

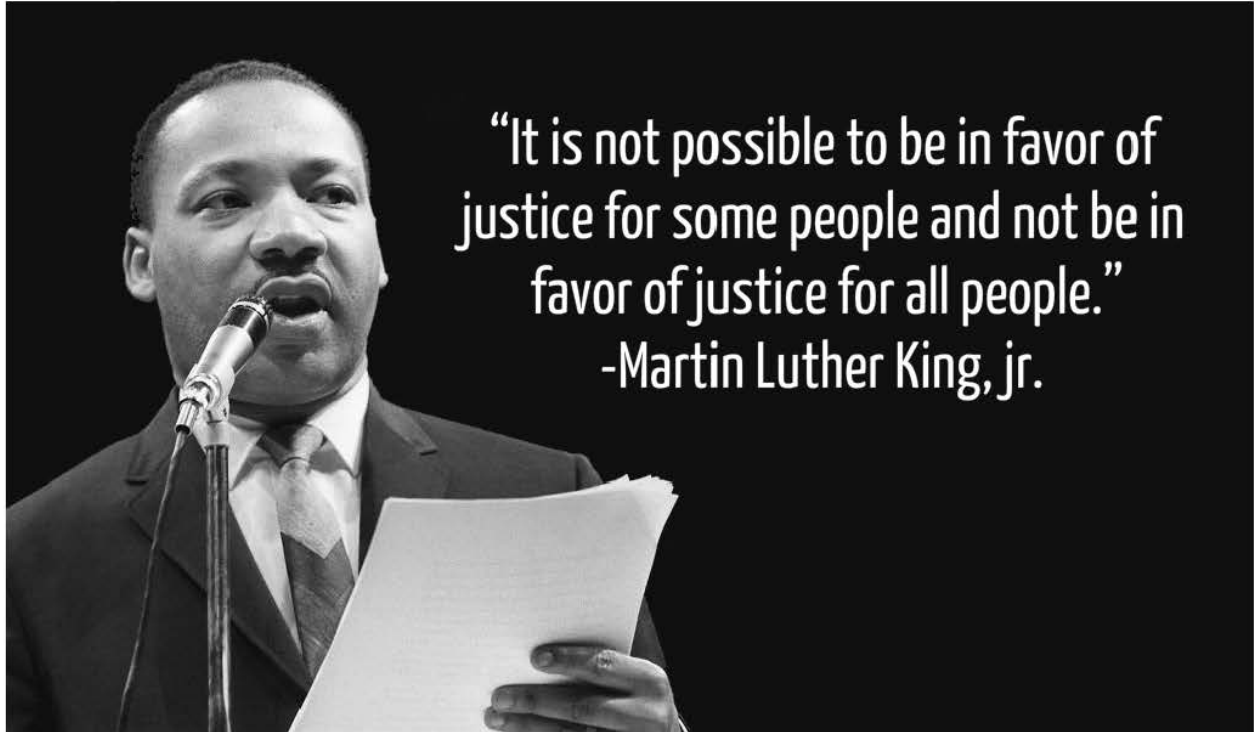


## **Report to the President**

Strengthening an Inclusive Pathway for People with Intellectual Disabilities  
and Their Families



**2016**



“It is not possible to be in favor of justice for some people and not be in favor of justice for all people.”  
-Martin Luther King, jr.

## **DISCLAIMER**

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This document, Report to the President—*Strengthening an Inclusive Pathway for People with Intellectual Disabilities and Their Families*—does not necessarily reflect the views of the United States Department of Health and Human Services (HHS) or the agencies represented by the *ex officio* members of the President’s Committee for People with Intellectual Disabilities (PCPID).

Although some of the information and data contained in this Report were contributed by authorities in the fields of family support, education, disability research, public policy, and other related fields, the personal opinions that such contributors may hold or choose to express outside of this Report to the President do not necessarily reflect the views of the PCPID, HHS, or other federal agencies.

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President's Committee for People with Intellectual Disabilities  
Washington, D.C. 20447

August 4, 2016

President Barack Obama  
The White House  
1600 Pennsylvania Avenue, N.W.  
Washington, D.C. 20500

Dear Mr. President:

On behalf of the President's Committee for People with Intellectual Disabilities (PCPID), I wish to express appreciation for the honor to serve your Administration and the American people. The members of the President's Committee are committed to the fulfillment of the Committee's mission to provide advice and assistance to you and to the Secretary of Health and Human Services on a broad range of topics that relate to people with intellectual disabilities, and to the field of intellectual disabilities. For many of us, it is a personal relationship with intellectual disability that inspires us to work to improve the quality of life that is experienced by all people with intellectual disabilities and their families.

Mr. President, the members of the President's Committee appreciate the opportunity to submit for your consideration the 2016 Report, *Strengthening an Inclusive Pathway for People with Intellectual Disabilities and Their Families*. The intended outcome of this Report is to continue to increase the opportunities for full inclusion in all sectors of American life as envisioned by President John F. Kennedy in 1961 when he established a blue-ribbon panel to address the needs of people with intellectual disabilities and their families.

The report specifically examines the following areas to determine how a path can be forged for people with intellectual disabilities to be included in all aspects of society for an engaged life:

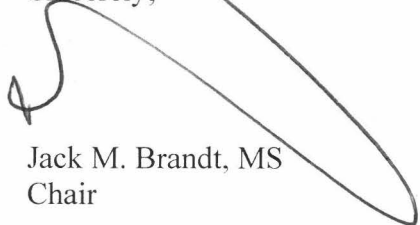
- Family Engagement early on in the process to support high expectations for students with disabilities
- Federal Education Policies and enforcement strategies to end segregation in schools
- Transitioning to adulthood as a critical timeframe for establishing paths to higher education and career development
- Self-Determination and Supported Decision-Making from early childhood throughout the individual's life span

Despite the efforts of people with intellectual disabilities, their family members, and the greater disability community, people with intellectual disabilities often are directed to a path that leads to limited work, isolation from their community, and limited options to pursue a full life.

The members of the President's Committee believe it is time to change that path. It is time to integrate the trajectory for people with intellectual disabilities with the path of all citizens. It is time to meld together the supports people with intellectual disabilities need with the education, services, supports, and opportunities to which all other American citizens have access. It is time for people with intellectual disabilities to follow a truly inclusive trajectory that will create the opportunities to be included, to be full participants, to live independently, and to be economically self-sufficient.

We are hopeful that this Report will provide a strategy for strengthening federal policies to create that new path and to place people with intellectual disabilities on a trajectory to full inclusion with access to opportunities for the highest possible quality of life.

Sincerely,

A handwritten signature in black ink, appearing to read 'Jack M. Brandt', written over a large, faint, oval-shaped watermark or background mark.

Jack M. Brandt, MS  
Chair

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## **COMMITTEE PROFILE**

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Americans with intellectual disabilities (ID) experience significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. This disability, using the definition set forth by the American Association on Intellectual and Developmental Disabilities, originates before the age of 18.

Intellectual disability and developmental disability (DD) are not the same thing. DD is an umbrella term that includes ID, but also includes other disabilities apparent during childhood, such as physical, motor, neurological, psychological, or sensory disabilities. High-quality inclusive services and supports (including natural, unpaid supports) in the education, health, employment, family, and other arenas often assist people with ID and DD to live full lives in their communities.

A portion of the research in the United States has focused on the prevalence of intellectual disability and the numbers of people affected. However, the findings of these research studies are not consistent. Estimates of people in the United States who have an ID or a DD range from 1 to 3 percent of the population, over six million citizens (Bryant, Seok, Ok, & Bryant, 2012).

In 1961, President John F. Kennedy called the nation's attention to deplorable living conditions in institutions and limited opportunities for people with ID in communities across the United States. To ensure the right of a "decent, dignified place in society" for people with ID, in 1966 President Lyndon B. Johnson established the President's Committee on Mental Retardation. To underscore the importance of respect and facilitate the removal of negative labeling, on April 25, 2003, the Committee was renamed the President's Committee for People with Intellectual Disabilities (PCPID).

PCPID serves in an advisory capacity to the President of the United States of America and the Secretary of Health and Human Services (HHS) on matters related to individuals with ID. The Committee upholds the right of all people with ID to pursue a quality of life that promotes independence, self-determination, and economic self-sufficiency. Presidential Executive Order

12994, as amended by Executive Orders 13309 and 13446, stipulates that the Committee shall provide advice to the President concerning the following: expansion of educational opportunities; promotion of homeownership; assurances of workplace integration; improvement of transportation options; expansion of full access to community living; and increased access to technology.

The Committee currently consists of thirteen citizen members appointed by the President, including a Chair who is responsible for planning the PCPID strategic direction, and thirteen *ex officio* (federal government) members designated by the President. The thirteen *ex officio* members are the Secretary of Health and Human Services, the Secretary of Education, the Secretary of Labor, the Secretary of Housing and Urban Development, the Secretary of Commerce, the Secretary of Transportation, the Secretary of the Interior, the Secretary of Homeland Security, the Attorney General of the United States, the CEO of the Corporation for National and Community Service, the Chair of the Equal Employment Opportunity Commission, the Chair of the National Council on Disability, and the Commissioner of the Social Security Administration.

PCPID is supported by federal employees and led by the Commissioner of the Administration on Disabilities (AoD), who also serves as the Committee's Designated Federal Officer. Within the AoD, the Administration on Intellectual and Developmental Disabilities (AIDD) is the federal agency responsible for implementation and administration of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Organizationally, AoD is located within the Administration for Community Living (ACL) at the U.S. Department of Health and Human Services.



## EXECUTIVE SUMMARY

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Great strides have been made since 1961 when President John F. Kennedy established a blue-ribbon panel to address the needs of people with intellectual disabilities (ID) and their families. The U.S. government and the states have addressed the needs of people with ID by opening the school doors, increasing health care options, conducting research into needed supports for individuals and their families, and acknowledging the over six million citizens with intellectual and developmental disabilities as an important part of our national fabric.

Despite these advances, the trajectory for a person with an intellectual disability remains limited. Recent research focused on expectations (low) for people with ID has shown that the advances made are not sufficient. In two states, Rhode Island and Oregon, young people with disabilities were routinely directed to subminimum wage and segregated employment options. When these practices were examined by the Department of Justice, they were found to be in violation of the Americans with Disabilities Act (ADA) and the 1999 Supreme Court Olmstead decision requiring that programming be provided in ways that support people with disabilities to work, learn, and participate alongside their peers without disabilities.

The President's Committee for People with Intellectual Disabilities has examined the following four areas to determine how a new path can be forged for people with ID to be included in all aspects of society as full participants and full opportunities for an engaged life:

1. **Family Engagement** early on in the process to support high expectations for students with disabilities

To begin, families of newborns and children with disabilities must be provided with the knowledge and supports to learn the possibilities for their children with ID. While strong messages regarding inclusion and high expectations come from many experienced families, self-advocates, and the greater disability community, families may still hear antiquated messages about their children's options. To combat these outdated messages and to provide families with the support and knowledge they need to help create the best

opportunities for their children with ID, PCPID recommends a coordinated effort on the part of executive branch agencies to communicate as early as possible with families about the available supports and possibilities for their children with ID related to education, employment, health, and inclusive community living.

2. **Federal Education Policies** and enforcement strategies to end segregation in schools

The President's Committee also found that education is a key component to directing young people with ID to a path of full citizenship and inclusion in their communities. Though great strides have been made to improving the academic outcomes for students with disabilities, challenges remain. Students with ID are often excluded from the general education classrooms, have significantly lower graduation rates, and rarely participate in postsecondary education. PCPID recommends that all educational settings be made more accessible, particularly using principles of universal design for learning, as well as improving the preparation of all teachers to be able to address the educational achievement needs of children with disabilities.

3. **Transition** as a critical timeframe for establishing paths to higher education and career development

To continue to improve the trajectory toward positive outcomes for people with ID, PCPID found that transition from school to postsecondary education and the workplace plays a major role. This is a time for youth with ID to begin to move from the safety and comfort of home to the uncertainty of adulthood and start to take on the responsibilities that come with that transition. To ensure this critical time period results in positive outcomes for young people with ID, PCPID recommends increasing postsecondary education options, identifying people with ID as a medically underserved population in order to increase health care resources, expanding mobility management instruction to increase transportation options, and ensuring that all young people with ID have the opportunity to participate in competitive, integrated work-based learning before leaving school.

4. **Self-Determination and Supported Decision-Making** from early childhood throughout the individual's life span

Finally, the President's Committee examined the topics of self-determination and supported decision-making as means for increasing opportunities for people with ID. Research findings are clear that when people with ID have the opportunity to learn about residential, employment, health care, education, and social options, they are able to make decisions or assist in making decisions and their quality of life is greater than when they do not have those choices. PCPID recommends that executive branch agencies, particularly the Administration for Community Living and the Office of Special Education and Rehabilitation Services, promote self-determination and supported decision-making instruction among their programs and as part of all of their grant programs.

The trajectory for people with ID has improved during the past 50 years. To continue that improvement and to reach the goals of the ADA in ensuring full participation and economic self-sufficiency for all people with ID, the path needs to be strengthened. To achieve these goals, the U.S. society must have high expectations and provide opportunities for people with ID to experience the quality of life envisioned by self-advocates and disability leaders since President Kennedy issued his charge in 1961.

## INTRODUCTION

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The Declaration of Independence, in its most important passage, proclaims:

We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness. That to secure these rights, Governments are instituted among Men, deriving their just powers from the consent of the governed.

Our founding document affirms that all people are created equal and that all have a right to the same opportunities. Our country's history is a long journey to making this declaration true, a journey we are still working to complete.

Our Constitution, unfortunately, established our country as one that separated and segregated groups of people. Until amended, it did not recognize women or persons of color as full citizens. And, as with many issues, the proclaimed values of our founding documents sometimes were met with fractured implementation. For the past 229 years, we have been working to make the Constitution's declared principles of equality a reality for all citizens.

Through a series of Supreme Court rulings, such as *Plessy v. Ferguson*, and laws such as those allowing for literacy tests in some southern states, from the late 1800s through the 1960s people of color were systematically excluded from some of the most basic functions of our society, including owning homes, attending schools, and voting.

For people with disabilities, particularly for those with intellectual disabilities (ID), the path to full citizenship and inclusion in American society has been similar to the road traveled by women and people of color. The journey has been long and filled with barriers—physical, legal, and attitudinal. Yet, even at the birth of our country, disability was present.

