



Advice for Professionals Working with Parents with Intellectual Disabilities

Introduction

Researchers and professionals are increasingly aware of the needs of parents with intellectual disabilities. However, there are still significant gaps in the experiences of parents with and without intellectual disabilities. Researchers from around the world and US government agencies have found that parents with intellectual disabilities face stereotyping, stigma, unequal health outcomes, poverty, and other adverse factors. A British study showed parents with intellectual disabilities experienced isolation from other parents, stereotyping and stigma, reluctance to attend prenatal classes with nondisabled parents, and difficulties understanding mainstream pregnancy and childcare materials¹. It is vital for professionals working with this population to understand the unique needs and challenges these parents face.

Despite common stereotypes, parental IQ alone **does not** actually predict how well a parent will raise a child². Many of the correlates associated with worse outcomes for children of parents with intellectual disabilities can be attributed to social and environmental factors that stem from a lack of support and resources³. Despite this fact, parents with intellectual disabilities in multiple countries often lose custody of their children under the false assumption that an intellectual disability on its own prevents parents from acting in the best interest of their children⁴⁵⁶.

¹ Leavis et al, 2010.

² Leavis et al, 2010.

³ Leaviss et al, 2010.

⁴ LaLiberte & Crudo, 2013.

⁵ Leaviss et al, 2010.

⁶ National Council on Disability, 2012.

To provide the best care possible for parents with intellectual disabilities and their children, it is important to take into account the intersecting cultural, social, and medical issues that affect their ability to raise and maintain custody of their children.

Advice for professionals

Here are some strategies professionals can use when working with parents with intellectual disabilities, whether they are helping parents before, during, or after childbirth.

- **Presume competence.** Parents with intellectual disabilities can and have raised children well. Sometimes parents with intellectual disabilities may need more support in some areas than parents without intellectual disabilities, but that is different from declaring that no parent with an intellectual disability can raise a child.
- **Presume people with intellectual disabilities want to excel as parents.** Like most parents, those with intellectual disabilities want to be effective parents who do a good job raising their children. They want to raise happy and healthy children.
- **Learn about the needs of parents with intellectual disabilities.** Knowing more about the specific needs that arise when people with intellectual disabilities have children will help you provide the care they need.
- **Make explanations and informational material understandable for people with intellectual disabilities.** Use repetition, visual demonstrations, and concrete examples to help fix concepts in parents' minds. Many individuals with intellectual disabilities have limited literacy, so ensure informational materials do not require large amounts of reading. If you must produce materials that require reading, make sure paragraphs and sentences are short, simple, and do not contain too many concepts at once.
- **Provide support for parents before, during, and after childbirth.** Unequal access to health care, poverty, social isolation, depression, and anxiety can individually and cumulatively lead to highly negative outcomes for children whose parents have intellectual disabilities. Providing comprehensive support geared towards families' particular needs will help parents and children thrive.

- **Provide individualized support for parents with intellectual disabilities.** Though all people with intellectual disabilities share the diagnostic criteria of slower learning, longer processing time, and increased support needs in daily life, each person's skills and interests are unique. Some parents struggle with making appointments, while others may need help knowing how to respond to a baby's cries more than they do keeping appointments. Needs vary widely and the only way to be effective in supporting these parents is to learn what their individual needs are.
- **Help parents with intellectual disabilities know their rights.** The United States currently has a patchwork of laws regarding the rights of parents with disabilities. Some states protect children whose parents have disabilities from unnecessary removals from the home, while other states lack legislation that explicitly protects the rights of parents with disabilities. The US Supreme Court has ruled that disability status alone is not sufficient grounds to terminate parental rights. The Americans with Disabilities Act also protects the rights of parents with disabilities.

References

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