



2019 Public Policy Platform

Our Mission:

“The Arc Maryland works to create a world where children and adults with intellectual and developmental disabilities (I/DD) have and enjoy equal rights and opportunities.”

2019 Priorities

I. FUNDING FOR COMMUNITY PROGRAMS

Protect current funding and secure additional funds to ensure a stable, quality system of Community Programs funded by the Developmental Disabilities Administration (DDA) that supports all individuals, regardless of age and severity of disability. Supports shall be provided to assist individuals live fulfilling and respectful lives in their community. Community programs include residential, employment, vocational, habilitation, and individual and family supports.

Ensure funds to provide an annual cost of living increase for DDA community programs and direct support professionals. This is important to reverse the declining wage factor in the provider rates which contributes to the declining availability of Direct Support Professionals in Maryland¹.

II. WAITING LIST

Waiting list and registry numbers are neither available nor transparent but should be for accountability. Obtain accurate numbers of people in each category of the waiting list and advocate for additional waiver slots

¹ According to ANCOR, Turnover of DSP workers has increased nationwide to 45% and the need for DSP Workers is expected to double in the next 10 years. (2018)

and services for people in need.

In 2017, the Maryland state approved budget included funding for two new capped waivers to support a total of 400 children and 400 adults from the DDA Waiting List. DDA did not begin to fill slots initially. DDA needed to create waiver definitions of services available under each waiver, and much of the money went unspent with a suspected reversion of funding for these new services back to the General Fund.

In 2018, the Maryland state approved budget again was contained funding for the two new waivers (annualized) however there continue to be several slots unfilled, especially in the Family Support Waiver .

Funding was included in the Maryland State Department of Education budget to add 100 more children through the Autism Waiver program in the 2017 and 2018 sessions. Even with these additional resources, the Autism Waiver Registry continues to grow and people on the registry who are gaining access to services are those who were on the Registry as of 2010-2011.

III. TRANSITIONING YOUTH

Ensure families are involved in the transition process and have access to reliable information on the transition process.

Fully fund all Transitioning Youth (TY) who exit the school system at age 21 so they have the supports they need to participate in their community, jobs, and life-long learning and/or higher education to ensure meaningful adult life and opportunities.

Ensure TYs are properly counted and accounted for to ensure that TYs who want day supports have timely and appropriate access to supports from a provider, and with a service or services, of choice.

Ensure TYs successfully and timely secure day supports of their choice and/or successfully enrollment in post-secondary education.

IV. EDUCATION & CHILDREN'S SERVICES

Ensure students with I/DD have access to inclusive, quality, free and appropriate public education (preschool, primary, secondary, and post-secondary education) and receive appropriate accommodations to participate in all aspects of education life.

Ensure students with I/DD are not disproportionately disciplined, suspended, or expelled and that teachers/school personnel have access to training and other supports to provide and promote fair and equitable treatment of students.

Ensure children with I/DD are included in neighborhood child care, before and after school programs, and camps regardless of the nature or level of their disability.

V. EMPLOYMENT

Increase opportunities for competitive, integrated employment at fair wages for people with Intellectual and developmental disabilities.

Ensure funding is sufficient to provide quality community supports with an “employment first” focus.

VI. AFFORDABLE HOUSING

Increase affordable and accessible housing so people with I/DD can live in the community. Accessible housing includes physical access, as well as, access to transportation for jobs and social opportunities.

VII. LAW ENFORCEMENT AND JUSTICE

Support police training efforts that reduce stigma, increase safety, and inspire relationships of acceptance and support for all Marylanders.

VIII. CIVIL RIGHTS

- Close the remaining state institutions and oppose the expansion of State Residential Centers (SRCs) and new admissions including respite care.

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GENERAL PRINCIPLES

The Arc Maryland is the largest and strongest statewide advocacy organization advocating for and with people with intellectual and developmental disabilities and their families in Maryland. Our membership includes people with intellectual and developmental disabilities, families, educators, professionals, and interested people from the general public.

Historically, people with I/DD have been denied fundamental human and civil rights and have been subjected to institutionalization, segregation, abuse, and neglect. The last decades of the twentieth century signaled a turning point with the passage of hard-won landmark federal legislation that altered the lives of people with I/DD and their families. Despite these great strides toward expanding rights, there still remain several policy issues (on the federal, state, and local levels) that continue to restrict and deny the rights of people with I/DD to live inclusive lives in their communities.

Over 94,000³ individuals with I/DD live in Maryland. The State of Maryland has specific obligations to uphold the rights of individuals with I/DD, without discrimination based on the severity or complexity of disability. To support these rights, The Arc Maryland subscribes to the following general principles:

³ Source: State of the State of Intellectual and Developmental Disabilities, 2017

- Respect for difference and acceptance of people with disabilities as part of human diversity;
- Respect for inherent dignity and individual autonomy, including the freedom to make one's own choices;
- Full and effective participation and inclusion in society;
- Accessibility;
- Non-discrimination;
- Equality of opportunity.