Stephen Hopkins, a nine-time governor of the colony of Rhode Island and one of its representatives to the Second Continental Congress, had cerebral palsy (Bjorklund, 2007). As he signed the Declaration of Independence, he said, “My hand trembles, but my heart does not.”

A handwritten signature in cursive script that reads "Step. Hopkins". The ink is dark and the handwriting is fluid, with some loops and flourishes characteristic of 18th-century cursive.

Disability was also present by way of family connections at the signing of the Declaration. The primary author, Thomas Jefferson, had two siblings with disabilities. His brother, Randolph, most likely had a significant learning disability, resulting in difficulties in writing, reading, and calculations (Richards & Singer, 1998). His sister, Elizabeth, had an intellectual disability (Brodie, 1974; Mapp, 1987; Randolph, 1958). Jefferson was especially devoted to his sister and cared for her after the death of his parents, ensuring that she was treated with dignity and lived a life of “well-being” (Smith, 2007, p. 407).

Despite the presence of disability at the founding of our country, the reality for most people with ID was not one of acceptance and inclusion. Instead, a system of segregation and low or no expectations existed. Those systemic barriers and attitudes did not begin to crumble until the country was almost 200 years old, and we continue to confront such barriers today.

While some of the earliest laws of our country dictated the establishment of public schools (e.g., the Land Ordinance of 1785), during the first fifty years of the United States’ existence a separate, segregated patchwork system of education and services took shape for people with ID. By the mid-1800s, a long list of asylums and institutions had been established for children and adults with disabilities. These included the Massachusetts Experimental School for Teaching and Training Idiotic Children (1848), the New York State Asylum for Idiots (1851), and the Pennsylvania Training School for Feeble-Minded Children (1853).

Our country sent its citizens dual messages. It said that all people deserved opportunities to excel and, at the same time, that some people were not worthy of or should not be given those opportunities. The founders of those early schools and asylums, such as Samuel Howe,

acknowledged the ability of people with ID to learn, even while offering curricula and experiences that separated them from general society and expected far less of them than of children and youth without such disabilities. When established, these segregated facilities were seen as a humane way to address the needs of people with ID and their families while separating them from the rest of society. Since then, we have learned that separate experiences are unequal experiences.

With the publication of Darwin's *On the Origin of Species* in 1859, a new and more ominous reason for separation of people with ID began to form in our country: the elimination of people considered "inferior." In the late 1800s, states began to establish laws that prohibited people with ID and other types of disabilities from marrying. By the early 1900s, thirty states had compulsory sterilization laws for people with ID. In 1926, the Supreme Court of the United States legitimized forced sterilization of people with ID. In the *Buck v. Bell* case, the Supreme Court issued a decision allowing Virginia to sterilize a young woman who was identified as having an intellectual disability. From that time until the mid-1960s, over 60,000 forced sterilizations were performed on people with ID. The sense that a disabled life is worth less than a non-disabled life remains with us. Whether in philosophy (Singer, 1980), the courtroom (Gross, 2013), or popular culture (Ladau, 2016), the indirect and sometimes direct message is that it is sometimes acceptable to kill a person with disability when our norms would never permit the killing of a person without disability.

From the late 1800s until the early 1970s, the number of institutions for people with ID increased significantly. Most of these were established by states and located in rural settings, far from where residents' families lived. These new institutions, along with the original ones to educate children and serve adults, created a culture of separation and segregation of people with ID. The institutions also reinforced the messages that people with ID should be taken care of far from the general public and that if they remained at home, they would be a burden for both their families and their communities (Turnbull & Turnbull, 1978).

During this time period, the systematic institutionalization of children, youth, and adults with ID reinforced the low expectations society had for them. Physicians would often counsel

parents that their children with Down syndrome or other types of intellectual disability would never be able to read, have friends, interact within typical society, or hold a job. The medical community routinely recommended that children with ID be institutionalized and that parents “forget” about them.

By the mid-20<sup>th</sup> century, however, the conventional wisdom about people with ID began to be questioned. As segregation and separation were challenged along racial lines in the post–World War II era, so too were the separation and segregation of people with ID questioned. The change occurred because families began to question and disagree with the advice offered by the medical community. Pioneers such as Elizabeth Boggs and Patti McGill Smith, themselves parents of individuals with ID, resisted the recommendations of physicians that they “give up” their children. Instead, these and other pioneers of the family disability rights movement began their own schools for their children with ID. They formed support groups to care for one another’s children. They banded together to advocate for education and services for their children and adult family members with ID. In the 1950s, they became a political force, and by 1961, they had an ally in the White House: President John F. Kennedy, who shared the experience of having a family member with an intellectual disability, his sister Rosemary.

The efforts of those family pioneers resulted in such organizations as The Arc of the United States, Easter Seals, and many local and state family support organizations, which in turn developed schools and services. The parents who led those organizations also advocated for their children to attend neighborhood schools and to be part of their communities. They petitioned their local, state, and federal government representatives and sued localities and states to allow their children with ID access to the services and activities available to children and youth without disabilities.

Throughout the 1950s, ’60s, and ’70s, their efforts resulted in judicial decisions and new laws that opened schools and services to people with ID. The landmark cases of *PARC v. the Commonwealth of Pennsylvania* (1971) and *Mills v. the Board of Education of the District of Columbia* (1972) confirmed the legal right of children with disabilities to have access to education, just as their non-disabled peers did.

The passage of the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act of 1975 (now known as the Individuals with Disabilities Education Act, or IDEA) established standards for access to government services and education for all people with disabilities, including those with ID.

However, despite the herculean efforts of families, self-advocates, legislators, and allies, and decades after the passage of disability civil rights laws, there remain vestiges of our country's history that segregate people with ID. One shocking example is from our public schools. Though a key component of IDEA, known as "least restrictive environment," calls for children with ID to be taught alongside their peers in the general education setting to the greatest degree possible, the most recent report from U.S. Department of Education indicates that a majority (56.7%) of children with ID are still taught in segregated settings (Kleinert et al., 2015; add OSERS).

In fact, the very notion of "special education" signifies education that is separate from and different than the education received by all other children. Disability services are seen as something different than other human and social services and, by definition, as services furnished by specialized providers.

Two recent examples of the continued existence of low expectations and an assumption of segregation are among findings of the U.S. Department of Justice in Oregon and in Rhode Island.

In 2012 in Oregon, the U.S. Department of Justice found that people with ID were systematically placed in segregated employment settings that paid subminimum wage without efforts to provide them opportunities to work in competitive integrated settings. In December 2015, the Department of Justice reached a settlement agreement with Oregon to vindicate the rights of over 7,000 Oregonians with intellectual and developmental disabilities to leave segregated work environments and find employment in competitive integrated settings. Over 4,900 of those served by this settlement are youth under the age of 24.



In 2014 in Rhode Island, the U.S. Department of Justice found that young people with ID who were leaving school and transitioning to the community were routinely placed in programs that paid subminimum wage or segregated day treatment programs and that adults were unnecessarily segregated in adult day service programs including sheltered workshops. This occurred despite the 1999 Supreme Court *Olmstead* decision that the ADA requires the government to provide services to people with disabilities in the most integrated setting appropriate. The Justice Department also found that youth as young as fourteen were being directed to programs that prepared them to work in segregated, subminimum-wage positions without options to attempt or experience postsecondary education or competitive integrated employment. This systematic assumption at such an early age that people with ID could not be part of the community, work in integrated settings, benefit from postsecondary education, and be contributing members of society is an example of the legacy of low expectations and the felt need to provide separate, segregated services for people with ID. In April 2014, the Department of Justice reached a settlement agreement with Rhode Island to vindicate the rights of over 3,250 people in Rhode Island to obtain competitive employment, appropriate transition services, or both.

Both these examples involved state employment service systems and systemic and unjustified reliance on segregated settings that spanned decades; it was not a matter of isolated instances of funneling one or two young people with ID to segregated work settings. These long-term practices affect thousands of people with ID nationwide and are evidence that the historic low expectations and traditionally segregated supports for people with ID remain part of our country's culture. Indeed, many of the very service systems designed to support people with ID and their families retain the seeds of segregation to this day.

This lingering sense of separateness, whether seen or unseen, intended or unintended, means that people with disabilities are directed to follow a different path than all other citizens, a path that leads to lower levels of education, lower levels of employment, and higher levels of poverty.

It is time to change that path. It is time to integrate the trajectory for people with ID with that of all other citizens. It is time to meld together the supports people with ID need with the education, services, supports, and opportunities to which all other Americans have access. It is time for people with ID to follow a new and truly inclusive trajectory that will create opportunities to be included, to be full participants, to live independently, and to be economically self-sufficient.

With this Report, PCPID provides a strategy for using federal policies to strengthen an inclusive pathway for people with ID and their families.

## **ORGANIZATION OF THE RECOMMENDATIONS**

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Recommendations in this 2016 PCPID Report to the President are organized to highlight the following four focus areas:

1. **Family Engagement** early on in the process to support high expectations for students with disabilities
2. **Federal Education Policies** and enforcement strategies to end segregation in schools
3. **Transition** as a critical timeframe for establishing paths to higher education and career development
4. **Self-Determination and Supported Decision-Making** from early childhood throughout the individual's life span

With these recommendations, the PCPID working groups of self-advocates, experts, leaders, and advocates strive to contribute to federal policy that will: 1) create high expectations from all sectors of society for people with ID, 2) support families in receiving and using information to maximize the lives of their children with disabilities and support their family structure, 3) create paths that recognize competence and ability of people with ID, and 4) establish trajectories that create and sustain services, supports, and resources to enable people with ID to achieve the goals of the Americans with Disabilities Act: to take advantage of equal opportunity in all sectors of life, to be fully included in all aspects of society, to be able to live independently, and to be able to achieve economic self-sufficiency.

The text of each focus area includes a brief summary of research, existing barriers and challenges, and recommendations for addressing barriers and improving federal policies in order to meet the stated goals.

Finally, the PCPID wishes to direct attention to a fortuitous and timely occurrence: the work of a large group of stakeholders who, in the summer of 2015, established a set of goals for the field of intellectual disability. This group, which included people with ID, family members, researchers, and service providers, gathered at the 2015 National Goals Conference to create goals for the next decade focused on increasing the inclusion of people with ID in everyday U.S. society. Their work is parallel to and supportive of the PCPID's recommendations, and the Committee considers the publication that arose from the National Goals Conference, *Critical Issues in Intellectual and Developmental Disabilities* (AAIDD, 2016), a companion to this Report.

## **Focus Area 1: Family<sup>1</sup> Engagement**

### **Overview and Background:**

All citizens, including those with ID, should have the right not only to be present in their community but also to be socially and economically connected to that community. All citizens, including those with ID, should have the right to live self-determined lives, meaning that they have the opportunity to set goals for their lives and can take action toward achieving those goals (Turnbull & Turnbull, 2006).

Despite the considerable progress made over the past several decades, too many people with ID remain socially, economically, and physically excluded from the communities of their families and neighbors. People with ID face many societal barriers to meaningful inclusion and self-determination. Families, however, play an essential role in breaking down these barriers and promoting opportunities for inclusion and self-determination. Parents' expectations of their children and of the world in which they live and interact help determine their children's long-term outcomes. A recent study found that when parents have the expectation that their children with ID will work after high school, it is five times more likely that their young-adult child will have a job in a competitive integrated workplace (Carter, Austin, & Trainer, 2012). The effective engaging of families by professionals early and often can help achieve the goals of self-determination and inclusion for all citizens across the nation.

For people with intellectual and developmental disabilities, some of whom have lifelong needs, families most often serve as the primary provider of physical, economic, and emotional support. In the United States, only 25 percent of people with intellectual and developmental disabilities receive formal, paid services, and of those people, approximately half receive such services while living in their family home (Braddock et al., 2015; Larson et al., 2014).

Over the past ten years, the number of people receiving formal supports while living with their families has grown 3.3 times more rapidly than for those not living with family (Larson,

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<sup>1</sup> For this Report, family refers to all forms and that includes children in foster care

Ryan, Salmi, Smith, & Wuorio, 2012). In most of these households, parents and siblings provide the majority of care. In fact, unpaid caregivers provide approximately \$335 billion worth of caregiving annually to family members with disabilities (Feinberg, Reinhard, Houser, & Choula, 2011). However, in 2013, only 6.7 percent of all public funding for developmental disability services went to formal family supports such as respite care, family training, and counseling (Braddock et al., 2015). In about 25 percent of homes where a person with an intellectual disability lives with a family member, the family caregiver is over the age of 60 and may at some point find themselves in need of care (Factor et al, 2012).

### **Family Tasks and Decisions**

Parents and family members of children with disabilities face a multitude of unexpected decisions and tasks. Upon a child's ID diagnosis, parents may face a sense of loss (Ludlow, Skelly, C., & Rohleder, 2011). Many go through a process of re-conceptualizing roles and expectations for themselves and their children in a society where awareness of people with disabilities is limited and the view of them is often narrow. At the same time, the type of support and encouragement families receive early on from professionals can play an important role in the family's outlook and their setting of expectations for their child (Heiman, 2002; Sanders, 2006). Some parents, for the first time through their connection with their child, find themselves part of a marginalized underrepresented group for whom access to their community is difficult (Ferguson, 2001). For members of families in the minority linguistically, socioeconomically, racially, or in terms of gender and/or sexuality, new experiences with society's lack of accommodations for and acceptance of those who function differently intersect with already marginalized identities, making it all the more difficult to access the supports needed (Vargas et al., 2012). Parents of children with additional care needs must learn to navigate complex health care and educational systems and to take on not only the task of care provision but also that of service coordination and advocacy (Vargas et al., 2012). Although there are many positive aspects of caregiving (Heller, Miller, & Factor, 1997), caregivers often face insufficient access to health care, symptoms of depression, and financial hardships (Davenport & Eidelman, 2008; Ha, Hong, Seltzer, & Greenberg, 2008). Families often have difficulty finding paid support services due to lack of awareness of services, lack of knowledge about the process for obtaining services,

lack of availability of and waiting lists for services, financial barriers, and lack of transportation (Chou, Lee, Lin, Chang, & Huang, 2008; Samuel, Hobden, LeRoy, & Lacey, 2011).

