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Facilitated Communication

ABSTRACT

This monograph considers issues in the training of sexuality skills in students with severe mental retardation. An introduction stresses the importance of such skills for these students. A profile of 12 common characteristics of this population and a summary of human commonalities precede the body of the guide. Common manifestations of sexuality often experienced in this population are considered, including: public masturbation; pregnancy, incest, and rape; being used as sexual "objects"; lack of privacy; and lack of recognition of chronological age. An ideal sexuality program is described, including staff responsibilities focusing on ensuring dignity and respect and on skill training objectives (e.g., awareness of body parts that others are not allowed to touch and recognition of public rest room symbols). Sample forms used in Wayne County (Michigan) to identify annual goals and instructional objectives are attached. A six-step outline gives guidelines for program initiation and implementation. Important additional issues are briefly considered. These include puberty, menstruation, inappropriate sexual behaviors, birth control, sterilization, sexual urge inhibitor medications, sexual abuse, nurturing, intimacy, and the need to give and receive love. Also attached are a list of indicators of possible sexual abuse, information on facilitated communication and charges of sexual abuse, and a paper on normal sexual development. Contains a list of 11 resources. (DB)



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SEXUALITY EDUCATION ISSUES AND STUDENTS STATUSED SEVERELY MENTALLY IMPAIRED REGARDLESS OF ADDITIONAL HANDICAPS

SEXUALITY EDUCATION

PROMOTES

DIGNITY

RESPECT

SELF-ESTEEM

FIEALTHY DECISION MAKING

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1993

An in-house informational assist for classroom use

ERIC

Sexuality Education Issues and Students Statused Severely Mentally Impaired Regardless of Additional Handicaps

OUTLINE

- 1. Introduction
- 2. Profile of the Population
- 3. A Common Understanding MORE LIKE THAN UNLIKE
- 4. Manifestations of "Sexuality" This Population Commonly Experiences
 - * public masturbation
 - * pregnancy, incest, rape
 - * used as sexual "objects"
 - * lack of privacy
 - * lack of an expressive communication system
 - * lack of recognition of chronological age
 - * care-giver's behaviors and attitudes
- 5. An Ideal Sexuality Program
 - * dignity and respect issues
 - * means of communication respected
 - * identification
 - * adult responsibility and attitudes
 - * skill training
- 6. An Outline for Program Initiation and Implementation
- 7. Important Additional Issues
 - * puberty
 - * menstruation
 - * inappropriate sexual behavior
 - * birth control
 - * sterilization
 - * medications to reduce sex drive
 - * abuse
 - * nurturing
 - * intimacy
 - * the need to give and receive love
- 8. Normal Sexual Development Written by J. Ingrid Amberson, Ph.D.
- 9. Resources



INTRODUCTION

I began really thinking about the concept of sexuality and this unique population when I met with a great deal of resistance from school staff (administrators, teachers and paraprofessionals) around the issue of toileting in private areas.

When I asked what the problem was, the standard answer was that these students wouldn't know if they were being changed on 5th avenue or in a private changing area so what was the big issue, anyhow.

It is a very little jump from that attitude to the attitude and behaviors that indicate staff and parents honestly do not believe these students have any component that by any stretch of the imagination could ever be called sexuality. They rarely associate their information requests for assistance with masturbation issues, disrobing, inappropriate social distance, "drugs to stop all of this", sterilization and hesitancy to have their children/young adults out and about in the community with the inherent sexual component of the students.

This "denial" attitude around sexuality and the group of people labeled severely mentally impaired is fairly universal.

"When one comes right down to it, acknowledging the existence of and development of sexuality in a child/young adult who is handicapped is extremely difficult for the parent and society. There is a great tendency on the part of the parent and society to infantilize the individual with developmental disabilities, regardless of chronological age. Included in this infantilization is the concept of asexuality, or lack of sexuality, which extends to the lack of necessity for learning about one's self, one's sexuality, or one's psychosexual development. Therefore, as they go through the process of maturation, many individuals with developmental disabilities find themselves in a position where no one in their environment is willing to deal with or even recognize their developing sexuality.

In institutions or people with developmental disabilities, community programs for the developmentally disabled, etc., the subject of sexuality seems to be a very threatening taboo topic. Staff and administrators approach the area as if it is one that would automatically cause problems. It is the hope of most parents and administrators that, in the area of sexuality. . . . everything will be just "O.K." and not have to be handled or discussed.



...these individuals have the right to express and develop their own sexuality and to feel comfortable with itwe need to acknowledge that the sexuality "skills" of persons with disabilities is as important as the development of adaptive, communicative, academic, or other personal social skills." Monat (1982).

I think it follows that if every single other area of daily living requires skill training, education and consistency across environments then so does skill training around sexuality. I think there is an added responsibility for professionals to also offer workshops and specialized training to the parents and educational staff of these children. The student's dignity, their being in a "safe" environment, their quality of life is dependent on their "caretakers". It is my opinion that this area needs priority consideration because vulnerability makes our students particularly in danger of:

* physical and sexual abuse,

* unwitting participation in illegal, dangerous and harmful practices,

* trouble with the law and an inability understand any

aspect of the "legal process"

* feeling hurt/frustrated/angry without any way to handle or explain the situation.

This monograph I hope, is the beginning.



PROFILE OF THE POPULATION



Profile of the People Labeled Severely Mentally Handicapped

- a. Development at a rate approximately 4 1/2 or more standard deviations below the mean as determined through intellectual assessment.
- b. Lack of development clearly in the cognitive domain although no domain functions fully at chronological age.
- c. Can have any combination of sensory impairments so severe that any one of those modalities is not sufficient to use as a primary learning channel.
- d. Little or no understandable speech.
- e. Will always need 24 hour assistance for "daily routine" supervision and decision making. The cognition level does not permit anything else.
- f. Functions primarily by having basic needs met.
- g. Predominant reactions are impulsive.
- h. Extremely limited ability to predict or foresee consequences of sensual/sexual behavior.
- i. Techniques of behavior modification must often be used to effect change.
- j. No areas of skill acquisition that is much beyond 3 1/2 years by any currently used scale.
- k. Often are also physically impaired to the point where care by others is required daily to sustain life.
- 1. Affect and body language are not always clearly understood. The "communicative intent" is often subtle and requires a sincere desire for interaction in order for it to be established as expressive communication.
 - (Michigan public school districts report 1 to about 3% of their total Special education populations as statused as SMI, SMI/SXI, Dual Sensory Impaired, SMI/A.I., A.I.(1992).



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MORE LIKE THAN UNLIKE



A Common Understanding MORE LIKE THAN UNLIKE

ALL HUMANS SHARE

- a. the <u>same hormonal and chemical properties</u>. Puberty, awareness of the opposite sex, awareness of their physical body and new sensations and feelings as they go through life's stages is present in all.
- b. all humans go through the <u>life cycle</u> (birth, babyhood, childhood, teenager, young adult, adult, senior, death) regardless of cognitive function.
- c. all humans <u>look like humans</u>. anytime you see a human you recognize the "form" as human. You may not care for the physical characteristics, but there never is a question around species type.
- d. all humans have the <u>potential for creating life</u>. . .the reproductive system matures and develops in most humans regardless of functioning level.
- e. all humans have the <u>same emotional development and range</u>. All humans have the capacity for pleasure, surprise, disgust, distress, joy, anger, sadness, fear. No one working with students statused severely mentally impaired, doubts their ability to like, love, fall "in crush" with someone, prefer some people over other people. They also "read" people. A lot of our students can "run" people and classrooms by manipulation. The ability to communicate these emotions and awareness is often impaired. Family and staff often need very specialized training to learn how to "read" their children and students . . . but emotional capacity is innately present.
- f. all humans have <u>memory</u>. Staff often report seeing expressions of fear when students see a certain person, huge smiles when seeing certain persons and having "favorite" TV shows, toys, articles of clothing, etc.

The majority of the components that make up the sexual part of our lives make up the sexual component of our students lives. The sexual components that rely on cognitive skills of course are not present: awareness of media pressure, peer pressure and (mis) information around sexual issues, ability to knowingly "tease" sexually, recognizing the subtle sexual cues from co workers, caretaking staff, etc. and recognizing potentially sexually dangerous people and situations.



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I'M SPECIAL...

IN ALL THE WORLD THERE'S NOBODY LIKE ME.

NOBODY HAS MY SMILE.

NOBODY HAS MY EYES, NOSE, HAIR OR VOICE.

I'M SPECIAL...

NO ONE LAUGHS LIKE ME OR CRIES LIKE ME.

NO ONE SEES THINGS JUST AS I DO.

NO ONE REACTS JUST AS I WOULD REACT.

I'M SPECIAL...
I'M THE ONLY ONE IN ALL CREATION WHO HAS MY
SET OF ABILITIES.
MY UNIQUE COMBINATION OF GIFTS, TALENTS AND
ABILITIES ARE AN ORIGINAL SYMPHONY.

I'M SPECIAL...

I'M RARE.

AND IN ALL RARITY THERE IS GREAT VALUE.

