

New York Supreme Court
APPELLATE DIVISION—FIRST DEPARTMENT

In the Matter of Commitment of the Guardianship and Custody of

XAVIER BLADE LEE BILLY JOE S., also known as Xavier S.,
CLAUDIA KATHLEEN ROSE STORM S., also known as Claudia S.,

Dependent Children Under 18 years of Age Pursuant to § 384-b
of the Social Services Law of the State of New York.

THE CHILDREN'S AID SOCIETY,
Petitioner-Appellant.

JOSEFINA S.,
Respondent-Respondent.

**PROPOSED BRIEF OF THE ARC, THE AUTISTIC SELF-ADVOCACY
NETWORK, THE CIVIL RIGHTS EDUCATION AND ENFORCEMENT
CENTER, DISABILITY RIGHTS ADVOCATES, PROFESSOR ROBYN M.
POWELL, AND PROFESSOR CHARISA SMITH AS *AMICI CURIAE***

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PRELIMINARY STATEMENT

Amici The Arc, the Autistic Self-Advocacy Network, the Civil Rights Education and Enforcement Center, Disability Rights Advocates, Professor Robyn M. Powell, and Professor Charisa Smith respectfully submit this brief in support of Respondent-Respondent Josefina S., the mother of Xavier and Claudia. *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 misunderstanding of, and systemic bias against, parents with intellectual disability throughout the child welfare system lead to the unnecessary termination of these parents' rights. *Amici* recognize the important role of New York courts in enforcing the rights of parents with intellectual disability, including mandating the provision of supports and accommodations needed to preserve and reunify their families. *Amici* urge this Court to uphold the Family Court's thoughtful and nuanced decision and order dismissing the petition for termination of Josefina S.'s parental rights to Xavier and Claudia on the ground that the agency failed to meet its burden to show, by clear and convincing evidence, that Josefina S. permanently neglected her children.

Amici fully support the arguments made by counsel for Josephina S. and the child Claudia regarding the validity of the Family Court's legal analysis, and do not repeat those arguments here. Rather, *Amici* submit this brief to augment this Court's

knowledge about the meaning of a diagnosis of “intellectual disability”; the long-standing research demonstrating that persons with intellectual disability can flourish as parents when provided with the supports and services they need to thrive; and the importance of the specific supports at issue in this case. Individuals with intellectual disability can learn how to parent, improve their parenting skills, and parent successfully with appropriate support. Robust and routine enforcement of the provisions of the Social Service Law requiring agencies to make diligent efforts to address the particular problems faced by a family before moving to terminate a parent’s rights—precisely the sort of enforcement provided by the Family Court in this case—is essential to guaranteeing that they have an equal opportunity to do so.

ARGUMENT

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 disability¹ 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,

¹ “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.

and maintain new skills. Individuals with intellectual disability must be 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 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).

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 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 other individuals 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.

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 holistic approach to the assessment of individuals with intellectual disability. *See* AAIDD Manual, at 13-19. First, as noted above, it is important to keep the purpose of the 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 have strengths in another, 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 takes account of the environment in which the person now functions or will be expected to function. Environment can have an enormous impact on the ability to function successfully. *Id.* at 7, 17-18, 162.

Third, individuals with intellectual disability cannot be assessed in a vacuum. In determining an individual's ability to function within a particular environment or 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, an individual's capacity is also 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://archives.nih.gov/asites/report/09-09-2019/report.nih.gov/nihfactsheets/Pdfs/IntellectualandDevelopmentalDisabilities\(NICHHD\).pdf](https://archives.nih.gov/asites/report/09-09-2019/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 affect of these limitations vary from person to person, circumstance to circumstance, and over time. As discussed below, this variance is no less true with regard to ability to parent than in any other context.

II. PERSONS WITH INTELLECTUAL DISABILITY CAN AND DO PARENT SUCCESSFULLY.

As Professor Robyn Powell explains, “discrimination against parents with intellectual disability is predicated on two overarching assumptions. ... [C]hild welfare policies, practices, and adjudications are based—implicitly and at times, explicitly—on the postulation that parents with intellectual disabilit[y] are inherently unfit because of their disability,” and that they simply cannot learn how

to parent. 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). 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 a solid body of social science establishing both that parents with intellectual disability *can* improve their parenting skills, and what kind of training and assistance works best for them. See David McConnell & Gwynnyth Llewellyn, *Stereotypes, Parents with Intellectual Disability, and Child Protection*, 24 J. Soc. Welfare & Fam. L. 297, 306-07 (2002) (hereinafter *Parents with Intellectual Disability*) (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 countless experiences of persons with intellectual disability and their children, which illustrate what it is like to parent with intellectual disability, or to be parented by a person with intellectual disability. These accounts make clear that persons with intellectual disability can parent when provided with appropriate supports.

