2019 Annual Business Meeting

Sunday, October 13, 2019
1:15 pm - 2:45pm

THE ARC OF THE UNITED STATES

October 13, 2019
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ANNUAL BUSINESS MEETING AGENDA
Sunday October 13, 2019
1:15 pm – 2:45 pm
Independence Ballroom
Grand Hyatt

1:15 pm – 1:30 pm
Call to Order & Welcome
Fred Misilo, President

Establishment of Quorum
Doug Church, Secretary

Review of Business Meeting Operating Rules
Fred Misilo, President

Appointments – Timekeeper
Fred Misilo, President

Approval of Annual Business Meeting Minutes
Fred Misilo, President

1:30 – 1:40 pm
Executive Committee
Proposed Bylaws Amendments
Fred Misilo, President
Elise McMillan, Ad Hoc Bylaws Work Group Chair

1:40 pm – 1:50 pm
President’s Report
Fred Misilo, President

1:50 pm – 2:00 pm
Chief Executive’s Report
Peter V. Berns, Chief Executive Officer

2:00 pm – 2:05 pm
NCE Report
Karen Shoemaker, Chair of NCE

2:05 pm – 2:40 pm
Policy and Positions Committee
Listening Session: Position Statements
Ken Oakes, Chair

2:40 pm – 2:45 pm
Announcements
Fred Misilo, President

Adjourn
Fred Misilo, President
PROPOSED BUSINESS MEETING OPERATING RULES

Please note that The Arc’s Bylaws contains the procedures for submitting and adopting amendments to the Bylaws and procedures for submitting and adopting substantive resolutions.

1. VOTING BODY: The voting body consists of Chapters, by their Chapter voting representatives or by proxy votes submitted.

2. QUORUM: A quorum for the transaction of business at the annual meeting of the Members and at any special meeting of Members shall consist of those Chapters present in person, or by proxy, holding not less than one-half (1/2) of the total number of votes held by all of the Chapters.

3. SEATING: There are no voting representatives or Chapter designated seating; however, all Chapter voting representatives must wear their name badge.

4. PRIVILEGE OF THE FLOOR: Unless otherwise decided by a majority of the Chapter Voting Representatives, the Chair shall recognize only the following person(s) for the purpose of discussion: Chapter Voting Representatives, State Presidents, National Board Members, National Committee Chairpersons, and National Past Presidents.

5. RECOGNITION OF SPEAKERS: To be recognized by the Chair, a person who wants to speak must first go to the nearest available microphone, stating the speaker's name, title (if applicable), state and local chapter. A member wishing to be recognized by the Chair for any other legitimate purpose may use the nearest available microphone and state the speaker's name, title (if applicable), state and local chapter, and for what purpose they wish to be recognized. Assistance will be provided to any member physically unable to go to a microphone.

6. SPEECH LIMITS:
   a. Each person may speak for up to two minutes when recognized by the Chair.
   b. A Chapter voting representative wishing to speak a second time on a motion yields to anyone who has not yet spoken once.
   c. No one may speak more than twice on a subject without consent of the assembly.
   d. The Chair may make accommodations to meet the needs of individual speakers.

7. PARLIAMENTARY AUTHORITY: The rules contained in the current edition of The Standard Code of Parliamentary Procedure (Sturgis) shall govern the annual business meeting in all cases to which they are applicable and in which they are not inconsistent with the Bylaws, these business meeting rules or any other rules of the Association.

8. Per the bylaws of The ARC, The President of The Arc shall have the power to appoint a parliamentarian and shall interpret these Bylaws when a question arises as to the meaning of any part of it. The President’s decision shall be final, unless overruled by a vote of two-thirds (2/3) of all the votes held and entitled to be cast by Chapters of The Arc that are present in person or by proxy.
Meeting Minutes

Section 3

THE ARC OF THE UNITED STATES

October 13, 2019
Minutes of the 69th Annual Convention  
Nashville, TN  
Friday, November 9, 2018

