



GEORGETOWN UNIVERSITY CENTER FOR
EXCELLENCE IN DEVELOPMENTAL DISABILITIES

Transition Supports for Parents with Intellectual and Developmental Disabilities Partnership

ACTION PLAN & PROJECT FINAL REPORT FOR THE DISTRICT OF COLUMBIA

Submitted By

Georgetown University Center
for Excellence in Developmental Disabilities

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WHY ARE WE PARTNERING?

“When parents get their children into school- they won’t feel left out with no services available. They need to know that they’re not alone when going through this process.”

10/2020

If adults [with disabilities] are planning to become parents, they should receive parenting classes and have a mentor. Then, when it gets frustrating, they won’t run away from it [their parenting responsibilities].”

October 2020



Mr. Ricardo & Mrs. Donna Thornton

Parent Partners

“When my oldest son was little, I feel like I got more help with doing things for him like getting him enrolled in school, in after school or summer camp, getting healthcare, everything like that. As he got older there was not as much help, and that made it harder for me to learn about services and to get them.”

“Being my two son’s Mom is the biggest job I ever had. I wish I had a map or some kind of book that said go this way, or that way, go to this agency or not that agency, but if there is one, I never saw it. And the agencies don’t talk to each other, so they can’t always say, try this one, or that one...It can make you as a Mom feel lost, until you can get some help.”

October 2020



Ms. Arnetta Kinney

Parent Partner

Grant Opportunity and Overview

The Georgetown University Center for Excellence in Developmental Disabilities (GUCEDD) was one of ten UCEDDs nationally selected to conduct a Community-based Transition Partnership Planning project. This one-year planning grant (7/1/20 – 8/31/21) was funded by the US Department of Health and Human Services, Administration for Community Living (ACL), Administration on Disabilities (AoD) specifically: “AoD seeks to fund up to ten planning grants for existing UCEDDs to convene partnerships in states to develop plans for community integration, through the creation of sustainable community-based transition pilots, for youth and adults with intellectual disabilities and development disabilities.”

Need and Context

Historic and present day view of parents with intellectual and developmental disabilities

The desire to become a parent is an inherently natural instinct and occurrence. Laws in all states and the District of Columbia that specify parental rights including legal custody of their children acknowledge being a parent. However, for persons with disabilities, including intellectual and developmental disabilities (IDD), this inherent desire has long been pre-empted by societal biases. Despite the increasing number of people with disabilities becoming parents, most still struggle with family, community, and social ambivalence about this choice.¹ For example, the legacy of the Eugenics movements continues to manifest today. Adults with IDD are discouraged from being parents in general and in some instances encouraged to terminate pregnancies because of biases about their capacity. Childrearing is a challenge for all parents and like other parents, parents with IDD can benefit from support with traversing each critical period in their child’s development and transitions across the life course. Nonetheless, this support may be less available for those most vulnerable, including parents with intellectual disabilities.²

What are intellectual disability and developmental disabilities?

The American Association on Intellectual and Developmental Disabilities defines intellectual disability as significant limitation originating before the age 18 in intellectual functioning and in social and practical skills to function adaptively.³ This definition of intellectual disability encompasses many social and practical skills in everyday life. Persons with intellectual disability have trouble with general cognitive capacity, such as learning, reasoning, planning, problem solving, abstract thinking, understanding complex ideas, and learning from experience; and may have lower than average communication and judgement abilities.⁴ Persons with intellectual disability may also have challenges with conceptual, social, practical, and occupational skills.⁵

Intellectual disability varies significantly from person to person in degree of disability.⁶ States and the District of Columbia have different criteria (cognitive and adaptive functioning) to both diagnose intellectual disability and establish eligibility for services and supports. It is estimated that up to 5% of the general population have intellectual disability.⁷ While frequently used together, intellectual disability and developmental disabilities are defined differently and have different legal ramifications depending on state statutes. Figure 1 cites the federal definition of developmental disability under which intellectual disability is subsumed. Since a person can have a developmental disability but not an intellectual disability, both terms (ID and DD) are used in specific instances in this Action Plan because of state law and regulations in the District of Columbia.

Figure 1: Developmental Disabilities Assistance and Bill of Rights Act of 2000⁸

The term developmental disability means a severe, chronic disability of an individual that:
is attributable to a mental or physical impairment or combination of mental and physical impairments;

- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in 3 or more of the following areas of major life activity: Self-care, (2) Receptive and Expressive language, (3) Learning, (4) mobility, (5) Self-direction, (6) Capacity for independent living, and (7) Economic self-sufficiency; and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or

Parenting – what it means for persons with intellectual and developmental disabilities

The Olmstead Decision of 1999⁹ required that people with disabilities be in the least restrictive environment, and as people with disabilities were increasingly included in the community, the likelihood of engagement in intimate relationships, getting married, and having children increased. In recent times, there has been a shift in how people with disabilities exercise their choices and rights and these extend to parenting. While more people with intellectual disability and developmental disabilities are having children, many are involved in the child welfare system and have their parental rights terminated at high rates.¹⁰⁻¹² Despite a number of studies showing that having an intellectual disability or developmental disabilities is not necessarily correlated with the likelihood for abuse or neglect, this still happens.^{13, 14} The reasons for high rates of child welfare involvement are multifactorial, ranging from negative attitudes of child welfare workers¹⁵ to lack of appropriate supports¹⁶ to state laws which explicitly name intellectual disability as one of the grounds for terminating parental rights.¹⁷

