



CW360°

a comprehensive look at a prevalent child welfare issue



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The Intersection of Child Welfare and Disability: Focus on Parents
Fall 2013

From the Editors

Beyond an examination of the prevalence of parents with disabilities and mental illness within child welfare, it is critical to understand what happens to these parents and their families as they receive services. Are they treated fairly? Are they afforded respect and dignity? Are they allowed and/or encouraged to utilize their support systems to help them parent, the same as other parents? Are they viewed as weak, unreliable, or incapable merely because of their diagnosis? These are the questions that we must explore.

The spring 2013 issue of *CW360°* explored issues related to children with disabilities in the child welfare system. We received an overwhelming response to that publication in addition to anticipation for this issue which focuses on the intersection of child welfare and parents with disabilities. It was clear in preparing these two publications that the content is vast and encompasses a wide range of conditions or diagnoses that are considered to be ‘disabilities.’ Articles in this issue address mental illness; intellectual and developmental disabilities; and physical, sensory, and communication disabilities. Parents have a wide range of abilities, capacities, and limitations, not all parents self-identify or consider themselves to have a ‘disability,’ nor do all parents with significant limitations meet programmatic thresholds for disability services and/or resources. That said, this publication is intended to provide practitioners with the broadest understanding of the strengths and challenges, unique assessment and service needs, and environmental factors faced by these families.

The preparation for this issue of *CW360°* began with consultation with content experts followed by an extensive literature review and exploration of best practices in the field. We would like to give special thanks to Dr. Elizabeth Lightfoot for her generous contribution of time and expertise.

Each issue of *CW360°* is divided into three sections: overview, practice, and perspectives. In the overview section, articles focus on the current state of research and policy concerning parents with disabilities in child welfare. The practice section highlights evidence-informed and promising practices as well as innovative examples of cross-system collaborations in the field. Lastly, the



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Archived video presentations and materials available from the Center for Advanced Studies in Child Welfare's 14th annual child welfare conference

The Intersection of Child Welfare and Disability

Held on May 7, 2013 at the University of Minnesota and via live webstream

Access archived video presentations and materials here: <http://z.umn.edu/cwdisability>

The 14th annual conference provided an overview of the overrepresentation in the child welfare system of both children with disabilities and parents with disabilities, as well as the circumstances under which they become involved.

Presenters included:

- Dr. Dick Sobsey (*University of Alberta*)
- Dr. Traci LaLiberte (*Center for Advanced Studies in Child Welfare*)
- Dr. Elizabeth Lightfoot (*University of Minnesota School of Social Work*)

The conference also featured guest presenters from the National Resource Center for Youth Development and two panel presentations, one on children with disabilities in child welfare and the other on parents with disabilities in child welfare.

<http://z.umn.edu/cwdisability>



perspectives section presents articles from a variety of child welfare stakeholders offering practical suggestions and strategies for system and practice improvements.

We have provided you with information and tools throughout this publication that will help you apply the research, practice, and perspectives to your own work settings and identify opportunities to apply this new learning. **Please refer to the discussion guide at the end of the publication to help start discussions with workers and administrators at your agency.**

We also invite readers to view the archived video from our spring conference, “The Intersection of Child Welfare and Disability,” held on May 7, 2013. The conference, which focused on both children and parents with disabilities who are involved in (or at risk of involvement in) the child welfare system, included as speakers *CW360°* contributors Traci LaLiberte, Elizabeth Lightfoot, Sue Abderholden, Bryce Fier, and Jennifer Shea Thomas. Two panels reacted and interacted with the keynote speakers on the impact and application of the research, policy, and best practices presented. To access the archived materials of the event, including both video

and handouts, visit the conference webpage at <http://z.umn.edu/cwdisability>.

Another way to join the conversation on this topic, as well as other challenging questions facing the child welfare system today, is through our Child Welfare Video Wall (<http://z.umn.edu/videoall>). Several researchers, practitioners, and parents have recorded their thoughts about how we can improve child welfare services for people with disabilities. Take a few minutes to peruse the videos already contributed and then take 90 seconds to record your own reflections and ideas!

On a personal note, from Traci LaLiberte, this issue of *CW360°* is one that builds upon more than 20 years of my work as a practitioner, academic, researcher, and advocate. I join with and have learned from many other researchers, practitioners, advocates, and self-advocates in an effort to ensure the safety of children while affording parents with disabilities the opportunity to raise their children, which, as for all parents, is their basic right. It is through the tremendous pain, hardships, and triumphs experienced by parents with disabilities and their children that each of us can learn to improve.

Table of Contents

Overview

Parenting with Disability—What Do We Know?, <i>Traci L. LaLiberte, PhD & Elizabeth Lightfoot, PhD</i>	4
Child Welfare Involvement among Parents with Mental Illnesses, <i>Katy Kaplan, PhD, MEd</i>	6
The Out-of-Home Placement of Children Born to Parents with Intellectual Disability, <i>David McConnell, PhD</i>	8
Needs of Parents with Intellectual Disabilities: An Ecological Perspective, <i>Sarah H. Bernard, MD, MB ChB, FRCPsych, DRCOG & Jean O’Hara, MBBS, FRCPsych</i>	10
Idaho’s Success Story.	11
Understanding and Supporting Parents with Cognitive Limitations, <i>Marjorie Aunos, PhD & Laura Pacheco, MSW</i>	12
Change Attitudes, Change Practice, <i>Margaret Spencer, PhD</i>	13
Parents with Mental Disabilities: The Legal Landscape, <i>Dale Margolin Cecka, JD</i>	14

Practice

Assessment of Parental Capacity Among Parents with Cognitive Disabilities in the Child Welfare System <i>Sandra T. Azar, PhD</i>	16
Working with Parents Who Have Cognitive Limitations: The Parent Support Project, <i>Bryce Fier, MSW</i>	17
Adapting Assessment, Diagnosis, and Communication for Individuals with Dual Diagnosis, <i>Darlene B. Sweetland, PhD</i>	18
Interventions for Parents with Disabilities, <i>Maurice A. Feldman, PhD, CPsych, BCBA-D</i>	20
An Overview of Parental Supports for Child Welfare Practice, <i>Elizabeth Lightfoot, PhD & Traci L. LaLiberte, PhD</i>	21
Family Teaming to Enhance Engagement and Opportunity for More Families in Child Welfare, <i>Ben Kerman, PhD, Judy Lee, PhD, & Lauren Frey, MSW, LICSW</i>	22
Peer Navigation in Vermont, <i>Susan Yuan, PhD</i>	23
When a Parent Has a Mental Illness, <i>Sue Abderholden, MPH</i>	24
An International Perspective on Current Trends and Future Prospects for Parents with Intellectual Disabilities and Their Children, <i>Gwynnyth Llewellyn, PhD</i>	25
Federal Agency Sheds Light on the Experiences of Parents with Disabilities and Their Children, <i>Robyn Powell, JD</i>	26

Perspectives

Common (Higher) Ground: What Social Workers and Parents’ Attorneys Can Do to Maximize Justice for Parents with Disabilities and Their Children, <i>Ella Callow, JD</i>	27
From Child Protection to Adult Mental Health: A County Worker’s Perspective, <i>Selena Stevens, MA</i>	28
Being a Mom Is Special, <i>Molly Saunders</i>	29
When Professional Approaches in Human Services Can Harm or Help Mental Health Recovery: One Mother’s Story, <i>Jennifer Shea Thomas</i>	30
Ghosts in the Nursery, <i>Erica Harrigan-Orr</i>	32
Lost in a System That Didn’t Exist, <i>Sharon Bryant, MEd</i>	33
Generational Support in Treatment Foster Care for Parents with Mental Illness, <i>Crystal Peterson, MSSW, APSW</i>	34
Commentary on the Intersection of Child Welfare and Parents with Cognitive/Intellectual Disabilities, <i>Anita P. Barbee, MSSW, PhD</i>	35

References

Integrated Bibliography	37
Agency Discussion Guide	42
Resources	43

Parenting with Disability—What Do We Know?

Traci L. LaLiberte, PhD & Elizabeth Lightfoot, PhD

Child welfare caseloads continue to change as new practice approaches are developed, evidence emerges to support shifts in practice, and new challenges erupt in the lives of parents and families. As prevention programs become better and programs such as Alternative Response assume strong footholds in state and county practice, the families who remain in child welfare face critical and complex issues often while living in difficult and adversarial environments. Parents with disabilities¹ are ever present within these complex child welfare caseloads in disproportionate numbers. Just as it is our responsibility to examine child welfare practices and other factors that may contribute to the over representation of communities of color in child welfare, we must also examine factors and practices with parents with disabilities.

Historically, adults with disabilities, including adults with severe mental illness, were often segregated from the rest of society, usually in various types of institutions. People were further segregated by gender so as to prevent sexual activity and the possibility of procreation. In the early twentieth century many states adopted eugenics laws allowing for the forced sterilization of people with disabilities against their will and without their consent. As the result of a growing awareness that people with disabilities should be included in society, people with disabilities began leaving institutions in the 1970s and living in community settings. The Olmstead Decision of 1999 requires that people with disabilities be in the least restrictive environment. As people with disabilities were increasingly included in the community, they



how people with disabilities exercise their rights and choices including those that include parenting.

While we know that people with disabilities are parents, it is difficult to determine exactly how many parents with disabilities there are overall or how many parents with disabilities are involved in the

with disabilities, so there hasn't been much research on this population in the United States although a broader base of international research also exists. Finally, many child welfare agencies haven't been tracking how many parents with disabilities are on their caseloads.

While there hasn't been much attention paid to prevalence of parents with disabilities in society or in the child welfare system, we do have some pretty good estimates indicating this is a significant population. First, we know that people with disabilities make up a significant part of the American population. Data from the 2010 Survey of Income and Program Participation (SIPP) indicates that there are 56.7 million adults who report some type of disability, with 38.3 million reporting a severe disability. This is about 19 percent of the population (US Census, 2012). People with mental illness constitute a large share of the adults with disabilities. SAMHSA (2012) estimates that 13.6 million people have a serious mental illness and many people with mental illness have co-occurring disorders. Serious mental illnesses include bi-polar

Why is it so important to look at ourselves, our child welfare practice, and our social service system related to parents with disabilities and mental illness? Any time there is a disproportionate inclusion of a particular group, especially within an involuntary service system, it warrants careful examination of practices and policies.

became more likely to engage in intimate relationships, marry, and have children. In addition, as people with disabilities were more included in mainstream society, they also experienced new forms of victimization – at times resulting in pregnancy. The new millennium has seen tremendous shifts in

child welfare system. One reason is that it is very difficult to measure “disability.” There are currently about 200 different federal definitions of disabilities, and researchers measuring disability also use many different definitions. Another reason is that there hasn't been that much attention placed on parents

¹In this article, the term “disability” is used to describe people/parents with a variety of diagnoses and limitations including those people with severe mental illness.

disorder (6.1 million adults), schizophrenia (2.6 million adults), and major depression (6.7 million adults) (NAMI, 2013; NIH & NIMH, n.d). With many adults in the United States having a disability, we can assume that there are many adults with disabilities who are parents. However, the only national statistics on parents with disabilities comes from the 1994-1995 Disability Supplement to the National Health Interview Survey. Analyzing the NHIS- Disability Supplement, Larson et al. (2001) found that there were approximately 1.4 million mothers with a disability in the United States. More recently, the National Council on Disability, in its groundbreaking *Rocking the Cradle Report*, estimated that approximately 4.1 million parents have at least one reported disability (National Council on Disability, 2012). This represents more than six percent of all American parents. *These are not insignificant numbers.*

Our knowledge regarding the incidence of parents with disabilities within the child welfare system is also limited. In the United States, we have no national data estimating the prevalence. However, data from Canada, using the Canadian Incidence Study of Reported Child Abuse and Neglect (McConnell, Feldman, Aunos, & Prasad, 2011), shows that parents with intellectual disabilities make up over 10% of child maltreatment investigation reports while representing only 1-3% of the general population. Kaplan's article ([in this publication](#)) discusses how adults with mental illness are just as likely as those without mental illness to be parents and for numerous reasons more likely to be found within child welfare caseloads.

Child welfare cases involving parents with disabilities, including mental illness, often have an outcome of court involvement and termination of parental rights, and many states still have parental disability listed in their grounds for termination of parental rights (Lightfoot, Hill, & LaLiberte, 2010). McConnell et al. reported that 27% of child maltreatment court-involved cases in their sample involved at least one parent with an intellectual disability. This is a staggering rate. Likewise, LaLiberte, Lightfoot, Singh, Piescher, & Hong (2012) found that parents with various disability labels were two times more likely than their peers without a disability label to experience child welfare involvement. It was further determined in this study that parents with disabilities were three times more likely to experience a termination of their parental rights (TPR) once involved with the child welfare system.

Why is it so important to look at ourselves, our child welfare practice, and our social service system related to parents with

disabilities and mental illness? Any time there is a disproportionate inclusion of a particular group, especially within an involuntary service system, it warrants careful examination of practices and policies. The paradigm of child welfare has shifted over time from one of independent parenting, where a parent stood in front of the Court as a single being to have his or her parenting assessed irrespective of other supportive factors, to one of interdependent parenting. Few parents in this world parent in isolation. Parents struggled to demonstrate independent parenting, and parents with disabilities and mental illness struggled even more. In our new paradigm, we encourage and value the support of family and community, and we have embraced practices such as Family Group Decision Making (see Kerman, in this issue) and Alternative Response. This new paradigm, if extended equally to parents with disabilities and mental illness, provides the opportunity for individualized assessments (see Azar, Sweetland, and Fier, in this issue) as well as parental supports (see Lightfoot & LaLiberte, in this issue). It also provides the opportunity to shift away from outdated beliefs that an IQ level or the mere presence of a disability or mental illness diagnosis can tell you everything there is to know about a person's ability to parent a child.

Is it true that some parents with mental illness and/or disabilities cannot parent their children safely? Of course it is, just as it is true that some parents who do not have mental illness and/or disabilities cannot safely parent their children. The bottom line is that *all* parents, regardless of diagnostic label, must be engaged and assessed based upon their abilities, strengths, limitations and challenges, access and use of resources, etc. It is essential to note as an extension of this statement that child welfare workers, supervisors, managers, and contracted providers must possess the knowledge, skills, and attitudes necessary to conduct such appropriate assessments and ask for help from disability and mental health experts so that they are able, subsequently, to deliver appropriate, accessible services.

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How can you improve child welfare services for children and/or parents with disabilities?

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Child Welfare Involvement among Parents with Mental Illnesses

Katy Kaplan, PhD, MEd

In a given year an estimated quarter of all adults in the United States are living with a diagnosable mental illness (Kessler, Chiu, Demler, & Walters, 2005). Data from the National Comorbidity Study found that of the individuals who met the criteria for having a serious and persistent mental illness 65% of them were mothers and 52% were fathers. Therefore, individuals with mental illnesses are just as likely to have children as the general population (Nicholson, Biebel, Katz-Leavy, & Williams, 2002). Also, they have a greater likelihood of living in the community and raising their children following the

Barriers to Maintaining Custody

Individuals with mental illnesses are infrequently supported in their role as parents by the adult mental health service system, as parenting issues tend to be viewed as either a child welfare issue or the responsibility of the children's mental health system (Ackerson, 2003). In fact, less than half of State Mental Health Authorities (SMHA) reported that they formally identify whether an adult client is a parent; only 27% of SMHAs reported having specific services or programs designed for their adult clients who are parents (Biebel, Nicholson, Williams, & Hinden, 2004).

Stigma and discrimination, including within legislative and judicial systems, also pose a significant barrier to maintaining custody for parents with mental illnesses. Women with disabilities, including psychiatric disabilities, continue to confront coercive tactics designed to encourage abortions or sterilization (National Council on Disability, 2012). Some states under the Adoption and Safe Families Act (ASFA) list mental illness as an aggravated circumstance for not providing reasonable efforts to reunify a family. As such, the focus shifts from parenting behaviors or functioning to disability status or condition (Lightfoot & LaLiberte, 2006; Risley-Curtiss, Stromwall, Hunt, & Teska, 2004).

Focusing on parental behaviors rather than on condition or disability ensures that parents with mental illnesses are given a fair chance to reunify with their children.

Barriers to Reunification

Parents with mental illnesses can face numerous barriers during the reunification process. Given that mental illnesses are often cyclical in nature with periods where the parent is functioning well and other times where they may need additional supports, a one-time evaluation will not adequately capture their strengths and needs (Friesen, Nicholson, Kaplan, & Solomon, 2009). Furthermore, parents rarely receive services that are specific to their disability (Mathis & Giliberti, 2000). For example, parents with a mental illness would likely benefit

deinstitutionalization movement (Oyserman, Mowbray, Meares, & Firminger, 2000). More importantly, regardless of custody status, parents with a mental illness define themselves as parents first and as psychiatric consumers or patients last (Nicholson & Deveney, 2009). However, because of numerous barriers they are much more likely to have child welfare involvement or lose custody of their children (Park, Solomon, & Mandell, 2006).

For the services that do exist, parents may face additional barriers to accessing services such as transportation and child care. Finally, parents with mental illnesses may fear seeking out treatment will lead to increased scrutiny that could result in child welfare involvement. Therefore, parents may forgo needed mental health services in an effort to keep their families together and maintain their roles as custodial parents (Hay & Jones, 1994; Park et al., 2006).



from information regarding how to talk to their children about their illness or how to help their children cope if they were to get hospitalized. Finally, it may be that parents with mental illnesses need additional time to meet the goals of their permanency plan (Lightfoot, LaLiberte, & Hill, 2007). There have been documented cases where judges have recognized parents with mental illnesses have made progress toward reunification but not within the required ASFA timeframe, resulting in termination of parental rights (McWey, Henderson, & Tice, 2006).

