2020 Annual Business Meeting

October 27, 2020 from 2:00PM-3:30PM EST

Annual Business Meeting (convenes and voting)

October 28, 2020 from 2:30PM-4:00PM EST

Annual Business Meeting (speeches, reports & open forum)

THE ARC OF THE UNITED STATES

Achieve with us.®

Agenda

Section 1

THE ARC OF THE UNITED STATES

October 27, 2020

ANNUAL BUSINESS MEETING AGENDA

Tuesday October 27, 2020, 2:00pm – 3:30 pm

Wednesday October 28, 2020, 2:30pm – 4:00 pm

ONLINE

TUESDAY OCTOBER 27, 2020

2:00 pm – 2:15 pm (15 min)	
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
2:15 pm – 2:30 pm (15 min)	Fred Misilo, President
Executive Committee	Elise McMillan, Ad Hoc Bylaws
Proposed Bylaws Amendments, Diversity Committee	Work Group Chair
2:30 pm – 2:45 pm (15 min)	
Board Development Committee Report	Elise McMillan, Chair
a. Election of Officers and Directors	
2:45 pm – 2:30 pm (45 min)	
Policy and Positions Committee	Ken Oakes, Chair
a. Consideration/Vote on Position Statements • Family Support • Long Term Supports and Services • Self-Advocacy and Leadership • Transportation	
b. Listening Session/Input on Public Policy Agenda	
2:30 pm	
Adjourn to continue on Wednesday October 28, 2020	Fred Misilo, President

WEDNESDAY OCTOBER 28, 2020

2:30 pm -2:35 pm (5 min)	
Reconvene and Call to Order	Fred Misilo, President
2:35 pm – 2:45 pm (10 min)	
President's Report	Fred Misilo, President
2:45 pm – 2:55 pm (10 min)	
Chief Executive's Report	Peter V. Berns, Chief Executive Officer

2:55 pm – 3:05 pm (10 min)	
NCE Report	Karen Shoemaker, Chair of NCE
3:05 pm – 3:20 pm (15 min)	Ken Oakes, Incoming President
Remarks from Incoming President	
3:20 pm – 3:55 pm (35 min)	
Open Forum – What’s on your mind?	Fred Misilo, President
3:55 pm – 4:00 pm (5 min)	
New Business	Fred Misilo, President
Announcements	Fred Misilo, President
4:00 pm	
Adjourn *Sine Die*	Fred Misilo, President

Operating Rules and Protocols

Section 2

THE ARC OF THE UNITED STATES

October 27, 2020

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.

NOTICE

Notice pursuant to MD Corps & Assoc Code Ann, § 5-206: If a quorum is not present at the annual business meeting, and a majority of those present vote to call an additional meeting, then an additional meeting shall be held upon no less than 15 days notice of time, place and purpose. At such additional meeting, those present in person or by proxy shall constitute a quorum and a majority may take any action that otherwise could be taken at this annual meeting.

Speaking the Member’s Language

Seeking Recognition	**“Mr. (Madam) Chairman”** **-or-** **“Mr. (Madam) President”**
Making Motions	*On your own:* **“I move that…”**
Seconding Motions	**“Second!”** *NOTE: you do not need to be recognized to second a motion.*
Making Amendments	**“I move to amend the motion by …** *Use one of the three following methods, describing which words to change:* **. . .Striking the following words(s): …”** **. . .Adding the following words(s): …”** **. . .Striking the words(s): - AND inserting the word(s):…”** *Make sure the motion reads correctly if amended with your proposal.*
Closing Debate	**“I move to close debate on …”**
Voting by General Consent	*If you object, you do not need to be recognized to say:* **“I object!”** *NOTE: you also do not need to give a reason.* *If you agree, remain silent when the chair calls for objections.*
Protecting the Rules	**“Point of Order!”** *You protect the rules by raising a point of order. You do not need to be recognized. Once you have called out as above, be prepared to state what rule is being violated.*
Ask a Procedural Question	**“Parliamentary Inquiry!”** *This motion is used to ask procedural questions, which are answered by the chair or parliamentarian. For example, you can tell the chair what you want to do and ask which motion would be appropriate.*
Seek Information About the Motion	**“I have a question about the motion.”** *If you need to know more about a motion that is on the floor, you can be recognized to ask your question. Don’t try to debate or make comments; this special recognition is for getting information, not giving it.*

Making Motions for Members

1. **Member states motion.**
   Clearly state your proposal – what you say is what they debate. You may be asked to write it down on a form.

2. **Another member seconds.**
   If you did not make the motion, but agree it should be considered, say "second!"

3. **Chair states motion.**
   Make sure the chair repeats the motion accurately before beginning discussion.

4. **Members debate motion.**
   State your opinion with decorum, make other motions as appropriate and listen carefully to other opinions.

5. **Chair takes vote.**
   Cast your vote in the best interest of the association as a whole.

6. **Chair announces result and effect.**
   Listen to the chair announce the result of the vote. Respect and support the group decision.