Many families have unmet support needs. A study conducted by The Arc of the United States on the perception of family caregivers on a range of issues across the life span found that most caregivers believed their loved one with an intellectual disability was not being fully included in school or in the workforce (The Arc, 2011). Many families reported not feeling prepared for a future in which they might not be able to care for their family member with a disability. Most families also reported physical, psychological, and financial strain as a result of limited or nonexistent supports (The Arc, 2011).

Families of people with ID have played a vital role in the development and advancement of the disability rights movement. Their advocacy has helped, and continues to help, create a path toward more inclusive schools and communities, as well as greater opportunities for people with ID (Carrie, 2009). Read (2000) provides evidence that mothers of children with ID often work to produce opportunities for their children not only in day-to-day situations but also through work as activists. The disability rights movement has spurred a societal shift in the understanding of ID and the role of formal and informal support systems, often composed of family members.

Intellectual disabilities, like other disabilities, are becoming recognized more and more as a natural aspect of human diversity. Support services are increasingly seen as a means to assist individuals with ID to access their human and civil rights, which include being treated with dignity and respect, making their own life goal decisions, and taking action toward those goals. Family members play a vital role in shaping the opportunities people with ID have to develop self-determination skills and behaviors, learn decision-making skills, and connect with their communities (Brotherson, Cook, Erwin, & Weigel, 2008).

The ability to define one's life goals and take action to achieve them becomes increasingly important throughout the life course (Turnbull & Turnbull, 2006). However, self-determination does not inevitably emerge as a person ages. The development of self-determination skills needs to be supported and nurtured (Turnbull & Turnbull, 2006).

It is often believed that individuals with ID have restricted opportunities for self-determination and choice-making due to social barriers including limitations in communication, lack of decisions to be made and low expectations of them. Families can play a key role in supporting the early development of self-determination by providing and maintaining a child's opportunities for choice and decision-making in day-to-day activities (Shogren & Turnbull, 2006). Families shape the home setting that often serves as the child's primary learning environment and frequently have input on their child's placement in inclusive or segregated educational services (Dunst, Hamby, Trivette, Raab, & Bruder, 2002).

Families have been found to influence their child's expectations,

### The Perry Family

Expectations are a two-way street. We have high expectations for our son, a 9-year-old with Down syndrome, but he also gets to have high expectations for us – not just his parents, but the society in which he lives. We expect him to learn, and grow, and become independent, to pursue education, employment, and friendships of all sorts. We expect society to provide pathways for people with intellectual and development disabilities to achieve these things, and work hard to ensure those opportunities exist (and not just for white, upper middle class families like ours).

Take speech, for example. Our son is functionally non-verbal, but highly communicative. He has hundreds of words that he utters in approximate sounds (jargon), a few clear words, does some sign language, can read, and uses a speech app. Our expectation is that as he gets older, he'll be able to communicate as needed, whether with verbal speech or by pulling out a phone and launching an app. He's working hard to master those skills.

Is society doing the work it needs to do? When he doesn't respond right away, whether to a salesperson behind a register, a friend playing Frisbee at the park, or a police officer asking for proof of identity, will they be patient as he types into his app, or will they turn away, try to speak for him, or even get physical from frustration? Nico will be ready. I wish I could be sure society was going to be.



*Nico and his sister, Ellie, getting ready for school.*



options, and decisions regarding employment as well. Family members often introduce the idea of employment, are sought out by the young person for advice, and frequently serve as models of a work ethic (Ankeny, Wilkins, & Spain, 2009; Way & Rossman, 1996). Family members also provide significant practical support, such as transportation and help with skill development, enabling people with ID to maintain competitive integrated employment (Dixon & Reddacliff, 2001).

As people with intellectual disabilities age, family members continue to play a role in shaping opportunities for them. The number of people 60 and over with ID is projected to more than double to 1.2 million by 2030 (Factor, Heller, & Janicki, 2012). For the first time in history, the life span of people with disabilities, including ID, is almost comparable to that of people without disabilities. As people with ID grow older, along with their family caregivers, families may need to look for formal supports (Heller, Caldwell, & Factor, 2007). Planning prior to crisis may help increase opportunities for self-determination and avoid restrictive residential placements (Heller, Caldwell, & Factor, 2007). Although every family is different, many siblings of people with ID expect to take a greater role in caregiving and support as their parents age. These siblings may also then take on the role of supporting their loved one with ID in realizing their right to self-direction.

Based on very recent data, Smith (2016) found that people with ID living in specific family arrangements had greater outcomes when it came to independence, self-sufficiency, and quality of life. For instance, individuals without a formal guardianship arrangement had more positive outcomes than those with such an arrangement. He also found that those who lived in informal, unlicensed family arrangements and who were employed had the best outcomes.

### **Supporting Families and Engagement**

Supporting families is a complex and individualized process. At the Wingspread coalition gathering on supporting families in 2011, stakeholders from across the country agreed that the goal of supporting families “is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love, and facilitate opportunities for the achievement of self-

determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members” (Hecht & Reynolds, 2011).

Supporting families, both formally through paid programs and informally, has been determined to benefit the individual in the family as well as the family as a whole (Hecht & Reynolds, 2011). For instance, family expectations can be influenced by the information they do or do not receive, how the information is delivered, and, for school-age children, how family members perceive their children are progressing in school (Hirano & Rowe, 2015). In order for the trajectory of people with ID to change from segregation and exclusion to meaningful inclusion, families will need information, support, and service options. The earlier families receive information about high expectations and positive outcomes for their children, the more likely children will attain more advanced skills and abilities. Education decisions (e.g., ensuring that a child has access to general education instruction and remains on the path to a general education diploma) have a long-term impact on the adult lives of people with ID (Davis et al., 2011). When families have access to evidence-based knowledge of what services and supports will positively impact their child in the long term, they become more active advocates for securing those services and supports (Hirano & Rowe, 2015).

Professionals in health care, education and other disciplines play a significant role in helping families develop expectations for their children with ID. While there is no comprehensive family support system in the United States, there are a patchwork of services and supports from governments at all levels and from non-profit agencies, family networks, and faith-based organizations. These family supports include the traditional services such as respite services as well as the more comprehensive and critical services that address the psycho-social, socio-emotional, financial, and physical needs of family caregivers.

Government interventions may include the provision of long-term services and supports, including care coordination. A popular service delivery model that maximizes beneficiary autonomy is known as self-direction or consumer-direction, in which participants and their families can manage their own service budget through Medicaid Home and Community Based Service (HCBS) waivers. When this model is chosen by the state, individuals and families

directly hire home health aides or personal assistants, as well as decide whether to access day programs, transportation, and/or assistive technology within an overall budget (Heller, Gibbons, & Fisher, 2015). Programs also might include funding for respite care, which involves short-term reprieve from caregiving. Care-coordination interventions are programs in which professionals streamline the process of obtaining and scheduling services and ensuring that families are aware of and have access to service options (Heller, Gibbons, & Fisher, 2015).

A very small federal program, the Lifespan Respite Care Program, provides funding to states to support respite care and services for families. The program, however, has been funded at such low level (approximately \$2.5 million annually for the past five years) that it can support only a very few families, leaving states with extensive waiting lists.

### **Existing Federal Initiatives to Engage Families in Inclusive Trajectories**

A number of federal programs are poised to both inform and support families as they in turn support their family members with intellectual disabilities in moving from segregated and separate lives to more fully included lives.

Foremost among these programs is Part C of the Individuals with Disabilities Education Act (IDEA), also known as the Early Intervention Program for Infants and Toddlers. The program, passed in 1986 as part of the reauthorization of the Education for All Handicapped Children Act, operates from the philosophy that the family is the system that supports a very young child with a disability. Both the child with a disability and the family members are the target of this program.

Two other components of IDEA focus on families and their support of children and youth with disabilities. Part B, the preschool-through-age-22<sup>2</sup> special education program, requires that parents be part of the educational planning for their children with disabilities. IDEA also ensures

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<sup>2</sup> With the exception of Michigan, where IDEA eligibility extends through the 26th birthday

that family members are involved in the transition planning process for youth with disabilities from high school to postsecondary education and employment.

IDEA also authorizes what are known as parent training and information centers (also known as PTIs) that serve parents of children from birth to age 22 (age 26 in Michigan) with all types of disabilities. These parent centers provide information and instruction about special education, particularly to underserved parents and parents of children who may be inappropriately identified as needing special education. In addition to their information and education role, the centers assist in dispute resolution between families and local school districts. The centers provide family members with information about the mediation process and their due process rights under IDEA and assist in facilitating resolutions.

Promoting Readiness of Minors in Supplemental Security Income (PROMISE) is an interagency collaboration of the U.S. Department of Education (the lead agency), Health and Human Services, Labor, and the Social Security Administration. Under this program, state agencies have partnered to develop and implement model demonstration projects that provide coordinated services and supports designed to improve the education and career outcomes of children with disabilities who receive Supplemental Security Income (SSI). Services target both the eligible youth and their families. In five states and a six-state consortium, youth with disabilities, including ID, and their families are receiving interventions to increase the likelihood that the youth will attend postsecondary education and secure competitive integrated employment. Two important components of the program are family support and counseling to provide information about possibilities for their children, and self-determination skill development for the youth themselves. Previous studies (Haber et al., 2016; Test et al., 2009) indicate that providing families with information about possibilities for their children and providing self-determination skill development for youth increase young people's likelihood of continuing with education and obtaining a job.

Finally, the ACL-Family Information System Project (FISP) has documented the need for additional information about what supports families need in order to ensure that their children experience a higher quality of life. The many barriers and decisions faced by families, as well as

the lack of information about possible outcomes for their children with ID, must continue to be addressed.

### **Recommendations: Family Engagement**

**Recommendation #1: Create a task force consisting of federal agencies and stakeholders to identify the key information and services necessary to support family members in gaining skills and knowledge to foster self-determination and to advocate for the inclusion of their child with intellectual disabilities in the community.**

The structure for providing such information and skills is in place; however, the specific content has not been identified and systematically developed for families. A cross-agency task force, led by the individuals with ID and including family members, researchers, and service providers, should identify the key information and skills necessary to promote self-determination in children and youth with ID.

**Recommendation #2: Expand the infrastructure of the IDEA-funded Parent Training Information (PTI) centers to provide families and service providers with the most up-to-date and culturally component evidence-based information regarding the impact of high expectations for children with disabilities.**

Expand the investment in PTIs to increase their ability to raise the expectations of family members, professionals, and community members related to the opportunities for individuals with ID. PTIs should increase public awareness of positive outcomes for children and youth with ID and share success stories from their geographic service area and across the country. Also, included in the expanded charge should be a focus on helping families learn about self-determination and supported decision-making for children and youth with ID and the possible positive outcomes of teaching those skills.

**Recommendation #3: Expand investments in personnel development in education, allied health, and human services focusing on family support and increased expectations for people with intellectual disabilities.**

During budget preparations and in budget negotiations, advocate for increased funding for IDEA Part D programs that prepare teachers and faculty members to support families. Encourage including in these personnel-preparation programs information on self-determination, supported decision-making, and family support, as well as the leading predictors of postschool success for individuals with ID.

Additionally, advocate for increased funding for the Leadership and Education in Neurodevelopmental Disabilities (LEND) trainee programs and the University Centers of Excellence in Developmental Disabilities (UCEDD) trainee programs to expand the number of pre-service trainees in education, human services, and allied health fields, and include a focus on instruction in high expectations for children and youth with ID. Trainees should become knowledgeable of predictors of postschool success and should learn about and meet self-advocates and families experiencing positive outcomes. Trainees should also receive information about self-determination, supported decision-making, and family support.

**Recommendation #4: Coordinate grant priorities across the U.S. Departments of Education, Health and Human Services, and Labor to ensure a focus on the provision of information to families about high expectations for children with intellectual disabilities, self-determination, supported decision-making, and family support.**

Develop a cross-agency task force to coordinate priorities and language for both formula and competitive grants that address children and youth with ID and their families. The team would identify grants and create language to support high expectations, as well as the development of self-determination skills and supported decision-making. Such grants would include Section 619 and Parts B, C, and D of IDEA; Parent Training and Information Centers; Community Parent Resource Centers; Family-to-Family Health Centers; Family Respite grants;

Statewide Family Network programs; home visiting programs; and other grants identified by the task force.

**Recommendation #5: Update the IDEA Parent Involvement Measures (Indicator 8) to track meaningful engagement of parents/families of students with disabilities as full partners in their children’s progress to positive postschool outcomes. Also, ensure a means to measure parent/family awareness of the predictors of postschool success, and the role of the local education agency (LEA) in promoting the same.**

While traditional models of parent engagement in school currently emphasize the parents’ roles in reinforcing classroom learning, many family advocates have called for a shift in focus toward the school supporting families by working toward shared goals and aspirations for their children (Pekel et al., 2015).

**Recommendation #6: Work with cross-agency partners, particularly within the U.S. Department of Health and Human Services, to expand the data collection of national surveys to include items about services received by children and youth with intellectual disabilities and their families.**

In both the National Health Interview Survey (NHIS) and the American Community Survey (ACS), include questions that ask about intellectual disabilities, developmental disabilities, and autism spectrum disorder (ASD), and allow for determination of the prevalence of these conditions. Also include questions about access to services and supports for people with ID and their families, support needs, and family caregiver needs.

**Recommendation #7: Charge the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) under the Rehabilitation Act reauthorization in 2014, with assessing family needs and including investigation of family support models in their field-initiated competitions.**

In keeping with NIDILRR's mission as stated in the 2014 Workforce Innovation and Opportunity Act (WIOA), which included a reauthorization of the Rehabilitation Act, solicit research about how to best develop information and instruction for family members related to promoting high expectations for their children and youth with ID, and how to develop family skills to encourage self-determination behaviors and abilities in their children. Also, include in the charge to NIDILRR a call for research efforts to determine how to support adult siblings of individuals with ID, how to develop strong natural supports in communities, how to support parents who have ID, how and when it is most effective to provide families with information about high expectations for their children with ID, and what procedures are most effective in providing family members with skills and knowledge to support the development of self-determination in their children.

**Recommendation #8: Charge the U.S. Departments of Education, Health and Human Services, and Labor with working collaboratively with institutions of higher education and professional organizations to establish competencies for family support specialists and family navigators.**

Working with representatives from higher education and accrediting organizations in education, health care, allied health, social work, and other human services professions, examine and expand the competencies of the Community Health Worker model to address family support needs, as well as high expectations and self-determination for people with ID.

