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**Parenting With Intellectual Disabilities — Changing Times**
**By Lindsey Getz**
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*Not so long ago, many believed that people with intellectual disabilities shouldn’t parent children. Read about new attitudes and what advocates recommend to help support these parents.*

Lindsay Brillhart says that, like anything in life, parenting can be hard at times and easy at others. Ten years ago, when she had her first child, there was a period when parenting was harder. That’s because Brillhart has Asperger’s syndrome, and there wasn’t much support for parents with intellectual disabilities.

Today, attitudes have come a long way and when Brillhart had her second child (seven months prior to press time), it was a whole new world.

“When I had my first little girl 10 years ago, we didn’t have any support staff,” Brillhart remembers. “I had some support, but my child didn’t. It took a while to get the agency we worked with back then to understand it’s important to be in the kids’ lives too.”

One of the more recent supports Brillhart has taken advantage of is a parenting program that gave her a “pretend baby” and helped walk her through some of the skills she’d be using with a newborn. Brillhart says it helped a lot, adding that the support she receives from her family and her boyfriend has been vital.

Brillhart recommends that anyone with an intellectual disability who is considering having children makes sure he or she has as much extra support in place as possible. But until recently, a lot of that support simply didn’t exist.

**A Shift in Beliefs**
According to Bernadette Irwin, assistant director of PACT, an affiliate of the Kennedy Krieger Institute, parenting as a right for individuals with intellectual disabilities is a relatively new concept. In the last 40 years or so, the attitude toward individuals with intellectual disabilities who desire to be parents has taken a dramatic shift. Instead of viewing it as impossible, a conversation has emerged about ways to make it possible and what needs to be done to put support systems in place.

Increased research and attention on the issue of parenting with an intellectual disability has helped contribute to this shift in thought, as has the formation of some organizations with the mission to better support such parents. In 2009, The Association for Successful Parenting was founded with the purpose of formally addressing the needs of parents with intellectual disabilities.

“Our tagline is ‘enhancing the lives of families when parents have learning disabilities,’” says Irwin, who is copresident of the organization. “It is intentionally somewhat broad, as there are folks that could benefit from what we’re learning even though they might not fit the rigid definition of an intellectual disability.”

In June 2010, the first meeting of the Parents With Development Disabilities/Intellectual Disabilities Task Force was held at the annual American Association of Intellectual and Developmental Disabilities conference. The newly formed task group developed a set of recommendations, including an initiative for more supportive legislation for parents with intellectual or developmental disabilities, an improved coordination between the child welfare and disability systems, and better strengths-based training for psychologists.

Irwin says it is these types of efforts that are really shifting the belief system.

“There’s now a national movement,” she says. “The issues that were once kept in the dark are now being brought to light.”

**Debunking Myths and Uniting Cultures**
Over the years, various misunderstandings about intellectual disabilities have led to false presumptions regarding these individuals’ ability to parent.

“It’s often assumed that low IQ means low capability, but that’s not always true,” says Christopher Egan, MSW, LCSW, coordinator of the Developmental Disabilities Training Institute at the Jordan Institute for Families in the School of Social Work at the University of North Carolina at Chapel Hill. “Individuals with intellectual disabilities can negotiate life, be mostly independent, and be good parents.”

Susan Yuan, PhD, professor emerita in the College of Education and Social Services at the University of Vermont, agrees. “The idea that IQ is important in raising a child is a myth,” she says. “Research shows that IQ has to be below 50 before you can say with any definitiveness that IQ and parenting skill are connected.”

Yuan says another common myth is that parents with intellectual disabilities can’t learn the skills they need to be parents. In reality, they can learn with good teaching, good materials, and a lot of practice.

“Parenting is something you can learn, like anything else,” she says. “Building on strengths and breaking down the task into small parts—teaching each part—is important. A good teaching program uses pictures or video. The teacher doesn’t just talk or use printed materials. Good teaching also gives the student time to learn. One of the problems with parenting skills programs that are set up for anyone to take is that they go too fast. Parents with intellectual disabilities need to find a program that lets them stop and repeat the lesson if they’re not there yet.”

While some of these myths can get in the way of support or even dictate how support is given, disability advocates like Egan urge social workers and other support staff to see past the assumptions.

“I would advise that social workers shouldn’t assume that just because a parent has a label of a disability means that they don’t have a right to be a parent,” he says. “The key issue is the ability of the parent to support their child and to manage that role effectively. Sometimes that may include the support of other people and that’s OK.”

But it’s that need for additional support that can sometimes be misinterpreted as being incapable in what Irwin calls the “child welfare world.” It’s some of the differences between the child welfare world and the “intellectual disability world” that have continued to pose challenges.

“In the disability world, we speak about things that have to do with support,” says Irwin. “If we can’t teach you to do it, we will find ways to support you in doing it. But in the child welfare world, this is frowned upon because they’re looking for independence. They’re more likely to believe if you can’t do it, then perhaps you shouldn’t be caring for a child.”

