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Disabled parents face loss of kids

AP (http://connect.oregonlive.com/user/oliveassocpr/index.html) By The Associated Press
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Twins Abigail and Noah Thomas, 8, ride on the motorized wheelchair of their mother, Jenn Thomas, on their way to a school book fair in Arlington Heights, Ill., earlier this month. Thomas, a 36-year-old mom who has cerebral palsy, says her twins occasionally complain about having to do a few extra chores around the house to help her. Abigail, nods and smiles upon hearing this, but says for the most part, their lives are "kind of normal." For her, having a mom with a disability is just how it is, she says, shrugging.

The Associated Press

Millions of Americans with disabilities have gained innumerable rights and opportunities since Congress passed landmark legislation on their behalf in 1990. And yet advocates say barriers and bias still abound when it comes to one basic human right: To be a parent.

A Kansas City, Mo., couple had their daughter taken into custody by the state two days after her birth because both parents were blind. A Chicago mother, because she is quadriplegic, endured an 18-month legal battle to keep

custody of her young son. A California woman paid an advance fee to an adoption agency, then was told she might be unfit to adopt because she has cerebral palsy.

Such cases are found nationwide, according to a new report by the **National Council on Disability** (http://www.ncd.gov/), an independent federal agency. The 445-page document is viewed by the disability-rights community as by far the most comprehensive ever on the topic — simultaneously an encyclopedic accounting of the status quo and an emotional plea for change.

"Parents with disabilities continue to be the only distinct community that has to fight to retain — and sometimes gain — custody of their own children," said autism-rights activist Ari Ne'eman, a member of the council. "The need to correct this unfair bias could not be more urgent or clear."

The U.S. legal system is not adequately protecting the rights of parents with disabilities, the report says, citing child welfare laws in most states allowing courts to determine that a parent is unfit on the basis of a disability. Terminating parental rights on such grounds "clearly violates" the intent of the 1990 **Americans with Disabilities Act** (http://www.ada.gov/), the report contends.

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Child-welfare experts, responding to the report, said they shared its goals of expanding supports for disabled parents and striving to keep their families together. But they said removals of children from their parents — notably in cases of significant intellectual disabilities — are sometimes necessary even if wrenching.

"At the end of the day, the child's interest in having permanence and stability has to be the priority over the interests of their parents," said Judith Schagrin, a veteran child-welfare administrator in Maryland.

In the bulk of difficult cases, ensuring vital support for disabled parents may be all that's needed to eliminate risks or lessen problems, many advocates say.

The new report, titled "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children," estimates that 6.1 million U.S. children have disabled parents. It says these parents are more at risk than other parents of losing custody of their children, including removal rates as high as 80 percent for parents with psychiatric or intellectual disabilities.

Parents with all types of disabilities — physical or mental — are more likely to lose custody of their children after divorce, have more difficulty accessing assisted-reproductive treatments to bear children, and face significant barriers to adopting children, the report says.

One of the cases it details involved Erika Johnson and Blake Sinnett of Kansas City, whose 2-day-old daughter, Mikaela, was taken into custody by Missouri authorities because both parents were blind. The action occurred after a hospital nurse reported that Johnson seemed to be having trouble with her first attempts at breast-feeding — which Johnson said happens with many first-time mothers.

During a 57-day legal battle, before the couple regained custody, they were allowed to visit Mikaela only two to three times a week, for an hour at a time, with a foster parent monitoring.

Since then, the family has been left in peace, said Johnson, who tries to offer support to other disabled parents facing similar challenges.

"Some parents just give up or don't have the resources," she said in a telephone interview.

A Windsor, Colo., woman with disabilities says the prejudice she encountered prompted her to go to law school, to better defend her own rights and those of other disabled parents.

Carrie Ann Lucas uses a power wheelchair and is reliant on a ventilator due to a form of muscular dystrophy. She is a single mother of four adopted children, ages 22, 17, 13 and 11, all of whom also have disabilities, including two who use wheelchairs and three with intellectual disabilities.