A. Persons with Intellectual Disability Can Parent Successfully.

As 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 (2013), <https://thearc.org/position-statements/parents-with-intellectual-developmental-disabilities>.

Despite longstanding stereotypes to the contrary, studies have consistently found that there is no clear relationship between intelligence and parenting ability. See, e.g., Tim Booth & Wendy Booth, *Parenting with Learning Disabilities*, 23 Br. J. Soc. Work 459, 461-462 (1993) (hereinafter Booth, *Parenting with Learning Disabilities*) (“On this point . . . 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 initial studies that “discredited the idea that one’s IQ was the sole predictor of child outcomes”); *Parents with Intellectual*

Disability, 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 Disabilities*, at 476. As with the children of parents without disabilities, contextual characteristics—such as racial inequities, extreme poverty 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 itself. 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); 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).

Accordingly, parenting weaknesses should never be assumed and when a parent with intellectual disability is struggling to parent 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 entire assessment of parenting capability. Instead, a proper approach would include a competence-based parenting assessment—incorporating 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. See Elizabeth Lightfoot & Traci LaLiberte, *Parental Supports for Parents with Intellectual and Developmental Disabilities*, 49 *Intell. & Develop. Disabilities* 1, 3 (2011). See also generally Feldman & Aunos, *Competence-Based Parenting Assessment* (providing a detailed model for an appropriate 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 adaptive functioning, such as housekeeping and budgeting assistance, self-advocacy and assertiveness training, and vocational training. Maurice A Feldman & Munazza Tahir, *Skills Training for Parents with Intellectual Disabilities*, Handbook of Evidence-Based Practices in Intellectual and Developmental Disabilities 615-31, 625 (2016). For parents with intellectual disability “involved in multiple, complicated systems,” collaboration between caseworkers involved in their child protective matter and the other, disability-specific service providers and programs is pivotal. Sandra T. Azar, et al., *Practice Changes in the Child Protection System to Address the Needs of Parents with Cognitive Disabilities*, 7 J. Public Child Welfare 610, 612 (2013); see also Sandra T. Azar and Kristin N. Read, *Parental Cognitive Disabilities and Child Protection Services: The Need for Human Capacity Building*, 36 J. of Sociology

and Social Welfare 127, 143-44 (2009) (“Networks of professionals in the local community that have expertise relevant to cognitive challenges are necessary.”).

Parents with intellectual disability also benefit from flexible, strengths-based, individualized casework by social workers with experience working with parents with disabilities. Straightforward steps by social workers, such as reading aloud the case plan to a client who has a hard time retaining written information, or developing alternative reminders for a parent who has difficulty using a clock to tell when she needs to meet her son’s bus, can make a significant difference for families with little effort. *See* Kathy Ballard, *When Doing Your Best Isn’t Good Enough: Parents with Intellectual Disabilities and the Child Welfare System* 78-81 (2015); Elizabeth Lightfoot & M. Zheng, *Promising Practices to Support Parents with Intellectual Disabilities*, Practice Notes, No. 34. (Fall 2019), https://cascw.umn.edu/wp-content/uploads/2019/11/PN34_WEB508.pdf.

When it comes to parenting training for parents with intellectual disability, numerous studies have shown what works: the more effective programs “typically involve intensive (primarily behavioral) intervention. Using task analysis, instructions, modeling, feedback, and tangible reinforcement, parent educators have taught parents with intellectual disabilit[y] 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. *See, e.g.*, MacLean & Aunos, at 19-20; Feldman & Tahir, at 618-20; Ballard, at 22-23. Parents also benefit from checklists, 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 parents are not only able to learn new skills, but are also able to retain this knowledge over time. *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 law—including the provisions of the Social Service Law requiring agencies to make “affirmative, repeated, and meaningful efforts” to address the particular problems faced by a family before moving to terminate a parent’s rights—ensures that they are given access to the specialized services and supports they need. *Matter of Sheila G.*, 61 N.Y.2d 368, 385 (1984) (“An agency must always determine the particular problems facing a

parent with respect to the return of his or her child and make affirmative, repeated, and meaningful efforts to assist the parent in overcoming [them].”)

