, reinforced in real situations, or possibly videotapes so the individual can identify the correct behavior.
   c. Adolescents and adults with disabilities often need to be taught specifically how to show affection in appropriate ways. For reasons of safety, they need to be taught when touching (from others) is not appropriate and who to tell if they are approached. For each way of appropriate touching (hugging, shaking hands, patting an arm or back) times and places for such contact and who can touch need to be specified. A set of instructional cards could be made which set the guidelines.
   d. Dating skills can be defined and systematically taught if the individual wishes to initiate a romantic relationship.

6. Learn to do something about sexual feelings.
   a. Learn to masturbate
   b. Keep active
   c. Learn to seek appropriate partners

7. Learn about "safe" sex.

Objectives for social/sexual instruction may vary considerably based on the individual involved.

Beliefs that may hinder sex education programs for people who are developmentally disabled or that interfere with typical sexual expression:

- Sexual behavior is private behavior.
- Nonproductive members of society don't have adult status.
- Sex is for reproduction, not pleasure.
- Sex is for perfect, beautiful people.
- Sexual behaviors can't be talked about explicitly.
- Pictures of sexual behaviors are taboo.
- Sexual expression "comes naturally" and can't be taught.

Being sexual" may be difficult for people with autism because:

- they are highly supervised and therefore have less privacy.
- they may have a poor self-image.
- they may be confused about body changes.
- they have problems with social interaction.
- they can't "read" social cues.
- they are dependent on others.
- they have trouble with abstract concepts.
- they learn by doing and need concrete examples.
- they do not generalize easily.
- they are tied to routines and rules.
- they often initiate social contact at a low level.
- they may be perseverative and echolalic.
- they have often been rejected.

From: Sex Education: Issues for the Person with Autism. By Detmer, Dalrymple, and Sinex. 7/87

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Revised by Dalrymple, Gray, & Ruble, 7/91

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PRACTICAL STEPS TO TOILET TRAINING PROGRAM FOR YOUNG CHILDREN WITH AUTISM

General Considerations

- Expect training to take time. Trainers must be consistent and patient. Learning to use the toilet is part of being socialized. For young children with autism the expectations are less clear. What is wanted from them? Why? How often can the skill be practiced? How can it become a functional part of the daily routine? How can it be kept from becoming a control issue?

Medical Considerations

- Rule out or treat any medical problems.

Keep Careful Data - Analyze Regularly

- Design data charts to meet your needs.
- Analyze weekly, then over months.
- Keep track of successes and accidents and times.
- Keep track of illnesses, food, and drink.
- Questions: How long does the person stay dry? When is the child most likely to have bowel movements or urinate?
- When is the child ready to participate? Starting at the age of two when most children's training begins may be too early and cause the duration of training to be long, thereby resulting in frustration for the child and parent.

Environmental Considerations

- Sometimes it's easier for the child to remember to sit for all toileting at first, even if a male. However, if he/she imitates others, standing may be easier to learn for a male, while sitting 1-2 times a day for BM's.
- Consider location of potty chair, toilet devices or both, (height, in or out of bathroom, near people, stalls, etc.)
- Consider comfort level of child. Can the child relax and sit long enough? Is the seat the right size? Is it too cold or too hard? Do the child's feet rest on something?
- Consider the number of different situations in which the child must toilet, (limit number in the beginning.)
- Consider other distracting stimuli, (noise, movement, fans, mirrors, etc.)

Clear Expectations - Communicated Clearly

- Chart times most likely to need toilet sits or toilet visits.
- Establish a set toilet schedule following natural activities like after dinner or before going out, rather than clock times.
- Establish a set toilet routine, (sometimes sitting for a length of time is difficult: establish a "finished" cue using visual timers or music.)
- Teach hygiene including wiping and washing and drying hands as part of the routine.
- Use consistent people within each environment to train.
- Design a positive program that uses:
  - Modelling
  - Positive practice
  - Pants checks for dry and clean pants to raise awareness

Reinforcement

- It might help to have special toys, books, videos, or music to use only while sitting on the toilet.
- Use strong and individualized reinforcers for trying and success.
- Give reinforcer immediately.
- Give every time for successive steps (from just sitting to self initiating toileting).
- Big people pants might become reinforcers and can be used in the beginning for part of a day to reinforce keeping them dry.