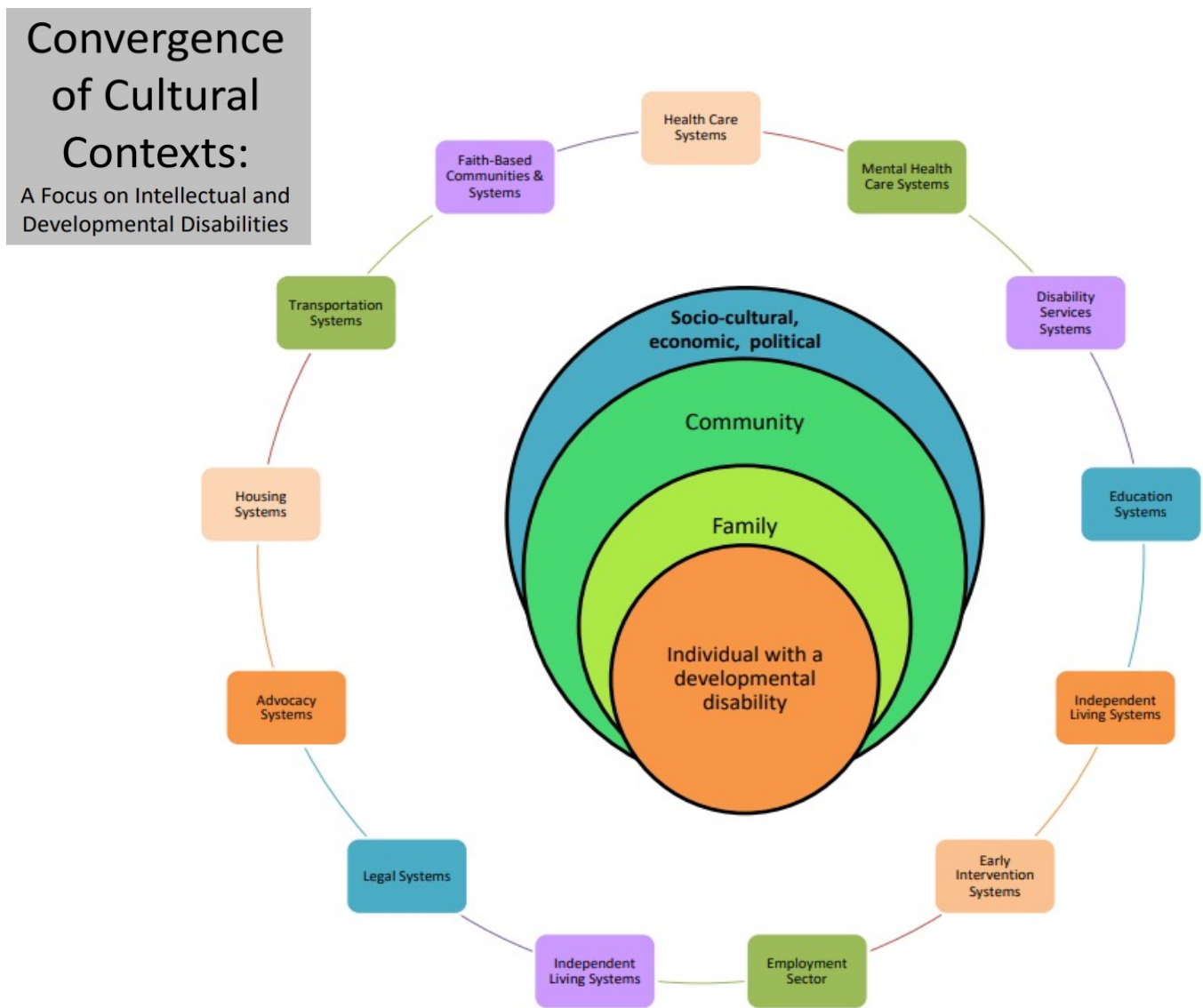
Families headed by parents with IDD face a number of challenges, including economic instability, unsafe and inadequate housing, poor health, and unequal access to health care, and higher than normal rates of depression, anxiety and stress.¹⁸ Moreover, parents with IDD grapple with high rates of child removal, poverty, social isolation, and multiple service agencies and systems that have few structures in place to provide effective cross-system responses and are often poorly equipped to meet the parents' unique learning and support needs. Many factors influence parents' ability to parent their children; and may include victimization, lack of exposure to appropriate models of parenting, poor relationships resulting in psychological stressors, and cultural influences.¹¹ Susceptibility to these factors, effects the coping strategies of parents with IDD as they strive to respond to the changing demands of raising a child, including developmental transition stages, while simultaneously ensuring that they address other aspects of their lives.

Parenting with intellectual disability and developmental disabilities in the District of Columbia

Persons with intellectual disability or developmental disabilities, including parents and their families, may require involvement in multiple systems throughout the life course. Convergence of Cultural Contexts¹⁹ provides a framework and graphic representation of the possible array of systems. Refer to Figure 2.

This may include but is not limited to DC government - Superior Court, Child and Family Services Administration, Department on Disability Services, DC Public Schools, DC Health, Department of Behavioral Health; and other non-profit community-based organizations such as the Strengthening Families Collaboratives, self-advocacy and advocacy groups, and health/social service agencies tailored to specific racial and ethnic communities. Each system has its own culture – norms, rules, language, decision-making processes, approaches to communication, defined roles and responsibilities, ways of interacting with those seeking/receiving services and so forth. The culture of each of these systems is learned by employees and transmitted through policies, structures, and practices in both formal and informal ways. Parents with intellectual disability or developmental disabilities in the District face the challenge of navigating these systems with varying degrees of effectiveness and success. Eligibility in the current system of services and supports under the auspices of the Department on Disability Services only includes adults (aged 18 and over) with intellectual disability. Persons with developmental disabilities are not eligible unless they have both diagnoses.

Figure 2: Convergence of Cultural Contexts



The literature documents that many parents with intellectual or developmental disabilities benefit from parent education and supportive services. Such services increase their knowledge and skills about child growth and development, nurturance, parent-child interactions, and creating learning experiences.^{20, 21} Currently there are few formal supports in the District of Columbia to assist parents with intellectual and developmental disabilities in their parenting roles for their children during transitional stages through the life course. Government-funded formal supports for these adults focus on their disability rather than their roles as parents and caregivers. While there have been a number of promising interventions developed to assist people with disabilities in general in parenting, these tend to focus on parent training rather than supports to increase parenting skills.^{22, 23} This is not unique to the District.

Supports for the important social role of parenting, which is normative for many working-age adults, have received little attention in the field of disabilities in general and IDD in particular. Supports are defined as “resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning.”²⁴ The concept of supports is crucial in the lives of all people, and especially for those with intellectual and developmental disabilities. While parent education was an important component in eight years of implementing a program for parents with intellectual and developmental disabilities in the District of Columbia, GUCEDD faculty documented supports were even more essential. There are few formal constructed sources of support to assist parents with intellectual disability and developmental disabilities in the role of parenting and many of these parents have to rely on informal supports. Importantly, a review of the current literature reveals that there are no formal systems of support that help parents with intellectual and developmental disabilities negotiate their children’s developmental transitions from early childhood through post-secondary education or work.

Demographic makeup of parents with intellectual and developmental disabilities in the District of Columbia

The most recently reported nationally representative estimates regarding parents with disabilities found that 6 percent (4.1 million) of parents of children under the age of 18 had disabilities.²⁵ In the District of Columbia it is estimated that 2.8 % or 2,700 parents with a disability have a cognitive disability and have children under 18 years of age.²⁵ Many are unknown to the system, disappearing after graduating high school, or dropping out of secondary school. Despite this, as of January 2020, the Department on Disability Services (DDS) reports that it provides or contracts for services and supports for 90 parents who have 106 children under age 18. The majority of families known to the DDS are Black or African American men and women, between the ages of 20 and 45. Most of the parents are unmarried, though there are a few that are married or in committed relationships. The parents engage in an array of co-parenting arrangements, with noncustodial parents, family members, fictive kin, and partners. While the majority of parents served by Developmental Disabilities Administration (DDA) have custody of their children, some share custody with the child’s non-custodial parent or other family members, and unfortunately, some children are in the custody of the Child and Family Services Administration. The children range in age from toddlers to young adults; some have disabilities, and others are typically developing. Given these data and other data that specify the number of students with intellectual disability and developmental disabilities who have matriculated or dropped out of secondary school indicate that many adults who may be parents are unknown to the current IDD service system. Anecdotal data GUCEDD collected in preparation for the Transition Partnership proposal submitted to ACL indicated that DC Government agencies struggle to identify parents who may have IDD because of reluctance on the part of the parents to self-disclose their disability and a lack of policies and procedures to assess and identify individuals with IDD across governmental programs. These data do not include the number of parents with developmental disabilities who do not have intellectual disability.

Supports for parents with intellectual and developmental disabilities: The contextual reality in the District of Columbia

With few exceptions, services and supports for people with intellectual and developmental disabilities are provided in community-based settings. The District converted to a community-based system of services of supports upon closure of Forest Haven, its institution for people with intellectual disabilities in the early 1990s. DDS provides an array of services to qualifying adults with intellectual disabilities who may reside independently or with spouses and/or family members in their natural environments, or in residential supported living settings such as group home settings, shared apartments, and semi-independent living environments.

