



# TODAY

# Living With

## Developmental Disabilities



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# LivingWith Developmental Disabilities

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### EDITORS

Pam Mettler, Marketing Director  
Mary Donovan

### GRAPHIC DESIGNER

Mary Lindberg

### STAFF PHOTOGRAPHER

David Leale / Kevin Owens

### PRINTER

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*Someone Special Just Like You.* Tricia Brown and Fran Ortiz. Henry Holt and Company, LLC. 1982.



300 68th Street SE,  
P.O. Box 165  
Grand Rapids, MI 49501-0165  
616/455.6500

# Living with a Developmental Disability: *A Family's Perspective*

by Barb Barton, MSW, CQ Manager

In 1961, Neil Vogel waited alone in the designated 'Father's Waiting Room', excitedly anticipating word on his fourth child. His wife, Rayda's, OB/GYN came in and announced: "Congratulations, you have a son. But I have bad news. He's Mongoloid." Rayda was not notified until a day later. Mongoloidism was the euphemism for what is now known as Down Syndrome, a chromosomal disorder.

## Diagnosis and Definition

The Vogels describe their reactions upon diagnosis as shock, devastation, and tears. "What does all this mean and what will the future hold? Who will take care of him when we are gone?" Neil wondered if he would be able to afford to keep his job as a schoolteacher, and they didn't know how their traditional family camping trips would be possible.

According to the Association for Retarded Citizens (ARC), 2.5 to 3 percent of the general population has various diagnoses of mental retardation. The 1990 census estimates that 6.2 to 7.5 million people have mental retardation, affecting one out of ten families. A diagnosis of mental retardation is based on three criteria: 1) intellectual functioning (IQ) is below 70-75; 2) significant limitations exist in two or more adaptive skill areas; and 3) the condition is present from childhood (defined as age 18 or younger). (*American Association for Mental Retardation, 1992*) Causes are generally attributable to five categories:

1) Genetic (such as PKU)/chromosomal (such as Down Syndrome) conditions

2) Problems during pregnancy, such as alcohol/drug use, maternal illness or malnutrition, or HIV

3) Problems at birth like low birth weight or prematurity

4) Problems after birth, such as childhood diseases, anoxic injuries, and lead or other environmental toxins

5) Poverty and cultural deprivation. Children in poor families are at high risk for malnutrition, disease-producing conditions, inadequate medical and pre-natal care, and environmental health hazards. Research also suggests that deprivation of common cultural, peer and structured day-to-day life experiences can produce understimulation and result in developmental delays.

The American Association for Mental Retardation (AAMR) process for diagnosing and classifying a person as having mental retardation contains three steps and describes the system of supports a person needs to overcome limits in adaptive skills:

1) Administration of standardized

intelligence tests and a standardized adaptive skills test.

2) A description of the person's strengths and weaknesses across four dimensions: Intellectual and adaptive behavior skills, psychological/emotional considerations, physical/health/etiological issues, and environmental considerations. This information is gathered through formal testing, observation, interviewing key

*"Developmental disabilities cut across the lines of racial, ethnic, educational, social and economic backgrounds"*

people in the person's life, interviewing the individual, or interacting with the person in his/her daily life.

3) An interdisciplinary team determines needed supports across the above four dimensions and determines the level of service intensity- intermittent, limited, extensive, pervasive. Frequently, agencies funded through the state, such as Community Mental Health Agencies, provide case managers to assist families through this process.

Specific criteria for the State of Michigan exist for the diagnosis of a ‘developmental disability’. If applied to an individual older than five years, a severe, chronic condition must exist that meets all of the following criteria:

- 1) Is attributable to a mental and/ or physical impairment.
- 2) Is manifested before the individual is 22 years old.
- 3) Is likely to continue indefinitely.
- 4) Results in substantial functional limitations in three or more areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, individual needs for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services that are of lifelong duration and are individually planned and coordinated.
- 5) If applied to a minor from birth to age five, a substantial developmental delay or a specific congenital or acquired condition with a high probability resulting in a developmental disability if services aren’t provided.

Developmental disabilities cut across the lines of racial, ethnic, educational, social and economic backgrounds. Of those diagnosed, 87% will be mildly impaired and many will be able to live supported in the community with successful vocational and social experiences. The remaining 13%, those with IQ’s under 50, will most likely have serious limitations in functioning. However, with early intervention, educational planning, and appropriate supports as adults, all can lead satisfying lives in the community.

## Coming to Terms

When the Vogels received their son Ron’s diagnosis, very little information was available. Educational support legislation had not been passed. Professionals seemed uninformed. They just did not know what to expect. They were told Ron wouldn’t live past his teen years, and that he would have sparse hair. He would have substantial medical complications for which no drugs were available.

Due to advances in treatment, care, diagnosis, and early intervention, most people with developmental disabilities live a high quality of life, enjoying their favorite activities, working, and socializing with peers. However, due to issues regarding medical fragility, there can be a lifespan reduction of 10 to 20 years.

Wherever possible, it’s important to work with the family to present options for supporting their child, teen, or adult, which focus on strengths and abilities, enhance self-esteem, promote psychosocial functioning, provide needed support to the family unit, and enable the individual to live as independently as possible.

With the availability of increased information about developmental disabilities and enhanced disability awareness, families and professionals need to be conscious of the emotional impact such a diagnosis may have on a family. Unlike an acute illness, a developmental disability requires a lifelong commitment to family role modification and social adjustments.

The process is often compared to the Grief Cycle, in which parents can rotate between any stage:

- 1) *Denial and Isolation.* When parents are first handed their newborn son or daughter who has a developmental disability, feelings of shock and disbelief can be overwhelming. They may go to multiple specialists, certain there has been a mistake. Careful evaluation and assessment should be encouraged, even involving other professionals; but providers should be aware that the family is looking for hope at this stage. This is also the stage where families tend to receive good educational information about the diagnosis.

