LIFE IN THE COMMUNITY SUMMARY

All people, regardless of disability, deserve the opportunity for a full life in their community where they can live, learn, work, and play alongside each other through all stages of life. People with intellectual and/or developmental disabilities[1] need varying degrees of support to reach personal goals and establish a sense of satisfaction with their lives.

AGING

People with intellectual and/or developmental disabilities who are 55 years of age or older have a right to the same opportunities to enjoy full lives as other older people. They are entitled to full access to community supports, including support from those agencies that serve all older people.

BEHAVIORAL SUPPORTS

A full and active life supported by caring relationships can reduce the occurrence of challenging behaviors in people with intellectual and/or developmental disabilities. However, if such behaviors occur, people with intellectual and/or developmental disabilities and those who support them must have access to positive behavioral supports that focus on improved quality of life as well as reductions in the behaviors.

EARLY CHILDHOOD SERVICES

All young children who are at-risk for or who have been identified with intellectual and/or developmental disabilities should have access to high-quality, affordable developmental services in natural environments. These services should build on the strengths of the child and family, address their needs, be responsive to their culture and personal priorities, and be delivered through research-based practices.

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[1] Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as "The DD Act", are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym "IDD" is used to describe a group that includes either people with both ID and another DD or a group that includes people with ID or another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

EDUCATION

All children and youth with intellectual and/or developmental disabilities (IDD) must receive a free appropriate public education that includes fair evaluation, ambitious goals, challenging objectives, the right to progress, individualized supports and services, high quality instruction, and access to the general education curriculum in age-appropriate inclusive settings. These are essential for achieving the nation's four policy goals of equality of opportunity, full participation, independent living, and economic self-sufficiency (the four policy goals). Parents and families must be supported as essential partners in the education and transition to adult life of their sons and daughters.

EMPLOYMENT

People with intellectual and/or developmental disabilities (IDD) can be employed in the community alongside people without disabilities and earn competitive wages. They should be supported to make informed choices about their work and careers and have the resources to seek, obtain, and be successful in community employment.

FAMILY SUPPORT

Family support services and other means of supporting families across the lifespan should be available to all families to strengthen their capacities to support family members with intellectual and/or developmental disabilities (IDD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency. Family caregivers include, but are not limited to, parents (including those with IDD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships.

HEALTH

All people, including people with intellectual and/or developmental disabilities (IDD), should have timely access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs, maximizes health, well-being and function, and increases independence and community participation.

The health care system must be aligned to principles of nondiscrimination, comprehensiveness, continuity, appropriateness, and equity. Both comprehensive public and private health insurance must provide for necessary health care without regard to the nature or severity of disability, pre-existing conditions, or other health status.

HOUSING

People with intellectual and/or developmental disabilities (IDD), like all Americans, have a right to live in their own homes, in the community. Children and youth belong with families. Adults should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities.

INDIVIDUAL SUPPORTS

People with intellectual and/or developmental disabilities (IDD) must have access to individual supports, such as assistive technology and personal assistance, to support their participation in daily life.

OPPORTUNITIES FOR FINANCIAL ASSET BUILDING

People with intellectual and/or developmental disabilities (IDD) must have the same opportunities to advance their economic and personal freedom by earning and saving money to enhance their physical, social, emotional, and financial well-being and the right to exercise choice in investment and spending decisions as their peers who do not have disabilities.

PARENTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

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

SEXUALITY

People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected.

SPIRITUALITY

People with intellectual and/or developmental disabilities have the right to choose their own expressions of spirituality, to practice those beliefs and expressions and to participate in the faith community of their choice or other spiritual activities. They also have a right to choose not to participate in religious or spiritual activity.

TRANSPORTATION

People with intellectual and/or developmental disabilities (IDD) must have access to both public and private transportation to lead full, self-directed lives.

AGING

People with intellectual and/or developmental disabilities[1] who are 55 years of age or older have a right to the same opportunities to enjoy full lives as other older people. They are entitled to full access to community supports, including support from those agencies that serve all older people.

ISSUE

For the first time in history, Americans living in the 21st century will experience millions of people with intellectual and/or developmental disabilities living into their "senior" years. These Americans with disabilities want to enjoy their older years in the same manner as other people their age. Unfortunately, the discrimination that older people often experience in accessing community activities, housing, services, and supports and in enjoying all aspects of community life as they age, is experienced to a much greater degree by people with intellectual and/or developmental disabilities as they age.

Like other older Americans, people with intellectual and/or developmental disabilities may require greater levels of support to allow them to live full, active and healthy lives in their communities as independently and as long as possible. Unfortunately, many older people with intellectual and/or developmental disabilities lack basic housing supports, as well as the specialized services needed to enable them to live more independently. They also lack the access to the health care services they need as they grow older, particularly access to preventative services and to ongoing habilitation and rehabilitation services.

Additionally, family members of people with intellectual and/or developmental disabilities often lack information about and access to resources to enable them to support the person who is growing older. Many people with disabilities see no future for themselves as they grow older, other than one inside the walls of a nursing home or other institutional setting.

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These problems are compounded by the fact that many community-based services for senior citizens are not prepared to meet the special needs of older adults with intellectual and/or developmental disabilities. Likewise, many disability-based organizations have historically not planned for the challenges faced by older people with intellectual and/or developmental disabilities and are not prepared to address these unique needs, including providing education and training on mitigating the risk of elder abuse and neglect for a potentially more vulnerable population of older people. In addition, a disconcerting trend is occurring. More and more aging individuals with disabilities are becoming caregivers for their even older parents.

POSITION

As they age, people with intellectual and/or developmental disabilities must have every opportunity to be recognized as respected members of the community. Community services and supports that are geared to older community members must accommodate the supports needed by those who have also experienced lifelong disabilities.

People with intellectual and/or developmental disabilities who are aging should:

- Be afforded the same rights, dignity, respect, and opportunities as other older people in their communities;
- Be empowered, together with their families if asked, to advocate for themselves;
- Be free from discrimination on the basis of disability and/or aging;
- Have access to appropriate community-based social services, transportation, legal services, and other services;
- Have access to a full array of affordable housing services appropriate to their age and physical and mental condition;
- Have access to a full array of health care services appropriate to their age and physical and mental condition, including preventive health care, ongoing habilitation and rehabilitation services for as long as they are needed, including appropriate end-of-life care;
- Receive the supports they need to live, work, play, and retire when, where, and how they prefer, including supports for family members who can assist them in the pursuit of a quality and self-determined aging experience;
- Be free from the fear of inappropriate institutionalization;
- Be free from the fear of elder abuse and neglect by family members, providers or community members; and
- Have access to financial supports that will provide them with retirement opportunities like those that are available to other older people who no longer work.

Rev’d 2019

Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

BEHAVIORAL SUPPORTS

A full and active life supported by caring relationships can reduce the occurrence of challenging behaviors in people with intellectual and/or developmental disabilities[1]. However, if such behaviors occur, people with intellectual and/or developmental disabilities and those who support them must have access to positive behavioral supports that focus on improved quality of life as well as reductions in the behaviors.

ISSUE

People with intellectual and/or developmental disabilities need supportive and caring relationships in order to develop full and active lives. Historically, people with intellectual and/or developmental disabilities across the age span have frequently been subjected to aversive procedures (i.e., electric shock, cold water sprays and deprivations like withholding food or visitation with friends and family) that may cause physical pain, discomfort and/or psychological harm. Children and adults with intellectual and/or developmental disabilities are frequently subjected to physical restraint, including the use of life-threatening prone restraint and seclusion for long periods of time.

Research indicates that aversive procedures such as deprivation, physical restraint and seclusion do not reduce challenging behaviors, and in fact can inhibit the development of appropriate skills and behaviors. These practices are dangerous, dehumanizing, result in a loss of dignity, and are unacceptable in a civilized society.