Yuan says the issues of parenting rights vs. family court challenges essentially require “mediating between two cultures.” The key concept of the child protection culture is “ensuring the safety and welfare of the child,” says Yuan, while in the disability culture, it’s “maximizing the potential of the person for a full life,” which includes the right to parent.

Yuan says that, whenever possible, both goals should be worked toward simultaneously. However, she adds, it must be acknowledged that this isn’t always possible.

Some myths about parents with intellectual disabilities, including the correlation between IQ and the ability to parent or the idea that parents must be completely independent, have contributed to a high number of parental rights terminations. In a 1991 article in ***Canadian Psychology***, “Parents With Mental Retardation and Their Children: Review of Research Relevant to Professional Practice,” the authors estimated that between 40% and 80% of parents with developmental disabilities (encompassing intellectual disability) permanently lose custody of their child.

But Yuan says she’s witnessed proof that even with minimal supports, these parents could successfully raise children. Grant efforts over the course of five years in Vermont have helped build support for parents with intellectual disabilities, resulting in a significantly reduced rate of parental rights terminations. Less than 2% of the parents within the support program lost custody.

“It wasn’t very complex support we put in place,” says Yuan. “Part of it was just providing someone to talk to that could offer education on some basic concerns. What we found was that if you put some very basic supports in place, parents with intellectual disabilities can be successful.”

The problem, Yuan says, is that often the supports put into place for a parent with an intellectual disability are short-term solutions. While these parents typically need only minimal support, they do need it for the longterm. Largely that’s because the children’s needs are ever changing.

“It’s important that as the children grow and change, that they have somewhere to turn,” says Yuan. “Any supports that are put into place need to keep up with the changes in the children as well.”

**Additional Barriers**
While there’s been tremendous progress in this arena, there’s still a long way to go with plenty of barriers left to hurdle. Some of the “clashing of cultures” between child welfare and disability advocates certainly creates additional obstacles.

Yuan says it’s important to help child protection services better understand the issues related to intellectual disability. In Vermont, disability awareness training was part of the grant-funded effort. Since 2006, family service workers in all districts have received introductory training on supporting parents with disabilities. Some areas about which child welfare agents can typically use better education include IQ and mental age generalizations, the ability of parents with intellectual disability to learn, and dissolving the notion that parents need to do it all on their own.

But Yuan says there are issues that are essential for the parent to understand as well, including the constraints on freedom that will become inherent when having a child, the primacy of the child’s needs, and the importance of accepting supports. It’s also important for parents with intellectual disabilities to have some understanding of the perspective of child welfare—that the organization is acting in what is believed to be the child’s best interest.

Parents also need to be aware of the importance of maintaining a positive relationship with their case manager, says Yuan.

“In the disability world, you can complain to someone higher if you don’t like how things are going, but that’s not usually the case in the child protection world,” she explains. “It’s important for parents to try and get along with their case manager.”

Another challenge has been the self-identification of parents with intellectual disabilities.

“I don’t think we’ve ever come across a parent that has self-identified as a parent with an intellectual disability,” says Irwin. “Most will say, ‘I was in special ed’ or ‘I’m a little bit slow,’ but that’s typically as far as you’re going to get on the topic.”

If attempting to work with and support a parent with intellectual disability that hasn’t self-identified this way, Irwin suggests some questions social workers should ask are, “Do you receive SSI?” or “Do you know why you receive SSI?” which may help give an indication of their status or needs.

“But you can’t expect the person to self-identify and that can be a barrier to getting paperwork,” she adds.

Adding a layer of complication is the fact that many people with intellectual disabilities have a dual diagnosis or other situational challenges.

“If an additional mental health issue is also occurring, that can create challenges in working with the patient,” says Irwin. “Plus, poverty is another challenge that parents with an intellectual disability might be dealing with. You can barely rent a place on SSI.”

These additional circumstances complicate the support. “Because you’re dealing with multiple issues, you’re now talking about dealing with multiple systems and that always makes it more challenging,” says Irwin. “All of these different systems speak different languages and getting everyone to work together can be tough.”

**A Good Support System**
While there’s still a long way to go, there’s no question that the support and rights for parents with intellectual disabilities have already come far. For social workers who may encounter these clients, taking the opportunity to better understand the client and his or her needs can facilitate success.

“As social workers, we don’t want to make assumptions about skill based on the label of a disability,” says Egan. “We want to engage with the patient in order to better understand. There’s always risk when it comes to perception. In the name of being sure children are protected, it may be assumed that a person with a disability is unable. But with the right supports in place, people with disabilities can be great parents.”

“I would want to make sure social workers understand learning styles of people with disabilities, remembering that repetition is critical to these families,” Irwin says. “Providing information in small chunks and giving frequent feedback about those small chunks of information is how parents with intellectual disability can learn. It’s just teaching—very basic 101 type of teaching.”

Yuan recommends ***Step by Step Child Care***, a manual by Maurice Feldman and Laurie Case that walks parents with disabilities through child care using photos and descriptions of each step.

But in the end, it definitely comes down to support. “The most successful parents are the ones with a good support system,” says Yuan. “If parents with intellectual disabilities decide they want to have a baby, they should identify their support system to help them plan for the baby.”

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