*“Wherever possible, it’s important to work with the family to present options for supporting their child, teen, or adult, which focus on strengths and abilities...”*

2) *Anger*. “Why me? Why us?” are the questions frequently asked. The parents are looking for causes and for someone to blame. Frequently, the rage is directed at professionals who they believe are not giving them timely or accurate information. The family is feeling a sense of urgency to do something, anything, *now*. They may start examining their own patterns of behavior, such as smoking or alcohol use. Marital discord and blame can surface, and unless intervention is provided, the couple will have a difficult time being allies, advocates and partners in the care of their child.

3) *Bargaining*. There is a heavy spiritual shift in this stage. Parents may recommit to formerly held, but sublimated, spiritual beliefs. They may enhance their spiritual commitment, promising to fully dedicate their life to living out the purest of religious beliefs and tenets ‘...if only’ the diagnosis could be changed.

4) *Depression*. There are many losses associated with the shattered dreams

of the birth of a less-than-perfect child. Parents are concerned about the child’s future. Family finances. Sibling and family relationships, and changing family roles. Educational, social and community supports. Where to get the most current treatment and **d i a g n o s i s**  
**i n f o r m a t i o n**.

Providers need to be sure that appropriate assessment and treatment are provided and that the whole family receives sufficient levels of support.

5) *Acceptance*. Positive adjustment occurs when a family feels a sense of control over the diagnosis and confidence that they can manage the many unknowns of raising a child with a developmental disability. This could mean finding a secure residential placement, a caring school environment, connections with other families in similar situations, and trusting relationships with treatment professionals. Throughout their son’s or daughter’s developmental stages, his or her skills and abilities emerge and his or her place in the family is more easily defined. Expectations are set and routines emerge that promote healthy family adjustment.

For the Vogels, they gradually learned what was helpful, what caused disruptive behavior in Ron, and what enjoyable activities they could do as a family. With some modifications, they kept their camping outings, and Ron learned to play Frisbee from his siblings. The family discovered the best way to cope with

what Neil refers to as Ron’s “stubbornness” is through cajoling rather than making demands. Ron and Neil enjoy walks together when Ron

*“Becoming strong advocates for their child from the time of birth is critical for parents.”*

returns home from Pine Rest’s Southwood Cottage, where he has resided since 1993. (Prior to that, Ron attended Pine Rest’s former Retreat School while he lived at home.) The Vogels utilized family and friends to provide respite.

## What is it like for the siblings?

According to Neil and Rayda Vogel, their other three children grew “ more sensitive to others with disabilities. For a while they didn’t realize their brother was particularly different and took things in stride.” Unlike many children with developmental disabilities, Ron wasn’t teased by others his age, but his siblings were asked what ‘happened’, or what was ‘wrong’ with Ron. For other families, however, sibling issues do develop. In those families where one of the children is disabled, the following concerns have been reported (*Meyer and Vadasy 1994*):

- 1) *Guilt about not having a disability*. Some siblings may even feel they are to blame for the disability.
- 2) *Embarrassment of the sibling’s behavior or appearance*. Contact may be avoided and friends might not be invited over to the family’s home.



*"Families often rely on their spiritual strength to work through the lifelong process of parenting."*

- 3) *Fear* that they might develop the disability, and that it is contagious.
- 4) *Anger or jealousy* over the amount of attention their brother or sister receives, especially if special care is needed.
- 5) *Isolation* and feeling like no one else knows what it is like to have a sibling with a disability.
- 6) *Pressure to achieve* in order to "make up for" a brother or sister's inabilities.
- 7) *Caregiving*, especially if it conflicts with plans with friends or the responsibility becomes burdensome.
- 8) *Information about the disability itself*: Why did he or she get it? How will it affect us as a family? How can I help?

Just like the Vogels' children, researchers also have found that children who have a sibling with a disability can become more mature, responsible, self-confident, independent and patient. These siblings can also become more altruistic, more charitable, more sensitive to humanitarian efforts, and have a greater sense of closeness to family. (*Lobato, 1990; Powell, 1993*).

## **Suggestions for Parents**

Becoming strong advocates for their child from the time of birth is critical for parents.

Parents should thoroughly understand Federal programs such as Social Security and Medicare, State programs such as Medicaid and special education programming, and

become comfortable contacting legislators and lawmakers regarding advocating for services. Information on Special Needs Legislation, which mandates the provision of educational and support services, should also be garnered to guarantee effective planning through the school's Individual Educational Plan (IEP). Parents should gather information on Public Law 94-142 (1975), which guarantees that all children with disabilities are entitled to a free, appropriate education in the least restrictive environment. The Individuals with Disabilities Act of 1990 (IDEA), or public law 101-476, which expanded the definition of disability, requires IEP's address transition services especially for those age 16 and older, and makes assistive technology provisions. The Vocational Act of 1973 (especially Section 504) and the Americans with Disabilities Act of 1990 both provide fairly comprehensive provisions for health and social services, and anti-discrimination clauses for people with disabilities.

Families often rely on their spiritual strength to work through the lifelong process of parenting a son or daughter with a developmental disability. Rayda Vogel's faith is especially strong.

"If you have faith, all things work together for good to those who love God. Everyone has a purpose on this earth. Everyone."

Neil and Rayda Vogel also advise parents who face similar challenges, "Find out what help is available and learn all you can about

the diagnosis. There wasn't anything out there when Ron was born; we were so unaware." The Association for Retarded Citizens also offers these suggestions to parents of children at any age:

- 1) Encourage independence and allow your child to explore his or her world.
- 2) Children need to learn that what they say or do is important and can influence others. Encourage your child to ask questions and express opinions.
- 3) Self-worth and self-confidence are important factors in developing self-determination. Tell your child often that he or she is important.
- 4) Don't run away from your child's questions about differences related to his or her disability.
- 5) Teach your child about working toward goals. Talk about the steps to complete the tasks.