I NEED NOT IMITATE OTHERS. I WILL ACCEPTYES, CELEBRATE- MY DIFFERENCES.

I'M SPECIAL...

AND I'M BEGINNING TO SEE THAT GOD MADE

ME SPECIAL FOR A VERY SPECIAL PURPOSE.

HE HAS A JOB FOR ME THAT NO ONE ELSE CAN

DO AS WELL AS I DO. OUT OF ALL THE

APPLICANTS ONLY ONE IS QUALIFIED.

THAT ONE IS ME.

BECAUSE . . .

I'M SPECIAL!

MANIFESTATIONS OF "OPPORTUNITIES" THIS POPULATION COMMONLY EXPERIENCES



Manifestations of Sexuality "Opportunities" this Population Commonly Experiences

Sexuality - the sum of a person's identity, role expectations, selfesteem, feelings and beliefs about masculinity and femininity, how men and women express affection and love permeated by personal religious, ethnic, cultural and moral values.

What is significant about our population is that the students CANNOT independently control or develop any part of their own sexuality. Everything is done FOR our students at some level because of their functioning level. Therefore, recognizing and respecting essential sexuality becomes the responsibility of the caregivers.

One of the disturbing aspects of defining sexuality and then recognizing the sexuality components of our population is reviewing the "sexuality opportunities" our students do experience:

1. <u>Masturbating in Public</u>

It appears that this behavior is probably THE sexual behavior that people notice about people labeled the severely mentally impaired. The number of incidents reported by public schools is higher in this population than ir. any other. The major reason for the behavior being seen in public appears to be family and school reluctance to teach our students that this behavior is "private" and then to consistently reinforce that concept. SEE Masturbation and the Severely Mentally Impaired. WC RESA, Heler, 1993.

2. <u>Pregnancy/Rape/Incest</u>

Group homes and workshops both have records of pregnancy and birth. (How could the young women have EVER given their consent to intercourse?) Think for a moment of a young woman going through a pregnancy and birth without understanding any part of the process.

3. <u>Sexual Objects</u> (fondling, touching without actual intercourse, sexual acts involving any number of things, etc.).

The number of incidents is very probably high. One of the only ways we have to measure the number of students affected is by the number of instances



recorded <u>after</u> our students have a means of expressive communication and they tell us what happened in their institution, group home or family home. See the article on pages 29-31.

Dick Sobsey, University of Alberta, Saskatchuan, CANADA has done research in this area and has found an inordinate number of group home and institution employees with a past history of child abuse and other sexuality related crimes. His theory is that these people prey on the vulnerable and our students provide a very fertile field for their illegal and disgusting activities.

"What makes individuals with mental retardation and developmental disabilities more susceptible to sexual victimization? The simplest answer seems to lie in the belief of the perpetrator either than no one will find out that the victimization has occurred, because the individual with mental retardation or developmental disabilities will not have the communication skills to inform others of the abuse so, if the victim does inform others, that 1.0 one will believe him or her." (Monat-Haller, 1992).

See Chapter 7 for a chart of possible indicators of sexual abuse.

A "vulnerability" list, generic to our population, that is commonly agreed upon is:

- * Lack of communication skills sufficient enough to explain anything.
- * Lack of ability to physically leave a dangerous situation or push anyone away independently.
- * Lack of ability to discern honest attention and affection from "scum" behavior.
- * Great need for affection and friends of any kind.
- * No control over any aspect of their life.
- Lack of any method of signaling for help.
- 4. <u>Lack of Privacy</u> (during toileting, clothes changing, bathing)

The number of students that have had their "private parts" on public display is disheartening. The belief that our students don't have the cognitive ability to understand the concepts of privacy, embarrassment,



humiliation or sexual connotations has probably been the basis for not providing very elemental privacy. "Do unto others as you would have others do unto you" often is not a criteria for staff working with these students because the basic belief. our students are valid and valued humans. . . . is not yet completely agreed upon.

- Most of these students need some form of augmentative system. There is something that will work. . . . assistive technology in communication is quite sophisticated. Communication boards, hand signing, voice output communication aids, loop tape messages, eye gaze systems and communicative intent personal dictionaries are all well known. Respecting a person's unique communication style, helping decipher that communication style AND explaining a person's unique communication style to all who came in contact with that person are clear issues of basic respect for that person.
- 6. <u>Lack of Recognition for Chronological Age</u>
 Sexuality also entails respecting the person's chronological age in everything: environments, clothing, hair styles, activities, TV/videos and so on.

Often the student's chronological age is not celebrated once they become teenagers and young adults. (Just look at the gifts they receive on birthdays.)

During transition meetings there is rarely any discussion of that student's "love and affection" needs. We should seriously discuss the need to love and give love and what we can all do to facilitate this.

7. Care-giver's Behavior and Attitudes
Unfortunately, because these students cannot express themselves clearly, some people perceive that as an immunity to their own poor behavior. The students are ignored while staff discusses the last weekend, where they intend to go for lunch, anything and everything except the skill training and activities that are going on in the classroom. There have been instances of very inappropriate language in a classroom, rudeness (eating in front of the students, blatant favoritism) and crude handling techniques. This behavior is not seen in other classrooms where the students can talk.

AN IDEAL SEXUALITY PROGRAM



An Ideal Sexuality Program For Our Students

Looking at the few pieces of literature on this subject and from experience, it appears that a complete school program is going to have two components: staff responsibilities and an actual skill training program.

Our students have a range of cognitive abilities even within the SMI and SMI/SXI range. Not all of the sexuality objectives are going to be appropriate, BUT ALL of the suggested staff responsibilities remain the same.

Part I - Staff Responsibilities

To insure that dignity and respect and sexuality issues are addressed in a forthright and mature manner, the following list was developed:

- a. Students are humans with gender and are valid and valued.
- b. Privacy for toileting and being toileted and having all daily care done in a respectful manner regardless of age. SEE WC RESA TOILETING STANDARDS (Heler, 1989).
- c. Privacy for clothes changing that involves any "private parts" that general society does not allow to be shown.
- d. Chronological age appropriate classroom and materials and activities.
- e. Regularly scheduled <u>parent</u> workshops around sexuality issues that are age and developmentally appropriate as well as issues regarding specific subjects or students.
- f. Regularly scheduled <u>staff</u> workshops around sexuality issues that are age and developmentally appropriate as well as issues regarding specific subjects or students.
- g. Allowing the students to participate, however minimally, in their own self-care tasks. Developing skills in this area as far as potential allows. If this is, in fact, going to be very minimal, always explaining exactly what you are doing as you do it and always ASKING PERMISSION before you begin any self-care task. (Remember, if the answer is no, then you must



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acknowledge that answer and either respect the answer in that you do not do whatever the task was and do something else, or you do the task, explaining exactly WHY it has to be done at this particular time).

- h. Being aware of potential "dangerous situations" of any kind and taking great precautions that our students are not in any of those kinds of situations.
- i. Having identification on the person that is age appropriate and easily seen. The identification should minimally have a telephone number that is ALWAYS available, student's name and address and any medical information that may be needed: times of medications and the medication's name, seizure activity, etc. In short, anything that is out of the ordinary including the phrase "has no understandable speech."
- j. Means of expressive communication respected no matter what the style: body language, facial expression, sign or anything else. ATREC (Judy Arkwright, Judy Phelps, Jan Jarrell) will certainly respond to any request for communication system evaluation. "Everyone Communicates!" is available for the very low functioning. The building speech therapists or Ann Heler can respond to requests for assistance with that if needed.
- k. Reminding parents at IEP's and other meetings that regular dental, eye, ear, gynecological and medical care applies to this population also.
- 1. Sharing menses records and data on PMS symptoms with the young woman's family.
- m. Constantly evaluating your classroom to make sure that it's program is appropriate for ALL of your students. There seems to be fewer incidents of masturbatory behavior when the students are working at tasks that make sense to them and that periods of sitting and moving are interwoven throughout the day.

Part II - Skill Training Objectives

The WC RESA - IEP form has an Instructional Objective for sexuality. It is IO-C under Annual Goal VII-Improves Interpersonal Skills in the Independent/Functional Living Section. See pages 14-18 for the adapted objectives applied to the Washtenaw urriculum. These pages can be duplicated for skill training work.

Personal identity and Social Skills

- 1. recognizing own name
- 2. recognizing own sex
- 3. recognizing sex of peers and people in general
- 4. recognition of family members and people in own environment (neighbors, people who visit home, relatives, bus/cab driver, classroom staff and support staff, family pets)
- 5. appropriate greetings
 - handshakes
 - vocalizations or words
- 6. appropriate show of affection
- 7. appropriate social distance
 - strangers
 - peers
 - people known to student
 - dancing
 - hugs
- 8. compassion for others and animals
- 9. recognizing the international bathroom/rest room pictures for "men" and "women" AND identifying the correct rest room in public places
- 10. awareness of "public places" and "private places"
- 11. awareness of body parts that others are NOT allowed to touch
- 12. appropriate menstruation behaviors



- 13. appropriate appearance behaviors (no disrobing, masturbation in public, touching own private body parts in public, touching others inappropriately).
- 14. has an established expressive communication system.

