DOCUMENT RESUME

ED 418 555 EC 306 364

AUTHOR	Mandeville, Howard, Ed.; Anderson, Lynda, Ed.; Lakin, Charlie, Ed.
TITLE	Supporting Parents Who Have Cognitive Limitations.
INSTITUTION	Minnesota Univ., Minneapolis. Research and Training Center on Community Living.; Minnesota Univ., Minneapolis. Inst. on Community Integration.
SPONS AGENCY	Administration on Developmental Disabilities (DHHS), Washington, DC.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	1998-00-00
NOTE	29p.; A "Feature Issue," with all fifteen articles on the theme subject.
CONTRACT	90DD032301; H133B30072
AVAILABLE FROM	Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive, S.E., Minneapolis, MN 55455; telephone: 612-624-4512.
PUB TYPE	Collected Works - Serials (022) -- Guides - Non-Classroom (055)
JOURNAL CIT	Impact; v11 n1 Spr 1998
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Adult Children; Adults; Advocacy; Agency Cooperation; *Child Rearing; Helping Relationship; *Mental Retardation; *Parent Child Relationship; *Parenting Skills; *Parents with Disabilities; Social Services; *Social Support Groups

ABSTRACT

This feature issue focuses on strategies to support parents who have cognitive limitations to be successful in raising their children. Articles include: (1) "Encounters with Entropy: Marge's Journey from System to System" (John Franz and Pat Miles) that tells a fictional story of a mother with disabilities to illustrate the tendency of human service systems to operate independently of one another, to stay locked into rigidly structured responses, and to avoid collaborative responses; (2) "Helping Parents Be Parents" (Howard Mandeville and Polly Snodgrass); (3) "Mothers with Developmental Disabilities: Common Issues and Needs" (Bette Keltner); (4) "Parents with Cognitive Limitations: What Do We Know about Providing Support?" (Lynda Anderson and K. Charlie Lakin); (5) "Perpetuating the Sprit of Kako'o" (Stacy Kong); (6) "Supporting Parenting Rights: Arc Hennepin" (Lori Gildersleeve); (7) "Two Decades of Parent Support: Reuben Lindh Parenting Program" (Audrey Kvist); (8) "Supporting Fathers with Cognitive Limitations" (Mark D. Simpson and others); (9) "Parents with Cognitive Limitations: Challenging Myths, Changing Perceptions" (Alexander J. Tymchuk); (10) "Supporting Parents and Children during Termination of Parental Rights" (Deborah Muenzer-Doy and Lynda Anderson); (11) "Strengthening Families of Older Children" (Gwynnyth Llewellyn); (12) "The Adult Children of Parents with Learning Difficulties" (Tim Booth and Wendy Booth); (13) "Welfare Reform and Parents with Disabilities" (Caroline Hoffman and Howard Mandeville); (14) "System Abuse and the Power of Advocacy" (Tim Booth and Wendy Booth); and (15) "How Small Initiatives Make a Difference" (Rick Brooks). The issue closes with a list of supported parenting resources. (CR)

Impact

Feature Issue on Supporting Parents Who Have Cognitive Limitations

Published by the Institute on Community Integration (UAP) · Research and Training Center on Community Living

Volume 11 · Number 1 · Spring 1998

For Kayleen, Harold, and their daughters, the spirit of kako'o – of true support – in parenting services has strengthened their family. See story on page 8

Encounters with Entropy: Marge's Journey from System to System

by John Franz and Pat Miles

Once upon a time a baby girl is born. We'll say her name is Marge. Some inborn genetic traits, combined with injuries that occurred during a difficult birth, affect the way her body operates. For awhile her care is the responsibility of the health care system. As she gets older, it becomes clear that the inborn traits and birth trauma also affect the ways she learns. Now the educational system begins to provide services. A few years later, her parents are having trouble taking care of her and are having difficulties in their own lives. In anger, her father hits her. A social services agency intervenes and Marge is moved to her first foster home. Over the years of Marge's childhood, her parents divorce and go separate ways. Marge's foster parents and schools have a hard time dealing with her because she is often angry and doesn't get along well with others. She moves frequently from home to home and school to school.

When Marge is 18 she can no longer stay in foster homes that the child welfare system operates, so she is transferred to the responsibility of the adult developmental disabilities system. With some difficulty, because of limited resources and Marge's history of noncompliance, they find a group home that will accept her. Marge changes

[Franz continued on page 26]

From the Editors

Few occurrences are more joyful than the birth of a child. But, what happens when that child is born to a parent or parents with cognitive limitations? On such an occasion, the joy of birth and its promise for the future often become shrouded in ambiguity. How can a person with a cognitive impairment manage the complexities of parenting?

As with all parents, the answer is, "with support." The recently popularized saying, "It takes a whole village to raise a child" applies to parents who not only struggle with the demands of parenting faced by all those raising children, but who also struggle with barriers related to disability, as well as (often) to poverty and prejudice.

This issue of *Impact* is focused on how "the village" in many different locations is actively engaged in supporting persons with cognitive limitations to be successful in raising their children. This support is offered while also giving priority to every child's birthright to a safe, healthy, loving, and stimulating childhood. It is our hope that the attitudes, strategies, and personal stories found in these pages will offer service providers, policymakers, and others a less commonly experienced perspective on what it means to be a parent and on what it takes to raise a child.

What's Inside

The College of Education & Human Development
UNIVERSITY OF MINNESOTA

Helping Parents Be Parents

by Howard Mandeville and Polly Snodgrass

On a rainy Saturday a group of parents met in Madison, Wisconsin, in a room with a view of Lake Mendota, and talked about what it's like to be a parent these days. What distinguished these 11 men and women from other parents was their involvement in supported parenting programs – personalized support intended to strengthen families headed by parents with cognitive limitations. In common with most parents was their concern for their families and their hopes for their children's future. At the meeting parents identified their dreams: "I dream of a home that will be ours – with a yard and sidewalks for my kids to play on"; "My dream is to have my daughter grow up and go to college"; "I hope I can find a safe neighborhood where my kids won't get hurt."

In a stone courthouse in a rural Wisconsin county, a judge sat in his chambers reviewing 200 pages of documentation regarding a woman with cognitive disabilities and her two daughters. The fate of a family was in his hands. The documentation went to great length inventorying a host of deficits and mistakes made by the mother over the two-year period her children were in foster care. Buried in the documentation were a few revealing statements that allowed a perceptive reader to dig beneath the surface and discover parent-child bonds that survived long separation, supervised visitations, and the skepticism, hostility, and incompetence of a system that interpreted its duty as detecting the parent's failures. The judge pondered the limits of his understanding: the mother has a disability that won't go away, the social workers told him what they tried hadn't worked, the foster family would like to adopt and they are a very nice family. He had already decided how he'd rule. He hoped the mother wouldn't make a scene.

The problems of families headed by parents with cognitive disabilities are notable for their ambiguity. They do not present circumstances that lend themselves well to clear-cut laws, policies, and agency procedures. Much is left to the judgment of the person the family turns to for support, thus placing an already vulnerable parent at the mercy of the "eye of the beholder." Therefore, it is not only characteristics of the parents' disabilities that influence outcomes, but also attitudes, values and assumptions of agencies and courts regarding a person with disabilities in a parental role.

Many of the challenges encountered by parents with disabilities are also common to others in the general population exhibiting problematic parenting. The most devastating barrier to adequate parenting is poverty. Living in poverty leads to chronic anxiety, strain, and frustration. It contributes to depression, lack of self-esteem, and apathy – all of which are significant causal factors in child abuse and neglect. Additionally, recent reforms in the welfare system significantly threaten the viability of many families living in poverty, including those headed by parents with disabilities. Services provided to such parents must make a commitment of time, energy, and resources to assure the family's access to the basic support they need.

Supported Parenting Philosophy

Supported parenting is a philosophy, not a curriculum – an attitude, not a clinical specialty. Support is based on an understanding and acceptance of the characteristics, life circumstances, needs, and desires of persons with developmental disabilities. The word *supported* carries the same importance as the word *parent* in this model. We begin with the assumption that parents are capable of adequate parenting and – with appropriate supports that last through the children's growing-up years – will learn, grow, and change. We view the parent with cognitive limitations as a "developing resource."

Parents known for their disabilities also have abilities that can be enhanced by our support services. It is important to separate personality from disability, to acknowledge that cognitive limitation is only about how people learn. Rarely is it the most significant factor in deciding whether someone can parent adequately. Attending to the well-being and health of families headed by parents with disabilities requires identifying and overcoming the barriers to support.

Supporting Through Teaching

Successful teaching of parents with cognitive limitations requires not only an understanding and acceptance of the characteristics of their disabilities and life circumstances, but also a knowledge of appropriate techniques for their successful learning. Mark Sweet (WCDD, 1990) has helped us learn what is important to consider when putting together an instructional strategy. We need to look at the parent's individual learning style, current knowledge, behavior, attitudes, beliefs, values, available support systems, and available resources. The instructional focus should be on one thing at a time, with each parenting session having only one objective or technique, addressed in various ways, using various learning modalities. The learning environment should be one that reflects positive expectations of success, and there should be mutual respect and enjoyment. The sessions should always begin and end with a positive comment. It is important that each visit is an oasis in lives of crisis and desperation, not another stressor.

Parents with cognitive limitations may have difficulty with abstract thinking, problem-solving, and judgment. Learning occurs more slowly and the instructional strategy has to account for the learner's limits in memory and retention. Teaching should include concrete methods, combining showing with telling. The person providing instruction should demonstrate, model, and repeat the behaviors we want the parent to learn. It helps to have parents observe then demonstrate the skill while the parent educator reinforces their effort with praise. It can be useful to provide pictures, charts, or other kinds of visual cues that will help in recalling the teaching. Skills are best taught in the context in which they will be used, and learning should be experiential and enjoyable.

> ***Our prerogative is not to choose "better parents" for children, but only to protect them from life-threatening ones. So, the wisest and most ethical course seems to be to diligently devote ourselves to providing supports and services to the natural parents.***

Teaching should be specific, complete, and concrete, with tasks broken down into parts. For parents with low literacy skills, written materials should be used sparingly. It is important to determine what approaches are helpful, then teach parents to teach others in their support system those support and instructional methods that work. For example, a parent may need to ask to have appointments or directions written down, or ask for a phone call reminder, or ask to be shown what is needed.

We need to teach principles and methods of self-advocacy so parents can learn that there is a difference between fighting *for your family* in the system, and fighting *with everyone* in the system. Social and relationship skills are developed naturally when families have opportunities to come together in groups for learning and play. We can help families overcome their isolation by helping them participate in neighborhoods, schools, and communities. Enormous personal growth occurs when families are "providers" as well as "recipients."

Supporting Recovery from Abuse

Cognitive disability brings its own set of obstacles to successful parenting, but for most families, the parent's cognitive limitations are not the primary reason for failure. Research on sexual abuse and people with cognitive disabilities indicates a disturbingly high percentage of people with disabilities experience sexual abuse, over 80% in some studies (Sobsey, 1994; Froemming, 1991). This is of particular concern because of the effects of sexual abuse on parents' own self-esteem and their capacity to develop healthy relationships with family members. This phenomenon is so common, it should almost be assumed. For many mothers, the long-term relationship with supported parenting educators or home visitors provides the safety and security needed to disclose past abuse.

Reevaluating Interventions

One of the most challenging aspects in supporting families headed by parents with disabilities is encountering the gray line that separates parental care that may be less than optimal but "good enough" from parental behavior that is detrimental to the child. A trend can be discerned from recent trial court cases and federal and state legislative initiatives that suggests a shift away from the family preservation policies that, in many ways, were consistent with the principles of supported parenting. Instead of mobilizing support for families to keep them intact, we see policies, practices, and court rulings that communicate impatience with long-term interventions and favor the acceleration of the process that results in terminating parental rights. Support providers are brought into this debate when they are called upon to make judgments about a family's prospects. Their opinions influence whether or not the family stays intact. Only compelling evidence of harm should trigger termination of parental rights. Permanency planning policy is premised on the idea that direct, time-limited interventions will lead to prompt answers regarding whether the family stays intact or a child is freed for another permanent option such as adoption. This approach conflicts with what we know about the complex and continuing issues facing a parent whose disability is permanent. Delaying court intervention may compromise the rights of a child; however, the rights of the parent may be compromised by actions that lead to a swift termination of parental rights. The immediate risk to the child may be alleviated by out of home placement, but the long-term harm of losing the identifying connection to the birth parent can be devastating.

It is understandable that well-meaning individuals who care for children would look favorably upon placing them in environments perceived to be more promising. However, our prerogative is not to choose "better parents" for children, but only to protect them from life-threatening ones. Therefore, the wisest and most ethical course seems to be to diligently devote ourselves to providing supports and services to the natural parents to increase their capabilities and to establish a natural support system that will sustain them.

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Howard Mandeville is Community Resource Specialist with the Wisconsin Council on Developmental Disabilities, Madison. He may be reached at 608/266-9538. Polly Snodgrass is Supervisor with the Healthy Families Program, Family Services Association, Green Bay, Wisconsin. She may be reached at 920/436-4360, ext. 1262.

