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**Court of Appeals**  
STATE OF NEW YORK

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In the Matter of LACEE L.,  
a child under the age of eighteen years,

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STEPHANIE L.,  
Respondent-Appellant,

—against—

ADMINISTRATION FOR CHILDREN'S SERVICES,  
Petitioner-Respondent.

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**PROPOSED BRIEF OF THE ARC, THE AUTISTIC SELF-ADVOCACY  
NETWORK, DISABLED PARENTS' RIGHTS, AND ROBYN M. POWELL  
AS AMICI CURIAE IN SUPPORT OF APPELLANT**

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July 27, 2018

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## CORPORATE DISCLOSURE STATEMENT

Pursuant to Rule 500.1(f) of the Rules of Practice of the Court of Appeals of the State of New York, proposed *amici curiae* The Arc, the Autistic Self-Advocacy Network, and Disabled Parents' Rights disclose that they are non-profit organizations that have no parents or subsidiaries. Disabled Parents' Rights has no affiliates. The Arc has a nationwide network of nearly 700 state and local chapters, a complete list of which is available here: <https://www.thearc.org/find-a-chapter/state-executive-directors-list>. The Autistic Self-Advocacy Network is a national grassroots disability rights organization for the autistic community, with a number local chapters throughout the United States, a complete list of which is available here: <http://autisticadvocacy.org/chapters/#usachapters>.

Dated: July 27, 2018  
Brooklyn, New York



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## **INTEREST OF AMICI CURIAE**

The Arc of the United States, founded in 1950, is the nation's largest community-based organization of and for people with intellectual and/or developmental disabilities (I/DD). The Arc promotes and protects the rights of people with I/DD and actively supports their full inclusion and participation in the community. The Arc has a vital interest in ensuring that people with I/DD receive the protections and supports provided by law. The Arc has long taken the position that people with I/DD have the right to make decisions about having and raising children and to have access to the proper supports on an individual basis to assist them in raising their children within their own homes. With over 600 state and local chapters, The Arc is well positioned to comment on the impact of state child welfare practice upon people with I/DD and their children.

The Autistic Self Advocacy Network (“ASAN”) is a national, private, nonprofit organization, run by and for autistic individuals. ASAN provides public education and promotes public policies that benefit autistic individuals and others with developmental or other disabilities. ASAN’s advocacy activities include combating stigma, discrimination, and violence against autistic people and others with disabilities; promoting access to health care and long-term supports in integrated community settings; and educating the public about the access needs of autistic people. ASAN takes a strong interest in cases that affect the rights of

autistic individuals and others with disabilities to participate fully in community life and enjoy the same rights as others without disabilities.

Disabled Parents Rights (“DPR”) is a Colorado non-profit organization dedicated to combating discrimination that impacts parenting for disabled parents. DPR was founded in response to the widespread involvement of parents with disabilities in child welfare cases. DPR represented respondent parents in dependency and neglect cases throughout the state of Colorado, and provides technical assistance to attorneys representing parents across the United States and abroad. DPR staff teaches continuing legal education, seminars, and classes to attorneys, judges, and social workers about best practices in representing disabled parents, as well as compliance with state and federal law and regulations. Through direct representation, education, research, and training, DPR combats discrimination that impacts parenting for disabled parents. Focused exclusively on the rights and representation of disabled parents, DPR is particularly suited to comment on the treatment of parents with disabilities in child welfare systems.

Robyn M. Powell is a disability rights attorney with more than a decade of professional experience. Currently, she is a Research Associate at the Lurie Institute for Disability Policy as well as a disability law and policy consultant. Ms. Powell also serves as co-investigator of the National Research Center for Parents with Disabilities. She is Team Leader of the Disabled Parenting Project. For nearly five

years, Ms. Powell served as an Attorney Advisor at the National Council on Disability (“NCD”), an independent federal agency that advises the President and Congress on matters concerning people with disabilities.

## PRELIMINARY STATEMENT

*Amici* The Arc, the Autistic Self-Advocacy Network, Disabled Parents' Rights, and Robyn M. Powell respectfully submit this brief in support of Appellant Stephanie L., the mother of Lacey L. *Amici* are individuals and organizations with experience working with persons with intellectual and other developmental disabilities both inside and outside of the child welfare system. They are concerned that, if affirmed, the Appellate Division's ruling that the protections of the Americans with Disabilities Act (ADA) are not justiciable in the context of family court proceedings would allow the perpetuation of systemic bias against parents with intellectual disability throughout New York State's child welfare system.

*Amici* urge this Court to recognize the important role that this state's family and appellate courts have in enforcing the rights of parents with intellectual disability to the supports and accommodations they need to preserve and reunify their families.

In ruling on this important legal question, this Court should understand that it is not a formality whether the ADA's protections apply here. If given the benefit of those protections—including the individualized consideration to which they are entitled—many parents who currently are unnecessarily separated from their children might not be. *Amici* fully support the legal arguments made by the Appellant and by other *Amici* regarding the requirements of the ADA and its applicability to child welfare proceedings, and do not repeat those arguments here.