**Recommendation #9: In the President's annual funding, make funding Title II of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 a priority.**

Title II of the DD Act, which focuses on family support, has never been funded. The findings in the 2000 Act clearly state the need for family support and for information to help families raise their children with ID and/or DD to be included in society. The Act also expresses the need for society to provide people with ID and/or DD with the access and resources necessary to live as full citizens. The lack of funding has limited states' ability to participate in systems change activities to provide such family-centered support. The executive branch should



include funding of Title II in its next proposed budget, and should advocate with Congress for the inclusion of funding for FY 2018.

**Recommendation #10: Expand and improve access to multiple types of family intervention.**

Although there is a need for more inclusive research on the effectiveness of programs and practices for supporting families, the research that has been conducted to date is promising (Reynolds et al., 2015). A number of studies have found that access to the government intervention of home and financial support allows for better access to services for individuals with ID and their families. Families have reported fewer out-of-pocket caregiving costs and fewer unmet service needs (Caldwell, 2006; Caldwell & Heller, 2007). Caregivers with access to consumer-directed services also reported that they and their loved ones were more active in the community and had better access to health care, and that the individual with ID had a higher likelihood of remaining at home (Caldwell, 2006).

Evaluations of government care-coordination programs have found benefits to the individual with ID in terms of increased community participation, and benefits to families, including feeling better able to plan for the future and experiencing greater service access (Bigby, Ozanne, and Gorden, 2002; Bigby & Ozanne, 2004).

The small-group education-and-training and social-support-and-counseling programs have also shown themselves to be beneficial in terms of increasing family members' confidence, social connectedness, and knowledge of service options (Botsford & Rule, 2004; Smith, Majeski, & McClenny, 1996).

Although more research and knowledge is needed, programs currently available to some families are proving beneficial in helping them meet their needs and enabling them to support greater community inclusion. These programs, which include psychosocial support, education, home and financial support, and care coordination, should be expanded through targeted budgeting within the Department of Health and Human Services to serve more families.

Within the Department of Education, this recommendation includes exploring and funding updated school-family engagement models for parents of students with disabilities, focusing on more effectively engaging with the family and partnering on a shared path to reach positive postschool outcomes.

**Recommendation #11: Continue and expand inclusive research on recommended practices in family supports, with a particular focus on non-majority racial, ethnicity, partner combination, and cultural families.**

Although there is evidence in the literature that family supports are effective, there is still a lack of knowledge as to how best to reach all families, what interventions work best for whom, and when those interventions should be implemented. Like all families, those with a member with an intellectual disability are diverse and complex systems affected by culture, economics, and structure, among other things. As Fujiura (2014) states, “There is no prototypical family with disabilities” (p. 13). However, much of the research on support services for individuals with ID and their families has been conducted by Caucasian researchers and has targeted Caucasian, middle-class families in which the mother is the primary caregiver (Reynolds et al., 2015). Access to programs needs to be ensured across all types of families, including those of racial, gender, sexual, and linguistic minorities as well as families in which a father or sibling is the primary caregiver. Evaluation of the diversity in family needs and the effectiveness of interventions across all families will help increase access to and improve the effectiveness of programs.

**Recommendation #12: Ensure that federally funded and supported programs for children, youth, and adults with intellectual disabilities engage families early, often, and effectively.**

Families begin to form their expectations for what life can look like for their child early, and often have to construct a picture of what their loved one’s adult life may look like without access to or knowledge of other adults with ID. It can be highly beneficial for service providers to reach out to connect with the families of young children with ID, sharing with them knowledge about self-determination, choice, control, interdependence, and access to the

community as an adult. Such engagement can help parents and mentors, among others, set high expectations for children's futures. The larger focus should connect communities of mentors who have ID, including youth and young adults.

Accessing and navigating needed educational and medical systems can be complex and difficult. Engaging families early in a way that is linguistically and culturally appropriate, and connecting them with other parents who know how to navigate systems, may help not only to improve service access and decrease family stress but also to increase families' social support networks. Increasing children's and adults' access to and awareness of role models with ID, whether personally or in the media, may also help people, regardless of ability, see new possibilities. More frequent engagement with parents may also help improve overall relations between a family and service providers who otherwise tend only to interact at times of crisis. Both family support and service accessibility influence opportunities for the person with ID to have control over their life and to be socially and economically engaged in their community in a meaningful way.

The priorities and procedures of federally funded early intervention, early childhood programs, health care services, and other federally funded systems should be examined and evaluated for opportunities to expand high-expectations engagement with families from the point of earliest diagnosis or identification of disability. Executive branch agencies that fund services for families (e.g., the Part C program of IDEA) or directly provide funding for programs (e.g., the Administration for Children and Families Early Head Start program) should provide guidance to managers and personnel about ensuring early conversations about the possible positive outcomes for children with ID.

Executive branch agencies should also explore the use of technology and social media to develop networks of families to provide information about positive outcomes to new parents of children with intellectual and developmental disabilities. These networks should be encouraged to create mentorship relationships between families with a new member with ID and families who can be role models and supports.

**Recommendation #13: Develop family supports from sources other than state-level developmental disabilities agencies.**

Regardless of ability or disability, all families are members of the community, and community connection contributes to each individual's overall quality of life. When people with disabilities and their family members understand and use resources used by all community members, not just those with disabilities, they may have a heightened sense of community connection. All families need access to social support, recreation, and physical resources. Determining where and how those resources are provided in ways that have nothing specific to do with disability, and then helping families with disabilities connect with those resources<sup>3</sup>, may benefit the individual with ID, their family, and the entire community.

Increased presence of families with disabilities in the community may also contribute to changing community attitudes toward disabilities (Reynolds et al., 2015). The Americans with Disabilities Act not only requires that a program, service, or activity, when viewed in its entirety, is readily accessible to and usable by people with disabilities but also that reasonable modifications be provided to ensure meaningful access to programs and services. This could include ensuring that programs and services are cognitively accessible.

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<sup>3</sup> A good example of this type of support is the Department of Labor Job Center network. This network is designed for all citizens, including individuals with disabilities. Another federally funded and administered program that provides support to families with and without disabilities is Head Start. Other executive branch programs that directly serve citizens across the nation should be designed to include people with disabilities. A systematic examination of general family support programs, such as the Maternal, Infant, and Early Childhood Home Visiting Program, should be conducted and include the disability and family support components.

## Focus Area 2: Education Policies

### Overview and Background:

The 1975 passage of the Education for All Handicapped Children Act (EAHCA)—now known as the Individuals with Disabilities Education Act (IDEA)—established a framework to support all children with disabilities. EAHCA included eight key principles and provisions:

- that all students are entitled to a free appropriate public education (FAPE);
- that all children referred for eligibility determination will receive an unbiased multidisciplinary evaluation to determine eligibility for special education and related services;
- that all children found eligible for special education and related services have the right to an individual education plan (IEP);
- that all children will receive their services and supports in the least restrictive environment (LRE)—that is, the educational setting as much like the typical one provided to children without disabilities as possible;
- child find—that is, that the responsibility lies with states and local school districts to actively identify children in need of special education and related services;
- that there be parent participation in the development of their children’s services and in the guidance of special education and related services;
- that families have a right to due process—that is, to challenge their child’s school if they believe their child is not receiving a free appropriate public education or is not receiving the services and supports determined in their child’s IEP; and
- zero reject—that *all* children with disabilities are to be provided an education, with no child deemed too disabled to be educated.

The principles and provisions were a great advancement and created a framework for all children with disabilities to be included in general education settings in public schools.

In addition to the concepts of no reject and least restrictive environment, the Rehabilitation Act of 1973, as amended, prohibits discrimination on the basis of disability by any entity that receives federal funding. All states and virtually all school districts receive federal funds through the Elementary and Secondary Education Act (ESEA) of 1965 for the purpose of enhancing education for children living in poverty. States and local school districts also receive federal funding for other purposes, such as USDA funds to provide free and reduced meals to eligible students, and funds for professional development under Title II of ESEA.

Likewise, Title II of the Americans with Disabilities Act prohibits discrimination against people with disabilities where services are offered by state and local governments, including the provision of public education.<sup>4</sup>

With the passage of the No Child Left Behind (NCLB) law in 2001, students with disabilities were intimately woven into the accountability process of public schools. As part of NCLB, states were required to ensure that all students would successfully meet academic standards by 2014, including students with disabilities, and those with the most significant cognitive disabilities—a category established by NCLB composed mostly of children with ID.

While this goal proved untenable, the inclusion of students with disabilities in school accountability programs created a shift in how these young people were viewed by school leaders. Instead of seeing children with disabilities as a group separate from the general student population, school leaders were required to consider the students' academic instructional needs and how they could be provided supports in order to successfully meet academic standards. While significant effort has been dedicated to increasing the academic achievement of children and youth with disabilities, assessment results and least restrictive-environment data indicate we have not yet fully achieved this outcome.

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<sup>4</sup> While most challenges to denial of access to general education in terms of instruction and/or placement have been based on the least restrictive environment provision of IDEA, some recent challenges have used Title II of the ADA. The most noteworthy example is the U.S. Department of Justice finding in July 2015 that Georgia systematically discriminated against students with disabilities by placing them in restrictive settings and denying them access to the general education curriculum.

For students with disabilities, there were two important outcomes of NCLB. One was that for the first time, all school personnel, family members, and communities could see how well students with disabilities as a group did on state academic standards, including such measures as high school graduation rates. The second important outcome was that, because students with disabilities were included in the accountability process, they were taught the content of the general curriculum and academically assessed on that content instead of being taught to lower standards or receiving instruction not tied to state academic standards.

The result of NCLB was a significant increase in the academic achievement and high school graduation rate of students with disabilities. Between 2001 and 2013, the high school graduation rate for all students with disabilities increased from 47 to 62 percent. While still lagging significantly behind the over-80 percent rate of high school graduation for the general student population, this increase meant that many students with disabilities had additional options for postsecondary education and employment (Butterworth et al., 2014; Grigal et al., 2015).

Though the 15 percent increase in high school graduation for students with disabilities is generally good news, it must be noted that the same graduation rate increase did not occur for youth with ID and the most significant disabilities. Carter et al. (2011) found that while there has been some increase in the number of youth with intellectual and other significant disabilities graduating from high school and obtaining competitive integrated employment, these better outcomes are largely the result of family engagement, IEP goals that include work-based experiences, and the availability of transportation.

Shogren and Plotner (2012) found similar results when they examined longitudinal outcomes for youth with intellectual and other significant disabilities. They found that this group of youth rarely had goals for postsecondary education or competitive integrated work experiences. In addition, they found that students with autism and intellectual disabilities were rarely involved in their transition goal planning. The findings of Carter et al. (2011) and Shogren and Plotner (2012) indicate: 1) more limited education and employment outcomes for youth with ID, and 2) evidence of continued low expectations for these youth.

With the passage of the Every Student Succeeds Act (ESSA) of 2015, children and youth with disabilities continue to be included in the accountability systems of all public schools. ESSA clearly states that students with disabilities must have access to the general education curriculum that all students have access to and that they must be given the opportunities to graduate from high school with a regular diploma. This most recent general education law emphasizes that children and youth with disabilities are the responsibility of all educators in a school district and that they must be afforded the supports necessary to be able to achieve the best possible academic outcomes.

### **Barriers and Possible Solutions**

The Individuals with Disabilities Education Act (IDEA) solidified the right to an education for all children and youth with disabilities, as clarified by the court cases of the early 1970s. It also established standards for education provided by states and local school districts. Congress, however, did not provide the full amount of funding promised to support the services and resources necessary to provide free appropriate public education for all, including students with ID.

However, a side effect of IDEA and its thirteen eligibility categories was that groups of children with specific types of disabilities began to be separated into programs and different settings. During the first two decades of IDEA's implementation, students were often segregated into settings serving those with health impairments, learning disabilities, and intellectual disabilities (often subdivided into "levels" such as mild, moderate, and severe) [Bowe, 2007].

To accommodate this type of segregation, institutions of higher education established departments and majors to prepare teachers to work with these separate categories of students in segregated settings. Students with ID tended to be grouped together, despite often needing significantly different approaches to instruction and benefiting from instruction in general education settings (Turnbull et al., 2006). Contrary to this placement approach, emerging evidence showed that most students demonstrated higher academic achievement when they were



included in classes that taught the general education curriculum and when they were with students who did not have disabilities (Bowe, 2007).

Yet even today, students with ID, unlike students with other types of disabilities, remain far less likely to receive their curriculum instruction in general education placements. Morningstar, Kurth, & Johnson (2015) found that children and youth with ID were nine times more likely than those with other disabilities to be found in highly restrictive settings.

This segregation of students with ID is a significant problem. In self-contained classroom settings students have fewer opportunities to respond to instruction and social interactions, they are more likely to be passive in their instructional and social engagement, the quality of instruction is likely to be less robust than in the general education setting, and there are more distractions (Quirk, 2016).

The findings of comprehensive education projects such as the Schoolwide Integrated Framework for Transformation (SWIFT) indicate that specific strategies for inclusion of students with ID will result both in increased academic outcomes and social opportunities, and in the development of natural support networks (Sailor et al., 2015).

The work of the SWIFT project has found that the following educational strategies will result in better outcomes for students with disabilities, including those with ID:

- provision of services that meet student needs in general education settings;
- making multi-tiered systems of support available to all students at the intensity of their needs in the general education setting;
- focusing on providing students with intellectual disabilities educational services and supports at the intensity of service they need; and
- having all educators begin with the assumption that all students can benefit from and learn the general education curriculum (Quirk, 2016).

As stated, IDEA was a significant advancement in access to the school setting for students with disabilities. Yet, as Kleinert et al. (2015) found, as recently as 2011, only 7 percent of students with the most significant cognitive disabilities were being educated in general education settings.

A critical complication has resulted from the use of separate settings to serve children with disabilities, rather than creating and using a continuum of intensity of services and supports. That unintended consequence is the disproportionate assignment of students of color to more restrictive educational settings (Losen et al., 2014). In the U.S. Department of Education's 2016 analysis of disproportionality, it was determined that over 8,000 school districts (more than 60 percent nationwide) had over-identified students of color in a disability category, assigned students of color to more restrictive settings, or used disciplinary measures more frequently than with white students. These practices segregate students of color and reduce their opportunities for access to the general curriculum, as well as opportunities to learn from their peers.