In the District of Columbia, the only formal system for supporting transition services for children and youth is for those who have disabilities (0-21 years) as defined by the Individuals with Disabilities Education Act of 2004 (IDEA).²⁶ But for parents with intellectual and developmental disabilities, there are no individualized supports in place to help the parents navigate their child's transition from Strong Start (Part C) into special education services (Part B). The District of Columbia Public Schools (DCPS) system implements a transition program beginning in Pre-kindergarten, in support of the ultimate outcome of independent living for all students commensurate with their preferences, limitations and abilities. While parent involvement is a hallmark of DCPS transition process, there are currently no policies nor procedures in place for ensuring assistance for parents with intellectual and developmental disabilities to understand and support their children through these transitions. There are a number of parents currently served by the Department on Disability Services who have children with developmental delay and disabilities.

In response to this need, and commensurate with the goal and objectives of this one-year planning grant, the GUCEDD in partnership with key stakeholders created this sustainable action plan for the District of Columbia that addresses the unique needs of parents with intellectual and developmental disabilities to support the transition of their children with and without disabilities throughout the life course.

Goal and Objectives

Goal

Convene a partnership in the District of Columbia to develop a sustainable plan that addresses the unique needs of parents with intellectual and developmental disabilities to support the transition of their children with and without disabilities throughout the life course.

Objectives

1. Conduct a comprehensive assessment of cross-system services for parents with intellectual and developmental disabilities to examine the extent to which they are responsive to parental needs to support their children as they transition from early childhood, middle childhood, adolescence, to young adulthood.
2. Engage in a consensus process to develop a city-wide cross-system action plan that describes a set of core principles, identifies barriers, gaps and current capacity, delineates best and promising practices, and advances the implementation of a pilot that enables parents with intellectual and developmental disabilities to support the transition of their children throughout the life course.

Outcome

The first citywide consensus plan and stakeholder partnership focused on the unique interests and needs of parents with intellectual and developmental disabilities and defined cross-system changes that will enable them to support their children with agency through their life course transitions.

Transition Partnership Members - Chart I

Name	Organization/Role
Rochanda Hiligh-Thomas	Advocates for Justice in Education, Inc. Executive Director
Margaret A. Nygren	American Association on Intellectual and Developmental Disabilities Executive Director & CEO
Penelope Griffith	Collaborative Solutions for Communities Executive Director
Melisa Jensen Octavia Shaw	D.C. Child & Family Services Administration Health Services Program Specialist Program Manager, Families First DC
Ian Paregol	D.C. Coalition of Disability Service Providers Executive Director
Barbara Bazron	D.C. Department of Behavioral Health Director
Andrew Reese	D.C. Department on Disability Services Director
Alison Whyte	D.C. Developmental Disabilities Council Executive Director
Erica McClaskey	D.C. Health Community Health Administration Family Health Bureau Chief
Mathew McCullough	D.C. Office of Disability Rights Executive Director
Allan J. Phillips	D.C. Office of the State Superintendent of Education Special Assistant Part C
Wilina Robeson	D.C. Public Schools Director of Transition
Julie Camerata	D.C. Special Education Cooperative Executive Director
Peter Krauthammer	District of Columbia Superior Court Associate Judge
Jane Brown	Disability Rights DC Executive Director
Yetta Myrick	Family Support Council Parent & Co-chair
Karen Feinstein	Georgia Avenue Family Support Collaborative Executive Director
Wilma Eley	Georgetown UCEDD Advisory Council Parent & Member
Lisa Proctor Kyndra Jones Marjorie Hernandez	Health Services for Children with Special Needs VP Marketing/Community Outreach Senior Marketing Specialist Bilingual Program Coordinator
Angelique Speight	Mothering Hands/ Child Born Free Peer Parent
Mary Sowers	National Association of State Directors of Developmental Disabilities Services Executive Director
Arnetta Kinney Cicely Brown	Parent Partners [former Project Impact participants]
Ricardo Thornton Thomas Mangrum	Project ACTION! Co-Presidents
Tina Campanella Phyllis Holton	Quality Trust for Individuals with Disabilities Chief Executive Officer & Deputy Director for Operations

The Process to Assess The Multi-System Capacity that Supports Parents with Intellectual and Developmental Disabilities In DC

The GUCEDD used a multifaceted approach to conduct an assessment of the capacity of multiple systems in the District of Columbia that interact with and serve parents with intellectual and developmental disabilities. The GUCEDD used innovative strategies to both elicit and share data with Transition Partners listed in Chart 1. Each member of the Transition Partnership was asked to collect and report specific data about policies, practices, and experiences related to parents with intellectual and developmental disabilities and de-identified data on the number and characteristics of these parents that they serve and/or encounter. During bi-monthly meetings, Transition Partnership members engaged in large and small group dialogue to gather and share additional data across the multiple systems that encounter parents with intellectual and developmental disabilities. In addition, partners engaged in key informant interviews to expand upon survey responses or to offer additional perspectives. The GUCEDD employed a data platform featuring Gizmo and Qualtrics survey software for data collection and management as well as small group notes submitted by Transition Partnership members. All meetings were conducted virtually due to COVID-19 restrictions. Chart 2 describes data collected and outcomes that informed the development of this action plan.

Transition partners provided a wealth of information about the gaps and challenges in supports and services for parents with intellectual disability and developmental disabilities in the District of Columbia. In addition, a broad array of recommendations was offered to increase the capacity of public and private sector agencies/organizations across systems to support the needs of parents with intellectual and developmental disabilities through systems change efforts at the policy, administrative functions, practice, service delivery and supports, persons with lived experience of intellectual and developmental disabilities, and community levels. Many of the recommendations put forth by the partners informed this action plan; and others were incorporated into the activities in the grant application for the next phase of this planning grant, the Transition Implementation Partnership (TIP) grant, or form the basis of some of the real-time advocacy and change work in the TIP grant application.

Chart 2: Data Collection Methodology and Assessment Outcome

Small Group Dialogue	Survey Data Collected	Assessment Outcome
<p>Engage in dialogue by responding to the following questions or prompts.</p> <ul style="list-style-type: none"> • Has your organization/agency experienced barriers in delivering supports/services to parents with IDD? If so, describe the barriers. • If your organization/agency has not experienced barriers, describe approaches that have been effective. • Has your organization or agency encountered barriers in determining if parents have IDD? If so, what factors contribute to these barriers? • From your organization /agency’s perspective, describe the primary needs of parents with IDD. 	<ol style="list-style-type: none"> 1. How many parents with IDD received supports/services from your organization/agency in the past 12 months? 2. How does your organization/agency define parents with IDD? Include your organization/agency’s definition here. 3. What are the demographic characteristics of these parents (e.g., gender, age, race or ethnicity, languages spoken, services or supports received)? 	<p>Generate definitions of ID, DD, and IDD and initial prevalence figures from DC organizations/agencies</p> <p>Generate a list of barriers to determining which parents have IDD within organizations/ agencies and within the broader system of services and supports</p>
<p>Engage in dialogue and generate ideas about:</p> <ul style="list-style-type: none"> • How to shift from the understanding of and approach to “transition focused on what the child through young adult is doing” • How to shift to “transition as a parenting task that an adult with IDD may need support or assistance with.” 	<ol style="list-style-type: none"> 1. How does your organization/agency define “transition” for individuals and families that receive supports and services? 2. What “transition supports” are currently in place for parents with IDD in your organization/agency? 	<p>Shared understanding of the Transition Partnership’s definition of “transition” through a life course framework</p>
<p>Engage in dialogue and respond to the following questions or prompts.</p> <ul style="list-style-type: none"> • What are the way in which systems already support parents with IDD? • What are the barriers to fully actualizing the array of needed supports in your organization/agency? 	<ol style="list-style-type: none"> 1. What specific programs, services, supports are in place to help adults with and without IDD to navigate their children’s life transitions? 2. How can the Transition Partnership build upon these existing programs, services, and supports? 3. Identify levers that could be shifted to better support parents with IDD. 4. Use the following categories to capture these shifts: <ul style="list-style-type: none"> • policy • administrative • practice & delivery of services and supports • Individual and/or family • community 	<p>Shared understanding of the array of programs, services and supports that could be mobilized to support parents with IDD.</p> <p>Documentation of current barriers at policy and practice levels</p>
<p>Engage in dialogue using data to reach consensus on the following components of an action plan: (a) citywide system to identify parents with IDD; (b) policies, resources, and processes to assess individuals’ needs for parenting support; (c) cross agency policies and practices to ensure that parents experience no wrong door; (d) legislation; (e) professional development and training for the workforce; (f) education and self-advocacy.</p>	<ol style="list-style-type: none"> 1. What can my organization/agency do differently to support parents with IDD tomorrow with and without additional resources? 	<p>Identification and consensus on major components of transition supports for families with IDD are identified</p> <p>Identification of major elements of cross-systems transition supports for patents with IDD</p> <p>Identification of practical, actionable changes within organizations/agencies to provide transition supports to parents with IDD</p>



