

Supporting Children with Parents Have Cognitive Challenges

Needs Assessment Results from Specialized Clinics in Utah

Catherine M. Haarstad

April 27th, 2007

Abstract

The results of a needs assessment are presented and resources that may be useful in supporting parents with cognitive challenges are discussed. The process used to develop and implement the needs assessment tool is described. Critical issues and practical challenges associated with efforts to measure and address the support needs of clinic staff are discussed.

Introduction

Parenting is one of the most challenging tasks attempted by men and women. Most adults receive little/no formal training in child-raising prior to becoming parents. Much of what we do know about parenting we learn on-the-job, by observing and imitating other families including our own. Raising a child often requires families to participate in periodic meetings with healthcare professionals to exchange information and plan. These activities may include informal and formal visits with physicians, nurses, pharmacists, therapists and other healthcare professionals as well as receptionists and lab technicians. If a child has a disability, then parents are also expected to share information about their child's unique needs as well as his or her response to treatment and preferences for healthcare.

Parents with intellectual and other cognitive challenges face unique challenges in raising and caring for their children (Haarstad, 2005). This is especially true when those children have complex healthcare needs. Access to healthcare is a critical component of successful parenting. Because of children's need for adult protection and guidance, their health and development depend greatly on their families' health and socioeconomic status (Kastner, 2004). Although not all children born to parents with intellectual challenges have disabilities or chronic healthcare needs, when they do, their parents may have extraordinary difficulty in managing and coordinating care.

Parents of children with special healthcare needs may themselves have an array of cognitive and intellectual challenges. These can include limitations in problem-solving that are sometimes associated with developmental and learning disabilities, traumatic brain injury, fetal alcohol syndrome, emotional or behavioral challenges or substance abuse. Related cognitive limitations may include difficulties with literacy, memory, judgment, organization, reasoning and problem solving (Tymchuk, 2006). These problems may negatively impact a parent's ability to remember or get to appointments on time, stay focused during long conversations, comprehend abstract medical jargon or concepts, participate in complex decision making, demonstrate effective parenting skills, organize family routines to administer medications as prescribed or follow through with related therapies or health activities.

The number of parents with cognitive limitations whose children are seen at specialized clinics is unknown. However, emerging data sources suggest that the prevalence of families in which parents have cognitive disabilities may be higher than previously suspected and a significant risk factor in family disintegration (Tymchuck, 2006). The World Health Organization (2001) estimates that twenty-five percent of adults in developed countries have

some type of mental or behavioral disorder. Other national experts (Welner, 2003) place the national estimate of those having an IQ <75 at 5.5%. This estimate does not include those parents with IQs >75 who may have difficulty with participation due to learning disabilities, mental health or substance abuse challenges. Keltner and Tymchuk (1992) have estimated that at least 120,000 babies are born each year to mothers with cognitive disabilities. Lightfoot and LaLiberte (2004) report that children with disabilities are an extraordinarily large percentage of the total number of children being served by child welfare agencies (Wescott & Jones, 1999), and there are increasing numbers of children whose parents have a cognitive disability (Booth & Booth, 1998; Muenzer-Doy & Anderson, 1998).

Parents with cognitive disabilities often experience social stigma related to having been in special education in school and frequently attempt to hide any limitations by smiling and nodding or preferring to appear incompetent rather than “disabled.” Clinic staff may be unaware of underlying disabilities or may be unsure of how to support parents. They may be faced with situations in which they must evaluate a parent’s competency to raise and care for a child, provide extra support for giving medications or carefully assess a families support needs.

Multidisciplinary clinics are designed to serve diverse families and respond to an array of conditions that complicate the lives of children. What happens in a clinic when the parents of a child with special needs also have learning challenges? Are specialized clinics prepared when the parents of a child have difficulties with problem solving that are not related to being an English language learner? Do the healthcare professionals at specialty clinics have the resources and tools they need to modify treatment strategies or communicate successfully with parents who have intellectual or cognitive disabilities?