Rather, *Amici* submit this brief in order to provide the Court with information about the meaning of a diagnosis of “intellectual disability”; the long history of discrimination against persons with intellectual disability who wish to become parents or to parent their own children; and the social science and personal stories that show how persons with intellectual disability can flourish as parents when provided the supports and services they need to thrive. Individuals with intellectual disability can learn how to parent, improve their parenting skills, and parent successfully with appropriate support. Robust enforcement of the reasonable accommodations requirement of the ADA is essential to guaranteeing that they have an equal opportunity to do so. This Court should reverse the Appellate Division’s finding that this requirement does not apply to the judicial proceedings at issue here.

## ARGUMENT

In November 2012, “Sara Gordon,” a young woman with an intellectual disability, gave birth to a daughter, “Dana.”<sup>1</sup> Ms. Gordon’s plan was to raise her

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<sup>1</sup> “Sara Gordon” and “Dana Gordon” are pseudonyms used by the United States Department of Justice and Department of Health and Human Services in their joint letter of findings to the Massachusetts Department of Children and Families. See Letter from U.S. Dep’t of Justice, Civil Rights Div. & U.S. Dep’t of Health and Human Serv., Office for Civil Rights, to Erin Deveney, Interim Comm’r, Mass. Dep’t of Children & Families (Jan. 29, 2015) (hereinafter DOJ/HHS Letter of Findings), [https://www.ada.gov/ma\\_docf\\_lof.pdf](https://www.ada.gov/ma_docf_lof.pdf). This narrative is adapted from articles in the Daily Beast, see Elizabeth Picciuto, *Mom With Disabilities and Daughter Reunited After Two-Year Court Battle*, The Daily Beast (Mar. 16, 2015), <https://www.thedailybeast.com/mom-with-disabilities-and-daughter-reunited-after-two-year-court-battle>, and New York Magazine, see Lisa Miller, *Who Knows Best*, New York Magazine (Jan. 24, 2016), <https://www.nymag.com>

daughter with the assistance of her parents, with whom she lived; her mother had already quit her job in order to be a full-time help to Ms. Gordon in raising Dana. Yet before Ms. Gordon and her daughter even left the hospital, the Massachusetts Department of Children and Families had opened an investigation into Ms. Gordon's fitness to parent. A caseworker reported that she saw Ms. Gordon burp Dana incorrectly, and that Ms. Gordon had missed a feeding due to her inability to read an analog clock. Rather than instructing Ms. Gordon in how to burp her daughter, or supplying her with a digital clock, the Department removed Dana from her mother and placed her in foster care on the grounds that Ms. Gordon's intellectual disability rendered her unable to provide adequate care for her daughter.

Ms. Gordon's battle to be reunited with her daughter lasted for over two years. Instead of conducting an individualized assessment of Ms. Gordon's current and future capacity to parent Dana with in-home services and family supports, the Department focused on obtaining a diagnosis and repeatedly emphasized the importance of determining Ms. Gordon's IQ before they could figure out how to assist her. While acknowledging that Ms. Gordon might benefit from working one-on-one with a parent aide during visits to strengthen her parenting skills, it did not actually provide these services for more than eight months and limited the aide's participation to the last thirty minutes of Ms. Gordon's one-hour-per-week visits

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[www.thecut.com/2016/01/how-intelligent-to-be-a-parent.html](http://www.thecut.com/2016/01/how-intelligent-to-be-a-parent.html), and from the letter of findings itself.

with Dana. Despite their plan to parent Dana together, the Department also forbade Ms. Gordon's mother from assisting her daughter with Dana's care during visits, as caseworkers wanted to see if Ms. Gordon could parent "on her own."

In January 2015, the United States Department of Justice and Department of Health and Human Services intervened, issuing a joint letter of findings concluding that the Department of Children and Families had violated Ms. Gordon's rights under the ADA by acting based on assumptions regarding Ms. Gordon's ability to parent and by denying her a full and equal opportunity to participate in and benefit from the Department's program to pursue reunification with her daughter. Had the federal government not intervened, Ms. Gordon may have lost her daughter forever; despite Ms. Gordon's efforts to do whatever was required to bring her daughter home, and her plan to parent alongside her own parents, Dana's permanency goal had been changed from reunification to adoption before the letter of findings was issued. Instead, two months later, Ms. Gordon and her daughter were reunited.

As the present appeal shows, the experience of Sara and Dana Gordon is not a unique one. Each day, parents with intellectual disability contend with prejudicial child welfare practices based on the presumption that they are unfit to parent. While some persons with intellectual disability may be unable to parent safely, all parents with intellectual disability deserve the opportunity to establish that they can parent, and access to the services and supports that they need to do so, if they can.

Persons with intellectual disability are a heterogeneous group, with a wide range of strengths and needs, and they, like all parents, must be assessed and treated as individuals. Far too often, they are not. Although current social science establishes that parents with intellectual disability are not inherently unable to parent and that they can learn and apply new parenting skills, as well as telling us what services and supports work best for these parents, parents with intellectual disability remain subject to longstanding, prejudicial assumptions about their inability to parent. If we are to give parents with intellectual disability and their children a full and equal opportunity to preserve their families, we must dispel these assumptions.