The following are suggestions that were offered by teachers who are actively involved in this skill training:

- 1. Preferred behavior is introduced early and taught and/or reinforced throughout ALL school years.
- 2. Close school/parent interaction and concern because of the student's cognitive limitations and the need for cross environment skill training.
- 3. Regularly scheduled parent workshops to help parents understand and handle social/sexual issues that will occur throughout their child's life.
- 4. Most of the skill training is one-on-one and only very occasionally in small groups.
- 5. ALL teaching techniques are:
 - * tailored to each particular student
 - * consistent across environments
 - taught at functionally correct times during the day
 - * use and expand upon the expressive communication system used by each particular student.
- 6. IEP considerations are the same as with any other skill training area.
- 7. Teaching staff are not required to have the P.A. 226 "certificate" because of the basic nature of the objectives. It is recommended that they go through a P.A. 226 training for up-dated information needed for parent conferences and their own information.



WAYNE COUNTY REGIONAL EDUCATIONAL SERVICE AGENCY **ANNUAL GOALS AND SHORT TERM OBJECTIVES EVALUATION PROCEDURES** Student Name: A. % of time 1. Systematic Observation COLUMN TITLE B. % on test 2. Informal Test CODES: District: C. ___times out of __trials
D. developmental/grade level 3. Formal Test C - Criteria 4. Report Card M - Massumment E. grade 5. Completion E - Evaluation F. Other: specify _ 6 Other: specify Date: Procedures C/M E C/M E INDEPENDENT/FUNCTIONAL LIVING LEISURE/RECREATION O AG I: Learne Skille Related To Flanning/Preparing/Eating Meets O AG I: Learne General Skills Melated To Preparing For/ IO-A Learns skills specific to eating in catetoria Accessing Leisure/Decreation Activities IO-B Learns skills specific to preparing and eating "sack funch" IOA Prepares to participate in leisure/recreation activity IO-C Plans menu and shope for groceries IO-B Accesses leisure/recreation activity IO-D Prepares family-style meal IO-E Sets table and eats O AG II: Plays in Sprid/Water IO-F Cleans kitchen after eating IO-A Flays in send IOB Plays in water O AG II: Learne Clothing Care Skille, Weering, Laundering, O AG III: Plays With Toys, Games, Computers/lee A Hobby Shopping IO-A Learns advanced dressing skills IOA Plays with toys
IOB Plays table games and electrofic/computer games IO-B Shoos for clothes IO-C Cares for dothes (e.g. washing, repairing) IQC Completes puzzles JOD Has a hobby/collection O AG III: Uses Community Facilities IO-A Learns money skills necessary for using community facilities AG IV: Listens/Watches/Reads For Entertainment IO-B Learns skills related to using a vending machine _IO-A Listens to tapes, radio, records/watches TV IO-C Learns skills related to eating in a fast-food restaurant IO-B Looks at/reads books IO-D Learns skills related to eating in a full-service restaurant DE Learns skills related to going to a barber/beauty shoo O AG V: Develops Art/Craft/Drama/Music Skills IC-F Learns skills related to using a laundromat IO-A Learns art shills IO-B Learns craft skills O AG IV: Improves Mobility In The Community IO-C Role plays/develops drame and music skills IO-A Learns basic skills related to neighborhood mobility IO-B Uses neighborhood mobility skills to go to and return from a O AG VI: Exercises And Participates in Group/Individual Sports specific destination IC-A Exercises to improve/maintain physical fitness IO-C Uses transportation IO-B Learns to swip IO-D Uses public telephone IO-C Learns bowling skills IO-E Uses doors, elevators, restrooms, drinking fountains, etc., in IO-D Learns softball/T-ball skills public buildings IO-E Learns kickball skills IO-F Learns basketball skills O AG V: Uses Adaptive Equipment/Procedures IO-G Learns foor hockey skills IO-A Uses adaptive activating devices (switches) IOH Learns volleyball skills IO-B Uses a wheelcheir 10-1 Learns soccer skills IO-C. Uses a walker Plans backyard/home games 101 IO-D Uses crutches/cane IO-E Wears brace/solint IO-F Acquires skills related to tapple visual/auditory learning and pre-mobility IO-B Participates in social activities (e.g. parties) IO-G Uses sighted-guide/trajifng/protective techniques/cane IO-C Attends community events/activities IO-H Uses amolification devices Learns to type
Uses other adaptive devices (e.g. eyeglasses, reachers, in i O AG VIII: Cores For Pets And Plants

Cores for a pet
Cores for plants **IOJ** ieoboards) Cares for plants O AG VI: Follows/floutines IO-A Pollogic daily school schedule IO-B Pollogic daily routine, including home maintenance tasks **ADDITIONAL ANNUAL GOAL(S)** AND SHORT-TERM INSTRUCTIONAL OBJECTIVES IOC Uses calendar to keep track of activities/performs non-daily maintenance routine IO-D Follows seesonal/weather related routines AG VIR Improves Interpersonal Skills -18-A Learns skills related to family interaction IO-B Learns skills related to maintaining friendships DIRECTIONS C/M 1. Enter the abbreviation for the selected chierie in the first IO-C Learns information related to sexuality column immediately following the IO. 8 80 2 2. Enter the measurement in the second column, e.g. 80 (%), O AG VIII: Learns Skills Related To Health And Safety 3/4 (3 times out of 4 treats), "B." _IO-A Learns good health practices and takes medication C 34 1 3. Choose an evaluation procedure suitable for the selected responsibly

IO-B Follows indoor safety procedures

IO-C Follows outdoor safety procedures

IO-D Follows basic first aid procedures

4. Enter the abbreviation for the selected evaluation method.

0 200 3

in the third column.



WAYNE COUNTY REGIONAL EDUCATIONAL SERVICE AGENCY ANNUAL GOALS AND SHORT TERM OBJECTIVES

	CHE	D/ A		
Student Name:	A. %	of time	System Conduction COLUMN TIT	15
District:	2. % c C.	times	2. Informatifiest CODES:	_
Teacher:	D. dev E. gra	elopm de	M = Measurem	
Date:	F. Oth	er: e	pecity 5 Offer: specif E = Evaluation Procedure	
<u>:</u>	10.00	V		74
COCHETIVE	C/M	7 E		ME
COGNITIVE O AG I: Acquiree Learning Skille	1	1	IO-C Responds to positive reinforcement (and generalizes skills	
IO-A Increases motivation to interact		ı	\ <i>[77]</i>	1 1
IO-B Attends to instructor/task		ł	COMMUNICATION	
IO-C imitates vocalizations/actions		1	OAG D Acquires Functional/Plagmatic Language Skills	
IO-D Matches objects/pictures IO-E identifies/makes choices among objects		1		
IO-F Follows directions				1 1
IO-G Improves short-term memory		1	// information	1 1
IO-H Improves long-term memory IO-I Learns to use comowers		1		
10-1 Learns to use comparters		1/	/ / Coc Uses social privases	
O AG II: Develope Basic Cognitive Abilities		\boldsymbol{V}	AG II: Develope Early Phonological/Speech Production Skills	
IO-A _acquires object permanence/seerches for objects		1 /	IO-A Learns phonetic/pillonological aspects of speech production	
IO-B Statacts with/represents objects and learns early play skills IO-C Understands cause and effect relationships	1/	1/	(speech sounds) LiO-B Controls intensity of vocalization (e.g. doesn't speak too loud	1 1
(O-D) Learns problem-solving skills		X/	or tho soft)	-
	1 /	V	IO-C Controls pitch, attonation and rate of vocalization	
O AG III: Proceeses Information Relating to Attributes IO-A Matches/iden/ifies/names colors	1//	1	O AG III: Acquires Skills Related To Improving Articulation	1 1
IO-B Matches/identifies/names shapes	VY		IO-A Improves oral motor skills	1 1
IO-C Matches/identifies/names sizes	$\Lambda\Lambda$		IO-B Improves resiliratory control	1 1
IO-D Metches/identifies/names textures	I	1	IO-C Imitzles vocalizations and motor movements	1 1
IO-E Names/demonstrates function of objectsIO-F Sorts items by attributes	1		IC-D Improves pronume production (pronunciation of speech sounds)	
IO-G Describes/compares objects		1		
		1	O AG IV: Improves Auditory Perception and Discrimination	
O AG IV: Learns Selected Reading Skills IO-A Looks at books			O-A Improves auditory attention and awareness	
IO-B Attends to/retells stories/events	1		IO-B Improves auditory discrimination	1 1
1O-C Learns survival words/symbols		1	O AG V: Learns Focabulary	1 1
IO-D Reads words/phrases related to following written directions	1 1	1		1 1
IO-E Reads words/phrases related to personal/messagesIO-F Learns sight word vocabulary necessary for yearing		1	OC Learn modifiers	
individually developed/selected books	1 1	1	IO-D Learis pronouns	1 1
IO-G Learns alphabet and beginning work attack skills		İ	IO-E Leavis prepositions	
O AG V: Learns Selected Wating Skills		1	IO-F Leans conjunctions	
IOA Learns/improves/graintains pre-writing skills		ı	O AG VI: Veems Language Structure	1 1
IO-B Writes name/legters/numeraj6		1	IO-A # farns basic declarative sentence patterns	
IO-C Writes words and phrases (e.g. lists, messages)		1	IO-B Usarns noun and verb phrases IO-C donioins words, phrases, sentences	
○ AG VI: Learns Splected Math Skills		1	IO-C	
IO-A Learns quantitative goncepts (e.g. more/less)			IO-E Learns interrogative sentence patterns (i.e. questions)	
IO-B Matches/identifies/sets /			IO-F Learns-Imperative sentence patterns	
10-C Counts/constructs sets 10-D Learns numerals			QG Learns noun, adjective and adverb inflections (e.g. plurals)	
IO-E Jeens time/galenda/ skills		1	OH Cearns verb inflections and tense (e.g. past and future)	
SOCIAL			O G VI) Learns Non-Vocal Communication Skills	
AG I.) Develops Positive Self-Concept				
IO-A Move's through stages of attachment, separation and early independence			pictures/rebus representations/Bliss symbols/words	
IO-BIncreases self-awareness		1	IO-C Learns to use electronic devices for communication	
O-Q Behavy's appropriately when expressing feelings				
IO To Participates in class activities			DIRECTIONS C/M E	
(AG II) Improves interpersonal Relationships			Enter the abbreviation for the selected criteria in the first	
ICA Improves interaction with adults		1	column immediately following the IO 2 Enter the measurement in the second column, e.g. 80 (%).	
IO-B Comproves interaction with peers		1	3/4 (3 times out of 4 thals), "B" C 3/4 1	
○ (GM:) Improves Classroom Behavior and Learns Self-Control	1		3 Choose an evaluation procedure suitable for the selected	
		1	Criteria.	
tasks)		1	4 Enter the abbreviation for the selected evaluation method in the third column	
IO-BLearns self-control		<u> </u>		1 1