To address these questions, a simple needs assessment survey was developed and conducted at five multi-disciplinary clinics in Utah. This needs assessment was implemented as part of a leadership training project through the Utah Leadership in Education in Neurodevelopmental Disorders or URLEND program at Utah State University. While the scope and formation of the project were not designed to make a substantive contribution to the literature, it was hoped that the project could be a first step in identifying general issues that may be examined more thoroughly in subsequent research.

Underlying Assumptions

Two primary assumptions underlie this research project. First, it was assumed that most specialty clinics take on greater responsibility than serving the individual children that are brought to the clinic for treatment. It was thought that clinic staff would recognize the need to collaborate with and support parents as agents whose primary responsibility would be to carry out complex treatment plans at home and in the community. Second, it was hoped that the majority of clinics included in the survey would have some previous experience with special needs parents. Since the extent of each participant’s general experiences was unknown, the survey design was modified to include background information and raise awareness as to how intellectual challenges might impact treatment.

Survey Design and Implementation

Three basic approaches were used to design and conduct the needs assessment. First, a comprehensive review of the literature was conducted prior to developing the needs assessment. Although numerous articles describing the characteristics of parents with cognitive limitations were found, and several curricula for supporting parents were available, data on the specific support needs of clinics serving children with special healthcare needs whose parents also had cognitive limitations were not available in the literature. Studies of the healthcare needs of adults with developmental disabilities who live in group homes have been conducted by Levy et al. Although these samples are described as representing a diverse and complex group in terms of functioning, behavioral and medical conditions, few are parents of children with disabilities. The skills needed to support such parents in clinical settings have not been identified.

Next, the idea of conducting a needs assessment was discussed with several ULEND staff aligned with important clinics in Utah. A two- part proposal for designing and implementing a needs assessment was submitted to the Institutional Review Board at Utah State University and subsequently approved. A focus group was held with interested clinic staff and LEND trainees in December of 2006. The purpose of the focus group was to identify parameters for development of the assessment tool and the approach used to engage clinics in the needs assessment. Several recommendations emerged from this session. Participants stressed the need to provide clinic staff with general information about parents with cognitive limitations within the survey instrument. Several clinical staff members believed that clinics might not see serving families as their primary responsibility. Before asking participants for feedback about this population it would be necessary to highlight the connection between the target population and clinical missions and treatment protocols. The group discussed using an online survey tool to enhance the ease of participation. Several formats incorporating both closed and open ended questions as well as typical scenario situations that may take place in specialty clinics were suggested. Finally, participants suggested a value-added component for interested clinics in which the LEND trainee would offer to meet with staff from at least one clinic in a face-to-face follow-up session to explore responses and training needs.

Following this focus group, a draft survey was developed. Information about parents with cognitive limitations was included in the survey to address issues raised by focus group participants. Closed and open ended items were selected to address diverse perspectives among those who might respond. The draft survey was shared with several LEND faculty as well as research consultants at the North Dakota Center for Persons with Disabilities at Minot State University. Revisions were made to the survey which was then placed in a survey monkey format. Changes were sent to the IRB at Utah State and final approval to conduct the assessment was obtained.

Participants for the needs assessment were recruited by email and through personal contacts made during a week long visit to clinics at the University of Utah and Utah State University. Additional participants were recruited through the Children's Special Healthcare Needs program in ND. The survey was opened on March 1, 2007 and closed on April 5th, 2007. Participants were offered the opportunity to visit with the LEND trainee on a face-to-face basis but no participating clinics or individuals expressed a desire to do so.

Survey Results and Analysis

Research Question: Research questions that we hope to answer include:

1. How aware are clinic staff members of the needs of parents with cognitive limitations?
2. What resources would clinic staff find helpful when serving families in which parents have cognitive limitations?
 - a. How important is this topic to staff?
 - b. What challenges do they encounter
 - c. What resources (information, training, tools) are already available to staff?

What other information/resources do they need?

Generic Information: This series of questions established information about who responded to the survey, the clinic at which they worked, the date of their response and the role and gender of each respondent.