Strategies for Working with Parents with Mental Illnesses

Focusing on parental behaviors rather than on condition or disability ensures that parents with mental illnesses are given a fair chance to reunify with their children. A parent's disability is only relevant where it is apparent that they are not receiving services or accommodations to which they are entitled under the Americans with Disabilities Act (Mathis & Giliberti, 2000). Helping parents with mental illnesses understand the timeline requirements under ASFA may result in fewer cases where parents have their rights terminated. Despite the difficulties of parenting with a mental illness, it is important

to remember that being a parent can serve as a strong motivating factor for treatment (Ackerson, 2003; Fox, 1999; Oyserman et al., 2000; Sands, Koppelman, & Solomon, 2004).

Moving in the Right Direction

The mental health system has been striving to provide services that promote mental health recovery and community inclusion, meaning that individuals with mental illnesses can live full and meaningful lives in the community (Hogan, 2003; New Freedom Commission on Mental Health, 2003). Efforts to promote recovery and community inclusion have helped call attention to the lack of supports individuals with mental illnesses have received in their role as parents. As a result, the significance of parenting in the lives of individuals with mental illnesses is gaining more attention; and the workforce in systems that come into contact with parents with mental illnesses, namely child welfare workers, has become more engaged in trainings on how to support their clients who are parents. Evidence of the growing recognition of the importance of this issue is evident in the National Council on Disability's decision to make parenting a top priority in 2012 (see Powell, in this issue). Lastly, the selection of the United States as the next site for the

April 2014 Fourth International Conference on Families with Parental Mental Health Challenges, *Addressing the Needs of the Whole Family*, is a positive indicator that parenting with a mental illness is worthy of more attention.

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The Temple University (TU) Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities is a NIDRR-funded National Rehabilitation Research and Training Center. The TU Collaborative "seeks to broaden understanding about community integration and improve opportunities for individuals with psychiatric disabilities to participate more fully in community life." For more information, please visit their website:

<http://tucollaborative.org>



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The Out-of-Home Placement of Children Born to Parents with Intellectual Disability

David McConnell, PhD

Some scholars estimate that as many as one in two children born to mothers with intellectual disability will be taken from them and placed out-of-home although the absolute risk is not known (Aunos, Goupil, & Feldman, 2004; Larson, Lakin, Anderson, & Kwak, 2001a; Llewellyn, McConnell, & Ferronato, 2003). The question addressed in this brief report is “why are children born to mothers with intellectual disability so often taken from them when the research record clearly shows that (a) intellectual disability per se is a poor proxy for parenting competence and (b) with appropriate instruction and support, parents with intellectual disabilities can learn, adapt and overcome perceived parenting deficiencies?”

The Clustering of Risk and Vulnerability Factors

In a recent study of over 12,000 child maltreatment investigations in Canada, Dr. Marjorie Aunos, Dr. Maurice Feldman, and I found that mothers with intellectual disability were substantially more likely than mothers without intellectual disability to have been maltreated in their own upbringing, to have mental health issues, to use drugs or alcohol, and to have few social supports (Feldman, McConnell, & Aunos, 2012; McConnell, Feldman, Aunos, & Prasad, 2011b). Figure 1 shows the distribution of these and other risk and vulnerability factors in cases featuring mothers with and without intellectual disability.

In our analysis, we looked to see if these concomitant factors could explain why cases featuring mothers with intellectual disability so often resulted in out-of-home placement. The results, summarized in Figure 2, show that these factors contribute to but do not fully account for between-group differences. The adjusted odds ratios indicate that, *all else being equal*, the odds of out-of-home placement remain almost two times greater for children of mothers with intellectual disability than they are for children of mothers without intellectual disability.

Discrimination in the Child Welfare System

Another factor contributing to the overrepresentation of children of parents with intellectual disability in out-of-home care is *discrimination* (Booth, McConnell, & Booth, 2006; Hayman, 1990; McConnell & Llewellyn, 2002). Parents with intellectual

disability are subject to discrimination when ‘universal’ services fail to accommodate their particular support and learning needs. In-depth studies have also revealed that child protection and judicial decision-making may be influenced by pejorative social representations of persons with intellectual disability (Booth, 2000; McConnell,

Preventing Child Maltreatment and Unjust Child Apprehension

The clustering of risk and vulnerability factors and the well documented discrimination suggest that a dual strategy is needed to reduce the risk of out-of-home placement for children of parents with intellectual

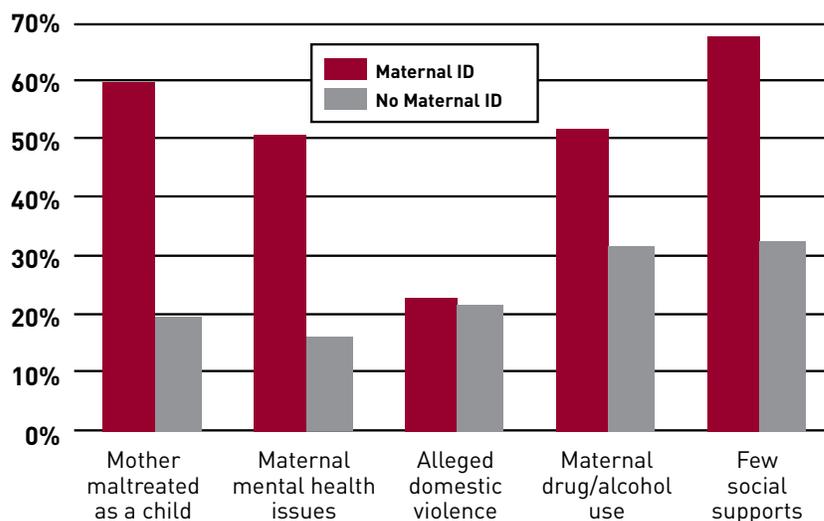
Why are children born to mothers with intellectual disability so often taken from them when the research record clearly shows that (a) intellectual disability per se is a poor proxy for parenting competence and (b) with appropriate instruction and support, parents with intellectual disabilities can learn, adapt and overcome perceived parenting deficiencies?

Llewellyn, & Ferronato, 2002; Watkins, 1995). These translate into an expectation of parenting failure. And when professionals expect parents with intellectual disability to fail, they will (unknowingly) look for and inevitably find ‘evidence’ that is consistent with this expectation and filter out dissonant information. Furthermore, when parents with intellectual disability are expected to fail, any perceived parenting deficiencies are more likely to be attributed to the parent’s intellectual disability. Parental intellectual disability and parenting deficiencies are then conflated, and because intellectual disability is thought to be immutable, any perceived parenting deficiencies may be too.

disability. Clearly, the challenge of preventing maltreatment and the challenge of preventing unnecessary out-of-home placement are not the same thing. These are two different challenges requiring two different sets of solutions.

To prevent child maltreatment, the dissemination and implementation of evidence-based parenting training strategies is important. However, this may be insufficient if policy makers and practitioners do not simultaneously address the adverse social conditions in which most parents with intellectual disability have to bring up their children. Alleviating poverty, strengthening the social relationships of parents with intellectual disability, and ensuring that they receive appropriate health care is

Figure 1. Risk and vulnerability factors in cases featuring mothers with and without intellectual disability



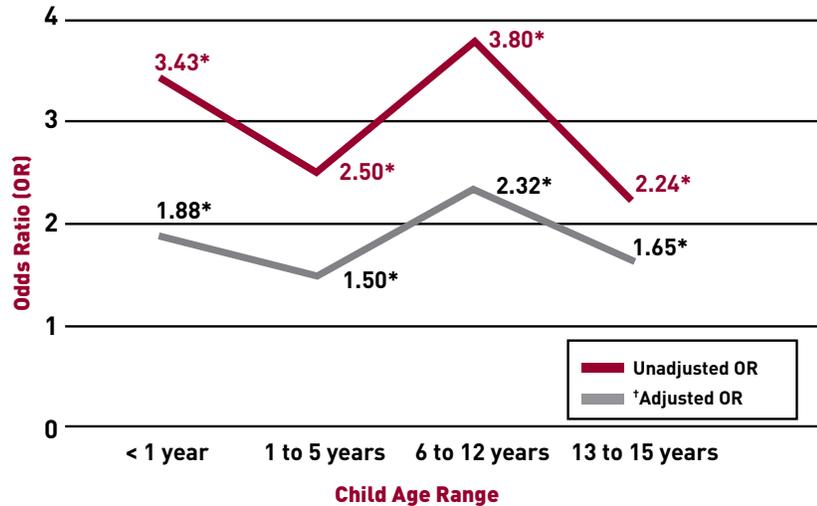
foundational. In addition, their children will almost certainly benefit, along with other children exposed to poverty, from direct services, including but not limited to participation in early childhood programs and services.

To prevent unnecessary out-of-home placement, a range of strategies and reforms have to be considered. Continuing professional education is one: every social work program ought to include a unit of study on parents and parenting with intellectual disability. The implementation of consensus-based models of decision-making and the utilisation of alternative dispute resolution may also be necessary. *Notably, in our study of child maltreatment investigations we found that parents with intellectual disability were less often perceived as cooperative, but when they were perceived as such, they were far less likely to have their children taken from them* (McConnell, Feldman, Aunos, & Prasad, 2011a). In addition, outmoded and inept parenting and risk assessment practices must be abandoned in favor of context-sensitive, in-vivo (i.e., naturalistic), observation-based assessments of functioning.

Conclusion

More than 50 years ago, Brandon (1957) investigated outcomes for children of “certified mental defectives” and found

Figure 2. Relative odds of out-of-home placement for children of mothers with intellectual disability



*OR Adjusted for history of maltreatment in the mothers own upbringing, maternal mental health issues, the use of drugs and/or alcohol, exposure to domestic violence and limited social support. *p<0.05

that most were faring well. In conclusion, Brandon (1957) stated: “It is hoped that this survey will help to avoid the inhuman and expensive administration process whereby an allegedly feeble-minded mother is permanently separated from her child” (p. 710). Surely the hope for today is that we will not still be talking about the unnecessary separation

of children from mothers and fathers with intellectual disabilities in another 50 years.

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Needs of Parents with Intellectual Disabilities: An Ecological Perspective

Sarah H. Bernard, MD, MB ChB, FRCPsych, DRCOG & Jean O'Hara, MBBS, FRCPsych

The interest in the parenting ability and subsequent needs of parents with intellectual disabilities has moved from one of morality and eugenics to one of a recognition of the rights of these parents and how they can be supported to meet their child's needs (O'Keefe & O'Hara, 2008). Despite this more positive interest, there also remains the need to assess and manage risks posed to the child.

People with intellectual disabilities have to confront many barriers. They are some of the most vulnerable people in society who vary significantly in the nature and degree of their disabilities (Carnaby, 2007). How society has viewed people with intellectual disabilities has changed over time. The needs of individuals often lead to the need for an organizational response. Often, and certainly in the case of public child welfare services, the organizational response is shaped in turn by society's attitudes and values (Carnaby, 2007).

Individual Factors and Community-Level Supports for Parents with Intellectual Disabilities

There are many factors which influence parents' ability to parent their children. These factors are relevant across the intellectual range and include isolation, victimisation, poor models of parenting, poor relationships

with psychological stressors, and cultural influences (O'Hara & Martin, 2003). It is appreciated that people with intellectual disabilities are more susceptible to these factors. This, in turn, results in an effect on their coping strategies when having to address the changing demands of raising a child while ensuring that other aspects of their lives continue to be addressed.

In England there are a number of

reasons not lying with poor parenting alone (Bernard, 2007). It is recognised that a lack of community-level supports, such as service provision and poor professional practices, will affect whether or not a child is removed from his or her family. In addition, there has been a lack of understanding of the mental health needs of these parents and the right to specialist support (O'Keefe & O'Hara, 2008).

Parents with intellectual disabilities require

Parents with intellectual disabilities are more likely to have their children removed for reasons not lying with poor parenting alone.

policies and a range of legislation to ensure that people with intellectual disabilities are supported within society. The Disability Discrimination Act (2005), the Mental Capacity Act (2005), the Children Act (1989), and others assist in ensuring that parental rights are upheld while keeping a child's needs paramount. When considering parents with intellectual disabilities it is important to value parents' rights but not lose sight of the needs of the child (England Department of Health, 2001).

Parents with intellectual disabilities are more likely to have their children removed for

a significant amount of well coordinated and professional support in order to ensure their children are parented appropriately (Booth & Booth, 1994). Identification of parents with intellectual disabilities, consideration of the family needs and the needs of the children are paramount when planning services (Emerson, Malam, Davies, & Spencer, 2005).

The epidemiological data concerning the number of parents with intellectual disabilities is uncertain (McGaw, 1998). This reflects the lack of systematic research, which can be used to inform commissioners and service providers and to ensure that the rights and needs of parents are met while being proactive



in supporting children within their families (England Department of Health, 2001).

Assessment

There is little research evidence on which to develop assessment frameworks. Many reviews concentrate on the individual aspects of parenting, focusing on the lack of parenting capacity rather than thinking about how parenting can be optimised through community supports (Dowdney & Skuse, 1993).

Assessment of parenting ability has in general considered many criteria. Although much of this looks at the physical wellbeing of the child (i.e. basic needs and general health and medical needs are being met), the importance of the parent's ability to tap into supports in the community, such as accessing education and social activities, should also be considered (Mattinson, 1970).

Other factors that contribute to good enough parenting include family size,

family relationships, characteristics of the father and the extended family including support networks. Child factors are also important with the characteristics of the child influencing the parents' ability to parent. In particular, if the child has a complex physical disability, then additional skills will be demanded. Emotional and behavioural problems in children will also require above-average parenting skills. The child's age influences the nature of parenting. Finally, there has been a concern that although IQ does not relate to competent parenting directly, at the lower end (IQ less than 60) it is likely to be significant (Dowdney & Skuse, 1993).

Conclusion

In conclusion, parents with intellectual disabilities have an equal right to parent their children as do those without. A delicate balance needs to be struck between ensuring parental rights whilst also ensuring the

wellbeing of children. Early detection of parents at risk, taking into consideration both individual factors and level of community support, is crucial. Comprehensive assessment is important in order to understand the complex needs of parents with intellectual disabilities in the child welfare system.

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Idaho's Success Story

In 1999 parents with disabilities in Idaho raised concerns about losing custody of their children based on parental disability. The Idaho SILC developed a committee, called FAMILY (Fathers and Mothers Independently Living with their Youth), to examine the issue. FAMILY consisted of people with disabilities, advocates, legislators and members of disability organizations. They determined that legislative reform was necessary to meet their goal of creating "a process that was consistent and guaranteed that no parent would lose custody of his/her children solely due to the fact that they had a disability (Idaho SILC, 2005)." Working as a coalition representing parents with all kinds of disabilities, FAMILY intended to eliminate inappropriate disability language in Idaho statutes and create a fair and consistent parental evaluation system that allowed parents with disabilities to show how adaptive equipment and support services helped them parent their children.

FAMILY's advocacy efforts took four years. They relied on a national organization, Through the Looking Glass, for important technical assistance and consultation. FAMILY also partnered with Senator Robbi Barrutia, who was passionate and determined to pass this legislation. Bills were introduced in the Idaho legislature in 2000 and 2001. However, despite numerous testimonials by parents with disabilities who had lost



parental rights based upon their disability, and overwhelming support in the Senate, the House blocked legislative reform both years.

In 2002, the Chair of the House Health and Welfare Committee happened to see *I am Sam*, a movie about a father with a developmental disability who lost custody of his daughter through a child protection action. Impressed with the movie, the Chair took the entire Committee along with Kelly Buckland, the director of the Idaho SILC, to see the film. The portrayal of the father's

abilities to parent his daughter and his struggle within the system were eye opening to committee members.

FAMILY introduced legislation in 2002, this time focusing on divorce, adoption, guardianship, and termination of parental rights, with an emphasis on provisions that allow parents to present evidence detailing how adaptive equipment and support services enable them to parent effectively. This bill passed the House and Senate, and became law. In 2003, FAMILY introduced legislation regarding child protection, with a special emphasis on creating an evaluation system that is consistent and fair for parents, and requiring that child protection investigators be knowledgeable about disability accommodations. This legislation also passed, and Idaho became the first state in the nation to include disability protections in their termination of parental rights statutes.

Reprinted with permission from the University of Minnesota. Reviewed by content expert Kelly Buckland, Executive Director of the National Council of Independent Living. Original citation: Lightfoot, E., LaLiberte, T., & Hill, K. (2007). Guide for creating legislative change: Disability in the termination of parental rights and other child custody statutes. Minneapolis, MN: University of Minnesota.

Understanding and Supporting Parents with Cognitive Limitations

Marjorie Aunos, PhD & Laura Pacheco, MSW

Parenting by persons with cognitive impairments (CI) has too often and for too long been associated with parenting faults. What impacts parenting is a series of factors found in most families who are involved in child welfare, but the impact of these factors is erroneously perceived as being more important in families headed by a parent with cognitive limitations.

Overview of situation

Parents with CI are overrepresented in youth protection and family court. The most common reasons for youth protection referral are neglect and (perceived) parental non-cooperation.

Neglect

Research has shown that parents with CI face both personal and systemic barriers that increase the likelihood of child removal. Biased attitudes such as the presumption of parental incompetence can lead to an assessment that emphasizes neglect or likelihood of future harm to children. The most common child welfare concerns are that the mother with CI lacks parenting skills or that the mother is unable to provide “adequate care” to her children. These concerns, though they are not specific, can



Non-cooperation

Single parenthood and perceived parental non-cooperation with services are also strong predictors for court action. Attending and participating in parenting services, though, seem to reduce the risk for court action.

parents and children specific to their needs and of adapting the types of support as the needs evolve. Advocating for a fair and thorough assessment of needs leads all involved towards concrete goals, specific to the family's context. Algood, Hong, and Gourdine (2013) spoke of using Bronfenbrenner's ecological model in working with children with disabilities; in parenting, Feldman's model of parenting (see [Feldman, in this issue](#)) allows professionals to identify areas of a family's environment, current situation, and past and personal characteristics that could potentially affect parenting abilities and parent-child interactions. High parenting stress can lead toward a more hostile and inconsistent parenting style and exacerbates the impact on the family. Parental support influences how we perceive parenting abilities as strong advocacy seems to be related to a perceived lower risk factor.

Participation in adapted services often refers to parent education programs that are individualised or in small group settings and include strategies that follow a more behavioral approach, targeting specific skills and taking into consideration psychosocial needs. A long list of specific programs to enhance parenting skills of parents with CI now exists and is readily accessible to most (Healthy Start, 2010).