*"Find out what help is available and learn all you can about the diagnosis."*

- 6) Schedule opportunities for your child to interact with children of different ages and backgrounds.
- 7) Don't become complacent about your child's abilities. Undertake activities

that challenge his or her current skills.

- 8) Allow your child to take responsibility for his or her actions, both positive and negative. Let him or her know why you took certain actions.
- 9) Take every opportunity for your child to make choices. This may be in what your child wears, eats, or even where you go on vacation.
- 10) Provide honest, positive feedback. Focus on behavior or tasks that need to be changed, but don't make your child feel like a failure.

Families who have a son or daughter with a developmental disability can face tremendous challenges, but with the right tools - education, the support of family and friends, a strong faith, a supportive treatment team... and a belief in the discovery of *abilities*, life can be highly enriching.

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*Special appreciation to Rayda and Neil Vogel who graciously shared their personal story. Neil is a member of the Developmental Disabilities Subcommittee of PRCMHS Board of Directors, and the Chairman of the Developmental Disabilities Family Advisory Group.*

### **About the Author**

**Barb Barton, MSW, CQ Mgr**, is the Director of Residential Services for Adults with Developmental Disabilities at Pine Rest. In her current position, Barton oversees the staff and patient care for residents of Pine Rest's six adult foster homes, supported living apartments, and Day Program. She received her Master's degree in Social Work from Michigan State University, received certification as a Certified Quality Manager in 1998 from the American Society for Quality, and received certification in 1999 as a Certified Lead Quality Auditor from the Irish Quality Centre. She has over 16 years' experience in team training and management, program development including services for adults with severe brain injury, and medical rehabilitation.



## SUGGESTED WEB SITES

American Association on Mental Retardation  
[www.aamr.org](http://www.aamr.org)

National Association of Developmental Disabilities Council  
[www.igc.org/NADDC](http://www.igc.org/NADDC)

The Arc  
[www.thearc.org](http://www.thearc.org)

National Information Center for Children and Youth with Disabilities  
[www.nichy.org](http://www.nichy.org)

Autism Society  
[www.autism-society.org](http://www.autism-society.org)

Asperger's Syndrome Support Network Home Page  
<http://www.vicnet.net.au/vicnet/community/asperger>

The Center for the Study of Autism (autism research)  
[www.Autism.org](http://www.Autism.org)

On-Line Asperger's Syndrome Information and Support (O.A.S.I.S.)  
<http://udel.edu/bkirby/asperger>

Future Horizons (publishing company for autism literature)  
<http://www.onramp.net.org>

President's Committee on Mental Retardation  
[www.ncor.org/pcmr.htm](http://www.ncor.org/pcmr.htm)

# Promoting Mental Health in People with Disabilities

by David S. Laman, PhD

Millions of children, adolescents, and adults across the United States and throughout the world experience long-term disabilities that significantly affect their lives. These disabilities include developmental disabilities such as mental retardation and autism, physical disabilities, vision and hearing impairments, and a host of medical, genetic, and neurological conditions.

In recent years, more attention has been paid to the mental health needs of these groups of people. Unfortunately, it has been found

that people with disabilities are more likely to develop mental health disorders, and when they do, they have a harder time finding effective treatment. Among the reasons for increased mental health problems are frequent social problems they encounter such as feeling segregated and not really a part of society, being rejected and stigmatized because of their disabilities, and having restricted opportunities for employment, education, social and recreational activities.

As we have learned more about the mental health problems people with disabilities experience, **we are now in a position to explore ways in which we can promote mental health for these individuals.** Optimally, efforts to enhance emotional well-being would begin early in childhood and continue throughout individuals' lifetimes. Anyone involved in the life of a person with a disability plays a role in promoting positive mental health in a variety of ways. Three major areas important to mental health are promoting a positive sense of self, enhancing the environment to improve understanding and adjustment, and teaching skills that increase ability to adjust and obtain needed resources.

## Promoting a positive sense of self

Beginning in childhood, it is important for parents and caregivers to put much effort into helping their children with disabilities develop a positive and healthy sense of who they are. Parents and others need to continually send the messages to children that

- Their **value is unconditional** and comes simply from being themselves,

- **They are unique individuals with unique abilities,**
- Everyone has strengths and weaknesses and **they are more “abled”** than “disabled,”
- **They have something to offer other people,** and
- **They are capable of having control in their lives.**

These messages can be sent directly by showing and telling people how we feel about them, talking to people about how they feel about themselves, and by talking about the experiences people have in everyday life. Messages can also be sent in indirect ways such as engaging in play, using role-playing, using art to express feelings, and engaging with a person through books, music, and games that address these issues.

Whatever approaches are used, it is imperative that the development of a positive sense of self be a top priority. Individuals with disabilities who develop a positive sense of self are likely to be happier, less vulnerable to the high level of negative experiences they are likely to have, and less likely to develop mental health problems.