Twenty clinicians responded to the online survey. All were from Utah. The clinics represented included the Children with Special Healthcare Needs clinic, the Child Development Clinic, the Hearing, Speech & Vision Clinic, the ABLE Clinic and the Neonatal Follow-up Clinic. Although their clinical role was selected by each respondent that data is not being reported to avoid identification of specific responses. The following kinds of clinical roles were identified:

Administrator	2	15.4%
Physician	3	23.1%
Nurse	2	15.4%
Speech Therapist	1	7.7%
Physical therapist	2	14.3%
Health worker	2	15.4%
Other	2	15.4%

Seventy percent of respondents were female and 30 percent were male. Gender appeared to have no significant impact on findings. A simple trend analysis was conducted to identify response patterns that might be meaningful. A statistical analysis of findings was not completed given the limited number of respondents. The significance of the findings is limited and should be interpreted with caution. The benefit of the findings are best used to engage clinic staff in considering next steps to enhance understanding of and preparedness for supporting children when parents have learning challenges.

Perspective and mission: This series of questions identified general experience with the target population, provided background information on the relationship between learning challenges and clinical treatment and was designed to assess initial questions and perceptions that clinical staff might hold.

The first interesting result of the survey was that 100% of the respondents, after being given a general description of parents with cognitive limitations, no matter what their role at the clinic might be, indicated that they had encountered parents with cognitive limitations in their work at the clinic (Q = Have you ever observed a parent with cognitive limitations at the clinic?).

Respondents were asked to estimate the percentage of the patients seen at the clinic whose parents may have cognitive limitations using a rating scale from none to greater than two-thirds. Ninety two percent of the respondents selected the 'less than 1/3' rating while another 7 percent selected the 'none/rare category'.

Respondents were asked to identify 3 questions they had about parents with cognitive limitations. A complete listing of the question is attached at the end of the report. An analysis of responses showed that respondents had these seven types of questions:

1. What **capabilities** do these parents have and how can that be accurately determined?
2. How do I **assess parent need** for information and support?
3. What is the best way to **communicate** and assure understanding of my treatment plan?
4. How do I help these parents **connect** to a support network?
5. How do I help parents **coordinate** services?
6. Given the cognitive challenges, what is the **impact on the child** outside of the clinic?
7. How do I treat these parents with **dignity and respect**?

By rating each question into one of these seven categories, it is possible to show a pattern of interest or information seeking that while not statistically significant, may be helpful in prioritizing information and training for a clinic. Most questions were about finding accurate ways to determine what the parents understand (Q = 1), finding the best way to share information and assure parent understanding of a treatment plan (Q = 3) and learning about the impact of the cognitive limitation on parenting or caring for a child outside of the clinic setting (Q = 6). Participants asked five variations of each of these three questions. The remaining questions in order of frequency asked were about helping parents connect to a support network (Q =4) with four questions, and only two question asked about what it was that parents needed (Q = 2) and the best ways to help parents coordinate services (Q = 5). Only one respondent asked about how to respond to the family in a respectful manner (Q = 7). This preliminary data suggests that clinic staff see their role as effectively communicating treatment plans and assuring child well-being using strategies that are a match for what parents know or understand. A secondary role involves linking people with available support networks and helping parents coordinate services. Understanding what parents need (versus knowing what they understand) and deciding how to provide respectful services are less likely to be asked but may be equally important questions from a parent's perspective.

The next series of questions were scenario based. Scenario one presented an opportunity to consider the clinic's role in providing early intervention for a parent with cognitive limitations who struggled with the care of a young baby. Scenario two presented an opportunity to consider

the clinic's role in responding to a parent with cognitive limitations who was confused in following a plan for medication administration for his school aged child. Responses indicated that 58% of the respondents to scenario one and 65% of the respondents to scenario two had encountered similar experiences in their clinics. A trend analysis showed the following patterns of responses in order of frequency.

