

# Supported Parenting

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## Introduction

### **No single system takes responsibility**

Families headed by parents with cognitive disabilities are becoming more visible in our communities and increasingly noticed within several service systems. Child protective services, health care, welfare and work programs, developmental disability services for families and children, developmental disability services for adults, family violence and child abuse agencies generally recognize that parents with disabilities and their children are both under-served and inadequately served in these systems. However, in state government and in most Wisconsin communities, there is no one system stepping forward to take primary responsibility for mobilizing and coordinating supports tailored specifically to the needs of parents with cognitive disabilities. Gradually, over the last 10 years, a few Wisconsin communities have begun to develop the capacity to support these families.

This chapter focuses on parents with cognitive disabilities and their families. Parents with other types of disabilities such as physical disabilities or mental illness require other support approaches than those of parents whose need for support results from their cognitive limitations.

### **Definition**

“Supported parenting” is the term used to describe supports adapted to the special needs of parents with cognitive disabilities. There is no organized system of supported parenting nor is there a designated funding source. Supported parenting is as much a philosophy or attitude as it is a specialized program. Support is based on an understanding and acceptance of the characteristics, life circumstances, needs, and desires of persons with disabilities.

Supported parenting can be found within agencies providing services to a wide range of individuals and families, and it can be found in programs with the single specialty of serving families headed by parents with disabilities. When specialized support for parents with disabilities is available it can come from a wide variety of systems.

There are few if any legal rights in federal or state statute which are specifically focused on supported parenting. However, adults with cognitive disabilities have some rights under Chapter 51, the Americans with Disabilities Act, Medicaid, and other laws/regulations which may apply in some circumstances. Children also have a variety of rights (especially in terms of protection from child abuse or neglect)

which are covered in this guide. (*See Child Welfare & Juvenile Justice Systems and Children with Complex and Enduring Needs chapter, pg. 149.*)

## Parents with Cognitive Disabilities

### What we know about parents with disabilities

Given the chance, most parents with cognitive disabilities successfully establish loving bonds with their children, but many have difficulty with the day-to-day demands of caring for their children. While a parent with cognitive disabilities has unique combinations of strengths and support needs, many seem to share some common problems. Parents with cognitive disabilities tend to have some difficulty retaining and correctly applying the information and skills needed for adequate parenting. Many lack social and play skills and have a hard time managing money. For parents who have difficulty in communication and social relationships, the effect is seen not only in the parent-child relationship but also in the family's ability to relate within the community and to the services coming into their lives.

### How the children fare

Interviews of adults who grew up in households headed by parents of disabilities reveal that while their parents' disabilities created some difficulties and embarrassment, on the whole, they loved their parents, felt loyal to their families, and grew up learning values and lessons that sustain them as adults.<sup>1</sup>

Children of parents who have cognitive disabilities have a somewhat greater chance of developing disabilities. But with supportive interventions available to the family, the likelihood of developing disabilities decreases. Child neglect is a greater risk for parents with cognitive disabilities than the risk of abuse. When neglect occurs, it is typically not purposeful neglect but the result of actions and judgments that reflect inadequate training and support. Parents with adequate and appropriate supports usually can learn and apply knowledge and skills when support is matched to the parents' learning style. When abuse occurs, it is usually not attributable to the parent's cognitive disability but to other attributes of the parent or to household members other than the parent with cognitive disabilities.



*Notice the bond between parent and child. Measure the resiliency and adaptability employed by the child to make the best of what sometimes seems a chaotic situation.*

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 disability is only about how people learn. Rarely is it the most significant factor in deciding whether someone can parent adequately.

### Predictors for successful parenting

Among parents with cognitive disabilities, those who have reading skills usually do better at parenting than those who do not read. Parents free of serious medical, psychiatric or substance abuse

conditions are generally more successful at parenting. Parents with cognitive disabilities who have experienced sexual abuse or who have an abusive partner also often have more difficulty parenting. Parents, themselves, identify sufficient and appropriate support as an important key to successful parenting.

## Characteristics of Current Systems

### Developmental disability service system

Parents with disabilities often have difficulty securing resources and negotiating the complexities of the human service system. Agencies with the most expertise in serving adults with developmental disabilities are typically the least likely to be involved with families. Typically, developmental disabilities services are set up to serve single adults or families in which the family member with the disability is a child. Residential and vocational support programs for adults with disabilities are not usually equipped to support parenting roles. Family support programs may have expertise in child disability but staff may not have the skills to adapt support to be useful to parents with disabilities.