Shifting the identification of need for special education services and supports to be based on a child's academic and social functioning, and providing services in inclusive settings, can address this disproportionate categorization of students. Using an inclusive model of educating students with disabilities will also reduce the segregation of students of color with disabilities that occurs because of the high rate of restrictive placements.

To build on the strengths of the federal policies found in IDEA, the 1973 Rehabilitation Act, as amended, Title II of the ADA, and the Elementary and Secondary Education Act (ESEA), PCPID makes the following recommendations.

### **Recommendations: Education Policies**

#### **Recommendation #14: Integrate the expected outcomes of ESSA and IDEA.**

The 2015 authorization of the Every Student Succeeds Act (ESSA) continues the requirement that students with disabilities be included in state accountability systems and that

data about their academic progress be publicly shared. In addition, ESSA increases the expectation that students with disabilities are *students* first, mentioning them as such over 100 times in the new law. To truly integrate the expected outcomes of ESSA and IDEA, the interpretation of an “appropriate” education for a student with a disability should be the expected educational outcome as described in ESSA: “a fair, equitable, high quality education to close the achievement gap” for all subgroups of students.

To continue the progress made in increasing expectations for students with disabilities, including those with ID, the outcome measures that states and local school districts must report should be integrated to focus on academic achievement, postsecondary education participation, and obtaining employment. This also means that the Results Drive Accountability process, focusing on outcomes rather than procedures, spearheaded by the Office of Special Education and Rehabilitation Services (OSERS) of the U.S. Department of Education must include students with the most significant disabilities (Delisle & Yudin, 2014).

In addition, Indicator 6 of IDEA, the least restrictive environment indicator, should be refined to ensure that families and community members, in addition to school leaders and educators as members of the IEP team determine what quality of inclusive experience a student is receiving, including the extent to which they are receiving high-quality instruction in the general education curriculum.

**Recommendation #15: Promote the use of universal design for learning in all school districts.**

Using a technical assistance model and guidance for the use of state administrative set-aside funds for both IDEA and Title I of ESSA, the U.S. Department of Education should develop technical assistance centers that will promote the use of universal design of learning (UDL), as defined in the Higher Education Opportunity Act (HEOA), in all schools. This technical assistance should increase student access to the general curriculum and ensure the student is able to be educated in the least restrictive environment with the goal being to provide education in the most inclusive environment.

**Recommendation #16: Pre-service teacher preparation for all teachers should include instruction in disabilities, inclusion, and high expectations for children with disabilities.**

Working jointly with accrediting organizations and institutions of higher education, the U.S. Department of Education should set professional standards for all educators, including school leaders, to be knowledgeable about the evidence-based practices of high-quality inclusive education and instruction for students with disabilities and to ensure that educators understand predictors of postschool success. A model such as that outlined by the Collaboration for Effective Educator Development, Accountability, and Reform ([CEEDAR](#)) would be a good place to start to incorporate evidence-based strategies into preparing educators to work with students of all abilities. Teacher and school leader preparation programs that create high-quality educators prepared to teach with the attitude of high expectations for all students and possessing the skills to teach all students will create opportunities for children and youth with disabilities to achieve academic excellence.

**Recommendation #17: The U.S. Department of Education should create a competitive grant program to provide incentives for school districts to increase the use of inclusive models of service for students with disabilities.**

Using discretionary funds, the U.S. Department of Education should continue to build on the work of the [SWIFT Schools](#) project and conduct a competitive grant program that would reward local school districts for increasing the use of evidence-based inclusive models of serving children with disabilities; decreasing or eliminating segregated, self-contained settings; and decreasing or eliminating out-of-district placements of students with disabilities. The program should be operated jointly by the Office of Special Education and Rehabilitation Services (OSERS) and the Office of Elementary and Secondary Education (OESE). This effort should include a component to track and analyze postschool outcomes for students with disabilities, including those with ID, for at least five years after leaving their preK–12/IDEA schooling.

**Recommendation #18: Combine ESSA and IDEA funds to promote the offering of multi-tiered systems of support in all schools.**

The U.S. Department of Education should offer guidance to states and local school districts on how to braid together funding from Title I and Title II of ESSA with Section 619 and Part B of IDEA to create comprehensive, multi-tiered systems of academic and behavioral support for all students. States and schools should be supported to scale up multi-tiered systems of support with fidelity and to expand those systems to address all tiers, with the focus on schools with poorest postschool outcomes for students with the most significant disabilities, including those with ID.

**Recommendation #19: Provide instruction for school board members, superintendents, building principals, and other school leaders about the effectiveness of high-quality, inclusive education instruction at improving outcomes for all children, including those with intellectual disabilities.**

In combination with private philanthropic foundations, the U.S. Department of Education should establish a set of regional institutes for school leaders to provide them with knowledge and skills related to the implementation of inclusive, high-quality instruction settings for all students, including those with ID. The institutes should be operated collaboratively by OSERS and OESE.

**Recommendation #20: Coordinate all the U.S. Department of Education grants (formula and competitive) to include inclusive education as the instructional model for students with disabilities.**

A task force composed of representatives from across all offices of the U.S. Department of Education, youth with intellectual and other disabilities, family members of children with intellectual disabilities, and researchers should identify all formula and competitive grants and create language to be used across all grant applications to promote the implementation of inclusive, high-quality instruction models to educate all students, including those with ID.

Additionally, all research funded by the Institute of Education Science should include a priority for studies conducted in inclusive classroom settings, particularly if the research subjects are students with disabilities or focus on special education instruction and personnel.

**Recommendation #21: The U.S. Department of Education should issue guidance that directs states and local school districts to purchase equipment and curricula that is universally designed and accessible for all students, including those with intellectual disabilities.**

In addition to such guidance, the U.S. Department of Education should establish a competitive grant program, available to states, local school districts, and non-profit organizations, to develop and disseminate technology and curricula that is accessible for all students. (See the PCPID 2015 Report to the President, [Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities](#))

**Recommendation #22: The U.S. Department of Education should develop a significant guidance document expanding upon the November 16, 2015, FAPE document.**

The new guidance should outline the need to focus on high expectations for students with ID, including the provision of FAPE and access to the general curriculum. The expanded guidance should provide analysis and implementation strategies for high expectations for children and youth with ID and for postsecondary education and employment opportunities.

**Recommendation #23: Ensure that all personnel development grants from the U.S. Department of Education include provisions to instruct new teachers and related service providers in high expectations for children with disabilities and the evidence base for inclusive education beginning in early intervention and extending through transition out of the preK–12 system.**

The U.S. Department of Education should include in all personnel preparation competitive grants the requirement that personnel preparation programs include evidence-based knowledge regarding the use of inclusive schooling models for students of all ages.

**Recommendation #24: Advocate with Congress to provide full funding for IDEA with the requirement that states and local educational authorities provide services for children and youth with disabilities, using inclusive models of instruction.**

Work with Congress to secure increased funding, up to the level promised by Congress when it passed IDEA in 1975. The President's budget should include this funding as a priority each year of the administration. All school districts should receive 75 percent of any additional funding provided by Congress. The remaining 25 percent should be used for competitive grants to states and local school districts both to implement an inclusive, high-quality instruction model of education for all students and to reward districts that use such a model and show increased academic outcomes for students with disabilities, including those with ID.

**Recommendation #25: Increase steps to ensure that the U.S. Department of Education's Civil Rights Data Collection (CRDC) is completed by all local school districts.**

The CRDC has proven to be a powerful tool for school personnel, advocates, and families when that data has been reported by districts. However, significant numbers of local school districts did not report data in either the 2011 or 2013 CRDC. The 2016 CRDC report showed increases in the data reported by schools; however, there were still significant gaps in data reporting. The U.S. Department of Education should continue to implement incentives for reporting accurate data and sanctions for not reporting data.

**Recommendation #26: The U.S. Department of Education should establish requirements for effective use of ESSA Title II professional development funds that focus on evidence-based practices that support inclusion, high academic outcomes, and successful transitions for students with disabilities.**

The U.S. Department of Education should issue guidance on the use of Title II funds using the criteria of evidence-based professional development and providing an additional 5 percent funding if professional development results in an increase in use of high-quality, inclusive education models and improved academic outcomes for students with disabilities, including those with ID.

**Recommendation #27: The U.S. Department of Education should convene a blue-ribbon panel to study the impact of the IDEA requirement to provide a “continuum of services,” examining the requirement and its impact on student placement.**

There is evidence to suggest that policy makers at the state and local levels interpret current regulations concerning the continuum of services as a requirement to provide segregated schools, segregated classrooms, and out-of-district placement options for students. This interpretation of “continuum of services” is in direct conflict with the original intent of the EAHCA and, subsequently, the integration mandate of the ADA. Following the work of the blue-ribbon panel, the U.S. Department of Education should issue new regulations on the continuum of services based on the panel’s findings.

**Recommendation #28: The U.S. Departments of Education and Justice should jointly issue guidance related to the requirements of access to assistive technology and an evidence-based assistive technology evaluation for students with communication and other related technology needs as related to the child’s needs to access the least restrictive environment and to fulfill the requirements of Title II of the ADA.**

Because of the critical nature of communication in educational attainment, the U.S. Department of Education should issue guidance to states and local school districts regarding the responsibility of IEP teams to conduct high-quality communications assessments, performed by qualified and experienced personnel, and to provide the supports and services needed by students with communication needs in order for such students to access the general curriculum and communicate effectively with educators and their peers.



**Recommendation #29: Create a Protection and Advocacy Program to address the rights of children and youth who receive special education services through IDEA and services through the Rehabilitation Act of 1973, as amended.**

While children and youth with disabilities who receive services through IDEA and their families have a right to due process when disagreements occur between the child's family and a school district, there is no legal program to support those families as they navigate the complaint system. For adults with ID who receive services from developmental disabilities agencies, there has been a protection and advocacy system in place for four decades. A parallel system of legal support is needed for children and youth enrolled in the preK-12 system.

**Recommendation #30: Inclusion of Students with the Most Significant Cognitive Disabilities Assigned to be Assessed Using the State Alternate Assessment.**

The U.S. Department of Education should issue guidance, and State Educational Agencies (SEA) should monitor, issue specific guidance and provide technical assistance, to ensure students assigned to be assessed using the state alternate academic achievement standards are held to high expectations and have meaningful access to a State's academic content standards for the grade in which the child is enrolled, including default placement in the general education classroom. Guidance and technical assistance shall include implementation strategies for high expectations including standards-based IEPs, meaningful tracking of postsecondary goals, instruction designed to help the child make progress in the enrolled grade general curriculum as required in IDEA and ESSA. The U.S. Department of Education guidance and SEA monitoring and technical assistance should also ensure that these students' rights to an education in the least restrictive environment are not being violated. IDEA clearly requires that the general education classroom must be the first setting considered by the IEP team and more restrictive settings should only be considered if the student cannot be satisfactorily educated in the general education classroom even with supplementary aids and services. Research has clearly indicated that this group of students thrives both academically and socially in inclusive settings; however, descriptive research indicates that this group is routinely segregated in separate classes and even separate school buildings. Reporting on the percentage of time spent in the general education

classroom for this group of students in each state should be included in the periodic Civil Rights Data Collection report issued by the Office of Civil Rights of the U.S. Department of Education.

## **Focus Area 3: Transition**

### **Overview and Background:**

Transitions for children and youth with intellectual disabilities occur at numerous points in the first two decades of their lives. Transition includes from place of birth to home, from home to early intervention programs, from early intervention programs to preschool disability programs, from preschool disability programs to K–12 education programs, and from K–12 education programs to postsecondary education and, ultimately, competitive integrated employment.

Along the way, there may be many other transitions that affect outcomes, just as they would for any child or youth, regardless of ability: family relocations, changes in family structure, changes in family economic well-being, and many other events.

While all of these transitions are important to the development and outcomes of children with ID, this portion of the Report focuses on the transition of youth with ID out of the preK–12 education system. This transition period typically spans from age 14 through the end of their eligibility for IDEA services, which can be as late as their twenty-second birthday in most states. A student's IEP can include such services as assessment of employment interests, work-based experiences, and job shadowing. This is a critical transition for the young person with an intellectual disability, as well as for their family—a transition that can launch a young person with ID into an inclusive setting or segregate this individual from his or her peers without disabilities.

The two examples from Oregon and Rhode Island highlighted in the introduction to this Report illustrate how transition activities that assume low levels of ability and have low expectations of youth with ID result in their beginning adult life in segregated settings, lacking the opportunity to participate in postsecondary education, and having limited, segregated options for employment.

In contrast, David Test and his colleagues (2009) found that if a young person with an intellectual or developmental disability has one work-based learning experience in high school, the young person's chances of becoming employed in a competitive integrated setting double. If the young person has two work-based learning experiences, their likelihood of being employed in a competitive integrated setting is five times that of a young person with ID who has no work-based experiences.

This early adult transition for youth with ID involves at least three key areas of their lives: postsecondary education, community living, and employment. Each of these sectors is discussed below, and recommendations are offered to enhance the inclusion of youth with disabilities in the ebb and flow of typical community life. References have been geared toward career exploration, career development, and career pathways for youth with ID to emphasize the high expectation of paving the way for long-term careers for people with ID.

### **Postsecondary Education**

Postsecondary education is a formative time of life for many young people. Not only is it a chance to gain new, focused skills and knowledge; it is also the opportunity to create relationships that will have long-term impacts on a person's life. Postsecondary education is also a time when individuals have the opportunity to observe and interact with people different than themselves. This exposes young people to different cultures, behaviors, and beliefs. Postsecondary education also allows for experiences that may not have been available in a young person's high school or the place where they grew up. Finally, postsecondary education is a time to both explore and select who one wants to become and to try new roles and ways of living.

The benefits of postsecondary education are extensive: better health outcomes, greater reported happiness, higher rates of participation in community, and longer life (McMahon, 2009). Additionally, those who participate in postsecondary education are more likely to be employed. On average they earn at least 50 percent more than their peers with a high school degree and are more likely to have health insurance (Baum & Ma, 2007; Bureau of Labor Statistics, 2010; Mischel, Bernstein, & Allegretto, 2007).