<table>
<thead>
<tr>
<th>Call to Order</th>
<th>The Business Meeting of the 69th Annual Convention of The Arc was called to order by President Elise McMillan at 1:52pm.</th>
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<tbody>
<tr>
<td>Welcome</td>
<td>President McMillan welcomed the visitors and guests to the Business portion of the Convention and introduced the other members at the head table: Fred Misilo, Vice President; Carol Wheeler, Secretary; Doug Church, Treasurer; Ronald Brown, Immediate Past President; Peter Berns, Chief Executive Officer; and Carrie Hobbs-Guiden, NCE Steering Committee Chair.</td>
</tr>
<tr>
<td>Credentials Report</td>
<td>Secretary Wheeler read the credentialing report: a total of 2542 of 4045 possible votes had registered at the convention with 37 states being represented.</td>
</tr>
<tr>
<td>Establishment of Quorum</td>
<td>Secretary Wheeler declared that a quorum was present.</td>
</tr>
<tr>
<td>Review of Business Meeting Operating Rules</td>
<td>President McMillan informed the attendees that the Operating Rules have been pre-circulated, and the chair will use them as a guide for conducting today’s meeting.</td>
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<tr>
<td>Review of Business Meeting Agenda</td>
<td>President McMillan informed the attendees that the meeting agenda has been pre-circulated and the Chair will follow this order of business.</td>
</tr>
<tr>
<td>Appointments</td>
<td>President McMillan announced that Doug Church was appointed as timekeeper.</td>
</tr>
<tr>
<td>Annual Business Meeting Minutes</td>
<td>President McMillan explained the minutes of the 2017 Annual Business Meeting have been published and asked if there are any questions or corrections. No one approached the microphone.</td>
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<tr>
<td>President’s Report</td>
<td>The President, Elise McMillan, delivered her report.</td>
</tr>
<tr>
<td>Chief Executive Officer’s Report</td>
<td>The CEO, Peter Berns, delivered his report.</td>
</tr>
<tr>
<td>NCE Report</td>
<td>The Chair of the NCE Steering Committee, Carrie Hobbs-Guiden, delivered her report.</td>
</tr>
<tr>
<td>Board Development Committee Report &amp; Election: Presentation of Slate of Nominees</td>
<td>President McMillan welcomed Ron Brown, Chair of the Board Development Committee to the podium. Ron presented the Slate of Nominees. In the absence of any</td>
</tr>
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</table>
contested positions, President McMillian declared the following elected as officers and directors:

**Officers:**
- President - Fred Misilo
- Vice President - Carol Wheeler
- Secretary - Doug Church
- Treasurer - Hugh Evans

**Directors:**
- Laura Kennedy
- Chloe Rothschild
- Mitch Routon
- Hussain Ismail
- Kathleen Stauffer

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<tr>
<th>Presentation of Position Statements: Education and Self-Determination</th>
<th>President McMillian welcomed Fred Misilo, Chair of Policy and Positions Committee to the podium. Fred presented the position statements. Education passed with 2510 votes in favor, 22 votes opposed. Self-Determination passed with 2141 votes in favor, 387 votes opposed.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listening Session: Public Policy Agenda</td>
<td>President McMillian welcomed Fred Misilo, Chair of Policy and Positions Committee to the podium. Fred shared the Public Policy Agenda and invited comments from attendees.</td>
</tr>
<tr>
<td>Remarks from the Incoming President</td>
<td>President McMillian welcomed the Incoming President, Fred Misilo to the podium who shared his remarks.</td>
</tr>
<tr>
<td>New Business</td>
<td>President McMillan stated that there was no new business submitted in accordance with the rules.</td>
</tr>
<tr>
<td>Announcements</td>
<td>President McMillan asked if there was any announcement before the meeting is adjourned.</td>
</tr>
<tr>
<td>Adjourn</td>
<td>There being no further business, President McMillan adjourned the 69th Annual Convention Business Meeting at 3:38pm.</td>
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Proposed Bylaws Amendment

Section 4

THE ARC OF THE UNITED STATES

October 13, 2019
MEMORANDUM

DATE: August 11, 2019
TO: Chapters of The Arc
FROM: Board of Directors
SUBJECT: Proposed Bylaws Amendments

At a meeting held on April 7, 2019, the Board of Directors of The Arc of the United States, Inc. (the Corporation) approved proposed amendments to Article 6 of the Bylaws of The Arc of the United States, Inc. (the Bylaws). The proposed amendments are recommended for adoption by Chapters of The Arc as voting members of the Corporation.

Pursuant to Article 10 of the Bylaws, “a vote of two-thirds (2/3rds) of all the votes held and entitled to be cast by Chapters of The Arc that are present in person or by proxy” is required for adoption.

A marked up copy of Article 6 is attached, indicating the proposed amendments. The current Bylaws in their entirety may be found on the website under About Us>Financials and Reporting>Organizing Documents>Bylaws.