**I. PERSONS WITH INTELLECTUAL DISABILITY HAVE A WIDE RANGE OF ABILITIES AND CHALLENGES AND THEIR NEEDS MUST BE ASSESSED INDIVIDUALLY AND HOLISTICALLY.**

There are an estimated 7 million persons with intellectual disability<sup>2</sup> in the United States, and while each of these individuals share a common diagnosis, they have a wide range of abilities, needs, and experiences. Moreover, intellectual disability is not a static diagnosis; with appropriate supports and teaching techniques, individuals with intellectual disability can learn, apply new knowledge, and maintain new skills. Individuals with intellectual disability must be

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<sup>2</sup> “Intellectual disability” is a term of art that is used in the singular. *Amici* use “intellectual disability” instead of “mental retardation,” except when the latter term appears in quoted case law or other sources. *See Hall v. Florida*, 134S Ct 1986, 1990 (2014) (“[p]revious opinions of this Court have employed the term ‘mental retardation.’ This opinion uses the term ‘intellectual disability’ to describe the identical phenomenon”).

approached *as* individuals, not on the basis of generalizations or stereotypes, and their strengths and needs must be assessed holistically, with reference to each individual's social context, experiences, past opportunities for growth, and the supports and services available to assist them both now and in the future.

A diagnosis of intellectual disability is defined by three criteria:

(1) Significant intellectual limitations, as measured by a valid and standardized intelligence test administered by a trained professional. Significant intellectual limitations usually means an IQ score at least two standard deviations below the mean.

(2) Significant limitations in at least one of the three domains of key adaptive skills: conceptual skills (e.g., language, writing, reading, money concepts), social skills (e.g., self-esteem, respect of rules, vulnerability), or practical skills (e.g., daily living, vocational, safety).

(3) Age of onset before the age of 18 years old.

*See* American Association on Intellectual and Developmental Disabilities, *Intellectual Disability: Definition, Classification, and Systems of Supports* 3-12, 44 (11th Ed. 2010) (hereinafter *AAIDD Manual*). *See also* American Psychological Association, *Diagnostic and Statistical Manual on Mental Disorders* 33-36 (5th ed. 2013) (hereinafter *DSM-V*) (giving criteria for diagnosis of intellectual disability).

Persons with intellectual disability are a heterogeneous group and have very different strengths and needs for support. The *DSM-V* divides individuals with intellectual disability into four groups: mild, moderate, severe, and profound. *See* *DSM-V*, at 34-36. Because these categories are generally determined solely based

on IQ score alone—without consideration of an individual’s adaptive functioning or her social context—many experts on intellectual disability question their usefulness in practice. *See, e.g.,* Donald L. Macmillan et al., *A Challenge to the Viability of Mild Mental Retardation as a Diagnostic Category*, 62 *Exceptional Child*. 356 (1996) (discussing concerns about IQ-based classifications). As the American Association on Intellectual and Developmental Disabilities (“AAIDD”)—the oldest and largest interdisciplinary organization of professionals and citizens concerned with intellectual and developmental disabilities—explains, while IQ-based categories “might be appropriate for a research study in which measured intelligence is a relevant variable, it is not useful for decisions about residential or educational placement. Instead, such classification decisions should be based on more meaningful assessment information and planning procedures related to the purpose of developing support systems.” AAIDD Manual, at 22.

In order to better account for the wide range of individual characteristics of persons diagnosed as having intellectual disability, the AAIDD recommends reliance upon a “multidimensional model of human functioning” that takes a more holistic approach to the assessment of individuals with intellectual disability. *See* AAIDD Manual, at 13-19. First, as the above quote indicates, it is important to keep the purpose of any particular assessment in mind when drawing conclusions about an individual’s functioning. Capacity is fluid, and a person who has

limitations in one area of functioning may very well have strengths in another area, even within the same general category of adaptive functioning (i.e., conceptual, social, or practical). *Id.* at 7, 16. Second, capacity is contextual. An individual may function extremely well day-to-day in the community in which she was raised, but struggle in an unfamiliar setting that places different expectations upon her. An appropriate assessment will take account of the environment in which the person with intellectual disability functions or is expected to function, and her ability to do so successfully. *Id.* at 7, 17-18, 162. Third, individuals with intellectual disability do not exist in a vacuum, and they cannot be assessed in a vacuum either. In determining an individual's ability to function within a particular environment or to succeed in a particular role, the assessment must take account of the supports available to her. *Id.* at 18, 21-26. *See also* Maurice Feldman & Marjorie Aunos, *Comprehensive, Competence-Based Parenting Assessment for Parents with Learning Difficulties and Their Children* 7 (2011) (hereinafter *Feldman & Aunos, Competence-Based Parenting Assessment*).