The reality is that we all have parenting deficits in one way or another and that all children will outwit their parents at some point. Parents with [cognitive impairments] and their children are no different.

lead to child removal as parental CI is often seen as untreatable (McConnell & Llewellyn, 2002). Another major contributing factor is poverty, which leads to increased parenting stress, diminished coping strategies and difficulty accessing resources.

On a micro level, neglect can partly be traced back to parenting skill deficiencies. Though parents with CI are a heterogeneous group, the research has identified some general areas of parenting difficulty for parents with CI, including child development and stimulation, providing a safe home environment, problem-solving, and dealing with medical emergencies (Feldman, 2004). It must be noted that many parents with CI did not have adequate parenting role models themselves or had unresolved issues of grief and loss which can significantly contribute to some of their parenting difficulties (Aunos, Goupil, & Feldman, 2004).

Yet, often services are not offered or they are offered but not adapted to the needs of these parents, and thus, they have a limited impact on parenting. This reinforces the notion that the parent is not cooperating fully or does not have the capacity to learn. The tendency is to blame the parent for non-cooperation rather than try to understand the causes leading to difficulties in collaborating with services.

Children of parents with CI may be more at risk of having developmental delays or behavioral issues due to genetics, yet referrals are not always made to support the parents. Instead, their children's special needs are too often perceived as an outcome of parenting failure when it is still unclear how genetic components interact with environmental factors.

Best practices

Five decades of research highlights the importance of offering services to both

Change Attitudes, Change Practice

Margaret Spencer, PhD

“When did you know you wanted to be a mother?” Without hesitating Charole said, “Forever” (Spencer, 2012). Charole is one of an increasing number of women with disabilities claiming her right to fulfil her aspiration to be a parent.

Persons with disabilities “now enjoy a historically unprecedented opportunity to become parents” (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). Across the western world, statutes that once allowed people with disabilities to be involuntarily or coercively sterilized have been by and large repealed. Today, the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) affirms the right of

- will be incapable of learning the skills required to parent or incapable learning these skills fast enough to keep up with their child.
- will require long term support that just isn't available because of how the family support services are structured and resourced.

McConnell, Llewellyn, and Ferronato (2002) found a strong tendency for participants (including child protection workers and lawyers) to conflate intellectual disability with perceived parenting deficiencies failing to give due consideration to other factors such as poverty or limited family support. There was also a tendency to further



with disabilities, in the performance of their child rearing duties” (United Nations, 2006). Greater onus needs be placed on child welfare services to demonstrate that “appropriate assistance” is provided through the provision of programs and casework that meets best practice guidelines for working with parents with intellectual disability. If this is not happening, disability discrimination statutes must be amended to enable parents with disabilities to take action against the State or service provider.

Fourth, parents with disabilities need to be given more say and control over the support they receive (Spencer & Llewellyn, 2007; Wade, Mildon, & Matthews, 2006). Moreover, they need to receive that support because they have a right to receive it not because they are deemed ‘at risk’ or ‘vulnerable.’ Furthermore, their access to such support needs to see them through their child rearing responsibilities. (For an example of this concept, see DisabilityCare Australia, 2013.)

Finally, we need to give voice and face to these parents and their children. We need to empower parents with intellectual disability to be proud of who they are, to find strength in numbers, to stand up for themselves and to tell their stories. Empirical research and advocacy by the likes of people like me can do so much, but hearing, seeing, and having firsthand encounters with the families themselves is what will change the hearts and minds of communities and, in turn, how these families fare.

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What I see as the biggest barrier [to supporting parents with disabilities and their children] is the attitudes, assumptions, and stereotypes that we professionals, advocates, and policymakers harbor.

persons with disabilities to “marry and found a family” (see Article 23; United Nations, 2006).

Yet, in spite of what has been won and what we know, parents with intellectual disabilities like Charole continue to face opposition, are given little support, and are too quickly judged and presumed to be “not up to the job.” Studies worldwide confirm that children of parents with disabilities are more likely to be removed from their family of birth and placed in foster care before they reach their first birthday (Booth, Booth, & McConnell, 2005; Llewellyn, McConnell, & Ferronato, 2003; McConnell, Feldman, Aunos, & Prasad, 2010; McConnell & Sigurjonsdottir, 2010). What gets in the way of the child welfare system supporting these parents and their children?

What I see as the biggest barrier is the attitudes, assumptions, and stereotypes that we professionals, advocates, and policymakers harbor. Despite empirical evidence to the contrary (Feldman, 1994), pejorative attitudes, assumptions, and stereotypes about parents with intellectual disability endure (McConnell & Llewellyn, 2002).

It is assumed parents with intellectual disability:

- will be erratic in their care and fail to protect their child from harm.
- will fail to understand and respond to their child's developmental needs resulting in the child being held back or ‘outgrowing’ their parent and becoming the parent in the relationship.

presume that, in light of the “irreversible” nature of intellectual disability, parenting deficiencies could not be overcome or corrected and that putting supports in place is a short-term fix and not sustainable in the long term.

So what needs to happen to change attitudes and, in turn, change practice?

First, disability awareness and understanding as well as education focusing on the rights of persons with disabilities needs to be embedded at all levels of learning, from elementary schools to postsecondary programs. Changing views post-graduation and once professionals have been acculturated into the ‘group think’ of their agencies is too late.

Second, we need to better prepare our young people with disabilities for parenthood. For many families who have a young adult with a disability the issue of sexual expression and reproductive rights is contentious, and this stage of development is often negotiated poorly (Cuskell & Bryde, 2004). Just as there are programs out there to help parents and young adults with disabilities make the transition to work and into community living, there need to be programs, accessible resources, and counselling available to negotiate intimate relationships and parenthood.

Third, State Parties need to meet their obligation under Article 23 of the CRPD to “render appropriate assistance to persons

Parents with Mental Disabilities: The Legal Landscape

Dale Margolin Cecka, JD

"It is better for all the world, if . . . society can prevent those who are manifestly unfit from continuing their kind. . . . Three generations of imbeciles are enough." (Justice Holmes, *Buck v. Bell*, 1927)

In the first part of the twentieth century, individuals with mental disabilities were sterilized by institutions to prevent them from having offspring (Downey & Skuse, 1993). Although we have abandoned this as public policy, parents with mental disabilities still lose custody of their children at much higher rates than their non-disabled peers (National Technical Assistance for State Mental Health Planning, 2000).

The Americans with Disabilities Act of 1990 (ADA)

The ADA was enacted in 1990 to remedy discrimination against individuals with disabilities (ADA, 2006). Over 54 million Americans are protected under the ADA (Office on Disability, 2005). Title II of the ADA prohibits discrimination on the basis of disability by a public entity, which includes (1) any state or local government, and (2) any department, agency, special purpose district, or other instrumentality of a state or states or local government. According to its regulations, the ADA applies to "all services, programs, and activities provided or made available by public entities."

The ADA requires that "a public entity . . . make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability." Title II of the ADA does not require public entities to make "fundamental alterations" to the nature of their programs or services.

A state's department of social services is a public entity and when it initiates a termination of parental rights (TPR) proceeding, it should be considered state activity. Reunification and family preservation services should also be considered services, programs, or activities which may need to be "reasonably modified" in order for states to provide equal access to parents with disabilities.

Federal and state courts, however, have consistently held that the ADA does not apply to parents facing TPRs. The reasons include: (1) TPR proceedings are not a "service, program or activity" within the meaning of the ADA (see *In re Adoption of Gregory*, 2001; *In the Matter of Terry*, 2000; *In re Antony B*, 1999; *In the Interest of B. K.*



F., 1997; and *In re B. S.*, 1997); (2) a juvenile court's jurisdiction cannot interpret a federal law or conduct "an open-ended inquiry into how the parents might respond to alternative services and why those services have not

Dependency of C. C., 1999; *J. T. v. Arkansas Department of Human Services*, 1997; *In re Karrlo K.*, 1994; and *In the Matter of K. D. W.*, 1994). Still, those courts have ruled that sufficient reasonable modifications in

State child welfare laws require reasonable efforts in order to comply with the [Adoption and Safe Families Act]. . . . The state laws also do not specifically require the reasonable efforts to be tailored to meet the needs of parents with disabilities.

been provided" (see *In re B. S.*, 1997; *In the Interest of Torrance P.*, 1994; and *In re Maryia R.*, 1997); and (3) Title II provides plaintiffs with a private right of action against a public entity but cannot be used as a legal defense (*In re Doe*, 2002; *In the Matter of Rodriguez*, 1999).

A handful of courts have allowed the ADA to be a defense to a TPR (see *In the Matter of John D.*, 1997), some without specifically ruling on its applicability (e.g. *In the Matter of J. B.*, 1996; *In re Caresse B.*, 1997; *In the Interest of C. C.*, 1995; *In re*

family preservation services were made to accommodate individuals' mental disabilities, and therefore no ADA violations occurred. One exception was *In the Interest of K. K. W.* (1995), where the courts found that the state violated the ADA by failing to modify its reunification services to assure equally effective services to a parent with schizophrenia: the state provided only services that are offered to parents without disabilities.

According to a few courts, the ADA can be raised in child welfare proceedings but only prior to a TPR proceeding. *In the interest of S.*

L. P. (1999) held that the issues of adequate services and reasonable accommodations for parents with disabilities need to be addressed at review hearings or when they are offered, and that it is too late to challenge the service plan at the TPR proceeding. (See also *In the Matter of Terry*, 2000; *In the Interest of A. M.*, 1999; *Stone v. Daviess*, 1995; *In re Antony B.*, 1999; *In re B. S.*, 1997; *In re M. J. M.*, 2002; and *In the Matter of Terry*, 2000). But at least one court has held that the ADA may not be raised in dependency proceedings either: *In M. C. v. Department of Children & Families* (2000), the court found that dependency proceedings are held for the benefit of the child, not the parent, and therefore the ADA may not be used as a defense in such proceedings.

Thus far, courts that find the ADA applicable to child welfare cases usually do not hold agencies accountable for offering unique services to parents with mental disabilities (see *In the Matter of Terry*, 2000; *In the Matter of the Welfare of H. S.*, 1999; *In re Caresse B.*, 1997; and *Bartley v. State*, 1996). Courts seem to have made the assumption that this would fundamentally alter a state's child welfare program, presumably because of financial or other burdens. However, advocates for parents can counter this argument (Margolin, 2007). Many alternative services actually save the state money in the long run. The question of an undue financial burden is a fact-specific inquiry; under the ADA, there is no justification for a total absence of services that actually help parents with mental disabilities. Parents with disabilities are entitled to services that have the same potential, with or without reasonable modification, for facilitating reunification as parents without disabilities.

The Adoption and Safe Families Act (ASFA) & "Reasonable Efforts" Requirements Under State Law

In addition to the ADA's reasonable modification requirement, the federal Adoption and Safe Families Act (ASFA) requires states to make "reasonable efforts" to preserve and reunify families in order to prevent or eliminate the removal of a child (ASFA, 1997). State child welfare laws require reasonable efforts in order to comply with ASFA. ASFA does not provide a private right of action for parents to enforce these "reasonable efforts" laws (*Suter v. Artist M.*, 1992). The state laws also do not specifically require the reasonable efforts to be tailored to meet the needs of parents with disabilities. Arkansas is the only exception: its statute does require the state to make reasonable accommodations in accordance with the ADA to parents with disabilities (Ark Code Ann. § 9-27-341). Advocates can attempt to argue that services are not "reasonable" if they do

not take into account a parent's disability. However, most courts, including most cited in this article, "rubber stamp" reasonable efforts even when they appear to be ill-suited to a particular parent.

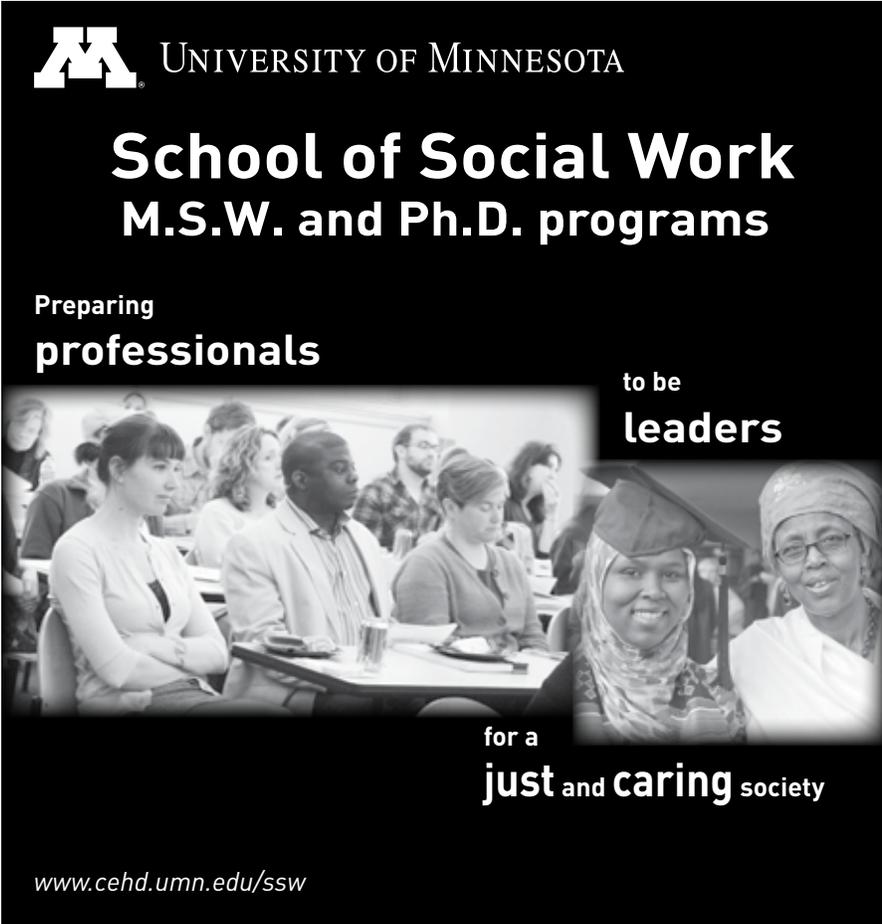
There have been some exceptions (see *In re Adoption/Guardianship*, 2002; *Mary Ellen C. v. Arizona Department of Economic Security*, 1999; *In re the Dependency of H. W. & V. W.*, 1998; and *In re Victoria M.*, 1989). These courts have examined whether the "reasonable efforts" were appropriate to the needs of parents with disabilities. The decisions also required child welfare agencies to work with the developmental disabilities or mental health service system. In *In re P. A. B.* (1990), the court reversed a termination order because the bond between parents with mental disabilities and their children had not been considered by the trial court before terminating rights. In *Division of Family Services v. Murphy* (2000), the court allowed two parents with mental disabilities to regain custody of their children because, by working together, they could adequately address the needs of their children. The court also noted that even though parents might require agency assistance from time to time, their children should not be placed in foster care.

Some appeals courts have also reversed TPRs where courts made decisions based on stereotypes about individuals with disabilities. For example, *In re C. W.* (2007) found that the trial court inappropriately relied on an outdated psychiatric assessment when terminating a mother's rights. Without expert testimony about the mother's current mental health status or the child's needs, the court's decision emanated from assumptions and speculation. (See also *In re Adoption/Guardianship*, 2002.)

Conclusion

The ADA, coupled with federal and state child welfare laws, provides broad brush strokes for advocates of parents with mental disabilities and their children. To effectuate parents' rights, child welfare professionals must work with the parents themselves, as well as with other state departments, to form service plans that are tailored for the success of each individual family.

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Assessment of Parental Capacity Among Parents with Cognitive Disabilities in the Child Welfare System

Sandra T. Azar, PhD

Current practices in parenting evaluations have been sharply criticized, and those conducted with parents with cognitive disabilities (PCD) are fraught with even more difficulties (e.g., lack of professional training, bias affecting evaluators, stereotype threat) (Nisbett et al., 2012; Azar, Robinson, & Proctor, 2012; Benjet, Azar, & Kuersten-Hogan, 2003; Proctor & Azar, 2012). Well-articulated frameworks with standardized measures for this population have been slow to develop. Consequently, the quality of what parents receive is highly variable.

outlines capacities that can be used in a modular way, selecting elements linked to referral questions with an emphasis on behavioral assessment.

Parenting Skills Domain

Tymchuk (1998, 2006) suggests four basic child care areas: (1) *fundamental knowledge and skills* (e.g., hygiene, child management); (2) *health related knowledge/skills* (e.g., understanding common illnesses/medicines, evaluating symptom severity); (3) *safety knowledge and skills* (e.g., dangers in the home/

Vignettes assesses generalized attributions of negative intent to child behavior (even if developmentally typical). A similar instrument has been modified for maladaptive attributions to the behavior of other adults (family, friends, partner) (Azar, Stevenson et al., 2012) and videotaped scenarios have also been used (Basquill, Nezu, Nezu, & Klein, 2004). Another questionnaire, the Parent Attribution Questionnaire assesses beliefs that children have more power than parents (Bugental, Mantyla, & Lewis, 1989). Maladaptive attributions may increase feelings of incompetence and/or anger and can contribute to withdrawal from the caregiving role and/or harsh responses. They signal the need for re-attribution work. The Parenting Problem Solving Instrument assesses parents' mean ends thinking in caregiving situations (Wasik, Bryant, & Fishbein, 1981) and more general interpersonal problem solving has been assessed using videotaped or written adult dilemmas where elements of problem solving capacity can be assessed (e.g., identifying the problem, generating alternative solutions, behavioral enactment) (Basquill et al., 2004).

Although further work is needed, there are beginning research efforts to validate the use of neuropsychological measures such as the Wisconsin Card Sort, The Alternate Uses Test, and other measures of attention, planning and memory as linked to parenting, household functioning and everyday tasks (e.g., financial planning, Willner, Bailey, Parry, & Dymond, 2010; harsh punishment and home chaos, Deater-Deckard, Sewell, Petrill, & Thompson, 2010). These are vital capacities for parenting and can be targeted for treatment if deficits are identified. They can also inform the actions of treatment agents (e.g., identify learning adaptations needed).