The Arc Maryland seeks to promote and ensure the full realization of human rights and fundamental freedoms for all people with disabilities without discrimination of any kind. To this end, we will work to help and urge the State of Maryland to:

- Adopt all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in this Policy Platform;
- Take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs, and practices that constitute discrimination against people with disabilities;
- Protect and promote the human rights of people with disabilities in all policies and programs;
- Take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization, or private enterprise;
- Promote the training of professionals and staff who support people with I/DD so they understand the rights outlined in this platform and can better provide the assistance and services guaranteed by those rights;
- Closely consult with and actively involve people with I/DD in the development and implementation of legislation and policies to implement these rights.

POLICY ISSUES

I. FUNDING

Budget and tax policies determine the availability of programs and services that people with I/DD rely on for their health, safety, and quality of life. Sufficient funding is required to ensure quality programs. There is a shortage of Direct Support Professionals (DSP) nationally. In Maryland, turnover is higher than 43% on average and the position of Direct Support Professional is not promoted as a viable career. The Department of Labor does not have a labor code for the position of DSP, which is a hybrid of a couple of positions including case manager, care provider, medication technician, personal care assistant, and counselor. The Arc Maryland supports that there should be a DOL code for Direct Support Professional to recognize the complexity of the position.

The Arc Maryland is committed to working with the State of Maryland to develop a strategy for recruiting and retaining DSPs in the system. This will likely require recognition at the state level that the position is not an entry level job, but one of a professional nature. We advocate to ensure developmental disabilities services are provided efficiently and effectively, while promoting the health, safety, and desired outcomes of the individuals

served. We collaborate with the State to work through issues related to Federal and State requirements for funding as well as matching federal funds for Medicaid, Medicaid Waivers, and Vocational Rehabilitation.

The State must provide leadership, sufficient funding and meaningful oversight to ensure that state agencies supporting individuals with I/DD uphold their statutory responsibilities. Funding should align with infrastructure and systemic changes so that organizations that support people with I/DD can transition to comply with the settings requirements of the final rule while continuing to ensure people with I/DD are supported in meaningful ways.

State agencies include: Developmental Disabilities Administration (DDA), Maryland State Department of Education (MSDE), Department of Disabilities (DOD), Department of Human Services (DHS), and Division of Rehabilitation Services (DORS).

We advocate to:

- Protect current and secure additional funds to ensure a stable, quality system of Community Programs funded by the DDA that supports all individuals, regardless of age and severity of disability, so they can be respected and live fulfilling lives in their community. Community programs include but are not limited to residential, employment, vocational, habilitation, individual and family supports, and educational and recreational programs.
- Fully fund all Transitioning Youth (TY) who exit the school system at age 21 years so they have the supports they need to participate in their community, jobs, and life-long learning and/or higher education to ensure meaningful adult life and opportunities.
- Ensure there is adequate funding for Community Programs to meet the needs of those with multiple and complex disabilities, such as individuals who require 1-to-1 support and other accommodations, and individuals with forensic involvement;
- Fund Respite Care through DDA and DHS budgets;
- Reform the current DDA payment system so funding pays for actual needs and costs
- Ensure that new rates for services are sufficient for those who self-direct and for providers organizations to deliver quality and meaningful services and supports to individuals;
- Retain a pool of one-time only adverse weather payments, and state-only funds for emergencies, enhancing respite, and family supports;
- Adequately fund individuals who are receiving services and supports at home;
- Secure additional funding and fully meet the needs of all crisis and emergency categories of the DDA Waiting List;
- Adequately fund children and youth in need (including infants, toddlers, and school age children ages birth-21, in and out of school time);
- Fund and provide supports for aging and vulnerable citizens with increasing needs so they can age in place and remain in non-institutional, community-based programs;
- Recommit funds annually, and advocate for new state legislation that requires an annual increase in the wages of direct support professionals in community programs funded by DDA .
- Ensure there is training for providers, individuals with I/DD and families on services systems and transformational changes within the structure of the system, with an

emphasis on the use of technology to promote greater independence, and this training is funded and supported by our state.

“adequate and sufficient” funding means funding that is “necessary” to ensure quality of life and viability of the service delivery system in Maryland.

II. EDUCATION & CHILDREN’S SERVICES

Education is the gateway to achieving full potential and independence for people with I/DD. The education system must have high expectations, offer integrated instruction by highly qualified teachers, require appropriate assessments, and use only positive behavioral supports.

Early intervention services are of vital importance to infants, toddlers and children with disabilities. Critical phases of brain development occur during the time between the ages of 0 and 3. Early detection is essential. Once a child is diagnosed, families must be given comprehensive, affordable access to a wide variety of therapies, including speech, occupational, and physical as well as behavioral supports. A robust education system is needed to guarantee that all children have the opportunity to achieve their potential, academically and socially, with accommodations made based on disability and cultural and linguistic needs.