POSITION

Research-based positive behavioral supports should be readily available in natural settings including the family home. Families, caregivers, educators, direct support personnel, and other professionals and paraprofessionals should be provided with training and support in implementing effective positive behavioral interventions and supports in all environments.

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Behavioral supports should be individually designed and positive, emphasize learning, offer choice and social integration, be culturally appropriate, and include modifying environments as needed.

The Arc and AAIDD are opposed to all aversive procedures, such as electric shock, deprivation, seclusion and isolation. Interventions must not withhold essential food and drink, cause physical and/or psychological pain or result in humiliation or discomfort. Physical restraints should only be used as a last resort to eliminate the danger of physical injury to self or others.

The following factors should be considered in developing a positive behavioral intervention plan:

- The circumstances and environment in which the behavior occurred;
- The perspectives of the individual, his or her family and their social/cultural background and values;
- The contributing factors, such as physical or medical conditions, social and environmental influences;
- The completeness and accuracy of any data which has been collected about the behavior;
- The nature, extent, and frequency of the perceived challenging behavior; and
- The function of the behavior, especially what the person may be trying to communicate.

Further, any positive behavioral inventions must also include consideration of:

- The potential secondary effects and risks associated with the intervention;
- The legal, social and ethical implications;
- The ease and practicality of implementation; and
- The consistency with values of the individual's culture.

Positive behavioral supports should be:

- Designed in a person-centered process involving the individual;
- Developed within the broader context of providing quality medical, psychological, educational, and facilitative services;
- Based on a functional analysis of the behavior and the circumstances under which it occurred, a thorough assessment of each individual's unique abilities and contributions, and an understanding of how previous interventions worked;
- Provided through a least restrictive strategy and described in a written plan;
- Grounded in evidence-based procedures that will:
    - prevent challenging behaviors;
    - teach new skills that may replace challenging behaviors;
    - prevent the on-going reward of a challenging behavior;
    - reinforce positive behavior;
    - ensure safety (when necessary); and
    - provide systemic information on the effectiveness of the support.

- Used in a humane and caring manner respecting individual dignity;
- Implemented in positive, socially supportive and culturally appropriate environments, including the home;
- Carried out by individuals (i.e., staff, family members and others) who have been trained and are qualified to effectively apply positive, non-aversive approaches;
- Include adaptations to the environment and reinforcers that people with intellectual and/or developmental disabilities and their families identify as positive; and
- Monitored continuously and systematically to ensure appropriate implementation and that the support is consistent with individual needs, positive in its methods, successful in achieving established goals, and changed in a timely fashion if success is not evident or occurring at an appropriate rate.

Rev'd 2021

Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

EARLY CHILDHOOD SERVICES

All young children who are at-risk for or who have been identified with intellectual and/or developmental disabilities[1] should have access to high-quality, affordable developmental services in natural environments. These services should build on the strengths of the child and family, address their needs, be responsive to their culture and personal priorities, and be delivered through research-based practices.

ISSUE

Access to and quality of intensive intervention for children with developmental delays and disabilities remains inadequate, despite a validated knowledge-base that establishes its critical importance. Early intervention services are inconsistent at the state and local level. Often such services are neither appropriate, nor well-timed, nor sufficient in intensity and quality to promote positive development or to prevent secondary conditions. Many children at risk for developmental disabilities due to environmental and/or biological factors are not identified in a timely fashion. Major barriers include inadequate funding and service systems which do not accommodate the needs of families.

POSITION

Early childhood services must be strengthened at the national, state, and local level. Screening and early identification must be readily available in the community and widely publicized through awareness campaigns and local child-find initiatives. Early childhood services should enhance the overall well-being and development of children who have or are “at risk” for developmental disabilities. Early childhood services should also provide family support that:

- Responds to families’ strengths and needs;
- Is delivered in a family-centered way;
- Improves family quality of life; and

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- Assists family members in carrying out appropriate therapeutic practices in the home.

Children with, or at risk for, developmental disabilities must be identified and served as early as possible. Clear evidence has established that:

- Earlier is typically better when providing early childhood services and supports; and
- Providing services to children who are at-risk for developmental delay is a sound developmental and fiscal investment.

Measurable, cost-effective, and sound intervention will advance the development of children and support their health, well-being, and community participation. Substantial research and successful experience have established that early childhood services should:

- Be delivered in natural settings and, to the maximum extent possible, with same-aged peers who do not have disabilities; and
- Maximize opportunities for children to experience family, school, and community participation.

Families are the constant in children's lives, and the primary source of lifelong support and early learning. Families should be supported in making informed decisions and in partnering effectively with professionals to achieve positive outcomes. Research and practical experience have established that:

- Families must have full access to the best available research, family wisdom and professional expertise to enable them to make informed decisions;
- Family partnerships with professionals which are based on mutual respect and trust are effective and contribute to family quality of life outcomes; and
- Children who are either in foster care or adoptive homes must be particularly targeted for screening for at-risk issues.

Children and families must have access to a system of evidence-based services which is:

- Community-based and coordinated;
- Responsive to individual and cultural differences;
- Provided by supportive and skilled personnel;
- Directed towards:
    - seamless transitions between early intervention and public education;
    - community inclusion; and
    - measurable benefits for children and their families.

Research and successful practical experience have established that:

- When early childhood services are provided in natural environments, both children and families will experience increased community inclusion during early childhood and across the life span;
- State-of-the-art service coordination will enhance the access of children and families to support and services from multiple agencies and community resources; and
- Ongoing monitoring and evaluation of services will ensure measurable outcomes, equity and effectiveness.

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities support universal access to high quality, research-based, family-centered early childhood services for all children, between birth and five years at risk for developmental delay.

Rev'd 2019
Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

EDUCATION

All children and youth with intellectual and/or developmental disabilities[1] (IDD) must receive a free appropriate public education that includes fair evaluation, ambitious goals, challenging objectives, the right to progress, individualized supports and services, high quality instruction, and access to the general education curriculum in age-appropriate inclusive settings. These are essential for achieving the nation's four policy goals of equality of opportunity, full participation, independent living, and economic self-sufficiency (the four policy goals). Parents and families must be supported as essential partners in the education and transition to adult life of their sons and daughters.

ISSUE

People with IDD continue to face numerous barriers in their education. Lifelong education is essential for all individuals with IDD to achieve the four policy goals of the Individuals with Disabilities Education Act (IDEA) and to pursue opportunities for rich lives and contribute to the public good. "Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." (IDEA, Individuals with Disabilities Education Act).

Many students with IDD remain segregated in self-contained classrooms or separate schools, with few or no opportunities for academic achievement or social engagement in inclusive settings. Students with IDD frequently do not have appropriately ambitious[2] and personalized goals, challenging objectives, high quality instruction, individualized transition planning, and related services and supports necessary to engage as full members of their school learning communities. Consequently, many students with IDD leave school unprepared for further education, employment, and independent living in the community.

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Many schools have policies and practices that push youth with IDD out of school and into the juvenile justice system (known as the "school to prison pipeline"). Further, many of those in detention facilities with qualifying disabilities are not provided special education and related services.

Many parents, families, and students themselves are excluded from systemic participation as essential partners in the evaluation of the student's strengths and limitations, as well as the development and implementation of their Individualized Education Programs (IEPs).

Administrators, educators, and support staff too often lack sufficient training and knowledge about the legal rights, learning needs, and abilities of these students. School districts struggle to identify, recruit, and retain qualified special education personnel. Paraprofessionals providing support in inclusive classrooms are often poorly paid and do not always receive or seek professional development relevant to students' learning needs.