Well-conducted evaluations are essential to reduce bias entering decision-making. Research is needed to completely operationalize the framework outlined here. Better training to do such assessments is also essential (American Psychological Association, 2013; Azar & Reid, 2009).

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Well-conducted evaluations are essential to reduce bias entering decision-making.

A developmental-functional-contextual approach is needed that provides data linking a parent's individual skills/deficits with the capacity to parent a particular child(ren) within the specific contexts available to them (e.g., social supports). Such a prescriptive approach is useful for making risk judgments, targeting services, and/or making end stage decisions (e.g., termination of parental rights) (Azar, Lauretti, & Loding, 1998).

Five skill domains are relevant to child outcomes: (1) *specific parenting skills* that vary with children's development; (2) *stress management*, (3) *behavioral and emotional regulation*; (4) *social skills*, and (5) *social cognitive and neurocognitive capacities* (Azar & Twentyman, 1986; Azar, 1997; Azar & Weinzierl, 2005). The discussion here will focus on the first and last elements (see Azar et al., 1998 for further details). It should be noted that obstacles to parenting (e.g., mental health) and extra-familial resources (supports) should also be assessed. Evaluations should also focus on strengths present that may balance out deficits (Feldman & Aunos, 2010).

The first domain is central to parenting actions. The next three contribute to an overall environment conducive to optimal parenting and affect transactions both within and outside the family. For example, one must use anger management skills with children, one's partner, and teachers. The last domain has recently been linked to parenting and is targeted in successful maltreatment prevention programs such as Triple P and enhanced Healthy Start. It undergirds the others. Cognitive capacities are needed to activate and effectively deploy skills (ability to problem solve, make accurate appraisals, and be cognitively flexible). This approach

community), and (4) *mutual parent-child enjoyment capacities* (e.g., playing together). He and others (Whitman, Lutzker, Feldman) have developed measures for many elements (some descriptive [risk counts] and others assessing capacity to take remediating actions). Their formats are particularly suited for PCD (e.g., using pictures to assess skills at identifying safety risks). One protocol has tasks that are common to specific developmental periods (e.g., bathing babies, feeding toddlers) and breaks them into defined behaviorally specific sub-steps (Feldman, 1998a). Such functional analytic protocols lead directly to targeted interventions and allow for an assessment of progress.

Social Cognitive and Neurocognitive Capacities

Social information processing parenting models provide more nuanced ways to conceptualize cognitive impairments than global IQ. Azar, Stevenson, and Johnson (2012) found that three areas of social cognition (expectations regarding children/adults, interpersonal problem solving, and attributional biases), as well as neurocognitive functioning (cognitive flexibility), were associated with child neglect over and above IQ. A standard battery is not yet available, but might include measures that have been used in research and well validated neuropsychological tests that are associated with everyday functioning and parenting.

For example, the Parent Opinion Questionnaire assesses inappropriate expectations of children at various ages that if held strongly are likely to lead to parental frustration and risk to the child. The Child

Working with Parents Who Have Cognitive Limitations: The Parent Support Project

Bryce Fier, MSW

Case managers, evaluators, and direct providers play a critical role in helping parents with cognitive limitations enhance their skills. It is equally important to remember that support systems will play an integral role in assisting these families. Working in the direction of interdependence and collaboration with supports should be the direction of a parenting professional. No one parents alone today so we should not expect that a parent with cognitive limitations does so.

The Parent Support Project

The Parent Support Project (PSP) existed in Hennepin County from 1988-2008. It was a collaborative effort between Adult Disability Services (ADS) and Child Protection (CP). It became clear that parents with cognitive impairments were highly represented in the child protection caseloads

however, currently the county makes referrals to community organizations when parents with disabilities need assistance.

Strategies for Working with Parents with Disabilities

All good parenting work begins with a complete and thorough assessment of the parent's knowledge, skills, capacities, and abilities. Knowing the level of understanding about child development, healthcare needs, and community resources is a starting point in the assessment. Nurturing capacity, child safety awareness, and the ability to provide consistency and structure in their homes also needs evaluation. The assessment should take place over several meetings and be conducted in the parents' home whenever possible in order to understand the home environment and the realities that influence their lives.



Parenting professionals must possess a non-judgmental/non-threatening style to encourage parental engagement; they must also have the ability to meet parents at their level of functioning. Parenting professionals should be prepared to work with parents and families on a weekly basis for 16-24 months.

A mentoring, coaching, guiding, and teaching format will serve this parent population well. In my experience, a "hands on" perspective, such as teaching by example and using videotaping to stress important learning concepts, will allow for their capacity potential to be reached.

The professional's observation skills and ongoing assessment will dictate the parenting areas that need attention. The weekly sessions will clarify their capacity and capabilities as well as their own acknowledgement of limitations that need attention. Professionals should assist parents with developing the support system that will fill the gap in their limitations. Additionally, it is important to help parents address issues related to poverty, housing, and lack of food, as this will make parents more available for parenting services and support.

Parenting professionals should be prepared to advocate for the parents with whom they are working and expect to be challenged as to the capacities of parents and their support systems. Many will not support the notion that parents with cognitive limitations deserve the opportunity to parent their own child(ren) with the support of others.

This work can be extremely rewarding when parental capacity grows and support systems develop that enhance the child's life experience and potential.

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The expectation was that PSP would provide more comprehensive assessments to assist the court in making permanency decisions and would also provide ongoing services to parents that would help them reach their parenting capacity given their cognitive limitations.

with limited specialized services available in the community to assist them with their parenting skills. A majority of PSP referrals came from CP, with many also coming from ADS case managers. There was also concern about the quality of the parenting assessment that was being completed on this population. The courts and CP were asking for a more comprehensive and thorough assessment of parenting capability as well as future parenting capacity. There was recognition that this type of assessment was going to take significantly longer and would require more direct contact with the parent being assessed.

PSP began with four social workers, supervised by ADS, with budget costs shared between CP and ADS. The expectation was that PSP would provide more comprehensive assessments to assist the court in making permanency decisions and would also provide ongoing services to parents that would help them reach their parenting capacity given their cognitive limitations. According to case managers, parenting practices and, consequently, children's lives improved after families began participating in PSP.

Eventually PSP lost funding due to budget cuts. There has been some talk about enhancing services to this population again;

The assessment must include parent/child interaction observation and the parents' ability to follow through on a parenting concept directive. Using a vocabulary that they understand will be important and will help determine how they learn best. Helping parents define their support system (formal and informal) and what they will provide is critical to developing a parenting plan. Assessing the parents' limitations, the parents' own knowledge and acceptance of their limitations, and the ability to accept help (in developing a plan of interdependence) is integral to a successful assessment. Understanding their coping skill capacity, problem-solving ability and their ability to express their thoughts and feelings is equally important.

Assessors will need to possess a broad understanding of cognitive limitations, the ability to discern the parents' capacity to learn and accept help, and the support system's willingness to provide what they have committed to provide. Parents who are unwilling to accept and acknowledge their own limitations will need to be taught that seeking support is a parenting strength. The inability to ask for and accept help should be viewed as a red flag.

Adapting Assessment, Diagnosis, and Communication for Individuals with Dual Diagnosis

Darlene B. Sweetland, PhD

The challenges of identifying mental health disorders for individuals with intellectual disability

Approximately 1% of the general population is identified to have an intellectual disability (Yeargin-Allsopp, Boyle, Braun, & Trevathan, 2008), yet parents with cognitive impairment are significantly overrepresented in child custody cases (Feldman, McConnell, & Aunos, 2012). In addition, Feldman, McConnell, and Aunos (2012) found that over 60% of the parents with cognitive impairment in their sample of child custody cases had co-occurring mental health issues.

Mental health considerations

While mental health disorders are very common for individuals with intellectual disability (ID), identifying accurate diagnoses can be challenging and very often overlooked. The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*; American Psychiatric Association [APA], 2013), which replaced the revised fourth edition (APA, 2000), is the most common method of identifying mental health disorders for the general population. However, using the DSM-5 criteria to accurately diagnose mental health disorders for people with ID is challenging in many ways. First, many

or decreased sleep, weight loss or gain, and diminished ability to think or concentrate. On the other hand, the daily lives of many individuals with ID are guided by support people. Therefore, their daily meals, activities, and sleep schedules are structured for them and these symptoms are often not apparent.

Using supplements to the DSM-5 can be very useful in more accurately identifying mental health disorders. *The Diagnostic Manual—Intellectual Disability: A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID)*, is a comprehensive source which addresses the limitations “in applying DSM-IV-TR criteria to people with ID” and provides adaptations to each diagnosis (Fletcher, Loschen, Stavrakaki, & First, 2007).

Cognitive considerations

To obtain an accurate mental health diagnosis it is essential to assess the level of cognitive functioning of the individual and to understand the neurological processes that are impaired for that individual. There are five cognitive processes that are very often impacted for a person with ID.

First, **expressive language** is very often a significant challenge for individuals with ID. This includes pragmatic language, which is the meaningful use of language. An individual with a well-developed vocabulary



Short-term memory is required when a person is learning new information or receiving instructions. If a person is distracted at all, they can forget the information they just heard because it was never integrated into long-term memory. Individuals with ID tend to have short attention spans and are more easily distracted, so remembering too much information can be difficult. If a person is emotionally overwhelmed or experiencing side effects of medication, short-term memory can be impacted even more.

Long-term retrieval is the ability to fluently retrieve learned information from long-term memory. This means the person has the information stored in long-term memory but has difficulty recalling and communicating it. Therefore, when presented an open-ended question they will often provide the same response or one of only a few responses. Often these individuals will resort to past patterns of coping and behavioral reactions when they are overwhelmed because it is difficult to think of alternative options.

Finally, **executive functioning** is almost always significantly impaired in individuals with ID. Executive functioning refers to multi-step processes such as planning, organizing, initiating, concentrating, problem-solving, and multi-tasking. These are abilities that are required every day for basic skills, such as maintaining a schedule or self-help skills. For example, when preparing a meal a person needs to plan the ingredients, timing, and materials, even before preparing the food. Now think about how executive functioning can be compromised when a person is expected to use good judgment while experiencing symptoms of a mental health disorder. Executive functioning is needed even more in situations related to child-rearing and coping.

While mental health disorders are very common for individuals with intellectual disability (ID), identifying accurate diagnoses can be challenging and very often overlooked.

psychiatric disorders are enhanced, expressed, and coped with using cognitive processes. Consider how a typically developed adult experiences and copes with anxiety; it is very often related to their thoughts. On the other hand, an individual with ID is more likely to express anxiety through behavior (repetitive questions, impulsive behavior, and low frustration tolerance). Second, some of the language in the DSM-5 is general and would be interpreted differently for a person with ID. For example, what might be considered “abnormal” for a typically developed adult may not be for a person with ID and vice versa. Third, the life circumstances needed for a diagnosis are often very different for a person with ID. A typically developed adult experiencing depression may exhibit diminished interest in activities, increased

can still have difficulty using the words in a meaningful way. For example, a person with ID is likely to have a lot of difficulty describing the duration and severity of their mental health symptoms. Instead, they may focus on a recent incident that is causing them a lot of frustration. Often an individual with ID will use behavior to communicate instead of words.

Receptive language is also often delayed for an individual with ID. A person with poor receptive language can become easily overwhelmed with too much verbal input or instruction. Abstract words or terms are generally not understood or remembered. This is very important to consider because parents in the child welfare system are often participants in meetings that are primarily discussion and language based.

Atypical symptom presentation

One reason mental health diagnoses are often overlooked for people with ID is because the symptom presentation is often atypical. Not only do individuals with ID have difficulty talking about the symptoms they are experiencing, but they very often exhibit them differently. For example, the typically developed adult may think about and manage symptoms of a mood disorder internally (negative self talk, isolation, low energy, low motivation, etc.). On the other hand, a person with ID is more likely to manage symptoms externally. Behavioral patterns such as low frustration tolerance, agitation, difficulty sleeping, rumination, and repetitive phone calls may be indicators of a mental health disorder (depression, anxiety, mania, or thought disorder). Before classifying a behavior pattern as “attention seeking,” the result of the intellectual disability, or a personality trait it is very important to rule out a mental health disorder. For more information about how symptom presentation may differ for a person with ID refer to *Intellectual Disability and Mental Health: A Training Manual in Dual Diagnosis* (McGilvery & Sweetland, 2011).

Cross-Systems Collaboration

One of the most complicated factors when working with an individual who is dually diagnosed is working with multiple service systems. The systems that support individuals with ID work very differently and provide very different supports than the systems that support individuals with mental health disorders. Then, when the child welfare system is added to that dynamic, the result is a lot of information being communicated in many different ways. For a person with ID, this can be very overwhelming and extremely challenging. Information is easily lost, messages are confused, and expectations are not met.

Cross-systems collaboration is essential when working with this group of people. It is very difficult for a person who is receiving information from many different people to consolidate and integrate everything s/he is hearing. In addition, it is very difficult for a person who is dually diagnosed to be the person who is responsible for communicating the information across systems.

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Adapting Communication for Individuals with ID/MH

One of the most important ways to support individuals with ID who are working with multiple systems is to adapt the way information is communicated and goals are set:

1. Use notes, picture cues, and symbols when communicating information. Many people with ID are much stronger visual learners, and this puts the information in context, which makes it more meaningful. In addition, the reading level of a person with ID is likely to be well below the level of the forms, reports, and other paperwork provided.
2. Discuss only one piece of new information at a time. Then, have the person repeat what was said in his/her own words. Not only does this ensure understanding, but it helps with memory as well.
3. Develop a calendar together as a team. This calendar should include only the amount of information the person can process at one time. This may include showing only one week at a time, with picture icons instead of writing.
4. Provide concrete goals and expectations for the person. Make sure the goals are obtainable and set the person up for success. If there are any areas that are noted to be particularly challenging, the person may need support from others to maintain the goals.
5. Given the nature of many child welfare meetings, parents may feel uncomfortable acknowledging challenges or confusion. They may feel it reflects poorly on their ability to care for their children and agree to things they don't understand, so talk about these challenges with sensitivity.

DCWC

Disability Child Welfare Collaborative

The DCWC brings together practitioners and researchers from the fields of child welfare, disability, and education in an effort to improve outcomes for parents and children with disabilities in the child welfare system.

On our website you will find more information about child welfare, disability, and special education, as well as how those systems interact. This website is a clearinghouse of information, including materials that we have developed, as well as links to other organizations and resources that you may find helpful. There is also information about us and the organizations that are collaborating with us in our work.

<http://z.umn.edu/dcwc>



Interventions for Parents with Disabilities

Maurice A. Feldman, PhD, CPsych, BCBA-D

The Americans with Disabilities Act (United States Congress, 2008) and similar legislation in other countries attempt to eliminate discrimination and remove barriers to full inclusion of persons with disabilities.

Modifications to physical environments (e.g., ramps, auditory pedestrian crossing signals) and modes of service delivery (e.g., using Braille, sign language) to increase accessibility of persons with disabilities are much more commonplace than in the past. One area of full inclusion that appears to be lagging is parenting by persons with disabilities.

Accommodations for parenting

Having a disability does not automatically make one an incompetent parent or put

evidence-based parent education can improve a wide range of parenting skills, including basic child care, child health and safety, decision-making, and positive and stimulating interactions, with corresponding benefits to their children and family permanence (Feldman, 1994; Wade, Llewellyn, & Matthews, 2008). Effective interventions for parents with intellectual disabilities are based primarily on universal design and behavioral education principles and are home-based, individualized and skill-focused.

Universal design. Universal design means creating an environment from the outset that is as inclusive as possible (Center for Applied Special Technology, 2011). This principle can

task analysis; simple instructions; modeling; audiovisual aids; verbal, gestural and physical prompting; roleplaying; practice; and positive and corrective feedback. To supplement parent education, other interventions to empower parents in building natural social support networks and positive relationships have been developed, and preliminary studies show promising results (McConnell, Dalziel, Llewellyn, Laidlaw, & Hindmarsh, 2009).

Conclusion

While accommodations and evidence-based programs now exist to support parents with disabilities, it is not clear if they are sufficiently available and accessible to parents with disabilities involved in the child welfare system (National Council on Disability, 2012). While child welfare laws state that reasonable efforts should be made to support family permanence, the lack of knowledge about and availability of appropriate services may result in child removal. The cost-benefit ratio of providing timely services may be far better than child removal. What is “in the best interests of the child” may not be being placed in foster care (Feldman & Aunos, 2010). Further work is needed in several areas, such as improving professional education in working with parents with disabilities and increasing access to appropriate supports. More research is needed on identifying evidence-based services for parents with disabilities with older children and the long-term impact of providing appropriate supports and interventions on child and family outcomes. The time has come to remove the stigma of being a parent with disabilities and to increase access to the accommodations and supports they need to be successful parents.

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The notion that parents with disabilities must be fully self-reliant in order to keep their children creates a higher standard than for the rest of us who routinely rely on others to help with child care.

children at risk. Parents with disabilities cannot be lumped together as there are many different disabilities with a wide range of implications (Kirshbaum & Olkin, 2002). As with accessibility to fulfill different roles in the community, different child care accommodations are needed depending on compensatory need. For instance, a parent with significant hearing loss may need a signalling light or vibrating pager to let the parent know the child is crying in her bedroom (Harris & Bamford, 2001). A person with physical limitations may need an adapted crib, so that the parent can safely put the baby to bed and pick him up. As with most parents, parents with disabilities sometimes may need the support of others to carry out certain parenting functions. The notion that parents with disabilities must be fully self-reliant in order to keep their children creates a higher standard than for the rest of us who routinely rely on others to help with child care (Drew, 2009; Kroese, Hussein, Clifford, & Ahmed, 2002; McConnell & Llewellyn, 2000).