Mothers with Developmental Disabilities: Common Issues and Needs

by Bette Keltner

Priscilla is a white, single mother who had her fourth child in 1974. Her three older children had been placed in foster homes when each became a toddler. I met Priscilla soon after the birth of her last child because at that time in the community all Medicaid mothers received home visits from public health nurses for the first year of a new baby's life. Because Priscilla had mental retardation, she received frequent home visits and was taught how to take care of her baby. She loved all of her children deeply. She had pictures of each child and told anyone who would listen about their lives as babies. Every day Priscilla would catch the bus and spend two or three hours walking around the social services building downtown. This building housed the people who had removed her children and she thought that if she looked hard enough she might catch a glimpse of one of her children. When her fourth child turned one year old, home visits ended according to policy. Most mothers benefitted from "anticipatory guidance," information about child development that could be learned and used in the future, generalizing basic principles to a variety of situations. Priscilla didn't relate information to future situations and couldn't generalize from one similar situation to another. As her baby started walking, he had more frequent injuries. Eventually her fourth child was removed from her home. Priscilla continued her daily trips downtown, walking all day even in the rain, hoping to see one of her children. Priscilla was the first woman to teach me about special needs of mothers with developmental disabilities. Over the years, many other women and their families have added to this knowledge.

> *The major pregnancy-related issues are the lack of realistic expectations in becoming a parent, inadequate sex education, and partnering not just with immature men, but with men who are likely to be involved in criminal behavior, drug addicted, or sociopathic.*

Health care and social advances have resulted in new opportunities and challenges for people with developmental disabilities. Among these changes is an increasing number of women with mental retardation who are mothers. Supports for inclusion rarely address parenting as a life role. Becoming a mother is a normal life experience, but one distinctly different since the well-being of the child born to a woman with mental retardation must be protected and promoted along with that of the parent. Through clinical and research projects, four common findings have emerged as key considerations for professionals and others who desire to assure the best possible health and development for mothers with mental retardation and their children: (a) many women with mental retardation want to become mothers, (b) social supports can become strained or suspect, (c) professionals generally know little about adults with mental retardation, and (d) both poverty and disability make parenting difficult for mothers with mental retardation.

The Motherhood Milestone

Becoming a mother is an expectation most women have. Women with mental retardation have similar physical and biological motivations. Few of these women have had developmentally appropriate sex education. Since causes of mental retardation are more prevalent among families in poverty, proportionately more of these young women live in neighborhoods with high crime and lack of some of the barriers that could protect from rape and exploitation. For all women, becoming a mother is a developmental milestone. Young women from poor neighborhoods live in an environment where early childbearing is more common. Furthermore, this is one developmental milestone that women with mental retardation can do at the same age or earlier than their peers. After working with mothers who have mental retardation for two decades in five states, I have found that the major pregnancy-related issues are the lack of realistic expectations in becoming a parent, inadequate sex education, and partnering not just with immature men but with men who are likely to be involved in criminal behavior, drug addicted, or sociopathic.

Teen pregnancy programs are inextricably linked to education in this country. In most communities, parenting instruction is available only for teens in school; in short-term, fast-paced community programs; or associated with child abuse services. The measure of program success is often academic mastery of the content, which places young women with mental retardation at a disadvantage. Women with mental retardation love their children with the same intensity as other women, and love for a child provides a powerful motivation to learn and be dutiful with responsibilities. However, there is a terrible lack of appropriate preparation for parenthood among women with mental retardation who have or want to have children.

The Need for Connections

Mothers with mental retardation need regular, healthy social support. Social support involves both practical and emotional support provided by family and friends. Women with mental retardation tend to have smaller friendship networks and rely more on family for social support. Increasingly, health and social services are shifting many responsibilities to natural supports to provide things like transportation or basic nursing care. When the social network is limited or dysfunctional, the mother with mental retardation is left in a precarious situation. Families in poverty have more demands and fewer resources that must be stretched to help a young mother with special needs. Even in large extended families, there are generally only a few people who have the will and ability to support mothers with mental retardation. In these situations, family members often become "worn out." Frequently, people who start with noble intentions abandon or extract some kind of payment from the mother with mental retardation. One young mother desiring to make a good home for her child rented furniture for her apartment that exceeded her monthly income. The first time the furniture was repossessed, family and friends came to comfort her and supply her with a few basic household items. However, the same furniture company (knowing her monthly income) rented to her again and again. After the third repossession her neighbors and relatives became disgusted and no longer would take her to the clinic or talk to her. The abdication of formal services because a mother "has a big extended family" sets a stage for potential parenting problems. Many measures of social support that we have used rely on a woman counting the number of family and friends she thinks will do things for her. Rarely is it considered that this network might be strained or dysfunctional. Problems mothers have with dysfunctional helpers lead to more serious difficulties. Mothers with mental retardation are susceptible to exploitation by many people. If their environment is populated with dysfunctional people, there is danger of harm to the children.

> *While it is certainly true that not all poor mothers have mental retardation, essentially all mothers with mental retardation are poor. Poverty and maternal disability both pose risks for childrearing.*

The Response of Professionals

Mothers with young children meet health care providers and teachers routinely in caring for their children. These professionals have often learned about developmental disabilities, but only from the perspective of childhood disabilities. Rarely do they recognize or know how to respond to an adult, a parent, with mental retardation. Many young adults with mild mental retardation leave the developmental disabilities service system. This is partly a function of inadequate transition plans and outreach, and partly a personal choice related to the stigma of mental retardation in our society. Most of the mothers with mental retardation I have met over the years would prefer to be called "irresponsible" rather than "mentally retarded." Although mothers with mental retardation are rarely asked by the professionals they meet if they had special education services, many would deny it because of the social stigma. A dynamic is set up in the service delivery system by which maternal disability is unrecognized. Consequently, interactions and expectations by professionals do not fit these mothers' abilities. There is considerable truth carried in the perception of stigma. One of the mothers I have met told me that she always tells the clinic staff that she left her glasses at home because then they are nice to her when they help. If she tells them she cannot read, they are not nice to her.

The Impact of Poverty

Much has been written about children raised by mothers with mental retardation. Rates of developmental delay and child abuse are reported to be higher among these children. A major confounding factor in these outcomes, however, is poverty. While it is certainly true that not all poor mothers have mental retardation, essentially all mothers with mental retardation are poor. Poverty and maternal disability both pose risks for childrearing. One study that identified 100 poor pregnant women, half of whom had mental retardation, followed these families for four years. It was found that maternal-child interaction was the main parenting deficit for mothers with mental retardation. Few women in any society are expected to care for their children in isolation. The kind of childrearing supports women have depends on their abilities, limitations, and socioeconomic resources.

Every parenting situation is unique, and every mother with mental retardation is a unique individual. It is important, however, for human service workers to become familiar with the common issues and needs experienced by mothers with mental retardation. Priscilla was "given a chance" at parenting without an acknowledgment of her support needs, and the result was the pain and loss of being unsupported and of losing her children.

Bette Keltner is Senior Scientist with Civitan International Research Center, University of Alabama at Birmingham. She may be reached at 937/645-8492.

Parents with Cognitive Limitations: What Do We Know About Providing Support?

by Lynda Anderson and K. Charlie Lakin

In considering the ability of persons with cognitive limitations to be successful parents, there has been a tendency to fall back to views of intelligence as a single dimension of mental activity. The idea that people have a set amount of intelligence that determines one's performance in all cognitive activities, including those required in parenting, has prevailed throughout this century. Only in the past 20 years has it been challenged by theories of "multiple intelligences," most often associated with Howard Gardner (Gardner, 1993). His research led him to conclude that cognitive ability is not a single trait, but is an "ensemble" of abilities (e.g., social, motor, mathematical). He does not suggest that there are not central nervous system dysfunctions that can affect people in multiple domains. Difficulties often associated with lower IQ (e.g., difficulties in literacy, meta-cognitive strategies, or perspective taking) do translate into significant challenges in important aspects of parenting roles. However, people who have great difficulty completing verbal analogies, remembering sequences of numbers, recreating visual patterns or performing other mental activities included in a typical IQ test may be more adept in skills of direct relevance to parenting.

What is most important to bear in mind is that, with support, many parents with cognitive limitations do provide appropriate care and stimulation to their children. Most need help with one or more of the many responsibilities of parenting, and a number of factors have been identified as being important to providing that help.

Interagency Collaboration

When parents struggle with parenting and are identified as having limited competence in parenting, involvement with social service agencies (e.g. child protective services, parent education programs, public health nurses) frequently occurs. Often families have multiple service providers working with them to solve their parenting and other family problems. The level of involvement of so many agencies requires a high degree of collaboration on the part of the service providers to develop an integrated service plan with the parents. The Individual Family Service Plan (IFSP), typically used with families to plan for special education and other services for children with disabilities, can be used to coordinate services between agencies for families with a parent who has cognitive limitations. Using an IFSP or adopting a similar planning approach not only coordinates services better, it eliminates duplicative services, limits the number of providers having direct involvement with families, provides for greater consistency in the messages given to parents, reduces strain on parents, and enhances communication among professionals and agencies with different perspectives and responsibilities with respect to parents and children. Parents with cognitive limitations often have many different support needs. Effective supports often depend on a coordinated "division of labor" among all the agencies and individuals with an interest in the family's success.

Access to Ongoing Supports

A number of service approaches have been shown to be effective individually and in combination in supporting parents and teaching parenting skills. These include home visiting programs, parenting groups, center-based programs, and shared parenting models.

Many in-home or home-visiting programs have been shown to be effective in increasing parenting skills and in preventing child abuse or neglect in families headed by parents with cognitive limitations. Effective in-home programs provide an opportunity to model and teach parenting skills in the setting where the parent will use them, making generalization and the transfer of skills easier for the parents. Because in-home programs provide support in the family home, areas of concern such as nutrition, cleanliness, or unsafe housing conditions are easily identified by support providers, and appropriate interventions can occur. In-home programs also benefit parents by assisting in identifying and securing supports they need and assisting them to use services available to them by accessing transportation, developing strategies to decrease missed visits, and so forth. The strength of in-home support approaches is their flexibility to the unique and constantly changing circumstances and needs of each family.

Parenting groups have been shown to be effective and efficient ways to solve family problems and transmit parenting skills. Parenting groups have been used to instruct parents on discipline techniques, child development, health and safety issues, and decision-making skills. In multiple studies of the effectiveness of parenting groups, parents with cognitive limitations have consistently gained skills in these areas after participating. They have also been successful as parent supports in which parents come together to address their own topics and offer advice to peers. Parenting groups have been shown to be most successful when paired with home-visiting by helping parents transfer the abstract ideas and skills learned in the group session to the home setting and by providing for observation and reinforcement of their use.

Center-based programs provide a variety of services to groups of parents and children at a program site, instead of the family home. However, the most effective center-based programs are supplemented with in-home components. Center-based programs have the benefit of being able to provide services to the parent and the child jointly and separately at the same site. Center-based programs typically offer a wider variety of services and instruction (e.g., parenting, cooking, financial support, school enrollment) than parent groups or in-home services, because they serve larger numbers of families over a longer time.

> ***People who have great difficulty completing verbal analogies, remembering sequences of numbers, recreating visual patterns, or performing other mental activities in a typical IQ test may be more adept in skills of direct relevance to parenting.***

When it becomes clear that a parent with cognitive limitations will continue to struggle with parenting when only limited services are provided, some agencies and programs are developing more intense supports for parents and children. Full-time support models have been developed in which the parent and child live in foster care together and the foster provider acts as a "co-parent" to ensure the needs of the children are met. Shared parenting also provides an effective way to help children remain in contact with their parents when their parents are unable to fully meet their needs. When parents are unable to provide adequate care for their children even when receiving intensive supports, open adoption has been used to help parents and children maintain a relationship. Open adoption is a form of adoption in which the birth parents maintain contact with their child after the adoption has occurred.

Research on the short-term and long-term effectiveness of these approaches in supporting families is limited and comparisons between models sparse. Little research has been specifically devoted to parents with cognitive limitations, and most published accounts are anecdotal.

Respect for the Parent

While most published research has focused on parenting by parents with cognitive limitations from the provider/researcher point of view, there has been research on what parents themselves identify as useful and respectful and what they find less useful and more intrusive in supports. Parents have expressed a need for support, but are often unhappy with the way they receive it. They tend to be most happy with support from their partners and believe that family and provider support is often intrusive, rather than helpful. Parents have also expressed some displeasure with supports provided, in that they aren't always what they believe would be the most helpful for their families, but rather are what others believe would be most helpful. Among those approaches that may be most useful to parents are parenting support groups, teaching parents how to exercise their rights and navigate systems, and using family-centered planning approaches that involve parents in deciding what supports and services they need and desire.