Outdated, inaccurate beliefs about students with IDD persist, leading to low expectations, segregated classrooms, inappropriate disciplinary practices, and diminished accountability for these students. In some communities, an unexamined sole focus on student performance has led to an erroneous conclusion that students with IDD are "bringing down" test scores and are to blame when schools and school systems do not achieve adequate progress.

POSITION

To ensure students with IDD receive the education to which they are legally entitled, all those involved in the education of these students must work to fully implement our nation's civil rights and education laws and accomplish the following actions.

All Means All: Zero Reject

- Assure timely evaluation, identification, and provision of education and related services to all students with IDD, incorporating all aspects of the students' diversity, including age, gender, ethnicity, culture, language, socio-economic circumstances, sexual orientation, and family environment.
- Disciplinary actions (suspension, expulsion, segregation) and alternate placements should not exclude the student from access to appropriate education and related services.

Non-Discriminatory and Comprehensive Eligibility Evaluations and Appropriate Assessments

- Assure that the needs of the individual are considered fairly and comprehensively, including cognitive, emotional, functional, and developmental needs, as well as all areas of suspected disability and mental health needs.

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[2] In March 2017, the U.S. Supreme Court issued a unanimous decision in Endrew F. v. Douglas County School District RE-1 clarifying the test for determining whether school districts have met their obligation to provide a free appropriate public education (FAPE) to students with disabilities guaranteed by the Individuals with Disabilities Education Act. The Court ruled that a child's educational program must be "appropriately ambitious in light of his circumstances," a more demanding standard than the "merely more than de minimis" test applied by the Tenth Circuit.

- Assure that multiple assessments, including those that identify a student's strengths and abilities, are used and that IQ is not the sole measure of human functioning, nor does IQ alone determine placement or access to the general curriculum.
- Exercise clinical judgment that is built upon respect for the person and emerges from specialized training and experience in IDD, specific knowledge of the person and his/her environments, extensive data, and use of critical thinking skills.
- Assure that any predictions about a student's potential learning are evidence-based and founded in high expectations for further education, employment, and independent living.
- Assure that all educators implement appropriately ambitious goals and challenging objectives and use measurements of progress that are aligned to the unique ways that students with IDD learn. Develop adaptations for assessment and grading, when necessary, that accurately capture the strengths and limitations of students with IDD.

High Expectations and Free Appropriate Public Education (FAPE)

- Develop and implement IEPs with high expectations that include appropriately ambitious personalized goals and challenging objectives and that build on a student's strengths; meet the student's learning, employment, and independent living needs; and offer related services and supplementary services necessary and likely, based on evidence, to ensure the student will make progress toward achieving the nation's four policy goals.
- Ensure that all students have access to the general education curriculum. General education includes the academic curriculum, extracurricular activities, and other school activities.
- Incorporate evidence-based, peer-reviewed instructional strategies and interventions, provided by professionally qualified teachers, related services personnel, and other staff, all of whom receive the training, preparation, and supports they need to be effective professionals.
- Ensure that a range of appropriate technology options are made available in a timely and culturally and linguistically appropriate manner to all students who could benefit from them, and that the necessary training for use of the technology is provided immediately and consistently.

Autonomy, Self-Determination, and Decision-Making Supports

- Incorporate and support the development of autonomy, self-determination, self-advocacy, and leadership skills throughout students' educational experiences, including meaningful participation in the student's IEP.
- Assure that school policy and semi-annual in-service training emphasizes autonomy, self-determination, and decision-making supports, and that teachers and other non-lawyers do not give families legal advice related to guardianship.

Inclusion and the Least Restrictive Environment (LRE)

- To the maximum extent appropriate, every student has a right to be educated in their inclusive neighborhood school and in the general education curriculum in that school. Any exception should be rare and considered only when education in the general education classroom cannot be satisfactorily achieved. Each student has a right to the related services, supplementary aids and services, accommodations, and modifications needed to learn alongside students without disabilities.

- Assure that the student is integrated in academic and social aspects of the general curriculum.
- Include an explicit written plan to achieve more integration in both academic and social aspects of the general curriculum when the student is currently in a restricted setting.
- Foster the development of peer relationships and membership in the school community to create a receptive, welcoming atmosphere, including extracurricular activities and school trips.
- Avoid the long-term costs of segregating students with IDD, including the reduced opportunities for learning, employment, independent living, and social engagement.
- Ensure that all teachers and related services personnel are trained, prepared, and supported to teach and support students effectively in the general education curriculum and in inclusive settings.

Safe and Supportive Education Environments

- Ensure safe school environments that provide mental health supports and protection against bullying.
- Ensure that all students with IDD have effective culturally and linguistically appropriate communication systems and technology that reduces the need to use behavior to communicate and maximize educational engagement.
- Assure development and ongoing use of school-wide and system-wide intervention models, including school-wide positive behavioral supports and using the principles of universal design for learning (UDL) in designing curricula, materials, instruction, and assessments to create maximum access to learning environments for students with diverse abilities and learning styles.
- Avoid harsh policies and procedures, such as “zero tolerance”, that lead to exclusion, injury, loss of education, or involvement with the criminal justice system by implementing school-wide positive behavior support that includes students with disabilities to prevent or eliminate such situations. Assure appropriate evaluations and IEPs, and avoid the criminalization of behaviors that are the manifestation of the student’s disabilities.
- Prohibit the use of mechanical or chemical restraint, isolation, or aversives. Emergency, time-limited, monitored restraint may be used only by trained personnel and only when the student’s behavior presents an imminent danger of serious physical harm to the student or others and less restrictive interventions are insufficient to mitigate the imminent danger of serious physical harm. Physical restraint which restricts airflow, including prone restraint, and mechanical restraint must be prohibited.
- Ensure that supports and strategies are planned and implemented to successfully reintegrate a student who has been restrained or secluded back into the school or classroom environment.
- Assure that students are not disciplined for the manifestation of their disabilities.

- Assure safe school transportation for all students with disabilities, provided by trained and monitored drivers with background checks, in order to avoid abuse and maltreatment of students. Schools must assure the sufficient allocation of transportation resources such that transportation is not used to justify early departures, late arrivals, or excessive travel times.

School Choice

- Charter schools and private schools that accept public funds through a voucher or voucher-like system must comply with IDEA, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act (Section 504). Specifically, they must provide zero reject and free appropriate public education in the least restrictive environment, including nondiscriminatory evaluation, individualized appropriate education plan, access to the general curriculum (academic, extracurricular, and other school activities), procedural safeguards, and parent participation.
- Ensure that school choice efforts do not diminish the resources and effectiveness of public school systems in which they operate.

Family and Student Participation

- Ensure the meaningful participation of students, families, and their chosen advisors in the evaluation of students and the design and monitoring of the students' IEPs.
- Assure that parents with special needs, including those with disabilities or language or cultural differences, receive the information, supports, services, and full ADA/504 rights to effectively exercise their rights to partner in the education of their children.
- Expeditiously connect students and families with information, resources, and training that help them understand and exercise their rights under the IDEA, Section 504, the ADA, Family Educational Rights and Privacy Act (FERPA), and the Every Student Succeeds Act (ESSA).
- Assure that school personnel provide timely explanations that are understandable and use functional descriptive language for special education and related services being proposed for the student.

Lifelong Education, Transition, and Post-Secondary Education

- Provide early intervention and preschool services to infants, toddlers, and preschool-age children with disabilities alongside their typical peers and provide transition planning for children to ensure access to the general education curriculum and full integration in neighborhood schools as they move to kindergarten or first grade.
- Develop and implement transition plans based on student strengths, preferences, and interests to facilitate each student's successful movement from school to adult life, including postsecondary and vocational education, competitive integrated employment, independent living, and community participation.
- Develop an individualized postsecondary and/or pre-employment program, including choices and creative career exploration through apprenticeships and internships, in coordination with IDEA and the Workforce Innovation and Opportunity Act (WIOA).
- Ensure that all students receive meaningful evidence of their school achievements including diplomas.