Parliamentary Motions Guide

Based on *Sturgis Standard Code of Parliamentary Procedure (4th Ed.)*

Motions are listed in order of precedence. A motion can be introduced if it is higher than the pending motion.

YOU WANT TO:	YOU SAY:	INTERRUPT?	2ND?	DEBATE?	AMEND?	VOTE?
(77) Close meeting	I move that we **adjourn**	No	Yes	Yes	Yes	Majority
(75) Take break	I move to **recess** for	No	Yes	Yes	Yes	Majority
(72) Register complaint	I rise to a **question of privilege**	Yes	No	No	No	None
(68) Lay aside temporarily	I move that the main motion be **postponed temporarily**	No	Yes	No	No	Varies
(65) Close debate and vote immediately	I move to **close debate**	No	Yes	No	No	2/3
(62) **Limit or extend debate**	I move to limit debate to ...	No	Yes	Yes	Yes	2/3
(58) **Postpone to certain time**	I move to postpone the motion until ...	No	Yes	Yes	Yes	Majority
(55) **Refer** to committee	I move to refer the motion to …	No	Yes	Yes	Yes	Majority
(47) Modify wording of motion	I move to **amend** the motion by ...	No	Yes	Yes	Yes	Majority
(p 32) Bring business before assembly (a **main motion**)	I move that …	No	Yes	Yes	Yes	Majority

Parliamentary Motions Guide

Based on *Sturgis Standard Code of Parliamentary Procedure (4th Ed.)*

Incidental Motions - no order of precedence. Arise incidentally and decided immediately.

YOU WANT TO:	YOU SAY:	INTERRUPT	2ND?	DEBATE?	AMEND?	VOTE?
(82) Submit matter to assembly	I **appeal** the decision of the chair	Yes	Yes	Yes	No	Majority
(84) Suspend rules	I move to **suspend the rule** requiring	No	Yes	No	No	2/3
(87) Enforce rules	**Point of order**	Yes	No	No	No	None
(90) Parliamentary question	**Parliamentary inquiry**	Yes	No	No	No	None
(94) **Withdraw motion**	I wish to withdraw my motion	Yes	No	No	No	None
(96) **Divide motion**	I request that the motion be divided	No	No	No	No	None
(99) Demand rising vote	I call for a **division of the assembly**	Yes	No	No	No	None

Restorative Main Motions - no order of precedence. Introduce only when nothing else pending.

(36) **Amend previous action**	I move to amend the motion …	No	Yes	Yes	Yes	Varies
(38) Reconsider motion	I move to **reconsider**	Yes	Yes	Yes	No	Majority
(42) Cancel action	I move to **rescind**…	No	Yes	Yes	No	Majority
(44) Take from table	I move to **resume consideration** of …	No	Yes	No	No	Majority

Minutes

Section 3

THE ARC OF THE UNITED STATES

October 27, 2020

The Arc

Minutes of the 70th Annual Convention
Washington, D.C.
Sunday, October 13, 2019

Call to Order	The Business Meeting of the 70th Annual Convention of The Arc was called to order by President Fred Misilo.
Welcome	President Misilo welcomed the visitors and guests to the Business portion of the Convention and introduced the other members at the head table: Carol Wheeler, Vice President; Doug Church, Secretary; Hugh Evans, Treasurer; Elise McMillan, Immediate Past President; Peter Berns, Chief Executive Officer; and Karen Shoemaker, NCE Steering Committee Chair.
Credentials Report	Secretary Church read the credentialing report: a total of 2780 of 3871 possible votes had registered at the convention with 23 states being represented.
Establishment of Quorum	Secretary Church declared that a quorum was present.
Review of Business Meeting Operating Rules	President Misilo 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.
Review of Business Meeting Agenda	President Misilo informed the attendees that the meeting agenda has been pre-circulated, and the Chair will follow this order of business.
Appointments	President Misilo announced that Peter Berns was appointed as timekeeper.
Annual Business Meeting Minutes	President Misilo explained the minutes of the 2018 Annual Business Meeting have been published and asked if there are any questions or corrections. No one approached the microphone. Minutes approved as printed.
Proposed Bylaws Amendments	President Misilo explained the Proposed Bylaws Amendments have been pre-circulated prior to the meeting. Converting the Legal Advocacy Committee to a Standing Committee passed. Eliminating the two subcommittees of NCE – The Chapter Excellence Subcommittee and the Program Excellence Subcommittee. The Bylaws amendment passed.
President's Report	The President, Fred Misilo, delivered his report.
Chief Executive Officer's Report	The CEO, Peter Berns, delivered his report.

NCE Report	The Chair of the NCE Steering Committee, Karen Shoemaker, delivered her report.
Listening Session: Public Policy Position Statements	President Misilo welcomed Ken Oakes, Chair of Policy and Positions Committee to the podium. Ken presented the 4 position statements for information and discussion only. • Family Support • Long Term Supports and Services • Self-Advocacy • Transportation There was no formal voting on these 4 position statements
New Business	President Misilo stated that there was no new business submitted in accordance with the rules.
Announcements	President Misilo asked if there were any announcements before the meeting is adjourned.
Adjourn	There being no further business, President Misilo adjourned the 70th Annual Convention Business Meeting at 2:24 pm.