Postsecondary education for youth with ID has been rare. Until the passage of the Higher Education Opportunity Act in 2008, reauthorizing the Higher Education Act of 1965, postsecondary education for youth with disabilities had never been mentioned in federal statute. In a significant change, the new version of the law in 2008 not only mentioned students with disabilities; it also created a program to encourage the development of postsecondary education programs for youth with ID at institutions of higher education.

Over the past eight years, Congress has appropriated funds for, and the U.S. Department of Education has awarded, fifty-two grants to institutions of higher education to create postsecondary education programs for students with disabilities.

The Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) provides grants to institutions of higher education or consortia of institutions of higher education to enable them to create or expand high quality, inclusive model comprehensive transition and postsecondary programs for students with ID.

### Adam Parker Moss

Adam Moss is a 2015 graduate of the Ohio State University Transition Options in Postsecondary Settings (TOPS) program. The program provides the opportunity for young people with intellectual disabilities to continue their education on campus in an inclusive setting, attending classes with their non-disabled peers, working, and learning self-advocacy skills.

Born with an intellectual disability, Adam says that he was “blessed to be born with parents with high expectations.”

As a junior in high school, Adam began to ask his parents about attending college. He especially wanted to attend Ohio State University because his parents are alumni.

Adam was enrolled in TOPS for four years, graduating with a concentration in political science. One of his professors said of Adam that “he is a deeply engaged student who not only cares about learning the structures of American government but also how citizens can become involved.”

Adam reports that the TOPS program allowed him to pursue his dream of attending college and at the same time taught him valuable skills about work and interacting with others.



*Above, Adam Parker Moss with his mother. Adam is 23 and now works 20 hours a week at the Woody Hayes Athletic Center at Ohio State University.*

These programs have resulted in thousands of young people with ID attending postsecondary education programs. Preliminary data indicate that participation in these programs results in higher rates of employment compared to participants' same-age peers, as well as yielding social, health, and quality-of-life benefits (Grigal et al., 2015).

There are at least 250 postsecondary programs for people with ID at higher education institutions throughout the United States (Hart & Grigal, 2009). But despite this notable increase from virtually none prior to 2008, even eight years after the passage of HEOA, a complete profile of the programs offered and clear understanding of what variables promote the type of positive outcomes for youth with ID (as those typically find among the general population) remain unknown. Compared to the general population youth with ID are still only half as likely to participate in postsecondary education (Butterworth et al., 2013).

Significant research related to the effectiveness of postsecondary programs for youth with intellectual and developmental disabilities has been conducted during the past decade. This research has helped identify key components of programs to support postsecondary students with ID. Some such components have to do with the level at which students with ID are integrated in course work, social activities, and living arrangements. Other important components are availability of coaching, support models, and the academic approach of the programs (McEathron et al., 2013).

Initial outcomes and anecdotal evidence from youth with ID, their family members, and higher education personnel indicate that postsecondary education for youth with ID does have significant positive outcomes, though more data is needed to determine exactly what type of postsecondary programs and experiences yield the most benefits (Ross et al., 2013). Nonetheless, it is clear that in order to help people with ID travel a new trajectory to a more inclusive life, more opportunities for postsecondary education are needed for this group of young people.

## **Recommendations: Postsecondary Education**

**Recommendation #31: The U.S. Department of Education should begin a large-scale comparative study, comparable to the PROMISE controlled randomized trial study, to determine the most effective models and the key variables of postsecondary education programming for youth with intellectual disabilities.**

This study should be conducted for two purposes: 1) to determine the program structures that contribute to positive outcomes for youth with ID, and 2) to track students with ID for ten years and compare outcomes of those who attend postsecondary education programs with outcomes of those who do not.

**Recommendation #32: The U.S. Department of Education, in collaboration with stakeholders, including youth with disabilities, family members, researchers, philanthropists and foundation personnel, and higher education personnel and accreditors, should create a task force to establish standards for high-quality inclusive postsecondary education programs.**

The variation in program models and quality is vast among the fifty-two congressionally funded postsecondary programs. As reported in the most recent annual report on these programs, approximately half the courses in which students are enrolled are segregated and specialized. Other program variations have to do with campus housing, peer mentoring, specialized orientation programs, family participation, cost and other program components. This task force should establish high-quality guidelines for inclusive postsecondary education programs and encourage higher education accrediting agencies to use the standards when reviewing colleges and universities for overall accreditation.

**Recommendation #33: The U.S. Department of Education should create a state-level competitive grant program to encourage the development of postsecondary education programming for youth with intellectual disabilities within all state university systems.**

State public colleges and universities were established to provide their citizens with advanced education that would improve the standard of living for the individual, their family, and the state. State higher education systems should be open to all citizens, including those with ID. This competitive grant program would assist states in establishing programs for students with ID to gain the same experiences and opportunities at their state colleges and universities as their peers without disabilities.

**Recommendation #34: The U.S. Department of Education should create a competitive grant to establish technical assistance centers to collect and disseminate information about postsecondary education opportunities for youth with intellectual disabilities.**

These technical assistance centers should collect information about the postsecondary education options from around the country for students with ID, and publish the information in formats that are easily accessible to students and families. The technical assistance centers should also provide students and family members with qualitative information about postsecondary education programs and outcomes. The technical assistance centers should also provide information about program costs and availability of federal student loans, as well as state and institution student loans.

**Recommendation #35: The U.S. Department of Education should create a competitive grant to establish technical assistance centers to assist colleges and universities with creating programs for youth with intellectual disabilities and to support colleges and universities as they serve this population.**

These technical assistance centers should assist colleges and universities to create high-quality inclusive postsecondary programs for students with ID, help staff and faculty to create and provide course accommodations for students with ID, and help the colleges and universities make their programs and services accessible to students with ID.



**Recommendation #36: The U.S. Department of Education should work to remove the barriers that make it difficult for students with intellectual disabilities and their families to secure federal student loans to attend postsecondary education programs.**

The U.S. Department of Education should ensure that information about student loans for students with ID is widely available to those students and their families, and that institutions of higher education are aware that students with ID are eligible for federal student loans when they attend accredited, inclusive postsecondary education programs.

## **Community Living**

A second major area of importance for transition-age youth is access to community living. This includes such aspects of life as transportation and health care, as well as supports to live inclusively in communities with peers and neighbors with and without disabilities. In this section we address two of the most critical areas for community living: health care and transportation.

### **Health Care**

The vast majority of people with ID begin their care with pediatricians or developmental pediatricians. In urban areas, many are served through hospitals with a mission to serve children with special health care needs. It is clear that the transition to adult health care is much more difficult and sometimes impossible for youth with ID as compared with the general population, thus continuing their care via pediatricians and health care systems designed for children. Krahn et al. (2006) and Peter et al. (2009) noted the difficulty in finding health care providers with experience serving adults with ID. Peter et al. (2009) also described the significant need to train family physicians and internists in the care of adults with ID.

Hogg et al. (2001) noted that assisting youth with ID to transition from pediatric health care to adult health care can help them become more aware of the changes in their body and their health care needs as they age. Such knowledge is not necessarily available in settings that primarily care for pediatric patients with ID.

Kennedy and Sawyer (2008) found scattered health care services, in many cases through subclinical settings that provide excellent services in helping youth with ID to transition to adult health care. They note, however, that these are isolated examples and there is “little evidence of hospital-wide or regional planning” (p. 408). They, too, urge that more training be conducted with adult care providers to enable them to provide adult and aging health care services for people with ID.

A more global but related concern about the health care of people with ID is the overall continued high rate of secondary health concerns such as hypertension, diabetes, and obesity (Evenhuis et al., 2000; Lollar, 2001). Despite significant investment of funds into addressing the health of adults with ID, improvement has not occurred. In 2002, the Surgeon General’s office warned that as the education and social supports for people with ID evolve, health care services must also evolve. Part of that proposed evolution is to identify people with ID as a medically underserved population. This recommendation has been made by the American Academy of Developmental Medicine and Dentistry (2013), the American Medical Association (2014), the American Dental Association (2014), the American College of Physicians (2014), the American Physical Therapy Association (2015), and the American Academy of Pediatric Dentistry (2014).

### **Transportation**

To be included in all that life has to offer, people have to get where they are going. Mobility is necessary to obtain education, to find and keep a job, to stay healthy, and to fully engage in one’s community. For people with intellectual disabilities the transportation gap is large. Thirty-one percent of people with disabilities report insufficient transportation compared to thirteen percent of the general population (AAPD, 2012).

There are several reasons for this transportation gap for people with disabilities, including a lack of information, knowledge and skills needed to utilize public transportation; fear and apprehension among people with ID and their support systems; poor availability of options; and cost.

Across the government, there are several programs and initiatives that help address these key barriers. These include mobility management, a person-centered, holistic approach to transportation system design that aims to better connect citizens with existing transportation options; travel instruction for people with intellectual disabilities; and technology supports such as [TravelMate](#), an app for tablet computers that supports travelers with cognitive disabilities (The Arc of Northern Virginia).

In addition, a growing number of persons with disabilities are using fixed-route public transportation service. The Transit Cooperative Research Program (TCRP) Report 163, [Strategy Guide to Enable and Promote the Use of Fixed-Route Transit by People with Disabilities](#), found that, nationally, ridership by people with disabilities on the fixed-route system compared with ADA-mandated paratransit ranges between 1:1 and 5:1 or higher. In other words, between one and five or more times as many people with disabilities are riding the fixed-route system as compared to the ADA-mandated paratransit system.

Both accessible, quality health care and accessible, reliable transportation make it possible for people with ID to be active, inclusive members of their communities and society as a whole. Based on the continued need for quality healthcare and reliable transportation, PCPID makes the following recommendations:

### **Recommendations: Community Living**

**Recommendation #37: The U.S. Department of Health and Human Services should petition Congress to designate people with intellectual disabilities as a medically underserved population<sup>5</sup>.**

This designation will funnel additional resources to children and youth with ID and increase their health outcomes so their trajectory will continue toward integration in their communities rather than toward settings that are clinical in nature. This designation will further

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<sup>5</sup> Members of the President's Committee agree that the entire disability community should be considered as a medically underserved population. However, this Report solely focuses on people with intellectual disabilities and provides an advice to the President regarding issues pertaining to intellectual disabilities.

support people with ID to be able to advocate for concrete actions to decrease their health disparities by improving their overall health, and reducing barriers to their health care.

**Recommendation #38: The Disability and Health Office of the Centers for Disease Control and Prevention, in collaboration with the Administration for Community Living, the Health Resources and Services Administration, and the Society for Adolescent Health and Medicine should establish standards for transitioning youth with intellectual and other disabilities to adult health care.**

A task force composed of representatives from each of the agencies named above, along with an extensive group of youth and young adults with ID, should draft standards for transitioning youth with all types of disabilities, including those with intellectual and developmental disabilities, from pediatric health care to adult health care. The task force should also offer strategies specifically to address the shortage of adult health care providers for people with intellectual and developmental disabilities.

**Recommendation #39: An interagency group composed of the U.S. Departments of Education, Labor, and Health and Human Services should work to develop strategies to implement the six goals of the 2002 Surgeon General’s Report on “health disparities and people with intellectual disabilities”.**

The six goals of the 2002 Surgeon General’s Report are designed to increase the capacity of the national health care system to address the health needs of people with ID, to increase the knowledge and skills of physicians and allied health professionals regarding care for adults with ID, and to ensure that health care services are accessible to those with ID. Implementing the strategies suggested by the Surgeon General’s office would greatly increase the likelihood of improved health outcomes for adults with ID.

**Recommendation #40: Expand the mobility management project operated by the Federal Transit Administration (FTA) to increase the ability of people with intellectual disabilities to navigate transportation networks in their communities.**

In order to support people with ID to expand their use of fixed route transportation options, expand the capital expenditures of the FTA to local transportation providers to provide instruction to people with ID regarding the options and means for using fixed route transportation. This would include increased access to those transportation options while increasing the ability for people with ID to use those systems safely and reliably.

**Recommendation #41: In order to address the transportation needs of people with intellectual disabilities in communities that are transportation deserts, expand the Section 5310 program to create additional transportation opportunities.**

In both rural and suburban areas of the country where accessible transportation is absent, use the Section 5310 program to expand options and create new strategies to address the transportation needs of people with ID. The Section 5310 program provides formula funding to states for the purpose of assisting non-profit groups to meet the transportation needs of older adults and people with disabilities.

## **Employment**

People with ID have one of the lowest rates of participation in the workforce of any subgroup in the country, if not the lowest. Their rate is far lower than any group of color and lower than almost all subgroups of people with disabilities. As summarized by the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities in their *Interim Report* (2015), youth with ID are less likely than their peers to graduate from high school, less likely to pursue postsecondary education, more likely to participate in sheltered-workshops and significantly more likely to be unemployed for much or all of their adult lives.

Research during the past fifteen years has clearly identified the factors that increase the likelihood of youth with disabilities securing a job. Work-based experiences in competitive integrated employment are the number one factor affecting the likelihood of a person with a

disability securing competitive integrated work after they leave school (Carter et al., 2012; Luecking & Luecking, 2015; Test et al., 2009).

Other factors that contribute to the higher likelihood of securing a job after school are early connections to vocational rehabilitation services (Luecking & Luecking, 2015; Schall et al., 2015), instruction and practice in self-determination activities (Berry et al., 2012; Getzel & Wehman, 2005), participation in the general education curriculum during high school (Berry et al., 2012), and family expectations (Wehman, 2013).

A number of pilot projects conducted over the past decade have resulted in youth with ID achieving jobs in competitive integrated settings at the 60–70 percent level, compared to the 14–18 percent level of most adults with ID. Projects such as Partnerships in Employment (PIE) sponsored by AIDD (Partnerships in Employment National Transition Systems Change Project, 2016), Project SEARCH (Schall et al., 2015), Transition Systems Integration Model (Certo et al., 2009), and the Seamless Transition Model (Luecking & Luecking, 2015) have all been successful at increasing the employment outcomes of young adults with ID.