System Capacity Development, Funding, Oversight, and Accountability

- Assure that the training, preparation, compensation, supports, and accountability systems needed to build a cadre of effective professional teachers, other education personnel such as school principals, related services personnel, paraprofessionals, and other staff are evidence-based and effective to meet the child's specific needs.
- Assure a cadre of effective lay and legal advocates to assist families and individuals to exercise their rights.
- Increase active monitoring and enforcement through local, state, and federal agencies to ensure that the IDEA, ADA, Section 504, and state special education laws and mandates are met.
- Fulfill the federal commitment to fully fund the IDEA.
- Ensure that all students with disabilities, including those with the most significant cognitive disabilities, continue to be included in public school, district, and state level accountability systems. Ensure that states are not allowed to exempt more than 1% of students (that is, exempt only those students that the state determines have the most significant cognitive disabilities up to 1%) from their general accountability data.

Rev'd 2018

Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

EMPLOYMENT

People with intellectual and/or developmental disabilities[1] (IDD) can be employed in the community alongside people without disabilities and earn competitive wages. They should be supported to make informed choices about their work and careers and have the resources to seek, obtain, and be successful in community employment.

ISSUE

Historically, the majority of people with IDD have been either unemployed or underemployed despite their ability, desire, and willingness to work in the community. Many have been placed in "prevocational" programs and "disability-only" workshops where they are paid below minimum wage and have little expectation of moving into jobs where they work alongside people without disabilities.

People often leave school with little community-based vocational experience or planning for transition from school to work or post-secondary education. Adult service agencies have struggled to move people into the workforce using personnel who often do not have proper training in best practices for either finding or supporting people in jobs. When employed, few people have opportunities to advance, explore new possibilities, or, in their later years, retire.

Barriers to employment include, first and foremost, low societal expectations that foster job discrimination. In addition, unrealistically low limits on assets and earnings make people fear losing vital public benefits if they work too many hours or earn too much. Systemically, public resources fund service hours rather than outcomes and are often neither sufficient nor flexible enough to allow collaboration and blending of employment funding streams. Lack of other services like transportation or of accommodations like assistive technology can also hinder success.

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POSITION

People with IDD should have the supports necessary from individuals and systems to enable them to find and keep community jobs based on their preferences, interests, and strengths, work alongside people without disabilities, receive comparable wages, and be free from workplace discrimination. Requirements related to employment include:

- Opportunities for post-secondary education, including college and vocational training, to gain knowledge and skills to allow people to get better jobs.
- Ongoing planning to promote job advancement and career development.
- Fair and reasonable wages and benefits.
- Opportunities for self-employment and business ownership.
- Opportunities to work with and, in the case of people with IDD who own small businesses, employ people without disabilities.
- The ability to explore new directions over time and, at the appropriate time, retire.
- Opportunities to work and increase earnings and assets without losing eligibility for needed public benefits.

Best Practices

- Employment supports and services should use best practices, including assessing skills and interests, working with employers, matching jobs to skill sets and employer needs, providing individualized and ongoing job supports, designing reasonable job accommodations, integrating people into the workforce, building social skills necessary in the workplace, and securing necessary ancillary services such as transportation.
- People with IDD must have training and information on how to access supports needed to find and keep jobs.

School-to-Work Transition

- Transition planning should start early.
- Transition activities should foster individualized exploration of and experiences with community-based employment options that enable youth to make informed choices.
- Transition activities should include career assessments to identify students' interests and preferences, exposure to post-secondary education and career opportunities, training to develop job-seeking and workplace skills, and participation in multiple on-the-job activities and experiences in paid and unpaid settings. Transition activities should not be limited to unpaid internships at pre-set community worksites.
- Students should leave high school with opportunities to pursue post-secondary education and/or with an appropriate job or an action plan for finding one.

Training of Staff and People with IDD

- Staff of employment and school-to-work transition programs must receive training in best practices to help people find and keep jobs.
- Along with ensuring appropriate on-the-job training, people with IDD should receive guidance, if needed, in acquiring the social skills necessary in the workplace.

- People with IDD must have training, including, if desired, driver's education, to allow them to travel in the community so they can get to jobs and enhance their independence.

Systems

For all people with IDD, publicly funded employment programs should first explore employment alongside people without disabilities at comparable wages, with comparable benefits, before considering other options in the community. Ancillary services like transportation and accommodations like assistive technology must be available to individuals and support agencies. Public policy should encourage employers to hire people with IDD.

Publicly funded employment programs should also:

- Be available to all people with IDD who wish to explore opportunities to work, regardless of the nature and extent of their disabilities.
- Enable people to make informed choices by providing individualized exploration of and experiences with community-based employment and by presenting all information needed to make informed choices in an understandable way.
- Provide sufficient resources to support people to work in the community and be flexible enough to foster collaboration and braiding of employment-related funds.
- Build infrastructure and supports needed to phase out the issuance of subminimum wage certificates, increase opportunities for competitive integrated employment, and put in place safeguards to protect the interests of any people affected by this shift.
- Measure and publicly report on outcomes on an ongoing basis.

Rev'd 2017
Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

FAMILY SUPPORT

Family support services[1] and other means of supporting families across the lifespan should be available to all families to strengthen their capacities to support family members with intellectual and/or developmental disabilities[2] (IDD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency. Family caregivers include, but are not limited to, parents (including those with IDD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships.

ISSUE

The vast majority of people with IDD live in the family home and families are overwhelmingly the primary source of support for their family member with IDD. Changing demographics are resulting in even greater demands on these family caregivers. The aging baby boom generation of caregivers has unique need for family support, such as assistance in developing desired in-home support plans or transition plans to community living for their family member with IDD when they are no longer able to continue in their caregiving role. In addition, an increasing number of persons with IDD are becoming parents and may require more support navigating service systems for their own children.

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[1] Traditionally, government-sponsored family support has consisted of: 1) Cash assistance from federal, state, and local governmental sources that is provided: a) Over and above any other federal cash benefit or medical, educational, or welfare benefit programs (including those under any title of the Social Security Act, Individuals with Disabilities Education Act, and Developmental Disabilities Assistance and Bill of Rights Act); b) Because of the disability of a family member ; and c) To the family as the primary beneficiary of the family support program; 2) Information and emotional and instrumental support provided by: a) Professionals, including those in generic (non-disability)-and disability specializing professions and entities; b) Friends or members of the individual's family; and c) Entities that support families or parents, including parent-to-parent and community-based family resource centers, or 3) Any combination of the above. Specific examples of family support services are respite, counseling, cash assistance, training, support groups, minor home modifications, and information and referral.

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State IDD service systems are increasingly being built around the expectation that adults with IDD will reside in the family home. This is not consistent with other national policies for vulnerable populations. Nor is it consistent with the vision of self-determination.

Unfortunately, the increasing reliance on families is not being met with commensurate support. A generation ago, families were discouraged from keeping their family members with IDD at home and encouraged to use costly publicly financed institutional placements. Today, they face the other extreme where they are expected to be willing and able to provide lifelong support to their family member with IDD in place of appropriate community supports, even in cases when residing in the family home may not be a good option for adults with IDD or the family caregivers.

There is no comprehensive family support system in the U.S. Instead, the vast majority of publicly provided family support services are funded through Medicaid home and community-based services (HCBS) waivers and some states provide limited family support using state general fund dollars. Consequently, beneficiaries of family support experience the same portability and mobility limitations as those receiving other Medicaid HCBS. This affects families (including military families) who either have to relocate to another state and begin the application and waiting process anew or who have to forfeit personal or career opportunities in other states.

