

# **The Project**

The Disability and Parental Rights Legislative Change Project was initiated at the University of Minnesota as a collaborative project in the College of Education and Human Development between the School of Social Work and the Institute on Community Integration. The collaboration developed following the identification of discriminatory legislation within child custody and termination of parental rights statutes. The goal of the project is to assist interested groups in removing disability from these statutes to eliminate discrimination, with the ultimate goal of ensuring the safety, permanency and well-being of children. This guide provides an overview of the problem; key principles for protecting parents with disabilities: model statutory language and accompanying definitions; a legislative change strategy; practice suggestions for modifying services and providing parental accommodations; frequently asked questions and answers; and resources.

Historically, social policy has regulated the parenting of people with disabilities in several different ways including forced sterilization, institutionalization and segregation. In the United States, some social policies have changed, however laws exist that can limit the parental rights of people with disabilities. More than two-thirds of states in the U.S. have laws that include "parental disability" as one of their grounds for termination of parental rights. Although recent research has found that parents with disabilities are not more likely to maltreat their children than parents without disabilities, studies have found very high rates of termination of the rights of parents with disabilities.

These legal obstacles to parents with disabilities reflect widespread attitudinal discrimination they face from the general public. For example, in the 1962/2007 Minnesota Survey of Attitudes Regarding Developmental Disabilities, over one-third of the respondents disagree with the statement, "People with developmental disabilities should be allowed to have children, just like everyone else." These types of attitudes about disabilities are also reflected in many state laws regarding parenting (such as divorce and child custody statutes).

Both the Americans with Disabilities Act and the Rehabilitation Act prohibit state and local governments from discriminating against people with disabilities in their programs and services. However, one area that these anti-discrimination laws do not cover is child custody and child protection proceedings, and many parents with disabilities still face discrimination in these arenas.

### **Parental rights legislation**

All states have state laws outlining the grounds for termination of parental rights in relation to child abuse and neglect. When rights are terminated, parents lose all legal rights and ties to their children. The federal law, The Adoption and Safe Families Act, mandates certain circumstances in which rights must be terminated, such as abandonment or excessive time in foster care. States vary in which other circumstances require termination of parental rights, including such grounds as chronic substance abuse, failure to maintain contact with a child, or failure to maintain support of a child.

A recent review of all state laws in the United States found that 36 states and the District of Columbia had laws that included disability-related grounds for termination of parental rights, while 15 states did not. All of the states that include disability in their grounds for termination specify explicit types of disabilities for courts to consider, including mental illness (36 states), intellectual or developmental disability (32 states), emotional illness (18 states) and physical disability (7 states).

Many of these state laws used outdated terminology and imprecise definitions for describing people with disabilities. For example, the most common combination of disability descriptions was "emotional illness, mental illness and mental deficiency," which is the language used by 11 states in their state codes. This type of language was common in the 1940s and 1950s, and is considered very inappropriate today. Also, many states failed to include any definitions for disabilities within their state laws relating to child protection.

A significant concern about the inclusion of disability in the grounds for termination is that such inclusion can shift the focus from a parent's behavior to a parent's condition. Disability is one of the only grounds for termination that is based on a parent's condition, rather than a parent's behavior. While no state says that disability can be grounds by itself for termination of parental rights, if disability is included as grounds for termination, it can become the focus of a child protection case.

Several states have recently removed the disability language from their state termination of parental rights laws. One of these states, Idaho, has also added language in its state law that both protects people with disabilities from discrimination in child protection or child custody proceedings, and specifies that a parent with a disability has a right to demonstrate their parenting ability with the use of adaptive equipment or supportive services.

While, currently, parents with disabilities in many states may face discrimination in child custody and termination of parental rights proceedings, this can be changed. States need to reconsider the inclusion of disability in child custody codes. At the very minimum, states should update the disability-related terminology and definitions in their state's codes.