## Enhancing the environment to improve understanding and adjustment

A second area of focus in promoting mental health is optimizing environments in order to maximize opportunities for individuals with

## Philosophy for Whole Person Treatment

- Recognize that all people have value simply for being who they are
- Treat all people with respect, dignity, compassion, and as being “whole”
- Value people for who they are, not what they do
- Recognize unique abilities, not disabilities
- Empower people to have control in their lives
- Teach people, don't manage behavior
- Help people find meaning in their lives

# FACTS ABOUT MENTAL ILLNESS & DEVELOPMENTAL DISABILITIES

- People with developmental disabilities experience mental health disorders about 2 to 3 times as frequently as the general population
- They experience the full range of mental health disorders including depression, anxiety, bipolar disorder, and psychotic disorders
- About 1/3 of People with Developmental Disabilities have never even been referred for an evaluation
- Those with combinations of DD and Mental Illness are among the most segregated people in society. Mental Health problems interfere with the ability to function in the community and threaten the quality of life for persons with DD

disabilities to adjust and cope effectively. One of the most important things others need to provide is a **high level of social support**. There is evidence that inadequate levels of social support are associated with increased mental health problems. To provide needed social support, families, friends, and caregivers need to take the time to really listen, discuss, respect, love, and be there when needed. For children with disabilities, parents need to take more initiative to ensure their children are coming to them with concerns, fears, problems, and issues, to make themselves available to their children, and to read signs their children may need some special attention. Caregivers need to make sure that interacting, sharing, and giving positive, focused attention are as important as, or more important than, “taking care” of people with disabilities. Finally, both families and caregivers need to allow relationships with individuals with disabilities to be mutual rather than one-sided, offering those with disabilities the opportunity to give as well as receive support.

There are other important ways to optimize environments to improve understanding and adjustment.

- It is important to **empower both children and adults with disabilities to have as much control as possible** in their lives. Having control through making choices and decisions is an important aspect of mental health and self-esteem.
- Parents and caregivers need to help **prepare people with disabilities for changes and challenges** they will face in life, such as school placement, transition to work, and changes in living situations.
- Environments need to be structured to **maximize opportunities** for people with disabilities. People with disabilities do not need

to be protected or sheltered from real life. They need to be able to be involved fully in families and communities and to experience a wide variety of social, educational, occupational, recreational, and spiritual opportunities.

- Parents and caregivers need to **support the hopes, dreams, and faith** of people with disabilities.

## Teaching skills that increase ability to adjust and obtain needed resources

Additional requirements for mental health involve being able to obtain what one needs from the environment and being able to adjust when the environment changes. To do this effectively, people must possess certain skills. Individuals with disabilities may, depending on the type and severity of disability as well as age, need additional help learning important skills. While some of these skills may be taught formally, many need to be learned through everyday life. This again points to the importance of both children and adults with disabilities having as many experiences and opportunities to learn as possible, and being highly involved with other people in order to learn through modeling, interacting, and practicing skills.

There are many types of skills that have been found to be important to mental health and there are many ways people with disabilities can learn them. These include modeling and feedback by others, practice through role-playing, playing games that teach skills, focused play with children, and practice in group or family situations. The types of skills that need to receive attention include:

- **Coping skills** play a valuable role in adjustment to everyday problems as well as major life changes and transitions. Everyday life provides people with disabilities many

## CREATIVE ACTIVITIES FOR PARENTS TO PROMOTE MENTAL HEALTH IN CHILDREN WITH DISABILITIES

- Engage in children's play to gain insights into issues children are dealing with and help children safely explore and cope with these.
- Help children practice skills and prepare for challenges by creating role-play situations at home. Video tape these to make the role-playing fun and to provide feedback for children.
- Participate in art activities with children to allow them to safely explore and express feelings without interference from communication problems.
- Play games, read books, and watch videos that deal with feelings, solving problems, coping with problems or teach other skills.

opportunities to practice coping and this can be an effective way to learn, particularly if there are other people involved to support, help process, and give feedback.

- **Social skills** are essential for obtaining social support, needed assistance, and for taking care of oneself in problem situations.
- **Skills to recognize, understand, express, and manage feelings** are critical to mental health, yet these skills receive very little attention. When feelings such as anger, frustration, anxiety, sadness, and hopelessness are not dealt with, more severe emotional or behavioral problems can develop. Parents and caregivers need to take the time to really listen, help their children recognize what they are feeling, put those feelings into words or express them in another way, and explore ways to cope with the feelings.
- **Skills that allow people to enjoy life** are also very important. Without adequate skills such as recognizing what activities they might enjoy, how to express those wants and desires, and how to access these opportunities or accommodate for certain disabilities, individuals often are left with few enjoyable experiences to look forward to in life.

### Summary

We have made progress in recent years in understanding and addressing the mental health needs of people with disabilities. People with disabilities experience more challenges and are subjected to more negative social conditions than most people. As a result, they are more vulnerable to mental health problems. As we have identified some of the factors involved in this, we are in a position to use our knowledge to begin focusing on promoting

mental health for people with disabilities. Childhood is an ideal time to start teaching, supporting, and creating opportunities for children with disabilities to learn how to feel good about themselves, adjust and cope with the many challenges they will face, and feel like valued members of our communities. Changes also need to occur on a societal level, from how we view people with disabilities to the opportunities that we afford them. In order to make a difference, the issue of promoting mental health for people with disabilities will require much more attention than it has received.

### About the Author

#### *David Laman, PhD*

is a psychologist and the Director of the Center for Developmental Disabilities at Pine Rest. He has over 15 years' experience assessing and treating the mental health issues faced by children, adolescents and adults with developmental disabilities. He received his Doctorate in Clinical Psychology (Specialty: Developmental Psychology and Developmental Disabilities) from University of Illinois at Chicago. Dr. Laman has written and presented extensively on mental illness and people with developmental disabilities.