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Independen./Functional Living INTERPERSOMAL Sexuality

C: Learns Information Related to Sexuality (Continued)

ANNUAL GOAL VII: IMPROVES INTERPERSONAL SKILLS

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IMPROVES INTERPERSONAL SKILLS ANNUAL GOAL VII:

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AN OUTLINE FOR PROGRAM INITIATION AND IMPLEMENTATION



An Outline for Program Initiation and Implementation

The following six steps gives staff the administrative backing and tools needed to implement a solid program. The <u>only</u> thing that will keep a program <u>successful</u> is stan agreeing on the validity of the program.

These six steps were the "minimum" teachers felt would give them the impetus to institute a sexuality program:

- I. <u>Acceptance</u> of the concept of "sexuality and the severely mentally impaired"
 - a. administrative approval
 - b. objectives placed in the curriculum "bank" and their use encouraged
 - c. parent and staff workshops organized and implemented.
- II. Review of the "staff responsibilities" list district and building level.
 - a. design specific classroom plans to implement the responsibility list.
 - b. build into the implementation plan an evaluation of the room's progress to their agreed upon goals.

III. <u>Hold the first parent workshop</u>

- a. school's plan
 - 1. staff responsibility tasks
 - 2. objectives and goals
- b. developmental sequence information
- c. specific student/problem solving
- d. awareness of local school and community resources
- e. set up dates for the next workshop



It is recommended that there be one workshop per year. The information, then, can be current and specific problems, hopefully, will be dealt with earlier, thereby reducing the number of social/sexual crisis later on.

IV. Hold the first staff in service

- a. current issues in sexuality (birth control, sterilization, etc.). Staff may not need this information for student skill training, but perhaps for their own and parent information.
- b. answer any questions around concept of sexuality and this population
- c. describe developmental sequence when to expect what
- d. specific questions around objectives, activities, specific students.
- e. school policy on abuse/neglect issues, handling bodily fluids, contagious/infectious disease controls.

It is recommended that there be one workshop per year. The information, then, can be current and specific problems, hopefully, will be dealt with earlier, thereby reducing the number of social/sexual crisis later on.

- V. Begin to include the <u>objectives</u> as needed, in the IEP's. Have home plans and suggestions ready for families.
- VI. Have administration <u>review</u> the "staff responsibilities" by classroom observation and reminder memos.



IMPORTANT ADDITIONAL ISSUES



Important Additional Issues

The following ten items are frequently misunderstood. (Parents and educators often have questions around these items):

· 1. Puberty

Our students go through all of the changes of puberty as do all other humans. Delayed puberty by 2 or 3 years is not uncommon. Staff and parents can look for the "traditional" puberty changes anywhere from 10 - 17 years CA.

2. Menstruation

Our students go through menstruation just as other young ladies do. Menses can begin anytime after their 10th birthday. The on-coming signs are also the same as for general education students.

Parents will often inquire into medications that will inhibit the monthly menses. WC RESA and Human Rights committees do NOT agree with this policy unless there is more than one medical opinion and family history information. The drugs are very powerful and have severe side effects. The most common medication is "Depo-Provera." Because our students cannot talk, there is no sure way of having any idea exactly what the medication is doing to the young lady in terms of physical pains or changes, moods, etc.

Another issue that is becoming more frequent is the request by parents to have ONLY female staff members toilet and change sanitary napkins once the young ladies reach puberty. If this is part of an IEP, it has to be done. Dignity and respect, of course, would indicate that staff would ask parents if they would like this consideration. Our union contracts do not have separate job descriptions for male and female staff, so this kind of request has to be done building-by-building, and on a cooperative basis between staff.

Research seems to show also that our students will probably have the same PMS symptoms that her family members have. Families and school staff should share this information and be prepared to assist to alleviate those symptoms should they occur.



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Unfortunately, more than one young lady has been put on a formal behavior plan for behaviors when all it would have taken is something to relieve very painful or irritating PMS symptoms.

3. <u>Inappropriate Sexual Behaviors</u>

Masturbation in public, disrobing, approaching others. . . these are the common sexual misbehaviors that are seen in this population.

All of these behaviors are priority that is, all of these behaviors need to be in IEP's until the problem is under control. Because the problems are so severe, community placement and general education school placement can be jeopardized.

WC RESA's <u>Masturbation Issues in Populations Statused</u> <u>Severely Mentally Impaired</u> (Heler, 1993) has strategies to eliminate the behavior from occuring in school and in public.

WC RESA's <u>Guidelines for Behavioral Intervention</u> (McEvoy, Kronk, Saunders-LaCombe, 1991) clearly outlines various techniques that can be used to either fade or jut outright eliminate any of these behaviors from your classroom.

WC RESA's stated policy also is that "if any of these behaviors are present, then the IEP should reflect awareness of the particular problem and steps being taken to either fade or completely eliminate the behavior in public."

4. Birth Control

Forms of birth control have been prescribed for our young women. As with all medications and this population, caregivers are responsible for monitoring the medication closely. If a family cannot find a physician, either ARC or the Reproductive health Concerns clinic in Ann Arbor can assist. Both of these resources are listed in the Resource chapter.

5. Sterilization

Our young adults CAN be sterilized, BUT the procedure has to be approved by Probate Court. Either the ARC's or the Reproductive Health Clinic in Ann Arbor can help families with both the decision and



the procedures for approval. At this point, if the family wants a sterilization because they are afraid of rape or sexual abuse, their request will probably be denied because sterilization does not prevent either. The school social worker can direct families to assistance.

6. <u>Sexual Urge Inhibitor Medications</u>

These medications are available, but once again very probably will not be prescribed simply because of cognitive functioning level. There has to be a number of factors present and evidence of a number of alternative strategies having been tried before they are ever considered. The Reproductive health Clinic in Ann Arbor has a great deal of experience with these medications.

7. Sexual Abuse

The signs of sexual abuse are the same as for general education. The tricky part in our population is that the clues are so easily hidden in their behaviors. Physical signs are as clear as in the general population, but the emotional signs are often only "more"... more vocalizations, more self-abuse, more agitation and so on. This is one area where staff really need to know their students; normal emotional states, behaviors, vocalizations, etc.

SEE page 26 for "Indicators of Possible Sexual Abuse."

SEE the next chapter: "Normal Sexual Development: An overview", written by J. Ingrid Amberson. I have included this because the sexual development of our students takes a little from each stage depending on each individual's cognitive development. Simply because it has been determined that a student functions at 4 1/2 CA does not mean that IN EVERY AREA of his life he functions at this level. Our students frequently function at a number of age levels concurrently.

I am afraid that it is true that abuse goes unrecognized because of the subtlety of clues, the cynical belief that no one will believe you or the students and Protective Services/DSS has so little experience with this population.