Lucas says she's been the subject of several investigations by child welfare officials that she attributed to bias linked to her disabilities.

"Each one of these referrals that gets accepted for investigation causes a great deal of stress, not only for me, but for my children," Lucas wrote in an email.

She said the investigations dated back to her first efforts to adopt Heather, her biological niece, in 1999, after the girl was placed in foster care. At one point in a long procedural struggle, a social worker told a judge that "there was no way that handicapped woman could care for that handicapped child."

"We are nearly 13 years later, and Heather is still doing very well," Lucas wrote.

As a lawyer, Lucas has represented many other parents with disabilities.

"I have had parents with paralysis be threatened with removal of their children, deaf parents punished for using sign language with their hearing children, and blind parents told that a social worker can't possibly fathom how they could parent a newborn," Lucas said. "When families do need intervention, it is often because the services they need are not available outside a punitive social services case."

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The lead author of the new report, disability-rights lawyer Robyn Powell, says her goal was to challenge presumptions that disabled people can't be effective parents.

"Of course there are going to be some parents with disabilities who would be lousy parents — that's the same with parents without disabilities," she said. "If there is neglect, is it due to the disability? And can it be rectified by providing the necessary support?"

Ella Callow, a lawyer with the National Center for Parents with Disabilities and their Families, said the report raises fundamental questions about America's social priorities — given that state and federal laws value both the well-being of children and the rights of disabled people. The ultimate goal, she said, would be to promote both values by expanding support for disabled parents.

"If we really believe that families are the key unit on which society is built, then we have to enable these families to be healthy and functioning, even at public expense," Callow said. "We know foster care isn't a good place for children to be — they do better with their own parents, at their own home."

Callow, who is based in Berkeley, Calif., said child welfare agencies need to provide more funding and specialized training with the aim of improving services for disabled parents.

"Child welfare is so incredibly underfunded, and the workers are so incredibly overwhelmed, their attitude is, 'Really, you want my attention on this?'" Callow said. "There's a tendency to think these families aren't the same as our families. But these children, when they lose their families, have the same type of grief."

Schagrin, the Maryland child-welfare official, said she found parts of the report troubling because they seemed to suggest children were sometimes removed from their families only on account of parental disabilities.

"That's not why they are taken away," she said. "They are taken away because the disability has continued to the point where there's an episode of maltreatment or neglect."

She said one recourse is to find members of the extended family — or other types of support — to help a parent with psychiatric or intellectual disabilities care for a child. But she said this approach could be taken too far, for example if a mother with intellectual disabilities was placed in a group home with other disabled parents.

"What kind of way is that for a child to live — being raised by a shift of caregivers in a mom-and-child group home?" she asked. "Is that really better than an open-adoption agreement?"

Andrea Bartolo, a senior consultant at the Child Welfare League of America, said there is no question that some disabled parents encounter discrimination in the child welfare system, "sometimes inadvertently, sometimes very overtly."

Under current practices, Bartolo said, an expert assessment of a child's home life and the possible provision of services to the disabled parents might occur only after the child has been removed and "the damage has been done." Going forward, she hopes child-welfare agencies will try harder to provide support before a problem worsens, potentially reducing the need for foster-care placements.

The report praises a few states — including Idaho, Kansas and California — for modifying child-custody laws to the benefit of disabled parents. It urges Congress to amend the Americans with Disabilities Act to add protections for parents, and it calls on state lawmakers to eliminate disability as a distinct ground for terminating parental rights.

Christine Waters, an attorney with Legal Services of Central New York, based in Syracuse, worked with colleagues in 2008-09 in a bid to change the state law specifying that parental rights can be terminated if a parent has psychiatric problems or is intellectually impaired. Some legislators expressed support, Waters said, but the effort ultimately failed.

"Everything would look like it was going fine ... and then there would be some well-publicized, awful incident where someone who had a mental illness — without support —

did something shocking and horrible, and a child was seriously harmed or died and we'd be back to square one," Waters said.

Waters said some child-welfare officials resisted any change, wary of being held responsible if something went wrong.