*Advocate for the involvement of absent systems if the lack of supports is detrimentally affecting the family. For instance, if the mother meets the criteria to be served by the developmental disabilities system and that system could make a positive difference, advocate for the openness and flexibility needed by that system to serve her.*

### Child protective services

Families headed by parents with cognitive disabilities may be referred to child protective services when there are concerns about neglect or abuse. Protective services can be voluntary but, due to budget constraints, are often available only on a court-ordered basis. For the court to order services, explicit risk of harm to the child must be evident. Protective services ordinarily are crisis-oriented, short-term interventions designed to correct a particular problem. Most protective service agencies are not organized to provide help to parents who will need support over the long term. Caseloads are large and workers are expected to have cases turn over rapidly. Protective service workers can find themselves in the contradictory role of trying to establish a helping relationship with the family while gathering evidence of parental inadequacy and influencing whether the family remains intact.



*Discover the adaptations a parent makes to account for his/her disability. Do more than inventory parent faults. Be on the look out for protective service workers who too quickly assume that the presence of a disability automatically “disqualifies” a parent.*

### Health care

Families headed by parents with cognitive disabilities may have contact with pediatric health care providers and local public health nursing agencies, especially around the birth of a child and during the infancy and early childhood years. Interventions often rely on the parent's ability to read and to apply instructions in various circumstances. There is a large variation in the quantity and intensity of pediatric care

and public health nursing available to families. Common characteristics include the expectation that services will be specific and brief.

**W-2** Wisconsin Works (W-2) work programs exclude parents with disabilities if they are eligible for Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). Parents with disabilities who participate in W-2 work programs can be sanctioned with loss of income for missing appointments or failing to complete tasks. The singular focus on employment may have the unintended effect of preempting the parent's availability for involvement in parenting programs. *(See W-2 and Related Programs chapter, pg. 130.)*

**Schools** School personnel may assume parents of students will have the ability to respond to written information sent home with the child. When parents can't read or respond to school expectations, or when students come to school unprepared to learn because of a disorganized home environment, school personnel do not ordinarily have the capacity to respond in ways that are supportive or helpful to the parent with cognitive disabilities.

Many schools have special programs for students who become parents while still enrolled in school. Rarely are these available or adapted to the learning needs of special education students who become parents.

### **Barriers to community resources**

Parents with disabilities find similar barriers to other community resources for parents and families, such as family resource centers, child abuse prevention programs, domestic abuse shelters, and law enforcement agencies. In those circumstances when a family overcomes the barriers to entry into a community service or program, the family's needs may result in a cascade of referrals and involvement with an overwhelming number of programs, agencies, and workers. Lacking coordination of these multiple involvements, providers may experience confusion about their various roles and boundaries. Parents may have difficulty understanding the deluge of often contradictory information, advice, and expectations, and may cease to participate. Parents with cognitive disabilities are sometimes interpreted as noncompliant or overly dependent while their cognitive limitations are not always acknowledged or understood.

## **Qualities of Effective Support**

### **Supporting through teaching**

Successful teaching of parents with cognitive disabilities requires not only an understanding and acceptance of the characteristics of their disabilities and life circumstances, but also knowledge of appropriate techniques for their successful learning. The following are important issues to take into account when putting together an instructional strategy: the parent's individual learning style; the parent's current knowledge, behavior, attitudes, beliefs, values; available support systems; and available resources.<sup>2</sup>

**Supporting recovery from abuse**

Cognitive disability brings its own set of obstacles to successful parenting, but for most families, the parent's cognitive disability is not the primary reason for failure. Research shows that the mental health of the mother can be a critical factor. 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.<sup>3</sup> Virtually all the mothers interviewed in a Wisconsin Council on Developmental Disabilities supported parenting learning project described themselves as survivors of past or current sexual and physical abuse.<sup>4</sup> 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. Providing counseling and/or teaching self protective behaviors is often of benefit to both parents and children when abuse is part of the family's history.

**Re-evaluating 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.<sup>5</sup>

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, recent agency practices and court rulings 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.



*Discover the family's strengths. When an attorney representing the parent in an out-of-home placement or termination of parental rights action receives a referral regarding a family headed by a parent with a disability, the referral typically will come with ample information documenting all that is wrong with the family, but not enough about what is right. Attorneys or other specialists to whom the family is referred will be in a better position to help families if they mobilize advocacy around family strengths.*

**The system is to protect and support,  
not choose "better parents"**

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, the system's prerogative is not to choose "better parents" for children, but only to protect them from life threatening ones. Therefore, the wisest and most ethical

first course should be to diligently devote system resources to providing supports and services to the natural parents to increase their capabilities, and to establish a natural support system that will sustain them.

## What Parents Want in Support Services

### Listen to parents

A parent's disability, in itself, does not necessarily determine whether a parent will be a "good enough" parent. While the individual characteristics of the parent are important, the characteristics of the supports available have a lot of influence over whether parents will succeed.