The following is a description of the substance and purpose of the amendments.

Section 6.7 - The Legal Advocacy Subcommittee is converted into a Standing Committee. The Composition, Roles and Responsibilities are defined in terms substantially equivalent to other Standing Committees. The Legal Advocacy Subcommittee was originally constituted as a subcommittee of the Policy and Positions Committee. The Board believes it is more appropriately a separate Standing Committee given The Arc’s increased use of legal advocacy, the need for timely and effective input into the legal advocacy work, and the different knowledge and skills required for and beneficial to legal advocacy, as opposed to legislative and regulatory advocacy.

Section 6.8 – Two subcommittees of the National Conference of Executives -- the Chapter Excellence Subcommittee and the Program Excellence Subcommittee -- are eliminated. This change is being proposed at the request of the NCE Steering Committees as these subcommittees have never been empaneled. Instead, the NCE Steering Committee utilizes a work group structure, constituting and empaneling different work groups from time to time as needed to fulfill the goals and objectives of NCE. The listed subcommittees were unnecessary.

A number of additional non-substantive changes are made to correct ministerial errors in the original document.

Section 6.1 Standing Committees. The Standing Committees of the Board of Directors shall be the Executive Committee, Board Development Committee, Budget & Finance and Audit Committee, and Policy and Positions Committee and Legal Advocacy Committee. The Board of Directors may establish such additional standing committees as it determines are appropriate for the conduct of the business of the Corporation. Members of standing committees shall be chaired by a member of the Board of Directors and composed of no fewer than six persons.

Section 6.2 Committee Appointments. Except where otherwise stated in this Article, the President shall be responsible for appointing members to Standing Committees, as needed, in consultation with the Chair of each committee. Prior to making such appointments, the President shall invite Chapters of The Arc to submit recommendations of persons who should be considered to serve on such committees. Each committee shall include at least one member who is a board member, and at least one member who is a chief executive officer or other senior-level staff, of a state or local Chapter of The Arc.

Section 6.3 Executive Committee.

6.3.1 Composition. The Executive Committee shall consist of the President, the Vice President, the Secretary, the Treasurer, the Immediate Past-President, and the Chair of the Policy and Positions Committee, the Chair of the National Conference of Executives and, at the request of the President, one or more of the Directors who are serving as Chairs of Standing Committees of the Corporation.

6.3.2 Roles and Responsibilities. The Executive Committee is responsible for developing and implementing the annual work plan of the Board, monitoring the work of all board committees, leading the board’s planning efforts, and supervising the chief executive officer. The Committee is further responsible for oversight of the governance structure and process of the organization and for assuring adherence to the highest standards of ethics and accountability. As needed, the Committee develops
recommendations for improvements in governance, including necessary changes to the articles of incorporation, bylaws, corporate resolutions or policies of the organization. The Committee also provides guidance and oversight for the policies and practice involved in the affiliation between The Arc and individual state and local chapters, including efforts to protect the organization’s name and trademarks. The Committee reviews and guides action in response to proposed resolutions, bylaws amendments or other corporate actions proposed or to be considered by Chapters of The Arc.

6.3.3 Minutes of Decisions. The Executive Committee shall prepare and maintain minutes reflecting its decisions which it shall provide to the Board of Directors at its next meeting.

6.3.4 Expeditious Action. In instances where special circumstances require expeditious action between meetings of the Board of Directors, the Executive Committee shall have the power to take the necessary actions, subject to any prior limitation imposed by the Board of Directors. The minutes of the Executive Committee shall include a summary of the circumstances requiring any expeditious action taken by the Executive Committee and the minutes shall be submitted to the Board of Directors.

Section 6.4 Board Development Committee.

6.4.1 Composition. The Board Development Committee shall be chaired by the Immediate Past President and shall be composed of no fewer than six persons. The additional members shall be appointed in the manner described in section 6.2 with the approval by the Board of Directors. At least two-thirds (2/3) of the members of the Board Development Committee shall be persons who are not currently serving and have not previously served on the Board of Directors. The Immediate Past-Chair of the National Conference of Executives shall be a member, ex officio, of the Board Development Committee. No person shall serve on the Board Development Committee for more than four (4) years.

6.4.2 Roles and Responsibilities. The Board Development Committee is responsible for assuring that the composition of the Board of Directors meets the current and future leadership needs of the Corporation. The Committee is responsible for recommending persons to serve as Officers and Directors of the Corporation and for
administering the nominating and election process as described in Article 7, herein. The Board Development Committee is further responsible for ongoing evaluation, training and leadership development.