#### Action

As a result of this review of state statues and the potential for discrimination, the Disability and Parental Rights Legislative Change Project brought together a mulit-disciplinary advisory group to develop model legislative language that self-advocates, advocacy groups, and disability professionals can use to mobilize efforts in their states to remove disability as a grounds for termination of parental rights (TPR) in their states. It should be noted that the focus and the work of this advisory group extends beyond TPR to include adoption, and child custody statutes (separation, divorce, and guardianship); all of which aims to promote the safety, permanency and well-being of children. The objectives of the project include the development of a guide with strategies for creating legislative change, the provision of technical assistance to four states as they begin efforts to change their state legislation, and wide dissemination of the related research and product materials.

# Key principles

In order to successfully move forward to ensure fair treatment of parents or guardians with disabilities in child custody and child protection cases, while promoting the safety, stability, and well-being of their children, six key principles must be present in state statutes. For each key principle, model statute language and accompanying definitions are provided for use in changing state statues. Together these will act to guide groups as they advocate changing their state laws.

# 1 State statutes are free from discriminatory language.

Places to look for discriminatory language include termination of parental rights statutes, adoption statutes, and child custody statutes (separation and divorce). While definition sections may include language that needs to be changed, discriminatory language is often found throughout the statute.

#### Model language

This is an example of how Idaho removed discriminatory language from their statute —

'Whose parents, guardian or other custodian are failing to discharge their responsibilities to and for the child and, as a result of such failure, the child lacks the parental care necessary for his health, safety or well-being.'

# State statutes affirm that no part of the statute should be used or interpreted as discriminating against people with disabilities.

This should be put in the general purpose section(s) dealing with parental custody and parental rights. It is important to note that in statutes where state agencies are providing services, they MUST provide modifications in accordance with Title II of the Americans with Disabilities Act.

#### Model language\*

'Nothing in this chapter should be construed to allow discrimination against a parent or guardian on the basis of disability. State services must comply with the Americans with Disabilities Act.'

#### **Definitions**

**Disability:** Consider a definition such as the one included in the Americans with Disabilities Act. The ADA defines a person with a disability as: A person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others to have such an impairment.

# State statutes acknowledge that successful parenting can take place with accommodations including adaptive equipment and parental supports.

This affirmative step on the part of parents or guardians with disabilities is likely a new concept to many states and legislators. This change in paradigm requires that statutes consider a broader vision of parenting thus eliminating deeper systemic forms of discrimination.

#### Model language\*

'If the parent or guardian has a disability, the parent or guardian shall have the right to provide evidence to the court regarding the manner in which the use of accommodations such as adaptive equipment or parental supports will enable the parent to carry out the responsibilities of parenting the child. The agency shall advise parents or guardians of such right as soon as disability is identified. Courts shall also advise parents and guardians of this right.'

4. State statutes require that assessment of parenting by people with disabilities is focused on behaviors rather than conditions, and appropriate assessments are conducted by experts knowledgeable in parenting skills and disability accommodations.

Requiring that assessments be conducted by people that are knowledgeable in parenting skills and disability accommodations is essential. Simply being an expert in standardized assessments is not sufficient in termination and custody cases involving parents or guardians with disabilities. Assessment instruments and subsequent reports that do not evaluate parenting abilities in the context of service modifications and/or accommodations do not accurately assess the parent's or guardian's abilities.

### Model language\*

'Evaluation of parental fitness shall take into account the use of adaptive equipment and parental supports for parents or guardians with disabilities and shall be conducted by, or with the assistance of, a person who has expertise concerning such equipment and support services.'

#### Definitions

**Accommodation:** Accommodations may be defined broadly to include strategies and techniques designed to support the parent or guardian with a disability in their parenting activities including, adaptive equipment and parental supports.

Adaptive equipment: Adaptive equipment refers to any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve parenting capabilities of individuals with disabilities.

Parental supports: Parental support includes supportive services and personal care services designed to assist parents or quardians with a disability to compensate for those aspects of their disability which affect their ability to care for their child and which will enable them to discharge their parental responsibilities. Parents may need human support in Activities of Daily Living (ADLs) such as dressing, bathing, walking, transferring, feeding, toileting; Instrumental Activities of Daily Living (IADLs) such as meal planning and preparation, managing finances, shopping for food, clothing, and other essential items, performing essential household chores, communicating by phone and other media, and getting around and participating in the community; education and training to help develop parenting skills; and parenting activities such as parental care and supervision, subsistence, medical or other care or supervision necessary for child well being.