The Arc Maryland reaffirms the rights of people with I/DD to a Free and Appropriate Public Education (FAPE) in accordance with IDEA and with supports to ensure their full participation in an inclusive and least restrictive environment that is free of bullying and the unnecessary use of restraint and seclusion.

In order to help ensure the realization of lifelong learning, we believe the State of Maryland should take appropriate measures to support and fund improved teacher preparation and professional development for educating children with I/DD. This should include training in the use of Positive Behavioral Interventions & Supports (PBIS), alternative communications, and Universal Design for Learning (UDL) educational techniques and materials.

We advocate to:

- Fully fund the Infants and Toddlers Program to ensure detection, supports, and early intervention are available for all families.
- Increase funding for the Community-Based Services Waiver for Children with Autism Spectrum Disorder (Autism Waiver). As of August 31, 2017, there were 5326 children on the statewide registry for an increase of 726 children (almost 16%) added to the registry in the span of a year. MSDE is currently working to fill the 100 waiver slots added in 2018 with children on the list as of 2010.
- Ensure students with I/DD have access to inclusive, quality, free and appropriate public education (preschool, primary, and secondary education) and receive appropriate accommodations to participate in all arenas of education life. Reasonable accommodations must be based on individual needs include, but are not limited to, facilitating the learning of various communications techniques including sign language, Braille, and alternative script, augmentative and alternative modes, means, and formats of communication, orientation and mobility skills, and facilitating peer support and mentoring;

- Ensure people with I/DD have equal access to higher education, vocational training, adult education, appropriate sensory environments as a reasonable accommodation, and lifelong learning without discrimination;
- Ensure comprehensive transition planning begins for students with I/DD no later than age 14, if not sooner;
- Enhance and increase education and technical support to parents on the transition process so they may effectively partner with their child(ren) and the schools to plan for the future;
- Ensure the continuation of academic learning through the transition period and up through graduation;
- Urge MSDE and DDA to develop a unified tracking system of TY for outcomes up to two years post-school. Outcomes for tracking to include ability of TYs to access supports from a provider of choice, and numbers of people supported in competitive employment, supported employment, day habilitation, medical day, and other supports;
- Establish and create new opportunities for young adults of college age to experience the same social, educational, and employment experiences as their peers without disabilities in age-appropriate community settings;
- Ensure school-based job exploration focuses on the individual's skills and interests and targets placement in community jobs at fair wages, rather than segregated, sheltered workshops or enclaves that pay less than minimum wage to workers with disabilities;
- Ensure continuing disabilities training including Positive Behavioral Interventions & Supports (PBIS) and Universal Design for Learning (UDL) for educational professionals and school staff;
- Advocate for the adoption of recommendations to implement restorative practices and restorative justice in all Maryland schools by 2025.
- Apply Universal Design for Learning (UDL) practices, including tailoring state assessments so that all children have adequate opportunities to learn and demonstrate their knowledge;
- Ensure families and children have access to respite care, inclusive child care, inclusive before and after school programs and camps;
- Ensure families and children have access to child care without discrimination based on the child's severity or level of disability;
- Expand educational opportunities, including opportunities across the lifespan, inside and outside of school settings, such as recreational activities, sports, college, and job training;
- Ensure IEPs are available in formats accessible to families and students;
- Help bring fairness and equity to special education disputes by shifting the burden of proof from the party seeking relief to the party providing supports and services.
- Advocate for schools to adopt self advocacy training prior to or during transition years to encourage involvement in academic planning and self-determination.

III. EMPLOYMENT

Employment is the cornerstone of community life for most adults in our society, including people with I/DD. People with I/DD overwhelmingly express the desire and willingness to engage in meaningful work. Competitive integrated employment programs, including supported employment, must be properly funded and administered to provide job development and placement, skills training, job coaching, and other services necessary to help find and maintain employment, in accordance with the person's skills, talents and interests. The Arc Maryland supports phasing out segregated facility-based day programs and sheltered workshops for people with intellectual and developmental disabilities, including people with the most significant disabilities

The Arc Maryland reaffirms the rights of people with I/DD to have meaningful jobs with competitive wages. This includes the right to earn a living by work that is freely chosen or accepted in a labor market, and to conduct work in an environment that is open, inclusive, and accessible to people with I/DD. We support the promotion of meaningful employment opportunities and career advancement for people with I/DD in the Federal, state, local, and public sectors; assisting with people with I/DD for self-employment and ensuring a fair and equitable work environment with income equality.