Relatively small proportions of federal and state funding for persons with IDD are committed to family support, despite increasing numbers of people with IDD living with family for longer periods. Consequently, though family support is often critical for avoiding more segregated placements in costly and inappropriate institutions for the family member with IDD, the needed supports are frequently insufficient or unavailable.

POSITION

Comprehensive, universally accessible family support must be provided in order to strengthen families socially, emotionally, physically, and financially. It must:

- Strengthen the caregiving efforts of families, with special emphasis on their emotional and physical health, financial and material needs, and parenting and family interaction;
- Enhance the quality of life of all family members, and increase their access to supports and services for themselves and their members with IDD;
- Create and provide meaningful support to parents with IDD designed to ensure maximum opportunity for family wellness and cohesion;
- Enable families to make informed choices regarding the nature of community supports for themselves and their members with disabilities, including the use of supported decision making for family members with IDD;
- Help families with minor members to stay intact, preventing any type of out-of-home placements for a minor child, particularly institutions or congregate settings;
- Ensure that all employed caregivers have access to comprehensive paid leave, including job protection and sufficient wage replacement;
- Provide information, resources, and support to families of people transitioning from institutional placements to community homes;

- Provide support for families navigating systems of care, including early intervention, education, mental/behavioral health, and other systems;
- Provide information and support for siblings to better prepare them to be advocates and caregivers; and
- Ensure aging caregivers are able to provide care for their loved one as long as necessary and appropriate while honoring self-determination.

Policies of family support and public and private systems for supporting families must:

- Recognize that relying on families to provide lifelong care cannot be a substitute for creating a national solution to provide appropriate long term supports and services;
- Be addressed in conjunction with the HCBS waiting list and direct support professional (DSP) crisis for family members with IDD;
- Be prioritized for when the need is most acute, such as when caregivers first receive a disability diagnosis for their child; during service system transitions or personal crises; and at the end of life;
- Be provided in a manner that builds on the family's strengths;
- Be provided in ways that are sensitive to the family's cultural and linguistic backgrounds, immigration status, values, religion, LGBTQ+, and socio-economic status;
- Assist the individual and family to maximize self-determination of the individual with IDD;
- Assist parents with IDD in being self-determined in creating supports around their family;
- Be controlled, determined, and directed by the family itself, in partnership with those who provide the service;
- Be provided through best practices and state-of-the-art methods;
- Be available to all families regardless of whether the person with IDD resides in the family home or is presently receiving publicly funded services;
- Provide options for family members to be compensated for their time providing essential supports at home. These choices should be available throughout the lifetime of a person with IDD and subject to change as the person's and family needs or wants change; and
- Be defined as a comprehensive system of policies, practices, and procedures for supporting families, and not just "family support" programs sponsored by a government or private-sector entity.

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HEALTH

All people, including people with intellectual and/or developmental disabilities[1] (IDD), should have timely access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs, maximizes health, well-being and function, and increases independence and community participation. The health care system must be aligned to principles of nondiscrimination, comprehensiveness, continuity, appropriateness, and equity. Both comprehensive public and private health insurance must provide for necessary health care without regard to the nature or severity of disability, pre-existing conditions, or other health status.

ISSUE

Health can be understood broadly as a state of complete physical, mental, and social well-being, not merely the absence of disease or disability. The term "health care" encompasses physical, mental, behavioral, vision, hearing, oral and dental health care, substance abuse and addiction services, and services and supports that assist in attaining, maintaining, and improving skills, function, and community participation.

The current health care system is fragmented and does not provide uniform access to a comprehensive array of health services and supports.

While many people encounter difficulty in finding affordable, high quality health care, people with IDD face additional barriers, sometimes life-threatening, when attempting to access timely, appropriate health services in their communities. These barriers include:

- **Access.** Underinvestment in public health and wellness targeted to people with IDD results in preventable health care disparities and poorer health outcomes. Inadequate training, lack of coordinated care, and inadequate levels of reimbursement are some of the factors that create programmatic barriers while inaccessible clinical settings and diagnostic and

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medical equipment, along with translation and interpretation challenges, create physical barriers.

- **Discrimination.** Health care providers sometimes provide inadequate or inappropriate interventions and treatments or deny appropriate care for people with IDD because of professional ignorance as well as personal and/or societal bias. State statutory liability damage limits discriminate against people with severe and/or life-long disabilities because they fail to provide sufficient compensation.
- **Affordability.** People with IDD are more likely to live in poverty and cannot afford cost-sharing. For cost containment purposes, many public and private health care plans limit access to specialists and critical services. Even when services are available in a community, many people with IDD lack adequate public or private insurance to pay for them.
- **Communication and personal decision making.** People with IDD may have difficulties communicating their needs and making health care decisions without support. Their decisions may not be respected and implemented by health care providers and, where applicable, surrogate decision makers[2]. People have not been ensured access to all necessary supports and information required to understand a health care decision and communicate their choices.

POSITION

Important elements of this Health Position Statement include timely access, nondiscrimination, affordability, and communication and personal decision-making, including surrogate decision-making. These elements are described more fully below:

Access

- Wellness, prevention, health promotion, and a robust public health infrastructure are essential components of health care.
- Health care providers for persons with IDD must meet the highest standards of quality, including a comprehensive approach to treatment, disease prevention, and health maintenance.
- People with IDD deserve access to health care providers who have received specialized training to understand and respond to their needs. This access should be provided in the community.
- People with IDD need access to effective strategies to manage their care including care coordination, referral processes, transition assistance, and health promotion efforts.

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[2] Surrogate decision-maker: a person who makes health care decisions for a person who is unable to make decisions about personal health care. A surrogate decision maker may be an appointed agent under a durable power of attorney for health care or a court-appointed guardian with authority to make health care decisions. If there is no appointed surrogate, normal custom and practice, as well as the law in most states, permits health care practitioners to turn to next of kin as default surrogate decision makers. A growing number of states also authorize a close friend to act as default surrogate. All surrogates have an obligation to follow the expressed wishes of the adult person. If the individual's wishes are not known, the surrogate must follow the person's probable wishes, taking into account the person's known values, and as a fall back to act in the person's best interests. (Charlie Sabatino and Erica Wood, Commission on Law and Aging, American Bar Association. Presentation at the National Aging and Law Conference, December 2010, http://new.abanet.org/aging/Pages/CLE.aspx)

- Data collection and the assessment of health outcomes must include disability status. Public health initiatives must support the goal of reducing health care disparities for people with disabilities and improving health and function.
- The health care system must be fully accessible with respect to facilities and equipment, as well as communication needs and related accommodations such as sufficient time, explanations, translators, and interpreters when necessary.

Nondiscrimination

- People with IDD must not experience disability-related discrimination in decisions to provide, delay, deny, or limit health care interventions or treatments. Protections must be in place to assure that an individual's health and well-being are the only justifiable basis for making medical decisions.
- A person with a disability should have an equal opportunity to receive life sustaining treatments including cancer therapy and transplantation. Physician assisted suicide is never acceptable.
- Health plans must cover treatment for mental illness on the same terms and conditions as all other medical diagnoses.
- Providers of health care services for persons with IDD must follow practices regarding health information and records consistent with the guarantees of confidentiality contained in the Health Insurance Portability and Accountability Act (HIPAA).
- Treatments for persons with IDD that are proposed primarily for the convenience of the caregiver (such as medical procedures that interfere with typical growth and development) must be denied.

Affordability

- People with IDD should have universal access to comprehensive, affordable, quality health care.
- Efforts to contain health care costs should not create obstacles to care for people with IDD by making needed services or treatments unaffordable or otherwise unavailable. The medical need for care must be determined on an individualized basis.
- Payment methodologies for health services provided to people with IDD should compensate for the true cost of providing those services. This includes the costs of treating more complex health needs, and the greater amounts of time often required to understand and respond to those needs. Payment methodologies should not create disincentives to the provision of timely and appropriate services to persons with IDD.