In addition to the variability of an individual's capacity at a particular moment in time, depending on the relevant task, social setting, and available supports, an individual's capacity is not static over time. Contrary to discriminatory historical understandings of the diagnosis, persons with intellectual disability have the ability to learn and grow, both intellectually and in terms of their

adaptive functioning. *See* Nat’l Insts. Health, Fact Sheet: Intellectual and Developmental Disabilities 2 (Oct. 2010), [https://report.nih.gov/nihfactsheets/Pdfs/IntellectualandDevelopmentalDisabilities\(NICHHD\).pdf](https://report.nih.gov/nihfactsheets/Pdfs/IntellectualandDevelopmentalDisabilities(NICHHD).pdf). As the AAIDD explains: “With appropriate personalized supports over a sustained period, the life functioning of the person with [intellectual disability] will generally improve.” AAIDD Manual, at 7. “Improvement in functioning should be expected from appropriate supports, except in rare cases,” and “[a] lack of improvement in functioning can serve as a basis for reevaluating the profile of needed supports.” *Id.*

In short, while all persons with intellectual disability do have certain characteristics in common—namely, significant limitations in intellectual and adaptive functioning—the way that these limitations affect them varies from person to person, circumstance to circumstance, and over time. As discussed below, this is no less true with regard to ability to parent than in any other context.

## **II. PERSONS WITH INTELLECTUAL DISABILITY HAVE LONG FACED DISCRIMINATION AND OTHER OBSTACLES TO HAVING AND PARENTING CHILDREN.**

Persons with intellectual disability have experienced a lengthy history of discrimination. With a diagnosis of intellectual disability seen as an insurmountable barrier to achieving independence and self-sufficiency, individuals with intellectual disability have been involuntarily institutionalized, segregated

from the community, and denied access to education, employment opportunities, and romantic relationships. *See, e.g.*, James W. Trent Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (1994).

Notably, despite the Supreme Court’s many pronouncements about the importance of the parental relationship, *see, e.g.*, *Santosky v. Kramer*, 455 U.S. 745, 753 (1982) (discussing “[t]he fundamental liberty interest of natural parents in the care, custody, and management of their child”), discrimination against persons with intellectual disability has long focused specifically on their role as parents and potential parents. Most shamefully, women with intellectual disability were targeted as early subjects of what would become a sweeping global eugenics movement that spanned from 1890 to the 1970s. *See* Adam Cohen, *Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carrie Buck* 299-320 (2016). Approximately 70,000 people were forcibly sterilized in the United States during the eugenics movement—a practice upheld by the Supreme Court in a 1927 decision that has never been overruled. *Buck v. Bell*, 274 U.S. 200, 206 (1927). *See, e.g.*, *Vaughn v. Ruoff*, 253 F.3d 1124, 1129 (8th Cir. 2001) (citing *Buck* for the proposition that involuntary sterilization is not always unconstitutional, and that “the mentally handicapped, depending on their circumstance, may be subjected to various degrees of government intrusion that would be unjustified if directed at other segments of society”); *Doe ex rel. Tarlow v. D.C.*, 920 F. Supp. 2d 112, 119

(D.D.C. 2013) (“[T]he Supreme Court has never reconsidered its holding that compulsory sterilization can comport with the requirements of substantive due process—that the public interest may sometimes justify involuntary sterilization.”).

Over the last several decades, there has been significant progress in both the acknowledgment and the enforcement of the rights of individuals with intellectual disability in all aspects of life. Persons with intellectual disability have become more integrated into society and have moved from segregated institutions into community-based living environments, where they can live, work, learn, and recreate among their peers with and without disabilities and lead self-determined lives. Yet discrimination against parents with intellectual disability persists. Even today, several states still have some form of involuntary sterilization law, and women with intellectual disability “still contend with coercive tactics designed to encourage sterilization or abortion because they are not deemed fit for motherhood.” National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 15 (Sept. 27, 2012) (hereinafter NCD Report), <http://www.ncd.gov/publications/2012/Sep272012>.

When persons with intellectual disability do have children, they face shockingly disproportionate odds of having those children removed from their care. Removal rates for the children of parents with intellectual disability have been found to be as high as 80 percent, and once these families become involved

with the child welfare system, there is evidence that they are “permanently separated at disproportionately high rates” as well. *Id.* at 18, 78. *See also* S. Singh, et al., Parental Disability and Termination of Parental Rights in Child Welfare, Minn-Link Br. No. 12 (2012), <http://www.cehd.umn.edu/ssw/cascw/research/minnlink/minnlinkpublications.asp> (parents with disabilities may have their rights terminated over three times as frequently as parents without disabilities).

The disproportionate representation of parents with intellectual disability in child welfare proceedings and the disproportionately negative outcomes for their families extends well beyond anything warranted by these parents’ actual abilities for several reasons. First, mandated reporters, caseworkers, attorneys, and judges are largely influenced by common misunderstandings and stereotypes about the abilities of persons with intellectual disability. Primary among these are the belief that persons with intellectual disability are simply unable to parent successfully, and the belief that they cannot improve their parenting and other daily living skills, or can do so only to a very limited extent. As legal scholar Robert Hayman, Jr. explained in his groundbreaking Harvard Law Review article:

Differential treatment of the mentally retarded parent rests logically and legally on two empirical premises. The first is that the bare “fact” of mental retardation substantially increases the likelihood that the mentally retarded person is or will be a deficient parent. In the juvenile court process, this likelihood may rise to the level of a substantial certainty, and may even amount to a literal equation of mental and parental deficiency. The second premise is that the bare

“fact” of mental retardation substantially decreases the likelihood that the parent will be able to remedy deficiencies in parenting.