Arnetta Kinney

Parent Partner

“I don’t know a lot about how to make peoples to come together for people like me with disabilities, you know. But I do know that if I was trying to work on something like this plan you was talking about Ms. Wendy, I would say:

It (the Action Plan) needs to have people like me to say what we needs and wants, cause we the ones whose living the life with our kids, so we knows what we needs ...We can tell the kind of help, how we need the help, when we need the help, and who can help.

The people that’s gonna help needs to learn how to work with people with disabilities, whatever they disability may be ... what works for me may not work for the next person.

They got to put what they gonna do on paper, that way everybody understands the same thing, and does things the same way.

I hope they would try this (Action Plan) out, and if it needs a little fixing up, do it and try again.....parents like me and my children need all the help we can get.”

Introduction to the Action Plan

Commensurate with the Transition Partnership Project goal, objectives, and outcome the GUCEDD leveraged four essential inputs to guide and ultimately create this action plan. The GUCEDD led a stakeholder-engaged consensus process to develop a multi-system action plan that: 1) describes a set of core principles; 2) identifies solutions to barriers, gaps, and current capacity; and 3) delineates evidence-based practices as well as emerging best and promising practices. This action plan positions the District of Columbia to advance the necessary multi-system change in response to the unique interests and needs of adults with intellectual and developmental disabilities to support their children with agency throughout life course transitions from infancy to adulthood. These four essential inputs included the following.

- **Theory of change** is a description and illustration of why a particular way of working will be effective, showing how change happens in the short, medium, and long-term to achieve the intended outcomes within a particular context. The most effective theory of change efforts involve meaningful stakeholder engagement – those persons and organizations that will most benefit from the intended change. To implement this action plan successfully, theory of change frameworks at both the system/organizational and individual levels will be required in the District of Columbia.
- **Foundational definitions and conceptual frameworks** were selected by the GUCEDD to underpin the work of a sustainable, citywide, multi-system plan in the District of Columbia that addresses the unique interests and needs of the racially and ethnically diverse parents with intellectual and developmental disabilities to support the transition of their children with and without disabilities throughout the life course. These include the following evidence-based and best practice approaches (a) life course theory, (b) self-determination, (c)

inclusion, (d) person-centered, (e) cultural competence, (f) linguistic competence, (g) Convergence of Cultural Contexts in Developmental Disabilities, and (h) leadership. Each definition and framework is described in the Appendix.

- **Centering change areas of emphasis delineated in P.L. 106-402 Developmental Disabilities Bill of Rights and Assistance Act of 2000** is essential to the full community inclusion of parents with intellectual and developmental disabilities in all aspects of life in the District of Columbia. This action plan focuses on multi-system change within the eight areas of emphasis of the DD Act including education, health, transportation, housing, employment, childcare, early intervention, and recreation based on the Transition Partnership stakeholder consensus process.
- **Influencing policy, practice, and attitudes about parents with intellectual and developmental disabilities** are essential to effect systems change in the District of Columbia. The GUCEDD organized this action plan to reflect change that is needed in policy, administrative functions, practice and service delivery and supports to parents with the lived experience of intellectual and developmental disabilities, and community engagement and inclusion.

The multi-system assessment conducted by the Transition Partnership included two systems that are not specified in the areas of emphasis in the Developmental Disabilities Bill of Rights and Assistance Act of 2000 – child welfare and the court system. In addition to the eight areas of emphasis in the Developmental Disabilities Bill of Rights and Assistance Act of 2000, this action plan includes specific findings and recommendations for the Child and Family Services Administration (CFSA) and the Superior

Court of the District of Columbia. CFSA and the Superior Court of the District of Columbia have frequent and prolonged interactions with persons with intellectual disabilities including those who are parents. Some recommendations, if accepted and acted upon by the Superior Court of the District of Columbia, may have implications for public and private sector entities in the city. These recommendations are included on pages ²⁵⁻²⁷.

This action plan (1) is actionable, practical, realistic; (2) addresses problems and proposes remedies and solutions; (3) identifies partners and key stakeholders in implementation; and (4) can be immediately acted upon and/or clearly sets forth the necessary next steps in implementation.

Recommended Actions to Enhance Supports for Parents with Intellectual and Developmental Disabilities

Policy

For the purposes of this action plan, policy is a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions, agencies, and programs. This action plan differentiates formal and informal policy. Formal policy is written and codified. Informal policy may be shared and understood verbally, however compliance may or may not be enforceable and adherence may vary. Recommended actions for policy development and implementation in intellectual and developmental disabilities span the eight areas of focus delineated in the DD Act.

Finding

The multi-system assessment conducted by the Transition Partnership revealed that there are no policies in either the public or private sector that specifically focus on the supports parents with intellectual and developmental disabilities need to support their children when they transition from early childhood, middle childhood, adolescence, to young adulthood. While some recommendations can be implemented at the department level of DC Government, others may require legislation and funding through the Council of the District of Columbia. These recommended actions are at the discretion of each DC Government department, administration, or agency. This will apply accordingly to private sector organizations and agencies.