Parents with Intellectual Disabilities: Evidence-Based Interventions

Of all the disabilities, having an intellectual disability puts a parent at the highest risk for termination of parenting rights, often in the absence of actual abuse or neglect (Drew, 2009; Feldman & Aunos, 2010). Intervention research over the past 27 years shows that parents with intellectual disabilities receiving

be applied to virtually any human endeavour including teaching parenting skills. The Step-by-Step parent education program developed and researched by Feldman and associates (Feldman, 1998b, 2004) utilizes universal design principles by incorporating materials and instructions that are suitable for persons with below-average cognitive and reading abilities. Child care tasks, such as diapering, bathing, home safety, handling emergencies and parent-child interactions, are broken down into small steps (task analysis). Step-by-step checklists are prepared and validated to monitor current parenting skills and progress during instruction (Feldman & Case, 1993). Another aspect of universal design for cognitive disability and low literacy skills includes visual aids such as picture books that illustrate each child care step alongside simply worded descriptions (less than 6th grade level) to increase comprehension (Feldman & Case, 1993). If the parent cannot read the simple text, then audio and video clips are provided. While the picture books originally were meant to supplement parent educator-led training, in fact most parents with intellectual disabilities were able to learn child care skills to the same level as parents without intellectual disabilities just using the picture books alone without training by a parent educator (Feldman, 2004).

Behavioural education. Behavioural education has been shown to be a highly effective way of teaching child care skills and positive parent-child interactions to parents with intellectual disabilities (Feldman, 2010). Behavioural teaching involves using

An Overview of Parental Supports for Child Welfare Practice

Elizabeth Lightfoot, PhD & Traci L. LaLiberte, PhD

Almost all parents use a range of formal and informal supports to assist with parenting their children. Formal supports that many parents use for raising their children include paid daycare, house cleaning, or after-school programs. Informal supports that parents often make use of include relatives providing regular or occasional child care, carpools to children's activities, or parenting advice from friends. Parents with disabilities need similar types of supports when parenting their children as do parents without disabilities, and these types of supports for parents with disabilities are called *parental supports*. While most parents make use of some array of formal or informal supports when parenting their children, the child welfare system has historically assessed people with disabilities as to whether they can independently parent their children without taking account of potential parental supports.

Parental supports for parents with disabilities are simply "technologies or personal supports that enhance family functioning in families headed by a parent or guardian with a disability" (Lightfoot & LaLiberte, 2011, p. 390). The idea of parental supports builds on the general notion of

Personal parental supports are any support designed to assist parents with a disability to parent their children. Personal parental supports include daycare or respite care, in-home parenting training, homework assistance for children, accessible transportation so that a parent can attend children's activities with the child, or housekeeping and meal preparation. The focus of personal parental supports is to assist a parent with a disability to parent their children rather than to assist a parent with a disability with his or her own needs.

The notion of taking into account parental supports when assessing parenting is a paradigm shift for the field of child welfare, which has viewed independent parenting as essential. Parents have often been assessed based on whether they can independently be responsible for all aspects of caring for their children even though most parents rely on various formal and informal parental supports for raising their children. However, there are recent shifts in some state laws requiring child welfare agencies to take into account the various formal and informal parental supports when conducting assessments. For example, the state of Idaho now requires courts to



few programs dedicated to parents with disabilities nationwide are available. While people with disabilities often receive funding for individual supports needs through the disability service sector, such as through state or county developmental disabilities services, this funding is not designed to support parenting activities. Thus, parents with a disability might be able to receive accessible transportation for themselves but not be able to take their children with them. While some formal supports and funding streams are flexible, most parents with disabilities rely on informal sources of parental supports. As state laws begin to recognize the parental support needs of parents with disabilities, more funding for parental supports may be available.

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The notion of taking into account parental supports when assessing parenting is a paradigm shift for the field of child welfare, which has viewed *independent* parenting as essential.

"supports" in the field of disabilities, which typically focus on the support needs of *individuals* with disabilities, such as supports to assist individuals with *daily living* tasks, transportation, education, or employment. In contrast, parental supports are technologies or personal supports that assist parents with disabilities in their *parenting activities*.

Parental support technologies are any technological device or program that can support parenting. Examples of parental support technologies are: a smart phone which provides reminders for feeding a baby for parents with memory issues, a roll-under crib which allows a parent who uses a wheelchair to pick up his or her baby, a wheelchair-mounted baby carrier, a talking thermometer for a parent who is blind, or a baby monitor with a flashing light that alerts a deaf parent that his or her baby is awake. While some parental support technologies are available through online catalogues, parents often have to create their own parental support technologies based on their own needs.

consider parental support technologies and personal parental supports before terminating parental rights (See [Idaho's Success Story, in this issue](#)). In addition, the National Council on Disability's report *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* also urges states to take into account parental support needs of parents with disabilities (see [Powell, in this issue](#)). Thus, it is likely that in the near future all child welfare agencies will be required to take into account parental supports when assessing parents with disabilities and developing plans for families with a parent with a disability. Child welfare workers will need to become better acquainted with parental supports that parents with disabilities could and do use when parenting their children and also be able to link parents with disabilities with such parental supports.

Although there are shifts in policies in some states requiring attention to parental supports, there currently is little financial support for parental supports, and only a

Family Teaming to Enhance Engagement and Opportunity for More Families in Child Welfare

Ben Kerman, PhD, Judy Lee, PhD, & Lauren Frey, MSW, LICSW

Family teaming practices, a diverse set of approaches increasingly applied in Child Welfare, share a set of core practices that can bring significant value to work with families in which a parent has a disability. Teaming presupposes that plans and decisions made by families and young people working collaboratively with professionals tap strengths, maintain kinship ties, access more resources, and honor cultural connections (American Humane Association, 2008). While nuances distinguish particular teaming models, each aims to facilitate more engaged parents and children, convene structured meetings with family, extended family, natural supports and professionals, and empower the family while maintaining focus on child safety, permanence and well-being.

Core teaming principles and practices are applied across numerous systems (e.g., state, nonprofit, and private agencies) with a variety of procedures. For example, both Family Group Conferencing and Family Group Decision Making utilize an independent, non-case carrying coordinator to convene the family group with professionals; in contrast, Family Team Conferencing uses the lead case manager as facilitator. Team Decision Making and Family Team Meetings convene meetings at critical decision-making junctures (e.g., initial placement, case termination) while Lifelong Families (LLF) maintains an ongoing team.

Given the extra risk toward dissolution and disempowerment faced by families led by parents with disabilities, teaming can help ensure that the system works for all. In fact, flexible response, intensive engagement and preventive planning are even more urgent given the biases and dearth of services that exist once children are removed. Practitioners using teaming actively attend to the power balance between professionals, parents and family members, preparing individuals and facilitating meetings so that disabilities do not undermine participation in agenda setting, meeting discussion and follow-up. They reach out to parents wherever they are and schedule meetings to maximize their presence, comfort and competence. They invite parents to work with other team members to customize child and family contingency plans for when disabilities grow more acute and disruptive ensuring attention to long-term post permanency planning as family needs evolve. Simultaneously, practitioners reach out to professionals and authorities to clarify safety and liability concerns.



Two brief examples reflect the potential benefits of teaming for addressing the needs of parent, child and family. In one case, a mother with a severe episodic mental illness worked with her team to develop a plan for when she recognized that her illness was recurring and she was in need of respite or

and searches for family and kin supports have demonstrated positive outcomes for parents, families, and children's permanency (Marcenko, Brown, DeVoy, & Conway, 2010; Child Welfare Information Gateway, 2011). California Department of Social Services' researchers found that early, positive,

The principles that underlie teaming practices aid not only in the achievement of case goals but in the empowerment of families through engagement, structured decision-making, member preparation, contingency planning, and recognition of strengths/assets.

re-hospitalization: with one call, she could alert her son's respite foster parents, signal her service provider, and even trigger her kennel for her dogs. Moreover, she overcame her fears of acknowledging recurrence and impairment because her permanent relationship with her son was not threatened. In another case, a patient, loving team of extended family members and professionals helped a mother with cognitive disabilities recognize that she could not provide the permanent parenting her three cognitively impaired young sons needed. They helped her create videos the boys could watch as they grew older, explaining her perspective and encouraging her sons to feel blameless for this loss and free to attach to their new adoptive families.

Available research suggests that effective parent engagement with parents with disabilities, while difficult, yields positive results. Innovations like the Parent Mentoring and Parent Partners Programs as well as those which use family team meetings encourage foster parents' support of birth parents,

and intensive engagement (in contrast to 'adversarial' contacts) along with a strengths-based, collaborative approach produce desired effects among families and youth (Larsen-Rife & Brooks, 2009). Child Trends' synthesis involving 67 evaluations of parent involvement interventions concluded "programs that actively engage parents generally have positive impacts" (Mbwana, Terzian, & Moore, 2009). In child protection, parental engagement by competent, supportive workers yields effective results, too (Schreiber, Fuller, & Pacey, 2013).

Experience applying LLF teaming with more than 400 foster children and youth facing numerous challenges and/or disabilities suggests that the approach is flexible, feasible and effective (Lee, Kerman, & Frey, 2013). Like other family engagement approaches, LLF uses a team that includes parents, youth, family members, and professionals to achieve a committed, supportive legal

Continued on page 36

¹Full team was defined as including a birth parent or kin, youth over 12, foster parent, state worker, and another professional.

Peer Navigation in Vermont

Susan Yuan, PhD

In the first decade of the 21st century, reorganization of the Agency of Human Services (AHS) in Vermont coincided with a grant opportunity from the federal Administration on Developmental Disabilities to build one-stop support for targeted underserved families with members with disabilities. Vermont chose to target parents with disabilities to reduce the incidence of termination of parental rights. The grant funded the Peer Navigator program over a period of six years, assisting 890 families with the most complex needs through Peer Navigators. Fewer than 2% of parents involved in this program lost permanent custody of their children.

The Peer Navigator Concept

What is a Peer Navigator? Most importantly, a peer—a person with the closest possible identification with the families served. Having life experience with a disability is a requisite, either as a parent with his or



Program Implementation in Vermont

The Peer Navigator program was in place for six years in Vermont. During those six years, Peer Navigators helped families identify their own goals and find their way through systems of support to reach those goals. Often this meant helping families connect to formal supports; sometimes, it required creativity in finding or creating supports where none existed. For many families, goals were

vigorously for families and often needed guidance to be strategic in their activism.

Although AHS held the grant, Peer Navigators were employed and supervised by the nonprofit organizations VT Federation of Families for Children's Mental Health and the Vermont Family Network. This contributed to their independence and engendered greater trust in families. While not mandated reporters, Navigators were trained in a moral obligation to be sure that children were safe.

Families were not “cherry-picked;” on the contrary, they were referred because of the complexity of their situations. Fifty-six percent of the families had at least one parent with a developmental disability. Many other families had mental health issues and all experienced poverty. At the beginning most referrals came from regional AHS Field Directors where most Navigators were co-located. Over time, referrals came from families themselves as word of mouth spread that Navigators were trustworthy.

The grant required serving 250 families over five years; however, no one was turned away and by the time funding ended more than three times as many had been served. Some were served for a short time, especially if they could be connected to formal supports. Most of the families were served longer, often returning when they next needed help.

Complementary Initiatives

While efforts are underway to reinstate funding to this successful program, several complementary initiatives, such as multidisciplinary training, competence-based parenting assessments, and court communication specialists continue to contribute to success for families with disabilities in Vermont.

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Peer Navigators are based on the concept of the “reliable ally,” a trusted support person available over time.

her own disability or as a parent of a child with a disability. These part-time, regionally based parents need to know services in their region from the inside out in order to be the most effective. Personal experience with child welfare is considered a plus so long as they had a positive resolution of their child's situation, and they have an attitude of possibility.

Peer Navigators are based on the concept of the “reliable ally,” a trusted support person available over time (Santelli, Singer, DiVenere, Ginsberg, & Powers, 1998). According to Bandura (1997), the “model” with most positive impact on self-efficacy perception is the person perceived as most like the person she is trying to help. In earlier Vermont research (Yuan, 1998), parents of children with disabilities responded,

“We still need a person to talk to... human contact means too much to me.”

“... a check would supply a lot, but I wouldn't necessarily know where to get services...not without the human side, too.”

“(I need) the human contact, being able to talk to someone or know that I can call so and so, and if she doesn't know, she knows someone who does, or just to say, ‘gee, it sounds like you had a bad day!’”

immediate and pressing—urgent needs of the moment, such as housing. Once basic needs were met, Navigators began to introduce longer-range planning using person-centered tools such as PATHs (Planning Alternative Tomorrows with Hope; O'Brien, Pearpoint, & Kahn, 2010). The goals were ones developed by the family, not those written in formal service plans. For families whose children were in state custody, however, the most common goal was getting their children back. Navigators worked with families to identify what was standing in the way of goal achievement and helped them brainstorm and problem-solve.

Peer Navigators in Vermont received initial participatory training using materials on philosophy and culture from *Family Support, Self-Determination and Disability* (Yuan, 2001). Quarterly trainings featured aspects of the child welfare system, the court system, moral responsibility to report abuse or neglect, dealing with domestic violence, confidentiality, emergency preparedness, person-centered planning, and other relevant topics as the need arose.

Since most Peer Navigators did not have professional experience supporting other families, individual and group supervision were essential in helping them address issues arising from the complex situations the families were facing. Peer Navigators advocated

When a Parent Has a Mental Illness

Sue Abderholden, MPH

We all want her to just stop being sick. For our lives to stop being the constant know of tension and fatigue and fear. And so we push for wellness. We all try to smile and put forth a huge effort to show one another and the world how normal things are. But for me, it feels like my face will crack from the mask I wear. (Holman, 2003, p. 200)

Virginia Holman's (2003) book is just one of many memoirs, published in the past decade, where the parent had a mental illness. With twenty to twenty-five percent of adults having a mental illness, the odds are good that there are many children growing up with a parent with a mental illness, albeit with a range of severity. The impact it will have on a child will vary depending on the symptoms, the natural supports for the family, economic status, access to treatment, and the child's own resilience.

Surprisingly, our mental health system has been slow to recognize that people with mental illnesses, including serious ones, are parents. Until very recently, our longer term residential programs didn't even include on their discharge forms how parents would be reunited with their children. The assumption



access treatment out of fear that it will put them into the child protection system or be viewed negatively during a divorce.

The third concept is to build the parent's natural supports. No one gets through a serious illness by themselves. People depend on support from the community through needed items, food, and household help. When you have a mental illness, those supports are often not there. These parents need a "family crisis plan" so that the parent and their children obtain support and help during difficult times. It could be that the

of" nor does having this illness mean that they are a bad parent. Many fiercely love their children, but their illness at times may make it difficult to care for them.

It is not uncommon, knowing that there can be a genetic basis, for the child to have a mental illness as well. How stressful for this family to have two case managers and different in-home providers coming and going with no coordination between the two. We need everyone—professionals and family members—working toward the same goals in a collaborative, supportive relationship.

There is hope on the horizon. A new law in Minnesota adds "parenting skills" to what can be provided under Adult Rehabilitation Mental Health Services. In addition, a bill was introduced during the 2013 legislative session that would expand child care assistance to MFIP child-only cases where the parent is on Social Security and has a mental illness. NAMI is working to establish peer support groups for parents who live with a mental illness and hopes to begin a new project within the year to begin addressing systemic issues facing these parents. Only when we recognize that what we are doing isn't working well can we begin to make it better.

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[T]reat the whole family. Children need age-appropriate information and support so that they can understand what is going on and know that they are not alone. The parent who is ill needs empathy and support.

was that people with serious mental illnesses were not parents. But they are.

There are a number of key concepts to keep in mind when trying to help a child who has a parent with a serious mental illness. The first concept is to recognize that recovery is possible. Just because the parent is experiencing significant symptoms now that make it difficult for them to care for their child doesn't mean it will always be that way. The symptoms of mental illnesses can be cyclical in nature, but again, recovery is possible.

The second one is to eliminate barriers to treatment. The parent could have health insurance with a high deductible or co-pays or a limited network, a job that makes it difficult to take off work, or lack of reliable transportation to get to the clinic. An even larger hurdle, especially for parents who are on Social Security, is that you can't access child care assistance for treatment and yet few mental health clinics offer child care. If these parents don't have family and friends to support them, they may simply forgo treatment. Some parents may be afraid to

grandmother or an aunt takes the children for a couple of days or weeks when the parent isn't doing well.

Most people don't understand mental illnesses. It's not really talked about so people don't instinctively know what to do. Many relatives report being "turned away" by mental health professionals under the guise of data privacy laws. So a valuable source of information and assistance is lost. The parent's family needs education and support in order to know how to help. The parent needs to come up with a list of family members or friends who can provide assistance when they aren't feeling well.

The last concept is to treat the whole family. Children need age-appropriate information and support so that they can understand what is going on and know that they are not alone. They may need help from a mental health professional to deal with the stress or instability in the home. The parent who is ill needs empathy and support. It's not something that they can "pull themselves out

The National Alliance on Mental Illness (NAMI) of Minnesota is a nonprofit organization dedicated to improving the lives of adults and children with mental illness (MI) and their families. To learn more about their advocacy projects, support groups, and other resources on parenting with MI, visit their website at:

<http://www.namihelps.org/>

An International Perspective on Current Trends and Future Prospects for Parents with Intellectual Disabilities and Their Children

Gwynnyth Llewellyn, PhD

“As adults, they [people with mild cognitive limitations] struggle to find significant life partners, keep their marriage or other relationships stable, raise children, and make enough money to survive. Most of them have the added problems of low incomes, not being well educated, and not knowing where to find the assistance that they need. It is not surprising that many of them have mental health problems and may have difficulty finding happiness.” (President’s Committee on Mental Retardation, 1999, p.87)

This observation remains familiar today to child welfare practitioners, policy makers, advocates, and researchers in high income countries such as the United States of

There is also work underway using national survey data (Hindmarsh, Llewellyn, & Emerson, 2013) and administrative health visitor data (Emerson & Brigham, 2013) from the United Kingdom to identify the *relative* contribution of parental cognitive limitations to parental health and parenting difficulties. Already we know that exposure to a range of adversities (such as low income, poor housing, unsafe neighborhoods, unemployment) are strong influences over and above cognitive limitations on health for adults with intellectual disability (Emerson et al., 2012; Emerson, 2011) and on child welfare involvement (McConnell, Feldman, Aunos, & Prasad, 2011a). This reminds us not to assume that the parent’s cognitive limitation

because we strongly believe that the voice of parents with an intellectual disability needs to be heard and not denied (personal communication, March 7, 2013).