## RISK FACTORS FOR MENTAL HEALTH PROBLEMS

### People with disabilities:

- are not fully accepted as part of society and face frequent rejection
- are considered to be less than “whole” people
- face restricted opportunities and choices in life
- often are allowed to have less control in their lives
- experience frequent social disruption
- are more often victims of abuse, neglect, and crimes
- often suffer from a lack of real meaning in their lives
- are often treated like children even as adults



# Meeting the Mental Health Needs of Persons with Developmental Disabilities

by Tracey L. Kroeger, PhD

John is thirty-four years old and has a history of Mental Retardation, or significantly below average intellectual and independent daily functioning diagnosed between birth and 22 years of age. Six months ago, he began a new job. Shortly afterward, he moved into a new, much larger residence with five other adults with developmental disabilities. Following these two events, staff members at his residence noticed that John was having difficulty falling asleep, getting in arguments with peers, demonstrating yelling, name-calling and tearfulness. In addition, he was spending more time in his bedroom and his appetite had decreased. Concerned, residential staff took John to see a psychologist, who concluded that he was experiencing depression related to his adjustment to new living and working situations. Depression is considered a mental health problem because it interferes with the way a person thinks, feels and behaves.

People with developmental disabilities experience the full range of mental health disorders, and yet are among the most underserved populations by the mental health industry. Approximately one third of all people with developmental disabilities, or one to two million Americans, have a significant behavioral, mental, or personality disorder requiring mental health services. For a variety of reasons, individuals with a “dual diagnosis” - or both a developmental disabil-

ity and a mental health problem - rarely receive the necessary mental health services. One of the most common reasons for neglect of mental health issues is the misunderstanding of inappropriate behaviors as part of the developmental disability, as opposed to a potential separate emotional or behavioral problem. This phenomenon is referred to as “diagnostic overshadowing.”

People with developmental disabilities are likely to develop mental health problems due

*“People with developmental disabilities are likely to develop mental health problems due to a number of social and developmental risk factors.”*

to a number of social and developmental risk factors. They are exposed over a lifetime to negative social conditions. From a young age they are labeled as “different” and treated with prejudice. Often considered somehow less deserving of typical experiences, they are frequently expected to attend school, find employment and participate in social activities separate from peers without developmental disabilities. As adults, these individuals face restricted vocational and social opportunities, which can reduce quality of life. People with developmental disabilities also experience high rates of physical, emotional and sexual victimization. In addition, they often have inadequate social

support networks and limited social skills (i.e., poor social problem-solving, assertiveness or leisure skills). Limited understanding and/or expression of language are also leading risk factors, as effective communication is important for social success. Lastly, frequent negative self-concept and expectations of failure may also make people with developmental disabilities vulnerable to the development of mental health problems.

Without treatment, emotional and behavioral problems for people with developmental disabilities have been found to continue over many years. Persistence of mental health problems can create additional complications for these individuals, such as decrease in independent living skills and problem-solving ability, suicide attempts, substance abuse, legal trouble and, in cases of severe behavioral problems, self-injury. Mental health problems greatly interfere with educational, vocational and social success and significantly reduce quality of life.

Providing mental health services to people with developmental disabilities, while necessary and critical, is complicated by many assessment and treatment challenges. Developmental issues such as low overall intellectual functioning may interfere with accurate self-report. People with developmental disabilities may under- or over-report important symptoms, deny symptoms in an effort to appear competent or misreport information because interview questions are not clearly understood. Most importantly, the way in which people with developmental disabilities demonstrate common mental health problems such as depression or anxiety may be very different compared to individuals in the general population. For instance, a child with autism may demonstrate extreme anxiety through an increase in repetitive behaviors (i.e., ordering rituals, preoccupation with a favorite topic, repetitive movements).

In order to provide effective services to those with developmental disabilities, clinicians have to familiarize themselves with “typical” developmental processes, as well as those for children, adolescents and adults with various developmental differences. Both inpatient and outpatient mental health services involve multiple goals, including the following:

- *Individual Therapy* for the person with a developmental disability in an effort to reduce ineffective or disruptive behaviors, build

*“Providing mental health services to people with developmental disabilities...is complicated by many assessment and treatment challenges.”*

appropriate coping strategies and promote overall mental health

- *Family Therapy* to address interpersonal behaviors, communication styles and teaching approaches which encourage development of appropriate coping skills for the person with developmental disabilities
- *Education for people with developmental disabilities and their caregivers/family members* regarding the specific developmental disability, appropriate behavioral expectations and information processing style, and the function of certain “symptomatic” behaviors
- *Collaboration with caregivers/family members* regarding effective behavior management/parenting styles within the home
- *Consultation with educators, employers, case managers, psychiatrists and primary care physicians* to address disruptive behaviors and promote mental health for the person with a developmental disability
- *Identification of additional support services within the community* to help in the development of an adequate support network for the person with a developmental disability and associated caregivers/family members

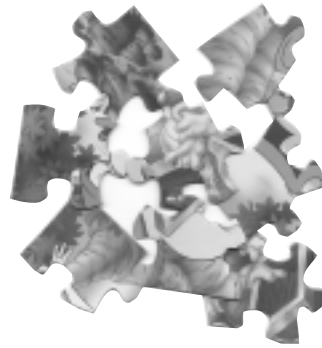
Engaging people with developmental disabilities in either testing or psychotherapy requires creativity, flexibility and patience. Testing often must be accomplished over the course of several sessions, involve multiple breaks and rewards, and include input from various people in the client’s life. It is important to consider the client’s communication style, comfort level with the examiner and testing environment, and information processing strengths, as they may significantly affect the results of the evaluation. A combination of assessment measures is typically used, including those available for use with the general population, as well as those specifically designed for use with individuals with developmental disabilities. Often times, a variety of rating scales,



test instruments and interactive processes are necessary to gain an accurate picture of the emotional, behavioral and cognitive functioning.