Communication and Personal Decision-Making

In all matters of health, individuals with IDD have basic rights that must be protected, including the right to information and appropriate accommodations to assure informed consent[3] that allows an individual, or under appropriate legal conditions, a guardian, a health care power of attorney, or a surrogate decision-maker of the individual's choice to accept or refuse health-related services based on:

- Sufficient information to understand the risks, demands, potential for significant pain, and benefits of any procedure for which consent is sought provided in ways that

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[3] Informed consent has three elements: capacity of the consent-giver, information supplied to the consent-giver, and voluntary action by the consent-giver.

accommodate reading, language, learning, and other limitations that are common among persons with IDD;

- Opportunities to ask questions and receive answers about the proposed treatment in understandable and understood language;
- Full disclosure that declining treatment may affect access to other treatments or services that the person is receiving or might otherwise receive;
- Protection from coercion or deceit to accept or decline a particular treatment;
- Reasonable efforts when a guardian, health care power of attorney, or surrogate decision-maker is involved to monitor, honor, and accommodate indications of "implied assent" to treatment; and
- Having specific expressed desires regarding the use of life-sustaining treatments communicated in written or oral form and recorded in an advance directive[4] by individuals with IDD, as appropriate to their understanding of the nature, implications, and reversibility of their decision. Advance directives of people with IDD should be honored.

Surrogate Decision-Making

Individuals may temporarily or permanently lack the capacity to make some or all health care decisions. This lack of capacity may not be global and the individual should always be assisted in making those decisions which they can and in participating in all other decisions as much as they are able. When an individual has been determined to lack capacity to make health care decisions and does not have an advance directive such as a "Living Will," or a health care power of attorney, a surrogate decision-maker should be identified to make these decisions, whenever possible before a crisis arises. People who have such authority under state laws include the parent of a minor child, the guardian/conservator of an incapacitated adult, or surrogate decision-makers designated under a health care consent law.

All decision-making by a surrogate decision-maker should be consistent with the principles expressed in the sections above regarding health care and informed consent. Surrogate decision-makers must follow the expressed wishes of the individual. When the individual's wishes are not knowable, the surrogate must follow the person's probable wishes, taking into account the person's known values, and, as a fall back, act in the person's best interests. In decisions involving the refusal of medical treatments, or nutrition and hydration, when such refusal will result in the death of the individual, the legal authority of the surrogate decision-maker should be limited to those situations in which all three of the following conditions exist: (1) the person's condition is terminal, (2) death is imminent, and (3) any continuation or provision of treatment, nutrition and/or hydration would only serve to prolong dying. However, in such situations, people with IDD must be provided appropriate palliative care, including medical treatment to relieve pain, sustenance as medically indicated, and care designed to relieve isolation, fear, and physical discomfort.

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[4] Advance directive: Written advance directives include living wills and the durable power of attorney for health care. Living wills enable individuals to describe the treatment they would like to receive in the event that decision-making capacity is lost. The latter enables a patient to appoint a surrogate to make decisions if the patient becomes unable to do so (Ethics Manual, American College of Physicians, 2012.)

HOUSING

People with intellectual and/or developmental disabilities[1] (IDD), like all Americans, have a right to live in their own homes, in the community. Children and youth belong with families. Adults should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities.

ISSUE

People with IDD face a housing crisis with many contributing factors, such as a serious lack of safe, affordable, accessible and integrated housing, and significant housing-related discrimination. Outmoded public policy and programs which unnecessarily segregate people with IDD, as well as lack of coordination among funding systems, also pose major barriers.

Historically, families with a child with a disability had to either place their child in an institution, or manage without any supports or services at home. Institutions create an isolated, unnatural way of life that is inappropriate and unnecessary, while consuming a disproportionate share of limited public resources. As people with IDD have left institutions or their family homes, they frequently have been placed in group homes, often larger than family-sized, typically owned or leased by provider agencies. People in those settings may have little control over where and with whom they live, the services they receive, or the routines of daily life.

The recognition that people with IDD belong in the community has led to a growing demand for community-based housing. This demand is fueled by persons choosing to leave institutional settings, by young adults educated in inclusive schools, and by adults with IDD who live with elderly parents.

However, people with IDD are among the nation's poorest citizens. For many, Social Security and Supplemental Security Income benefits, which are often far lower than typical rents, are their primary or sole source of income; beneficiaries are generally priced out of rental markets across the country.

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Affordable housing programs are drastically underfunded, with long waiting lists. In addition, Medicaid, the principal source of funding for services and supports for people with IDD, typically does not allow funds to be used for rent or other community-based housing-related costs.

These factors pose major barriers to community living, making it difficult for people to move from segregated facilities into the community, and putting many people with IDD at risk of unnecessary institutionalization or homelessness.

POSITION

People with IDD have the right to live in safe, accessible, affordable housing in the community.

- People must have freedom, authority, and support to exercise control over their housing, including choice of where and with whom they live, privacy within their homes, access to flexible supports and services when and where they choose, choice in their daily routines and activities, freedom to come and go as they please, and housing that reflects their personal preferences and styles. Providers should honor individual choices and preferences.
- Housing should afford people with IDD the opportunity to interact with people without disabilities to the fullest extent possible.
- The health and safety of people with IDD must be safeguarded wherever they live, but should always be balanced with the right to take risks and exercise choice and control.
- To ensure that people with IDD can make informed decisions about where and with whom they live, they and their families must be given understandable information about the benefits of living in the community, have the chance to visit or have other experiences in community settings, have opportunities to meet other people with disabilities who are living in the community, and have any questions or concerns addressed.
- All children and youth need a home with a family that provides an atmosphere of love, security, and safety.
- Adults with IDD should receive the supports they need to transition out of the family home when they wish to do so.
- Housing for people with IDD must be coordinated with home and community-based support systems, including transportation services, and should ensure access to other typical public resources.
- There must be adequate funding of services to support people to live in the community. Funding must be stable and not subject to arbitrary limits or cuts. People with IDD must not be subjected to unnecessary institutionalization or removal from their homes and communities due to state budget cuts.
- Public policy should promote small, typical living situations for people with IDD. Information about innovative housing models that promote independence should be widely disseminated.
- Housing for people with disabilities should be scattered within typical neighborhoods and communities, and should reflect the natural proportion of people with disabilities in the general population.

- Public funds must be shifted from restrictive institutional settings to community supports. Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with IDD, regardless of type or severity of disability.
- Affordable housing options must be available to people with IDD, including those with very low incomes. Affordable housing programs must be expanded and funded to eliminate long waiting lists. Public policies must ensure that people with IDD receive their fair share of all local, state, and national housing resources.
- Universal design and visitability[2] standards should be adopted for all new housing. New and significantly renovated multifamily housing should include fully accessible units in numbers that reflect the natural proportion of people with disabilities in the general population.
- People with IDD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right. People with IDD must have opportunities comparable to those of people without disabilities to rent or buy their own homes.

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[2] **Universal design** means buildings, products and environments that are inherently accessible to both people with and without disabilities. **Visitability** is a set of construction standards through which housing offers a few specific accessibility features making it possible for people with disabilities to visit friends, family and neighbors.

INDIVIDUAL SUPPORTS

People with intellectual and/or developmental disabilities[1] (IDD) must have access to individual supports, such as assistive technology and personal assistance, to support their participation in daily life.

ISSUE

People with intellectual and/or developmental disabilities are often able to better perform basic tasks of everyday life such as communicating, interacting with others, completing daily living routines, and moving in and around their homes and communities when individual supports are provided when needed. All too often, individual supports are denied because of restrictive criteria such as age, disability label, severity of the disability, problem behavior, motor or sensory limitations, or test scores. For many people, the opportunity to create individual supports is limited by the availability of funding due in some cases to waiting lists and the institutional bias in Medicaid.