In addition to strategies cited above for increasing the likelihood of employment after preK–12 education, participation in service learning, such as the activities conducted by the Corporation for National and Community Service (CNCS), can provide pre-employment skill-building to increase workforce participation (Spera et al., 2013). National service experiences provide young adults with ID with experiences and skill development similar to that gained through paid work in integrated settings. Those who complete a service term for one of the CNCS programs are eligible to receive an education award that can fund postsecondary education or pay down college debt. In addition, national service members may receive modest living allowances during their service terms that can assist with launching young people with disabilities into the workforce. While they should not be a substitute for paid work experiences, volunteer experiences can lead to employment and, as such, can be a strategy for increasing workforce participation for young adults with ID<sup>6</sup>.

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<sup>6</sup> Two recent publications on the topic of transition from preK-12 education to employment for youth with disabilities are: 1) The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy, and 2) The 2016 Interim Report from the Advisory

Despite the clear knowledge that has been gained about what factors can be implemented to increase the likelihood of employment for young adults with ID, availability of these strategies across the country varies greatly (Carter et al., 2009). Policies are needed to support the use of the strategies that have been identified through evidence-based research. The following recommendations highlight key points from the aforementioned publications (see footnote on page 56), and are designed to increase the likelihood of youth with ID securing and retaining employment as they transition from preK–12 schooling into adulthood.

### **Recommendations: Employment**

**Recommendation #42: The U.S. Department of Labor should continue to support States to expand their Employment First initiatives<sup>7</sup>.**

As of the writing of this Report, 46 states have initiated Employment First activities (APSE, 2016). However, these initiatives vary greatly. The U.S. Department of Labor should provide technical assistance to ensure such strategies, as customized employment and supported employment, make it possible for people with ID to work in competitive integrated settings.

**Recommendation #43: The U.S. Department of Education should issue guidance that encourages schools with transition-age youth with intellectual disabilities to participate in work-based learning.**

The work-based learning experiences provided to young people with ID should be in integrated settings where they are able to learn and implement job skills. Youth with ID should also have the opportunity to experience paid work at competitive wages in an integrated setting.

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Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities (set to be released in September 2016).

<sup>7</sup> A framework for systems change that is centered on the premise that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community living

**Recommendation #44: The U.S. Department of Education should issue guidance to states and local school districts to ensure that secondary and postsecondary career and technical education (CTE) programs are accessible to students with disabilities and that such students are recruited for CTE programs.**

The U.S. Department of Education, through the issuance of guidance and in the absence of reauthorization of the Perkins Career and Technical Education Act, should direct secondary public schools and postsecondary programs using federal CTE funds, to develop strategies to recruit, enroll, retain, and graduate students with disabilities. Such guidance should include strategies for states to develop technical assistance for local school districts and state community colleges to serve students with disabilities, including those with ID. The Department should also offer guidance to local school districts to promote the inclusion of CTE programming in the IEPs of youth with ID, when the program is consistent with the student’s academic and transition goals.

**Recommendation #45: The U.S. Department of Education should issue guidance that promotes at least one 10-week-minimum, paid, work-based experience in an integrated workplace setting.**

As part of their transition plan, students with ID should have at least one work-based learning experience in a competitive integrated setting. Students should not be placed in subminimum-wage settings for either pre-employment training experiences or work-based learning experiences. Based on the interventions used in the “Youth Transition” and the “PROMISE” studies a 10-week paid work experience should be made available for all transitioning youth with ID.

**Recommendation #46: The U.S. Department of Education should combine the use of IDEA Part D funds and ESSA Title II funds to create competitive grants for the purpose of developing new teacher and school leader workforce cohorts at the local level knowledgeable about strategies for increasing competitive integrated employment among students transitioning from preK–12 schooling.**



These cohorts can be developed through the creation of institutes, seminars, or long-term professional development experiences that provide educators with information about program models, curricula, and intervention strategies which, based on robust research findings, are likely to increase the chances of employment for students with intellectual disabilities. Such institutes should have at least the following components:

- examples of the impact of high expectations from teachers, counselors, school leaders, and other school personnel on the employment of students with intellectual disabilities;
- information about the impact of work-based learning and experiences in competitive integrated employment for students with intellectual disabilities;
- the effect of parent and family member expectations on the employment of students with intellectual disabilities;
- education in benefits counseling, to be able to accurately talk with youth with ID and their family members about the impact of working on SSI and other benefits; and
- train-the-trainers instruction in each of the above areas to enable cohort participants to effectively communicate the information to their school colleagues.

**Recommendation #47: The Rehabilitation Services Administration (RSA) should issue guidance to state Vocational Rehabilitation (VR) Services regarding effective strategies for collaborating with local school districts to develop transition plans for students with intellectual disabilities beginning at age fourteen.**

The Rehabilitation Services Administration should clarify with state VR programs, the role of VR counselors in the transition of youth with ID. State agreements, such as the one developed by Tennessee, should be implemented to ensure that local schools and VR services coordinate the services they provide (Tennessee Interagency Transition Agreement, 2012).

**Recommendation #48: The U.S. Department of Education should update guidance and enforcement of IDEA indicators 13 and 14 to promote the path toward competitive integrated employment for youth with intellectual disabilities.**

The U.S. Department of Education's reporting requirements related to the implementation of IDEA include a set of indicators about which local school districts and state education agencies must provide outcome data. Indicators 13 and 14 address transition planning and activities, and postschool outcomes, for students with disabilities. PCPID recommends that, as part of indicator 13, families receive quarterly updates on a student's progress toward achieving postschool outcomes, including participation in work-based learning activities. The President's Committee also recommends that the U.S. Department of Education monitor states and their oversight of local school districts regarding annual assessment of postschool outcomes for all exiting students, reporting on their postschool outcomes for at least five years. The Department should work with states to establish goals for local school districts related to student participation in postsecondary education and competitive integrated employment. Local school districts not achieving those goals should be provided with support and technical assistance from their state education agency.

**Recommendation #49: The U.S. Department of Education should issue guidance to update the IEP process to guide teams, including family members, to include goals that are outcome-based and inclusive of postsecondary education and competitive integrated employment.**

During the transition period of a youth with disabilities, including youth with ID, local school districts are required to convene IEP teams annually to review and update IEP transition goals, and include postsecondary education and competitive integrated employment goals as appropriate for the student.

The U.S. Department of Education should provide guidance for state education agencies and local school districts to ensure the provision of training for IEP team members on the most up-to-date evidence-based practices related to achieving postsecondary education and competitive integrated employment. Local school districts should be provided with strategies to track and report progress toward such goals from the start of transition planning for all students with disabilities. Data should be collected and reported by disability category.

## **Focus Area 4: Self-Determination and Supported Decision-Making**

### **Overview and Background:**

The creation, implementation, and enforcement of policies and practices that will shift the trajectory for people with intellectual disabilities toward opportunities for meaningful economic, social, educational, and physical connections to their communities are not actions of charity but actions driven by a foundational belief that inclusion and control over one's life are fundamental civil and human rights. Marginalized groups have had to fight to remove barriers in order to access rights they have been denied. One of the central goals of the disability rights movement is to fight against policies, practices, and attitudes that contribute to the oppression and marginalization of, and the discrimination against, people with disabilities (Winter, 2003). In doing so, the disability rights movement promotes full citizenship and the civil and human rights of all people regardless of ability. A person's right to make their own decisions, set their own goals, and pursue those goals is a cornerstone of the United States Constitution and of state constitutions. These rights have also been recognized internationally. Article 12 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) states that decision-making is a right that is not dependent on disability status and should be legally protected (Dinerstine, 2011–2012).

Decision-making and self-determination are not synonymous, but they are integrally related. Decision-making involves the ability to make judgments about which solution or option is best in a given situation (Baron & Brown, 1991). Decision-making requires not only skill but also opportunities and access to various courses of action. Self-determination describes the activity a person takes to control their own life in pursuit of their own goals (Blank & Martinis, 2015; Shogren et al., in press). It requires that one have opportunities to make decisions in one's life to set those goals, and then the freedom to take action in pursuing those goals.

For people with disabilities, and particularly for those with ID, policies and practices have developed over time that limit or remove their rights to make their own decisions, take action toward achieving their own life goals, and thereby take their place as equal citizens. To

shift the trajectory for people with ID toward full citizenship, policies and practices must be enacted to restore these rights.

### **Guardianship as a Barrier to Self-Determination**

The practice of legal guardianship, initially designed as a protection for people with ID, can be a barrier to self-determination. In the United States, the denial of rights on the basis of gender and race, though still a reality, has long been considered morally wrong (Carey, 2009). However, only within the past few decades has this discrimination been questioned in regard to individuals with limitations in intellectual functioning. Historically in the United States, access to formal care and support was integrally linked to the loss of personal freedom and control. Breaking this link has proven to be a difficult process (Carey, 2009). For most citizens, upon the legal age of adulthood, access to all civil rights is afforded. Decisions that previously could only be made by parents or guardians transfer to the young adult (Miller, 2007). However, if a court determines that an individual is cognitively incompetent; those rights are not afforded and instead are transferred to a proxy (Miller, 2007). This system is known as guardianship and was originally designed to protect specific groups of people, such as those with ID, from harm.

The automatic granting of guardianship for people with ID can, however, deny fundamental rights to self-determination and decision-making on the basis of “intellectual incompetence” regardless of the significance of such so-called incompetence in specific matters (Carey, 2009; Noll & Trent, 2004). Under guardianship, people are stripped of or denied rights to any legal and most personal decision-making (Carey, 2009). In this process a third party, be it a family member, friend, or unrelated individual, petitions the court to assume all or some decision-making rights on behalf of the individual (Carey, 2009). It is assumed that the proxy can and will make better decisions than the individual for whom they are the guardian.

There can be problems both with the assumption of and the process of guardianship as a whole. The belief that a proxy will always make better decisions than a person with intellectual disability assumes that decision-making is a static, concrete skill set that one has or does not have. Decision-making, however, is a complex process that requires skill, access to information

about options and potential consequences, knowledge of available resources, and knowledge of social contexts.

The process by which the policy of guardianship is practiced also can be problematic. No federal guidelines exist to unify state practices of guardianship, nor are states required to keep data on guardianship rulings (Millar & Renzaglia, 2002). The lack of data collection and record-keeping makes it difficult to determine, first, how many citizens are not provided their fundamental right to self-direction and, second, the consequences of such loss of rights for both the person and their community.

Guardianship itself is not a homogeneous occurrence. There are both different types and different degrees of guardianship (Millar & Renzaglia, 2002). One type is guardianship over the person, meaning that the person's guardian controls residential, daily-life, educational, and medical decisions. Another type is guardianship over the estate, meaning that the guardian has control over financial decisions for the individual (Millar & Renzaglia, 2002). Full guardianship, otherwise known as general or plenary guardianship, occurs when the guardian is legally authorized to make all decisions for the person. Limited or partial guardianship occurs when the guardian is authorized to make some of the person's decisions (Blank & Martinis, 2015). Available data demonstrate that in most cases, when a petition for guardianship of an adult is put forward, full guardianship is granted to the proxy (Teaster, Wood, Lawrence, & Schmidt, 2007).

In 1987, Claude Pepper, Chair of the House of Representatives Select Committee on Aging, was examining the issue of abuses in guardianship. In a summary of the committee's work he described guardianship as "the most punitive civil penalty that can be levied against an American citizen" (Pepper, 1987, p. 4). By definition, the system denies the individual the right to make their own decisions and direct their own life. In the United States, individual states control guardianship laws. Many states lack a system to monitor and review guardianship. Once guardianship has been established, it can be unclear how the decision is made to determine whether an individual continues to require guardianship and, if so, under what circumstances.

It is estimated that over 1,250,000 adult citizens in the United States have been deemed incompetent and unable to make decisions regarding their own lives (Lisi, Burns, & Lussenden, 1994). These individuals are not only people with intellectual disabilities; they also include older adults deemed incompetent due to age-related declines and individuals with mental illness. Even though full guardianship can severely restrict an individual's legal rights, studies find that courts often choose full guardianship over less restrictive alternatives. In 2007, one study found that in just fewer than 90 percent of guardianship cases, the proxy was granted full decision-making over all aspects of the individual's life (Teaster, Wood, Lawrence, & Schmidt, 2007).

People placed in circumstances where they are denied opportunities for self-determination, such as in the case of full guardianship, often report feelings of inadequacy, low self-worth, and potentially diminished quality of life (Winick, 1995). The practice of guardianship continues to be used inappropriately to block community integration despite Federal and State laws and Supreme Court holdings, such as the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the Supreme Court 1999 Olmstead Decision prohibiting unjustified segregation. Under guardianship a person can be denied the right to choose where and with whom they live, the right to get married, the type of employment they pursue, the medical services they use, and in many states the right to vote. The practice of preventing an adult from exercising, or stripping them of the legal right to make their own decisions on the basis of intellectual capacity also sends a message to the larger society that people with ID have the legal and social status of children and are not full and equal citizens. This may impact societal attitudes that contribute to ongoing discrimination and segregation of people with ID.

### **Supported Decision-Making**

Certain strategies can enhance the rights and decision-making power of people with ID, even if they have a guardian. In some cases, the use of such strategies may make it possible for an individual to make their own or participate in the making of decisions about their living arrangements, work, health, and finances. Supported decision-making is one such strategy.

Supported decision-making is often defined as an individual using a team of trusted people (e.g., friends, family members, advocates) to help them understand a situation and the choices they have so they may make their own informed decisions to the best of their ability (Dinerstein, 2011–2012; Quality Trust, 2013). In a specific situation, supported decision-making takes into account the diversity of decisions to be made and can adjust the support a person needs depending on the nature of a given decision.

Although guardianship is still prevalent, supported decision-making is increasingly used as an augmentation to guardianship or even an alternative in the United States (Kohn, Blumenthal, & Campbell, 2013). The UN Convention on the Rights of Persons with Disabilities recognizes supported decision-making as a means to ensure access to human and civil rights for persons with disabilities, and several states have passed laws studying and authorizing the use of supported decision-making (Blank & Martinis, 2015). Supported decision-making can provide individuals with ID the skills to live self-determined lives and to enjoy the rights afforded them as humans and as citizens (Kohn et al, 2013).