We advocate to:

- Ensure reasonable accommodations are provided to people with I/DD in the workplace;
- Prohibit discrimination on the basis of disability with regard to all matters concerning all aspects of employment, including recruitment, hiring, continuance of employment, career advancement, and safe and healthy working conditions;
- Build infrastructure and create incentives for employers to expand work opportunities for individuals with significant disabilities in competitive integrated employment;
- Protect the rights of people with I/DD to equal opportunities and equal remuneration for work of equal value, and safe and healthy working conditions, including protection from harassment and the opportunity to redress grievances;
- Increase opportunities for competitive integrated employment at fair wages (“Employment First”) with sufficient funding to provide these supports;
- Provide funding that assists individuals to be employed or involved in their community in inclusive settings, with funding incentives and technical assistance to downsize and convert sheltered workshops and segregated work programs into supported employment, competitive employment, and other inclusive community opportunities;
- Ensure that people with I/DD are not held in servitude and are protected from forced or compulsory labor;
- Promote employment opportunities and career advancement for people with I/DD in the labor market, as well as assistance in finding, obtaining, maintaining, and returning to employment;
- Promote opportunities for self-employment and entrepreneurship;
- Promote the employment of people with I/DD in the public and private sector through appropriate policies and measures, which may include affirmative action programs, incentives, and other measures;

- Require government agencies and administrations (local, state, and federal) to include individuals with I/DD in their hiring initiatives.

IV. HEALTH & PREVENTION

Health and wellness is a critical component of maintaining a healthy lifestyle for people with I/DD. Health care systems must be accountable for providing timely access to high quality, comprehensive, accessible, affordable, and appropriate services that meet individual needs. Today, individuals with I/DD may receive more comprehensive diagnoses, may have coexisting medical conditions, and are living longer. This increases the need for services that grow and adapt to meet individual needs throughout the lifespan.

The Arc Maryland reaffirms the rights of people with I/DD to achieve the highest standard of health without discrimination on the basis of disability. Health and wellness services should be available throughout the lifespan, and treat the full health of the individual, including any coexisting/co-occurring conditions.

Multiple systems (medical, aging, DD, mental health, substance abuse) may be necessary for treatment, services, and supports. However, those multiple components create the risk of gaps in continuity of care. Transitions from pediatric to adult health care systems and from adult to geriatric health care systems are not always smooth and often include gaps in information transfer and care continuity. The Arc Maryland seeks to work with the State, medical professionals and geriatric professionals to create seamless transitions from pediatric to adult healthcare provider systems, and adult to geriatric systems to close gaps between delivery systems, and to move toward holistic models of health care.

Some disabilities are caused by preventable factors, such as exposure to lead poisoning and other environmental variables, or by the use of alcohol or smoking during pregnancy. Education of expectant mothers and fathers, youth, families, and health professionals about environmental factors is important. Affordable access to comprehensive prenatal care is critical. The State should embark on a campaign, in collaboration with consumer and family organizations, to inform teens and expectant mothers and fathers of risk factors that could increase the likelihood of their child being born with a disability.

The prevalence of individuals with autism spectrum disorder in Maryland is higher than the national prevalence⁴. With so many people identified as having an autism spectrum diagnosis in our state, the government has an obligation to ensure that these people have the supports they need to live inclusive, meaningful lives, with access to all appropriate evidence-based treatment.

It is the obligation of the State to take effective and appropriate measures to enable people with I/DD to attain and maintain full physical, mental, social, and vocational capacity in order to support maximum independence and full participation in all aspects of life. This

⁴ The Centers for Disease Control and Prevention (CDC) in April, 2018 estimated in that 1 in 59 children in the United States have been identified with autism spectrum disorder (ASD). In Maryland, the prevalence is higher at 1 in 50 children. That is up from a ratio of 1 in 68 just two years ago in 2016, and a ratio of 1 in 88 children in 2012.

includes nursing and medical care for individuals with I/DD to prevent their institutionalization in state facilities and nursing facilities.

We advocate to:

- Provide people with I/DD with access to quality and appropriate healthcare and wellness services;
- Provide people with I/DD with access to affordable health care and wellness programs, including access to affordable treatments and prescription and over-the-counter medications;
- Provide those health services needed by people with I/DD specifically because of their disability and services designed to minimize and prevent further disability;
- Provide health services as close as possible to peoples' own communities, including rural areas;
- Prohibit discrimination against people with I/DD in the provision of health insurance and life insurance;
- Ensure affordable access to comprehensive prenatal care for expectant parents with and without disabilities;
- Educate youth, families, health professionals and expectant mothers and fathers on preventable factors that can cause I/DD;
- Continue to require health insurance companies to cover evidence-based treatments for individuals with I/DD, such as Applied Behavior Analysis (ABA) therapy and other therapies proven effective for various conditions;
- Prevent discriminatory denial of health care, health services, or food and fluids on the basis of disability;
- Ensure there are organized and comprehensive habilitation and rehabilitation services and programs, particularly in the areas of health, employment, education, and social services, in such a way that these services and programs:
 - Begin at the earliest possible stage, are family-centered, and are based on the multidisciplinary assessment of individual needs and strengths;
 - Support participation and inclusion in the community and in all aspects of society as close as possible to their own communities, including rural areas;
 - Promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services;
 - Promote the availability, knowledge, and use of assistive devices and technologies for communication, and health and wellness.