# 5 State statutes require specialized protocols for investigations involving a family member with a disability.

Protocols used during the child maltreatment investigation process should be tailored to individuals with varying types of disabilities. Risk assessments and interviews should be based upon the parent's or guardian's behavior and not focused on their condition.

#### Model language\*

'Investigations of child maltreatment cases involving people with disabilities shall use a protocol that has been modified based on the individual with disabilities' abilities.'

# 6. State statutes that require the use of multidisciplinary interagency teams shall include experts in disabilities.

Currently, many states require interagency and/or multidisciplinary teams to be involved in various parts of the child maltreatment case such as investigation, assessment, and service planning. For cases involving parents or guardians with a disability, teams should include people with expertise in parental supports and adaptive equipment.

#### Model language\*

The following language should be added to the existing list of team members identified in state statute —

'Persons knowledgeable about parental supports and adaptive equipment for parents or guardians with disabilities'.

\*This model language has been built on language developed for Idaho statutes.





For more information, visit the Disability and Parental Rights Legislative Change Project Web site. ssw.che.umn.edu/CASCW/parentdisability

# Idaho's success story



In 1999 parents with disabilities in Idaho raised concerns about losing custody of their children based on parental disability. The Idaho SILC developed a committee, called FAMILY (Fathers and Mothers Independently Living with their Youth), to examine

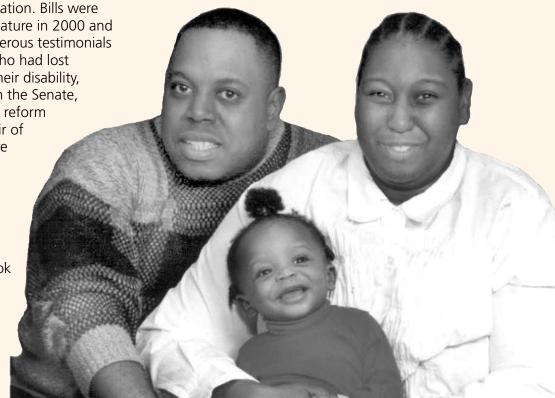
the issue. FAMILY consisted of people with disabilities, advocates, legislators and members of disability organizations. They determined that legislative reform was necessary to meet their goal of creating "a process that was consistent and guaranteed that no parent would lose custody of his/her children solely due to the fact that they had a disability (Idaho SILC, 2005)." Working as a coalition representing parents with all kinds of disabilities, FAMILY intended to eliminate inappropriate disability language in Idaho statutes and create a fair and consistent parental evaluation system that allowed parents with disabilities to show how adaptive equipment and support services helped them parent their children.

FAMILY's advocacy efforts took four years. They relied on a national organization, Through the Looking Glass, for important technical assistance and consultation. FAMILY also partnered with Senator Robbi Barrutia, who was passionate and determined to pass this legislation. Bills were introduced in the Idaho legislature in 2000 and 2001. However, despite numerous testimonials by parents with disabilities who had lost parental rights based upon their disability, and overwhelming support in the Senate, the House blocked legislative reform both years. In 2002, the Chair of the House Health and Welfare Committee happened to see I am Sam, a movie about a father with a developmental disability who lost custody of his daughter through a child protection action. Impressed with the movie, the Chair took

the entire Committee along with Kelly Buckland, the director of the Idaho SILC, to see the film. The portrayal of the father's abilities to parent his daughter and his struggle within the system were eye opening to committee members.

FAMILY introduced legislation in 2002, this time focusing on divorce, adoption, quardianship, and termination of parental rights, with an emphasis on provisions that allow parents to present evidence detailing how adaptive equipment and support services enable them to parent effectively. This bill passed the House and Senate, and became law. In 2003, FAMILY introduced legislation regarding child protection, with a special emphasis on creating an evaluation system that is consistent and fair for parents, and requiring that child protection investigators be knowledgeable about disability accommodations. This legislation also passed, and Idaho became the first state in the nation to include disability protections in their termination of parental rights statutes.