B. Persons with Intellectual Disability Do Parent Successfully.

Unfortunately, the experiences of parents with intellectual disability largely confirm the existence of widespread systemic bias. Parents with intellectual disability report being pressured to not have or keep their children; having their children removed at birth or soon after, before they ever had a chance to prove themselves able to parent; having their children removed based on speculation alone; 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.*, Tim Booth & Wendy Booth, *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties* 43 (1994); National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 95-96, 97 (2012) (hereinafter NCD Report), [http://www.ncd.gov/publications/2012/Sep 27 2012](http://www.ncd.gov/publications/2012/Sep%202012). 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 accounts of parents with intellectual disability reveal a great many successes. There are parents like “Sara Gordon”—whose treatment by the Massachusetts Department of Children and Families (“DCF”) was the subject of an investigation and lengthy findings letter by the federal departments of Justice and Health and Human Services in 2015, and who fought for over two years before overcoming DCF’s presumption of her unfitness to be reunited with her daughter, “Dana”²—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 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

² “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. Ms. Gordon’s experience is described in the findings letter itself, as well as in various news stories. *See, e.g.*, Lisa Miller, *Who Knows Best*, New York Magazine (Jan. 24, 2016), [https:// www.thecut.com/2016/01/how-intelligent-to-be-a-parent.html](https://www.thecut.com/2016/01/how-intelligent-to-be-a-parent.html).

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), https://www.delcotimes.com/news/intellectual-disability-can-t-stop-mother-daughter-team/article_29b605d0-cae1-57a2-b05e-9804233c7bbe.html. 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. Researchers Tim and Wendy Booth interviewed a number of adult children of parents with intellectual disability, and discovered that the vast majority recalled happy, beneficial 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 removed by child welfare authorities subsequently re-established contact and worked to rebuild relationships 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.

III. JOSEFINA S.’S CASE ILLUSTRATES THE IMPORTANCE OF DISABILITY-INFORMED SERVICES, COLLABORATIVE, STRENGTHS-BASED CASEWORK, AND CONSULTATION WITH EXPERTS.

Josefina S.’s experience illustrates the general principles described above. By her own description, it took Josefina S. longer to learn the same things as others. *Matter of Xavier Blade Lee Billy Joe S.*, 62 Misc. 3d 1212(A), 2019 N.Y. Slip Op. 50120(U), *4 (Fam. Ct., Bronx Cty 2019). By others’ description, she had difficulty with travel, time management, and multitasking. *Id.* She could read and write, but her reading skills were “not so good,” and she had difficulty following

written directions. *Id.* at *4, 9. She also struggled to implement verbal instructions and required reminders to apply new skills. *Id.* at *7.

Yet, when provided with appropriately tailored supports—such as dyadic therapy sessions that emphasized modeling over verbal prompting—Josefina S. learned and retained new skills, and progressed in her ability to parent. *Id.* at *8; *see also id.* at *9. Under Dr. Alkon’s guidance, Josefina S. improved her ability to engage in developmentally appropriate play. *Id.* at *8. Similarly, with Ms. Rodriguez’s assistance, Josefina S. worked out a routine for changing her children’s diapers during visits and began to implement it without prompting. She improved her ability to manage her children during visits, and met all of the goals of her therapeutic visitation sessions. *Id.* The successful growth of Josefina S.’s parenting skills in these individualized, one-on-one supportive relationships with providers who worked to earn her trust underscores the necessity of providing tailored and appropriate services to parents with intellectual disability.

At issue in the decision below are two specific steps that the agency failed to take to assist Josefina S. The Family Court found these omissions essential to the agency’s obligation to make particularized and targeted diligent efforts to strengthen and encourage the parental relationship between Josefina S. and her children. First, the agency failed to take the basic step of referring Josefina S. to the New York State Office for People with Developmental Disabilities

(“OPWDD”), through which she could have received the day habilitation services specifically recommended in her psychological evaluation. *Id.* at *5, 14. Second, the case planner assigned to Josefina S.’s case, Emily Rubin, had no training in working with parents with intellectual disability and did not consult with an expert either to develop an appropriate service plan for Josefina S. and her children or to determine how to adapt her typical case management practices to best assist Josefina S. *Id.* at *4, 15.

As the Family Court recognized, these omissions were not minor failings. OPWDD services would have provided Josefina S. with programs designed explicitly to support people with intellectual disabilities in strengthening daily living skills, while consultation with an expert would have allowed Ms. Rubin to better understand the services Ms. S. actually needed and to adapt her casework practices to meet those needs. Both are baseline efforts required to provide appropriate supports to parents with intellectual disability.