Advocate for the creation of a comprehensive medical records system which includes sharing records between healthcare professionals with consent that is compliant with HIPAA.

Ensure people with I/DD have access to all medical information about their care and medical professionals understand people with I/DD have the right to make their own healthcare decisions.

Advocate for hospitals to have ombudsmen/navigators available to people with I/DD to ensure their rights and wishes are heard and that their decisions are honored.

Advocate for the creation of a training program for healthcare professionals to introduce these professionals to how people with disabilities may present and how they may communicate their wishes and needs.

V. CIVIL RIGHTS

Civil rights are the foundation for the services and protections that people with I/DD enjoy today. Civil rights must be preserved through vigilant enforcement of laws and regulations as well as strong opposition to efforts to limit the rights of people with I/DD.

The Arc Maryland reaffirms that all people are equal under the law and are entitled to the equal protection and benefit of the law. Unjustified segregation is a violation of individual rights, and people with I/DD have the legal right to live inclusive lives within the community.

Every human being has a right to liberty and security of person, and to live free from exploitation, violence, and abuse. We support the rights of individuals, regardless of their place of residence or living arrangements, to maintain their privacy in information, correspondence, and communications. Further, we uphold the rights of people with I/DD to liberty of movement, and the freedom to choose their residence without being deprived or constricted arbitrarily on the basis of disability.

We advocate to:

- Eliminate discrimination in housing, transportation, recreation, education, employment, and community access;
- Enforce existing legislation and court rulings such as the Americans with Disabilities Act (ADA) and the *Olmstead* Supreme Court Decision;
- Ensure the civil rights of people in institutions and nursing homes to live in the most inclusive setting in the community, with appropriate supports;
- Protect people with I/DD from abuse in biomedical research;
- Protect equal access rights for community housing, including freedom from discrimination based on source of income, such as SSI;
- Protect individuals with I/DD, within and outside the home, from all forms of exploitation, violence, and abuse;
- Prevent all forms of exploitation, violence and abuse by ensuring appropriate forms of assistance and supports are available for people with I/DD, their families and caregivers, including the provision of information and education on how to avoid, recognize, and report incidents;
- Ensure that all facilities and programs designed to serve people with I/DD are effectively monitored by independent authorities;
- Promote the physical, cognitive, and psychological recovery, rehabilitation, and social reintegration of people with I/DD who are victimized;
- Ensure effective legislation and policies to guard against exploitation, violence and abuse of people with I/DD and to ensure alleged violations are identified, investigated, and prosecuted;
- Provide information intended for the general public in accessible formats and technologies;

- Urge private entities that provide services to the general public, including through the internet, to provide information and services in accessible formats for people with I/DD;
- Protect the privacy of personal, health, and rehabilitation information of people with I/DD;
- Ensure that funding for all necessary health-related services is accessible to people with I/DD, e.g. covered by insurance, Medicaid, and other appropriate state and federal agencies.

VI. FAMILY SUPPORTS

Family support is essential for caregivers of all ages throughout the lifespan. Counseling, mentoring, leadership training, training in meeting the family member’s needs, support groups, respite, cash assistance, and information and referral assistance must be made widely available to all family caregivers.

According to a US News article (August 2017) Maryland is the wealthiest state in the U.S., but ranks 38th in state funding for developmental disabilities services. Children and adults with I/DD should be able to receive supports in their home or community in small family-type settings rather than in institutions, congregate care programs, or out-of-state placements.

Families deserve to have a voice in decisions that affect their lives. The Arc Maryland urges a significant review of the Low Intensity Supports and Services Program (LISS) to ensure statewide consistency. We support an equitable distribution of resources to all regions of the State thereby assuring equal access to this important family resource.

The Arc Maryland reaffirms the rights of individuals with I/DD to equally and fully participate in relationships, marriage, family, and parenthood. With regard to guardianship, trusteeship, adoption of children, or similar cases, the best interests of the child shall always be paramount, without discrimination on the basis of disability.