Staff

- One person oversees and coordinates entire training program.
- Assign specific tasks to specific people.
- Meet regularly for ideas and updates, and to verify consistency across environments.
- Reinforce staff for being consistent, contributing ideas and data, ignoring accidents and smearing, and doing clean up.
- Carry the plan over 24 hours, if possible. If not, choose one time of day for practice.

Clean-up

- Use materials that make it easier and quicker (large towels, rubber gloves, wipe dries, disinfectants, etc.)

Fears

- Toilet flushing, sitting, soiling or wetting pants, and pain from constipation are some of the fears children with autism may have. Be gentle and do not punish the child. Constipation and fear of using certain bathrooms can last for many years.

Generalize

Once training is achieved, teach the child to toilet in different environments. Each bathroom will need specific teaching until generalization has occurred.

Independence

Even though a child may not self initiate he/she can learn to follow a set schedule and perform the routine independently. Each part of the routine, including wiping, must be taught as part of the whole.

Privacy

Because children often require help, they may depend on the presence of others to toilet. Early in the training, adult presence should be faded, bathroom doors should be closed and pants should be pulled up and down in the bathroom to avoid problems later.

Note: See Functional Programming for People with Autism: Toileting by Nancy Dalrymple and Margaret Boarman for a more detailed discussion.

Practical Steps to Toilet Training Program for Young Children with Autism was produced through support from Indiana University, Bloomington. The information presented herein does not necessarily reflect the position or policy of the Trustees of Indiana University and no official endorsement should be inferred.

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N. Dalrymple, 7/93

\wpdata\General\Toilet

Practical Steps to a Toilet Training Program for Older Individuals Who Are Developmentally Disabled

Expect training to take time. Training must be consistent and trainers must be patient.

Medical Evaluation and Consultation:
  Issues:
    Impaction
    Mega colon
    Large rectal vault
    Establish regularity with bulk and softness if needed
    Check for urinary tract infection
    Check for digestive problems
    Rule out other physical issues

Clean-up: Materials to make it easier and quicker
  Large white towels
  Latex gloves
  Buckets
  Cleaners - Pine-sol, disinfectants
  Wipe-dries
  Soaking bucket for clothes and towels
  Diapers during certain times - increase time without

Reinforcement:
  Strong
  Immediate
  Every time for successive steps
  Visually conveyed, i.e., toilet then X.

Clear Expectations: Communicated clearly
  Chart times most likely to need toileting and most likely to be free of accidents
  Establish a set toilet schedule around daily events
  Establish a set toilet routine
    Use easy to manage clothing
    Decide on standing vs. sitting for males
    Build in relaxation activities
    Teach privacy
    Teach wiping
    Teach washing and wiping hands
  Design a positive program
  Teach what you want done through:
    Pictures
    Positive practice - many opportunities to use the toilet
    Pants checks to reinforce dry/clean pants
    Reinforce
  Teach how to manage sexual feelings so confusion between toileting needs and sexual needs is minimized.

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Keep Careful Data: Analyze regularly
  - Design charts to meet specific needs
  - Analyze weekly, then over months
  - Keep track of successes and accidents

Staff: Involve and support parents, if at home
  - One person oversees entire program
  - Assign specific tasks to specific people
  - Meet regularly for ideas and suggestions
  - Reinforce staff for:
    - Ignoring smearing behavior
    - Getting cleaning help if needed
    - Being consistent
    - Contributing data and ideas
  - Carry over 24 hours

Practical Steps to a Toilet Training Program for Older Individuals Who Are Developmentally Disabled was produced through support from Indiana University, Bloomington.

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IRCA

Indiana Resource Center for Autism

Clarifying Services Available Through the Indiana Resource Center for Autism

Each day, the staff of the Indiana Resource Center for Autism (IRCA) receive numerous phone calls requesting on-site consultations on behalf of specific individuals with autism who present unique challenges to professionals and family members in his/her life. As the school year begins, it seems important to clarify the options and services available to those requesting assistance.

When providing consultation services, a primary goal of IRCA staff is to work with the individual's team to problem-solve programming strategies. Therefore, if a family member calls they will be asked if the building administrator, director of special education, or executive of the agency is aware that a phone call has been placed. If a professional calls, IRCA staff will ask if the family or individual him/herself is aware of the request. IRCA staff will not proceed until it is clear that a collaborative decision has been made to request our services. This step is not intended to discourage requests, but rather to encourage collaboration at the local level. In addition, many school systems and adult agencies have designated specific individuals as "in-house" consultants for autism as a result of their experience and knowledge about autism. Accessing and utilizing this local expertise is vital in building local capacity to effectively support individuals with autism.