See Robert L. Hayman, Jr., *Presumptions of Justice: Law, Politics, and the Mentally Retarded Parent*, 103 Harv. L. Rev. 1201, 1212 (1990) See also, e.g., David McConnell & Gwynnyth Llewellyn, *Stereotypes, Parents with Intellectual Disability, and Child Protection*, 24 J. Soc. Welfare & Fam. L. 297, 310 (2002) (hereinafter *Stereotypes, Parents with Intellectual Disability, and Child Protection*) (describing how parents with intellectual disability fare in child protection and court processes and offering both an empirical and legal critique of frequently encountered presumptions about their parenting capacity); Susan Kerr, *The Application of the Americans with Disabilities Act to the Termination of the Parental Rights of Individuals with Mental Disabilities*, 16 Contemp. Health L. & Pol'y 387, 402 (2000) (“[a]t any step in the process, societal prejudices, myths, and misconceptions [about parents with mental disabilities] may rear their heads[.]”).

Second, while consultation with properly qualified experts on parents with intellectual disability could help to counter these biases, caseworker and court reliance upon—and deference to—the conclusions of psychological and psychiatric experts in cases involving issues of intellectual disability often contributes to the disproportionality described above, rather than counteracting it. See *Stereotypes, Parents with Intellectual Disability, and Child Protection*, at 308-09 (“The discriminatory treatment of parents with intellectual disability may also

be reinforced by expert opinion. Legal scholars observe that courts frequently rely on expert opinion without any evidence of actual parenting performance.”)

The psychiatric and psychological experts used in these cases are often not experts on the topic of intellectual disability specifically, and very rarely so on the topic of parenting with intellectual disability. The social science they rely upon is frequently outdated, inadequate, and overwhelmingly focused on establishing the negative impact parents with intellectual disability are presumed to have on their children. NCD Report, at 185-86. *See also* Tim Booth & Wendy Booth, *Parenting with Learning Disabilities*, 23 Br. J. Soc. Work 459, 461-462 (1993) (hereinafter Booth, *Parenting with Learning Disabilities*) (discussing problems with older research on parents with intellectual disability). The assessments they employ are not specifically tailored to assess parenting ability, nor are they based upon best practices. *See Stereotypes, Parents with Intellectual Disability, and Child Protection*, at 308-09; NCD Report, at 129-37. *See also, generally*, Feldman & Aunos, *Competence-Based Parenting Assessment* (providing a model for a parenting assessment for parents with intellectual disability). Frequently, expert predictions of an individual’s ability to successfully parent their child are based upon nothing more than a standard intelligence test, an assessment of general adaptive functioning, and, in some cases, a brief observation of parent and child together in a formal, institutional setting. *See* Brandon R. White, *Termination of*

*Parental Rights of Mentally Disabled Parents in New York State*, 34 Buff. Pub. Int. L.J. 1, 13, 33-36 (2015-16) (discussing the lack of standards for and deficiencies of expert testimony regarding intellectual disability); Elizabeth Lightfoot & Traci LaLiberte, *Parental Supports for Parents with Intellectual and Developmental Disabilities*, 49 Intell. & Develop. Disabilities 1, 3 (2011) (hereinafter *Parental Supports*) (contrasting the “easier” task of diagnosing disability with completion of a parenting assessment). This approach essentially collapses an assessment of parenting ability into a simple test for intellectual disability, thereby “confirming” the prejudice that parents with intellectual disability are unable to parent.

Third, parents with intellectual disability are routinely held to higher and less flexible standards than those applied to parents without disabilities. *See* The Arc, Position Statement: Parents with Intellectual and/or Developmental Disabilities 1 (2008), <https://www.thearc.org/document.doc?id=3642>. Contrary to the diagnostic principles discussed in section I, above, the ability of individuals with intellectual disability to parent successfully is not being judged in context and with reference to available supports. For example, the common mantra that “it takes a village to raise a child” is accepted with regards to parents without disabilities who rely on family and other extended support networks to parent effectively, but parents with intellectual disability are frequently required to establish that they can parent alone, without any assistance from family, friends, or

other members of their support network. *See, e.g.,* DOJ/HHS Letter of Findings, at 12 (criticizing the Massachusetts Department of Children and Family services for its position that Sara Gordon had to be able to parent “on her own” in order to be reunited with her daughter, despite the fact that she never intended to parent alone); Kathy Ballard, *When Doing Your Best Isn’t Good Enough: Parents with Intellectual Disabilities and the Child Welfare System* 76-77 (2015) (quoting a child protective caseworker’s statement that “in other cases when we don’t have a parent with a disability they want to build up the support system; they always want to know what they can do to make the support better. But with these families it’s like they are testing them to prove something, but they don’t test everyone.”)