8. Nurturing

One of the great documented "lacks" in our student's lives is being touched or attended to in a loving and accepting way. Research has shown that our students are not touched as frequently as general education students by acquaintances, family or school staff. Keeping in mind that the research was talking about neutral touches (holding a hand while walking across the street, putting a hand on a student's shoulder while working with her, touch in greeting, being held simply because the adult wanted to hold a baby or young child). How could your classroom increase acceptable and age appropriate touches for all of your students?

9. <u>Intimacy</u>

This follows #8 closely. Research has also shown that our students rarely have "one on one" times with any member of their immediate family or extended family. The Dad and son going to a baseball game, the cousin and cousin going to "hang out at the mall" just doesn't happen with our students. How could your classroom encourage families to spend some "one on one" time with your student?

10. The Need To Give and Receive Love

All humans need to give and receive love. I could not find any research that documented this with our populations, but I am assuming that because our students are more "like than unlike" that this particular give and take is exactly the same. What activities in your classroom allow the students to give love?



INDICATORS OF POSSIBLE SEXUAL ABUSE

LOUISE R. KERLIN, ACSW/JOHN F. NEWMANN, JR., ACSW

Symptoms of sexual abuse may include physical and behavioral signs as well as indirect or direct comments made by the child. There are several clues to look for when considering the possibility of sexual child abuse. Any of the symptoms listed below, singularly or in combination, inclicate the need to explore the possibility of sexual abuse. Assessment of the symtoms should take into account the developmental level of the child and your knowledge of the child in determining the possibility of sexual abuse.

PHYSICAL SIGNS

- Sudden change in behavior
- Difficulty sitting, walking
- Semen around mouth, genitalia or on clothing
- Internal pain
- Bruising, scraping, irritation, bleeding, pain around penis, vagina, scrotum, anus, thighs, buttocks, belly
- Discharge from vagina or penis
- Pain or difficulty with urination
- Pregnancy under 12CA
- Sexually transmitted disease under 12 CA
- Torn, stained or bloody underclothing
- Swollen or red cervix, vulva or perinea

SIGNS OF SEXUALIZATION

- Sex becomes a bigger part of life and relationships than it usually is
- Sexual behaviors/inquiries/language too "old" for a child
- Partners too young, too old, or in other ways not appropriate
- Sexual behaviors which violate the rights of others
- Sexually promiscuous behavior
- Sexual expressions of anger
- Provocative behavior when not appropriate
- Vulnerability to sexual approaches
- Sexual self-consciousness
- Avoidance of or distaste for sex
- Unwillingness to undress or participate in physical education classes

SIGNS OF TRAUMATIC LOSS

Denial/Fear/Magical Thinking (Bargaining):

- Doesn't want to go home
- Doesn't want to go with a particular person



- coming to school early/leaving late
- running away
- Withdrawing from social relationships
- Acting younger than age--baby talk, crying, clinging, thumb sucking, etc.
- Acting older than age
- Pulling away when touched
- Bed wetting
- Substance abuse
- Nightmares
- Psychosomatic illnesses
- Refusal to go to school
- Sleeps a lot during the day
- Auditory, visual, and olfactory hallucinations (Ellenson, <u>Social</u> Caseworker, 1986).
- Inability to concentrate, sit still in school.
- Resistance to, or fear of, change.
- Buying friendship with gifts.

Anger (Usually mixed with other):

- Nervous, aggressive, hostile behavior to adults or peers.
- Hurting animals.
- Hurting smaller children.
- (Constant defiance, arguing, disobedience.
- Inability to concentrate, sit still in school.
- Avoidance of peers.
- "On the muscle," looking for trouble.
- Sexual offesnes.
- Soiling.
- Substance abuse--excessive use for age.
- Fire setting/fascination with fire.
- Acting retarded.
- Auditory, visual, and olfactory hallucinations (Ellenson, <u>Social</u> <u>Caseworker</u>, 1986).
- Joyriding (stealing cars).
- Theft.
- Sexual promiscuity.
- Poor personal hygiene.

Sadness (Usually mixed with other stages):

- No energy.
- Poor school performance.
- Sad expression.
- Suicidal notes or statements.
- Hopeless statements about the future.
- Poor personal hygiene.
- Lack of self-esteem, self-blame, guilty attitude.



- Lack of i nterest in people, life, food.
- Weight gain or loss.
- Eating disorders.
- Quick to cry.
- Worries about health.
- Sleep problems.
- Pack-ratting.
- Substance abuse.

Attempted Disclosures - Need Exploration:

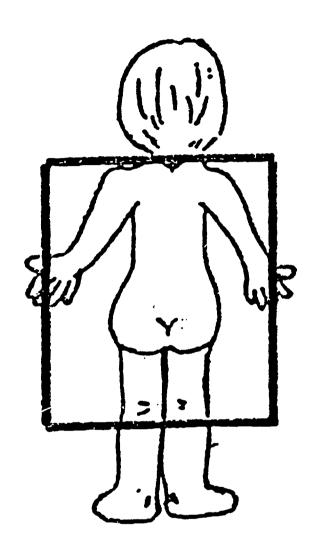
- He (she) fooled around with (or messed with) me
- She (he) bothers me
- I don't like to visit grandpa
- I'm afraid to go home tonight
- Will you take me home?
- Will you help me go live with my aunt?
- How could I get in a foster home?
- I hate my family
- I hate my stupid brother
- Manifestations through the child's school work, art, poems and stories of unusual sexual behavior or themes

Family Indicators:

- One child treated better or worse than others
- Children in adult roles
- Family without social connections
- Alcoholism, spouse abuse, child abuse
- Rigid male authoritarian families, especially with unusual belief systems
- Frequent absences from school justified by the male caretaker/parent
- Jealous or overly protective of child
- Isolation of child and family members within a community
- Frequent absences from home by one of the parents
- Inordinate participation by the father in family life and over dependency on him by the mother
- Encourages sexual behavior by child
- Sexually abused as a child
- Marital difficulties



PRIHARY TARGET ZONE



Injuries
found in this
area are suspicious. 70%
of nonaccidental
injuries occur
in this area.

*Saginaw County Protective Services receives an average of 85 child abuse and neglect reports per month. (1991)

*Referral sources are anonymous.

*Your report could save a child.



CENTER ON HUMAN POLICY

Controversy Over Facilitated Communication

by Doug Bilden

Facilitated communication is an altemative to speech that can be useful for many people who do not speak or whose speech is highly limited (e.g. echoed, repetitive, limited to one, two or three word utterances) and who cannot point independently and reliably. It involves typing with a single finger while being supported by a facilitator/communication partner. The support may include help in isolating the index finger, stabilizing the arm, backward resistance and slowing down the person as he or she points, pulling back after each selection, or just a light touch at the elbow or shoulder or other location. depending on the specific physical problems that impede independent, reliable pointing. The goal of independent typing or pointing should be realizeable for most individuals who learn to communicate with facilitation.

While the method seems quite simple, it can be complicated, for example if a person mixes intentional and echoed words in typing, if a person has word finding difficulties, if a person lacks confidence, if facilitators fail to ask clarifying questions when appropriate, if facilitators overinterpret an individual's typing, or if facilitators ignore important aspects of the method such as giving the least amount of physical support needed and monitoring to ensure that individuals look at the keyboard or other target. Another complicating factor is the content of whatpeople may type. People may express thoughts that others would rather not hear or which are confusing.

It is also very important to remember that for most individuals using facilitated communication, this marks the first time that they have had their communication monitored (i.e. heard and responded to). Let me give an example. Recently, a tecnager typed a page and a half description of how he had his his teaching assistant/facilitator. his speech teacher facilitated him as he expansed the incident. He said he was angry that he had to depend on this person to speak the words that he typed. We knew that these were the student's own words because he had typed out a similar statement with another teacher as his facilitator, expressing frustration at not being able to speak and of anger toward the teaching assistant/facilitator who can speak. But, when we checked on the hitting incident, we learned that it never happened. Rather, the

teenager later explained, he had only been thinking about such a scenario. Well, of course we all think about such things, if not about hitting someone then perhaps about yelling at scolding, or arguing with someone, but most of us have learned not to state such thoughts as having actually happened. This student had not yet learned the importance of clearly separating expressions of what has happened from what has merely been thought about, considered, or imagined. Presumably, because this student does not have a history of having his communication monitored, he has not learned this lesson. He will have to learn it now. At the same time, he has reported accurately on other matters and he has passed numerous messages that we were able to validate.