Individual therapy with people with developmental disabilities attempts to achieve the same outcome of psychotherapy with the general population: changes in thinking, feeling and behaving. Techniques range from the more traditional “talk therapy” to art, music or play therapy, none of which require speech. Exercises focus on:

- Identification of environmental stressors and related emotions
- Understanding of feelings and behaviors associated with depression, anxiety, grief, adjustment to changes, etc.
- Exploration and strengthening of relationships with family members, friends, co-workers, employers, educators
- Development of skills
  - social skills
  - relaxation skills
  - anger management skills
  - communication skills
  - problem-solving skills
  - goal-setting skills
  - self-monitoring skills



- Challenge and correction of irrational thought processes
- Identification of personal strengths and weaknesses
- Letter-writing
- Journaling
- List-making, scheduling, charting
- Role-playing
- Pretend playing with dolls, stuffed animals, legos, cars/trucks, puppets

Homework assignments to be completed during the time between therapy sessions assist with real-world practice and long-term success of learned skills and coping strategies.

In recognition of the need to provide quality mental health services for people with developmental disabilities, the Center for Developmental Disabilities (CDD) was created at Pine Rest Christian Mental Health Services in 1997. Since its initiation, the CDD has grown to include both in and outpatient clinical services with the expertise of multiple professionals including social workers, psychologists, psychiatrists and clinical pharmacologists. Inpatient services include thorough assessment of referral concerns, medication treatment, individual therapy, group therapy, and family

therapy for children, adolescents and adults with developmental disabilities. Outpatient services at the Psychological Consultation Center on Pine Rest’s main campus have focused on the provision of testing and therapy services to children, adolescents and adults with various developmental disabilities. Outpatient services provide individual and family therapy, as well as testing intended to explore intellectual and independent daily functioning, neuropsychological functioning, mental health and behavioral status, and diagnostic clarification.

## About the Author

**Tracy Kroeger, PhD, LLP**, has been providing outpatient services at Pine Rest Christian Mental Health Services since 1999 as part of its Center for



Developmental Disabilities. Dr. Kroeger received her Master’s degree and Doctorate in Psychology from The Ohio State University and has over ten years’ experience working with individuals who have neuropsychological differences and developmental disabilities. Through Pine Rest’s Psychological Consultation Center, she evaluates clients for intellectual functioning, neuropsychological functioning, adaptive functioning, differential diagnosis, and mental health issues. She also provides individual therapy to developmentally disabled clients and behavioral consultations with parents, caregivers, employers, educators, school counselors, case managers, physicians, and more.

# The Center for Developmental Disabilities at



This program serves persons with all types of developmental disabilities including mental retardation and autism.

## Services Include:

### *Crisis-focused, short-term*

#### *Inpatient Treatment*

intensive psychiatric and psychological intervention to stabilize crisis situations

#### *Outpatient Psychological Services*

psychological evaluation for accurate diagnosis

#### *Community-Based*

#### *Crisis Intervention*

access to a comprehensive array of services provided by resources within the patient's own community

#### *Staff Development*

specialized training for staff in schools, agencies, and other organizations

#### *Consultation*

to agencies, residential services, families, schools, physicians, and other professionals

For more information, please call Pine Rest Christian Mental Health Services: **616/281-6364**

## SUGGESTED READING AND VIDEOS

### BOOKS

Wehmeyer, Michael L and Patton, James R, eds. *Mental Retardation in the 21st Century* ProEd, Inc., Austin, Texas. 2000

Linfoot, Ken, ed. *Communication Strategies for People with Developmental Disabilities* Paul H. Brookes Publishing Co., Baltimore, MD. 1994

Streissguth, Ann *Fetal Alcohol Syndrome: A Guide for Families and Communities* Paul H. Brookes Publishing Co., Baltimore, MD. 1997

Schopler, Eric, ed. *Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders*. Plenum, New York, NY. 1995

Smith, Romaine, ed. *Children with Mental Retardation: A Parents' Guide*. Woodbine House, Bethesda, MD. 1993

Powers, Michael D., ed. *Children with Autism: A Parents' Guide*. Woodbine House, Bethesda, MD. 1989

Smith, B. et al.. *Asperger's Syndrome: A Guide for Educators and Parents*. Taylor & Francis, Inc. 1998

Murray-Slutsky, C. *Exploring the Spectrum of Autism and Pervasive Developmental Disorders: Intervention Strategies*. Therapy Skill Builders. 2000

Walt, M. *Pervasive Developmental Disorders: Finding the Right Diagnosis and Getting Help*. O'Reilly & Associates, Inc. 1999

### VIDEOS

*Different Moms*, Published by The Arc Publication Desk, Dr. Sharon Davis. Produced by Moxie Firecracker Films, Rory Kennedy and Liz Garbus.

# The Community and Persons with Developmental Disabilities

by Kathy Lentz, MM

Our world and our communities are becoming more diverse places. We see people from all walks of life, in all shapes, sizes, and colors, all with different experiences, preferences and abilities. People with disabilities are part of our diverse communities. Ever since the de-institutional movement of the 1960s, people with disabilities are participating in all aspects of community life.

Many people were cared for in institutional settings. There were a lot of dedicated people who wanted to provide professional level services to people with developmental disabilities in a safe (“locked”) setting. People in institutions were limited in their ability to belong to the larger community and limited in opportunities for development of social and employment skills. Along with the civil rights movement of the 1960s, the disability rights movement supported the rights of individuals with disabilities to choose where they wanted to live. Thus the movement to community based programs.

Today, the vast majority of individuals with developmental disabilities are in our communities and all but a few institutions have closed. Many individuals and their families, however, need support to adapt and adjust successfully. A wide range of services are available to meet the needs of individuals in their communities.

## Professional Supports

**Schools** — A wide variety of services are available for children with developmental disabilities through their school system. Services for children with disabilities can begin as early as six months of age, depending on the severity of the disability and the child’s developmental needs. Early intervention can help children make more progress in their development. Throughout the school years, children with disabilities are supported through individualized learning plans. Children with significant challenges may have the additional support

of professionals such as nurses, physical therapists, occupational therapists, speech therapists, and psychologists through their school. Support and learning plans can be developed for use in both the home and school.