We advocate to:

- Increase funding for family support services, such as counseling, support groups, mentoring, training, and respite;
- Preserve and expand availability of LISS funds to families. Address accessibility of the LISS application to ensure there are no language or other barriers to prevent access to the application and fund.
- Ensure children and adults with I/DD receive supports in their home or community in small family and/or community settings;
- Establish a multiyear Community and Family Supports initiative to meet the needs of individuals on the DDA Waiting List and build capacity in the community;
- Engage stakeholders in any potential changes made to funding or eligibility for family supports and waiver programs;
- Protect the rights of people with I/DD to marry and have a family;

⁵ Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2017

- Protect the reproductive rights of people with I/DD and provide access to appropriate reproductive information;
- Protect the rights of individuals with I/DD to retain their fertility;
- Prevent concealment, abandonment, neglect, and segregation of children with I/DD by:
 - Making available and providing early and comprehensive information, services, and supports to children with I/DD and their families, accompanied with necessary support to navigate multiple, complex State systems;
 - Ensuring that a child shall not be separated from his or her parents against the parent's will without judicial review to determine that such separation is necessary and in the best interest of the child;
 - Ensuring that no child shall be separated from his or her parents on the basis of disability of either the child or one or both of the parents; and
 - Ensuring that in cases where the immediate family is unable to care for a child with I/DD, the State should undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

VII. COMMUNITY LIVING

Inclusive community living, with an emphasis on self-determination and preferences of the individual, is the vision and mission of the disability rights movement. The Arc Maryland supports the rights of all people with I/DD to live in the community with choices equitable to others.

Self-Advocacy is the key to empowerment of people with I/DD; people with disabilities are the experts on what is best for their own lives. We believe in supporting the self-advocacy movement through meaningful inclusion of self-advocates in the development and implementation of all policies and programs that impact their lives. The Arc Maryland wholeheartedly supports the mantra of the self-advocacy movement: ***"NOTHING ABOUT US WITHOUT US!"***

Transportation is the pathway to employment, health care, recreation, and other aspects of community living for people. Accessible and reliable transportation systems and programs must be properly funded and administered and anti-discrimination policies in transportation must be enforced. The State should increase funding for the maintenance and expansion of an accessible and reliable public transportation system.

Technology is instrumental in making communication, education, independent living, and employment opportunities available for people with I/DD. Technology must be customized and made widely available to people who may benefit from it. Funding options, including in the home and community-based waiver, must be available to ensure people with I/DD can access technology, including technology to support their independence and reduce staff dependence, as appropriate.

Housing is critical for people with I/DD to live in the community. There must be an adequate supply of safe, accessible, and affordable housing. People with I/DD should have the opportunity to choose where and with whom they live, and should not be obliged to accept a

particular living arrangement. Individuals with I/DD should have access to a range of in-home, residential, and other community support services, including personal assistance necessary to support inclusion and to prevent isolation or segregation. Source of income discrimination should be outlawed statewide.

Institutions are obsolete and should be closed. People with I/DD have the right to live inclusive lives in the community, with quality supports and services. The Arc Maryland strongly opposes the expansion of State Residential Centers (SRCs), including the Secure Evaluation and Therapeutic Treatment (SETT) Center, and calls upon the Department of Health (MDH) to develop appropriate community capacity to eliminate institutions altogether.

Direct Support Professionals constitute the backbone for community living for people with disabilities. A well-trained, adequately compensated direct support workforce is essential for providing the necessary supports and services to individuals with I/DD where they live and work.

We advocate to:

- Empower self-advocacy organizations and the self-advocacy movement;
- Listen to the viewpoints and concerns of self-advocates as the experts on I/DD;
- Meaningfully include self-advocates in the development and implementation of policies, programs, and research that will have an impact on their lives;
- Uphold, protect, and enforce the Americans with Disabilities Act (ADA) and *Olmstead* Supreme Court Decision and close the remaining state institutions;
- Ensure that community services and facilities are available on an equal basis for people with I/DD and responsive to their needs;
- Ensure people with I/DD have equal access to the physical environment, transportation, information, communications, and other facilities and services open or provided to the public, in both urban and rural areas;
- Identify and eliminate all obstacles and barriers to accessibility, which may apply to:
 - Buildings, roads, transportation, and other indoor and outdoor facilities, including schools, housing, medical facilities, and workplaces;
 - Information, communications, and other services, including electronic services, emergency services, and all available technologies;
- Ensure reliable and accessible public transportation so people with I/DD can access community resources, employment, friends, and have greater control over their own lives and relationships;
- Ensure access by people with I/DD to quality mobility aids, devices, assistive technologies, and forms of personal assistance and intermediaries at affordable costs;
 - Regarding personal assistance, examine the condition of DSPS and their salaries, benefits, and standing as a profession. The position of DSP has been devalued in both recognition as a career and in funding/compensation in the form of state funding. This has resulted in the necessary access of public assistance by many DSPS. Consider collecting metrics on the use of assistance by DSPS of food stamps, section 8 etc. and the strain on state resources that could be diverted by channeling more funding into DSP wage and benefit enhancements