Scenario One:

1. The most frequent response involved referral to a service agency for follow-up support of some kind. Respondents described various referrals to early intervention, nutritionists, psychological services, social workers, public health nurses or family advocacy groups. The underlying assumption behind the referral seemed to be that the service agency could become involved either in providing in-home support or in a conversation about what could be provided in the home community.
2. The second most frequent responses involved assessing the child's health status and treating the underlying health problem although how this was to be done with a parent who could not implement a treatment plan was unclear.
3. The third most frequent response involved making efforts to gain the parent's trust, finding out about which procedures she preferred and asking her what might work. Usually the same respondents tried to think of a way to educate the parent through conversation.

Scenario Two:

1. The most frequent response involved referral to a service agency for follow-up support of some kind. Two respondents described general and very specific ways that pharmacists could become involved. Others again stated they would refer the family on to the human service network of early intervention, social work, psychologists etc.
2. Two respondents indicated a need to build an individual team of helpers using clinic staff and by working with other agencies and by assessing what the parent could do and teaching him how to administer the medication and complete forms.

Both of these scenarios present complex situations that are typical in some but not all general and specialty clinics. Some respondents simply begged the question by stating they did not serve children of a certain age. Referral to an outside specialist to conduct follow-up may assume that the specialist is trained to support parents with cognitive limitations, that best practice interventions involving in-home support are available and that the parent would be able to coordinate with an array of support specialists. It is difficult from the responses to know exactly what is in each clinician's mind. Many parents with cognitive limitations have difficulty working with multiple service agencies. A pharmacist may be skilled in demonstrating how to provide an injection or give a certain dosage but may not be able to determine what the parent will remember afterwards at home. None of the respondents raised questions about the parent's ability to care for a child with special needs on an ongoing basis. The social support network of mandated reporters for neglect is frequently called on as are

some physicians to make that assessment for the courts or in response to repetitive scenarios in which parent confusion or skill deficits place children at continuous risk. None of the respondents described how they would assess the adequacy of the support network. When respondents were asked if they had the information and skills to respond to these types of scenarios; 60% believed they did and 40% indicated they did not know.

Respondents were asked what other information would be helpful in responding to these types of scenarios. The responses indicated that the following kinds of information would be most helpful.

1. Finding out what outside supports are available
2. Deciding how best to assure frequent checks or follow-up with the family
3. Learning more about the families natural support network

Resources and Tools:

The final series of questions presented respondents with a list of resources and tools that might be of interest to clinics when children have parents with cognitive limitations. Each tool was named and briefly (1-2 sentences) described. Respondents were asked to rate their interest in the tool as no/low interest, some interest or high interest. Only 8 of 20 respondents replied to these items on the survey. A listing of each item and the interest rating is attached. The 4 items of highest interest were: 1) A picture planning tool to help parents learn about or discuss child development and health (75% of respondents), 2) A visual prescription that uses icons/checklists to help at-risk parents give medications correctly (62% of respondents), 3) Task analysis that staff can use to give PWCL step by step training or instructions (62% of respondents), and 4) A pictorial guide that staff can use to explain risk and obtain consent from PWCL (62% of respondents).

This data indicates that slightly under half of the respondents had no interest in any additional tools or resources or they simply didn't want to take the time to respond to that type of question for unknown reasons. Of the respondents who indicated interest, explaining child develop and health conditions took precedent over having a visual prescription and other risk assessments or task analysis tools. Comprehensive curricula or tools to assess parent skills and knowledge were not given as high an interest rating even though previous questions addressed those areas.

Summary:

Specialty clinics report that less than 1/3 of the children they serve in the clinic setting may have parents with intellectual or cognitive limitations. All clinics encounter these parents during their practices. Interdisciplinary clinics see their role as effectively communicating treatment plans and assuring child well-being using strategies that are a match for what parents know or understand. About 40% of the clinic staff who responded indicated that they did not have the tools and resources needed to serve children whose parents may have cognitive

limitations. The majority of clinic staff who responded to the survey refer parents with cognitive limitations to other support partners. The extent to which these support partners are prepared to address the families' unique needs is unknown but is likely to be limited. Those participants who are seeking other information and are most interested in resources are interested in tools and resources that they can use to help parents. Priorities include resources to help practitioners teach parents about child development and health, show families how to administer medication safely, provide step-by-step training and instruction and explain risk and obtain consent. An outline of curricula that address these and other related topics is enclosed. A comparison of data from the open ended questions and scenario based responses indicates that communicating clearly with parents who have cognitive limitations is the primary concern expressed by participating clinical staff members.