Support for the Child

While little has been published about the views of parents with cognitive limitations, even less has been written by or about their children's views of growing up in a household headed by a parent with cognitive limitations. Some children express ambivalence, recognizing the difficulties their parents had raising them, yet knowing that their parents loved them. Some adult children are much more emotional in describing love-hate relationships with parents who were unable to protect them, provide for them, or were a source of embarrassment to them. Often, in the cases of these children, now adults, supports and services were not available to their parents at all. Children in these families often describe the other family members that were important to them, frequently grandparents, aunts, and uncles all had a role in raising them and seeing that their needs were met. In addition, other supports that may help children of parents with cognitive limitations are early intervention services for at-risk infants and young children, after-school homework assistance for school-age children, and recreational and other after-school enrichment opportunities.

Conclusion

Since people with cognitive limitations have the right to live in the community, marry, and have children, and since the importance of stable families to children is undisputed, it is important to find effective ways to help parents with cognitive limitations provide adequate care to their children. These parents face major challenges, and yet, many become successful parents. Like most parents, they tend to be more successful when they have a strong support system.

Reference: Gardner, H. (1993). *Frames of mind: The theory of multiple intelligences* (2nd ed.). New York: Basic Books.

Lynda Anderson is a Research Assistant, and K. Charlie Lakin is Director with the Research and Training Center on Community Living, University of Minnesota, Minneapolis. Lynda may be reached at 612/626-7765 and Charlie at 612/624-5005. A list of references related to this article is available from Lynda.

Perpetuating the Spirit of Kako'o

by Stacy Kong

"Kako'o" is a Hawaiian term given to behaviors that are supportive; they do not dictate, and they do not speak for the person being supported. Someone who acts with "kako'o" is a person who paves the way, makes sure all the necessary details are taken care of so that those who are being supported can do what they need to do. A "kako'o" is always in communication with the person being supported; those "kako'o" who have excelled in this role are usually persons who have perfected their listening and observational skills to where they are able to anticipate the needs of the person they support. The spirit of "kako'o" is the guiding theme of this project.

Parenting can be a challenging job for anyone. Parents with disabilities may need extra support in tackling the challenging responsibility of meeting the needs of their child, especially if they don't have a strong natural support system in place. Early intervention is beneficial for the children of mothers with cognitive challenges. Ramey and Ramey (1992) found that children of mothers with low IQs responded positively to intensive, high-quality early intervention leading to a dramatic increase in child development indices. It is also true that, with intervention, parents with mental retardation can improve their parenting skills to benefit their children .

In response to the request from early intervention providers for more intensive services in working with parents with cognitive disabilities, Hawaii began to address the needs of these families during the past few years. In 1995, the Zero-To-Three Hawaii Services Section, Department of Health, was funded by the Early Education Program for Children with Disabilities of the U.S. Department of Education to begin a five-year model demonstration project, Project Kako'o: Supportive Parenting. The project provides additional supports to families where a parent with a cognitive disability is raising an infant or toddler. It also expands the awareness of service providers regarding this population through community education and training. The uniqueness of Project Kako'o is the use of volunteers to provide the additional support. Staff and volunteers are integrated into the existing system, rather than creating a separate delivery system. They do not replace professional and paraprofessional staff working with the family, but assist the parents to incorporate newly learned skills into their everyday lives.

Parents with at least one of the following criteria, *and* who have a child under the age of three, are eligible for additional support through Project Kako'o:

- Attended special education in high school.
- Currently receives services from community programs for individuals with mental retardation.
- Works or has worked in a program designed for persons with mental retardation.
- Has cognitive limitations reflected in the need for support in areas such as self-care, communication, following directions, parenting their child, and independent living.

Thirty-two families have participated in the project. The majority have continued to raise their children in their homes. Six families have had their children removed from the home by Child Protection Services: two families due to "failure to thrive," which may be a result of the parents' cognitive limitations, and the other four because of substance abuse and/or domestic violence that were interfering with their ability to meet the needs of their children. Some may argue that their decision to be in unhealthy situations were directly related to their cognitive disabilities; however, I believe that it was their life experiences and environments that played a bigger role in the choices they made. For example, some common elements of these families are growing up and continuing to live in poverty and abusive environments, and lack of a healthy and stable natural support system.

The earlier a family receives supportive services, the greater the chance of developing and strengthening the skills needed to meet the needs of the child. To be effective, supportive services must be a collaborative team effort that includes the family in the entire process. Having a "friend" or support person such as those available through Project Kako'o to help guide parents in knowing who and when to call for help increases their problem-solving and coping abilities. They become empowered and their self-confidence increases as they learn new skills and realize that someone believes in them. Some examples of the support volunteers of Project Kako'o provide to families are reinforcing what is taught by other providers, providing transportation, teaching meal preparation, going on community outings, and talking about concerns.

Family-centered care principles are the heart of Project Kako'o. The project recognizes that families are the constant in the child's life and, therefore, systems and personnel must respect and support families to enhance their capabilities in meeting the needs of their children. There is no magical formula when working with parents with cognitive challenges. It's "walking the walk" – putting family-centered care principles into practice and not changing the rules because of a person's disability.

The following are some tips and tools that we have found helpful in working with families with cognitive challenges: Start where the family is; ask them how they learn best and/or observe to see how they learn best; adapt your teaching style to meet their learning style; repeat as many times as needed; reinforce the positive; teach in natural settings; demonstrate; role play; provide opportunities for the family to practice and succeed; and celebrate successes. These suggestions would benefit any family, regardless of their ability or disability. A person's cognitive limitation does not determine the love they have for their child or the kind of parent they can be. This is clear when parents such as Kayleen talk about their lives.

Kayleen's Story

The first time I met Harold was when I worked in the Dole Cannery Cafeteria. I had a crush on him. My friend introduced us and then we started dating. Our first kiss was in the supply closet. I loved him from the first day I saw him. Some days we would watch movies, go to the beach or go shopping together. We had so much fun together.

Harold and I waited one year to have kids. When I was pregnant, Harold and I were happy to have a kid of our own. I was a little scared and giving birth to Haroleen was hard. When I was in the hospital, someone came to talk to me and told me that Hana Like (a part of Healthy Start) would be calling me. The Hana Like worker came to my house twice a week and taught me activities in the play book to do with my kid. Hana Like also taught me how to massage Haroleen to build her strength. Queen Liliuokalani Community Center (QLCC) also came and helped me with how to make decisions about my child and how to discipline her. When I had Haroleen, she was very slow in development so I took her to therapy every week. At that time, I was assigned to a public health nurse. She helped me complete a course "Read With Your Child."

When Haroleen was three months old, I got pregnant again. Harold and I were very happy again. We took care of our kids with a little help from my mom and family. My mom taught me how to give the kids a bath and how to feed them. It was fun to play with them every day. When I had Hannah Rae, it was so different. She was a very normal child. Hana Like asked me if I wanted a Supportive Parenting Volunteer. When I got Supportive Parenting, I felt more comfortable and liked the help. The volunteer was fun; we went walking and he helped me do what Hana Like was teaching me. I like going on the Supportive Parenting Project outings because I meet other people.

When I graduated Hana Like, I joined their Family Advisory Board. It feels good to be a part of that. We help decide what Hana Like can do to make their program better for families.

The girls are now ages 4 and 5. It's less stressful than it was before. They go to school and I go in and help Hannah's class. I help the children get things done. It's a good experience for me to help me learn what my child is learning. Haroleen is doing so much better now than before. Before it was hard because I was all alone; Harold worked at night, so having people come in was helpful. It's much easier now.

I love my kids. When the kids are sick, I take good care of them. We raised our kids from newborn. It's fun to see them grow up. All the workers made me feel better about myself and build my self-esteem. I am looking forward to the future.

References:

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Stacy M. Kong is Coordinator of Project Kako'o, Honolulu, Hawaii. She may be reached at 808/942-8252.

What Parents Want in Support Services

The Wisconsin Council on Developmental Disabilities has undertaken a number of learning projects to discover and promote the policies, practices, supports, and opportunities that are seen as helpful by parents with cognitive disabilities. We have learned that parents experience the following as effective support:

Build a trusting, mutual relationship with parents.

Acknowledge the parent's role as head of household.

Appreciate the love between parent and child, despite the problems.

Offer sustained, practical support directed toward building the parent's own skills and confidence.

Match the family with support personnel who have a genuine liking for the family.

Recognize the emotional needs of parents, and build parents' self-esteem and confidence.

Mobilize community supports; connect with other agencies involved with a family.

Integrate formal services with the support and involvement available from the extended family, neighbors, and friends.

Turn to the parent to determine the most effective direction for support.

Develop an advocacy role representing the family to the service system, rather than presenting oneself to the family as an agent of the system.

Contributed by Howard Mandeville, Wisconsin Council on Developmental Disabilities, Madison.

Supporting Parenting Rights: Arc Hennepin

by Lori Gildersleeve

Arc of Hennepin County is a non-profit organization that provides services to individuals with developmental disabilities and their family members, addressing issues in all areas of life including parenting. In 1995, we developed a position statement, *Parenting Rights of People with Developmental Disabilities,* which includes the following:

> The choice to parent is a basic human right. Yet, parents with developmental disabilities have often been denied this right based on an assumption that a child is "better off" in the care of someone else. Parental rights have often been terminated solely on the basis of disability without regard to the parent's actual abilities....Arc of Hennepin County believes that, in most situations, the natural parents are the best source of love, support, and care for children. To enable children to remain with natural parents, supports may need to be provided...

One of the many services we offer to parents with developmental disabilities is the Moms' Group, a collaborative effort between Arc and Southside Community Services. The group meets weekly on Mondays. Topical discussions on parenting are offered on the first and third Mondays of the month, an open group in which participants discuss life issues and concerns is held on the second Monday, and on the fourth Monday a guest speaker from a community resource agency joins the group to offer information on selected topics. The group has been an invaluable source of support for many mothers, reducing their isolation as well as helping them experience a greater sense of belonging and purpose. We operate under the assumption that providing emotional support to the moms is going to have a positive impact on their children. One mom who has found that to be true in her family's life is Dolores.

Dolores' Story

I grew up on a farm in northern Minnesota near the town of Plummer. The house that I grew up in had no electricity or indoor plumbing. I went to school with my three brothers and three sisters. I didn't receive any special education services because there weren't any.

When I was 21 years old, I knew that I didn't want to stay in Plummer. I answered an ad in the paper to be a live-in housekeeper for a family in a suburb of Minneapolis. I borrowed my dad's little suitcase and used my graduation money to buy a bus ticket.

I thought the house that the family lived in was a palace. It had carpet, electricity, running water, and a telephone. The woman I worked for taught me how to use an electric broom and how to make the beds a certain way. I was paid $20 a week. I never had that much money before.

Later, when working at a hotel in downtown Minneapolis, I met Ronnie. Ronnie and I were married in 1967 on a shoestring budget. In 1970, my son Troy was born. In 1971, Paul was born, and in 1981, my daughter June was born.

In 1987, I was very depressed. It was such a bad year. My husband had an operation and there was a tornado that hit our neighborhood and caused flooding. I was so depressed that I couldn't cook food or do anything for June and myself. Paul and Troy were older so they were able to take care of themselves, but June was only six.

I developed a phobia of electricity. I didn't dare open the refrigerator, cook food, or turn on any lights. I became so depressed that I couldn't sleep at nights. I stopped walking June to school because I just couldn't go with her. She was too little to be walking to school by herself. I didn't know what to do and my family didn't understand that everything was too much to cope with.

Finally, Ronnie took me to a psychiatrist. Each week, I would go to the psychiatrist and he would tell me to do things with electricity going step by step. Each week I would do something different until I could open the refrigerator again and do other things.

While I was going through my depression, a woman reported me to child protection. They said that I was neglecting June. Then a man came over and he wanted to take June away. He didn't understand me. I didn't like how he treated me, like I did something wrong.

Then I met a county social worker who told me about the Moms' Group. When I first started going to the Moms' Group, I didn't talk much. They asked me questions and we talked about different things. I've now learned to talk more to people. Even at home I wasn't telling people what I was thinking or feeling. When I was unhappy, I would pack a suitcase and put it in the hallway. It would stay there until Ronnie would put it away. Back when my children were younger, I felt like I was in prison. I stayed home and didn't think about different things that I could do. I felt controlled. Since I've been in Moms' Group, I've done things that I had never done before, like camping and sleeping in a tent during the annual Moms' Group retreat. Being listened to gives me hope that I can do things for myself and I don't have to be a slave. I've learned to ignore things people say that I don't like.

[Dolores, continued on page 27]

Two Decades of Parent Support: Reuben Lindh Parenting Program

by Audrey Kvist

In the past 20 years, Reuben Lindh Parenting Program has served over 600 parents with developmental disabilities. In recent years, young women whose mothers were among our first clients are participating as they become parents.

It was in the late 1960s that Dorothy Mollien began providing preschool services in South Minneapolis for young children with developmental disabilities. As teachers worked with these children, it became evident that some of the delays were due to parents not providing appropriate stimulation for their children. As staff got to know the parents of the children, they found that these delays were present not because of a genetic or biological reason, but because the parents had never been taught basic child care or child development. In many cases, the parents had not received adequate parenting themselves so had few positive memories of warm or nurturing parents. That discovery became the base from which the Reuben Lindh Parenting Program was formed.