Fourth, child welfare agencies fail to afford parents with intellectual disability the same access or opportunities to benefit from parenting services as parents without disabilities. Instead of receiving services tailored to their specific needs, parents with intellectual disability are regularly given the same generic case plans as other parents, and are not given any additional support to understand and complete these plans. *See* IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, *Parents Labeled with Intellectual Disability*, 21 *J. Applied Research in Intell. Disabilities* 296, 298 (2008). This is especially an issue given that many case plans require parents to keep up with a busy schedule of meetings, classes, and appointments; travel to new locations on

their own; and remember and act upon complicated verbal instructions after hearing them once—tasks which many persons with intellectual disability have difficulty completing without support. When parents with intellectual disability are unable to comply with the requirements of their service plans—which may or may not have any connection to their ability to parent successfully with appropriate support—they are deemed “noncompliant,” and this noncompliance is seen as a sign of their inability to parent their children, or their lack of interest in doing so. *See* NCD Report, at 89 (discussing how one-size-fits-all service plans set parents with disabilities up to fail). *Cf.* Maurice A Feldman & Munazza Tahir, *Skills Training for Parents with Intellectual Disabilities*, Handbook of Evidence-Based Practices in Intellectual and Developmental Disabilities 615-31, 615 (2016) (“Ineffective parenting skills training could lead to the removal of the child, as it is often assumed that because of the parent’s [intellectual disability] he is incapable of benefiting from training, rather than that the training was not effective.”)

The “power of the eugenics ideology persists.” NCD Report, at 15. While persons with intellectual disability are increasingly living in the community, engaging in romantic relationships, having children, and participating in all aspects of communal life, they continue to face a greatly elevated risk of family separation as a result of systemic bias, lack of understanding, and lack of access to

appropriate services and supports. The result is the exclusion of persons with intellectual disability from parenting and of family life, in violation of federal law.

### **III. PERSONS WITH INTELLECTUAL DISABILITY CAN AND DO PARENT SUCCESSFULLY.**

As discussed above, “discrimination against parents with intellectual disability is predicated on two overarching assumptions.” Robyn M. Powell, *Safeguarding the Rights of Parents with Intellectual Disabilities in Child Welfare Cases: The Convergence of Social Science and Law*, 20 CUNY L. Rev. 127, 141 (2016). “[C]hild welfare policies, practices, and adjudications are based—implicitly and at times, explicitly—on the postulation that parents with intellectual disability are inherently unfit because of their disability,” and that they simply cannot learn how to parent. *Id.* Parents with intellectual disability are denied access to appropriately tailored services and supports that could help them to reunify with their children—and their failure to complete their generic service plans is then seen as confirmation of their inherent unfitness and inability to learn.

Yet both of these assumptions are demonstrably untrue. There is now a solid body of social science establishing not only that parents with intellectual disability can improve their parenting skills, but also what kinds of training and assistance works best for these parents. *See Stereotypes, Parents with Intellectual Disability, and Child Protection*, at 306-07 (summarizing research on the ability of

parents with intellectual disability to learn parenting skills, and the most effective interventions). In addition, we have access to the stories of persons with intellectual disability and their children, which tell us what it is like to parent with an intellectual disability, or to be parented by a person with an intellectual disability. These stories make clear that people with intellectual disability can parent when provided with appropriate supports that enable them to thrive.

A. Persons with Intellectual Disability Can Parent Successfully.

As *Amicus Curiae* The Arc notes in its position statement on “Parents with Intellectual and/or Developmental Disabilities”:

The presence of an intellectual and/or developmental disability does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals solely on the basis of intellectual and/or developmental disabilities. Parents with intellectual and/or developmental disabilities should have access to support as needed to perform parental roles just as they are supported in other valued social roles and activities.

The Arc, Position Statement: Parents with Intellectual and/or Developmental Disabilities 1 (2008), <https://www.thearc.org/document.doc?id=3642>.

Despite longstanding stereotypes to the contrary, studies have consistently found that there is no clear relationship between intelligence and parenting ability. *See, e.g.,* Booth, *Parenting with Learning Disabilities*, at 461-462 (“On this point, however, the research evidence is consistent and persuasive. There is no clear relationship between parental competency and intelligence.”); Katie MacLean &

Marjorie Aunos, *Addressing the Needs of Parents with Intellectual Disabilities: Exploring a Parenting Policy Project*, 16 J. Develop. Disabilities 18, 18-19 (2010) (summarizing the initial group of studies that “discredited the idea that one’s IQ was the sole predictor of child outcomes”); *Stereotypes, Parents with Intellectual Disability, and Child Protection*, at 304 (“The findings on parental adequacy are reasonably consistent ... The clear message is that parents with intellectual disability are not a homogenous group and ... IQ score is a poor predictor.”).