If the Indiana Resource Center for Autism has previously conducted a consultation for the individual, information will be requested about the outcome of the consultation. If a report or other record of consultation was sent, IRCA staff will request updated information about the status of recommendations. If information from the report has not been utilized, IRCA staff may recommend that these suggestions be revisited before further consultation is conducted.

Information also may be requested about previous training or staff development efforts in which those involved with the individual have been engaged. Often times people need basic information that is best provided during conferences or in other formats. Each year, professionals and family members across Indiana have access to a variety of training options, including conferences and regional workshops to support their local efforts.

If more intensive assistance seems warranted, the IRCA staff member will try to gain specific information about desired outcomes of the consultation. For example:

- What do you hope to gain or what are your expectations if a consultation is scheduled?
- What are specific issues of concern?
- What have you or others done to date to address these issues?

During the initial phone call, a consultation date will not be scheduled until the IRCA team discusses how specific needs might best be met. Each Monday morning, a meeting is held to discuss requests and to form responses. Possible responses include that the following will occur:

- Phone call to discuss concerns and provide feedback on current procedures;

- Suggestions for materials that might be borrowed from the Institute for the Study of Developmental Disabilities library or for purchase through the Indiana Resource Center for Autism resource room;
- Phone call to parents from IRCA's social worker to provide support and suggestions; or
- Recommendations for training by IRCA staff or from outside consultants.

If the IRCA team determines that an individual consultation is needed and that IRCA staff have the capacity and expertise to address stated needs, the following will be requested:

- Updated reports sent in advance of consultation (e.g., psychological, individual program goals);
- Sufficient release time for staff to meet to discuss programming issues;
- Attendance at the meeting of those involved in the individual's life, including the individual him/herself (if appropriate), an administrator, and family members; and
- Time to meet, interact with, and observe the individual during naturally occurring situations. In addition to the observation, staff may request a videotape be prepared and sent before the consultation.

These guidelines may seem stringent. However, it is the expectation of IRCA staff that change will occur on behalf of the specific individual with autism as a result of the consultation. This type of change will require hard work and local commitment by key members of the person's team, and by those who can dedicate resources and implement program supports and strategies.

IRCA staff are pleased to spend time in a variety of settings across Indiana. Our goal is to ensure that all involved gain maximum benefit from our time, and that the individuals with autism receive needed support and assistance. For more information about services and training events, contact the Indiana Resource Center for Autism at (812) 855-6508.

Cathy Pratt, Director
Indiana Resource Center for Autism

The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

Indiana Resource Center for Autism
Autism Database Searches

What is the Autism File?

The Indiana Resource Center for Autism (IRCA) at the Institute for the Study of Developmental Disabilities (ISDD) collects and catalogs articles, papers, book chapters, videos, and other print materials on the subject of autism into a computerized database. This database differs from ERIC and PsychLit found in many large educational libraries in that it includes selected educational, psychological, and medical perspectives as well as unpublished papers and conference proceedings.

How Can the Autism File Help You Find Information?

If you need references on a specific topic related to the field of autism, IRCA can provide a list of citations from this database at a cost of $3.00 for a search that results in 1-5 pages of citations, or $5.00 for a search that results in 6-12 pages. Citations are categorized according to topics of issues related to autism (e.g., assessment, exercise, family). A *search* is a list of citations on the requested topic by authors, titles, and dates of publications.

These articles may be requested from your local library or through interlibrary loan. Interlibrary loan may take two or three weeks to retrieve items. If you have requested an item from interlibrary loan and still are unable to acquire it, IRCA may be able to assist you in securing the item in accordance with copyright restrictions (see below). Unpublished papers, conference proceedings, and IRCA publications and videotapes may be difficult to secure locally. Instead, you may want to request these directly from the IRCA. Duplication cost is 10¢ a page. Searches specify the number of pages for each article. Checks must be received with duplication order.

Notice
Warning Concerning Copyright Restrictions

The copyright law of the United States (Title 17, United States Code) governs the making of photocopies or other reproductions of copyrighted material.