The second example is the Australian Council of Human Rights Agencies which in March 2013 made investigating systemic violation of anti-discrimination and human rights instruments in relation to parents with intellectual disability a priority (Australian Council of Human Rights Agencies, 2013).

The United States is yet to sign the CRPD; however, the report *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children* (National Council on Disability, 2012) employs a rights-based approach; see Powell in this issue for more.

Utilizing a rights approach to overcome discrimination against parents with disabilities is becoming more commonplace.

America, Canada, the United Kingdom, the Scandinavian countries, and in the Asia Pacific region, Japan, Malaysia, Singapore, Australia and New Zealand. (The situation is different by country and context in low and middle income countries [Llewellyn, in press].)

Understanding the Life Circumstances of Parents and Their Children

Researchers have noted that knowledge from clinical samples does not inform us about the specific circumstances of the broader range of parents with intellectual disabilities or their circumstances compared to their non-disabled peers (IASSID Special Interest Group on Parents and Parenting with Intellectual Disabilities, 2008). To gain this knowledge, researchers are using national population surveys and administrative data sets. For example in a recent Swedish study, Hoglund and colleagues (2012a, 2012b) used the National Patient Register and the National Medical Birth Register and demonstrated that mothers with intellectual disability had a higher risk for preterm birth, cesarean section, non-use of nitrous oxide, and discharge from hospital to a place other than home, and their babies were at risk for being small for gestational age which can be an indicator of developmental delay. Child welfare practitioners need to be aware that for far too many mothers with intellectual disability and their babies there is a difficult start to life (Llewellyn, 2012).

is *the* presenting problem. Many parents with intellectual disabilities experienced disadvantaged childhoods (Llewellyn & McConnell, 2010). Adverse life circumstances critically affect child development as demonstrated in a recent video from the Center for the Developing Child at Harvard University (Center on the Developing Child, 2013).

Naming Discrimination and Using Legal Instruments to Advocate for the Rights of Parents with Disabilities

Article 23 of the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD; United Nations, 2006) states that:

States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.

Utilizing a rights approach to overcome discrimination against parents with disabilities is becoming more commonplace. Here are two quite different examples from Australia. The first comes from Susan Arthur, founder of Powerful Parent, a self-advocacy parent group in Victoria. She writes:

We started because of the numbers of parents with intellectual disability who do not get the support they need to support their children. Our group is important

What Might the Future Hold?

The trends above, which both address disadvantage and discrimination in the lives of parents with disabilities, are warmly welcomed. What else could be done? I offer three proposals that take a preventive approach and that could be implemented by child welfare and other health and social service professionals. These are: (1) children and young people with disabilities to receive evidence based programs promoting respect, choice and responsibility in sexuality, relationships and parenting, so as to prepare them as they become parents later in life; (2) mainstream services to enhance their capacity to respond appropriately to women and men with disabilities; and (3) practitioners to engage with family members to ensure that the choices of the person with disabilities about their sexuality, intimacy and parenthood are respected and not violated. While it remains important to focus on the *current circumstances* of parents with disabilities and their children, child welfare practitioners and policy makers are ideally placed to contribute wholeheartedly and significantly to ensuring better *future circumstances* for people with disabilities when they become parents.

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Federal Agency Sheds Light on the Experiences of Parents with Disabilities and Their Children

Robyn Powell, JD

In September 2012, the National Council on Disability (NCD) released *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, a comprehensive policy study which analyzes how disability law and policy apply to parents with disabilities in child welfare. This article provides an overview of the report's key recommendations relevant to the child welfare system.

Recommendations for the Administration and Federal Agencies

- Issuance of a Presidential Executive Order establishing an Interagency Committee on Parents with Disabilities. This committee should address the paucity of data and research on the prevalence of parents with disabilities, their needs, and their experiences in order to inform policy and programming that meet the needs of parents with disabilities and their children.
- The Department of Justice (DOJ), in collaboration with the Department of Health and Human Services (HHS), should address the discrimination faced by parents with disabilities and their children within the child welfare system by issuing guidance to child welfare agencies on their legal obligations to serve parents with disabilities, and increasing investigations and enforcement of violations of federal disability laws.
- Collaboration between HHS Children's Bureau and the National Institute on Disability and Rehabilitation Research (NIDRR) in funding and directing NIDRR's National Center for Parents with Disabilities and Their Families in order to allow the National Center to develop additional knowledge and provide additional technical assistance to federal, state, and local agencies and tribes to improve outcomes for families with parents with disabilities.

Recommendations for Congress

- Enactment of legislation similar to the Indian Child Welfare Act (ICWA) that will protect the rights of parents with disabilities and their families. This legislation should be in accordance with the language set forth in *Rocking the Cradle*. The impetus for the ICWA arose from circumstances similar to those surrounding families with parents who have disabilities. Both Native Americans and people with disabilities are historically oppressed minorities who have been denied civil and human rights in this country. Most important,

both groups have been subjected to involuntary sterilization programs and massive removals of their children. Lack of knowledge about the culture of Native American people and how they parent is very similar to lack of knowledge about the culture, adaptive equipment, supportive services, and strengths of the disability community and how people with disabilities parent. Portions of the ICWA that provide remedy for the Native American community should be borrowed

- Mandatory training related to parenting with a disability for all dependency court professionals—including judges, attorneys, and evaluation personnel.
- Require that state statutes, rules of court, and professional standards include parenting assessments that are fully accessible to parents with disabilities.
- Development and implementation of mechanisms that support integrated, family-centered, strengths-based care for parents with disabilities and their children.

[States should] amend state statutes by eliminating parental disability as grounds for termination of parental rights and adopting language set forth in *Rocking the Cradle*.

to strengthen new legislation to protect the children of parents with disabilities.

- Appropriation of funding for research on parents with disabilities and their families. Further, NCD recommends that federal agencies such as the Interagency Committee on Disability Research (ICDR), emulate and collaborate with NIDRR in dedicating funding to research on parents with disabilities and their families, focusing on their needs and how best to support them.
- Amend the Adoption and Safe Families Act (ASFA) to add protections for parents with disabilities, specifically to the "15/22" rule (to allow for additional time for parents with disabilities) and the "reasonable efforts" provision (to prevent unnecessary removal and promote reunification). The bypass provision, which allows states to bypass efforts to reunify families in certain situations, should not be applicable for parental disability.
- Shift funding priorities at the federal level so that states have a greater incentive to provide prevention and preservation services.
- Swift ratification of the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) because it reinforces the rights of people with disabilities to create and maintain families.

Recommendations for States and Child Welfare Agencies

- Amend state statutes by eliminating parental disability as grounds for termination of parental rights and adopting language set forth in *Rocking the Cradle*.

Conclusion

While parents with disabilities are especially affected by the issues discussed here, they are not alone. Indeed, in no community is the welfare of children...served by breaking up families based on fear and stereotype. If we are truly concerned about the welfare of children, we should invest more money and energy in preventive services for families rather than in parental rights termination and foster care. Our conception of the parent or parents as individuals standing alone, without help from the broader community, does children no service (Watkins, 1995, p. 1475).

NCD urges swift and thoughtful implementation of the recommendations set forth in *Rocking the Cradle*. A strong collaboration between the child welfare and disability communities is necessary to guarantee the rights of parents with disabilities and their children. Together, we can ensure that these families thrive!

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*The National Council on Disability is an independent federal agency committed to disability leadership since 1978. The *Rocking the Cradle* report can be found on their website, along with other disability resources:*

<http://www.ncd.gov/>

Common (Higher) Ground: What Social Workers and Parents' Attorneys Can Do to Maximize Justice for Parents with Disabilities and Their Children

Ella Callow, JD

A nation's success or failure in achieving democracy is judged in part by how well it responds to those at the bottom and the margins of the social order. (Supreme Court Justice Sandra Day O'Connor, Day O'Connor, 2004, p. 276)

Child welfare's impact on parents with disabilities and their children is a significant issue implicating the fundamental right to parent and associated 14th amendment rights to equal protection and due process (Santosky v. Kramer, 1972; Stanley v. Illinois, 1972). 6.1% of all parents have a disability, and they are raising 9 million children (Kaye, 2011), yet 12.9% of child welfare cases involve removal of a child from a caretaker with a disability (Callow, Buckland, & Jones, 2011). Approximately 40% of people with intellectual/developmental and 60% of those with psychiatric disabilities lose custody of their children (Llewellyn, Rannviog, McConnell, & Bjorg Sigurjonsdottir, 2010; McConnell & Llewelyn, 2002; Larson, Lakin, Anderson, & Kwak, 2001b; Kennedy, Garbus, & Davis, 1999; Kundra & Alexander, 2009; Nicholson, Biebel, Hinden, Henry, & Stier, 2001; Joseph, Joshi, Lewin, & Abrams, 1999; Mowbray, Oyserman, Zemencuk, & Ross, 1995). Parents with disabilities have heightened rates of poverty, unemployment



2010). Legal experts in the field of disability parenting agree that inelegantly crafted state laws are driving high rates of child welfare involvement for parents with disabilities (NCD, 2012).

Many states have recently improved their legislation to provide protection for

therapy assessments designed to ascertain if a parent with a physical disability, or who is Deaf or Blind, can safely care for a young child (Tuleja & DeMoss, 1999); evidence-based measures to evaluate parents with intellectual disabilities (Callow, 2013); and intervention services that are effective for parents with psychiatric disabilities (Callow, 2013). Even where capacity does exist it is often not known to the child welfare or legal community.

Absent reliable evidence as to fitness, the child welfare system often advocates for termination and the court rules on speculation. Social workers and attorneys must counter this by reaching out to TNC for free consultation at the beginning of these cases to determine what disability specific services are needed and where they can be found. Social workers should encourage their agencies to vendorize service providers having expertise with this population *or who commit to securing training and consultation*. Attorneys

Continued on page 36

Child welfare's impact on parents with disabilities and their children is a significant issue implicating the fundamental right to parent and associated 14th amendment rights to equal protection and due process.

and inadequate education (National Council on Disability [NCD], 2012). Truly, they are at the bottom and at the margins of the social order.

The National Center on Parents with Disabilities (TNC) works weekly with these parents, their social workers and attorneys who are doing their best to respond to this population and their needs. But we see that they face systemic barriers. While the parameters of this piece do not allow for a full discussion of such challenges, below are three challenges and strategies that are relevant to their work.

Bad law. The vast majority of states have child welfare law that allows the state to remove a child and/or terminate the parent-child relationship on the basis of parental disability (Lightfoot, Hill, & LaLiberte,

these families (e.g., Missouri Code §26.3 (6), 2011). This creates opportunities for attorneys and social workers. In states with new laws, they can implement them in their decision-making and litigating and can educate supervisors and judges regarding implications for system practice. In states with bad laws, they can collaborate and endeavor to replicate the successes in other states. It is always important to be mindful that the Americans with Disabilities Act applies to child welfare proceedings and should be pled early (NCD, 2012).

Lack of proper services. Lack of capacity to provide properly accommodated services frustrates attorneys and social workers (Callow, Gemmill, Jacob, & Riley, 2011). For example, the following TNC recommended services are typically unavailable: occupational

To learn more about Through the Looking Glass (TLG) and its projects, including The National Center for Parents with Disabilities and their Families, visit TLG's website at:

<http://www.lookingglass.org/>

From Child Protection to Adult Mental Health: A County Worker's Perspective

Selena Stevens, MA

I started working as an adult mental health case manager in January 2012 after 3 years in child protection. I assumed this to be a completely different type of work but quickly learned how much these two fields overlap. In my first few days as a case manager, I was given a list of clients along with their case files. After reviewing their diagnostic assessments and personal histories, I noticed a pattern of child protection involvement with nearly every client. Many of my clients had spent time in foster care, group homes, treatment centers or extended family care as children. They reported mental health symptoms from either being removed from their biological parents and the process of reunification or not being removed and enduring ongoing abuse/ neglect. They attributed many of their current mental health issues to the stresses and experiences they encountered as youth.

I thought back to my cases in child protection and realized the impact of the decisions I had made with families over the last three years. As an adult mental health worker now, I feel as though I am looking into the futures of the children I worked with, and I cannot help but wonder, "What could or should I have done differently?"

Over the years, many tools have been



as symptoms can be managed through medications and other interventions. Many parents with managed mental illness can effectively parent their children and provide a safe home. Parental capacities may only be affected during incidents of high crisis or stress, medication non-compliance, or when

parenting with mental illness groups, shared family foster care and other similar programs to better assist families in learning the skills needed to effectively and safely parent their children while addressing mental health needs. These programs or services should be made available voluntarily and at reduced or no cost so families can seek out supports without having to fear removal of their children.

Child protection and mental health professionals continue to work toward changing the negative stigma which has been historically associated with these fields. Through advanced training and skills, providers can assist families in understanding the needs and can more accurately identify supportive services available to be successful. Coordination of child protection and mental health can benefit families by providing support and education to keep families together in a safe, managed environment.

Selena Stevens, MA is a former child protection worker and current Adult Mental Health Case Manager at a public child welfare agency. She can be reached via email at selenagrace3@yahoo.com.

The fear of having their children removed prevents [parents with mental illness] from open disclosure, and as a result the family continues to suffer.

introduced to help child protection workers engage with families to better determine the needs and potential dangers and to gauge parental capacities. My previous employer required all child protection workers to complete the Global Appraisal of Individual Needs –Short Screen assessment (GAIN-SS) which opened up conversation with families in regard to substance abuse, mental health, criminal history and other potential risk factors. However, parents have little reason to trust child protection workers as the initial interaction is often short (1-2 hours), and any disclosures could result in a potential removal of their child(ren) or more intrusive interventions. Parents feel a need to protect their histories, giving minimal information about their past or current stressors. The mental health of the parents or children is often not apparent during the assessment

new symptoms arise or if a relapse of previous symptoms occurs. Without accurate disclosure and symptom management, child protection workers are forced to base decisions of child safety solely on the information they have acquired, which is often not the whole story.

Children in families with diminished parental capacities due to mental health who are not removed from the home may also experience traumatic stress. Parents with managed mental health or personality disorder may present to a provider as capable of providing a safe and nurturing environment but may actually be struggling with their mental illness. The fear of having their children removed prevents them from open disclosure, and as a result the family continues to suffer. This emphasizes the need for in home and community supportive programs/ services, peer support groups,

Being a Mom Is Special

Molly Saunders

My daughter Elizabeth was born on July 20th, 2004 at Frederick Memorial Hospital in Frederick, MD. I stayed in the hospital for three days to recover from a caesarean birth while Elizabeth who weighed 5 lbs. 8.5 ounces had to stay in the hospital for an additional five days. She was in an incubator and needed to be watched closely due to a medical condition related to my use of prescribed medications during my pregnancy. I was very concerned about her health, and it was hard to go home without her.

worker was judging me, causing me to be fearful that I'd do something wrong or make a mistake. She would watch me as I fed, bathed, changed, dressed, or rocked Elizabeth to sleep. All of these experiences were being scrutinized, and as a new mother this was difficult and I longed for some privacy.

Once Elizabeth was about two months old, I continued to have plenty of assistance and help with her care from our families and some folks from my church. The Arc of Frederick County helped me identify folks

save money so that I can take my daughter on vacation. Like any parent, I want to see her laugh, play, and have fun. I want for us to make special memories that will last a lifetime. It is also essential to me to that we spend lots of time together and that my daughter sees that I am doing my best and that she is the most important person in the world to me.

In thinking about the impact of CPS during those early years, I would like to share some of my thoughts.

- I wish the CPS worker would have sat down to observe us so that it might have felt a little more relaxed. She even watched me closely as I put my daughter to sleep. I longed for some privacy so that we could enjoy some personal and special bonding time for mother and daughter alone.
- I also wish I had been more open, but I was afraid to discuss with the CPS worker what she was looking for as she watched me care for Elizabeth.
- The CPS worker needed to realize that my family had given up our right to privacy. This lack of privacy was very hard on me and Elizabeth's father.
- I wish CPS had listened and followed-up better to concerns about Elizabeth's care from her father—I was not listened to.
- Don't **assume** that someone with a disability can't parent.

Of course, there were good times as well, and I appreciate that CPS was there to try to help. On one occasion the CPS worker took Elizabeth and me to the mall, and we had Elizabeth's photo taken with Santa. I still treasure that special memory and photo. CPS also provided us a sturdier and stronger stroller to push Elizabeth in, which was a wonderful surprise.

At the end of the day, I am grateful for all of the assistance I've had and I understand that we all try to do the best we can and there is so much more to learn.

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The Association for Successful Parenting (TASP) works to enhance the lives of families when parents have learning difficulties. Their October 2013 conference focuses on innovative partnerships and practices. Learn more about TASP on their website:

<http://www.achancetoparent.net/>

Like any parent, I want to see her laugh, play, and have fun. I want for us to make special memories that will last a lifetime.

When I took Elizabeth home, I felt excited and prepared. I had family support and the nurses in the hospital had shown me how to hold her properly, wrap her comfortably in her blanket, and feed and bathe her. We had all of the things that she would need, and homecoming was such a joyous day. Elizabeth would remain on medication for another ten days until her symptoms/condition completely subsided.

Once home, due to my cerebral palsy, a condition I've had since birth, Child Protective Services (CPS) assigned a case worker to see how I was taking care of Elizabeth. I was not allowed to be alone with Elizabeth. So, when her father was not home, someone had to be in the house. During these times, I felt nervous as though the CPS

for my support team; they were also available as a much needed 'listening ear.' Eventually, CPS reduced the frequency of their visits and would come out to see how we were doing approximately once per week.