For more information about the SILC's FAMILY Committee and its legislative efforts, see www.2.state.id.us/silc/legislupdate.htm.



# Legislative change process

The process of changing child protection and child custody statutes requires careful attention to legislative strategy. Using a core planning group can help to formulate a legislative change strategy. Two areas that require planning include how to frame your message and how to garner support. The following are some critical components to devising legislative change strategy aimed at removing discriminatory language and adding protections for parents with disabilities involved in child protection and child custody proceedings.

#### Frame the issue

An important step in legislative change strategy is to pay careful attention to framing the issue of concern. Framing an issue involves describing and explaining the context of an issue in the way your target audience understands. Thus, it is vitally important to understand the attitudes and beliefs of your target audience within your state, and be aware of any recent events or issues within your state with which you may be able to connect. Discrimination is certainly one way of framing this issue, and one reason why state laws should be changed. When statutory language lists disability within the grounds for termination of parental rights and does not require states to allow parents with disabilities to show their parenting capabilities with the assistance of adaptive technology or parental supports, there is a clear argument that these laws are unfair to parents with disabilities. However, there are other ways to frame this issue which may resonate better with some audiences. For example, in the child welfare system, there are currently three central themes: child safety, child permanency, and child well-being. Tying a legislative change strategy to these three themes may work well with some audiences in some states. Such an approach could involve arguing that treating a parent with a disability unfairly ultimately hurts his or her child, as removing a child from his or her parent disrupts the child-parent bond (e.g. permanency), which impacts a child's well-being.

### **Key stakeholders**

When proposing changes to the child custody and termination of parental rights statutes in your state, it is important to consider the key stakeholders in this issue. Key stakeholders are the individuals or groups who have an interest in the outcome of this proposed change -- either positive or negative. Knowing the key stakeholder groups within your state, and anticipating their positions on this issue, is an important step in building a coalition of support. For this issue, key stakeholders may include: disability advocacy groups (e.g. NAMI, The Arc, CILs), child welfare advocacy groups (e.g. Children's Defense Fund, Prevent Child Abuse America, Child Welfare League of America), parent groups, state prosecutors, Protection and Advocacy centers, parents with disabilities, children of parents with disabilities, professional association groups (e.g. State Chapter of National Association of Social Workers), civil liberties organizations and state and county agencies (e.g. Governor's Councils on Developmental Disabilities, Ombudsman offices, child protection services, developmental disability services, mental health services).

The more that key stakeholders can join into a coalition of support, the more likely your process is to succeed. Stakeholder groups can serve as a resource to your effort in a number of ways. including: providing information, helping to make connections with legislators, providing personal stories, providing a network for coalition building. deciding how to frame and market the issue, and providing financial backing to the effort. However, not all key stakeholder groups may support this legislative change effort, so it is wise to contact each group thoughtfully.

# Questions and answers

- O As a child welfare worker, I think we do a good job providing modifications and accommodations and we would never discriminate against a parent based on disability. Is this really a problem that requires a change to the law?
- A Yes. While there are child welfare professionals and agencies that do a good job in providing services to parents with disabilities there are some who do not. By taking disability out of the statute it removes the inclination to focus on a parent's condition rather than a parent's behavior. By adding affirmative language that allows the parent to demonstrate adequate parenting capabilities with the use of adaptive equipment or parental supports, it is less likely that intentional or unintentional discrimination will occur. Further, child welfare workers are not the only people involved in cases involving parents with disabilities, and legislative change is critical for others, such as judges, attorneys, other professionals, and family members. For examples of accommodations and modifications, see page 10.
- Q Does a change in child custody and termination of parental rights statutes put the rights of parents with disabilities ahead of the safety of their children?
- A Child safety, permanency and well-being should always be the central focus of child custody and child welfare decisions. Removing discriminatory language does not mean that parents' rights supersede their children's rights. Certainly parents with disabilities, like parents without disabilities, can have their rights terminated based upon poor parenting. Research has shown that child well being is enhanced when children can safely remain in their family of origin and this includes children whose parents have disabilities.