POSITION

People with intellectual and/or developmental disabilities must have access to the supports necessary to lead a meaningful life in the community. These supports should be provided based upon functional needs and choice. Supports should lead to opportunities for community involvement and development of individual interests. Individual supports may include:

- **Personal assistance.** Adults with intellectual and/or developmental disabilities (and parents of minor children with IDD) should be able to hire and fire personal assistants to help them perform everyday activities, make decisions, and exercise control over their lives.
- **Communication.** People learn to communicate in many ways, such as personalized gestures and sounds, picture symbols, manual signs, and spoken language. Support must

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be available to help improve an individual's communication and social interactions as well as reduce challenging behaviors.

- **Assistive technology.** People must have access to devices, services, and training that enhance independence, mobility, communication, environmental control, and self-determination. The ways assistive technology can be used must be assessed throughout a person's life cycle and as needs change. Designers, manufacturers, service providers, educators, and people with IDD and their families should be educated about the benefits of technology.

Supports must be individually planned and applied according to the principles of person-centered planning, self-determination and individual outcomes, flexible funding, and team collaboration. The individual supports must be independently and regularly monitored for quality, safety, and effectiveness.

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OPPORTUNITIES FOR FINANCIAL ASSET BUILDING

People with intellectual and/or developmental disabilities[1] (IDD) must have the same opportunities to advance their economic and personal freedom by earning and saving money to enhance their physical, social, emotional, and financial well-being and the right to exercise choice in investment and spending decisions as their peers who do not have disabilities.

ISSUE

Often, people with IDD face greater economic inequalities than their peers without disabilities. People with IDD also typically have not had adequate supports for full participation in financial life and decision-making, including earnings, saving, budgeting, spending, investments, and estate planning.

When people use government benefits, certain income-based and/or asset-limit eligibility policies put some people at risk of being denied for and/or losing critical supports such as Medicaid, Supplemental Security Income, and Social Security benefits if they earn or save very modest sums of money. While some savings are allowed through certain self-settled trusts and the ABLE Act which accommodate SSI and Medicaid means-testing rules, these plans do not address the needs of everyone. Thus many people with disabilities cannot plan and save for future needs like others, contributing to ongoing economic inequalities often resulting in lifelong poverty. Public policy should encourage rather than inhibit planning for financial independence, productivity, and self-determination.

In addition, families are the largest group of providers of physical, material, and emotional supports for people with IDD across the life course. Families incur increasing amounts of out-of-pocket expenses due, in part, to the decreasing federal funds contributing to family support services[2] in the states. Many families are restricted to a single income or underemployment due to the necessity to provide medical care or supports to their family member with IDD. This

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greater reliance on family support requires families to explore and invest in a variety of financial security strategies to ensure opportunities for self-directed options and family quality of life.[3]

POSITION

Individuals with IDD and their families should have equal access to economic self-security, including opportunities to save money and build financial assets to maintain or improve their basic economic and social status, strengthen their financial security, and save for retirement through education, financial literacy, employment, home ownership, and asset development.

These opportunities should include the following:

- Access to Individual Development Accounts (matched savings accounts similar to a 401(k)) that enable a person to save for education, home ownership, or one's own business and/or employment;
- Ensuring that government assistance programs allow people to retain reasonable portions of their income for daily living expenses, and permit savings. Access to low-cost, user-friendly approaches such as ABLE accounts (savings accounts that enable eligible individuals to save for disability related expenses), for people with disabilities of all ages, for acquiring, maintaining, and expending assets while remaining eligible for publicly financed services and benefits;
- Equity with other savings programs, such as catch-up provisions and reasonable increases and limits on contributions and maximum contributions;
- Ensuring incentives in the tax code for charitable gifts and special needs trusts (a legal vehicle that manages funds for the benefit of a person who needs some assistance in daily living); and
- Ensuring that tax rates for wealth accumulation by people with disabilities (such as special needs trusts) are not excessive.

Policy reforms must allow people with IDD to have opportunities to earn money and invest in their futures without risking the health care, benefits, and supports and services necessary to live a full life in their community.

On a personal level, people with IDD and their families should have opportunities to learn how to manage their money and spend it wisely through such means as:

- Supports for full participation in financial planning and decision-making, including earnings, saving, budgeting, spending, investments, including tax-deferred investments like IRAs and 401(k)s, and estate planning;
- Financial literacy education throughout the school years and, particularly, contemporary practices in financial literacy curricula in high schools and other educational settings;
- Inclusive adult and higher education and consultation/coaching in communities;

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[2] From The Arc and AAIDD position statement on Family Support: http://www.thearc.org/who-we-are/position-statements/life-in-the-community/family-support

[3] Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., & Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession.* Washington, DC: American Association on Intellectual and Developmental Disabilities (AAIDD).

- Access to free information in user-friendly print and electronic formats (similar to materials produced by the Consumer Financial Protection Bureau); and
- Training for human services support and professional staff, advocates, bank/credit union and investment personnel, government officials (from service coordinators to Internal Revenue Service (IRS) staff) in how best to help people enhance their assets.

Rev'd 2021

Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

PARENTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

The presence of an intellectual and/or developmental disability[1] does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals solely on the basis of intellectual and/or developmental disabilities. Parents with intellectual and/or developmental disabilities should have access to support as needed to perform parental roles just as they are supported in other valued social roles and activities.

ISSUE

The history of discrimination toward individuals with intellectual and/or developmental disabilities includes the denial of rights and opportunities to have and to raise their own children. This history has included segregation and involuntary sterilization of adolescents and adults. After birth, infants have been removed immediately from parental care, and through legal provisions, parents have been denied the opportunity to raise their children in their home.

Examples of social and social service biases and discriminatory practices include:

- Presumption of incompetence, that is, a general belief that people with intellectual and/or developmental disabilities are unfit to be parents;
- Limited supports to parents with intellectual and/or developmental disabilities;
- Professional emphasis on limitations of parents with intellectual and/or developmental disabilities to the point of weakening parents' sense of competence and potential for success;
- Public resources primarily focused on crisis-driven support;

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Developmental Disabilities (DD), first defined in 1975 federal legislation now known as "The DD Act", are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym "IDD" is used to describe a group that includes either people with both ID and another DD or a group that includes people with ID or another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

- Lack of trust of service providers or government officials by parents with intellectual and/or developmental disabilities based upon fears of losing their children and their vulnerability to arbitrary authority; and
- Disproportionate representation of parents with intellectual and/or developmental disabilities in child custody proceedings, where, their competence as parents is held to higher, less flexible and more frequently applied standards than those applied to other parents.

Despite research which documents the ability of many parents with intellectual and/or developmental disabilities to raise a child successfully with appropriate and effective supports, access to these supports continues to be limited, fragmented and uncertain. Few specialized programs exist. Many family support and early intervention programs are not equipped to provide the intensive and ongoing supports that parents with intellectual and/or developmental disabilities and their children are likely to require.

POSITION

All adults, when provided access to appropriate and effective supports as needed to fulfill the basic responsibilities of child rearing, are more likely to be effective in their roles as parents.