As long as this student was talking about hitting someone else, his account posed no great challenge to himself or to the people around him. They could all discuss it and work it through. But imagine if he had instead reported that he had been hit. Then the statement might well have evoked a formal investigation by legal authorities. In fact, I have described such an incident in my book. Communication Unbound. Another teenager reported that his father had his him, but he did so only in rearonse to leading questions. When asked about it, he reported to authorities that he accused his father of hitting him because he thought a particular facilitator wanted him to say that; the facilitator had been asking "Did your father hit you?" The only instance of being hit that he could give was of his father slapping his hands when he had pulled his sister's hair

Recently, faciliased communication has come into the news smidst controversy over allegations of abuse levelled builded who are using facilitated communicaand the maskers. Some of the allegations have led to the allegations layer hid to physical examinations of the complainants, shouldiggia several instances clear physical evidence of abuse. And some of the allegations have been either improvable or concocted. The first allegation that we became away of was made in April 1990 by a female student who had been using facilitation for only three months and whose typing skills were limited mainly to single word expressions. She disclosed that a teaching and had touched her inappropriately; there were nes and the teaching assistant confessed. The assistant plead guilty to a misdemeanor sex abuse charge and was placed on probation with the condition he cease working with children. In the one case that we know of in which facilitation was allowed in the courtroom, a residential worker in Kansas was found guilty of fondling an 11 year-old boy (Wichita Eagle, March 31, 1993, p.1). In two cases in New York State, sex abuse allegations were never aired in court because the family court judges disallowed testimony given by facultation, arguing that



TASH Tech workshop explores the techniques of facilitated communication with Doug Bilden.

the method had not yet been accepted in the scientific community. Some critics of facilitated communication have suggested that abuse allegations given by people who use facilitation are perhaps the products of witting or unwitting influence by facilitators; that is, they are the facilitators' thoughts and not those of the individuals with the communication disability.

Clearly, any allegation of abuse is a serious matter with serious consequences. And allegations of abuse, investigations of abuse, and prosecution of abuse are generally very complex, as witnessed by the many such cases involving nondisabled, speaking people in the news nearly every day. There is no reason to believe that such matters would be less complex when they involve people who use facilitated communication as their means of empression. And in fact there are several additional, potentially complicating factors such as automatic or echoed language and word finding problems to consider. Most important, any attempt to address allegations of abuse, whether made by people who can speak or by people who communicate with alternative or augmentative systems, demands thoughtfulness.

When we became aware of such abuse allegations by people who use facilitation to express themselves, we developed a statement to help parents, professionals, and legal authorities understand allegations of abuse that are made by people using the facilitated communication method. That statement is reprinted on the opposite page: this statement and supporting appendices, including an explanation of word retrieval problems and bibliography, are available from the Facilitated Communication Institute at Syracuse University (364 Huntington Hall, Syracuse, NY 13244-2340) at a charge of \$3,00.



Severe Communication Impairment, Facilitated Communication, and Disclosures of Abuse

by Chris Borthwick, Missy Morton, Doug Biklen & Rosemary Crossley

Severe Communication Impairment

A large number of children and adults with diagnoses such as intellectual impairment, autism, or severe cerebral palsy have no usable speech and cannot use sign language. People who are unable to communicate are obviously at increased risk of abuse.

Facilitated Communication Training

Facilitated communication training is an educational technique intended to allow people who cannot speak or sign to access communication devices. One person (the facilitator) provides support to the arm, wrist or hand of another person who is thus enabled to control their pointing sufficiently to point to pictures, words or letters. Support should be faded back as non-speaking persons



Doug Bilder

The ultimate aim is independent communication, but the need for support may persist for many years.

improve their pointing.

People with severe communication impairment have previously been thought to be unable to communicate because their intellect was insuffi-

ciently developed. The conclusion being drawn from the reported successes achieved through facilitated training is that these people have neurological defects of the same kind as those enumerated in post-trauma cases — apraxia (motor planning problems), aphasia (word-finding problems), disinhibition, and problems with initiation and perseveration — that do not necessarily affect their ability

to process information and which can be evaor in part through accessing a different out. Once offered the opportunity many students v of diagnoses have been able to demonstrate literacy and numeracy skills concealed by st poor motor skills and motor planning proble

Giving a voice to a group of people who ha silenced challenges many of our preconceabout what kinds of needs they have and ho meet them. Having a voice also means the able to speak out about what has happened to past, and many people have used their ne communicate to make statements about past abuse. Many such incidents have already reporting system, more are reported each we use of this method spreads such disclosures still more common. Some can be confirmed dent evidence, some cannot be; some may no All require serious attention.

Allegations of abuse can present difficulties even when accusations are made by people who can speak and are of full age. Accusations made with facilitation encounter these difficulties and present others of their own. They provide many challenges to existing educational, legal, and social support systems.

Disclosures of Abuse through Facilitation

Dealing with complaints made through facilitated communication may be seen as a series of decision points. At each point it is necessary to consider

- a) what decisions must be made:
- b) who should make the decision; and
- c) what decision-mal ag processes would be appropriate, including ,
- i) what considerations should be taken into account, and
- ii) what persons or bodies should be consulted?

At each stage, the person who has responsibility for the decision must both consider the problems that emerge for the first since at that stage and review what has been done at all the stages that have gone before. At each stage, also, the person will require counselling and support.

"Can the person communicate through facilitation?"

The facilitator has followed recommended communication practices, as set out in the literature and the person has apparently spelled out messages.

It is possible to be mistaken about this, and once the training is under way it is important to confirm at some stage that the method is working as intended. This can be done through incidental message passing (where a person it-veals information that others can verify but which was not known to the facilitator), through idiosyncratic lannage use (where a passon uses the same idioms or pellings with several facilitators), or through having two-acilitators, independingly merive the same message. It his hasn't yet, been possible — where, for example, the resen's first message is about abuse — something like it nay have to be done at a later stage.

Other laboratory-based tests involving such methodologies as shielding the facilitator with earphones have been proposed. Because of the continuing problems that these people have with initiation, motor planning, and wordfinding under pressure, such tests are seldom appropriate or successful. Such tests do not adequately provide for the efficus of the disabilities such as apraxia, aphasia, and disinhibition that have till now been marked from us by the assumption of returdation. These disabilities not only render existing tests inoperable but place immense difficulties in the path of any formal testing. Messagepassing is often the best available test, although even then allowances may have to be made for people with wordfinding problems who can give a message in general terms but not in its exact words.

"Has an allegation actually been made?"

The facilitator has received a message through facilitated communication that seems to relate to abuse.

Allegations of abuse have to be reported; all states now have mandatory reporting requirements, and facilitators should make themselves familiar with the requirements of their own state's legislation. It isn't the business of the

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facilitator to decide whether the alleganon is true, or ever if it's credible; it is important, however, to make sure that what the person actually wants to say is in fact an allegation. Facilitated communication is never as fast or at fluent as normal speech. Messages tend to be short, ever telegraphic, and may omit grammatical bridges. It is no always clear what message the person is trying to ge across with the words he or she has spelled out.

- The message may be incomplete:
 One person spelled out MY FATHER IS FUCKING
 ME clear enough, you would think, if the facilitator hadn't carried on to get MY FATHER IS
 FUCKING ME AROUND.
- The message may be telegraphic:
 One person spelled MY FATHER FUCKING
 CUNT and meant MY FATHER IS A FUCKING
 CUNT
- The message may be inherently ambiguous:
 One person spelled MOMSEXBOYFRIENDME.

which can be read either MOM SEX BOY FRIEND ME or MOMS EX-BOYFRIEND ME. These are different messages (and neither of them is clear). The letters or words chosen may not be those that the student really intended:

The person may have wordfinding problems, Difficulties with word-finding do not necessarily affect understanding or processing of spoken or written material, but can mean that the person is unable to think of the right word for what he or she wants to say and has to give another related word instead.

Care must be taken that asking of clarifying questions does not turn the receiving of a disclosure imo the kind of interview more appropriately conducted by law enforcement investigators. It is impossible to lay down firm rules, but facilitators should be aware of the possible complexities involved. It is also essential that clarifying questions are not leading questions and do not suggest what the person's response should be. In several cases what have seemed to be allegations of abuse have in fact been the sesuit of people with communication impairassuming yes' to leading questions. One is studied with self-administered bruises was affect that doublit you, didn't he? Why did he by he enswered "Yes" there was an The galice determined that no such ne had talestyless, and that he had merely been Tring the recess of sections in a secret of lead-

The student's immininge of the vocabulary may be

One Ameralian student typed out that a policeman had raped her mother. On questioning it turned out that Lya thought, 'raped' meant the same thing as 'flirted with.' (Such a usage should, of course, give rise to further inquiry.)

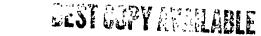
The investigator has received a report of an allegation of abuse.

One facilitator can in any given case he mistaken, or can be influencing the person, and as a precaution it is helpful to have the message repeated to a second facilitator. If this is not immediately feasible a decision has to be taken as to whether the situation will allow any decision to wait until a second facilitator can be introduced.

If with a second facilitator the message is confirmed in detail then it may be taken as confirmed that an allegation has been made.



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"Is the allegation credible?"

. The investigator has decided that an allegation has genuinely been made.

The protective agency must apply the same standards to the case as it would apply to any other case. It must neither downplay the testimony nor treat it as somehow more reliable because it is in print. It must be emphasized that

validation of the communication does not mean validation of the allegation. Many people accept that because an allegation 225 been voed is true. and, as a corollary, beieve that, if it



ums out not Rossmary Crossley with Annie, o be true, communicator extraordinaire.

then that means that the person didn't type it. People who can type can also — sometimes — lie or make mistakes, just like other people

The slowness of facilitated communication presents obvious problems in investigating a complaint. Someone using facilitated communication may be able to type 150 words in an hour, and may only be able to work for a few hours each day. This would be the equivalent of only a few minutes speech, and it may take some time to get a quantity of data together for examination.