- Q Does a change to our child custody and termination of parental rights statutes mean that state agencies are required to pay for parental supports to parents?
- A No, it does not. The model language outlined in this publication calls for states to recognize that people with disabilities can be good parents. In some cases, in order to successfully parent their child, a person with a disability may need to use parental supports or adaptive equipment. The language provided here does not require the state to pay for these supports or equipment, simply to recognize that they are available and can be used. States should be required to ensure that parents with disabilities are aware of the supports and services that are available to help them parent their children.
- What are the potential barriers our group might face in passing changes to our child custody and termination of parental rights statutes?
- A It is wise in any advocacy situation to identify barriers that the effort may encounter. Challenges will differ from state to state and you should identify and strategize about overcoming barriers that arise specific to your state. Examples of challenges that may be encountered include —
  - Worries of additional costs. There may be a concern that this will require states to fund additional services for parents. This model language does not require additional funding.
  - Lack of awareness of this as an issue. Not all stakeholders may recognize this issue as a problem, and there may need to be some general awareness provided about this issue as a "social problem".

 Splitting of disability groups. It may be easier to gain protections for people with certain types of disabilities, and groups will have to strategize about how to ensure rights for parents with all types of disabilities.

 Poor services/resources. There are very few service providers serving the parenting needs of adults with disabilities. Some may think that focusing on services is a better first step than focusing on discrimination in statutes. However, focusing first on statutes may help provide an impetus for better services.

Lack of knowledge about parenting abilities.
 There may be a lack of recognition that adults with disabilities can successfully parent their children, and a concern that a child may face additional burdens by having a parent with a disability. Education may be required.

 Concern of family members. Some family members of parents with disabilities may be concerned about their family member with a disability having a child. Their concerns typically relate to concerns of additional caregiving responsibilities, particularly by grandparents or siblings.

• What groups would be allies for us in our state legislative change project?

A Look for allies within the key stakeholder groups listed in this publication who you anticipate will support the rights of parents with disabilities. There may also be allies within key stakeholder groups that you might consider potential opponents, and it is useful to look for allies within this group as well.



# **Examples of modifications and accommodations for** parents with disabilities

Service providers and child protection agencies are responsible for identifying and providing modifications to the services they provide. Parents are responsible for identifying and providing the accommodations in parenting that are most appropriate for them.

#### **Modifications**

Title II of the American's with Disabilities Act requires that state and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services and activities. Agencies need to provide modifications to their services as appropriate. Examples of modifications include -

#### **Service Delivery**

- Increase frequency of service provision
- Extend length of time of service provision
- Increase repetition of information and training
- Modify counseling/parenting skills training to provide more concrete hands-on instruction in a natural environment
- Provide in-home parent modeling
- Links of parent with a co-parent or mentor
- Tailor parenting education to the needs of the parent
- Provide more extensive and thorough follow-up services
- Provide services at an individual's home or alternative accessible site
- Give frequent reminders for appointments/ services
- Provide accessible transportation

#### Communication

- Provide all information in large print, audio tape, Braille, or digital format
- Offer note-taking or transcriptions of meetings and court activities
- Assist in reading materials
- Provide interpreters

#### **Accommodations**

Accommodations include parental supports and adaptive equipment intended to support the parent or guardian with a disability in their parenting activities. Examples of accommodations include —

#### **Parental Supports**

- Day care services
- Respite care
- Co-parent or mentor
- Family or informal support networks (church, neighbors)
- Long-term family foster care
- Parent helper/child care assistant
- Aide or personal assistant
- Supported housing
- Accessible transportation
- Concrete calendar with appointments clearly identified
- Pictorial representation or reminders of tasks (step by step)
- Safety/emergency plan
- Service animals
- Money management assistance
- Housekeeping services

#### **Adaptations**

- Adaptive equipment (e.g. adaptive cribs and child care equipment, communication devices, specialized computer software, cooking/ feeding equipment)
- Adaptation to physical environment (e.g. ramps, lower counters, level handled door knobs)