**Section 6.5  Budget, Finance and Audit Committee.**

6.5.1 Composition. The Budget, Finance and Audit Committee shall be chaired by the Treasurer and shall be composed by no fewer than six persons. The additional members shall be appointed in the manner described in section 6.2.

6.5.2 Roles and Responsibilities. The Budget, Finance and Audit Committee is responsible for oversight of The Arc’s financial health. The Committee reviews and recommends approval of the annual budget, monitors financial performance and legal and regulatory compliance, retains the independent auditor and oversees the annual audit of the organization’s financial statements and develops and provides oversight regarding other financial policies and practices. The Committee is responsible to assure that the annual audited financial statements are presented to the Board of Directors. The Committee also annually reviews the performance of The Arc’s investments and recommends any changes to The Arc’s Investment Policy.

**Section 6.6  Policy and Positions Committee.**

6.6.1 Composition. The Policy and Positions Committee shall be chaired by a member of the Board of Directors and shall be composed by no fewer than six persons. The additional members shall be appointed in the manner described in section 6.2.

6.6.2 Roles and Responsibilities. The Policy and Positions Committee is responsible for recommending to the Board of Directors the policies and positions of The Arc on issues of concern to people with intellectual and developmental disabilities and their families consistent with the Core Values of the Corporation.

6.6.2.1 The Committee is responsible to develop The Arc’s Position Statements, with broad input from Chapter leaders as well as experts in the field, including both identifying and developing new statements and revising and updating existing statements. The Committee facilitates the full Board’s involvement in development of the Position Statements and, once completed, recommends the
Position Statements for approval by the Board and Chapters pursuant to the process described in these Bylaws.

6.6.2.2 A Legislative Agenda Subcommittee is responsible for developing, on a biennial basis corresponding to the term of Congress, a Legislative Agenda that is consistent with the Core Values, Position Statements and Federal Public Policy Agenda described in section 8.1, 8.2 and 8.3, respectively. The Legislative Agenda Subcommittee also recommends positions on new issues that are otherwise not covered by the Legislative Agenda.

Section 6.7 6.6.2.3 Legal Advocacy Committee
6.7.1 Composition. The Legal Advocacy Committee shall be chaired by a member of the Board of Directors and shall be composed of no fewer than six persons, including at least two members who are either Board members or senior-level chapter staff. The additional members shall be appointed in the manner described in section 6.2.

6.7.2 Roles and Responsibilities.
6.7.2.1 The Legal Advocacy Committee is responsible for determining whether The Arc’s participation in should become involved in litigation and the positions to be taken is relevant to and consistent with The Arc’s mission to promote and protect the rights of individuals with intellectual and developmental disabilities and their families and with The Arc’s existing Core Values, and Position Statements and Public Policy Agenda.

6.7.2.1 The Legal Advocacy Committee operates within and pursuant to the Legal Advocacy Committee Protocol, as may be amended from time to time by the Board of Directors (the “Protocol”), determining if, when and how The Arc should become involved in litigation.

Section 6.87 National Conference of Executives
6.78.1 Composition. The National Conference of Executives (NCE) shall be composed of the executive directors/chief executive officers of Chapters of The Arc without requirement of any additional payment of dues. NCE shall have a Steering
Committee, including a chairperson, the members of which are elected by NCE members. Additional categories of personnel of Chapters of The Arc as are determined by the Steering Committee may also be members of NCE upon payment of dues.

6.87.2 Roles and Responsibilities. The National Conference of Executives shall provide leadership, guidance and oversight of The Arc’s efforts to cultivate, support and sustain strong, effective and sustainable chapters at the state and local level. NCE’s focus shall include, but not necessarily be limited to: professional development, leadership development, fostering strong relationships, knowledge sharing and mutual support.

6.87.2.1 The Steering Committee is responsible to develop, and support and assist staff in implementing, a high quality program of professional development, including training, technical assistance and other supports and services, for executives, management staff and volunteer leaders of The Arc. The Steering Committee is further responsible to provide to the Board Development Committee the names of members of NCE whom the Committee believes meet the nominating priorities and are recommended for election to The Arc’s Board of Directors in the manner described in Article 7 of the Bylaws.

6.7.2.2 A Chapter Excellence Subcommittee is responsible for promoting best practices in the governance and management of chapters, including board governance, financial management, human resources management and fundraising, utilizing the Standards for Excellence® program platform.