Bibliography

- Booth, T., & Booth, W. (1998). The Adult Children of Parents with Learning Difficulties. *Impact*, 11, 18-19.
- Haarstad, C., (2005). Supporting families when parents have intellectual disabilities: a curriculum, North Dakota Center for Persons with Disabilities at Minot State University.
- Kastner, T.A., (2004). Managed care and children with special healthcare needs. Committee on children with disabilities. *Pediatrics* 114: 1693-1698.
- Keltner, B.R., & Tymchuk, A.J., 1992. Reaching out to mothers with mental retardation. *The American journal of maternal child nursing*. May-Jun;17(3):136-40.
- Lightfoot, E. & LaLiberte, T. (2004). Increasing disability competence in child protection professionals: a curriculum module. Center for Advanced Studies in Child Welfare, School of Social Work, University of Minnesota website:
<http://ssw.che.umn.edu/cascw.html>
- Muenzer-Day, D., & Anderson, L. (1998). Supporting parents and children during termination of parental rights. *Impact*, 11(1).
- Tymchuk, A. J. (2006). The health and wellness program: a parenting curriculum for families at risk. Paul H. Brookes Publishing Company. Baltimore, Maryland. 21285-0624
- Welner, M., 2003. Testimony before Texas state house of representatives; committee on criminal jurisprudence [Re: HB 614] Chairman of The Forensic Panel on April 8, 2003
- Westcott, H. L., & Jones, D. P. (1999). The abuse of disabled children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 40, 497–506.
- World Health Organization (2001), Mental and neurological disorders fact sheet Fact sheet N°265 retrieved on 11-04-06 at <http://www.who.int/mediacentre/factsheets/fs265/en/>
- Levy, J. M., Botuck, S. B., Damiani, M.R., Levy, P. H., Dern, T.A., & Freeman, S.E., (2006) Medical conditions and healthcare utilization among adults with intellectual disabilities living in group homes in New York city. *Journal of Policy and Practice in Intellectual Disabilities*. Volume 3 Issue 3 Page 195.

Questions Asked by Multi-disciplinary Clinic Personnel

Question One:

1. Is written material of any benefit?
2. Can they read?
3. Are they able to provide structure and support to their child's needs?
4. What is shown to be the best means of communication with PWCL?
5. How to successfully help a parent to access other resources
6. How do I truly verify that the parent understood instructions?
7. timely follow-up speech
8. How do you determine stress, worry from cognitive limitations?
9. Do they fully understand behavior terminology that I use?

Question 2

1. What types of supports are the most helpful?
2. If not what is the best way to give information to the parents?
3. Are they going to be able to manage medication?
4. What are the best means identified to assist PWCL to attend follow-up appointments?
5. How to successfully help a parent follow a home program for their child's specific needs
6. How can I encourage information from the poor historian?
7. Understanding the importance of follow up
8. Can't cognitive limitations appear as other issues, i.e., anxiety, stress?
9. Do they have social support outside of our clinic?

Question 3

1. Do these children of PWCL receive a different level of care?
2. Are there services available to help them?
3. Are they going to be able to stimulate their child recreationally and keep them engaged in activities that they enjoy?
4. Is there a resource in our community to help these PWCL coordinate their care or act as a resource for these families to ask questions they may have?
5. How to know with better certainty if a parent understands instructions given to them
6. What is the appropriate grade level at which instructions/handouts should be written?
7. How does one avoid inappropriate stigmatizing or stereotyping?
8. Do they understand effective discipline strategies?