Parents with intellectual disability “do not form a homogeneous group with a common history of family pathology. There are big variations among them in their characteristics and circumstances. Their experiences of parenthood and child-rearing show more similarities than differences with other ordinary families from the same social background, and the problems they encounter or present tend to mirror those of other 'at risk' groups.” Booth, *Parenting with Learning Disability*, at 476. As with the children of parents without disabilities, contextual characteristics—such as low socioeconomic status or a lack of social support—have a significant impact on the developmental outcomes of children of parents with intellectual disability, rather than the parent’s disability status alone. *See, e.g.,* Eric Emerson & Philip Brigham, *The Developmental Health of Children of Parents with Intellectual Disabilities: Cross-Sectional Study*, 35 Res. Dev. Disabilities 917 (2014) (low socioeconomic status rather than a parent’s disability

predicted child behavior problems); Maurice A. Feldman & Nicole Walton-Allen, *Effects of Maternal Mental Retardation and Poverty on Intellectual, Academic, and Behavioral Status of School-Age Children*, 101 Am. J. Mental Retardation 352 (1997) (decreased social support for parents can lead to worse academic and behavioral outcomes for children of parents with intellectual disability).

Accordingly, when a parent with an intellectual disability *is* struggling with parenting her children, the first step should be to perform an individualized assessment to determine what the parent's individual strengths are; what outside stressors—such as housing or income insecurity—might be affecting the family; what supports are already available to the parent and to the family as a whole; and what additional supports, services, and education could be provided to improve the family's functioning. Feldman & Aunos, *Competence-Based Parenting Assessment*, at 4-6. While a clear diagnosis may be an important part of this process, given the role that diagnosis plays in funding and access to services, an IQ test and an assessment of adaptive functioning—the basic elements of an evaluation for intellectual disability—cannot be the beginning and the end of an assessment of parenting capability. Instead, a proper approach would include a competence-based parenting assessment—including observations of parent-child interactions in a natural setting—and would also include an assessment of the family's circumstances, non-disability-related needs, and available supports.

*Parental Supports*, at 3 (2011). *See also generally* Feldman & Aunos, Competence-Based Parenting Assessment (providing a detailed model for an appropriate parenting assessment for parents with intellectual disability).

Moreover, assessment of parenting ability should include the assumption that parents with intellectual disability will receive and benefit from a wide range of services and supports, depending on their circumstances, many of which may be required by law as reasonable accommodations. In addition to generalized services such as housing and income support, and parenting-specific services such as parenting training or childcare assistance, parents with intellectual disability often benefit from disability-specific services available through the Medicaid waiver program that are aimed at improving their individual adaptive functioning, such as housekeeping and budgeting assistance, self-advocacy and assertiveness training, and vocational training. Feldman & Tahir, at 625. They also benefit from flexible, strengths-based, and creative casework by social workers with experience working with parents with disabilities. A social worker who thinks to read the case plan to her client, rather than expect them to read it themselves, or who comes up with a way to set reminders for a parent who has difficulty using the clock to tell when she needs to meet her son's bus, can make a huge difference for those families with just a little effort. Kathy Ballard, *When Doing Your Best Isn't Good Enough: Parents with Intellectual Disabilities and the Child Welfare System* 78-81 (2015).

When it comes to parenting training for parents with intellectual disability, numerous studies have shown what works: “The more effective parent education programs designed specifically for parents with intellectual disability typically involve intensive (primarily behavioral) intervention. Using task analysis, instructions, modeling, feedback, and tangible reinforcement, parent educators have taught parents with intellectual disability a wide-range of important child-care skills.” Maurice A Feldman & Laurie Case, *Teaching Child-Care and Safety Skills to Parents with Intellectual Disabilities Through Self-Learning*, 24 J. Intell. & Develop. Disability 27, 28 (1999). Parents with intellectual disability tend to learn better through one-on-one, hands-on lessons delivered in their homes or in home-like environments, rather than in classroom settings. *See, e.g.*, MacLean & Aunos, at 19-20; Feldman & Tahir, at 618-20; Kathy Ballard, *When Doing Your Best Isn’t Good Enough: Parents with Intellectual Disabilities and the Child Welfare System* 22-23. They also benefit from checklists, clear visual reminders of each step of a task, and concrete instructions that include a basic rationale for completing the task, *i.e.* “It is important to copy your child’s words because that is how she will learn to talk.” Feldman & Tahir, at 620. When parents with intellectual disability receive training that is geared to their method of learning, studies have shown that they are not only able to learn new skills, but are also able to retain this knowledge over time, to the benefit of their children. *Id.* at 615, 623.

Ultimately, what parents with intellectual disability need is what all parents need: support. With the proper support, parents with intellectual disability can learn new skills, address problems that arise in their lives, and thrive as parents. Social science tells us what kinds of services and supports work best for these parents, while robust and routine enforcement of the ADA—with its requirements of individualized assessment and reasonable accommodations—helps to ensure that they are given access to the specialized services and supports they need.