6.7.2.3 A Program Excellence Subcommittee is responsible to identify and promote the replication and proliferation of innovative and best practices in services and supports for people with intellectual disabilities.

6.87.2.4 Additional subcommittees may be established as the Steering Committee determines are necessary and appropriate to achieve the objectives of NCE.

Section 6.98 Special Committees. The President of the Corporation or the Board of Directors may establish such special committees, work groups or task forces as they shall determine are necessary for the functioning of the Corporation. Each such committee shall be given a specific charge and term. No special committee shall have
a term extending beyond one (1) year unless reappointed. The members of special committees shall be appointed by the President or by the Board of Directors.

Section 6.109 Advisory Councils. In order to build a strong movement of parents, siblings, other family members of people with I/DD, of individuals with I/DD themselves, and of the professionals leading the organizations that serve and support them, the Corporation shall establish and maintain, and members of the Board of Directors shall chair, a national self advocates council, a national siblings council and such other advisory councils as may be established from time to time (hereinafter “the Councils”). The Councils shall provide advice and counsel to inform the advocacy, programs, services and supports of The Arc at the national, state and local level.
Position Statements

Section 5

Presented for information & discussion only. There will be no formal voting on these 4 position statements.

THE ARC OF THE UNITED STATES

October 13, 2019
Family Support

Family support services’ and other means of supporting families should be available to all families to strengthen families’ capacities to support family members with intellectual and/or developmental disabilities (I/DD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency.

Issue

Individuals with I/DD frequently require support to perform basic daily activities and to achieve the national goals of equal opportunity, full participation, independent living, and economic self-sufficiency. Families are overwhelmingly the primary and often the major source of support for their family member with I/DD. Nearly three quarters of people with I/DD live in the family home and, according to The Arc’s Family and Individual Needs for Disability Supports (FINDS) survey, most of these family caregivers provide more than 40 hours of care per week (including 40% who provide more than 80 hours of care per week).

Changing demographics are placing even greater demands on this already limited service system. The aging of the baby boom generation is resulting in an increasing number of people with I/DD living with aging caregivers. These aging caregivers will have greater 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 I/DD when they are no longer able to continue in their caregiving role.

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 I/DD 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 I/DD in place of appropriate community supports, even in cases when residing in the family home may not be a good option for adult offspring with I/DD or themselves.

Our service system is increasingly being built around the expectation that adults with I/DD will reside in the family home. This is not consistent with other national policies for vulnerable populations.

Relatively small proportions of federal and state funding for persons with I/DD are committed to family support, despite increasing numbers of people with I/DD living with family for longer periods. Consequently, though family support is critical for avoiding placement in costly and inappropriate institutions for the family member with I/DD, the needed supports are frequently insufficient or unavailable.
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 mobility and portability limitations as those receiving other Medicaid HCBS. This problem is most acutely felt by military families who move frequently and have to begin the application and waiting process anew with each move between states.

Although family support has been a policy of the federal and state governments since the 1980s, families and individuals with I/DD increasingly are using their social capital to achieve the four national goals and attain quality of life outcomes, and are also benefiting from and seeking more policies, practices, and procedures of generic governmental and private-sector entities that support families. Families’ reliance on social capital and these other means for supporting families have become important as supplements to, not replacements of, governmental-sponsored family support programs.

**Position**

Comprehensive, universally accessible family support must be provided in order to:

- Assist families as they guide their member with a disability toward being self-determined individuals and achieving the nation’s goals for people with disabilities as set out in federal legislation, namely, equal opportunity, economic productivity, independent living, and full participation;
- 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 I/DD;
- Recognize that relying on families to provide care cannot be a substitute for creating a national solution to provide appropriate long term supports and services;
- Enable families to make informed choices regarding the nature of supports for themselves and their members with disabilities, including the use of supported decision making for family members with I/DD; and
- Help families with minor members to stay intact, preventing any type of out-of-home placements for a minor child, particularly institutions.

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

- Be provided in a manner that builds on the family’s strengths;
- Be provided in ways that are sensitive to the family’s culture, religion, and socio-economic status;
- Assist the individual and family to maximize the self-determination of its member with I/DD;
- 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 family caregivers, including, but not limited to, parents (including those with I/DD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships;

• Be available to all families regardless of whether the person with I/DD 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, while ensuring that such arrangements are mutually desired by the family caregiver and member with I/DD and do not impose inappropriate barriers under the guise of regulating medical services provided by paid family caregivers (such as requiring a nursing license to provide g-tube feeding or insulin shots as part of respite care); and

• Be defined as a system of policies, practices, and procedures for supporting families rather than as a “family support program” sponsored by a government or private-sector entity. Increasingly, these individualized supports should be available from generic (non-disability-specific) governmental and nongovernmental entities.