A. OPWDD is a Vital Resource for Parents with Disabilities.

In its decision, the Family Court faulted the agency for failing to refer Josefina S. to OPWDD.³ *Xavier Blade*, 2019 N.Y. Slip Op. 50120(U), *14. Had

³ Petitioner-Appellant’s brief suggests that its ability to refer Josefina S. to OPWDD services was somehow “blocked” by the Family Court’s decision that she should not be required to complete an additional parenting class at Sinergia and should, instead, engage in one-on-one services. (Pet.-App. Br. at 49, 51, 58-59.) This assertion reflects a flawed understanding of how one accesses OPWDD. As the Family Court understood, enrollment in OPWDD requires engagement with the “Front Door” process and is entirely distinct from enrollment in other

the agency referred her to OPWDD,⁴ and had she been found eligible, Josefina S. could have received day habilitation services, as specifically recommended in her psychiatric evaluation. *Id.* at *5. As OPWDD explains, day habilitation services “can assist individuals to acquire, retain or improve their self-help, socialization and adaptive skills, including communication, travel and other areas in adult education.” OPWDD, A Variety of Day Services: Day Habilitation, <https://opwdd.ny.gov/types-services/day-services>.

Socialization and adaptive skills include cooking, housekeeping, budgeting and time-management—all skills that would assist Josefina S. in parenting her children. In general, the activities in a day habilitation program “are designed to foster the development of skills and appropriate behavior, greater independence . . . relationship building, self-advocacy and informed choice.” *Id.* See also *Xavier Blade*, 2019 N.Y. Slip Op. 50120(U), *14 (day habilitation services are “designed precisely to help people with developmental disabilities daily living skills”). Day habilitation can be provided in a person’s own home or in the community where

programs, including programs provided by Sinergia. The Family Court’s decision not to require Josefina S. to attend an additional parenting class at Sinergia had no bearing on the agency’s ability or obligation to refer her to OPWDD.

⁴ In most cases, a mere “referral” to OPWDD would be insufficient, given the complexity of the application and enrollment processes. See OPWDD, *Front Door Access to Services*, https://opwdd.ny.gov/sites/default/files/documents/040_Front%20Door%20Access%20To%20Services_41119.pdf. However, because the agency in this case did not even refer Josefina S. to OPWDD, the sufficiency of a referral alone to establish that an agency made “diligent efforts” is not at issue here.

the skills are to be used. *See* AHRC, *Day Habilitation Without Walls*, <https://www.ahrcnyc.org/services/community/adult-day-services/without-walls/>.

Day habilitation is not the only service that Josefina S. and other parents with intellectual disability can obtain through OPWDD. As the primary state agency responsible for providing services to people with intellectual disability, OPWDD offers a range of meaningful and tailored services to the adults it serves. *See* OPWDD, *Person-Centered Supports and Services that Help You Live the Life You Want to Live*, <https://opwdd.ny.gov/types-services> (listing areas of support including employment, housing, assistive technology, and others). Many of these services—such as day and community habilitation, transportation training, budgeting, self-advocacy skills, and pre-vocational and vocational training—build independence while also strengthening skills inherent to parenting. It is no surprise that once Josefina S. was found eligible for and enrolled in OPWDD services—through the efforts of her attorney and well after the termination of parental rights petition was filed—she “made enormous strides in her independence.” *Xavier Blade*, 2019 N.Y. Slip Op. 50120(U), *14. By the time of her testimony in the termination proceeding, Josefina S. had moved out of her mother’s home, learned how to travel to a large number of destinations across all five boroughs, and learned to cook simple meals, which she prepared for her older son, Logan, who was at home with her on “trial discharge” status. *Id.* at *7, 14.

In sum, while OPWDD is aimed at providing general support to all persons in New York State with intellectual disability, OPWDD services can significantly enhance the support ACS and agencies provide to disabled *parents* specifically. *See* Feldman & Tahir, at 625 (explaining that services for a parent with intellectual disability “should include not just parent education, but also support for ancillary and personal issues,” such as housekeeping and money management; “social skills, self-advocacy and assertiveness training”; vocational training; “building natural systems of support”; and “accessing financial and community resources”); Azar & Read, at 143-44 (“The CPS system should focus attention on building ongoing networks of support within existing systems for the benefit of both [parents with cognitive disabilities] and CPS workers.”). Connecting parents to OPWDD may alleviate burdens on individual caseworkers and reduce the chance that parents with intellectual disability reenter the child welfare system by increasing their connections to supportive resources that can assist families in times of stress and crisis. *See* Azar & Read, at 143-44.