# Additional resources

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#### Web sites

#### The Arc of the United States

www.thearc.org 202.783.2229

#### **Bazelon Center for Mental Health Law**

http://www.bazelon.org 202.467.5730

#### **Center for Advanced Studies** in Child Welfare

http://ssw.che.umn.edu/cascw.html 612.624.4231

#### The National Association of Councils on Developmental Disabilities

www.nacdd.org 703.739.4400

#### **National Council on Independent** Living (NCIL)

http://www.ncil.org 202.207.0334

#### **National Disability Rights Network**

www.napas.org 202.408.9514

### **Parents with Disabilities Online**

http://www.disabledparents.net

# **Though the Looking Glass**

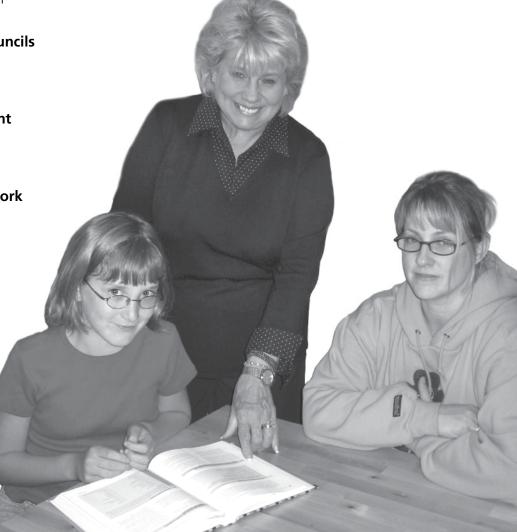
www.lookingglass.org 800.644.2666

# **Recent Court decisions**

State courts across the country have been involved in cases involving parental rights of people with disabilities. Two recent state Supreme Court decisions have ruled in favor of the parent with a disability, for varying reasons. These cases are offered as a resource for advocacy groups to learn more about this challenging issue.

In re D.A., 113 Ohio St. 3d 88 (Ohio 2007)

In re C.W., 211 S.W.3d 93, Case No. SC88049 (Mo. 2007)



#### School of Social Work

#### http://ssw.che.umn.edu

Since its founding in 1917, the University of Minnesota School of Social Work (SSW) has contributed to the development of the field. It is ranked as one of the nation's best schools of social work—a leader in creative learning ventures through distance education, interactive television, satellite, and independent study. SSW is home to five dynamic research and training centers and the national Social Welfare History Archives. As the nation's first graduate social work program at a public land-grant university, the SSW has been a national and international leader in education and scholarship.

Through its Master of Social Work (M.S.W.) program, SSW prepares professionals for social work practice, equipping them with advanced skills to help individuals, groups, and communities enhance or restore social functioning and maximize favorable social conditions. The curriculum emphasizes social justice, the value of human diversity, and the empowerment of oppressed people, and emphasizes practice focusing on client strengths and problem-solving capacities to foster change at multiple levels. Our Ph.D. program develops scholars who provide new knowledge and leadership in the rapidly changing world of social welfare.

#### Suggested citation

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# **Institute on Community Integration**

#### http://ici.umn.edu

The Institute on Community Integration (ICI) was founded out of the belief that universities had a great deal to offer people with disabilities in our society. Bringing together expertise from different fields — from the health sciences to education, psychology, social work and many others — creates a center of academic strength to push the frontiers of knowledge, and to connect that knowledge and the development of ideas to the needs of people with disabilities, their families and their communities.

ICI, a University Center for Excellence in Developmental Disabilities based at the University of Minnesota, is home to six affiliated centers and over 100 projects. Its work is guided by the belief that all people with disabilities should experience the benefits of family and community living while receiving the services necessary to fully develop their potential in the areas of personal independence, self-care, educational and vocational achievement and social participation.

### **Project participants**

This project was undertaken in cooperation with parents affected by this issue, the Center for Advanced Studies in Child Welfare, the Minnesota Governor's Council on Developmental Disabilities, the Metropolitan Center for Independent Living, the Minnesota Disability Law Center, the Office of Ombudsman for Mental Health and Developmental Disabilities, the National Alliance on Mental Illness-Minnesota, Through the Looking Glass, and the Idaho State Independent Living Council.

The College of Education & Human Development

University of Minnesota

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