Recommended Actions for Policy Development and Implementation

Education	Require that all publicly funded education programs in the District of Columbia: (1) recognize and affirm the rights of adults with intellectual and developmental disabilities in their role as parents; and (2) ensure that these parents receive the appropriate individual supports and services to assist them to advance the educational interests and needs of their children with and without disabilities during life course transitions.
Health	Establish policy within the public and private sectors to: <ul style="list-style-type: none"> • Help parents with intellectual and developmental disabilities receive the appropriate level of support they need to navigate the District's health care systems. • Specifically identify and address disparities in health and well-being experienced by parents with intellectual and developmental disabilities. • Provide prenatal and postnatal education, support, and follow-up to parents-to-be with intellectual and developmental disabilities.
Transportation	<ul style="list-style-type: none"> • Revisit existing policies to ensure that parents with intellectual and developmental disabilities have access to transportation for themselves and their children on an as needed basis across the life course
Housing	<ul style="list-style-type: none"> • Revisit policy directives within the public and private sectors to ensure the enforcement of the Americans with Disabilities Act (ADA), the Fair Housing Act, and other laws and regulations prohibiting discrimination against persons with disabilities in housing. • The DC Department on Disability Services should revisit and ensure equitable housing options and payment requirements for parents who require more than a two-bedroom apartment/home due to the number of children they have.
Employment	<p>The DC Department on Disability Services and Department of Employment Services should revisit and ensure that their policies take into consideration the unique issues, needs, and interests of parents with intellectual and developmental disabilities (e.g., childcare, transportation, hours of work, and parental leave).</p> <p>Private sector organizations and programs should establish policies that specifically focus on the array of supports to facilitate employment of parents with intellectual and developmental disabilities.</p>
Child Care	Ensure that policy established by the Office of State Superintendent of Education for all publicly funded or subsidized childcare programs is consistently implemented and is inclusive and supportive of parents with intellectual and developmental disabilities in order to assist them with the developmental transition of their children.
Early Intervention	<p>Establish policy within the Part-C program administered by DC Office of the State Superintendent of Education that specifically focuses on supporting the parents with intellectual and developmental disabilities to access, navigate, use, and have meaningful participation in early intervention programs under its auspices.</p> <p>Require all licensed early intervention providers in the District of Columbia to receive professional development and training on how to meet the interests and needs of parents with intellectual and developmental disabilities to support the developmental transitions of their children at-risk for and with developmental delay and disability.</p>
Recreation	Establish policy within the DC Department of Recreation to create a citywide task force charged with creating solutions for more inclusive and accessible recreational activities for children with disabilities and their parents including parents with intellectual and developmental disabilities.

Administrative Functions

For the purposes of this action plan, administrative functions are a set of system of rules that govern procedures for managing an organization, agency, or program. Administrative functions are designed to establish efficiency, consistency, responsibility, and accountability in achieving the mission and goals of an organization or agency. Administrative functions may include but are not limited to procedures and processes for planning, organizing, staffing, reporting, communicating, data management, budgeting, and the management of human and material resources and facilities. Administrative functions are universal in the public and private sector. Recommended actions for administrative functions in intellectual and developmental disabilities span the eight areas of focus delineated in the DD Act.

Finding

The multi-system assessment conducted by the Transition Partnership revealed that there are few administrative functions in either the public or private sector that specifically focus on the supports parents with intellectual and developmental disabilities need to assist their children when they transition from early childhood, middle childhood, adolescence, to young adulthood. These recommended actions are at the discretion of each DC Government department or administration and may require legislative, policy, or resource allocation to implement. This will apply accordingly to private sector organizations and agencies.

Recommended Actions for Administrative Functions

Education	<p>Require that the DC Office of the State Superintendent of Education (SEA) and DC Public Schools and Public Charter Schools (LEA) establish policy to ensure: (1) a designated department and staff have responsibility for coordinating supports for parents with intellectual and developmental disabilities for their children with and without disabilities (birth – 21 years of age); (2) supports are easy to access, navigate, and are evaluated for effectiveness and quality; (3) staff receive training on how to interact and communicate effectively with parents with the lived experience of intellectual and developmental disabilities.</p> <p>Provide guidelines for front-line and supervisory staff to increase access to all school programs (including before and after school) for parents with intellectual and developmental disabilities and their families.</p>
Health	<p>Establish administrative processes across all publicly-funded health care systems to support parents with intellectual and developmental disabilities by:</p> <ul style="list-style-type: none"> Assessing all aspects of their health and the health of their children (e.g. physical, mental health/emotional well-being, nutritional, safety) consistent with American Academy of Pediatric guidelines. Providing health, mental health, and developmental milestones in plain language, multimedia formats, and in languages other than English. Assess risk factors for health disparities, including those attributed to the social determinants of health. Providing clinicians and staff with training on how to interact and communicate effectively with parents with the lived experience of intellectual and developmental disabilities. Making referrals to parent support and home visiting programs to build parental capacity to increase their knowledge about child development, bonding, and attachment as an alternative to referrals to DC Child and Family Services Administration (CFSA) when safety is not a concern
Transportation	<p>Public and private sector organizations should: (1) Assess the extent to which transportation poses barriers to parents with intellectual disabilities and interfere with their capacity to get their children to and from school, child care, health appointments, and other activities of daily living including recreation; (2) Create administrative practices to mitigate such barriers.</p>
Housing	<ul style="list-style-type: none"> Establish administrative functions within DC Department on Disability Services, Department of Human Services, and Department of Housing and Community Development that are responsive to the housing interests and needs of parents with intellectual and developmental disabilities. Ensure such processes are easy to access and navigate and are expedited given the vulnerability of this population. Designate personnel that have responsibility, knowledge and skills to provide supports to parents with intellectual and developmental disabilities. Ensure that personnel across these departments, including DC Office of Consumer and Regulatory Affairs, enforce the Americans with Disabilities Act, the Fair Housing Act, and other laws and regulations prohibiting discrimination against persons with disabilities in housing.

Recommended Actions for Administrative Functions (cont'd)

Employment	The DC Department on Disability Services and Department of Employment Services should conduct a review of their administrative functions to determine the extent to which they take the unique issues, needs, and interests of parents with intellectual and developmental disabilities into consideration in the provision of supports and services (e.g., childcare, transportation, hours of work, and parental leave). Make changes based on assessment results including data gathering from parents with intellectual and developmental disabilities about their experiences.
Child Care	Office of State Superintendent of Education should implement regulations and procedures to ensure all publicly-funded or subsidized child care programs have administrative processes in place, that are culturally and linguistically competent and specifically dedicated to assisting parents with intellectual and developmental disabilities to support their children with and without disabilities through developmental transitions.
Early Intervention	<p>Establish administrative processes within the Part-C program administered by DC Office of the State Superintendent of Education:</p> <ul style="list-style-type: none"> • To implement rules and regulations that assist parents with intellectual and developmental disabilities to access, navigate, use, and have meaningful participation in early intervention programs under its auspices. • That require all licensed early intervention providers in the District of Columbia to receive professional development and training on how to meet the interests and needs of parents with intellectual and developmental disabilities to support the developmental transitions of their children at-risk for and with developmental delay and disability.
Recreation	Establish policy within the DC Department of Recreation to create a citywide task force charged with creating more inclusive and accessible recreational activities for children with disabilities and their parents, including parents with intellectual and developmental disabilities.

Practice, Service Delivery, and Supports

For the purposes of this action plan, practice, service delivery, and supports are defined as the range of usual, customary, habitual, or expected way of doing something and the underlying philosophy of belief to justify such approaches. For developmental disabilities, practice, service delivery, and supports span the eight areas of focus delineated in the DD Act listed below.

Finding

The multi-system assessment conducted by the Transition Partnership revealed that there are an array of approaches to practice, service delivery, and supports within both the public and private sectors which are responsive to the interests and needs of parents with intellectual and developmental disabilities that enhance their agency during their children’s transition stages from early childhood, middle childhood, and adolescence, to young adulthood. An important finding is that such services may not embrace or use evidence-based and promising practices that foster a life course approach, self-determination, inclusion, person-centered, cultural competence, linguistic competence, and leadership. These recommended actions are at the discretion of each DC Government department or administration and may require legislative, policy, or resource allocation to implement. This will apply accordingly to private sector organizations and agencies.