B. Working with Parents with Intellectual Disability Requires Thoughtful, Conscious Casework and Consultation with Experts.

OPWDD services are a supplement to, not a replacement for, agency casework and services in a child protection case. As a baseline, best practices for working with parents with intellectual disability involves utilizing a strengths-based approach. *See* Lightfoot & Zheng, at 3 (noting that “though most parents

with intellectual disabilities can effectively parent their children with appropriate supports . . . they often encounter professionals who focus primarily on their weaknesses”); Booth, *Parenting with Learning Disabilities*, at 463 (“When working with parents, practitioners must beware *the presumption of incompetence*; approach the case *with an open mind*; and avoid what might be called *the mistake of false attribution* or seeing all the problems the parents may be having entirely in terms of their leaning disability.”) (emphasis in original). To guard against bias, caseworkers must “actively consider plausible alternative explanations for any perceived parental deficiencies” in order to avoid incorrectly attributing challenges to disability. David McConnell *et al.*, *Child Maltreatment Investigations in Canada: Main and Moderating Effects of Primary Caregiver Cognitive Impairment*, *Child Maltreatment*, 9 (2020). Where a parent with intellectual disability is not benefiting from a service, “this may have more to do with a failure on the part of services to make reasonable accommodations than it does with the parent’s cognitive impairment.” *Id.*

Case workers and other providers can implement a variety of adjustments to their typical style of interacting with clients. Depending on the parent’s individual needs, such modifications can include modeling behavior, using concrete, clear, plain language, “repeating key concepts, listening for comprehension, and using pictorial or other visual communication methods.” Lightfoot & Zheng, at 3; *see*

also Feldman & Case, at 28; MacLean & Aunos, at 19-20; Feldman & Tahir, at 618-20; Ballard, at 22-23, 78-81, 90. Notably, these modifications, recommended by experts in working with individuals with intellectual disability and supported by social science research, are similar to the accommodations recommended in the federal EEOC guidance referenced by the Family Court. *Xavier Blade*, 2019 N.Y. Slip Op. 50120(U), *14 (describing a “broad range of accommodations” identified by the EEOC, including “training or detailed instructions to do the job, which may include having the trainer or supervisor give instructions at a slower pace; . . . breaking job tasks into sequential steps required to perform the task; using charts, pictures, or colors; [and] providing a tape recorder to record directions as a reminder of steps in a task”) (citation omitted).

While it is not realistic—or necessary—to ask that each caseworker be an expert in working with parents with intellectual disability, caseworkers must receive some training or consult with an expert. See Traci LaLiberte, *Are We Prepared? Child Welfare Work With Parents With Intellectual and/or Developmental Disabilities*, 7 J. Public Child Welfare 633, 636-37 (2013); Ballard, at 91 (“Parents with ID are entitled to workers who know, understand and can address their learning needs.”); Lightfoot & Zheng, at 3. As the Family Court found, the case planner assigned to Josefina S.’s case, Emily Rubin, was not an expert in working with individuals with intellectual disability and had received no

training in the area. *Xavier Blade*, 2019 N.Y. Slip Op. 50120(U), *4, 15. Nor did she consult with an expert to develop Josefina S.’s service plan or to learn how to adapt her methods of communicating and otherwise working with parents to Josefina’s S.’s needs.⁵ *Id.* As a result, Ms. Rubin developed a counterproductive relationship with Josefina S., wherein Ms. Rubin was “quick to criticize” and viewed her as unable or unwilling to improve her parenting in response to Ms. Rubin’s suggestions, while Josefina S. saw Ms. Rubin as her enemy rather than a source of assistance or support. *See id.* at *2, 6-7, 11. Ms. Rubin’s negative assumptions about Josefina S. were then circularly reinforced as Josefina S. failed to respond to her case work—case work that she had not individualized to meet Josefina S.’s needs as a person with an intellectual disability. *See id.* at 7, 9.

Josefina S.’s case typifies how a positive, collaborative approach to parenting can facilitate greater learning and engagement from a parent, whereas a negative, weakness-focused approach can lead to challenges and stalled learning. In contrast to her relationship with Ms. Rubin, Josefina S.’s relationships with service providers Dr. Alkon and Ms. Rodriguez, who focused on building trust and empowering her, led to her growth as a parent. Both Dr. Alkon and Ms. Rodriguez took the time to figure out how best to communicate with Josefina S., with Dr.