- Ensure training in mobility skills to people with I/DD and to their support staff;
- Advocate for laddering and credentialing for DSPS to create advancement paths and enhance retention of qualified caregivers, and funding to financially support this.
- Encourage entities that produce mobility aids, devices, and assistive technologies to take into account all aspects of mobility for people with I/DD;
- Increase and fund affordable housing options so people with I/DD can access and control their own housing opportunities by renting or buying their own homes. Encourage the availability of "seed money" and incentives to develop new options are needed for nonprofit organizations, developers, and people with disabilities. All affordable housing options need to include access to transportation so housing is accessible to jobs and community resources;
- Support the rights of people with I/DD to acquire assets as they strive for financial independence;
- Support the Bridge Subsidy Demonstration Program permanently in all counties so that people with I/DD can access short-term rental assistance while awaiting a permanent housing voucher;
- Advocate for more capacity and quality in Medicaid's 'Community First Choice' (CFC) Option, which is designed to improve access to community services, offer more consumer choice, and promote high quality services;
- Support CMS's Home and Community-Based Services (HCBS) Setting Rule, which requires that HCBS settings:
 - Must be integrated in the community,
 - Must not be located in a building that is also a publicly or privately operated facility that provides institutional treatment or custodial care,
 - Must not be located on the grounds of, or adjacent to, a public institution,
 - Must not be a housing complex designed expressly around an individual's specific diagnosis or disability.

Ensure that the state engages stakeholders in a meaningful way with regards to rule and policy development prior to rulemaking or directives. Information and support should be provided to people with I/DD and their families to understand new options; and technical assistance should be provided to agencies that provide supports to transition to new models.

- Support the promotion of "Visitability" - the incorporation of accessible architecture features into housing design including 0 step entrances including visitor entrances;
- Close the remaining state institutions, oppose the expansion of State Residential Centers (SRCs) and new admissions, and seek community alternatives for respite care.
- Advocate for a federal change in the limit on assets for SSI eligibility. The limit has been \$2000 for years and has not kept pace with the changed economy. The limit prevents self sustainability and deters independence.

VIII. LAW ENFORCEMENT & JUSTICE

The Arc Maryland reaffirms the rights of people with I/DD to have effective access to justice.

Individuals with disabilities are 4 to 10 times more likely to be victimized than those without disabilities, and 8 times more likely to be the victim of a sexual assault. Individuals with

disabilities are also overrepresented as victims, witnesses, and suspects in the criminal justice system. This does not mean that people with disabilities are more likely to commit crimes, but that they are more likely to experience difficulty when they come into contact with the legal system. When individuals with I/DD become involved in the criminal justice system, they often face miscommunication, fear, confusion, and prejudice. They are disproportionately secluded (solitary confinement) in numbers and in length of time in the state correctional facilities. The reasons for their segregation range from reactions to stress in incarceration, and inadequate mental health care to simple administrative infractions (failure to follow directions). People with disabilities often lack the information necessary to make informed decisions.

According to the Governor's Executive Order for the formation of the Maryland Commission for the Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities:

- “Many officials in positions of authority, including law enforcement officials, paramedics, and other first responders, receive limited training about responding to situations involving individuals with (I/DD).”
- “Maryland would benefit from statewide policies, guidelines, and best practices on standards for law enforcement officials, paramedics, and other first responders’ responses to situations involving individuals with (I/DD).”
- “Maryland would benefit from statewide training standards that educate individuals in positions of authority, particularly those in public sector positions such as law enforcement officials, paramedics, and other first responders, about the best approaches for safely managing situations involving individuals with (I/DD).”
- “Maryland would benefit from the development of a coordinated, collaborative, and comprehensive strategy to ensure enhanced responses to situations involving individuals with (I/DD).”

We advocate to:

- Assist in the development of comprehensive training, policies, practices, and sensitivity to ensure protection of the civil rights, safety, and to promote meaningful community inclusion of individuals with I/DD;
- Ensure all necessary measures are taken to provide safe harbor in emergencies for people with I/DD, including the adequate training of emergency personnel and first responders;
- Ensure adequate victim assistance and legal representation for people with I/DD;
- Ensure fair treatment in the criminal justice system for people with I/DD;
- Promote implementation and sustainability of the Ethan Saylor Alliance and its recommendations for law enforcement and other avenues to promote the inclusion of people with I/DD in their communities.

IX. PHYSICIAN ASSISTED SUICIDE

The Arc Maryland opposes legislation that would legalize physician assisted suicide in Maryland. This position is taken on behalf of our concerns regarding its potential impact on people with intellectual and developmental disabilities. The Arc Maryland's concerns include lack of protections, historic discrimination in the medical field based on perceived 'quality of

life' of persons with disabilities, and lack of treatment and other options for individuals with I/DD (such as palliative care, suicide prevention, mental health services, support services, etc.). Our constituency is unduly vulnerable to coercion by trusted individuals and professionals.