Rev’d 2014
Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

1 Traditionally, government-sponsored family support has consisted of the following types of support: 1) Cash assistance from federal, state, and local governmental sources that is provided: a) Over and above, to supplement but not to supplant, any other federal cash transfer or medical, educational, or welfare benefit programs (including without limitation 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 member of a family; and c) To the family as the primary beneficiary of the family support program, not to the member of the family who has a disability as the primary beneficiary; 2) Information and emotional and instrumental support provided by: a) Professionals, including those in disability-specializing professions and entities and those in generic, non-disability specializing professions and entities; b) Members of the family of the person with a disability or friends of the family or person; 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.

2 “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18,” as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, Intellectual Disability: Definition, Classification, and Systems of Supports (Schalock et al., 2010), and the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the Developmental Disabilities Assistance and Bill of Rights Act 2000. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.
Long Term Supports and Services

Individuals with intellectual and/or developmental disabilities (I/DD) deserve the opportunity for a full life in their community where they can live, learn, work, and socialize. To achieve this goal, they need a comprehensive, person-centered and directed, national system of appropriate high quality long-term supports and services (LTSS), with a reliable and immediately accessible funding source, including Medicaid, and a well-trained, fairly compensated workforce of providers and direct support professionals. Waiting must be eliminated.

Issue

Many barriers remain to ensuring that people with I/DD receive the long term supports and services they require to live a full life in the community.

National Crisis of Unmet Needs

The lack of a comprehensive community long term supports and services system is a national crisis requiring immediate national solutions. The patchwork of limited private LTSS options and the current public program are not designed to address or capable of meeting the demand for community-based LTSS for people of all ages. Individuals and families are forced to navigate a complex, frequently uncoordinated system of care including state-specific publicly funded services, limited supports funded by private pay and charitable giving, and often no clear path to assistance. Many individuals and families experience extraordinary stress due to lack of supports and services. Family caregivers play a critical role in providing services and supports. Almost a million Americans with I/DD are living at home with a caregiver of retirement age. Relying on families to provide care cannot be a substitute for creating a national solution to ensure that everyone who needs LTSS receives them.

Quality Supports and Services

Many individuals with I/DD have not had the opportunity or the support to make choices and decisions about important aspects of their lives. Ensuring that our system of LTSS is based on principles of self-determination, person-centered planning, and individualized supports is critical to having a system that supports people with I/DD. Too often decisions about supports and services are based on availability and cost, not on a person-centered approach made independently of the self-interests of the funder and/or the provider of services. Many people either accept services and supports that are available, but inappropriate and/or inadequate, or receive no supports at all.
**Medicaid**

While Medicaid is the lifeline for individuals with I/DD, it falls short of meeting their needs. Medicaid has been the major funding source for all LTSS for people with I/DD. Today most LTSS for people with I/DD are community supports and services; however, the institutional bias remains in the Medicaid program. To become or remain eligible for vital Medicaid LTSS, most people seeking services are forced to impoverish themselves and remain poor for a lifetime. To make matters worse, both federal and state policy makers have attempted to scale down the growth of Medicaid through regulatory and eligibility changes, budget cuts, and program changes designed to reduce costs rather than improve or expand services and supports. Increasingly states are shifting the management of LTSS to managed care organizations — a process that may result in more barriers to needed services.

**Waiting Lists and Unmet Needs**

The prevalence of people waiting for services and supports is an unacceptable national crisis. Often a state will not even have a process for developing and monitoring a waiting list for Medicaid supports and services. Individuals with disabilities often have to experience the death of a parent, a medical emergency, or other tragic event to obtain the services from Medicaid that they need. They are thus thrust into a new situation without planning at a time of family crisis. Individuals with I/DD remain on waiting lists for years — in some states it can take a decade or more — after requesting necessary supports and services. If ongoing supports and services are not available to young adults with I/DD transitioning out of the education system, educational gains will be lost.