Schools also offer transition planning for all children with disabilities, helping them and their families adapt or adjust to adult years. This may include vocational training and work experiences.

**Community Mental Health and Developmental Disabilities Councils** — All communities offer services to children and adults with developmental disabilities and their families. These public programs provide a wide range of services and many are provided with governmental support such as Medicaid. There is usually an assessment of the individual’s ability to pay for services (or the parents’ ability to pay for their child’s services). Examples of the services that these public organizations provide are:

- **Respite Services for children and their families.** Sometimes caregiving is a 24-hour, 7-day a week proposition. Families who provide this support need to take care of themselves and to take breaks from the constant demands of caregiving. Respite offers time away.
- **In-Home Support for children and their families.** When children with DD have very significant needs, there are times the family cannot meet all the needs on their own. Nursing support is provided in the home for children with complex disabilities. Home Help Aides are provided for children who need assistance with social or behavioral skills. These types of programs are designed to support the entire family, not just the child with a disability.
- **Coordination of Services and Benefits.** Individuals with disabilities often receive benefits from a variety of sources. Determining the resources people are entitled to, applying for those benefits, and making sure individuals do not lose the support, are critical factors for ensuring continuation of benefits. Service coordinators also help individuals and their families

*“A wide range of services are available to meet the needs of individuals in their communities.”*

find the type of services they need and qualify for in the community. They help put together a comprehensive plan of services and supports for the individual.

- **Skill Building and Work Programs.** programs are available to help the individuals with disabilities learn job skills, look for jobs, and be successful in their jobs. Basic skills are taught about attending to task and being on time, and job coaches can be provided in the work site to give that extra bit of support someone may need to be successful in his or her job. There are also programs for individuals who are working on more basic skills such as

*“All communities offer services to children and adults with developmental disabilities and their families.”*

responding to yes/no questions, gross motor skills (grasping, moving) and activities of daily living.

- **Clinical Services.** Often individuals with developmental disabilities have some additional physical challenges. These challenges may require professional support or intervention. An individual who is experiencing difficulty walking or an unsteady gait may see a Physical Therapist to learn and practice walking. A Speech

Therapist may help someone who has difficulty speaking and being understood or provide guidance for using assistive communication devices. Psychological services may be needed to address emotional and behavioral concerns.

- **Community Living Services.** There are a variety of public programs that help support individuals with developmental disabilities living in the community. There are a wide range of options, and individuals and families should think carefully about what they would like best and where their needs lie. If help is needed with daily activities such as eating, bathing, mobility, and to be safe, then some amount of direct staff support is necessary. Some individuals need more frequent intervention for social/behavior skills or for their specialized medical/physical needs (i.e. tube feeding, range of motion). Some people are very social and like living with other people. Others prefer more privacy and don't like to have lots of other people around. People's homes are one of the most important places to them. It is so important to carefully choose the type of home environment to address these needs and wants.

Communities offer a range of services to help assist and meet the needs of individuals with developmental disabilities. It is critical to research these before choosing the type of services that best meet the needs of the individual with the disability. Each community organization has a method for assessing the

*“Many individuals and their families, however, need support to adapt and adjust successfully.”*

needs of the individual and will help point him or her to services that will meet these needs.

## Natural Supports

In addition to professional services, it is critical that persons with developmental disabilities feel included in the community. All of the services referenced above represent paid services, either by the individual or through public dollars or programs. There are other ways communities can and do support people with disabilities. As people with developmental disabilities spend more time in their community, they are beginning to become more fully included in their community. They are attending churches, working in grocery stores, belonging to YMCAs, and living in apartment complexes. Belonging to groups can provide a great deal of support to individuals with disabilities. A group can help an individual determine some of the social situations/expectations of the community. A group can also help identify when and where additional support might be needed. Communities are becoming more accustomed to a broad diversity of individuals, including those who look different, use a wheelchair, act different or make different noises. There are more places where people are welcomed and truly invited to join and be a part of the community. There are many examples of these natural supports for individuals with DD in the community.

- **Churches.** Many churches and

synagogues and other houses of worship make it a priority to fully include and welcome people with disabilities into their worship. They are included in choirs, have worship groups geared toward their level of understanding, and have help with transportation.

- **Neighborhoods.** There are individuals with DD living in all communities. Children live with their families, adults live in their home or apartment or in group homes. Neighborhoods can provide natural supports to these individuals by including them in all neighborhood activities. Neighborhood Watch programs can help look out for individuals with disabilities.
- **Businesses.** As individuals with developmental disabilities are getting more jobs in the community, all of us are able to interact more. We may have an employee with developmental disabilities in our place of business. They may be helping us at the grocery store or the video store, or greeting us at the Walmart. Their co-workers may help them with rides, figuring out new timeclocks, invite them to work events, etc. Co-workers provide social contact and interaction. As people with developmental disabilities may serve us in the community (grocery store, video, newspaper), we can include them fully by recognizing their contribution, what they do for us. We can look at them, not by them (as we sometimes do to people who are service providers).
- **Recreation Programs.** Many community recreation programs welcome and gear activities to persons with developmental disabilities. Activities specifically geared toward persons with disabilities are becoming more common. Check with your local community education center for more information. Many gyms and YMCAs also welcome and accommodate people with disabilities.
- **Social groups** for children are more inclusive. Boy Scouts and Girl Scouts welcome people with disabilities. School groups welcome all kids. Intramural school sports invite all children to join.