In 1977, the Parenting Program became a reality. It is an in-center program providing transportation for mothers living in a limited metropolitan area. Fathers attend groups specifically for them at different times when a couple is co-parenting. Two groups of 10-11 families attend as often as four half-days a week. One "intake" group of five to six families attends one day a week. Loosely structured classes and discussions focus on parenting, child development, self-esteem, relationships, cooking, nutrition, health, sexuality, family planning, remedial reading, math, and money and time management. At least one session per week is devoted to a parent-child activity in which parents and their children share a meal, play time, and music. This session gives the staff an opportunity to provide hands on demonstrations and to observe the interaction between parent and child. It affords a prime opportunity to intervene and model appropriate parenting. In addition to in-center groups, time is spent working in the home of each family on a one-to-one basis. Our intensive time commitment allows us to become primary supporters to each family and we often act as intermediaries between other service agencies and the families.

The Parenting Program is part of a larger agency providing an array of services, including a therapeutic preschool, family counseling, family services for chemically dependent clients, and services for families reuniting after foster care. A small staff also provides a visitation program for families whose children are in foster care. Much of the funding for Reuben Lindh programs comes from Hennepin County contracts, largely in the Early Childhood Division, and from United Way.

While there is no typical participant in the Parenting Program, mothers attending it are usually young, single women who have one or more children and who live with or near their babies' fathers. Some are currently involved with child protective services and their children may be in foster care. Almost all were victims of physical, emotional, and/or sexual abuse as children. Some were "raised by the system," that is, removed from their parents' custody and placed in multiple foster homes. Sometimes the abuse continued in foster homes by the very people who were supposed to be protecting them. Adults who endure such childhoods have great difficulty forming healthy attachments. Consequently, parents whose needs were not met as children are less able to meet many needs of their own children. A large part of our program is providing a nurturing setting in which these adults can be reparented, building their self-esteem and healing some of their trauma.

We have devised an evaluation tool comprised of eight criteria that the clients in the Parenting Program are expected to meet. Criteria include indicators of willingness to change behaviors; attachment to child/children; adequate physical care for child/children; secure, stable environment for child/children; realistic expectations of child/children; knowledge and use of appropriate methods of behavior management with child/children; and ability to make appropriate choices for self and child/children. These are basic knowledge and skills that any family would need to ensure the safety and well-being of their children. This tool provides concrete goals that clearly spell out what parents have to accomplish. Closely working with each family to strengthen and enhance parenting skills hopefully will enable families to remain intact.

However, there are families in which "permanency" means that children are not reunited with their parents, but placed in permanent foster care or placed for adoption. While this is a devastating outcome for both parents and children, it is often the best solution. This outcome appears to have a direct relationship to the seriousness of the abuse suffered by the parent as a child. As we tell each parent as they enter the program, "We believe that parents have a right to raise their own children and we also believe that children have a right to be safe and to be loved."

Contributed by Audrey Kvist, Director, Parenting Program, Reuben Lindh Family Services, Minneapolis, Minnesota. She may be reached at 612/721-5111.

Supporting Fathers with Cognitive Limitations

by Mark D. Simpson, Steven W. Roecklein, and Bruce L. Kerber

Fathers with cognitive limitations are frequently under-served by programs providing support and education to parents. The Hennepin County Parent Support Project and Reuben Lindh Family Services are two programs that have worked extensively with fathers. The Parent Support Project, which has operated for 10 years, is part of the county Developmental Disabilities Division providing home-based services to families in which one or both adults have a cognitive limitation. Reuben Lindh Family Services is a private, non-profit social service organization that for 20 years has worked with families headed by parents with cognitive limitations. Through our experiences with supporting fathers in both programs, we've learned some lessons about what works in meeting the needs of this often invisible group.

Fathers with cognitive limitations have usually been the secondary recipients of parent education services. Many of the factors that traditionally limited the involvement in parenting of fathers in general are also true for fathers with limited cognitive ability, including: the bond between child and mother that results from the birth and feeding experience; self and/or social definition of the father's role; living away from the home; poor attachment experience with their own parents; abusive or violent behavior; and questions of paternity. We have found that many fathers can and do respond to support and encouragement to take an active, or even primary, parent role with their children.

Both programs start with determining what strengths each participant presents. This, combined with an assessment of individual and family needs, gives a more balanced picture of each parent. One common strength with the fathers is an interest in completing tasks. The fathers we serve typically respond best to a well-defined focus to problem solving, a focus that covers the issue from the beginning, to the current situation, to the anticipated conclusion. Side tangents and an array of options only tend to complicate the effort. The following is an example of this method. A single father was outraged with the staff at his child's daycare. There had been a serious oversight in the transportation of his child. When the father's caseworker arrived at his home, the father declared that he was planning to end the child's participation at the daycare. The worker had long supported the daycare service because it provided basic nutritional needs, the child was making rapid improvement in language development, and the father was able to work part-time. During the discussion the father revealed that there was a history of conflict with some of the transportation staff, including his experience of being treated disrespectfully. The father's conversation bounced between the present issue and the various past incidents with no clear connection or direction. The worker asked the father to clearly state the sequence of events. Together they developed a written report of what the problem had been, what his specific feelings had been, and came up with some ideas about who he should talk with regarding each problem.

Many of the fathers with whom we work want to fix things by minimizing the problems and focusing on the end point. They may, for example, want their children to behave simply because the child was told to do so. These fathers often overlook factors such as the context of their child's behavior (e.g., a change in a child's routine); the nature of the parent-child relationship (e.g., the child may need some time to connect with the father); as well as the child's developmental phase. By supporting fathers to look at the needs of their children, these fathers are less likely to feel failure or rejection when parenting.

We find that there are a number of common factors that challenge these fathers. It is not uncommon for many to have significant emotional and educational barriers that make it difficult for them to learn how to care for their children. In addition, many of the men are new to the whole arena of raising children. They have had few successes in this area, and often few successes in other life roles. They are frequently from racial or class backgrounds different from those of the workers who assist them with their families. They may have heard from family and friends that the social service system is intent on disbanding their family rather than helping keep the family together.

Our experience is that the fathers respond well to workers who directly acknowledge the father's role in the child's life. They also open up when the workers seek to uncover personal areas of success and competence, beginning with their understanding and unique knowledge about the child. It may also include some of the traditional male interest areas of sports, cars, and stereos. Fathers who are respected for their past learning will have more confidence that they can be successful learning new tasks of caring for their children.

We recommend that any person working with this population be alert to these men being very sensitive to the opinions and judgments of others. Fathers with a cognitive limitation may have become skilled at monitoring and mirroring social exchanges. They may focus a considerable amount of energy trying to get along with others. The advantage of this learning style is that they may be willing to try to learn from modeling the skills of others. In the home, the workers may be able to engage the child in a task, modeling the desired behaviors, and then switch roles with the observing father.

Group settings may be particularly effective in teaching fathers. They can be encouraged to discuss common issues between themselves, and avoid some of the expert-student tension. Feedback from peers may be received more readily than that from professionals.

Our two programs encourage parents to care for both the physical and emotional needs of their children. Often fathers are good planners and excellent at using their heads, or thinking skills. We believe that men could benefit by paying more attention to their hearts, or feelings, as they interact with their children (and partners). One way to assist fathers with their hearts has been to present the concept of Emotional Intelligence, or E.Q. (Goleman, 1995). Here the emphasis is to recognize, identify and express emotions among family members. By bringing emotions into the parent-child relationship equation, a missing part is addressed. Raising one's E.Q. completes the father because he uses both his intellect and his feelings.

Often fathers have either taken a passive role in the care of their children or have been relegated this role by the social service programs and helping professionals. Thankfully this is changing and change it must. Men are capable of being sensitive, nurturing, and effective parents. Education and support are, however, needed. Approaches that value these fathers for what they know and can achieve, instead of where they have failed, will be the most effective.

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Mark D. Simpson is a Senior Social Worker and Bruce L. Kerber is a Unit Supervisor with the Hennepin County Parent Support Project, Minneapolis, Minnesota. They may be reached at 612/348-5869. Steven W. Roecklein is a Family Therapist at Reuben Lindh Family Services, Minneapolis. He can be reached at 612/721-5111.

Darin and Diamond

As I was growing up, I came from a good family. A big family. I had a good dad in my life; I had a good mom in my life. They showed me what was right. They showed me the right road to go. We saw them struggling, trying to better themselves. I saw my dad doing things, you know, working with us kids, taking us to a lot of places. For me now, raising a child, I give what my father gave to me. That was having responsibilities, becoming a man before becoming anything. Today, as we talk now, my father is looking at me [he looks skyward]. I just want them to know I took it seriously.

Maybe I was a kid and joking around, but when my daughter got into Child Protection it kind of, how can I say this, woke me up because it was a serious thing. I knew that it was a human being involved. When we were raised up we didn't come from a family that had been in homes and like that. It was kind of a shock when the County people stepped in. I broke down and cried. But my brothers and sisters sat me down and let me know that I was raised from a good family. "You're the dad," they said, "and you can bring this child home." They gave me the support and love I needed. They keep me strong. I had got to the point of, "What do I do? I don't know what to do. They took my baby. What do I do now? I don't even know how to approach them. These are people I don't even know. This is new to me."

So, I went to the County and said, "Hey, I'm new to this. As a dad, what are my rights?" And they calmly sat me down and told me my rights and what I would have to do to get my child back. They called that the case plan. I said, "Well, what is the case plan?" The case plan, as told to me, was parenting class, urinalysis, and all that. So, I did all that. I worked with a lady who came into my home [from the Parent Support Project]. She's another one that I thank to this day for having belief in me, giving me all of the support I needed at that time. She gave me the belief that I could do things.

My child went into foster care. It was a hurting feeling to see her cry. I'd leave her in the van that took her back. The strong person I am, well, I'd say, "It's going to be okay, Diamond. Daddy's going to bring you home." I always had belief in that. I knew what I had to do and it was serious. I basically followed my case plan. And any person who has a daughter with the State, in my opinion, should be all for it. I mean, the case plan is not hard. I told her, "Daddy will bring you home" because that's what I want in life – to bring this child out of the system.

When she came home it was a real happy feeling. And it was like, now what do I do? Now, I'll be a daddy. I stopped all of my activities, I stopped my social life. Well, not all my social life. But, going out and stuff like that. At this age, Diamond be two, she needs someone to be with her at all times. She's into that age when she needs caring. It's not hard. It's my love going out for her. I just want her to know that everything is going to be okay. And with her progress, it's showing me I can do it, I can be a daddy.

Darin is a participant in the Hennepin County Parent Support Project and Reuben Lindh Family Services.

Parents With Cognitive Limitations: Challenging Myths, Changing Perceptions

by Alexander J. Tymchuk

In the early 1970s I received a call from a pediatrician working in the largest children's hospital serving people living in poverty in Los Angeles. She was requesting assistance with a young couple. It appeared that neither the woman nor her husband fully understood the consequences of their request for an abortion. It also was unclear to the pediatrician whether the woman was in fact pregnant and what were the actual circumstances of the pregnancy. Based on the couple's report, both had been in special education and both had been told that they had mental retardation. They were married, living in an apartment, and surviving on the man's salary from a supported employment setting as well as on what the woman could earn doing housework for others. The pediatrician was alarmed by the couple's serious and dangerous view of what to do before, during, and after pregnancy to ensure integrity of the fetus and care for an infant. She knew that for persons with mental retardation raising children was often presumed to be out of the question. And yet she also knew her responsibility to look carefully at the individuals and their circumstances. She called me, and I saw them the next day.

This call and visit changed my life. It turned out that the man had serious learning problems associated with his low cognitive abilities. The woman had serious learning disabilities and associated poor vision for which there had been little adaptation of methods while in school. She had rudimentary reading abilities and her general level of knowledge and skill in most areas was low. Her life had been difficult with limited models for adequate parenting. However, she knew how to survive and could speak out. This family was like many families being seen in our clinics: they had complicated issues to address in their lives.

At that time there was little scientific information on which to base a supported parenting model. With limited empirical evidence available regarding parenting by persons with cognitive limitations, many of the families were judged *a priori* as unable to provide such care or to learn how to do so. There was a complete disregard for individual autonomy, a state of affairs that continues to exist in many places today. One of my first court appearances taught me a valuable lesson when, as I presented testimony regarding the necessity for suitable services and supports for a woman and her infant daughter, the judge asked: "Do you have any scientific information to back up your claims?"

With my colleague Linda Andron at the University of California – Los Angeles (UCLA) and with limited resources we began to develop a multi-faceted program to provide scientific information of use in this challenging and ambiguous area. The program was called the SHARE/UCLA Parenting Project. Given the incredible degree of scrutiny to our contention that individuals with cognitive limitations could be adequate parents, we steadfastly adopted an empirical approach to assessment, treatment, curricula development, and program evaluation. We were probably seen by some as stubborn in our persistence in assessing individual abilities and needs, matching interventions to those needs, and assessing intervention outcomes. From all this, however, we were able to begin to build a knowledge base to support our approach.