Curricula for Supporting Parents with Cognitive Limitations

Title	Authors/Type	Publishing Information
Building Foundations – A Curriculum Guide for Supported Parenting	Bridget McCusker & Bernadette Irwin <ul style="list-style-type: none"> • Principles & Best Practices • Instructional Strategies • Core Areas & Resources • Manual with handouts 	Training Products Division Kennedy Krieger Institutue 7000 Tudsbury Road Baltimore, MD 21244 410-298-9286 www.kennedykrieger.org \$69.95
Supporting Families When Parents Have Intellectual Disabilities	Cathy Haarstad, MS <ul style="list-style-type: none"> • Beliefs • Assessment • Planning • Implementation Manual with handouts CD with Power Point training modules including practica activities & quizzes	ND Center for Persons with Disabilities 500 University Avenue W. Minot, ND 58707 701-858-3230 www.ndcpd.org cathy.haarstad@minotstateu.edu
“Working with Families with Children/Parents with Development Disabilities.”	Natasha Green, B.A. and Virginia Cruz, D.S.W., <ul style="list-style-type: none"> • training curriculum for child welfare workers and other helping professionals • Modules, videos, handouts 	The Social Work Program Metropolitan State College of Denver, P.O. Box 173362, Campus Box 70, Denver, Colorado 80217. (303) 556-4464 www.developmentaldisability.org/
HELP When the Parent has Disabilities	Stephanie Parks, M.A. <ul style="list-style-type: none"> • Activities and training techniques for directly involving parents with cognitive, sensory & physical limitations • Cross-referenced to the HELP skills (ages birth-2 years), • Offers special adaptations for parent training and involvement. 	VORT Corporation P.O. Box 60132 Palo Alto, CA 94306 TEL: (888) 757-VORT (8678) [toll free] TEL: (650) 322-8282 FAX: (650) 327-0747 http://www.vort.com/index.html
You Make the Difference in Helping Your Child Learn It Takes Two to Talk You & Your Baby	Manolson, Doddington & Ward <ul style="list-style-type: none"> • Guidebooks filled with illustrations helps parents connect with young children to foster self esteem, language development and learning. • Teaching Tapes – 9 ten 	The Hanen Centre 252 Bloor St. W. Ste 3-390 Toronto, Ontario Canada M5S IV5

	<p>minute modules.</p> <ul style="list-style-type: none"> • Especially designed for parents with limited literacy skills 	
<p>The Health and Wellness Program A Parenting Curriculum for Families at Risk</p>	<p>Tymchuk, Alexander. (2006)</p> <ul style="list-style-type: none"> • a program manual with background information on parents with disabilities • guidance on establishing a program and assessing parents' skills • overviews of what to teach in parent education programs • 18 printable workbook-style handouts to give to parents, each using clear, simple language and realistic colored illustrations to teach critical skills 	<p>Brookes Publishers (publication October 2006) Call toll-free 1-800-638-3775; Customer Service Department Brookes Publishing Co. P.O. Box 10624 Baltimore, MD 21285-0624</p>
<p>Working with Parents who have Cognitive Limitations</p>	<ul style="list-style-type: none"> • This research-based program helps teachers, healthcare and social service providers: • DVD with handouts on how to recognize when a parent might have cognitive limitations , develop a respectful working relationship with parents, communicate effectively with parents, & maximize appropriate and beneficial conditions for the parents' children 	<p>IRIS Media Inc. 258 East 10th Avenue, Suite B Eugene, OR 97401 Call us toll free at 1-877-343-4747 https://www.lookiris.com/contact_us/custserv@brookespublishing.com</p>
<p>Nurturing Program for Parents and Their Children with Health Challenges™</p> <p>Alternatives to Spanking Video Series</p>	<p>Michele Tryon BS, CCLS and Donna LaTour-Elefante BS, BA</p> <ul style="list-style-type: none"> • Eight 2 hour sessions meet one day a week for 8 weeks. • Parents and children meet concurrently in two separate groups. • Two facilitators run parents' group; two facilitators run the children's group. • Parents and children engage in a 30-minute Nurturing Time (Program Family Time) with games, songs, snacks and more. • Designed for School-Age children but can be modified 	<p>Nurturing Parent Family Development Resources, Inc. 3070 Rasmussen Road, Suite 190 Park City, UT 84098 Phone: 1-800-688-5822 http://www.nurturingparenting.com/order_info.htm</p>