There are many places and ways for people with developmental disabilities to fully enjoy community life. There are professional services and natural supports. We have a great opportunity to be natural supports for someone with a developmental disability. We can go out

## About the Author

**Kathy Lentz**, MM, is the Director for Spectrum Community Services, a private, non-profit organization supporting individuals with disabilities in their communities. Kathy began her career in the mental health field in 1980 at Pine Rest Christian Rehabilitation Services. She now has more than 20 years' experience working with individuals with disabilities in their community. Kathy received her Bachelor's degree in Philosophy from Calvin College and her Masters Degree in Management from Aquinas College.



## SOCIAL AND RECREATIONAL ACTIVITIES AND RESOURCES

### Kent Special Riding Program

**Phone:** (616) 891-8066

This horseback riding program offers the disabled the opportunity to develop physically, emotionally, mentally, and socially. (Kent County/MSU Cooperative Extension Service). Hours: M-Sat. 9:00am-8:00pm; Eligibility: must be age 3 and up; Fees: \$10 for 6 weeks.

### Special Olympics Michigan

Central Michigan University  
Mount Pleasant, MI 48859

**Phone:** (800) 644-6404

**Fax:** (989) 774-3034

**Email:** [somi@somi.org](mailto:somi@somi.org)

**Web site:** [www.somi.org](http://www.somi.org)

### Special Olympics, Inc.

1325 G Street, NW, Suite 500  
Washington, DC 20005 USA

**Phone:** (202) 628-3630

**Web site:** [www.specialolympics.org](http://www.specialolympics.org)

Community Parks and Recreation Departments

Community Education Programs

Local School Systems

## OTHER RESOURCES

Social Security Administration

[www.ssa.gov](http://www.ssa.gov)

Michigan Protection and Advocacy

106 West Allegan, Suite 210  
Lansing, MI 48933

## ASSOCIATIONS AND SOCIETIES

### Michigan Developmental Disabilities Council

Lewis Cass Building

Lansing, MI 48913

**Phone:**

(517) 334-6123

(517) 334-7354 (TTY)

**Fax:** (517) 334-7353

*A group of citizens representing people with physical and/or mental disabilities, family members and professionals, that conducts advocacy activities, works to facilitate support services, and organizes Regional Interagency Coordinating Committees to address community living, education and employment issues. Assists individuals and families with access to appropriate treatment, services and habilitation.*

### Autism Society of Michigan

6035 Executive Drive, Suite 109

Lansing, MI 48911

**Phone:** (517) 882-2800

**Fax:** (517) 882-2816

**E-mail:** [miautism@aol.com](mailto:miautism@aol.com)

*Provides advocacy, information and referrals. Approximately 15 chapters statewide.*

### The Arc - Michigan

333 South Washington Square, Suite 200

Lansing, MI 48933

**Phone:** (800) 292-7851; (517) 487-5426

**Fax:** (517) 487-0303

**E-mail:** [Arcmi@voyager.net](mailto:Arcmi@voyager.net)

**Website:** <http://www.arcmi.org>

*Many local chapters (49) statewide; call for the closest one. Provides statewide advocacy for persons with developmental disabilities and their families; technical assistance for local chapters.*

### **Down Syndrome Association of West Michigan**

P.O. Box 8804

Kentwood, MI 49518

**Phone:** (616) 956-3488

*A support and advocacy group; provides information and materials. Monthly meetings.*

### **National Association for the Dually Diagnosed**

132 Fair St.

Kingston, NY 12401-4802

**Phone:** (800) 331-5362

**Fax:** (914) 331-4569

**Email:** thenadd@aol.com

**Web site:** www.thenadd.org

*PURPOSE: A nonprofit organization for parents and professionals designed to promote the interests of individuals who have both mental illness and mental retardation.*

*SERVICE: Provides information and referral, holds conferences, performs advocacy work.*

*PUBLICATIONS: Produces an extensive catalog of audio and video tapes, newsletters and books on subjects such as diagnosis and assessment, drug therapy, residential services, social and sexual issues, family issues, and research.*

### **The ARC Kent County – Association for the Rights of Citizens with Developmental Disabilities**

**Phone:** (616) 459-3339

*Provides advocacy for people with developmental disabilities and their families. Hours: M-F 8:00am-5:00pm; Eligibility: none; Fees: none.*

### **Early On of Kent County**

**Phone:** (616) 365-2310

*Links families with services and supports they need to help infants and toddlers (birth to three) who may be developing slowly or have medical problems.*

*Special thanks to our contributors and Grand Rapids area ARC for resources and organizations.*

## **PINE REST HOUSING AVAILABLE IN ADULT RESIDENTIAL PROGRAM FOR PERSONS WITH DEVELOPMENTAL DISABILITIES**

*Pine Rest Christian Mental Health Services offers compassionate, high quality care for persons with developmental disabilities through its Adult Residential Program.*

- Focus on people's abilities and strengths
- Most levels of care available
  - Six licensed, adult foster care homes – on and around Pine Rest's main campus at 300 – 68<sup>th</sup> Street, Cutlerville - provide options from a secured house for individuals with both a mental illness and a developmental disability, an older adult residence, a home for individuals with impaired ADL (self care skills), and homes that provide mid-level support for people with moderate functional impairments.
  - Higher functioning clients can choose to live in one of five community-based apartments near Pine Rest's main campus. Day supervision and evening live-in staff help residents with cooking, grocery shopping, medication management, and transportation arrangements (i.e., to and from work or the grocery store).
- Educational and meaningful daily activities
  - Day Activity programs provide social and activity-based therapy. Residents spend six hours a day doing recreational activities such as swimming, visiting local museums, and craft projects. Events vary and every attempt is made to maximize choice and provide a variety of opportunities.
- Opportunities to improve skills of daily living and community integration
- Interdisciplinary approach combines medical, psychiatric, and psychological services
- Family involvement encouraged

**For more information, please call 616.281.6358**



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