Our resulting clinical program was designed to treat the child, mother, and father individually as well as within their relationship. We worked to incorporate naturally-occurring supports into the lives of these families. We provided training and did competency assessment and expert testimony. While program services were delivered for several years both within UCLA and in the community, eventually they were delivered solely within the community.

With the help of others we were able to start to identify barriers to integrating service delivery for families among the agencies with which low income, often minority, individuals with disabilities and their families interact during their lives. Based upon our findings, we obtained funding for the UCLA Parent/Child Health and Wellness Project. The project has conducted a random clinical trial of two approaches to self and infant injury prevention, as well as education with young low income parents or expectant parents. A major goal of this project has been to work across agencies to provide integrated services to mothers who do not learn following traditional methods.

So, after 25 years what have we accomplished and what is left undone? What once seemed to us like an isolated endeavor has become one with growing numbers of colleagues. Conferences are held by organizations around the world to address the supported parenting needs of persons with cognitive limitations. We provide legal and legislative testimony nationally and internationally. Requests for training come from around the world, and scholars and professionals come to spend time with us at UCLA. Having already won a substantial settlement in one court case, a class action suit has been brought against a jurisdiction for involuntary sterilization of several thousand other people on the basis of "unable to provide intelligent parenting." Twenty-five years later we are taken seriously as an issue and as a field.

Alexander J. Tymchuk is Professor in the Department of Psychiatry, School of Medicine, University of California - Los Angeles. He may be reached at 310/825-8473.

Supporting Parents and Children During Termination of Parental Rights

by Deborah Muenzer-Doy and Lynda Anderson

In the U.S., over half of the parents with cognitive limitations will at some time experience permanent or temporary removal of their children from the family home. This may result from parents lacking the judgment needed to provide safe homes for their children, being unable to adequately learn the skills necessary to care for their children, having inadequate support, and in some cases may even be influenced by misperceptions on the part of family or professionals about the ability of persons with cognitive limitations to parent. Whatever the reasons, losing a child through termination of parental rights is a devastating, confusing, and heartbreaking experience for parents and children. Yet, few supports exist for families when parental rights have been terminated.

At Nekton, we provide an array of services for persons with cognitive limitations and their families, including services to those in this most difficult of situations. When children are temporarily removed from their home by child protection services, the child protection system develops a case plan for the parents stipulating actions they must take to regain custody. At this point Nekton provides individualized parent education and support to help them fulfill their case plan and develop skills needed to regain and care for their children.

Unfortunately, some parents are unable to assure a safe and nurturing home for their children and parental rights are terminated. One of the best scenarios in this unfortunate outcome is when the parents reach the conclusion themselves that it is in the best interests of the children to be raised by someone else. If parents make the decision to voluntarily terminate parental rights, Nekton staff support them, communicating with the parents that this is a loving decision and that they are indeed planning for the best for their children.

More often, however, parental rights are terminated involuntarily. Often parents choose to go to trial to regain custody of their children, which is a very painful experience for all involved. If the judge has determined that a termination of parental rights is warranted, then the parents lose all contact with their children. Understandably, parents often become angry at the loss of their rights, and may also feel shame and guilt that it was believed that they were unable to be good parents to their children.

Both parents and children experience feelings of grief and loss that endures long after the separation of parent and child, regardless of how the decision to terminate parental rights was made. While no one can completely repair such damage, parents and children can be helped to deal with their feelings in a number of ways.

Having a connection with their roots is important to children, just as knowing that there is a connection to their children is important to parents. One of the ways Nekton facilitates this when parents and children will be separated is to create a "Child's Life Story Book". This book contains the history of the child's life with the birth parent. It may include the birth certificate, photographs, a written family history, letters to the child from the parent, and whatever else is deemed important by the parents. A copy made for both children and parents to give them remembrances of the bond they will always share.

When rights and contact are terminated, a final meeting is also scheduled with the parents and the children to say goodbye. While this meeting can be filled with emotion, it is necessary to give the children and the parents a sense of closure by helping them grieve and begin to continue on with their lives. The parents are helped to communicate with their children that what happened was not the fault of the children, that they love their children though they can't take care of them, and that the children have permission to begin a new life. The meeting is videotaped for the children and parents to keep.

Unfortunately, the final meeting is often where the support ends for the parents. Many parents fill the void of their lost child by having another child, perhaps starting the cycle over. Clearly, ongoing supports are needed, including assisting parents to find counseling to deal with their feelings of grief over losing their children. Counseling may also help the parents address issues such as anger management, chemical abuse, or a personal history of sexual abuse that may have interfered with their ability to parent. Ongoing support groups for parents who have had their parental rights terminated would also beneficial.

Perhaps most importantly, parents need to be respected, treated with understanding, and allowed to have their feelings about the loss of parental rights acknowledged. By helping them come to understand that giving their children to somebody else to raise can be an act of love, we can help them move toward making peace with the decision.

Deborah Muenzer-Doy is Program Director of the Nekton In-Home Family Program of Nekton, Inc., a service provider in St. Paul, Minnesota. She can be reached at 612/644-7680. Lynda Anderson is a Research Assistant with the Research and Training Center on Community Living, University of Minnesota, Minneapolis. She may be reached at 612/626-7765.

Strengthening Families of Older Children

by Gwynnyth Llewellyn

What determines how parents "parent"? Beliefs about good parenting play a part. Our own parents play a part – how we were parented becomes the "default mode" when raising our own children. Parents also strive to do better with the next generation. Family factors also influence parenting. Each child is treated differently, despite parents' best intention, and each child affects their parents in different ways. Parenting behaviors also change over time. Parenting a twenty-four-year-old is very different from parenting a four-month old, a four-year-old, and a fourteen-year-old. There is speculation, but little hard data, about which parenting behaviors are needed when. There is even less evidence about how to prepare parents, in advance, for the next stage of parenting.

> *There are new parenting challenges presented in middle childhood, when children are around 6 to 12 years of age, as contrasted with early childhood.*

There are new parenting challenges presented in middle childhood, when children are around 6 to 12 years of age, as contrasted with early childhood. Prior to this time, the young child's world is mainly defined by household and family activities. When the child begins school, this changes dramatically. Parent and child are now part of a much wider community with increased expectations to conform to social and cultural mores. For parents with cognitive limitations these expectations can present major challenges in three areas: academic, social, and community expectations.

Academic Expectations

By academic we refer to the expectations placed on children's learning. Society values academic achievement. Parents are expected to support and engage in their children's learning. This translates into helping with homework, encouraging reading, stimulating interests, and providing opportunities for learning out of school time. Parents with cognitive limitations are hit hard by these expectations. With low educational levels, and literacy and math difficulties, often there is little they feel they can do to help their child. Their living situation may also mitigate against academic learning with limited access to reading material, restricted space or time for quiet reading or number work, and little concern for routine or regular bedtimes.

Several strategies are useful for homework and learning dilemmas. A family member, friend or an older neighborhood child may be happy to take on this role with the parents' consent. Supporting parents to recognize their difficulties without recrimination is essential. It is critical that the school is sensitive to helping the parent to fill in forms, monitor homework, or prepare items for show and tell. The parent-teacher relationship works well when teachers take the time to listen to parents – most parents with cognitive limitations will want to share information about their children verbally. Some parents have no one to offer homework support to their children. A school may be able to offer after-school homework assistance in small groups to children and parents.

Social Expectations

When children enter school there is a general expectation that they will listen, do as they are told, be quiet on request, and take turns. Learning these behaviors at home is more difficult for children who come from isolated families – and mothers with cognitive limitations are often among the most isolated in the community. Preventive activities are more likely to be successful than attempting to enforce "strict" rules on school entry. Every effort should be made to place young children in daycare or preschool settings so that they experience appropriate adult and child behaviors well before going to school. For the school-age child, active involvement in after-school activities, camps, and neighborhood programs is usually necessary to supplement the home environment. As children enter adolescence and their peer group becomes increasingly influential, relationships and appropriate relationship behavior may become a concern. Parents with cognitive limitations may need assistance to identify appropriate boundaries and to learn strategies to guide their adolescent children through these potentially turbulent years. Parents may also need help in establishing routines and ensuring their adolescent children remain involved in family activities.

Community Expectations

Community expectations of parents of 6- to 12-year-old children are high. We expect parents to enforce discipline, stimulate learning, help their children develop friendships, communicate with their children, help develop self-esteem, keep their children healthy, and prevent alcohol and drug use, sexual activity, and criminal behavior. This is a tall order for all parents. For parents who rarely have appropriate past or current role models, few financial resources and friends, and limited work opportunities undertaking these tasks alone may overwhelm them. All parents need some support with parenting; parents with cognitive limitations need supported parenting to meet community expectations.

In our discussion on academic and social expectations, we focused on child needs and support strategies. In this section we focus on parents' needs. First and foremost, the parents need to be acknowledged as their child's parents. This is particularly important when several others are involved with supporting the child. Mandatory consultation with parents, respect for their wishes, and promoting their involvement in every matter affecting their child – even when the child is primarily residing elsewhere – are fundamental to successful parent-caseworker relationships. In foster care or shared parenting, the parents' advice on matters ranging from getting a haircut to picking the child up from school to organizing residential and holiday arrangements must be sought. It is easy to slip into subconscious denial of the biological parent. However, no matter what the future holds, the child will always remain the biological parents' child; conversely, the parents remain the child's mother and father.

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Providing opportunities for parents to learn the skills and behaviors expected by the community is also fundamental. One of the best ways is by supporting parents to engage in school activities. This could include serving in the cafeteria, working in the school library, assisting in the playground or whatever other activities the school offers. In this way, parents get to see other children and parents in action. The child's classmates also get to know his or her mom or dad. Younger children thoroughly enjoy their mother and/or father being part of school, although as children get older this may change. Negotiating parents' appearances at school then needs to be done with parents and children together.

Parent-Child Roles

A contentious issue is whether, as children get older, they take on the parenting role for their parents with cognitive limitations. This statement oversimplifies a complicated issue. Certainly, many children take on math and literacy tasks associated with parenting such as filling in forms, reading notices, and obtaining Social Security benefits. These tasks may also be done in families where parents do not have cognitive limitations such as families for whom English is a second language or where parents have physical or sensory disabilities. A child taking on one task does not mean that the child has, in effect, become the parent. Parenting is also about authority, unconditional love, and adult experience in the face of the child's developing engagement with the world. It is uninformed to suggest "role reversal" when we know so little about how parents and children experience their changing roles during middle childhood.

Family Isolation

The final concern is the isolation that parents with cognitive limitations experience in their communities. For some, their living situation has been an across-generations experience of being a "welfare" family. By definition, being on welfare places parents in a subordinate and passive role. They may receive less information and poorer quality services or none at all on the grounds that they are non-compliant or unlikely to benefit. Advocating for and empowering parents with cognitive limitations is therefore a fundamental task for service providers.

Empowering parents to take control and speak up for themselves can be best facilitated by the group process. In Australia, several group programs have been successful in not only helping parents to manage difficult behaviors in older children, but also to seek support from each other and relevant community personnel. A successful Danish program uses the group process for parents with cognitive limitations to air their feelings, to share experiences, to learn skills, to provide support, to develop competence in social relationships, and most importantly to build hope and strengthen their ability to act on their own behalf. Finally, the group process provides a sense of community for parents and children with holiday camps, family nights, and child-minding clubs.

Conclusion

Parents with cognitive limitations are parents first and people with disabilities second. Their parenting is shaped by influences that are common to all parents. They may additionally be especially challenged by inappropriate or non-existent parenting role models, little or no experience of children's developmental needs, relationship problems, and poor financial, living , and employment situations. As their children grow older, the challenges of early childhood give way to those of middle childhood with its changing academic, social, and community expectations. By employing the strategies presented here for supporting parents with cognitive limitations and their children, the family relationships can become a solid cornerstone for the growing child's ever-widening engagement with the wider community.

Gwynnyth Llewellyn is Director of the Family Support and Services Project, and on the Faculty of Health Sciences at the University of Sydney, Sydney, Australia. She may be reached by e-mail at G.Llewellyn@cchs.usyd.edu.au

The Adult Children of Parents with Learning Difficulties

by Tim Booth and Wendy Booth

Parents with learning difficulties* are widely presumed to present a high risk of parenting breakdown. Studies have reported high rates (40-60%) for the removal of children from the family home. Research also suggests that the children of parents with learning difficulties are at risk of developmental delay, maltreatment, neglect, and abuse. This evidence has contributed to the view that people with learning difficulties lack the competence to provide good-enough parenting and is often used to support a general claim of parental inadequacy.