Decision-making and self-determination involve both opportunity and teachable skills. Young adults who receive instruction to increase self-determination exhibit better employment outcomes, increased independence in daily-life activities, and more extensive community integration than those who do not (Powers et al., 2012; Shogren et al., in press). Studies have indicated a positive relationship between self-determination and quality of life. One such study found that young adults with greater self-determination were more likely to want to manage their own money, be employed in competitive integrated settings, and live independently (Wehmeyer & Schwartz, 1997). Other studies have found that adults who exerted more self-determination were more likely to live independently, protect themselves from abuse, and have higher-paying jobs (Wehmeyer & Palmer, 2003; Kehemka, Hickson, & Reynolds, 2005). Supported decision-making may increase self-determination and have a positive influence on an individual's quality of life.

## **Recommendations: Self-Determination and Supported Decision-Making**

**Recommendation #50: The U.S. Department of Health and Human Services (HHS-ACL) and the U.S. Department of Justice should monitor and study current guardianship laws in order to develop incentives for the adoption and expansion of augmentations and alternatives to guardianship, including supported decision-making.**

Guardianship can be a problematic and a potentially abusive practice. More research must be conducted to determine the financial, political, and social incentives that maintain the system of guardianship. More research will also provide better data on the prevalence of guardianship and the monitoring that is or is not in place to protect people with guardians from abuse. In order for courts and providers to make informed decisions about guardianship and the use of alternatives such as supported decision-making, data regarding the use and outcomes of guardianship are necessary. As guardianship can severely limit an individual's civil rights, sound information is necessary for those in the position to determine whether a person is assigned a guardian. Research also should be conducted on the potential reduction or elimination of guardianship and the impact such a shift may have on those currently under guardianship.

**Recommendation #51: The Administration for Community Living (ACL), in collaboration with the Administration on Children, Youth, and Families (ACYF), should support the development and continued use of systems for sharing information about supported decision-making and alternatives to guardianship for individuals with intellectual disabilities, as well as for those who are aging.**

As new data and information emerge about best practices in supported decision-making, that information must become readily accessible and shared with families, courts, school personnel, and service providers. Organizations such as the National Resource Center for Supported Decision-Making (NRC-SDM) are leading and coordinating efforts to make supported decision-making a recognized alternative or augmentation to guardianship (Blank & Martinis, 2015). The NRC-SDM is acting as a clearinghouse for information on supported decision-



making, conducting research on best practices in supported decision-making, and establishing services, such as a website for families, self-advocates, and government officials, to share information and coordinate efforts in promoting supported decision-making. ACL should collaborate with NRC-SDM to ensure that information about supported decision-making is widely available.

**Recommendation #52: The Office of Special Education and Rehabilitation Services (OSERS) and the Administration for Community Living (ACL) should jointly promote and distribute information about supported decision-making and self-determination as methods to engage individuals with intellectual disabilities in their own lives and exercise their rights throughout their lives.**

The OSERS and the ACL should work jointly to disseminate information about self-determination skill development and supported decision-making for people with ID throughout their lives. This dissemination should frame decision-making and self-determination as basic human rights and as a natural part of the human experience. To improve the trajectory of inclusion for individuals with ID, they should be supported in developing such skills as early as possible. Professionals (e.g., teachers, child care providers, personal care attendants) should be knowledgeable about self-determination and supported decision-making skills and should provide opportunities for children and young people with ID to develop those skills.

Likewise, those in a position to make decisions about guardianship for people with ID should have access to information about alternatives. In a study exploring the awareness perception of guardianship and its alternatives among educators, students with disabilities, and parents, it was found that almost all parties were aware of the nature and process of guardianship but few were aware of any alternatives, such as supported decision-making (Millar, 2007). The ACL and the OSERS should put in place strategies to provide guardianship decision-makers, such as judges, court officials, social workers, and transition specialists, with information about alternatives to guardianship.

**Recommendation #53: The U.S. Departments of Education, Labor, and Health and Human Services should include in their personnel development grant programs requirements for education about supported decision-making and guardianship.**

For all competitive grants related to pre-service and professional development in each of the three departments, grantees should be required to provide evidence-based instruction about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

**Recommendation #54: The U.S. Department of Justice should consider including a competitive preference for its Bureau of Justice Assistance competitive grant programs to expand the knowledge of court officers about supported decision-making and guardianship.**

The Department of Justice, through its Bureau of Justice Assistance competitive grant programs, should offer a preference for applicants who include evidence-based instruction for judges and court officers about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

**Recommendation #55: The U.S. Department of Education should require, as part of the requirements for reporting data for IDEA Indicator 13, that the notice provided to families and youth with disabilities leading up to the age of majority include robust information about the implications of guardianship and options for supported decision-making.**

The U.S. Department of Education should include in its reporting requirements concerning transition activities the mandate for states and local school districts to supply data regarding the type of information they provide to families and youth with disabilities about shared decision-making and the implications of partial and full guardianship. The Department should use the most up-to-date information generated by the National Institute on Disability,

Independent Living, and Rehabilitation Research (NIDILRR), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the National Institute on Aging (NIA) about supported decision-making. The Department should also provide guidance about the quality of information to be shared. The percentage of families and students with disabilities receiving such information should be reported annually.

The members of the President's Committee for People with Intellectual Disabilities are hopeful that this Report will provide a strategy for strengthening federal policies in the areas of: family engagement, education, transition, and self-determination and supported decision-making to place people with intellectual disabilities on a new trajectory to full inclusion and access to opportunities for the highest quality of life.

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## **FREQUENTLY USED ACRONYMS**

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AAIDD	American Association on Intellectual and Developmental Disabilities
AIDD	Administration on Intellectual and Developmental Disabilities
AoD	Administration on Disabilities
ASD	Autism Spectrum Disorder
CE	Customized Employment
CIE	Competitive Integrated Employment
CNCS	Corporation for National and Community Service
CRDC	Civil Rights Data Collection
DD	Developmental Disabilities
EAHCA	Education for All Handicapped Children Act
ESEA	Elementary and Secondary Education Act
ESSA	Every Student Succeeds Act
FAPE	Free Appropriate Public Education
FINDS	Family and Individual Needs for Disability Supports
HCBS	Home and Community Based Services

HEOA	Higher Education Opportunity Act
HHS	U.S. Department of Health and Human Services
ID	Intellectual Disabilities
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
LEA	Local Educational Agency
LEND	Leadership and Education in Neurodevelopmental Disabilities
NCLB	No Child Left Behind
NHIS	National Health Interview Survey
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
OESE	Office of Elementary and Secondary Education
OSERS	Office of Special Education and Rehabilitation Services
PIE	Partnerships in Employment
PROMISE	Promoting Readiness of Minors in Supplemental Security Income
PTI	Parent Training and Information Centers
RSA	Rehabilitation Services Administration

SE	Supported Employment
SWIFT	Schoolwide Integrated Framework for Transformation
UDL	Universal Design for Learning
VR	Vocational Rehabilitation
WIOA	Workforce Innovation and Opportunity Act

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Benjamin “Bo” Tayloe, Jr.  
Deputy Chief  
Civil Rights Division, Special Litigation Section  
U.S. Department of Justice

Alternate Contact:  
Clarette Yen  
Attorney Advisor, Disability Rights  
U.S. Department of Justice

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*Represented by:*  
Mary Pletcher  
Deputy Assistant Secretary for Human Capital and Diversity  
U.S. Department of the Interior

Alternate Contact:  
Margaret Triebisch  
Committee Management Officer  
U.S. Department of the Interior

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*Represented by:*  
Tinisha Agramonte  
Director, Office of Civil Rights  
U.S. Department of Commerce

Alternate Contact:  
Kathy Anderson  
Deputy Director, Office of Civil Rights  
U.S. Department of Commerce

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**Secretary, U.S. Department of Labor**

*Represented by:*

Jennifer Sheehy  
Acting Assistant Secretary for Disability Employment Policy  
U.S. Department of Labor

Alternate Contact:

Michael Reardon  
Supervisory Policy Advisor, Office of Disability Employment Policy  
U.S. Department of Labor

**The Honorable Sylvia M. Burwell**  
**Secretary, U.S. Department of Health and Human Services**

*Represented by:*

Melissa L. Harris  
Senior Policy Advisor  
Disabled and Elderly Health Program Group  
Centers for Medicare & Medicaid Services  
U.S. Department of Health and Human Services

Alternate Contact:

Tiina Urv, PhD  
Program Director  
National Institutes of Health  
U.S. Department of Health and Human Services

**The Honorable Julián Castro**  
**Secretary, U.S. Department of Housing and Urban Development**

*Represented by:*

Michelle Aronowitz  
Deputy General Counsel for Enforcement and Fair Housing  
U.S. Department of Housing and Urban Development

Alternate Contact:

Charlene Wills  
Trial Attorney  
office of General Counsel  
U.S. Department of Housing and Urban Development



**The Honorable Anthony Foxx**  
**Secretary, U.S. Department of Transportation**

*Represented by:*  
Stephanie Jones  
Deputy Chief of Staff, Office of the Secretary  
Acting Director, Departmental Office of Civil Rights  
U.S. Department of Transportation

Alternate Contact:  
Yvette Rivera  
Associate Director, Equal Employment Opportunity Programs Division  
U.S. Department of Transportation

**The Honorable John B. King**  
**Acting Secretary, U.S. Department of Education**

*Represented by:*  
Sue Swenson  
Deputy Assistant Secretary  
Office of Special Education and Rehabilitative Services  
U.S. Department of Education

**The Honorable Jeh Johnson**  
**Secretary, U.S. Department of Homeland Security**

*Represented by:*  
Brian S. Parsons  
Senior Policy Advisor, Office for Civil Rights and Civil Liberties  
U.S. Department of Homeland Security

**The Honorable Wendy Spencer**  
**Chief Executive Officer, Corporation for National and Community Service**

*Represented by:*  
Stephanie Enyart  
Disability and Inclusion Advisor  
Corporation for National and Community Service

**The Honorable Carolyn W. Colvin**  
**Commissioner, U.S. Social Security Administration**

*Represented by:*  
Leola Brooks  
Senior Advisor for Disability Program Outreach  
Office of Retirement & Disability Policy  
U.S. Social Security Administration

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**Chair, U.S. Equal Employment Opportunity Commission**

*Represented by:*  
Mary Kay Mauren  
Senior Attorney/Advisor  
U.S. Equal Employment Opportunity Commission

**The Honorable Clyde E. Terry**  
**Chairperson, National Council on Disability**

*Represented by:*  
Gary Blumenthal  
Council Member  
National Council on Disability

***PCPID STAFF***

**Aaron Bishop, MSSW**  
Commissioner, Administration on Disabilities  
PCPID, Designated Federal Officer

**Michael Gamel-McCormick, PhD**  
Consultant

**Allison Cruz**  
Director, AIDD-Office of Innovation

**Madjid “MJ” Karimi, PhD, CPH**  
Team Lead and Report Project Manager

**Sheila Whittaker**  
Program Assistant

## **ADDITIONAL ACKNOWLEDGMENTS**

The President's Committee for People with Intellectual Disabilities wishes to thank the following individuals for their assistance, contributions, and review of this Report:

**Julia Bascom**

Deputy Executive Director  
Autistic Self Advocacy Network  
Washington, D.C.

**Molly Burgdorf, JD**

Senior Advisor  
Administration for Community Living  
Center for Disability and Aging Policy  
U.S. Department of Health and Human Services  
Washington, D.C.

**Dawn Carlson, PhD**

Rehabilitation Specialist  
Administration for Community Living  
National Institute on Disability, Independent Living,  
and Rehabilitation Research  
Washington, D.C.

**Erik Carter, PhD, FAIDD**

Associate Professor  
Department of Special Education  
Vanderbilt Peabody College  
Nashville, Tennessee

**Larissa Crossen**

Program Specialist  
Administration for Community Living  
Administration on Intellectual and Developmental Disabilities  
U.S. Department of Health and Human Services  
Washington, D.C.

**Richard A. Davis**  
Policy Advisor  
Workforce Systems Policy Team  
Office of Disability Employment Policy  
U.S. Department of Labor  
Washington, D.C.

**Curtis L. Decker, JD**  
Executive Director  
National Disability Rights Network  
Washington, D.C.

**Robert Dinerstein, JD**  
Professor of Law  
Associate Dean for Experiential Education  
American University, Washington College of Law  
Washington, D.C.

**Tawara Goode, MA**  
Director  
National Center for Cultural Competence  
Georgetown University Center for Child and Human Development  
Washington, D.C.

**Judith E. Heumann**  
Special Advisor for International Disability Rights  
U.S. Department of State  
Washington, D.C.

**Ryan King and Susie King**  
Advocates  
Washington, D.C.

**Regina “Gina” Kline**  
Senior Counsel  
Office of the Assistant Attorney General  
Civil Rights Division  
U.S. Department of Justice  
Washington, D.C.

**Serena Lowe, PhD**  
Senior Advisor  
Administration for Community Living  
Center for Disability and Aging Policy  
U.S. Department of Health and Human Services  
Washington, D.C.

**Heidi Mann**  
Writing Specialist  
Final Touch Proofreading & Editing, LLC.  
Ely, Minnesota

**Ophelia McLain, DHA**  
Director  
Office of Program Support  
Administration on Intellectual and Developmental Disabilities  
U.S. Department of Health and Human Services  
Washington, D.C.

**David O'Hara, PhD**  
Interim President and Chief Executive Officer  
Westchester Institute for Human Development  
Valhalla, New York

**Carol Quirk, EdD**  
Executive Director  
Maryland Coalition for Inclusive Education  
Executive Team of the SWIFT Center  
Hanover, Maryland

**Amanda Rich, PhD**  
Assistant Professor  
Behavioral Science/Sociology  
York College of Pennsylvania  
York, Pennsylvania

**Barb Trader**  
Executive Director  
TASH  
Washington, D.C.

**Eric Weakly, MSW, MBA**  
Aging Services Program Specialist  
Administration for Community Living  
Center for Disability and Aging Policy  
U.S. Department of Health and Human Services  
Washington, D.C.

**Corinne Weidenthal, EdD**  
Education Program Specialist  
Office of Special Education Programs  
U.S. Department of Education

**Morgan Whitlatch, JD**  
Senior Attorney  
Quality Trust for Individuals with Disabilities  
Washington, D.C.



The Administration for Community Living  
The Administration on Disabilities  
The President's Committee for People with Intellectual Disabilities

Mary E. Switzer Memorial Building  
330 C Street, S.W.  
Washington, D.C. 20201

**Phone:** (202) 795-7374

**Website:** <http://www.acl.gov/programs/aidd/Programs/PCPID/>