⁵ In fact, ACS has a Developmental Disabilities Unit where such consultation could have taken place; yet inexplicably, no such consultation occurred in this case.

Alkon explicitly “talk[ing] to Ms. S. about her learning process, which required repetition and hands-on practice.” *Id.* at *8. They also identified and affirmed her strengths as a parent, including her gentleness, calmness, dedication to improving her parenting, and evident love for her children. *Id.* As a result, Josefina S. was “receptive and open to constructive criticism” in her interactions with them, and able to learn and apply the skills they taught her. *Id.* at *8-9.

Josefina S.’s positive relationships with Dr. Alkon and Ms. Rodriguez also demonstrate another standard practice for case workers working with parents with intellectual disability which can easily be adopted at no or little additional cost: adaptation of traditional parenting skills based on the individual parent’s needs and understanding. *See* Lightfoot & Zheng, at 3; Ballard, at 78-81. Caseworkers can utilize technology, such as assisting parents with setting reminder alarms or practicing using the calendar function on their smartphone. If the parent does not have a smartphone, caseworkers can work with them to become familiar with paper calendaring and demonstrate the efficacy of written reminders around the home. Here, Ms. Rubin provided Josefina S. a printout of maps to get to new locations. *Xavier Blade*, 2019 N.Y. Slip Op. 50120 (U), *15. While this is a start, it may not be an appropriate accommodation for someone with gaps in analytical skills, such as Josefina S. *See id.* (noting that Josefina S.’s reading and analytical skills were limited). Depending on the specific needs of a parent, a more useful

accommodation may be provision of a list of directions, teaching the parent to use a maps function and turning on GPS navigation so directions can be read aloud, or providing the parent with audio or visual reminders about how to access directions on the phone. Still another option, and indeed what it seems would have been most helpful to Josefina S.—who increased her facility with traveling by repeating trips and becoming more comfortable with a given route, *id.*—would be to accompany a parent directly on several repeated trips to allow for modeling and in-the-moment travel training. *See* MacLean & Aunos, at 19-20 (discussing the importance of hands-on, *in vivo* training for parents with intellectual disability); Feldman & Tahir, at 619-20 (discussing the importance of skill-and-experience based rather than abstract, “classroom-based” training).

Caseworkers without expertise and experience working with parents with intellectual disabilities can and must consult with experts in the development of reunification plans. The highly individualized nature of intellectual and developmental disability, and the extent to which an individual parent’s capacity can vary depending on the context and environment in which they are, means that each parent “must be engaged and assessed based upon their abilities, strengths, limitations and challenges, access and use of resources, etc.” Traci LaLiberte & Elizabeth Lightfoot, *Parenting with Disability—What Do We Know?*, CW360 The Intersection of Child Welfare and Disability: Focus on Parents 4 (Fall 2013),

<https://casew.umn.edu/wp-content/uploads/2013/12/Fall-2013-CW360-WEB.pdf>.

Such detailed, individualized assessments require knowledge some child welfare caseworkers lack. While caseworkers would ideally have the relevant training themselves, when they do not, minimum standards of practice require consultation to ensure the caseworker understands the needs of the client well enough to design an effective, individualized plan for reunification. *Id.* (consultation with an expert is “essential” for delivery of “appropriate, accessible services). Failure to consult with an expert can, unfortunately, infect all aspects of casework and service provision for a parent with intellectual disability. As Josefina S.’s case demonstrates, caseworkers may become frustrated that their typical services are ineffective and begin to believe erroneously that the parent is “unable” to retain skills. *See Xavier Blade*, 2019 N.Y. Slip Op. 50120 (U), *5-6. When this happens, parents are often asked to complete multiple, duplicative services, none of which address the parent in ways they can understand. Such cycles do not benefit the families involved and cannot satisfy New York’s requirement of individualized service planning. *Matter of Sheila G.*, 61 N.Y.2d 368, 385 (1984).

CONCLUSION

Persons with intellectual disability can and do parent successfully. When parents with intellectual disability are struggling to parent successfully, they benefit from appropriately tailored services and supports, and can learn, apply new

knowledge, and maintain new parenting skills. Yet, parents with intellectual disability remain subject to discrimination and are overrepresented within a child welfare system that regularly fails to provide them with services that accommodate their disabilities. Robust enforcement of the provisions of the Social Service Law requiring agencies to make diligent efforts to address the particular problems faced by a family is essential to guaranteeing that parents with intellectual disability have an equal opportunity to benefit from services provided by the child welfare system, strengthen their families, and parent their children.

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