**Direct Support Professionals**

The quality and effectiveness of LTSS for persons with I/DD depend upon qualified providers of supports and services with necessary skills and training. Inadequate compensation hampers both recruitment and retention. Inadequate funding for training of direct support professionals (DSPs) and their supervisors, as well as lack of sufficient supervision, threatens health and safety.

**Position**

A comprehensive system of LTSS must include the following:

**National Solution**

- An LTSS system must enable anyone of any age and disability to obtain LTSS when needed;
- The system must include private and public financing mechanisms because the obligation to provide LTSS is not just a personal responsibility but a shared, societal responsibility;
- The system must be sustainable so that people can count on getting what they need when they need it; and
- Individuals or their families should not be required to impoverish themselves to receive the supports and services they need to live.
Quality Supports and Services

- It is not only a choice but also a basic civil right that individuals have adequate and appropriate supports and services needed for them to live in the community;
- Individuals must have opportunities to design and direct their own services to the extent that they wish and with the assistance they need;
- Plans must be person-centered and based on the unique needs of the individual and accompanied by measured progress toward person-centered outcomes and flexible funding to meet changing circumstances;
- Services must be delivered promptly in the most integrated setting and with sufficient quality and quantity to meet individual needs; and
- Effective quality monitoring programs to measure the individual and systems outcomes of LTSS need to be in place in every state.

Medicaid

- Medicaid must remain a viable option for individuals who need LTSS and have no access to private insurance options;
- Medicaid programs must enable people to participate fully in their communities, experience a high quality of life and, as adults, achieve economic security and personal independence;
- Medicaid programs should fund person-centered community supports and services with continuing efforts to redirect Medicaid funding from institutional care to home and community-based supports;
- Medicaid funding must be portable across states and other political jurisdictions;
- Medicaid funding must provide for living wages and decent fringe benefits to direct support workers;
- Medicaid reform must preserve the individual entitlement and not simply shift costs to individual beneficiaries or states and must preserve consumer protections such as minimal cost-sharing, appeals and grievance procedures, and independent assessments;
- Medicaid reform must address waiting lists and unmet needs and the quality of service providers and staff; and
- Medicaid service delivery system redesign must be transparent and involve meaningful input of all stakeholders.

Waiting Lists and Unmet Needs

Individuals who need LTSS should not have to wait to receive them. Because there is an absence of a national system of LTSS, where waiting exists at the state level:

- Public systems must actively reach out to individuals and to families with unmet needs to make them aware of the process for obtaining LTSS and must maintain transparency until waiting is eliminated;
- People must receive crucial supports that assist them while they wait for the availability of or enrollment in comprehensive community supports and services; and
• Until waiting is eliminated, states must develop systems to prioritize delivery of services to individuals who are waiting for services on the waiting list to ensure that those experiencing emergencies (loss of caregiver, imminent threat of institutionalization) receive supports and services immediately.

**Direct Support Professionals (DSPs)**

• Wages, benefits, and professional development opportunities must increase for DSPs so as to attract and retain the workforce needed to fully support people living in the community;

• Competency-based training must be available to DSPs that covers the essential knowledge, ethical principles and practices, and skills necessary to provide direct support to individuals. DSPs must receive training in the philosophy of self-determination and the value of full inclusion and community participation of individuals;

• National, state, and local private and public entities must engage in policy initiatives to recruit, train, and retain a high quality direct support workforce;

• Individuals who wish to employ DSPs must have access to high quality information, technical assistance, and training;

• Federal and state quality assurance programs must assess and monitor DSP vacancy rates, recruitment and retention, and competence as part of licensure, in order to recognize positive performance and to direct assistance to those programs with unacceptable performance;

• States must utilize a system for criminal background checks for all public and private DSPs working in the state; and

• States must also develop and make available a list of individuals for whom abuse and neglect charges have been substantiated.

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

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1 “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that—(i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.
Self-Advocacy

People with intellectual and/or developmental disabilities (I/DD) must have the right to and be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves, with supports in doing so, as necessary. This means they have a say in decision-making in all areas of their daily lives and in public policy decisions that affect them.

Issue

Historically, people with I/DD have experienced powerlessness and isolation resulting in loss and denial of basic human rights, segregation, and discrimination in almost all areas of personal and community life.

Before self-advocacy groups existed, only a small number of people with I/DD received education and support from people who had experiences like their own. Without these groups they did not have a way to learn about important self-advocacy skills or topics like:

- Their rights and responsibilities as citizens, such as the right to vote;
- Development of leadership and assertiveness skills;
- Confidence in their own abilities;
- Using their expertise as people living with disabilities;
- Development of public speaking skills and problem-solving techniques, and involvement in group decision-making; and
- Involvement on boards and task forces and with policymakers at the local, state, and national level.