Recommended Actions for Practice, Service Delivery, and Supports

Education	<ul style="list-style-type: none"> Require that the DC Office of the State Superintendent of Education (SEA) and DC Public Schools and DC Public Charter Schools (LEA), and public charter schools provide practice, service delivery, and supports to parents with intellectual and developmental disabilities that are responsive to the developmental transitions of their children with and without disabilities (ages birth-21 years) which: (1) are consistent with evidence-based and promising practices described in Chart 3; (2) provide information in accessible, plain language, and multimedia formats so that parents are knowledgeable of community resources they need and prefer; and (3) comply with DC and federal mandates for parents with limited English proficiency. Provide ongoing professional development to staff of DC public education systems on how to interact and communicate effectively with parents with the lived experience of intellectual and developmental disabilities. Professional development curricula and training sessions should have the input of and optimally co-led by parents with intellectual and developmental disabilities. Make adaptations and provide guidelines for all school programs (including before and after school) to ensure that parents with intellectual and developmental disabilities can participate and benefit from them.
Health	<ul style="list-style-type: none"> Ensure that practice, service delivery, and supports for parents with intellectual and developmental disabilities across all publicly-funded health care systems have the capacity to: <ul style="list-style-type: none"> Provide person-centered culturally and linguistically competent care. Respond to the literacy and health literacy needs. Provide language access services for parents with limited English proficiency. Provide appropriate information and address typical and atypical developmental needs and concerns for children from birth-21 years of age. Assess all aspects of health for parents and their children with and without disabilities (e.g., physical, mental health/emotional well-being, nutritional, safety) consistent with American Academy of Pediatric guidelines. Assess risk factors for health disparities, including those attributed to the social determinants of health and make timely and appropriate referrals.
Transportation	Query the extent to which reliable and accessible transportation present barriers for parents with intellectual and developmental disabilities, make appropriate social services referrals, and advocate to address these social determinants of health with policy makers and insurers.

Recommended Actions for Practice, Service Delivery, and Supports (cont'd)

Housing	<ul style="list-style-type: none"> • Housing in the District of Columbia is a complex problem due to gentrification and rising costs. Practice, service delivery, and supports are largely dependent upon housing policy and fiscal decisions within District Government and among the private sector. • • Ensure that personnel across District Government are knowledgeable of and responsive to the Americans with Disabilities Act), the Fair Housing Act, and other laws and regulations prohibiting discrimination against persons with disabilities in housing.
Employment	Implement practice, service delivery, and supports across the public and private sector that are responsive to the unique needs of parents with intellectual disabilities in employment (e.g., childcare, transportation, hours of work, and parental leave).
Child Care	The Office of State Superintendent of Education should ensure all publicly funded or subsidized childcare programs implement practices, service delivery, and supports in person-centered and culturally and linguistically competent manner specifically focused on parents with intellectual and developmental disabilities to support their children in developmental transitions. This may include but is not limited to mandated training, monitoring, guidance, and/or other requirements. This may also be a focus of quality improvement efforts.
Early Intervention	Ensure practice, service delivery, and supports for all early intervention providers under the auspices of Strong Start (Part-C program) administered by DC Office of the State Superintendent of Education are inclusive of parents with intellectual and developmental disabilities and the developmental needs of their children at-risk for and with developmental delay and disabilities ages birth through 36 months.
Recreation	Ensure DC Department of Recreation staff can provide practice, service delivery, and supports that are accessible and inclusive for parents with intellectual and developmental disabilities and their children with and without disabilities.

Parents with the Lived Experience of Intellectual and Developmental Disabilities

For the purposes of this action plan, parents refer to adults with the lived experience of intellectual and developmental disabilities. Both intellectual disability and developmental disabilities are described in this action plan on pages 1 and 2. The term lived experience originated in mental health and is increasingly being used in disability. To borrow from the mental health literature, lived experience refers to persons who have first-hand experience with a disability. The word “lived” is used to differentiate those who may have experience working in the disability space but have not personally lived with a disability. Recommended actions for parents with the lived experience of intellectual and developmental disabilities span the eight areas of focus delineated in the DD Act.

Finding

The multi-system assessment conducted by the Transition Partnership revealed that policies, administrative functions, and practice, service delivery and supports rarely elicit or are driven by the lived experience of parents with intellectual and developmental disabilities. While person-centered practices are designed to elicit, respect, and reflect the lived experience of persons with intellectual and developmental disabilities, they often fail to accomplish this outcome. There is a high degree of variability in approaches to person-centered practices. The evidence on person-centered practice is still emerging and a fidelity model has yet to be established and reported in the literature. Person-centered practice is often contingent upon how intellectual and developmental disability systems of services and supports are structured and funded. Moreover, the person-centered practice movement has only minimally attended to the cultural and linguistic differences among persons with intellectual and developmental disabilities. Defining what person-centeredness means for parents with intellectual and developmental disabilities within the context of supporting their children through developmental transitions across the life course is only starting to develop. These recommended actions are at the discretion of each DC Government department or administration and may require legislative, policy, or resource allocation to implement. This will apply accordingly to private sector organizations and agencies.

Recommended Actions for Parents with the Lived Experience of Intellectual and Developmental Disabilities

Education	<p>Consistent with the practices of self-determination and cultural and linguistic competence, ensure that parents with intellectual and developmental disabilities have the necessary supports and opportunities:</p> <ul style="list-style-type: none"> • To access and use web-based technology needed to conduct and participate in school business/affairs (e.g., child registration, school selection, communications with teachers and other school personnel, receive and respond to notifications). • For meaningful participation in meetings and other events related to their child’s education (e.g., parent teacher meetings, Back to School Night). • To participate effectively in all special education processes and meetings, including Individualized Education Plan (IEP) meetings. • For meaningful involvement in their child’s extracurricular activities (e.g., fieldtrips, drama/plays, sports, music, afterschool and PTA events/activities). • To access mediation and other legal services when their rights as parents are violated.
Health	<p>Consistent with the practices of self-determination, life course, and cultural and linguistic competence, ensure that parents (both mothers and fathers) with intellectual and developmental disabilities are supported to:</p> <ul style="list-style-type: none"> • Understand their own health (including preconception and prenatal) and the health of their children using a life course perspective. • Identify health and mental health concerns to primary care providers • Use health literacy tools to communicate effectively with health care providers and insurers. • Advocate for their own health and mental health care, interests, and needs and those of their children across the life course. • Participate in patient satisfaction surveys and measures about their experiences in the health and mental health care system.

Recommended Actions for Parents with the Lived Experience of Intellectual and Developmental Disabilities (cont'd)

Transportation	<p>Consistent with the practices of self-determination, ensure that parents (both mothers and fathers) with intellectual and developmental disabilities are supported to:</p> <ul style="list-style-type: none"> • Access and use public transportation for themselves and their children for activities of daily living and recreation. • Report failures of public and/contracted transportation services that hinder their ability to conduct activities of daily living and recreation for themselves or their children.
Housing	<p>Consistent with the practices of self-determination, ensure that parents (both mothers and fathers) with intellectual and developmental disabilities are supported to advocate on their own behalf:</p> <ul style="list-style-type: none"> • When their housing situation causes safety concerns or violates codes and regulations. • For alternative housing, particularly in shared living arrangements with other parents with intellectual and developmental disabilities.
Employment	<p>Support parents (both mothers and fathers) with intellectual and developmental disabilities to choose employment as a career option in their lives and to access the resources necessary to do so.</p>
Child Care	<p>Consistent with the practices of self-determination, life course, and cultural and linguistic competence, ensure that parents (both mothers and fathers) with intellectual and developmental disabilities are supported to:</p> <ul style="list-style-type: none"> • Access and use information about high quality developmentally appropriate childcare for their children with and without disabilities. • Obtain child care subsidy vouchers. • Participate in meetings that provide results of health and wellness screening (e.g., health, vision, and hearing). • Engage with childcare staff in developmental screening processes. • Communicate effectively with childcare personnel about the developmental needs of their children. • Participate and/or volunteer in planned events and activities that are provided for all parents and their children. • Report their concerns to childcare personnel and administrators for resolution.
Early Intervention	<p>Consistent with the practices of self-determination, life course, and cultural and linguistic competence, ensure that parents (both mothers and fathers) with intellectual and developmental disabilities are supported to:</p> <ul style="list-style-type: none"> • Have access to easy to understand information, in multiple formats and offered in multiple modes of delivery, about developmental stages and milestones for their children ages birth – 36 months. • Provide information that takes into consideration parents' ability to: a) read or not; b) literacy levels in English and other languages; and c) process, understand, respond, and act in the best interest of their children. • Access early intervention screening and other services if the parent is concerned that their child has a developmental delay or disability. • Participate effectively in all early interventions processes, meetings, and services including Individual Family Services Plan (IFSP) meetings. • Access and use web-based technology needed for participation in early intervention programs and services, including those that are remote. • Advocate for culturally and linguistically appropriate early intervention services for their families.
Recreation	<p>Consistent with the practices of self-determination, life course, and cultural and linguistic competence, ensure that parents (both mothers and fathers) with intellectual and developmental disabilities are supported to:</p> <ul style="list-style-type: none"> • Access information in a timely manner to enroll their children in summer camps and other recreational programs. • Advocate for inclusive and accessible recreation programs (both public and private) for their children with developmental delay and disabilities.