B. Persons with Intellectual Disability Do Parent Successfully.

Unfortunately, the stories of parents with intellectual disability largely confirm the existence of widespread systemic bias against them and their families. Parents with intellectual disability report having been pressured not to have or keep their children, *see, e.g.*, Tim Booth & Wendy Booth, *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties* 43 (1994); having their children removed at birth or soon after, before they ever had a chance to prove themselves able to parent, *see, e.g.*, NCD Report, at 95-96; having their children removed based on speculation alone, *see, e.g., id.* at 97; and living in fear of a call to child protective services and the investigation and removal they anticipate will result from that, *see, e.g., id.* As Michael Stein, an internationally recognized disability expert, explains: “Even with the accomplishment of parental tasks through different techniques, mothers with disabilities fear that mainstream society will

remove their children because of prevailing misconceptions. The result is the diminishment of parental joy for otherwise able and loving parents.” *Id.* at 84.

At the same time, the stories of parents with intellectual disability reveal a great many successes. There are parents like Sara Gordon, discussed above, who are able to overcome the presumption of unfitness and reunite with their children, and parents like Dameris L., who was under an order of guardianship when she gave birth to her daughter, but who had sufficient support from her husband, extended family, and community—including literacy classes, homemaking services, and childcare—to allow her not only to flourish as a mother but also to convince the court that the guardianship order should be revoked. *See In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848 (Surr. Ct., N.Y. Cnty 2012).

There are also parents like Bonnie Brown, who was the subject of a number of articles in 2009 describing how she was parenting her then-twelve-year-old academically gifted daughter, Maya, with support from a friend and services provided by an independent living program. Ms. Brown took group and one-on-one parenting skills classes before Maya was born, and received 20 hours a week of support through her independent living program during Maya’s childhood, including assistance with cooking, shopping, and bills. Maya described her mother as a “nurturer” who was “always there for her.” Vicky Thomas, *Intellectual Disability Can’t Stop Mother-Daughter Team*, Delco Times (Oct. 2, 2009),

<http://www.delcotimes.com/article/DC/20091002/NEWS/310029992>. Looking at photographs of Ms. Brown and Maya together, it is hard to imagine them apart—but Ms. Brown, like Sara Gordon, and Dameris L., would likely not have been able to be the mother she was to Maya without appropriate support. Ms. Brown’s need for support does not make her less of a parent. Rather, the support she receives allows her to be the parent she is, to her daughter’s benefit.

The stories of parents with intellectual disability also reveal the depth of love between parents and their children, and the importance of the parent-child relationship, even in the face of profound difficulties. Researchers Tim and Wendy Booth interviewed a number of adult children of parents with intellectual disability, and discovered that the vast majority recalled happy, if not entirely carefree, childhoods. Most of the interviewees expressed positive feelings of love and affection towards their parents, and all of them maintained close contact with their parents, especially their mothers. Notably, those who had been removed by child welfare authorities had subsequently re-established and maintained contact with their families of origin. Tim Booth & Wendy Booth, *Growing Up With Parents Who Have Learning Difficulties* 67-68 (1998). As the Booths summarize, noting the importance of the parent-child relationship to all of their adult subjects:

For children born into families that need a lot of support it is tempting to invent a future where they would be better off away from their parents. Looking back from their position in the adult world it is equally possible to see the harm that can be done by jumping too

readily to any such conclusion. The question of what is in the best interests of the child always invites a response in the future tense. The true answer often appears very different in hindsight. Unable to escape these uncertainties, it is important that policy-makers and practitioners bear in mind that the state can more easily provide the supports a family needs in order to cope than it can replace the love of a child for a parent or a parent for a child. As one person in our study said, what mattered most as a child was “the fact that we were living with people we loved.”

*Id.* at 208.

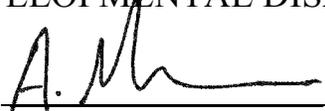
## CONCLUSION

Persons with intellectual disability can and do parent successfully. When parents with intellectual disability are struggling to parent successfully, they can benefit from appropriately tailored services and supports, and can learn, apply new knowledge, and maintain new parenting skills. Yet, despite this, parents with intellectual disability remain subject to discrimination and are overrepresented within the child welfare system. Because the Family Court’s ability to determine whether child welfare agencies are in compliance with the reasonable accommodations requirement of the ADA is vital to the success of parents with intellectual disability once they become involved in the child welfare system, *Amici* support the Appellant’s request that the Appellate Division’s decision be reversed and the case be remanded to the Family Court for a finding that New York City’s Administration for Children’s Services failed to make the required reasonable efforts towards reunification and did not comply with the ADA.

Dated: Brooklyn, New York  
July 27, 2018

Respectfully submitted,

BROOKLYN LAW SCHOOL  
DISABILITY & CIVIL RIGHTS CLINIC:  
ADVOCATING FOR ADULTS WITH  
INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES

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**NEW YORK STATE COURT OF APPEALS  
CERTIFICATE OF COMPLIANCE**

I hereby certify pursuant to 22 N.Y.C.R.R. Part 500.13(c)(1), that the foregoing brief was prepared on a computer using Microsoft Word. A proportionally spaced typeface was used, as follows:

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