Parents with cognitive disabilities have identified characteristics of both effective support and inadequate support.<sup>6,7</sup>

### Satisfactory support

Lessons learned from parents regarding effective support:

1. Build a trusting, mutual relationship with parents.
2. Acknowledge the parent's role as head of household.
3. Appreciate the love between parent and child, despite the problems.
4. Offer sustained, practical support directed toward building on and expanding the parent's own skills and confidence.
5. Match the family with personnel who have a genuine liking for the family.
6. Recognize the emotional needs of parents; build parents' self-esteem and confidence.
7. Mobilize community supports; connect with other agencies involved with a family.
8. Integrate formal services with support and involvement of extended family, neighbors and friends.
9. Turn to the parent to determine the most effective direction for support.
10. Develop an advocacy role representing the family to the service system rather than presenting oneself to the family as an agent of the system.



*Meet with the family at home. Meeting with parents in their home will find them in an environment more familiar and comfortable for them than an office. More will be learned by taking in the home environment. The parents will be more informative and will have*

*the context for providing information about their family and their parenting role.*

**Unsatisfactory support** Parents have also identified a number of practices that are not helpful and, in fact, create an additional layer of stress in lives already burdened with difficulties. Parents state their families do NOT benefit from involvement when workers and agencies:

1. Offer an inflexible, “one-size fits all” approach that doesn’t take individual differences into account.
2. Focus on deficits; overlook parents’ capacities.
3. Employ a judging, skeptical and punitive approach.
4. Use threats of removing the child to coerce compliance.
5. Conclude that parents are deficient in situations when really it is the service approach that is inadequate.
6. React to crises but fail to anticipate and prevent problems.
7. Fail to sustain continuity in the support relationship with the family and fail to coordinate and communicate with other agencies involved with a family.
8. Diminish the importance of family relationships and friends.
9. Assign workers who lack personal experience of parenting.

### **Supported Parenting Programs in Wisconsin**

Several Wisconsin communities have mobilized a variety of resources and funding sources to create flexible support options for parents with disabilities and their families. The programs listed below have established specialized supported parenting services. A growing number of other agencies are beginning to incorporate supported parenting principles and practices into the services they provide to a more generalized population so that they can tailor their services to meet the needs of parents with cognitive disabilities.

The specialized supported parenting programs listed here provide their direct support services to local families. Some have waiting lists. To a limited extent, they are able to provide information about their programs and some general information about supported parenting. Some training events and technical assistance activities are available occasionally in statewide or regional conferences and workshops. These have been co-sponsored by the University of Wisconsin Health Promotion Project, Department of Professional and Applied Studies, Division of Continuing Studies (608-265-2233) and the Wisconsin Council on Developmental Disabilities (608-266-7826).

**Neighbors Network**  
**Jackson County Department of Human Services**  
 PO Box 457, 420 Highway 54 West  
 Black River Falls, WI 54615  
 715-284-4301

**Parents and Children Together Program**  
**Exchange Center for the Prevention of Child Abuse**  
 2120 Fordem Avenue  
 Madison, WI 53704  
 608-241-3434

**Family Education and Resource Center**  
 540 North Eighth Street  
 Manitowoc, WI 54220  
 920-682-1742

**Supported Parenting Project**  
**Catholic Charities Waukesha**  
 741 North Grand Avenue  
 Waukesha, WI 53186  
 262-547-2463

**Supported Parenting Program**  
**Developmental Disability Counseling**  
 3311 Prairie Avenue  
 Beloit, WI 53511  
 608-365-8787

**Supported Parenting and Healthy Families Program**  
**Family Services**  
 131 South Madison Street  
 Green Bay, WI 54301  
 920-436-4416 x101

**Positive Parenting Program**  
**Brown County ARC**  
 PO Box 12770  
 1673 Dousman Street  
 Green Bay, WI 54307  
 920-498-2599

**Community Living Program**  
**Milwaukee Center for Independence**  
 1339 North Milwaukee Street  
 Milwaukee, WI 53202  
 414-272-9277

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1. Booth, Tim & Wendy, *Growing Up with Parents with Learning Difficulties*, New York, Routledge, 1998.
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  3. Sobsey, Dick, *Violence and Abuse in the Lives of People with Disabilities*, Baltimore, Brookes, 1994; Froemming, Roy, *At Greater Risk: Legal Issues in Sexual Abuse of Adults with Developmental Disabilities*, Madison, Wisconsin Council on Developmental Disabilities, 1991.
  4. Hoffman and Mandeville, *Amelioration of Health Problems of Children with Parents with Mental Retardation*, Madison, Wisconsin Council on Developmental Disabilities, 1991.
  5. Franz, John, *Facing the Challenge: The Children's Code and Families Headed by Parents with Mental Retardation*, Madison, Wisconsin Council on Developmental Disabilities, 1990.
  6. Liamba, Dolores, *Cultivating Competence: Directory and Resource Guide on Supported Parenting*, 2<sup>nd</sup> edition, Madison, Wisconsin Council on Developmental Disabilities, 2000.
  7. Booth, Tim & Wendy, *Advocacy for Parents with Learning Difficulties*, Brighton, England, Pavilion Publishing, 1998.