At two and a half years, Elizabeth went to live with her paternal grandmother, as her father and I no longer lived together. Her father was granted physical custody by a judge. CPS now visited both parents at our homes on a weekly basis to see how things were going. I had weekly visits with Elizabeth; however, I was still required to have another adult present. Things have continued under these circumstances, and Elizabeth is now eight years old and going into the fourth grade. I am working hard to be the best parent that I can, and I've recently begun to



When Professional Approaches in Human Services Can Harm or Help Mental Health Recovery: One Mother's Story

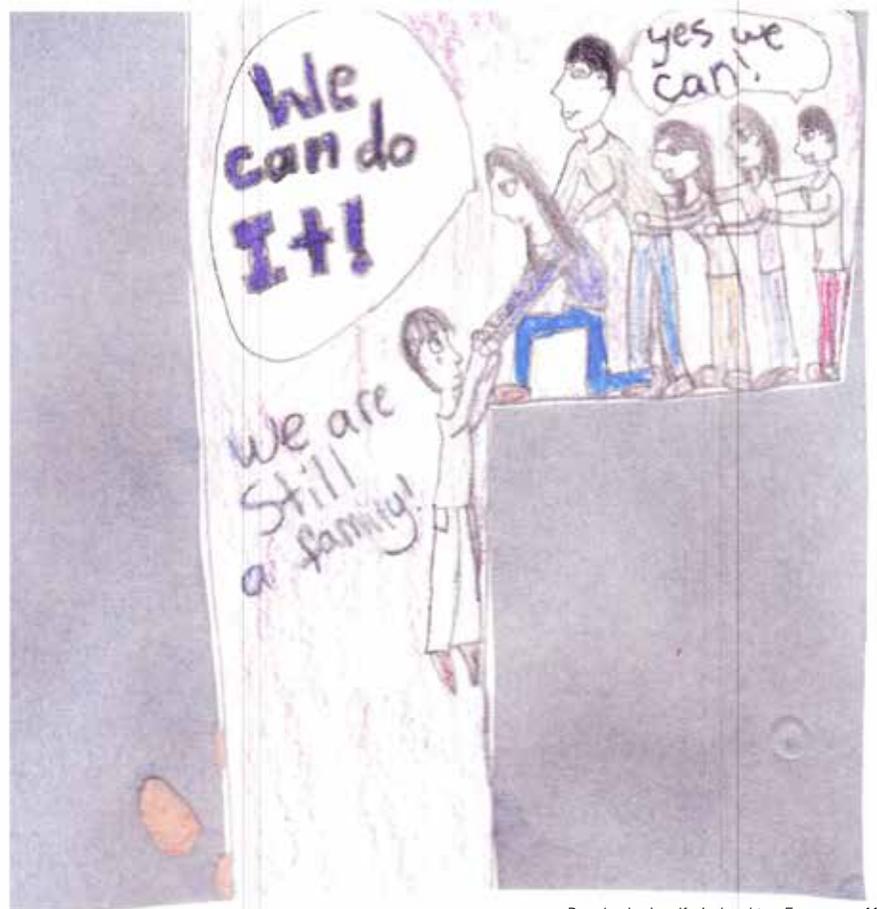
Jennifer Shea Thomas

I am a mother diagnosed with an anxiety disorder and post-traumatic stress disorder (PTSD). I was once told by a mental health clinician that it is not uncommon for mothers who raise children with disabilities to experience their own mental health difficulties because of the complicated and challenging responsibilities that can be involved in supporting their child's needs. I am one of these mothers.

My encounter with the child welfare system began in 2012 when I brought my then-11-year-old son to the ER. He was having ongoing thoughts to harm and kill others, including his siblings and me. My son has a long and complicated history of mental health symptoms that, when left without enough treatment and support, result in aggression towards himself and others. I knew I could not bring him home only to wait for his mental state to deteriorate further; that night I felt so alone knowing I was refusing to bring my son home if he did not meet hospital criteria for a mental health hold.

One of the challenges that parents face trying to navigate the mental health system for children like my son is that we don't always know what to expect from the different sources of services or how to communicate effectively with them. That night at the ER, the hospital assessor informed me that my son did not meet hospital criteria and that if I refused to bring him home, I could possibly have all four of my children removed from our family's home if I got Child Protective Services (CPS) involved. I was also told by the police officer who came to transport my son to the shelter that I had broken the law by "abandoning" my son at the hospital and that I could be taken that night to the police station. I fell apart. I contacted CPS myself. What could I do? By bringing him home, wasn't I knowingly placing all four of my children in a safety risk? To my surprise, the CPS contact validated my right to ask for the safety of all four of my children and said that CPS does not seek to take children from their home without well-founded reasoning.

So much of my anxiety and fears that night stemmed from not knowing what to do. There is uncertainty that comes from my son's symptoms, from not always being able to get the right help at the right time. There is uncertainty that comes about when I realize that daily life is getting more difficult to manage as our son gets older, and my husband and I are not always certain how we will afford his treatment and care needs over



Drawing by Jennifer's daughter, Emma, age 11.

time if services are not covered or available through the private health plan or public supports. There is uncertainty that comes when I realize that families like ours have sometimes been coerced towards custody relinquishment if adequate treatment and supports are not accessible, affordable, or agreed to by those who fund services.

Within the next 48 hours, my husband and I along with our three children at home and our son nearby at the crisis shelter were assessed by our county's CPS worker, who used a family-driven approach for the interview and assessment. She clearly communicated our rights to us as parents. Overall, her engagement with us during the experience put us at ease, and I remember her as an important person who helped our son at a crucial moment.

She concluded that we did not require a CPS file to be opened and was able to effectively advocate and secure a voluntary placement agreement for our son which would allow him access to treatment and services through Medical Assistance and our

county's Children's Mental Health (CMH) case management division.

The importance of coordinating care for a child like our son was evident. But an actual service that helped with that coordination of care between a private health plan, county services, medical assistance, and possible waived services was something we really didn't have available to us. While we had CMH case management services in the past, we discontinued these services due to such limitations and the high cost. At the time when our son's case was being shifted from CPS and back to the CMH agency, my son's mental health further deteriorated at the crisis shelter. This time, his symptoms were acute enough to warrant rehospitalization. The CMH case manager did not offer to develop a service plan or to work in partnership with my husband and me to actively assess and plan for our son's treatment needs. My husband and I knew something was amiss with the service as well as the communication, and I requested a complete copy of my son's county case file.

The file included a number of false, misleading, and unproductive comments about my husband and me written by one county case manager and two of his supervisors. The note-taking practices were highly subjective and, in a number of cases, unprofessional. I was documented by my son's case worker as 'controlling,' 'tends to triangulate,' and someone who 'didn't want her son home ever.' My husband was documented as a dad who 'did not like his son' and who 'isn't involved enough with his treatment.' I requested that the case manager be removed because of his bias against my

The mental health assessment was completed by a clinician who also was a parent of a child living with a complex mental health disorder. She was effective because she didn't rely on a clipboard of assessment questions but instead engaged me in a conversation to facilitate her understanding of my symptoms, challenges, and needs. I did not feel so alone, nor did I feel judged or criticized.

I left the hospital that evening with a diagnosis of post-traumatic stress disorder (PTSD). I was provided with helpful resources, a follow-up phone call from

me to come together with different agencies and service providers involved with my son's care who value working together in a partnership with our child, family, and one another.

As for my own mental health recovery, I have come to appreciate how challenging it can be to manage the internal symptoms of a mental health diagnosis while also needing to effectively engage the day at hand or the people nearby. It's not always easy. For now, I am bolstered by good friends and family, helpful mental health treatment for myself, playing an active role in children's mental health advocacy here in my county and state, and knowing that my son is getting needed treatment while our family continues to be a family, as it should be.

Jennifer Shea Thomas is a mother, spouse, and parent leader in her state and local community. She is a passionate contributor in the area of improved systems of care for children and youth with complex mental health conditions as well as for their families. She can be reached via email at Jennifer.Shea.Thomas@gmail.com.

I have come to appreciate how challenging it can be to manage the internal symptoms of a mental health diagnosis while also needing to effectively engage the day at hand or the people nearby.

husband and me. Though the leaders of the agency did eventually assign a new case manager, they failed to acknowledge whether the practices would change with the new case manager. This contributed to my own symptoms of heightened anxiety, growing sense of distrust, and a deeper sense of isolation engaging service providers within the mental health system. I realized that I had placed my trust in service providers who did not actively engage in open communication and collaboration with my husband and me. Instead, my son's case management services were being provided using an agency-driven, not family-driven approach.

The stress of these events did eventually spill over for me. I had watched my son's mental health deteriorate as he was moved from hospital to shelter not once but twice; it included watching him struggle in one of those hospitals as he was placed in 4-point restraints and given Haldol injections to the leg in response to his imminent risk of harm to himself and others. It included having no one to help us navigate the journey from the shelters to the hospitals and, eventually, transportation by ambulance to a third hospital nearly three hours away. It ended with my searching for a residential treatment program in the neighboring state of Wisconsin.

After visiting my son at the residential treatment program one afternoon, I experienced an impairing anxiety attack. I drove myself to a nearby ER. My anxiety significantly increased once I entered the ER assessment room. I remember being fearful to sit on the gurney. I was afraid to make eye contact with the hospital staff. My thoughts were racing, and I was afraid. I'd been in ER rooms many times for my son's mental health assessments. But this time it wasn't my son who was being assessed; it was me.

the nurse to see how I was doing, and an understanding that it was time for me to reach out for more help with my own mental health needs.

What has helped me along the way has been working with mental health professionals who seek to listen, understand, and strengthen our family system as a whole. It has helped me to meet case managers and supervisors who adhere to written and spoken communication practices that are objective, transparent with parents, and free from biases or subjective opinions. It has also helped for



Ghosts in the Nursery

Erica Harrigan-Orr

Almost three years ago, two child protective service workers came to my home. I wasn't surprised. At the time, I was off my medication for borderline personality disorder, not attending treatment regularly, fighting with my husband, and ending up in the psychiatric emergency room because of my tantrums. My daughters, ages two and four, must have been scared and confused.

Still, I could not understand the charges against me. I had never taken out my anger on my kids, and I felt that I provided them with the best care possible. They had a roof over their heads, food, clothes, diapers and toys, and I kept them up to date with appointments and services.

My husband and I both grew up in foster care. We didn't want our kids to fall into the same fate. From my first pregnancy on, I went to day treatment, took parenting classes, worked with a family support program, and got a homemaker to help me so that my children would not be at risk.

For two years, I was a steady mother. But now I see that when my daughter was diagnosed with autism, I started to fall apart. I feared that she would face the same pain as me: having to take medication, receive treatment and end up in a mental hospital.

My Daughter's Cries

When my daughter began working with a therapist at our home, I found it very painful. My daughter didn't like switching from one activity to another, which the therapist made her do. It was overwhelming to me to watch her get fussy, cry out of frustration, or try to fall asleep so she wouldn't have to learn.

Some days I am enraged by how the child welfare system treated my family and me. At the same time, I feel thankful for the knowledge I've obtained from attending services and for all the help I received.

Listening to my daughter cry reminded me of all the times that I was abused as a child and had no one to snatch me away from the pain. Many times I felt like snatching her up in the middle of the session to hug and kiss her, but that wouldn't help in the long run.

To deal with abuse as a child, I learned to leave the room mentally. When my daughter cried in therapy, I began to leave the room physically and mentally. I made myself busy during the day to avoid the sessions. Soon I was going out all the time. I didn't drink or do any drugs, but when I came home, I felt like a stranger in my own home.



Ashamed and Alone

The more distant I kept myself from my girls the more I started to feel useless as a mother. I saw Daddy soothing the baby, the homemaker taking care of important things like their hair, and the therapist giving my oldest the help she needed to develop. I started to think, "Where do I fit in?"

Thinking about my children's needs also reminded me that, when I was a child, I needed my mother and didn't have her. Playing with my children, I'd think, "I don't remember playing with toys as a little girl." I felt jealous of my kids, and I felt sad and overwhelmed to realize how many needs children really have.

I also feared that, because of my mental illness, my kids were only going to grow to be ashamed of me. I felt I was their burden and they'd be better off not getting to know me. No one knew how ugly and deformed I was seeing myself.

and I didn't realize that our kids would be emotionally affected by our feelings and actions. But looking back, I see that my older daughter was trying to break up those fights. Or, when I was missing in action (even mentally), my younger daughter was trying to bring me back by banging her head.

Imprisoned by my own painful experiences and numb to my children's needs and my own, I didn't show a connection to my girls beyond changing diapers, washing, dressing and feeding. My girls were acting up and acting strangely not only because of autism but also because they felt rejected and needed attention.

Growing Stronger Together

Some days I am enraged by how the child welfare system treated my family and me. At the same time, I feel thankful for the knowledge I've obtained from attending services and for all the help I received. These days, my older daughter is doing much better, and my youngest is no longer considered autistic. Some of their behavior was related to our instability at home and has calmed down.

Sometimes when we're playing I still feel like a scared, sad, jealous little girl. But I am getting better. The more that we keep playing, the more that I see my girls growing.

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Reprinted with permission from Rise, a magazine by and for parents affected by the child welfare system: <http://www.risemagazine.org>. To read Erica's updated story, visit this link: <http://z.umn.edu/harrigan>.

Seeing Myself

In the months after my family was investigated, the girls were removed twice. Each time they were taken for just a few days, but those separations were terrifying. Finally, a judge ordered an intensive set of services. For three years, my husband and I have been under court order to attend multiple support programs. What's helped the most was finding a therapist who really believed in me.

Now, things that were invisible to me have begun to make sense. I see that when child protection investigated, they saw that I was a devoted mother who loved her kids, but something was missing. My husband

Lost in a System That Didn't Exist

Sharon Bryant, MEd

“Sharon, what is happening? When are they going to stop? Sharon, why aren't we eating dinner? What are you going to do?” Those were words I heard from my siblings from the age of 5 until I was 9 years old. The first time I heard these words my siblings and I were hiding under the dining room table watching my father throw a cast iron frying pan at my mother; she retaliated by throwing an iron at him. I heard these words again a few years later when my father moved his girlfriend and her two children into our apartment just two days after my mother was admitted into the state hospital for treatment for her mental illness. Growing up with a mother who had a mental illness—schizophrenia

brother and me what we wanted to do, stay in foster care or return home. My brother was persuaded by my parents to return home and I chose to stay. Our foster parents wanted to fight for my brother to stay, but they were told by the social workers that if they let my brother go home, there was a better chance that my youngest brother and I could stay. After much deliberation the deal was finalized and my brother went home. My youngest brother was adopted, and I was allowed to stay in the foster home I had been in for the past four years.

When my siblings were sent home to live with my parents, there were no supports in place from social services. For my family

make sure that placement is appropriate and necessary. There are service plans that lay out goals for the parents, foster parents and social workers involved in the case. Counseling is offered to all the children along with the parents. In most cases, the goal of a service plan is to reunite the children with their parents within a specific amount of time, usually 12-18 months, not the 2-4 year time frame that my family encountered. Had this been in place when my family was involved with social services, we would have had a better chance of staying together as a family.

Advice to Workers

When working with foster children or children who have a mother or father with a mental illness, be sure to not only get the mother and father help but also the children because they are the ones that are impacted the most. When children are young, they believe that when things go wrong in their family that they somehow caused it or that they can cure it. Also, make sure the children get to play with other kids doing kid-like activities. Look at all the children and not just the ones who are acting out because sometimes the quietest one is the one that carries the heaviest burden.

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and bipolar—and a father who didn't have the coping skills to deal with her or us four kids had a tremendous effect on me. As the oldest of four children (at that time) all of the responsibilities that were my mother's became mine. I grew up very fast.

My three siblings and I went into our first foster home in 1969 when I was seven years old. At that time, foster care in the state I lived in was just coming into existence. The home that my siblings and I went to wasn't even a 'real' foster home but became one while we were there. After four months we returned home to our parents.

We entered care again in 1972. This time there were five of us. We were removed from our home because my mother's mental illness had progressed and she could no longer care for us. I had a two month old brother who was always sick. My uncle called the department of social services, and within a few days we were removed. Unlike the first time we went into care, we didn't all go to the same foster home. We were separated into pairs with the exception of my youngest brother who went alone.

After a few years in care, two of my siblings went home. The department of social services waited another two years before they came for me and my brother. A new social worker had been assigned to our family, and she realized that my two brothers and I hadn't gone home. The foster family that had my youngest brother wanted to adopt him, and the family that my brother and I were in wanted us to stay. Social services asked my

this became disastrous. My mother's mental illness had progressed further, and my parents split up. Two of my siblings stayed with my mother and my other sibling moved out with my father. Over time my family's situation deteriorated, and my siblings were raising themselves. My family fell through the cracks of a social services system that didn't exist. In the mid-1970s there were no checks and balances to make sure that the home my siblings returned to was a safe and stable environment.

Today, there are Foster Care Reviews who look at each case every six months to



Generational Support in Treatment Foster Care for Parents with Mental Illness

Crystal Peterson, MSSW, APSW

Stacia was born in a psychiatric facility on Thanksgiving Day. Her mother, a gifted seamstress and equestrian plagued with mental illness since her 20s, was inpatient again due to her debilitating symptoms. With a life of foster care ahead of her, Stacia would need the support of incredible people in her life in order to be successful. Thankfully she got it.

Mental illness in treatment foster care is as prevalent as anywhere else in child welfare. The generational impact is as intense, and the effects are just as distressing. Most of the children referred to Anu Family Services have a parent with some level of diagnosed mental illness with the severity ranging from mild to life debilitating. The impact of the parent's mental illness is profound for the children involved but also affords unique challenges for the foster parents. One family at Anu Family Services seems to have found the answers to working with the families who struggle with major mental illness.

Stacia came to the Phill and Mary Jo Klamm home at the age of 9. Like many foster youth, Stacia had disrupted from three other foster homes prior to landing at the Klamms'. She had the support of and a relationship with her maternal grandparents, but they were unable to take placement of her due to her behaviors. At this time, Stacia was already diagnosed with Reactive Attachment Disorder and Oppositional Defiant Disorder. Her behaviors were extreme due to the unstable and unpredictable situation in her mother's home where she lived from the age of 2-7. Stacia reflects on this time as incredibly painful and frightening, not knowing what kind of mood her mother would be in. One day she would gush over Stacia and express her thanks over such a gift on Thanksgiving. At other times she would yell and scream at Stacia for things she didn't understand. This resulted in extremely challenging, pain-based behaviors so common in children with a history of trauma, grief and loss. These behaviors came out in the safety of the foster home.