The study outlined here arose directly from our earlier work on parents with learning difficulties (Booth & Booth, 1994), which documented their lives and struggles through personal accounts of their own experience of childrearing and parenthood. This research showed that such blanket judgments of parental incompetence are not grounded in the lives of parents themselves. People with learning difficulties frequently fall victim to an expectation of parental inadequacy that is made real through the decisions and actions of those with the power to intervene in their lives. A common response to this research was that we had argued a case for parents that did not take account of the interests or welfare of their children. What, people wanted to know, becomes of children who grow up in such families? This study began as an attempt to address this question.

About the Study

The study included 30 people (16 men and 14 women). The median age of the group was 27, with over half between 20 and 30 years old. They divided equally into people with and without learning difficulties. Twenty eight of the thirty had just one parent who had learning difficulties, usually the mother. Twenty-three had a mother or father with learning difficulties who was still alive. Interviews with the 30 people were designed to produce first-person accounts of people's childhoods, family lives, and relationships that document their growing up and passage into adulthood in terms of their own experience. The findings in five areas are presented here: transition to adulthood, risk and resilience, parental competence, importance of family, and social exclusion.

The Transition to Adulthood

In establishing an adult status for themselves in society, the men and women without learning difficulties in our study experienced no problems of a type or magnitude sufficient to distinguish them from other people coming from the same socio-economic background. We are not saying all had easy childhoods and were now living happy and fulfilled lives. They hadn't and they weren't. But for people brought up on the breadline, in rough neighborhoods, marked by stigma, harassed into leading shuttered lives, and forever coming up against a bias in the system that put them down or cut them out, it is by no means clear that their troubles are exceptional or out of the ordinary.

The situation was somewhat different in the case of the adults with learning difficulties. Many experienced problems in negotiating the steps into adulthood, especially the men. The women seemed to find it easier to step into some aspects of the traditional female role, especially in establishing emotional relationships outside their family of origin. But there was nothing in our data to suggest that these problems were more pronounced for the people in our study than for others with learning difficulties, or that they were made worse by having a parent with learning difficulties.

Risk and Resilience

The experience of the people in our study clearly demonstrates that children's destinies are not determined by having a mother or father with learning difficulties. Some children show considerable resilience in coping with lives filled with difficulty. Such resilience is fostered or enhanced by protective factors that mediate children's responses to risk and shield them from the hazards of their environment. In line with other research in this field, the study points to three broad sets of variables that may act as protective factors producing resilience in children: personality characteristics, family characteristics, and external supports. These protective factors may be missing for some people, may change over time, or may be insufficient. The balance between the risks that heighten vulnerability and the protective factors that enhance resilience varies for different individuals and at different points in people's lives. From this perspective, resilience is better viewed as a process than as a fixed attribute of the person.

The Importance of Family

There are three crucial aspects of the family role in helping children overcome an unenviable childhood. First, family ties can nurture resilience in children. Second, family supports may compensate for a lack of competence on the part of the parents and ensure satisfactory care for the child. Third, adults need parents, too. For most of the now-adult children with learning difficulties in the study, their relationship with their mother and/or father provided the only close, secure and continuing emotional bond in their lives. Even for those without learning difficulties, this relationship lay at the heart of their adult identity.

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*Note: "Learning difficulties" is the preferred term of the self-advocacy movement in the United Kingdom and is used here in preference to mental retardation, intellectual disability, and other labels.

Social Exclusion

Most of the people in the study had been set apart and set upon throughout their childhood. The experience of exclusion was a common thread running through their stories. Few of those with learning difficulties had found respite in adulthood. On a personal level, people met with persistent name-calling and verbal abuse, bullying at school, and harassment and victimization at home and in the neighborhood. On an institutional level, the children were channeled into special schools and segregated from their peers, their parents were not listened to by people in authority, and the families were frequently subjected to forms of discriminatory treatment at the hands of official agencies sufficiently serious to warrant the label of system abuse. Economically, they were excluded by debt, unemployment, and the poverty trap. All these things worked together to place even greater strains on families who at the best of times had fewer personal resources on which to draw. Social exclusion was behind many of the troubles that blotted people's childhood and beset their families. All too often these troubles are put down to the limitations of the parents when they are more properly seen as a product of their situation.

The findings from our study suggest that the relationship between parental competence and child outcomes is more complicated than most current thinking allows. Children's destinies are not fixed by having a parent with learning difficulties, and competent parenting is not solely dependent on the abilities of the parents.

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Tim Booth is Professor of Social Policy and Wendy Booth is a Research Fellow with the Department of Sociological Studies, University of Sheffield, United Kingdom. They may be reached by e-mail at T.Booth@shef.ac.uk

An Enduring Bond

When Lisa was married six years ago, she was escorted down the aisle by two fathers: her birth father and her adoptive father. It didn't seem at all awkward for her; through placement in foster care and then an open adoption, she had grown accustomed to having two sets of parents. Today, with two children of her own, she reflects on her childhood, which included a mother and father with disabilities, and on the meaningful relationship her own family continues to have with both her birth and adoptive parents.*

Looking back on my childhood, I think I was a very lucky kid. I don't ever remember going without the necessities of life. In fact, I think I was a bit spoiled. Even though my father didn't know how to read or write due to cognitive disabilities, he always worked. After completing a janitorial training program, he got a job at a factory where he has worked for over 20 years. He even learned to drive a forklift! I remember that every time we went to the store he would buy me a treat, something he continues to do with his grandsons, ages four and five. Even when I was no longer living with my birth parents, they continued to buy me things. In fact, I feel a little guilty remembering how I would ask them for things my adopted parents thought I didn't need. While my dad was always kind to me, I do have memories of him and mom arguing, usually under the influence of alcohol. But they never hurt me; I don't think I even got a spanking.

My father always seemed frustrated that he couldn't read and write, something that bothers him still today. My mother has mental health problems and I think parenting was more challenging for her. I had a brother and sister who were also placed out of home. My brother grew up in foster care and my sister was adopted, but it wasn't an open adoption so she was not allowed to have a relationship with our birth parents like I did. I think this is such a loss for her, and a huge loss to my parents who still miss her and continue to sign her name on the family Christmas card. They haven't given up hope that someday they will see her again. I am allowed to see my sister, but only after promising her adopted mother not to tell her anything about our birth parents.

I'm really proud of my parents, especially my dad. He has always done his best. As far as what's helped the most, I think the attitude of my adoptive parents made a big difference. From the beginning, they made significant efforts to preserve the bond between me and my birth parents. They never spoke of them in a derogatory manner and always assured me that my parents loved me.

Even today we are all one big extended family. My husband and I work full time and volunteer with our sons' activities so we don't have much free time. But, we make time for grandmas and grandpas. When I was 16 and got my driver's license I was so happy because I was able to drive my birth parents shopping and to do errands. This is something I still do today. Every Thursday the boys and I take my birth parents grocery shopping. My dad continues his tradition of buying treats for the kids. My mother still needs a lot of emotional support, so I talk with her almost every day on the phone. Sometimes I feel overwhelmed thinking I am the one who will have to make all the arrangements for my parents as they get older, but I suppose many children feel this way even when parents don't have disabilities. For the time being, my kids really enjoy all their grandparents and, like me, are a bit spoiled.

Contributed by Lisa and by Susan Kidd Webster, Outreach Specialist, Waisman Center, University of Wisconsin, Madison. Susan may be reached at 608/249-2163.*

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Welfare Reform and Parents with Disabilities

by Caroline Hoffman and Howard Mandeville

Federal and state welfare reform is ending welfare as we know it. This enormous system change is beginning to be felt by families headed by parents with disabilities. As advocates, what do we need to know about the impact of welfare reform on people with disabilities and what are some ways to make the new welfare-to-work model accessible to parents with disabilities?

> *Welfare experts predict that adults with cognitive limitations will be among those hardest to place in work. Welfare-to-work programs should be created to help parents gain employment while keeping families intact.*

The Legislation

With the passage of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193), the Aid for Families with Dependent Children Program (AFDC) was transformed from an entitlement program to a sum-certain block grant program and renamed the Temporary Assistance to Needy Families (TANF) Block Grant. The number of parents with cognitive limitations losing AFDC is unknown. An estimated 10% to 40% of AFDC families included a parent or another family member with a disability.

The federal welfare reform legislation is silent on the unique needs of families headed by parents who have cognitive limitations. People with lifelong disabilities who do not meet the disability test of Supplemental Security Income (SSI) and are unable to find and keep employment without support are not given special consideration.

Of particular concern in the TANF program is the new 60-month lifetime limit (whether consecutive or not) that limits eligibility for federal funds for any individual. A state may use its own funds to support families beyond the 60-month limit. The state may also establish lifetime limits shorter than 60 months. A state may exempt up to 20% of its average monthly number of families receiving assistance from the lifetime limit by reason of hardship, including families who experience domestic violence. As the number of people on assistance decreases so will the number of people receiving exemptions. The parents remaining on the program will be those who are harder to place in the workforce, those who need more intensive supports to work, and those who cannot enter the workforce due to special circumstances. Welfare experts predict that adults with cognitive limitations will be among those hardest to place in work.

Just because a parent has a disability does not mean that he or she receives SSI. Many parents with "mild" cognitive limitations are not eligible for SSI. Only those with IQ scores of 59 and under meet disability requirements on the basis of cognitive limitations alone. When the individual's IQ is between 60 and 70, the disability examiner looks at other factors to determine eligibility. Examiners may consider parenthood a sign of competence, so a parent with an IQ between 60 and 70 may be denied SSI while others who are in the same range of IQ and functional ability – but are not parents – may be determined eligible.

Each state is designing its own program to replace welfare. The difficulties parents with cognitive disabilities may have in learning and judgment already challenge their capacity to hold jobs and navigate the systems that affect their children's education, their community services, and their health care. Since families headed by parents with cognitive limitations face unique challenges, the welfare-to-work programs should be crafted to help such parents gain employment while keeping families intact.

Creating Responsive Programs

As states build their new systems, the interests of parents with disabilities need to be considered. Advocates may find the following points helpful in guiding efforts to make welfare-to-work programs responsive to parents with cognitive limitations:

- Programs based on the new system have the responsibility to make reasonable accommodations for a wide range of participants. How information is presented can affect whether an adult is able to comply with the rules. Information should be conveyed in alternative formats in order to account for the range of literacy and learning styles.
- Intake workers in the new system should have the knowledge and skills to work with adults with cognitive limitations. Either all workers or specialized teams of workers should be trained in how to work effectively with adults with cognitive limitations.
- There should be appropriate intake and identification of parents with cognitive limitations. Many parents with cognitive disabilities will not self-identify and may be reluctant to admit that they cannot read and do not understand what is required of them. Without the appropriate skills, an intake worker may misinterpret this inability as noncompliance. The new programs should incorporate methods to discern the impact of

cognitive limitation and low literacy on ability to fill out forms and meet program and work requirements. The following questions can help identify parents who need further assistance:

– Do you have a legal guardian, protective payee, or some other person who makes decisions for you?

– Were you (or are you) in any special education classes?

– Have you ever had SSI (Supplemental Security Income) or SSDI (Social Security Disability Income)?

– Does someone else take care of your money or pay your bills for you?

– Have you ever been in a program for people with special needs?

– Do you receive any help from an agency that helps people who are slow learners?

– Do you need help to fill out forms? If so, what kind of help do you need?

– Do you have trouble getting yourself or your family to appointments, school, etc.? Please explain.

– What are your children's birthdays?

– How old will your oldest child be in three years?

- Case management services should be available to parents identified as having a disability. Effective case management can mitigate the hardships that will be present for families who try to participate in the welfare-to-work program only to fail. The case manager can help applicants with cognitive disabilities achieve success by helping them complete paperwork and understand the range of services offered, and by providing assistance with budgeting and financial planning.
- Referral to vocational rehabilitation and other vocational services should be available to parents with cognitive disabilities. Each parent identified as possibly having a cognitive disability should be evaluated for an appropriate work placement. The new programs should establish cooperative agreements with the vocational rehabilitation system and be familiar with services available in this sector. Appropriate job placement of parents with disabilities will include reasonable accommodations and appropriate adaptations in work routine, tasks, schedules, and environment. The vocational strategy should take into consideration the worker's preferences and capabilities as well as their limitations. Supported employment should be an option.
- Outreach efforts should precede sanctions. Many states sanction or penalize participants who are unsuccessful in meeting employment expectations. For adults who have difficulty understanding and complying with complex directions, there is a risk of losing their financial support and placing their families in jeopardy. Methods of ascertaining the reason for unsuccessful results are needed in order to avoid misplaced sanctions. Outreach efforts to confirm the reasons for inadequate performance should be flexible and individualized enough to account for problems associated with the parent's cognitive disability.
- Programs should accommodate two-parent households when both parents have disabilities. The federal TANF law requires a high level of work participation in two-parent households. The design of the welfare-to-work program should take into consideration the needs of two-parent households in which both adults have disabilities. The stress of requiring both parents to work full-time compounds the challenge parents with disabilities experience in trying to manage a family, and could result in breakup of the family unit.
- The new programs need to recognize participants who may be eligible for SSI. The welfare-to-work intake workers will encounter parents with cognitive limitations who had been relying on AFDC but who are probably eligible for SSI. They need a mechanism for assisting these participants in applying for SSI and providing financial support to their families while they wait for a determination of eligibility for SSI.
- States should keep track of what happens to families under welfare reform. The end of AFDC brings complicated changes that will cause difficulties for many families. As caseloads shrink, the new system needs to detect whether parents have entered the workforce successfully or have fallen through the safety net. To protect children in already fragile families, it is essential to know why families are no longer receiving financial support.

