



PRACTICE NOTES

PROMISING PRACTICES TO SUPPORT PARENTS WITH INTELLECTUAL DISABILITIES

Parents with intellectual disabilities have a high risk of child welfare involvement. There are a growing number of promising practices that can help support parents with intellectual disabilities, including interventions that focus on building parenting skills and increasing social connections and social supports.

Supporting Parents with Intellectual Disabilities

While in the early to middle twentieth century mothers with intellectual disabilities were routinely sterilized, there are now tens of thousands of children born each year to mothers with intellectual disabilities in the United States. Parents with intellectual disabilities have experienced enormous discrimination and many states still have laws allowing an intellectual disability to be considered as grounds for termination of parental rights¹. Despite no evidence that parents with intellectual disabilities are more likely to mistreat their children, they are much more likely to be involved in the child welfare system and have their parental rights terminated^{2,3}. Parents with intellectual disabilities often do have significant support needs, and practitioners who encounter parents with disabilities, whether in disability or child welfare settings, need to be aware of appropriate ways to provide appropriate services. Fortunately, there has been a growing array of research into the types of interventions that can help support parents with intellectual disabilities. While there are no interventions that can be classified as evidence-based interventions, as there has not yet been large-enough scale research studies, there are some promising practices that have research backing that show positive outcomes for parents with intellectual disabilities and their children.

Interventions aimed at parent skill development are the most widely researched type of intervention for supporting parents with intellectual disabilities. There are currently about 40 published studies exploring the effectiveness of such interventions. There are a variety of types of parent skill development interventions, ranging from the development of adapted parent training manuals⁴ to adapted training support groups⁵ to games⁶ to performance-based training⁷ to in-home intensive training⁸ to behaviorally oriented parenting programs⁹. Some programs target pregnant women⁵, while others target parents of infants and young children¹⁰ or parents of school-age children⁹. These include adapted versions of empirically supported training programs, such as Mellow Parenting, Positive Parenting Program (PPP), or SafeCare, or entirely new interventions designed for parents with intellectual disabilities. Some of the newer interventions with promising research outcomes involve

the use of technology, such as video-feedback program which resulted in lowered stress among mothers with intellectual disabilities¹¹ and a digital frame/pictorial information intervention which resulted in improved parent-infant interactions¹². What is common among all the interventions is that they are adapted to the needs and cognitive abilities of the parent, such as by using simple instructions, audiovisual approaches, least-to-most prompting, role-playing and frequent feedback¹³. Although, overall, the evidence for parent skill interventions is mixed, with some interventions showing no positive outcomes while others showing strong empirical support¹⁴, the growing array of empirically supported practice interventions indicate that parents with intellectual disabilities can acquire skills to improve their parenting ability.

“DESPITE NO EVIDENCE THAT PARENTS WITH INTELLECTUAL DISABILITIES ARE MORE LIKELY TO MISTREAT THEIR CHILDREN, THEY ARE MUCH MORE LIKELY TO HAVE THEIR PARENTAL RIGHTS TERMINATED”

The second type of empirically supported interventions for parents with intellectual disabilities are those aimed at improving social connections and/or social supports to assist in parenting. There has been much less research and program development in this area, though there are some equally promising practices in this domain. The most extensively studied approach is that of a structured support group. For example, researchers tested a 12-week social support program in Australia and found that participants had increased psychological wellbeing and perceived social support¹⁰, and a replication study in Canada showed similar results¹⁵. A newer intervention using a person-centered planning approach is another promising practice aimed at expanding social parental supports¹⁶.

Practice Considerations

Child welfare practitioners now have a variety of strategies that they can use when working with a parent with an intellectual disability. Here are a few ideas to consider when supporting these parents.