Under certain conditions specified in the law, libraries and archives are authorized to furnish a photocopy or other reproduction. One of these specified conditions is that the photocopy or other reproduction is not to be "used for any purpose other than private study, scholarship, or research." If a user makes a request for, or later uses, a photocopy or reproduction for purposes in excess of "fair use," that user may be liable for copyright infringement.

This institution reserves the right to refuse to accept a copying order if, in its judgement, fulfillment of the order would involve violation of copyright law.

How Do These Searches Work?

Two types of searches may be requested from the IRCA database: (1) author searches, and (2) subject searches. The database can **not** search subjects and authors at the same time. Author searches on this database are limited to one author per search.

While the database contains citations dating earlier than 1989, many items were published between 1989 and the present. IRCA requests that you provide a range of years within which to conduct your search. If you do not provide a range, we will initially conduct your search within the 1990-present year range, and only expand that range if no citations are retrieved.

For more information or a list of currently available topics that can be searched, please contact Cleta Bowman at (812) 855-6508.

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The Indiana Resource Center for Autism (IRCA) is one of seven centers supported by the Institute for the Study of Developmental Disabilities (ISDD). The Institute is dedicated to the promotion and maintenance of a seamless system of inclusionary services for all individuals with disabilities across the life span. The ISDD comprises three core program centers and four resource centers engaged in interdisciplinary training, information dissemination and research, and community service.

For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

INDIANA RESOURCE CENTER FOR AUTISM

Selected List of Books on Autism and Related Issues

The following list of books represents major ideas, philosophies, biographies, and novels about autism and related issues published in the last few years. Some books on this list focus specifically on people with autism. Others refer to individuals across disability labels, but provide important information about systems and supports which greatly impact people with autism. The information included in these books does not necessarily correspond to the philosophies of the Indiana Resource Center for Autism at the Institute for the Study of Developmental Disabilities.

Selected items may be available at your local library. Many may be borrowed by Indiana residents from the Library of the Institute for the Study of Developmental Disabilities, 2853 E. Tenth Street, Bloomington, IN 47408-2601, (800) 437-7924 (toll free in Indiana; voice/TT); (812) 855-9396 (Bloomington; voice/TT).

GENERAL AND DIAGNOSTIC ISSUES

Berkell, D. E. (Ed.). (1992). *Autism: Identification, education and treatment*. Hillsdale, NJ: Lawrence Erlbaum.

Cohen, D. J., & Donnellan, A. M. (Eds.). (1987). *Handbook of autism and pervasive developmental disorders*. New York, NY: John Wiley & Sons, Inc.

Cohen, D. J., & Volkmar, F. R. (Eds.). (1997). *Handbook of autism and pervasive developmental disorders* (2nd ed.). New York, NY: John Wiley & Sons.

Coleman, M. (1985). *The biology of the autistic syndrome*. New York, NY: Praeger Press.

Dawson, G. (Ed.). (1989). *Autism: Nature, diagnosis and treatment*. New York, NY: Guilford Press.

Donnellan, A. M., & Leary, M. R. (1995). *Movement differences and diversity in autism/mental retardation*. Madison, WI: DRI Press.

Gerdtz, J., & Bregman, J. (1990). *Autism: A practical guide for those who help others*. New York, NY: Continuum Publishing Company.

Gillberg, C. (Ed.). (1989). *Diagnosis and treatment of autism*. New York, NY: Plenum Press.

Gillberg, C., & Coleman, M. (1992). *The biology of the autistic syndromes* (2nd ed.). London: MacKeith Press.

Happe, F. (1995). *Autism: An introduction to psychological theory*. Cambridge, MA: Harvard University Press.

Hill, D. A., & Leary, M. R. (1993). *Movement disturbance: A clue to hidden competencies in persons diagnosed with autism and other developmental disabilities*. Madison, WI: DRI Press.

Peschel, R., Howe, C., & Howe, J. (Eds.). (1992). *Neurobiological disorders in children and adolescents*. San Francisco, CA: Jossey-Bass.

Schopler, E., & Mesibov, G. B. (1987). *Neurobiological issues in autism*. New York, NY: Plenum Press.

Schopler, E., & Mesibov, G. B. (1988). *Diagnosis and assessment in autism*. New York, NY: Plenum Press.