An Opportunity for Action

This article has only addressed the issues of parents with cognitive limitations who are not receiving SSI or SSDI. Also of concern are the parents who had been receiving SSI for themselves and AFDC for their children. The Wisconsin Council on Developmental Disabilities (WCDD) SSI Parents Initiative is gathering information and developing a legislative initiative to help parents on SSI. Under current Wisconsin law, a family's income can be cut by over 55% in the switch from AFDC to the new grant program. This reduction is placing families at risk for homelessness.

The WCDD project seeks information about what other states are learning about SSI parents who had been receiving AFDC and what responses are planned. For information on the SSI Parents Initiative or to share what your state is doing, contact Caroline Hoffman at WCDD, PO Box 7851, Madison WI 53707, 608/266-7707.

Caroline Hoffman is Prevention Specialist and Howard Mandeville is Community Resource Specialist with the Wisconsin Council on Developmental Disabilities, Madison. Caroline may be reached at 608/266-7707 and Howard at 608/266-9538.

System Abuse and the Power of Advocacy

by Tim Booth and Wendy Booth

For the past two years we have been running an action research project, called Parents Together, aimed at developing an advocacy support network for parents with learning difficulties* in Sheffield, England (pop. 560,000). The project arose from our earlier research (Booth & Booth, 1994; Booth & Booth, 1998) that showed that family life for parents with learning difficulties is constantly threatened by environmental pressures that undermine their ability to cope. To date, most support for parents with learning difficulties has been directed at improving their parenting skills by training. Parents Together has followed a different approach. Our goal as advocates has been to enhance parental competence by reducing the external pressures on families, thus lightening the parental load.

> *System abuse shows itself when people's problems are made worse by the services that are intended to support them.*

The action phase of the project has now concluded and we are beginning to assess the lessons. In this article, we focus on the disabling effects that system abuse can have on families and the role of advocacy in enabling them to resist its threat.

System Abuse

Experience on the Parents Together project has confirmed the findings of our earlier study that system abuse constitutes a significant threat to family stability that makes parenting even more of a challenge for parents with learning difficulties. System abuse shows itself when people's problems are made worse by the services that are intended to support them. As an umbrella term, it refers to institutional attitudes, policies and practices that hurt children, harm family integrity, or infringe basic rights (Gil, 1982). System abuse is a form of bad practice. But where bad practice does not always damage those it afflicts, system abuse does – either because the individual or family is particularly vulnerable or because the bad practice is particularly serious or sustained.

A huge amount of effort has been put into investigating physical and sexual abuse. By contrast, there has been very little research into system abuse. There are probably all sorts of reasons for this omission. Official agencies are more prone to secrecy than openness about their own failings, and whistle-blowers are often dealt with harshly. In any case, system abuse usually arises as a result of the actions of more than one agency. Only those affected may see the full picture and they usually lack the power to speak out or, when they do, their voices go unheard. Because system abuse has a long fuse, it is hard to link cause and effect without close knowledge of an individual's or family's personal history. Without such a perspective it is all too easy to mistake signs of system abuse for something else. For instance, problems encountered by parents with learning difficulties are frequently put down to their own limitations when they owe more to deficiencies in the support services (Booth & Booth, 1994).

System abuse presents itself in a myriad of different forms. Some of the characteristic manifestations of system abuse encountered (mostly in combination) by families in Parents Together included:

- Unwarranted intervention in family affairs.
- Lack of continuity in service delivery.
- Failure to involve parents in decisions affecting them or their children.
- Passing the buck.
- Taking advantage of the parents' learning difficulties.
- Treating the parents as less than fully adult.
- Undermining the parents' authority in their own home.
- Judging parents by standards and values that are foreign to their neighbors, family, and friends.
- Applying standards of behavior to the parents that are not maintained by service workers and professionals.
- Diminishing the importance of family relationships and undervaluing the strength of family bonds.
- Using parents' fears of losing their child to secure their acquiescence.
- Gender bias.
- Failing to respond to problems until a crisis erupts.
- Seeing only the evidence that confirms prior opinions.
- Forming snap judgments on the basis of partial evidence or inquiries.
- Experts deviating from their field of expertise.
- Practitioners interpreting their roles idiosyncratically and failing to follow established procedures.
- Communicating poorly with parents, having inaccessible practitioners, and providing contradictory, inaccurate, or insufficient information.

All these factors contribute to parents' widespread perception of the service system as a juggernaut before which they are hapless and unheard victims. For people and families operating on the edge of competence, whose coping abilities are stretched, the extra burden imposed by unresponsive services may be enough to break them.

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*Note: "Learning difficulties" is the preferred term of the self-advocacy movement in the United Kingdom and is used in this article in place of other labels such as mental retardation, intellectual disabilities and the like.

The Role of Advocacy

The lack of independent advice or advocacy for parents is an important factor contributing to the risk of system abuse. Advocacy is about working with people to support them in ways that are responsive to their own views of their needs. Our experience on Parents Together has highlighted the many different ways in which advocates can work with families headed by a parent or parents with learning difficulties to combat the threat of system abuse. At one time or another, often simultaneously, the following roles have come to the fore:

- Advocate as witness. Simply being there is often enough. "Being there" is not about acting for parents, but about lending them authority. Even this passive support empowers people and makes them feel that they can get things done. Knowing there is someone there watching what they are doing also helps to keep officials and practitioners on their toes and deters them from taking advantage of people who are seen as unable to fight back.
- Advocate as buffer. Helping to absorb some of the pressures on the family by fielding or deflecting matters that might exacerbate their troubles or stress.
- Advocate as voice. Making sure the parents' side of the story is represented and their views are heard.
- Advocate as go-between. Helping to facilitate and improve liaison between the family, practitioners and the services.
- Advocate as interpreter. Translating officialese into language the parents can understand and otherwise making information accessible to them.
- Advocate as listener. Reducing parents' feelings of isolation by enabling them to share their worries, air their grievances or just talk things over.
- Advocate as scribe. Writing letters and helping with form-filling.
- Advocate as problem-solver. Helping parents to identify the choices they face in dealing with their problems and then supporting them in their decisions, and also ensuring that practitioners are apprised of options they may have missed.
- Advocate as fixer. Sorting out problems of service delivery caused by poor coordination, errors, oversights and bureaucratic inertia.
- Advocate as conduit. Channelling the lessons learned in supporting one family for the benefit of another.
- Advocate as sounding-board. Encouraging families to have confidence in their own ability to cope by helping them to work things out for themselves.
- Advocate as confidante. Someone with whom private and confidential information can be safely shared in the sure knowledge that it will not be passed on or used against the family.
- Advocate as ally. Someone who is unambiguously on the family's side, prepared to stand by them, and whose actions are always consistent with this stance.
- Advocate as sleuth. Tracking down and searching out information that will help parents achieve positive objectives.
- Advocate as mentor. Sharing knowledge and experience of life in the capacity of a supportive equal rather than an expert.
- Advocate as observer. Keeping a look out for the early signs of stress or changes in personal circumstances that might impact on the parents' capacity to cope.
- Advocate as mover and shaker. Making things happen.

The Limits of Advocacy

Life is tough for parents with learning difficulties. The pressures that weigh down on parents can weary their advocates, too. An advocate cannot expect to change agency policies or practices that impact unfairly on families; make professionals like them or treat them with respect; undo the harm done by deficiencies in the services and support provided to families; shield people from discrimination and day-to-day harassment; or change the attitudes that fuel their victimization in the community. Equally, an advocate cannot erase past hurts or ensure a future free from distress.

Advocacy work with parents who have learning difficulties can be like pushing string. Too often the basic infrastructure of supports geared to the needs of these families is missing so that advocacy pressure fails to produce any progress. The upshot is that advocates frequently are pushed into taking on more than they can realistically manage or get worn down by the constant struggle to get anything done. Both bring an attendant danger of burnout. Despite these constraints on the advocate's role, the Parents Together project has convinced us that parents with learning difficulties will continue to receive rough justice and their children a raw deal without some kind of advocacy support against the effects of system abuse.

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Tim Booth is Professor of Social Policy and Wendy Booth is a Research Fellow with the Department of Sociological Studies, University of Sheffield, United Kingdom. They may be reached by e-mail at T.Booth@shef.ac.uk In August, 1998, their new book, Growing Up with Parents Who Have Learning Difficulties, will be published by Routledge.

How Small Initiatives Make a Difference

by Rick Brooks

How can state and local agencies develop more compassionate and effective long-term supports for families – especially the families challenged by the parents' learning styles? Such questions have been at the core of Wisconsin's approach to supported parenting for the past decade. Like many states, prior to the 1990s Wisconsin had no "system" for serving such families. Pioneers crafted distinct strategies built around social work and public health principles. But then, as now, the quality of the services depended as much on the sensitivity and perseverance of staff as it did on theoretical models.

When the Health Promotion Project at the University of Wisconsin-Madison applied for Maternal and Child Health block grant funds in 1995, the intent was simple: find good people running good supported parenting programs and help them share the wisdom of experience. Each grantee was asked to convene a parents' conference, offer training to other agencies' personnel, and coordinate an areawide work group or consortium to share ideas, enhance systems approaches, and locate new resources.

The Milwaukee Center for Independence, one of the three sub-grantees, promptly organized a networking approach, building on established relationships among agencies concerned with families and individuals with disabilities. They were joined by the county Human Services office, United Cerebral Palsy, ARC of Milwaukee and others – becoming the Milwaukee Supported Parenting Consortium – and began to meet to brainstorm common problems, barriers to service, and possible solutions. They wisely chose to have parents participate, offering insights on the intersection between good intentions and their own families.

Once or twice a year with help from the Wisconsin Council on Developmental Disabilities and the block grant, program representatives from throughout the state get together to share ideas. They have also conducted ongoing system advocacy ranging from offering legislators "real life" examples of the potential impact of specific welfare reforms on supported parenting families, to problem-solving with individual cases and sharing tips with other providers.

Overall, the approaches Wisconsin supported parenting programs have chosen revolve around personal knowledge of families and long-term relationships. Some lessons learned by these programs include the following:

- Get to know the family first. Look for strengths.
- Know you're in the equation for the long haul. Assume that one-time interventions will rarely have enduring effects.
- Offering a receptive ear and a stable source of emotional support can often make the difference between continual crisis and reasonable stability.
- Advocacy with other agencies, gatekeepers, and rule enforcers is a key to helping families whose daily lives are often overwhelming.

One example of how Wisconsin supported parenting programs are making a difference for families comes from the comments of a woman at one of the Milwaukee consortium meetings. She pointed to a flipchart and what looked like the "black hole" – the waiting list for services. "You see that place?" she asked. "A couple of years ago before I got into the Positive Parenting Program in Green Bay, that's where me and my kids would have been. Now, I know it doesn't have to be that way."

Rick Brooks is Director of the Health Promotion Project, University of Wisconsin, Madison. He can be reached at 608/265-4077.

Words from Parents

"They're shipping our kids all over the place. It's so hard to see my son, especially because I don't drive. "

"It makes me feel belittled to be able to get money when I need it only when two people's signatures are on the Social Security check. I think there's a better way of doing it."

"I want more information about the foster home my son is in. I came from a really bad situation. I want to make sure he is safe. Any parent wants that."

"They took my daughter at eight months old. She was a 'failure to thrive' baby. But I didn't know where the child went... I wanted to see the proof that they had the right to take the child away. It's like a straw being broken."

"There's big-time prejudice, just because you're a person with a disability."

"I want the future of my family to always be close and to never be far apart."

"I hope my daughter always feels love so that she doesn't have to go elsewhere... I would like to own a house someday, and my daughter living with me."

"I want my daughters to know how wonderful they are. I want to be someone who helps people feel good about themselves."

Quotes from the 1995 Green Bay (Wisconsin) Get-Away Parents' Conference, and the 1993 National Supported Parenting Conference in Madison, Wisconsin. Contributed by Dolores Liamba and Rick Brooks of the Health Promotion Project, University of Wisconsin, Madison.

Supported Parenting Resources: Materials and Organizations

The following may be useful to readers seeking to learn more about or improve provision of supported parenting options. Please contact the publisher or organization for additional information.