Without self-advocacy skills, people with I/DD have little impact on their own situations or on public policy that affects them.

Position

People with intellectual and/or developmental disabilities have the right to advocate for themselves. This means they have the right to speak or act on their own behalf or on behalf of other people with disabilities, whether the issue is personal (e.g., housing, work, friends) or related to public policy. Recognizing these rights in a respectful partnership between people with and without disabilities can lead to better outcomes and better lives in the community for everyone.
Self-advocates provide important knowledge, experience, and skills that individuals, organizations, and government agencies need in order to effectively support the needs and dreams of people with I/DD. To promote this participation, it is critical to acknowledge the important role that self-advocacy groups play in developing leadership skills and increasing people’s pride, influence, and opportunities. To achieve this partnership between self-advocates and their support persons or organizations, the following must occur:

• People with I/DD must have the power to make day-to-day decisions about their own lives and the services they receive free from the manipulation of others. Service providers and government agencies can offer significant supports in making sure informed decision making is in the hands of the self-advocate.

• People with I/DD should be provided accommodations or supports in order to have a visible, respected, and meaningful place in meetings, conferences, task forces, or other forums when issues and policies that are important to them are discussed (“Nothing about us without us” principle). These accommodations may include, but not be limited to:
  – Extra time planned for meetings to accommodate the unique communication and participation needs of each person;
  – Enhanced and alternative communication methods with easy-to-use formats;
  – Communication devices, sign language or other similar accommodations;
  – Supporting people to serve as “translators”; and
  – Appropriate transportation and funding.

• Respectful communication is important when talking to or about people with I/DD. This includes using people first language whenever talking directly to someone with disabilities, or describing their lives, and speaking to them in a way that takes into account their unique communication abilities.

• Policy development by any entity at a local, state, or national level must include self-advocates in matters of governance, and periodically evaluate the effectiveness of that inclusion.

• People who provide direct support and disability advocates should work actively with people with I/DD to develop and sustain self-advocacy organizations and individual participants in their states and communities.

• Families, advocacy organizations, service providers, and government agencies must also work with self-advocates to increase public awareness of the importance of the self-advocacy movement and the need to support it.

• Foundations and federal, state, and local funding agencies must promote self-advocacy as a key matter of policy. These entities must provide enough money and resources to make sure that (1) people with I/DD have accessible information, training, and education in self-advocacy and (2) providers have the information they need to deliver services that match the self-advocate-led trends in policy and design.
• Families, schools, direct service providers, and other agencies must have the support they need to make sure that children and youth have the chance to learn self-advocacy skills and put them into practice. They should have opportunities to use those skills in educational planning (including Individualized Education Plans or IEPs and transition plans) and all decision-making.

• Self-advocates, families, direct service providers, and other agencies must have the support they need to make sure that adults with I/DD have the chance to learn self-advocacy skills and put them into practice. They should have opportunities to use those skills in service planning and all decision-making.

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**Transportation**

People with intellectual and/or developmental disabilities\(^1\) must have access to both public and private transportation to lead full, independent lives.

**Issue**

Our constituents lack sufficient access to mass transit, paratransit, trains, ferries, airplanes, their own vehicles, and other modes of transportation to perform everyday activities. Even where accessible public transportation exists, adults with disabilities consider transportation inadequate. In the U.S., 24 million individuals with disabilities use public transit to maintain their independence and participate fully in society. For many, it is their only transit option.

Although federal and state legislation encourages more people with all types of disabilities to go to work, getting to work requires transportation. Inadequate transportation inhibits community involvement. Those living in rural areas often face the greatest challenge of all due to total lack of public transportation and long distances between destinations.

**Position**

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

- There is increasing flexibility and growth in available transportation options throughout the U.S. for our constituents, including those in rural areas.
- Public transportation is adequately funded and available.
- Existing public transportation is accessible, available in a timely manner, and equipped to suit the physical, sensory, and/or cognitive needs of all people.
- Paratransit systems for those who need them must be available at comparable cost and funded as an alternative to mass transportation.
- Our constituents have the option of owning and operating their vehicles.

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Rev’d 2013

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\(^1\) “People with intellectual disability and/or developmental disabilities” refers to those defined by AAIDD classification and *DSM IV*. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by *DSM IV*. 