The Klamms' relationship with Diana (Stacia's mother) started early in her placement through contact during supervised visits. Mary Jo would encourage Stacia to interact with her mom and provide the safety net that Stacia needed in Diana's presence early on. This allowed Stacia to feel supported and safe without threatening Diana's bond with her daughter. The Klamms also continued to support and



build on the relationship between Stacia and her grandparents. When Stacia's behaviors became challenging or overwhelming, the Klamms would call the grandparents who could sometimes calm Stacia or just provide a sounding board for Mary Jo. Mary Jo would do the same for them when Stacia was in their home on visits.

returned from two weeks at summer camp with a full out hug for Mary Jo, and Mary Jo thought to herself, "it's working."

The Klamms supported Stacia's relationship with her maternal grandparents who flew her to Florida every year for Christmas and paid for her summer camp every summer. Mary Jo remembers that she

The Klamms researched mental illness and explained it to Stacia in ways that she could understand. They helped Stacia see the difference between her mother and her mother's illness.

The Klamms researched mental illness and explained it to Stacia in ways that she could understand. They helped Stacia know that her mother's illness was not her fault, was not intentional and was very real. They helped Stacia see the difference between her mother and her mother's illness. When Stacia and her mom would go shopping, Mary Jo supported mom's involvement and acknowledged mom's generosity.

Stacia remained in the Klamm home and continued to build on her relationship with her mother, the Klamms, and her grandparents which led to her eventual healing. This was a long road and not without its challenges. When she first came to the home, she would give a hug to the foster parents with a simple finger touch. When she was 11, she told her therapist that if the Klamms kept her for two years she would give up her trying behaviors because then she knew they were strong enough to protect her. When she turned about 12, Stacia's behaviors began to change after another child with Reactive Attachment Disorder was placed, providing a mirror to her own behaviors. She

was pressured by county workers to adopt Stacia, to which she replied, "Why would we punish Diana **more** by taking her kid away?" The Klamms committed to providing a home to Stacia for as long as she needed, and they stand by that commitment today.

Stacia graduated high school in 2010 with her mom, grandparents and the Klamms in the audience. She applied to and was accepted at a four-year University and has successfully completed her sophomore year. Stacia just returned "home" to the Klamms for the summer before traveling to her maternal grandparents' home for a short visit. She maintains contact with her mother whenever her mom is able. Stacia is a self-proclaimed "bug-hugger" and plans to be an environmental scientist when she graduates.

Phill and Mary Jo Klamm are treatment foster parents with Anu Family Services.

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Commentary on the Intersection of Child Welfare and Parents with Cognitive/Intellectual Disabilities

Anita P. Barbee, MSSW, PhD

After the deinstitutionalization in the 1960s, children and adults with intellectual and developmental disabilities (I/DD) were mainstreamed into society; however, the community-based support services to help former patients were never funded at adequate levels. Those with strong family support networks were able to successfully complete schooling and live and work to the best of their abilities, many quite independently. It is still true today that those who have no informal supports not only have difficulty thriving but have no protection from predators, such as criminals and domestic violence perpetrators, who take advantage of their disabilities. It is when these most vulnerable people with cognitive or emotional impairments become parents that the child welfare system is mobilized.

My first involvement in child welfare was in evaluating staff training. In that state, there was no mention of parental cognitive disabilities in any of the training delivered to staff and supervisors. When I later worked

intentioned. Many could have benefited from behaviorally oriented parenting programs, continual in-home services, and support related to the provision of basic needs in order to keep their children. It seemed cruel to me to wait to intervene in the lives of adults with pre-identified cognitive impairments until after they had their children and failed to keep them safe. I wondered why we as a society don't have services in place from high school on to help these individuals develop support networks, learn about child development, and gain parenting skills so that when they do have children they can care for them safely and keep their families together.

Given the implications of parents with cognitive/intellectual disabilities for child welfare agencies and society, I offer some recommendations:

- 1. Primary Prevention:** Efforts need to be targeted to students with I/DD in schools and foster care (and their parents) to help prepare these youth to better navigate adolescence and adulthood, particularly in



help one another in child rearing and living responsibilities, to preserve these families while keeping children safe; and c) partnerships between courts, child welfare agencies and provider agencies need to be formed to tackle the policy, practice, and treatment implications of working with parents with disabilities, so that the rights of parents with disabilities are preserved and evidence based and evidence informed programs are in place to maximize parenting success.

- 3. Training** in child welfare needs to include information about how to work with parents with disabilities. Trainings typically do not discuss the likelihood that parents with cognitive/intellectual disabilities will be encountered. Thus, there is little to no emphasis on confronting worker prejudice, acknowledgement of the special needs of this population of parents, nor information about the implications of the co-occurrence of this type of impairment with other problems such as mental illness or vulnerability to predators. Furthermore, the child welfare workforce needs training on how to best communicate with and engage these parents, how to assess and build social support networks, and to learn about the programs in existence to help parents with cognitive/intellectual impairment for strengthen parenting skills and avoid neglect.

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on a team serving medically fragile children in an urban child welfare office, I noticed that about half of the parents on the team's collective caseload had IQs near or under 70. Upon further inspection I found that an estimated 20% of child welfare cases across the office involved a parent who was low functioning or cognitively impaired who often had a maltreatment history, was lacking a strong network, and was paired with dangerous partners who could or did sexually or physically abuse the children. These numbers may vary from state to state and location to location but are present in all child welfare offices.

Unfortunately, the supervisor who headed this team was biased and not well versed in the evidence based parenting programs aimed at parents with I/DD and insisted that her staff place the children of parents with I/DD into foster care. Despite the hesitancy of courts to terminate parental rights, that was the ultimate outcome of most of these cases. Each TPR was heart-wrenching given the fact that most of these parents were well-

the area of human sexuality, to keep them safe from rape, dating/domestic violence, unwanted pregnancy, and being exploited through human trafficking. While these children and youth have rights once they turn 18 and become legal adults, there should be more safeguards and protections in place to keep them safe and to help them navigate parenthood when that time in their lives arrives.

- 2. Secondary Prevention:** When young adults with I/DD do become parents, a) they should have the right to receive in-home services, like the *Healthy Start* program, for an extended period of time, in order to enhance their health and parenting and to prevent child abuse and neglect; b) alternately, it might be helpful to develop a nationwide network of communal living communities that include a mix of disabled and nondisabled parents with varying levels of skills to develop 'natural informal supports' to ensure that parents with limited personal support networks live in a type of "assisted living" community so as to

Understanding and Supporting Parents with Cognitive Limitations

Continued from page 12

Practice Points and Reflections on the Social Worker's Role

Social services are meant to support families, including those headed by parents with CI. Social workers are at the core of interventions for these families. Their objectiveness is thus important as their judgment will often orient recommendations. We do know from research that more experienced workers or those with higher education will assess families as having fewer risk factors than less experienced workers and will close youth protection files sooner. This informs us to the need for training, continued education, research-based knowledge transfer, and support from our supervisors and managers. Practice that is underpinned by a theoretical model, such as Feldman's parenting model, can reduce bias and decrease the likelihood that personal values and assumptions guide the assessment and interventions process.

Systemic and micro level interventions are needed to tackle the over-representation of parents with CI in the child welfare system. Creating national and international initiatives, such as Healthy Start in Australia (Healthy Start, 2010), would allow for the dissemination of best practices. This could also include training and collaboration with child welfare, lawyers and judges. It could help dismantle prejudicial assumptions and replace them with empirical evidence.

Parents with CI can parent. They may require support and reasonable accommodations, but they can parent and raise beautiful and healthy children. The reality is that we all have parenting deficits in one way or another (McConnell, 2012) and that all children will outwit their parents at some point. Parents with CI and their children are no different. If we all agree that the protection of children is everyone's responsibility, just as strengthening families is a goal to be achieved by all in collaboration, the system would then probably become more open to changes and expand partnerships that would impact these families for the better.

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Family Teaming to Enhance Engagement and Opportunity for More Families in Child Welfare

Continued from page 22

parent and family network. Interviews by program evaluators over six years with nearly 500 team participants described a variety of benefits. Over 90% felt included in shared decision-making and that the meetings met their expectations and offered opportunities to present their point of view. Two-thirds of cases involved at least one reconnection or improvement in a past relationship, and about three-quarters of cases involved creating a new "family-like" relationship. Because smaller personal meetings among team members occur between large meetings, two-thirds felt relationships improved. In fact, developing new relationships was twice as likely when the full team was assembled, and twenty times as likely when family finding was used.

Even though the evidence base for family teaming with these families is limited, an intuitive appeal drives scaling up of family teaming. The *United Nations Convention on the Rights of Persons with Disabilities* advocated for dignity, participation and inclusion, respect for difference, and equality of opportunity for people with disabilities (National Council on Disability, 2012). These same principles drive teaming practices in child welfare: engagement around parent strengths, preparation of team members, facilitated meeting participation, and tailored work in small groups.

The principles that underlie teaming practices aid not only in the achievement of case goals but in the empowerment of families through engagement, structured decision-making, member preparation, contingency planning, and recognition of strengths/assets.

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Common (Higher) Ground: What Social Workers and Parents' Attorneys Can Do to Maximize Justice for Parents with Disabilities and Their Children

Continued from page 27

must prioritize funding of qualified experts for evaluation, assessment, and parent-child intervention for parents with disabilities to counter the poor quality typical of non-accommodated services. They must also request collaboration from local Protection and Advocacy (P & A) agencies (P & A is a federally funded legal services program tasked with providing legal representation in certain cases involving disability rights).

Lack of expertise. Neither law students nor social welfare students receive adequate training on the intersection of the ADA and state child welfare law. This is extremely troubling; lack of access to appropriate services—which will continue unless professionals are educated to work with this population—is a significant indicator of poor outcomes for other disparately impacted communities (DePanflis & Girvin, 2005). Even disability studies programs ignore this topic: Of the 33 programs in the U.S. only three have any course specific to parenting *or even touching on the subject* (Callow & Miller, 2013).

Attorneys and social workers must recognize their *own* lack of training in working with these families. TNC has collections of case law and journal articles, materials on practice and policy, and links to other relevant disability organizations—all available via a phone call or email.

In the short-term, self-education, collaboration, and prioritization of quality services and experts will help address systemic barriers in daily practice. In the long term we must change the laws that underpin practice and replace speculation with evidence generated via well-designed services and well-trained professionals. Only then can we say we are truly responding adequately "to those at the bottom and the margins of the social order."

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Agency Discussion Guide

The Agency Discussion Guide is designed to help busy supervisors and managers initiate conversations with others to encourage thoughtful discussion about the information presented in this issue.

Conversation between Supervisor & Worker

1. Several of the articles in this issue emphasize the importance of the assessment process. Kaplan and Fier state that more than one assessment meeting may be necessary for parents with mental illness and/or cognitive limitations. Bernard and O'Hara urge assessors to consider environmental factors in order to develop a more comprehensive assessment. Thinking about our agency's current parenting assessment processes, what do we do right now that considers the needs of parents with disabilities and/or mental illness? Which, if any, modifications are necessary in order to ensure fair assessments for parents with disabilities and/or mental illness? See also Aunos & Pacheco, Azar, Feldman, and Sweetland.
2. How have you encouraged the use of parental supports—formal and informal—for parents with disabilities and/or mental illness? What are some examples of such supports? See Lightfoot & LaLiberte, Feldman, Barbee, and Abderholden.
3. Consider the recommendations for states and child welfare agencies from the *Rocking the Cradle* report as highlighted by Powell. For example, one of the recommendations called for the "development and implementation of mechanisms that support integrated, family-centered, strengths-based care for parents with disabilities and their children." Another would mandate training for dependency court professionals on parenting with a disability. How feasible do you think it would be to implement some of these recommendations at our agency?
4. Molly Saunders wrote about her experiences with the child welfare system as a new parent with a physical disability. Molly faced some considerable challenges while trying to parent her infant daughter, and her experiences with her child protection worker were not always welcome. How could Molly's CPS worker have helped Molly through some of the barriers she encountered while parenting? What are your thoughts about the recommendations Molly provided for CPS workers?
5. Cross-systems collaboration is essential in human services in order to provide the best possible outcomes for individuals needing services from multiple systems. What collaborative practice strategies could you (or do you) utilize in order to provide the most effective services to parents with disabilities and/or mental illness? How can you overcome challenges to working across systems? See Stevens, Thomas, and Fier.

Conversation between Manager & Supervisor

1. McConnell, Aunos & Pacheco, and Barbee stress the need for training and continuing professional education in order to prevent bias and assumptions from leading assessments and interventions. Many social work programs nationwide do not explicitly train future social workers on working with parents with disabilities and/or mental illness. How can we incorporate such training into our staff trainings? Furthermore, how can we encourage workers in our agency to attend professional development opportunities related to working with parents with disabilities and/or mental illness? See also Spencer and Callow.
2. A rights-based approach to working with parents with disabilities and/or mental illness includes assistance with parenting duties. Yet federal funding for individuals with disabilities is generally geared towards services that assist with daily living tasks, which do not always include parenting activities. What can we do to help parents with disabilities access parenting services when there are financial barriers to doing so? See Lightfoot & LaLiberte.
3. Which practices, if any, are we utilizing at our agency that are effective in working with parents with disabilities and/or mental illness? Consider the possibility of adopting some of the practices mentioned in this issue, e.g. Feldman's model of universal design and behavioral education, Yuan's Peer Navigator program, Kerman's examples of family group conferencing, and Fier's Parent Support Project. What is the likelihood of a successful introduction of such programs or practices? What are some barriers? Solutions?

Resources

Specific to Parents with Disabilities in Child Welfare

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), American Psychiatric Association. Available from <http://www.appi.org/Pages/DSM.aspx>

Guide for Creating Legislative Change: Disability Status in Termination of Parental Rights and Other Child Custody Statutes, University of Minnesota—<http://z.umn.edu/legchg>

Intellectual Disability and Mental Health: A Training Manual in Dual Diagnosis, S. McGilvery & D. Sweetland. Available from <http://www.dmid.org/>

Journal of Public Child Welfare special issue on Disabilities and Child Welfare, in press (due out 2013).

Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children, National Council on Disability—<http://z.umn.edu/ncdreport>

Services for parents with disabilities, Child Welfare Information Gateway—<http://z.umn.edu/cwinfodis>

United Nations Convention on the Rights of Persons with Disabilities. View at <http://z.umn.edu/crpd>

Select International Organizations

- The Centre for Disability Studies (Iceland): <http://fotlunarfraedi.hi.is/en/english>
- DisabilityCare Australia: <http://www.disabilitycareaustralia.gov.au/>
- Donald Beasley Institute (New Zealand): <http://donaldbeasley.org.nz/>
- Family and Disability Studies Initiative, University of Alberta (Canada): <http://www.fdsa.ualberta.ca/>
- Healthy Start (Australia): <http://www.healthystart.net.au/>
- Norah Fry Research Centre (UK): <http://www.bristol.ac.uk/norahfry/>
- Parent's Project Intellectual Disability Rights Service (Australia): <http://www.idrs.org.au/>

Select National Organizations

- American Association on Intellectual and Developmental Disabilities: <http://www.aaidd.org/>
- The Arc: <http://www.thearc.org/>
- The Association for Successful Parenting: <http://www.achancetoparent.net/>
- The Legal Program of the National Center for Parents with Disabilities: <http://pwd-legalprogram.org/>
- National Council on Disability: <http://www.ncd.gov/>
- National Alliance on Mental Illness (NAMI): <http://www.nami.org/>
- Through the Looking Glass: <http://www.lookingglass.org/>

Select Minnesota Statewide Organizations

- The Arc of Minnesota: <http://www.thearcofminnesota.org/>
- Disability Child Welfare Collaborative: <http://z.umn.edu/dcwc>
- Institute on Community Integration: <http://www.ici.umn.edu/>
- Minnesota State Council on Disability: <http://www.disability.state.mn.us/?agency=MSCOD>
- Minnesota Statewide Independent Living Council: <http://www.mnsilc.org/>
- NAMI-MN: <http://www.namihelps.org/>
- Opportunity Partners – Parent-Family Network: <http://opportunities.org/individuals-families/parent-family-network/>

About CW360°

Child Welfare 360° (CW360°) is an annual publication that provides communities, child welfare professionals, and other human service professionals comprehensive information on the latest research, policies and practices in a key area affecting child well-being today. The publication uses a multidisciplinary approach for its robust examination of an important issue in child welfare practice and invites articles from key stakeholders, including families, caregivers, service providers, a broad array of child welfare professionals (including educators, legal professionals, medical professionals and others), and researchers. Social issues are not one dimensional and cannot be addressed from a single vantage point. We hope that reading CW360° enhances the delivery of child welfare services across the country while working towards safety, permanency and well-being for all children and families being served.

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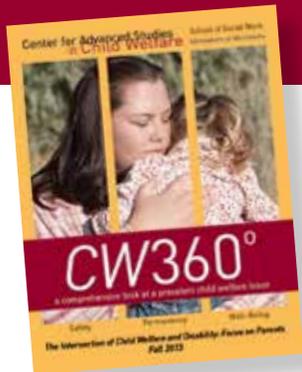


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In This Issue of CW360^o

- An overview of the disproportionate number of parents with disabilities and mental illness in the child welfare system and the impact of historical policies
- The influence of the Americans with Disabilities Act and the Adoption and Safe Families Act on parents with cognitive impairments in child welfare proceedings
- How bias and pre-conceived notions affect court outcomes and family preservation efforts for parents with disabilities
- Child welfare practice tips and strategies for working with parents with disabilities that encourage collaboration across systems and promote strengths-based assessments and evaluations
- The importance of modifying diagnostic assessments for parents with cognitive disabilities who may have mental health needs
- Perspectives from parents with disabilities and mental illness who are or were involved in the child welfare system

CW360^o

a comprehensive look at a prevalent child welfare issue

Feature Issue: : The Intersection of Child Welfare and Disability: Focus on Parents, Fall 2013

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