Parents with intellectual and/or developmental disabilities and their children deserve social and health supports that:

- Recognize the need of parents to be viewed as unique individuals able to learn and improve in their skills and to respond to the needs of their children;
- Distinguish the effects of the family's living conditions and economic status independently from assessing ability to perform a parenting role;
- Build a trusting relationship between the parents, child, and those who provide formal and informal supports to them;
- Recognize, include, and engage the informal supports of family members, neighbors, and their community members to assist parents and the family as a whole;
- Recognize that as the needs of children change, parenting skills must evolve and may require new forms of support for parents and children;
- Respond to the unique learning needs of parents with intellectual and/or developmental disabilities;
- Assist parents in becoming actively engaged in their children's school and community;
- Reflect the full range and multiple components of effective support programs including, as needed:
    - in-home visits to teach parenting skills;
    - assistance with daily living skills;
    - access to nutritional resources such as "ready to feed" formula;
    - child care, early intervention services, and counseling;
    - basic academic education for parents;
    - assistance in accessing public benefits as appropriate;

    - crisis intervention services, availability of intensive supports as needed, and volunteer mentoring programs; and
- Assure that access to parent supports and to the environments and programs in which parental participation is beneficial to the child and family are provided with proper consideration of Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and related accommodations.

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities support adoption of the United Nation's Convention on the Rights of Persons with Disabilities. Article 23, "Respect for Home and the Family," Obligation 4 states that "Parties shall ensure that a child shall not be separated from his or her parent against their will, except when competent authorities subject to judicial review determine, in accordance with applicable laws and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents."

Rev'd 2019

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SEXUALITY

People with intellectual disability and/or developmental disabilities[1], like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected.

ISSUE

For decades, people with intellectual disability and/or developmental disabilities have been thought to be asexual, having no need for loving and fulfilling relationships with others. Individual rights to sexuality, which is essential to human health and well-being, have been denied. This loss has negatively affected people with intellectual disability in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. People with intellectual or developmental disabilities frequently lack access to appropriate sex education in schools and other settings. At the same time, some individuals may engage in sexual activity as a result of poor options, manipulation, loneliness or physical force rather than as an expression of their sexuality.

POSITION

Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality.

All people have the right within interpersonal relationships to:

- Develop friendships and emotional and sexual relationships where they can love and be loved, and begin and end a relationship as they choose;
- Dignity and respect; and
- Privacy, confidentiality, and freedom of association.

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With respect to sexuality, individuals have a right to:

- Sexual expression and education, reflective of their own cultural, religious and moral values and of social responsibility;
- Individualized education and information to encourage informed decision-making, including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases; and
- Protection from sexual harassment and from physical, sexual, and emotional abuse.

With respect to sexuality, individuals have a responsibility to consider the values, rights, and feelings of others.

With respect to the potential for having and raising children, individuals with intellectual or developmental disabilities have the right to:

- Education and information about having and raising children that is individualized to reflect each person's unique ability to understand;
- Make their own decisions related to having and raising children with supports as necessary;
- Make their own decisions related to using birth control methods within the context of their personal or religious beliefs;
- Have control over their own bodies; and
- Be protected from sterilization solely because of their disability.

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Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

SPIRITUALITY

People with intellectual and/or developmental disabilities[1] have the right to choose their own expressions of spirituality, to practice those beliefs and expressions and to participate in the faith community of their choice or other spiritual activities. They also have a right to choose not to participate in religious or spiritual activity.

ISSUE

Spiritual or religious activities are seldom recognized as an important aspect of life or included in individual planning for people with intellectual and/or developmental disabilities. Some individuals may need assistance to participate in their chosen spiritual activities or faith communities.

Individuals with intellectual and/or developmental disabilities and their families also face a mixed response from faith-based communities, even though many faith communities have established model programs and strategies for including people with disabilities. Spiritual resources and faith communities are an underused resource in the community for people to exercise choice, develop relationships and social networks, demonstrate respect for cultural and family backgrounds, and serve others.

POSITION

Spirituality, spiritual growth and religious expression that respect a person's history, tradition and current preferences are rights that must be honored by service systems and faith-based communities, as should the choice not to participate.

- Spirituality is an important part of human experience that may be expressed both through religious practice and through other spiritual activities which carry personal meaning and reflect the person's values;

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- Supports and accommodations, such as transportation and easy-to-read materials, must be provided as needed to facilitate the individual's full participation in spiritual or religious activities of her/his choice;
- Supports and programs should be age-appropriate and inclusive;
- Faith communities should be encouraged to build their capacity to support and welcome individuals with intellectual and/or developmental disabilities and their families, and should be assisted in such efforts;
- Self-advocates, families, advocacy organizations, service providers, and faith communities should work together to develop training and other resources on the inclusion and support of people with intellectual and/or developmental disabilities and their families; and
- People with intellectual and/or developmental disabilities bring their own unique spiritual gifts and benefits to spiritual and religious communities, just as people without disabilities do.

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Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

TRANSPORTATION

People with intellectual and/or developmental disabilities[1] (IDD) must have access to both public and private transportation to lead full, self-directed lives.

ISSUE

People with IDD lack sufficient access to reliable, accessible, and safe modes of public and private transportation. Every mode of transportation, including air, water, road, rail, and even pedestrian transportation, presents barriers for individuals with IDD. These barriers prevent people with IDD from meaningful participation in everyday activities that promote high quality community living experiences. In the U.S., millions of individuals with disabilities use public transit to maintain their autonomy and participate fully in society. For many, it is their only transit option. However, even where accessible public transportation exists, adults with IDD consider transportation options inadequate.

Federal and state legislation encourages economic self-sufficiency for people with all types of disabilities, which requires transportation. Inadequate transportation inhibits community involvement, including successful employment. Where there is available transportation, there is often little to no training available to support individuals with IDD to make full use of it. For those providing the transportation, there is insufficient training to understand and meet their customers' needs, including cultural competencies. Those living in rural areas often face the greatest challenge of all due to lack of public transportation, limited private transportation options, and long distances between destinations.

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POSITION

Transportation industries, agencies, service providers, and advocacy organizations must ensure that:

- Transportation at comparable cost and service models is available to individuals of all abilities.
- When making decisions, planning, and testing transportation options and payment methods, individuals with IDD are involved in the process.
- Improved coordination maximizes existing transportation services.
- Public transportation is adequately funded, fully financially and physically accessible, reliable to meet people's needs, and equipped to suit the physical, sensory, and cognitive needs of all people.
- As technological innovations emerge (such as virtual wayfinding, autonomous vehicles, and digital ticketing), transportation modalities are designed to be accessible, usable, and reliable, including such things as language access, visual cues, safety considerations, and audio and hands-free options to meet individuals' needs and preferences.
- Technological platforms that relay information from users with IDD to transportation providers utilize inclusive research design to ensure accessibility and ease of use.
- Travel training is available for users covering all modes of travel, prioritizing peer-to-peer training where possible.
- Appropriate disability awareness training is available for service and transportation providers.
- As smart city initiatives advance, they are developed for users of all abilities and needs. Data collection and migration tools include users with IDD in the design, to ensure inclusive smart cities.
- The unique challenges and lack of options within suburban and rural areas are addressed.
- Technology and service providers protect a user's privacy by ensuring data such as contacts, camera, photos and files, health and disability status, and locations visited is not shared, or used for commercial or tracking purposes, without permission of the individual. For any information to be accessed or shared, customers must opt-in, versus opting-out, and have clear explanations of with whom and what will be shared. In light of data management, people with IDD must have the opportunity to receive training on self-directed data management and use.
- At the same time, transportation navigation software allows an individual to share appropriate information with a third party, to enhance efficiency and safety – for example, confirming arrival and indicating off-route warnings, as directed by users.
- Innovative vehicles and transportation options do not create additional barriers, based on where vehicles are parked, stored, and operated.
- People with IDD have the option of owning, modifying, and operating vehicles and other transportation options of their choice at affordable costs.
- All vehicles, public and privately owned, meet applicable federal, state, and local safety requirements.

- Autonomous Vehicles (AVs) are fully accessible and universally designed to take into account all individuals' abilities and disabilities to safely access and operate. Regulation of AVs must consider the needs of people with IDD, and avoid unnecessary licensing requirements that would restrict or eliminate access.

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