- **Growing Up with Parents Who Have Learning Difficulties.** By T. and W. Booth. This book provides new evidence and insights derived from original research and life stories to answer questions about what it means for a child to be brought up by a parent with learning difficulties, and whether this affects their well-being and adjustment in later life. Available August 1998 from Routledge, New York, 800/634-7064.
- **Discovering the Parent's Language of Learning** (1990). By M. Sweet. Describes an approach to interventions that can increase the effectiveness of the teaching that is involved in support offered to parents who have cognitive limitations. Available from Wisconsin Council on Developmental Disabilities, Madison, 608/266-7826.
- **Helping Parents Parent** (1992). By S. Heighway. A guide to techniques found to be useful in providing effective support to families headed by parents with cognitive limitations. Available from Wisconsin Council on Developmental Disabilities, Madison, 608/266-7826.
- **Nurturing Program for Parents with Special Learning Needs and Their Children** (1990). By A. Tymchuk, L. Andron, S. Bavolek, A. Quattrociocchi, and H. Henderson. An illustrated curriculum for use with parents with special learning needs. Focuses on child development and anticipatory guidance. Intended to be used in conjunction with other curricula either developed by or derived from the SHARE/UCLA Parenting Project, including the American Red Cross illustrated *Curriculum for Parents with Special Learning Needs* (American Red Cross, Los Angeles) that focuses on home safety and illness symptom recognition in infants; and the "Managing Illness and Injury" component of the *LifeFacts* curriculum (James Stanfield Publishing Company, Santa Barbara, CA) designed to train adults about self-healthcare and safety. Available from Family Development Resources, Park City, Utah, 435/649-5822.
- **Building the Foundation: Public Policy Issues in Supported Parenting** (1992). By H. Mandeville and D. Ullmer. A series of issue papers addressing obstacles in the current service system, and describing innovative options in designing and funding supported parenting services for families headed by parents with disabilities. Includes strategies for improving communication and coordination among agencies. Available from Wisconsin Council on Developmental Disabilities, Madison, 608/266-7826.
- **Caregiver Abuse and Domestic Violence in the Lives of Women with Disabilities.** By M.F. Strong and A. C. Freeman. A booklet designed for women with disabilities and providers of domestic violence and sexual assault services, as well as policymakers designing personal assistance services. It explains how violence and abuse can be different for women with disabilities, delineates barriers to obtaining services, and describes what women with disabilities and service providers can do to overcome those barriers. Available from Berkeley Planning Associates, Oakland, California, 800/897-0272.
- **Families in Perpetual Crisis** (1989). By R. Kagan and S. Schlosberg. Provides ideas about supporting families with multiple challenges. Available from W.W. Norton & Co., 800/233-4830 or on the Web at www.wwnorton.com.
- **HELP: When the Parent is Handicapped** (1984). By S. Parks. Practical suggestions for helping parents overcome barriers to parenting caused by their disability. Offers suggestions related to stages of child development for various disabilities. Available from VORT Corporation, Palo Alto, California, 415/322-8282 or on the Web at www.vort.com.
- **The Importance of Matching Educational Interventions to Parent Needs in Child Maltreatment. Issues, Methods, and Recommendations** (1998). By A. Tymchuk. In J. Lutzker (editor), *Handbook of Child Abuse Research and Treatment.* Discusses definition, assessment, education, and policy issues related to parenting by persons with disabilities. Presents current model of a support program within a context of child maltreatment, and how it is to be applied. Available from Plenum Publishing, New York, 212/620-8000.
- **Through the Looking Glass.** A community nonprofit agency creating models for direct service, advocacy, public policy, research and training in the field of parents with disabilities. Federally funded as a national Research and Training Center for Families of Adults with Disabilities. For information call 800/644-2666 or visit their Website at www.lookingglass.org.
- **Supported Parenting Listserv.** A newly forming listserv/e-mail discussion group for people interested in the topic of supported parenting. For information contact Lynda Anderson, Research and Training Center on Community Living, University of Minnesota, Minneapolis, at 612/626-7765 or by e-mail at Ander447@gold.tc.umn.edu.

[Franz, continued from page 1]

schools again because the group home is in another part of the county. After less than a year, the group home says that she is too much for them to handle and the county moves her again, this time to an adult foster home. Marge changes school districts again, but this time refuses to go the new school. She is sent to a sheltered workshop, where she works a little and plays around a lot. She spends most of her time hanging around her adult foster home or going downtown.

When Marge is 24 she becomes pregnant and has a little boy. The social services system that was responsible for her care when she was a child is now involved with her again. They tell Marge that she has to learn how to take care of her baby, or they will take her son away from her. There are public health nurses and social workers and birth-to-three teachers visiting her all the time. For a while she is at the focus of attention. She tries to do everything they ask. Then things start to run downhill. There are parenting classes she has to go to. They don't make much sense and she stops going. The lady who runs her adult foster home doesn't like all the fuss and Marge has to leave. She moves to an efficiency apartment with her baby. The baby cries a lot. Marge is lonely. She starts asking other people in her building to watch the baby so she can go downtown like she used to. One of the people calls social services after Marge doesn't come back when she said she would. Social services places the baby in foster care. The cycle begins again.

Systems and Entropy

This scenario is fiction, but it reflects a pattern that is found all too frequently in real life. Every service system involved with Marge did what it was supposed to do, yet the nearly inevitable course of events led to the ultimate juxtaposition of Marge's rights and needs and those of her baby. This seemingly inescapable progression can be compared with the concept of entropy in the physical sciences. Entropy is the natural tendency of all physical systems to move from more complex states to simpler states as energy is dissipated. Clocks and batteries run down, stars burn out. Marge's life unravels.

Categorical entropy is the tendency of human service systems to operate independently of one another, to stay locked into rigidly structured responses and to avoid collaborative solutions. Developmental disability systems deal with developmental disabilities. Child welfare systems deal with family problems. Health care systems deal with health issues. In Marge's story, categorical entropy set in each time responsibility for addressing her needs was passed on to a different system and the old system closed its books.

The good news is that things don't always happen the way that entropy would predict. In his book, *The Web of Life*, Fritjof Capra points out that life contradicts entropy. Although each of us winds down, life itself has continually evolved into more complex forms. The explanation for this is that life is a collection of open systems which share energy at many different levels of interaction and use it to self-organize into complex, adaptive structures.

Entropy and the Fix-it Mentality

Our traditional publicly funded human services – child welfare, developmental disabilities, juvenile justice, public health, education, mental health, housing, economic support, services for the elderly, and others – were all established out of a spirit of altruism. The community recognized that a group of people had needs not being met and created a mechanism to address those needs in a more structured way. Each time a need was recognized, a new response pattern was created, which grew into a new bureaucracy with its own culture, rules, language, and relationships. People whose needs line up well with the response provided by a single service system often gain a great deal of benefit from it. However, as needs diverge from the design of the system, or blend across too many systems, the effectiveness of the system's response diminishes.

If we are to interrupt the downward cycle that Marge's scenario represents, we need to find more effective ways to cross over these traditional boundaries and open the closed systems. One way to create this connectivity is to find a common perspective from which all of the systems can operate. At present, most systems tend to operate under a medical model in which the goal of each system is to cure or repair a specific illness or injury. We go to a different system for each type of problem.

Beyond the People Repair Shop

The problem with applying the medical model in situations like Marge's is that she is more than the sum of her problems. What if, instead of pursuing isolated paths of intervention after the fact of harm, we began to search for a way to create enough interconnections within our communities to reverse the tendency toward categorical entropy? In fact, a number of authors have proposed models for this sort of transformation. John McKnight, John and Connie O'Brien, and John VanDenBerg and Mary Grealish, each in his or her own way, have stated that we need to look at people who need help, and our response to them, in a new way. Instead of the medical model's reductionist analysis, in which we take things apart to see what's wrong, they suggest that we look at the overall pattern of each person's life and relationships, find out what is right, and build our response on the strengths we can discover in everyone. As Bateson pointed out over 20 years ago (Bateson, 1972), the patterns and relationships of people's lives must be seen as a complex, interacting whole if we are to help them address challenging issues – including finding ways of helping Marge play an active part in raising her child.

While the transition from a deficit-focus to a strength-based approach doesn't eliminate the conflict between the needs of a parent who has been labeled with a cognitive disability and those of her child, it will help us develop new ways to deal with them. In fact, the authors noted above believe that by restructuring the metaphor of help in our communities, we can create the opportunity for better lives not just for people like Marge and her child, but for all.

Building a System from the People Upward

Traditionally, when we spoke of improving our responses to the needs of families with parents who have cognitive disabilities, the discussion tended to focus either on programs or rules. We tried to change our service methodology or the standards we apply to measuring the adequacy of services. This wasn't bad, but it kept us looking only at the parts, not at the whole. It preserved the repair-oriented metaphor of the medical model and the essential duality between help-givers and help-getters.

The shift to a strength-based perspective begins with a recognition that help is a two-way street. In real communities and families, there are times when we offer assistance and other times when we receive it. By reframing human services as tools for enhancing natural patterns of reciprocal support among neighbors, we have the opportunity to see our systems of care as more than a series of variations on the outpatient clinic.

An example of the hidden interconnections that this new paradigm can bring to light is a recognition of the subtle interplay between our existing developmental disability and child welfare systems. In most communities, they seem to have little linkage with one another. Yet, as was the case with Marge and her child, what each does, over time, can have a profound impact on the lives of people who supposedly are attached only to one or the other system. Seeing the bigger picture helps us shift from short-term, incident-based, problem-focused reactions. Instead, we can begin to establish a proactive, multi-domain relationship with people who may need varying kinds and degrees of assistance over time, but who always are in need of improved connections with the rest of their communities.

In this context, when problems do occur – as happens in all of our lives – the response would no longer be to repair and retreat, but to work through it together and be ready for what comes next. Perhaps if Marge's place in the community had not been so dependent on her status as a certain type of categorical service recipient, there might have been room in the story for a more successful outcome. A broader perspective might have allowed us to fashion a pattern of formal and informal support in which both her needs and those of her child could have been addressed. We might have learned more about her than her diagnostics. Under the new paradigm, the story would be impossible without our knowing that Marge is stubborn, independent, mischievous, sports-minded, quick to anger, quick to forgive, a good dancer, collects pictures and statues of frogs, and keeps a neat apartment. We would share her search for friendship and her struggle with the challenges of adulthood. We would know what it felt like to sense that her baby was valued far more than its mother. Finally, we might come to understand those things that only Marge could provide for her baby.

Possibly, if that perspective had been in place all along, the conflicts which so disrupted everyone's lives could have been mediated or even avoided in the first place. But even at the point where her child was born, things could still have been different. More flexibility and interconnectedness might have allowed the various systems to work together on a coherent plan. Using the strengths that were there – the cautious bond between Marge and the adult foster provider that had somehow endured longer than any of Marge's previous relationships, and Marge's willingness to at least try to learn how to parent – they might have formulated a plan that met the needs of all three of the people in the household.

Perhaps not. But these extra linkages would have at least created the opportunity to overcome the categorical entropy which otherwise guaranteed a negative outcome. If we can learn from our current frustrations in supporting families with parents who have cognitive impairments, we can begin to change the context of our interactions with people who have disabilities at all of the stages in their lives. This would give us the opportunity to create a web of reciprocal support in our communities that insures a meaningful role for lively and challenging people like Marge.

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John Franz is a member of Simpler Way, a consulting collective in Madison, Wisconsin. He may be reached at 608/238-8448. Pat Miles is a partner in the Brown-Miles Consulting Group, Portland, Oregon. She may be reached at 503/618-1088.

[Dolores, continued from page 10]

I tell people how I feel about things, I can think for myself. I know now that I don't have to be dependent on everybody. I am more confident in myself and am happier. I can do things for myself like starting a garden, and joining a new church. I can ask June for help because I can't do everything by myself. I've learned more about how to take care of teenagers. I've learned to teach my children about responsibility.

June is applying for a job and I might apply for a job also. I can look at my life and feel good about what I can make happen. Receiving support from other moms and seeing them get through hard times has helped me learn that I, too, can make good things happen in my life.

Lori Gildersleeve, M.S., is a licensed psychologist with Arc of Hennepin County, Minneapolis, Minnesota. She may be reached at 612/920-0855.

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A publication of the Institute on Community Integration (UAP) and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. Dedicated to improving community services and social supports for persons with disabilities and their families.

Impact

Feature Issue on Supporting Parents Who Have Cognitive Limitations

Volume 11 · Number 1 · Spring 1998

Managing Editor: Vicki Gaylord

Issue Editors:

Howard Mandeville, Wisconsin Council on Developmental Disabilities, Madison

Lynda Anderson, Research and Training Center on Community Living, University of Minnesota, Minneapolis

Charlie Lakin, Research and Training Center on Community Living, University of Minnesota, Minneapolis

Impact is published quarterly by the Institute on Community Integration (University Affiliated Program), and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota.

This issue was supported, in part, by Grant #90DD032301 from the Administration on Developmental Disabilities, US Department of Health and Human Services; and Grant #H133B30072 from the National Institute on Disability and Rehabilitation Research, US Department of Education. The opinions expressed are those of the authors and do not necessarily reflect the views of the Institute, Center, University, or their funding sources. For additional information contact:

Institute on Community Integration
University of Minnesota
109 Pattee Hall, 150 Pillsbury Drive SE
Minneapolis, MN 55455
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