"Does the allegation appear to be true?"

The investigator has carried out an investigation and collected all available evidence.

Some persons making allegations have been able to provide supporting information that confirmed their account. Some persons have supporting witnesses; one case in a Syracuse school was also reported by some of the person's schoolmates, and the perpetrator made and signed a confession. Some other evidence can be collected by normal investigative means; in one case the boy and the alleged abuser were suffering from the same sexually transmitted disease. In cases where the person's statements have to stand alone then its credibility must be assessed by normal standards.

"How should the case be handled?"

The prosecutor has received a report suggesting that there is avidence of abuse.

As the questions above show, there are going to be obvious evidentiary problems. There will also probably be problems to do with the limited life experiences of these people. They may well have used only a few thousand words in their lives to date, an allowance that would last at ordinary person a week. Their communication training will have been conducted in an atmosphere of encouragement and acceptance, and their communication may well deteriorate considerably under pressure. If the facilitator increases support to compensate for the greater difficulty this may lead to other problems.

Even if it has been established (by say, message-passing between two facilisators) that the person with communication impairment can communicate, and even if it has been established also (by the use of several facilitators) that the person did make the allegation, it still remains hypothetically possible that a facilitator could still influence the output of the person in subsequent communication. There is no way to monitor a facilitator's work in a particular situation while it is going on. This is an inherent feature of the use of the method, and in this respect FCT reasonbles the use of an idiosyncratic sign language system.

The separting of abuse through facilitated communication has already allowed many people with communication impairment to challenge their exploitation. The process of establishing abuse is complicated and challenging, and if proper procedures are not followed the outcomes may be confused and instatisfactory. If done correctly, however, facilitated communication training has the potential to be an immensely powerful tool for people who until now have been denied the protections others take for granted.

This article and statement were prepared by the Facilitated Communication Institute at Syracuse University. The Facilitated Communication Institute is associated with the Center on Human Policy. Doug Biklen, Director of the Institute, has had a long association with the Center on Human Policy's Research and Traning-Center on Community Integration. The opinions expressed herein are solely those of the authors and no endorsement by the U.S. Department of Education should be inferred. Space in the Newsletter is provided under a subcontract with TASH.

NORMAL SEXUAL DEVELOPMENT



NORMAL SEXUAL DEVELOPMENT: AN OVERVIEW

J. Ingrid Amberson, Ph.D.

In considering the development of our sexuality, we must acknowledge that the culture in which that development occurs is a major factor in determining the final outcome. Our biological drive is present from birth, and even before. But the way in which we express that drive, the where, when, how, and with whom, is learned through our culture. Sexual behavior is primarily a learned behavior, learned from within the confines of our particular culture.

Most of us remember our early years only in terms of isolated memories or hazy general feelings. Yet that is the time when we are developing our basic sexual identity as male or female. We are also discovering our primary orientation to the same or opposite sex, and what arouses us and what turns us off. At the same time we are forming our sense of security and comfort as sexual beings, and our sexual fears and preoccupations. All of these continue with us into adulthood. And nearly all of these memories and impressions stem from the family and the culture into which we are born. There is, in other words, a givenness about much that relates to our own sexuality.

Dr. Amberson is a clinical assistant professor in the Department of Family Practice and Community Health, University of Minnesota. She has served as outside evaluator of this National Demonstration Project from its inception.

Yes You Can! A Guide for Sexuality Education That Affirms Abstinence Among

1937 Young Adolescents

Editor: Dorothy L. Williams

\$14.95 \$2.50 p/h

Search Institute

122 West Franklin Avenue Minneapolis, Minn. 55404

Anthropologists, in writing about sexuality in other societies, remind us that in pre-industrial cultures learning about sexuality and sexual behavior begins in infancy and is learned in logical developmental steps as the child matures. Sexual exploration is encouraged in most cultures of the world. But the industrial societies, of which ours is one, have for many years taken the attitude that people should not engage in sexual activity before marriage. This general agreement has led to the belief held by some that teaching young people about their own sexuality should also be delayed.

That second belief is now open to serious question because, in recent decades, adolescent pregnancy has reached epidemic proportions. One of the hypotheses about the reason for the epidemic is that young people have not been taught enough about sexuality to enable them to make responsible choices. Because sexual development occurs within the culture as a whole, our culture will have to make radical changes if we would improve our children's sexual development. The next few pages will discuss normal childhood sexual development in our society.

Infancy. Birth to Two-and-a-Half Years

Many of the learnings acquired in infancy continue with us through the years. One of the most important acquisitions is our perception of the world, whether we see it as hostile or friendly. The perception of a friendly world is translated into trust, and it affects how we relate to others. Children learn trust primarily through touch. The nurturing touch from mother and father, or lack of it, lets them know whether it is safe to reach out to others or whether it is best to withdraw.

Because our culture discourages touch, especially sensual or erotic touch, there is a lack of contact between many mothers and



their infant; mothers are more likely to console their infant with food. Generally speaking, we reward desexualized movements that keep the infant away from the mother. Studies have shown that when personal encounters are normal and the infant receives nurturing touch, genital play is present. When the infant-mother relationship is a problem, genital play is rarer. When the infant-mother encounter is absent, genital play is absent. We also know that many people who have been deprived of nurturing touch in infancy exhibit violent behavior and emotional disorders later in life.

Within the first 18 months, the infant learns his or her gender. Most parents treat boy babies very differently from girls and help to establish this developmental step. By age two, children are beginning to understand sex roles and make the distinction based on clothes and hair. During the period of infancy there is sensory exploration, naming of genitals, learning about urination, a beginning of interest in body differences, and handling of sex organs. Sexual response has been present from before birth and infants clearly derive pleasure from genital touching.

Masturbation is very common during childhood, but not all children masturbate. Touching or holding the genitals is often associated with security rather than anything erotic. Usually, children are not fully aware of what they are doing when they first masturbate, and the unusual feelings can come as quite a shock. They certainly do not know what the sensation means in adult terms; it just feels good.

Ages Three to Seven:

During this period there is a marked increase in sexual interest and capacity for erotic response. Kinsey (1949)



reported that children of this age range are aware of genital differences. Handling of the child's own genitals, cuddling, kissing mother and father, and touching and kissing others is common.

From the age of three onward, children remember some sexual experiences. There is same sex and opposite sex play, mild masturbation, cuddling of family members, touching and tickling. Three-year-olds ask questions and act out things they have seen or heard about.

Four-year-olds begin asking about babies and where they come from. They are also extremely interested in the bathroom activities of others, and will "show" each other and talk about elimination. They often play alone and have imaginary companions, but also like to play with others. At this age the play begins to divide along sex lines, with boys playing somewhat differently from girls. However, children do not seem to form clear gender differences until age five to seven and at ages three and four have difficulty learning these differences. They still use clothing and hairstyle to determine sex. Age four may also be a critical learning period for sexuality. Children often begin adding genitals to their drawings of people, and, in treating adults with sexual problems in a clinical situation, we often discover a sexual trauma which occurred around this age that is related to their adult pathology.

Children at age five are more self-contained and more serious about themselves than at age four. The inclination to "show" decreases and modesty increases. Boy-girl pairs still play often, but boys may begin to reject girls' roles and play at adult male activities. The interest of both sexes in babies continues, but there is more of a sense of past and future in that they relate to being a baby or to having a baby of their own. However, they still do not make a connection between a pregnant



woman and babies. Although they may have been told all the elements involved, they are as yet unclear how the elements come together, although they may have observed animals mating or even parents having intercourse.

Age six brings a marked awareness of and interest in male-female body structures. There are not only questions, if allowed by parents, but mutual investigation of peers. There is usually mild sex play or still some "showing" in school toilets. Often there is giggling or name-calling about elimination. Sometimes children may dress in opposite-sex clothes during play.

By age seven there is less mutual exploration and sex play. The child is self-conscious about his or her body and sensitive about body exposure. Teasing from the family or peers now can be very destructive, in that the child is ashamed of mistakes and has many fears. Male-female differences are centered around roles, and role definition has increased dramatically. Both sexes are well aware of what boys or girls "do" because of radio, television, popular songs, and instruction from peers and family. In addition, mild sexually oriented magazines are often first seen during this age but often without the child's understanding the content in any adult sense. Usually nude pictures are, of interest because of curiosity about bodies and how genitals look, or because it may come from an older friend or family member, or because parents would frown upon it. By this age, children do associate pregnant women with babies and often want a new baby in the house. There may be strong and persistent love affairs with the idea of marriage occurring.

Age Eight to Twelve

Children in this age range start the transition into adolescence and obvious physical changes begin to occur. The



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rate of change varies widely, however, with menarche in girls and ejaculation in boys starting somewhere between the ages of eight and fifteen.