Take a strengths approach	Most parents with intellectual disabilities can effectively parent their children with appropriate supports, though they often encounter professionals who focus primarily on their weaknesses. These parents can learn parenting skills and increase social supports and, so practitioners should employ a strengths approach when supporting these parents.
Focus on increasing parenting skills	Most parents with intellectual disabilities can learn parenting skills when traditional parent training approaches are adapted based on the individual parent's needs and understanding. This may require supplemental training, increased frequency of training, and/or providing training in the home or other familiar environment.
Focus on increasing parental supports	Parents with intellectual disabilities often have small social support networks, though some have an excellent network of family and friends to assist with their families. Practitioners can help parents identify their existing parental support network and then work with the current network to brainstorm ways to expanding this social support network.
Provide individually tailored accommodations	Social workers and child welfare agencies are required by law to make individually tailored modifications to their practices and procedures when working with parents with intellectual disabilities under the Americans with Disabilities Act and Section 503 of the Vocational Rehabilitation Act (https://tinyurl.com/doj-dhhs).
Use appropriate communication	Practitioners must ensure that parents with disabilities understand what is communicated to them. Some strategies for effective communication include establishing rapport, using plain and concrete language, repeating key concepts, listening for comprehension, and using pictorial or other visual communication methods. The Vanderbilt Kennedy Center has a great resource on communicating with parents with intellectual disabilities (https://tinyurl.com/IDD88).
Include disability related supports in case plans	Case plans for parents with intellectual disabilities should include their disability-related parental support service and accommodation needs. Child welfare agencies and partnering agencies are then obliged to provide such services and accommodations.
Seek consultation from disability experts	Practitioners should seek consultation from disability experts and advocates. These experts can be found in state or county disability services offices, Centers for Independent Living, or other local service and advocacy organizations.
Seek out resources on parenting with a cognitive disability	There are many resources geared towards practitioners and family members on the websites of the National Research Center for Parents with Disabilities (https://heller.brandeis.edu/parents-with-disabilities/) and The Association for Successful Parenting (www.achancetoparent.net).

CASE EXAMPLE

Julia is a 23-year old single mom of a 3-year old daughter named Isabel. Julia has a diagnosis of autism. Julia and Isabel live with Julia's mom, Crystal. Crystal took six months of unpaid leave from work to help Julia when Isabel was born, and takes responsibility for much of Isabel's care, such as making meals and scheduling appointments. Julia watches Isabel alone during the school day, while Crystal watches Isabel in the evenings when Julia is at work at her part-time evening job. Julia makes Isabel a healthy lunch every day, takes her to the park down the street before naptime, and takes her twice a week to story time at the library. A neighbor recently called the police when she saw Isabel playing at the park by herself in the mid-afternoon. The police found Julia at home listening to music, unaware Isabel was missing. Julia became very upset, thinking the police were there to

arrest her. The police made a report to child protection, noting Julia's atypical behavior. During the child protection investigation, the social worker learned that Isabel had run to the park once before when Crystal was home, but a different neighbor had found her and brought her back. Julia indicated that she had attended a "baby and me" class offered at the hospital when Isabel was born, but the teacher was so disapproving of her that she refused to attend any others. Crystal said that Julia was good at following the routines of childcare, but when Isabel was "acting out", Julia often put on headphones to "tune her out" rather than responding to Isabel or redirecting her behavior. Julia and Crystal said they had very little contact with other family members, as most family members had thought Julia should give up Isabel for adoption. Isabel had never had another caretaker aside from Julia and Crystal.

Using this case example and the information you have learned in this issue of *Practice Notes*, consider the questions below.

- » What are the strengths of Julia as a parent, and Crystal as a grandparent?
- » How might others' perceptions of Julia as a person with an intellectual disability affect her as a parent?
- » What types of parenting skills might Julia need to develop? What are some ways that Julia could learn these parenting skills?
- » What are some strategies you could use to increase the social network for Julia and Isabel?
- » Where could you seek out consultation for more ideas on how to develop an appropriate service plan for Julia?

Summary

There are now a variety of empirically supported promising practice for working with parents with intellectual disabilities. Practitioners can use the research knowledge described in this issue of *Practice Notes* by integrating it into their own practice with

parents with intellectual disabilities and their families and sharing this research knowledge with others. Below, please find questions for reflection as you take this research knowledge into your daily child welfare practice.

Reflection Questions

1. How do societal attitudes about parenting by people with disabilities affect the types of services that are offered to them?
2. What types of modification does your agency provide to people with intellectual disabilities?
3. Where specifically would you turn for consultation in your own community if you were working with a parent with an intellectual disability?
4. What can you do to share this information with other professionals?

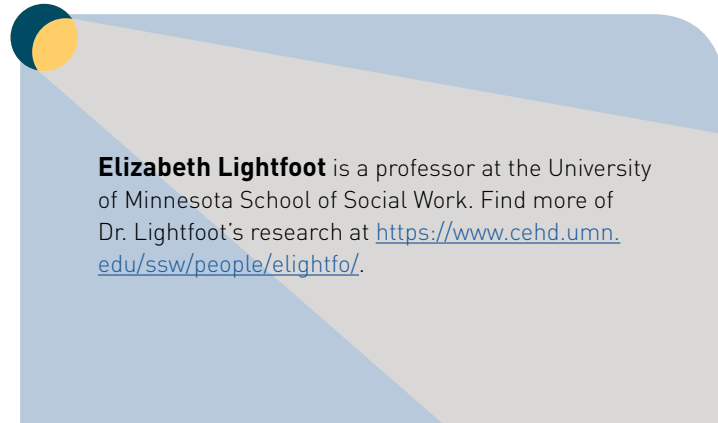
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