Siegel, B. (1996). *The world of the autistic child: Understanding and treating autistic spectrum disorders*. New York, NY: Oxford University Press.

Trevarthen, C., Aitken, K., Papoudi, D., & Robarts, J. (1996). *Children with autism: Diagnosis and interventions to meet their needs*. Bristol, PA: Jessica Kingsley Publishers.

Williams, D. (1996). *Autism: An inside-out approach*. Bristole, PA: Jessica Kingsley Publishers.

BEHAVIOR:

Attwood, T. (1993). *Why does Chris do that?: Some suggestions regarding the cause and management of the unusual behavior of children and adults with autism and Asperger syndrome*. London: National Autistic Society.

Carr, E. G., Levin, L., McConnachie, G., Carlson, J. I., Kemp, D. C., & Smith, C. E. (1994). *Communication-based intervention for problem behavior: A user's guide for producing positive change*. Baltimore, MD: Paul H. Brookes Publishing Company.

Donnellan, A. M., LaVigna, G. W., Negri-Shoultz, N., & Fossbender, R. L. (1988). *Progress without punishment: Effective approaches for learners with behavior problems*. New York, NY: Teachers College Press.

Durand, V. M. (1990). *Severe behavior problems: A functional communication training approach*. New York, NY: Guilford Press.

Koegel, L. K., Koegel, R. L., & Dunlap, G. (1996). *Positive behavioral support: Including people with difficult behavior in the community*. Baltimore, MD: Paul H. Brookes Publishing Company.

LaVigna, G. W., & Donnellan-Walsh, A. (1986). *Alternatives to punishment: Nonaversive strategies for solving behavior problems*. New York, NY: Irvington Publishing.

Lehr, D. H., & Brown, F. (1996). *People with disabilities who challenge the system*. Baltimore, MD: Paul H. Brookes Publishing Company.

Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior*. Baltimore, MD: Paul H. Brookes Publishing Company.

Meyer, L. H., & Evans, I. M. (1989). *Nonaversive intervention for behavior problems: A manual for home and community*. Baltimore, MD: Paul H. Brookes Publishing Company.

Reichle, J., & Wacker, D. (1993). *Communicative alternatives to challenging behavior*. Baltimore, MD: Paul H. Brooks Publishing Company.

Schopler, E., & Mesibov, G. B. (Eds.). (1994). *Behavioral issues in autism*. New York, NY: Plenum Press.

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Elder, P., & Goossens', C. (1994). *Engineering training environments for interactive, augmentative communication: Strategies for adolescents and adults who are moderately/severely developmentally delayed.* Birmingham, AL: Southeast Augmentative Communication Conference.

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Hodgdon, L. A. (1995). *Visual strategies for improving communication: Practical supports for school and home* (Vol. 1). Troy, MI: QuirkRoberts Publishing.

Light, J., & Binger, C. (In press). *Building communicative competence in individuals who use augmentative and alternative communication*. Baltimore, MD: Paul H. Brookes Publishing Company.

Quill, K. A. (1995). *Teaching children with autism: Strategies to enhance communication and socialization*. New York, NY: Delmar Publishers, Inc.

Reichle, J., & Wacker, D. (1993). *Communication alternatives to challenging behavior*. Baltimore, MD: Paul H. Brookes Publishing Company.

Schopler, E., & Mesibov, G. B. (Eds.). (1985). *Communication problems in autism*. New York, NY: Plenum Press.

Twachtman-Cullen, D. (1997). *A passion to believe: The facilitated communication-autism phenomenon*. Boulder, CO: Westview Press.

Vicker, B. (1996). *Using tangible symbols for communication purposes: An optional step in building the two-way communication process*. Bloomington, IN: Indiana University, Institute for the Study of Developmental Disabilities.

Watson, L., Lord, C., Schaffer, B., & Schopler, E. (1989). *Teaching spontaneous communication to autistic and developmentally handicapped children*. New York, NY: Irvington Publishers, Inc.

Wetherby, A. M., Warren, S. F., & Reichle, J. (In press). *Transitions in prelinguistic communication*. Baltimore, MD: Paul H. Brookes Publishing, Inc.

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For more information, contact: The Indiana Resource Center for Autism, Indiana University, Institute for the Study of Developmental Disabilities, 2853 East Tenth Street, Bloomington, IN 47408-2601, or call (812) 855-6508.

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