Community Engagement and Inclusion

For the purposes of this action plan, community engagement and inclusion refer to the extent to which parents with intellectual and developmental disabilities are accepted, have meaningful involvement in all aspects of community life.

Inclusion is an ongoing process of identifying and dismantling barriers that inhibit full participation, whether in the workplace, school, community, or elsewhere in society, and undertaking measures to facilitate direct and full participation of persons with disabilities²⁷.

Finding

The multi-system assessment conducted by the Transition Partnership revealed that the majority of parents with intellectual and developmental disabilities experience stigma, bias, and discrimination, as well as isolation in the communities in which they live in the District of Columbia. These include but are not limited to the attitudes of community members and professionals that persons with intellectual disabilities in particular should not be parents, do not have the capacity to raise children, present a danger to themselves and others, and are totally dependent on others for their basic needs.

Recommended Actions for Community Engagement and Inclusion of Parents with Intellectual and Developmental Disabilities

In order to promote the engagement and meaningful inclusion of parents with intellectual and developmental disabilities in all aspects of community life in the District of Columbia, the following actions are recommended across the eight areas of emphasis in the Developmental Disabilities Bill of Rights and Assistance Act.

- **Non-discrimination.** Ensure that parents with intellectual and developmental disabilities receive fair treatment and that systems (public and private sector) that provide human services comply with all laws (federal and state) that prohibit discrimination against persons with disabilities.
- **Universal design.** Ensure that products, materials and resources, communications, and the physical environment are accessible and easy to navigate and use by parents with intellectual and developmental disabilities.
- **Reasonable accommodations.** Ensure that system policies, administrative functions, practices, service delivery, and supports are designed in a manner that enables parents with intellectual and developmental disabilities to use them effectively.
- **Biases, stereotypes, and stigma.** Conduct citywide community engagement and inclusion activities that encourage new ways of thinking about parents with intellectual and developmental disabilities and eliminate the false beliefs, and associated actions, that they are unhealthy, less capable of raising children, and unable to contribute as productive members of their communities.

This action plan posits the belief that our attitudes drive our actions, and changes in our attitudes and actions can help create a society where all parents with intellectual and developmental disabilities have opportunities to live the lives of their dreams, have a sense of belonging, and are included in all areas of life.²⁸

Community engagement and inclusion of parents with intellectual and developmental disabilities will require that the District of Columbia honors the tenets of the Developmental Disabilities Bill of Rights and Assistance Act of 2000 as eloquently stated below.

“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.”⁷

DC Systems with which Parents with Intellectual and Developmental Disabilities Interface that are Not Included in the Areas of Emphasis in the Developmental Disabilities Bill of Rights and Assistance Act of 2000

The multi-system assessment conducted by the Transition Partnership included two systems that are not specified in the areas of emphasis in the Developmental Disabilities Bill of Rights and Assistance Act of 2000 – child welfare and the court system. The Child and Family Services Administration and the Superior Court of the District of Columbia have frequent interactions with persons with intellectual disabilities including those who are parents. Some recommendations, if accepted and acted upon by CFSA and Superior Court, may have implications for public and private sector entities in the city.

DC Child and Family Services Administration

Findings

- Assumptions and widely held beliefs within child welfare that parents with intellectual and developmental disabilities are less capable of caring for their children and providing a safe environment for their children than nondisabled parents.
- Lack of policies and administrative functions needed to conduct professional development and in-service training for social workers about parents with intellectual and developmental disabilities including but not limited to: (1) their strengths, resiliencies, and capabilities; (2) areas of support needed for successful parenting that incorporate evidence-based and best practices; (3) specific supports focused on developmental transitions of their children infancy through young adulthood; (4) challenging biases, stereotypes, discrimination faced by these parents and their children; and (5) cultural and linguistic barriers faced by these parents and their children.
- Conflict between lack of knowledge of parents with intellectual and developmental disabilities and the requirement to identify and assess cognitive/developmental capacity of these parents.
- Lack of knowledge and coordination between Child and Family Services Administration (CFSA) and other organizations and programs in the District that provide supports and services to parents with intellectual and developmental disabilities.

Recommended Actions

- Conduct combined advocacy and educational campaigns for CFSA personnel that provide facts on the capacity of parents with intellectual and developmental disabilities. Strongly consider using the voices and the lived experience of men and women with intellectual and developmental disabilities who are or have successfully parented their children.

- Revisit policies and administrative functions to ensure mechanisms are in place to conduct professional development for CFSA staff, at all levels and positions within this administration, designed to increase their understanding and knowledge about parents with intellectual and developmental disabilities (across racial, ethnic, and cultural groups) and the systems in the District of Columbia that support and serve them. Such policies and administrative functions should emphasize the nature and scope of supports that parents with intellectual and developmental disabilities need that assist them to be responsive to the developmental transitions of their children birth – young adulthood.
- Review and revise policies and administrative guidelines requiring CFSA social workers to make determinations about the cognitive/developmental capacity of parents with the lived experience of intellectual and developmental disabilities. This recommendation is put forth with a sense of urgency. It is essential given that many CFSA social workers have limited knowledge about intellectual and developmental disabilities in general – and the parents with intellectual and developmental disabilities in particular. This includes the lived experience of parents with intellectual and developmental disabilities, the impact of their disability, existing social-family and community supports, and the socio-cultural contexts in which they live.
- Establishment of policies and administrative functions to ensure collaboration between CFSA and entities that provide services and supports to parents with intellectual and developmental disabilities in the District of Columbia.

Superior Court of the District of Columbia

Findings

- Lack of policies, practices, and procedures to support professional development of Court personnel on characteristics, strengths, resilience, interest, and needs of parents with intellectual and developmental disabilities.
- Cultural and attitudinal shifts are needed to address perceptions, beliefs, and biases about the capacity of parents with intellectual and developmental disabilities to raise their children in the communities in which they live.

Need for judges to be trained on alternative methods to assess parental capacity to raise their children that include but are not limited to functional and skills-based assessments, parent-child interaction, and importantly methods other than the sole reliance on IQ scores for determination of capacity.

- Need to cease termination of parental rights of women and men with intellectual disability based solely on their diagnosis of intellectual disability or developmental disability.