The child at age eight notices and comments on differences from others, and the chief interest is his or her relationship to others. Usually children of this age are outgoing and can understand and comply with social standards. Girls and boys tend increasingly to play separately and demonstrate an increased identity with special social groups. This is the period of secret clubs, most of which are short-lived. Interest in sex is high, but sex play is less common. Boys recognize pretty girls and may have several girlfriends. Peeping, smutty jokes, provocative giggling, and whispering, writing, or spelling of sex words is common. By this time, also, the process of pregnancy is understood and more curiosity develops about the father's role.

By the age of nine, body self-consciousness may have developed to the point that the child does not want to be seen by the opposite sex parent. Sensitivity and embarrassment about being corrected or criticized is heightened; thus parents should be particularly aware of being respectful and understanding of their children's behavior and their new body changes. This may be somewhat difficult, since this is also the period of first conflict between adult codes and codes of peers, and this age group is beginning to orient more toward peers than parents. Crushes and hero-worship are common. Nine-year-olds sometimes profess to "hate" opposite-sex peers but are very much interested in sexuality. They discuss sex with friends of the same sex, are interested in sex organs and their functions, swear using sex words, and create sex poems. Mixed sex play may include kissing games and teasing about boy or girl friends.

The sexual expression of ten- to twelve-year-olds is often considered inappropriate by adults. There is a heightened



interest in smutty jokes at this age, part of a general sexual growth spurt. Smutty jokes seem to be an especially common method of transmitting sexual knowledge in our culture. They appear to provide a way to gain information and talk about sex while using humor to reduce guilt and discomfort. Teasing among preadolescents may also have a special function at this time. It is a time of awesome biological change. The development of such changes as growth of pubic hair, deepening voice and breast development must be acknowledged by peers, but because of the lack of information and lack of experience in discussing body functions, most do not know how to respond or feel. Teasing allows for recognition of changes without commitment to a position.

Boys begin to have erections that happen frequently and quickly, often without the boy's understanding why. They may result from a non-erotic stimulus, frequently associated with fear, excitement, or some other emotion, or with vibrations, as on a carnival ride or a bus. Usually boys masturbate, most beginning between the ages of nine and twelve. Fantasy often occurs with masturbation, and the subjects of fantasy depend upon the child's experience up to that time.

For girls at this age, there are usually conversations with same sex peers about breast development or whether menstruation has begun. They are very sensitive about what peers and family think about their development and may either try to "hide" their physical changes or want to "keep up" when no changes have occurred. Masturbation is less common for girls.

Mixed parties begin in preadolescence but seem to be mostly a middle class phenomenon. Boys, especially, have difficulty defining or accepting the behavior at these parties and may resort to roughhousing or avoiding them altogether. First paired dating involves walking home from movies, parents taking their



child places with a friend, sitting together at events, and going to parties. "Going steady" can occur early, and it usually involves exchanging bracelets or rings. Often the couple is not really dating except in fantasy, but sometimes they are. Touching involves rough play, teasing, and hitting. Kissing, though familiar from childhood, may include confusion, fear, embarrassment, and guilt in this new context. Petting and intercourse have become increasingly common among this age group in the past few years. Peer social pressure to have intercourse has escalated, and to many preadolescents it seems as if everyone is "doing it." Current estimates of the number of children having intercourse by age 12 is 10 percent. However, of this 10 percent, up to one-fifth may have included some form of coercion by an older person.

Ages Thirteen to Nineteen

Once the child moves into adolescence, the physical and social changes occur rapidly, with a speed that is confusing for both parent and adolescent. Learning to deal with opposite-sex relationships is a major developmental task for this period. As the focus on the opposite sex becomes more defined, adolescents begin to discover their sexual preference for a partner. For a few, this becomes a serious problem. There is still much fear about homosexuality in our culture, and adolescents are ruthless in upholding the heterosexual norm; therefore, those teenagers who begin to realize that they may desire their own sex must be careful about what they say and do. Many adolescents will deny and repress their same-sex feelings for as long as possible rather than face derision and shame.

Many adolescents today begin sexual relationships by the end of this period. The lack of responsibility that we see among teens in using birth control or in continuing abstinence may come



from one of our strong cultural myths--that sexual feelings are overwhelming and cannot be controlled. If the adolescents can convince themselves that their behavior is out of their control, it reduces their guilt and they do not have to face being a "bad" person for having sex. Eelief in this myth actually discourages the use of birth control methods, because to use birth control indicates that the teen had thought ahead. This assumed lack of control is especially bestowed by our culture on men, and it contributes to sexual aggression in our society. It is expected that the woman will be hesitant or resistant and that the man will push, since the woman "really" wants to participate in sex but has been taught not to. Taken to its logical extreme, it is a perfect background for rape, and even for less extreme forms of sexual aggression. Indeed, from sex offenders in clinical treatment, we hear this kind of misunderstanding of social cues repeatedly.

Today's adolescents are bombarded with sexual information and sexual situations in popular music, movies, television, and advertising. Unfortunately, many adolescents do not have the memory of discussions with their parents that would serve as a background against which to judge these media presentations that romanticize and glorify sex. As we said earlier, attitudes about sex come from home, but merely having a positive or negative attitude about sex does not prepare adolescents for the complex messages they must sort out. Often, the child has received a double message about sex from family. It goes, "Sex is dirty; save it for the one you love and marry." Further complicating matters is the fact that teens often equate sex and love, partly because our culture does not define the differences well and partly because the adolescent has not had experience in making the distinction.

With intellectual, emotional, and physical development occurring rapidly, and at different rates, adolescents may seem



like adults one hour and children the next. This characteristic flip-flop can be at once funny and disheartening for the parents who are trying to cope. However difficult it is for parents, though, we must remember that the adolescent is feeling it much more acutely and painfully. Adolescence is a period of insecurity in all areas, and to arrive at adulthood with minimum trauma, they must have support from parents and teachers, they must hear compliments, they must be given appropriate levels of responsibilty, and they must be allowed to begin making more decisions, and, yes, mistakes. The child and adolescent who like themselves and who can talk to their families about what is important to them, be it successes, problems, or sex, will have the inner strength and resources that we all want for our children and for ourselves.



RESOURCES



RESOURCES

1. WC RESA STAFF to assist families and school staff:

Andy Kronk, Ph.D., School Psychologist Chris McEvoy, Ed.S., Behavior Intervention Facilitator Liz Chamless, MSW, Social Worker Nancy Birchmeier, RN, School Nurse Ann Heler, M. Ed., Instructional Specialist

Simply call your child's school and they will connect you.

2. Clinic for the Reproductive Health and Sexuality Concerns of Men and Women with Mental Retardation

University of Michigan Women's Hospital Medical professional Building D2241-0718 1500 East medical Center Drive Ann Arbor, MI 48109-0270

Information: Sally Kope (313) 763-6597

They have the latest legal and medical information on a whole variety of sexual issues. They also conduct gynocological and testcular examinations; counsel and examine for birth control and sterilization issues; work with families, school and community around inappropriate social/sexual behaviors; and have information for special needs populations on every aspect of reproductive health.

They take a variety of insurances and have a sliding pay scale for people without insurance.

3. Social Concepts Consultation

30900 Ford Road Garden City, MI 48135 (313) 458-5180

Information: Colleen Wilson, MSW

SCC specializes in sexuality and appropriate sexual behavior issues. They take a variety of insurances and have a sliding pay scale for people without insurance.

4. The ARC (Association for Retarded Citizens)

Detroit Family Services (313) 831-0202 Downriver family Services (313) 425-7320

ARC keeps a current list of professionals that work with the severely mentally impaired populations. They also have a lot of suggestions for use of insurance, wills, and other legal issues parents encounter. Their services are free.

5. All Women Have Periods 11 minute video

Perennial Education 930 Pitner Avenue Evanston, IL 60202 1-800-323-5448

Explains in great detail sanitary pad change, hygiene during menses and has an elementary explanation of menstruation.

6. Are Children with Disabilities Vulnerable to Sexual Abuse?

Minnesota State Documents Division 117 University Ave. St. Paul, Minn 55155 50/\$7.00 + \$1.50 p/h

7. <u>Just Between Us: A Social-Sexual Guide for Parents and Professionals</u> Edwards and Elkins

PRO - ED \$15.00 8700 Shoal Creek Blvd. Austin, TX 78758 (512) 451-3246

This book was written especially for parents. It covers all of the significant social/sexual topics.

8. <u>Sexuality and the Mentally Retarded</u> - A Clinical and Therapeutic Guidebook Roslyn Kramer Monat

College Hill Press \$19.95 California, 1982

This is the first book to discuss <u>anything</u> about sexuality and the population statused severely mentally impaired.



9. A Collection of Readings and Articles Regarding Sexuality in Persons With Developmental Disabilities - A Handbook for Parents and Caregivers

WCAR 32233 Schoolcraft Suite 100 Livonia, MI 48150

10. <u>Masturbation Issues in Populations Statused Severely Mentally Impaired</u>

WC RESA Heler, 1993

11. Guidelines for Behavioral Intervention

WC RESA McEvoy, Kronk, Saunders-LaCombe, 1991