The assumption that people with disabilities can't parent "is bad for society and heartbreaking for families," Waters said. "The easy thing is to terminate the parental rights. We need to do the right thing, not the easy thing."

Disabled parents whose parenting ability comes into question often are placed at a disadvantage by parenting assessments that are inappropriate or unfair, the report says. It calls for better research to improve assessment standards and gain more knowledge about how various disabilities affect the ability to be an effective parent.

One topic worth further study, it said, is "parentification" — the phenomenon in which children of disabled parents take on various caregiving responsibilities, even at a young age.

In Arlington Heights, Ill., Jenn Thomas, a 36-year-old mom who has cerebral palsy, says her 8-year-old twins occasionally complain about having to do a few extra chores around the house to help her.

Her daughter, Abigail, nods and smiles upon hearing this, but says for the most part, their lives are "kind of normal." For her, having a mom with a disability is just how it is, she says, shrugging.

Sometimes, they ride on the chair with her — especially son Noah because he, like his father, D.J., is a "little person," the term used by the family and others for someone genetically predisposed to having unusually short stature. When activities are farther away, the couple has created a support network to help when D.J. is working. He drives, but Jenn does not.

"I want them to enjoy activities and not be limited because I am limited," she says. So she coordinates with neighbors to help get the kids to swimming, cello lessons or basketball practice. Or she arranges for "paratransit," a bus service for riders with disabilities and their families.

Friends also helped redesign their kitchen to make it more accessible.

The new report stresses that improved networks of support for disabled parents — encompassing transportation, housing, health care, and outside intervention when appropriate — should be welcomed, and not viewed as evidence that the parents on their own are incapable.

When children do face removal from their disabled parents, those parents may encounter barriers to meaningful participation in their legal cases, the report says. For example, financially struggling parents may have to rely on a court-appointed attorney with no special knowledge about the effects of disability.

Kaney O'Neill of Des Plaines, Ill., a quadriplegic Navy veteran, endured an 18-month legal battle to keep custody of her young son. Her ex-boyfriend filed for custody in 2009, when the boy was 10 weeks old, alleging that O'Neill was "not a fit and proper person" to care for the child because of her disability.

Refuting the allegation, with legal help from Ella Callow, Kaney demonstrated how she had prepared for motherhood by working with an occupational therapy program, adapting her house, securing specialized baby-care equipment, and using personal assistants to help her as needed.

"I lived in fear every single day that my son would be taken away from me," said O'Neill, 36. "In a lot of ways it made me a better mother because I felt that I had a lot to prove."

She says her son, who taught himself to climb up his mother's wheel chair into her lap, is now going to preschool twice a week and is thriving.

"If you are a parent with a disability, you don't have a role model — you have to figure out how you're going to be a mother and overcome challenges," she said.

For disabled women who either cannot bear children or choose not to, the possible option of adoption often can be complicated. Some foreign countries, notably China, rule out disabled people as potential adoptive parents.

Elizabeth Pazdral of Davis, Calif., who wears a brace and uses crutches to walk because of cerebral palsy, said she encountered discrimination several years ago when she and her husband sought to adopt a child. She said one local adoption agency billed her an advance fee of \$3,400, then advised that there were "serious reservations" about her ability to be a parent.

"I think it was dishonest to take my money and then tell me they were worried," said the 4-foot-tall Pazdral, 42, who is executive director of the California State Independent Living Council.

Initially distraught, Pazdral obtained legal help, paid for an occupational therapist to come to her house to assess her capabilities, and researched how other parents with disabilities had succeeded in raising children. The efforts paid off: The adoption agency dropped its objections, and in May 2008, Pazdral and her husband, a Stanford University physicist, adopted a baby girl named Madeleine.

"It was a huge life change — but that's true for any new parent," Pazdral said, recounting sleep-deprived nights, higher levels of chronic pain, and the challenge of maintaining one's energy level.

"But I start with the joy I get from being her mother — the rightness I feel," Pazdral said. "It's the best thing I have ever done with my life."

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