In Maryland, physician assisted suicide bills have provided no guarantees that physicians will be required to present all available options to someone who is terminally ill (including those with and without I/DD), and there is no guarantee that once a person is given their diagnosis, that they will also have the right to access mental health care in order to process the grieving cycle that may take place before making a potentially life-ending decision. There is no screening mechanism for depression before making this decision, and no acknowledgment of the reality that when given the news of a terminal illness, individuals may be incredibly vulnerable, and would benefit from first having access to mental health care before making decisions in a depressed state of mind.

In the profit-driven healthcare system and environment of cost containment, there is a clear danger that individuals with I/DD will not be advised of other options; there is a danger the health care system would steer individuals to the least expensive options rather than the above supports individuals may need. People with intellectual and developmental disabilities have historically and presently face discrimination and lack of access to medical care based on their perceived value. People with I/DD have been denied access to health care, basic needs such as food and water, organ transplants and surgery; historically their lives have been devalued compared to the lives of non-disabled people, which presents huge concerns when considering the possibility of physician assisted suicide as a legal "option" for those who either have a disability, or may acquire a disability as a result of their diagnosis.

Legislation was introduced in the 2015, 2016, and 2017 sessions, failing in the first two years and withdrawn in the third for lack of support. Legislation was not introduced in the 2018 session. Former bills contained no provision/ no requirement that a medical professional or independent witness be present when an individual takes the lethal dose of physician prescribed medication. Given the disproportionate levels at which people with I/DD are the victims of coercion and abuse (including by caretakers), this is concerning since there is no one present to verify that the individual taking the medication did so without being forced, and of their own free will.

Unfortunately, people with I/DD (including those with a dual diagnosis of mental illness, such as depression) often encounter a health care system that provides limited choices. Without access to the full array of supports, the legalization of physician assisted suicide is dangerous for people with I/DD. There are very few states and the District of Columbia that have legalized physician assisted suicide. The experiences of people with I/DD are unknown in these states. The Arc Maryland believes greater information on the experiential impact on people with I/DD is required to understand the full ramifications and unintended consequences. Maryland should not be an early adopter given the enormous concerns and lack of evidence of the impact upon people with I/DD.

Given these concerns, the history of marginalization faced by people with I/DD, and in concordance with The Arc U.S.'s national position, The Arc Maryland opposes legislation to legalize physician assisted suicide in Maryland.

GLOSSARY

ABA: Applied Behavioral Analysis - Evidence-based therapy designed for individuals on the autism spectrum that systematically applies interventions based upon the principles of learning theory to improve socially significant behavior and communication.

CFC: Community First Choice- Services available as part of the State Plan to expand access to individuals who require custodial services in their homes (Assistance with ADLS and IADLs)

DDA: Developmental Disabilities Administration - The state agency housed within the Department of Health and Mental Hygiene (DHMH) that is directly responsible for ensuring the quality of life, health, and safety of people with developmental disabilities.

Developmental Disability - Developmental disabilities are severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be lifelong. Examples of developmental disabilities include, but are not limited to: Cerebral Palsy, Down syndrome, Autism Spectrum Disorders, and Fetal Alcohol Syndrome.

MDH: Maryland Department of Health (Formerly the Department of Health and Mental Hygiene) - A State Department that encompasses several agencies of importance to people with developmental disabilities such as the Developmental Disabilities Administration (DDA) and the Office of Health Care Quality (OHCQ).

DHS: Department of Human Services (Formerly the Department of Human Resources) - The state department that supports children with disabilities in the foster care system and provides food and energy assistance.

DORS: Division of Rehabilitation Services - A division of the Maryland State Department of Education (MSDE) that funds vocational evaluations, job training, assistance with higher education by purchasing items that people with disabilities need to succeed in college or work, and tools that help them maximize their independence.

Habilitative Services - Therapies and services for people with disabilities who require ongoing intervention, training and therapy to achieve their potential and prevent regression. Therapies include physical, occupational, and speech/language therapy.

HCBS: Home and Community Based Services- The Federal Medicaid program that funds home and community services, such as supported employment, day programs, and residential services.

Intellectual Disability - A disability characterized by significant limitations in both intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior,

which covers a range of everyday social and practical skills. This disability originates before the age of 18.⁶

OHCQ: Office of Health Care Quality - The agency that has statutory responsibility to provide oversight of state-operated and community services that support people with intellectual and developmental disabilities. OHCQ investigates reports of abuse and neglect and evaluates trends in deaths and incidents of violation of health and safety.

Olmstead vs. L.C. (1999) - The 1999 Supreme Court decision that affirms that people with disabilities have the right to live in the most appropriate integrated setting based on h/her individual needs and preferences.

REM: Rare and Expensive Case Management Program - A case managed fee-for-service alternative to HealthChoice Managed Care Organization (MCO) participation for recipients with specified rare and expensive conditions.

⁶ AAIDD (American Association on Intellectual and Developmental Disabilities) Frequently Asked Questions.