Recommended Actions

- Develop and implement appropriate policies and administrative functions (i.e., practices and procedures) to conduct ongoing professional development concerning parents with intellectual and developmental disabilities for Family Court personnel (e.g., judges, lawyers, clerks, social services, childcare workers).

- Conduct combined advocacy and educational campaigns for Superior Court personnel that provide facts on the capacity of parents with intellectual and developmental disabilities. Strongly consider using the voices and lived experience of men and women with intellectual and developmental disabilities who are or have successfully parented their children.
- Use combined educational and advocacy campaigns to elevate the capacity of parents with intellectual and developmental disabilities tailored to court personnel. Strongly consider using the voices and the lived experience of men and women with intellectual and developmental disabilities who are or have successfully parented their children.
- Revisit and implement policies and administrative functions that are commensurate with evidence-based practice to assess the capacity of parents with intellectual and developmental disabilities. Best practice does not limit assessment to IQ scores only. Rather an assessment of a person's adaptive functioning (conceptual, social, and practical life skills) must be simultaneously administered to adhere to evidence-based and standard assessment of intellectual disability.
- Revisit any policies and administrative procedures that allow for the termination of parental rights of women and men with intellectual and developmental disabilities based solely on their diagnosis or IQ score.

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Appendix

CHART 3
Conceptual Frameworks and Definitions for the Transition Partnership

Life course. As a concept, a life course is defined as a sequence of socially defined events and roles that the individual enacts over time¹ These events and roles do not necessarily proceed in a given sequence, but rather constitute the sum total of the person's actual experience. In particular, it directs attention to the powerful connection between individual lives and the historical and socioeconomic context in which these lives unfold Thus the concept of life course implies age-differentiated social phenomena distinct from uniform life-cycle stages and the life span. The life course perspective elaborates the importance of time, context, process, and meaning on human development and family life.²

Life course looks at life not as disconnected stages, but an integrated continuum. It is a conceptual framework which recognizes that each stage of life is influenced by the stages that precede it, and it in turn influences the life stages that follow it. Most recently, life course theory is noted in public health, particularly in relationship to health disparities. This theory has been adapted to the disability context and its components include a: 1) a systems change framework consisting of catalysts, leadership and principles, and a set of performance indicators; and 2) the guiding principles of catalysts, infrastructure, innovations, and outcomes.³

Self-determination. People with IDD are entitled to opportunities, respectful support, and the authority to exert control in their lives, to direct their services, and to act on their own behalf.⁴ The Developmental Disabilities Assistance and Bill of Rights Act of 2000 describes self-determination activities as: activities that result in individuals with developmental disabilities, with appropriate assistance, having: 1) the ability and opportunity to communicate and make personal decisions; 2) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individual receives; 3) the authority to control resources to obtain needed services, supports, and other assistance; 4) opportunities to participate in, and contribute to their communities; and 5) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.⁸

Inclusion. Inclusion has different meanings for different groups of people and fields. For example, there are definitions of inclusion focused on human resource management/staffing, diversity, inclusion, and equity lens, LGBTQI community interests, and from the disability space. While there are many definitions of inclusion the following one will be used. Inclusion is active and meaningful engagement, where the inherent worth and dignity of all people are recognized. An inclusive environment promotes and sustains a sense of belonging; it values and practices respect for the abilities, beliefs, backgrounds, and ways of living of its members.

Inclusion in the disability space is characterized by: (1) Getting fair treatment from others (nondiscrimination); (2) Making products, communications, and the physical environment more usable by as many people as possible (universal design); (3) Modifying items, procedures, or systems to enable a person with a disability to use them to the maximum extent possible (reasonable accommodations); and (4) Eliminating the belief that people with disabilities are unhealthy or less capable of doing things (stigma, stereotypes).⁶

Person-centered. The National Center for Advancing Person-Centered Practices and Systems defines person-centered in three categories. (1) Person-centered thinking focuses on language, values, and actions toward respecting the views of the person and their loved ones. It emphasizes the quality of life, well-being, and informed choice. (2) Person-centered planning is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it. (3) Person-centered practices are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals.⁷

Cultural competence. In 1989, a work group under the auspices of the Georgetown University Child Development Center published *Toward a Culturally Competent System of Care, Volume 1*. This monograph, by Cross, Bazron, Dennis, and Isaacs, is considered a seminal work and created a conceptual framework and a definition of cultural competence that established a foundation for human services and education.⁸ The GUCEDD will use the following definition of cultural competence adapted from the work of Cross et al., 1989. Cultural competence requires that organizations: have a defined set of values and principles, and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally; have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and embed cultural knowledge and (5) adapt to diversity and the cultural contexts of the communities they serve; and incorporate the above in all aspects of policy making, administration, practice, service delivery and systematically involve consumers, key stakeholders, and communities. Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.⁸

CHART 3 continued
Conceptual Frameworks and Definitions for the Transition Partnership

Linguistic competence. The following definition, developed by the Georgetown University NCCC, will be used because it provides a foundation for determining linguistic competence in health care, mental health, education, and other human or social services systems. Linguistic competence is the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse groups including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competency requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served. The organization must have policies, structures, practices, procedures, and dedicated resources to support this capacity.^{8,9} Moreover interpretation and translation services must comply with all relevant Federal, state, and local mandates governing language access and similar requirements that ensure access for people with disabilities.

Convergence of Cultural Contexts in Developmental Disabilities. People with ID/DD and their families may require involvement in a number of systems throughout the life course. Convergence of Cultural Contexts, provides a conceptual framework and graphic representation of the possible array of systems. Each system has its own culture – norms, rules, language, decision-making processes, approaches to communication, defined roles and responsibilities, ways of interacting with those seeking/receiving services and so forth. The culture of each of these systems is learned by employees and transmitted through policies, structures, and practices both in formal and informal ways⁹.

Theory of change frameworks. Theory of Change is essentially a comprehensive description and illustration of how and why a desired change is expected to happen in a particular context. It is focused in particular on mapping out or “filling in” what has been described as the “missing middle” between what a program or change initiative does (its activities or interventions) and how these lead to desired goals being achieved. It does this by first identifying the desired long-term goals and then works back from these to identify all the conditions (outcomes) that must be in place (and how these related to one another causally) for the goals to occur¹⁰.

Person-centered. The National Center for Advancing Person-Centered Practices and Systems defines person-centered in three categories. (1) Person-centered thinking focuses on language, values, and actions toward respecting the views of the person and their loved ones. It emphasizes the quality of life, well-being, and informed choice. (2) Person-centered planning is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it. (3) Person-centered practices are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals.⁷

Leadership. The Transition Partnership will draw upon the works of renowned scholars and values-based principles in leadership literature.¹¹ Two definitions of leadership will be used in the work of the Partnership because they are commensurate with the values and principles of cultural and linguistic competence. Leadership is a set of personal attributes, qualities, and skills either intuitive and/or acquired that rouses and motivates others;¹² and Leadership is the ability of an individual to influence, motivate, and enable others to contribute toward the effectiveness and success of the organization of which they are members.¹¹ These definitions of leadership reinforce the value that being a leader is not limited to those persons who hold a high rank or position. This literature describes two categories in the exercise of leadership – actual and potential. These conceptualizations of leadership are highly relevant since the intended audiences of the Transition Partnership are both those individuals who are in actual leadership positions and those who have the potential to be in leadership positions. This literature also describes the fact that leadership is influenced by culture –not only the cultural identities and beliefs of individuals, but also the culture of communities, organizations, and systems – including the systems of services and supports for people with IDD.¹³

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