Executive Committee

Section 4

THE ARC OF THE UNITED STATES

October 27, 2020

The Arc
For people with intellectual
and developmental disabilities

The Arc
1825 K Street NW, Suite 1200
Washington, DC 20006

T 202 534-300
F 202 534-3731
www.thearc.org

MEMORANDUM

TO: Chapters of The Arc

FROM: Peter Berns, Chief Executive Officer

DATE: August 20, 2020

RE: Notice of Proposed Bylaws Amendment

Attached for consideration by Chapters of The Arc are proposed amendments to the Bylaws of The Arc of the United States, Inc. The amendments would add a Diversity Committee as a standing committee of The Arc.

Pursuant to Article X, section 10.3 of the Bylaws, as stated in the attached Resolution, these proposed amendments have been considered by The Arc's Board of Directors and are recommended for approval.

Pursuant to Article X, section 10.4 of the Bylaws, adoption by Chapters of The Arc of amendments to the Bylaws shall require 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.

A current copy of The Arc's Bylaws may be found on our website here.

Please free to email me at berns@thearc.org or telephone me at 202.534.3701 if you have any questions.

The Arc of the United States, Inc.

Board of Directors

Resolution for Approval of Amendments to Bylaws of The Arc of the United States, Inc.

5/21/2020

WHEREAS, the Executive Committee of the Board of Directors at its meeting on January 25, 2020, approved proposed amendments to the Bylaws of The Arc of the United States, Inc. ("Bylaws) to add a Diversity Committee as a Standing Committee of The Arc;

WHEREAS, the proposed amendments are in form set forth on the marked-up copy of the Bylaws, attached hereto;

WHEREAS, pursuant to section 10.1 of the Bylaws, a proposed amendment to the Bylaws must be approved by at least two-thirds of the members of the Board of Directors then serving;

NOW, THEREFORE, the Executive Committee hereby moves for adoption of a Resolution directing that, pursuant to section 10.2 of the Bylaws, the proposed amendments shall be presented for consideration by Chapters of The Arc at the 2020 annual meeting of the corporation or at a special meeting called for that purpose.

IT IS, HEREBY, RESOLVED by the Board of Directors, that the proposed Bylaws amendment shall be presented for consideration by Chapters, with the recommendation in support of their adoption.

Adopted by of the Board of Directors on May 21, 2020, by consent, with at least two-thirds of the members then serving in attendance.

The contents of this motion and approval shall be reflected in the Minutes of the Board Meeting

ARTICLE 6. Committees of the Corporation.

Section 6.1 Standing Committees. The Standing Committees of the Board of Directors shall be the Executive Committee, Board Development Committee, Budget Finance & Audit Committee, Diversity Committee, 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 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 by 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 litigation 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, Position Statements and Public Policy Agenda.

6.7.2.2 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 6.8 Diversity Committee

6.8.1. Composition. The Diversity 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 persons who are either board members or senior-level staff members of chapters of The Arc. The additional members shall be appointed in the manner described in section 6.2.

6.8.2 Roles and Responsibilities.

6.8.2.1 The Diversity Committee is responsible for oversight of development and implementation of The Arc's Diversity Strategic Action Plan, which shall be revised with such frequency as is determined by the Board of Directors.

6.8.2.2 The Diversity Committee will recommend objectives and strategic actions for the Board to accomplish in support of the Diversity Strategic Action Plan and monitor the Board's progress on meeting those goals and actions.

6.8.2.3 The Diversity Committee will report its progress to the Board and for inclusion in The Arc's Diversity Annual Report.

6.8.2.4 The Diversity Committee will serve as a resource to the Board, Standing Committees, Special Committees, and Advisory Councils described in this Article, on advancing and achieving the goals set forth in the Diversity Strategic Action Plan.

Section 6.9~~8~~ National Conference of Executives

6.9~~8~~.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.

6.9~~8~~.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.

6.9~~8~~.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.

6.9~~8~~.2.2 Subcommittees may be established as the Steering Committee determines are necessary and appropriate to achieve the objectives of NCE.

Section 6.10~~9~~ 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 6.11~~0~~ 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.

Board Development Committee Report

Section 5

THE ARC OF THE UNITED STATES

October 27, 2020

Board Development Committee Convention Report

October 2020

The Arc

For people with intellectual
and developmental disabilities

Board Development Committee Report, July 2020

The Board Development Committee is pleased to report that it has completed the process of preparing the slate of four Officers and ten Directors for election to the Board of Directors. The Committee will be recommending one candidate to the incoming Board President for nomination to and election by the Board of Directors at the first board meeting after the convention which is scheduled for January 2021.

The Committee is confident that it has identified and selected a group of candidates that, collectively, has the knowledge, skills and expertise to meet The Arc's leadership needs into the future as the organization implement our new *Strategic Framework for the Future of The Arc.*

The Committee has engaged in an exhaustive process while preparing the slate and additional recommendations. This process unfolded over the course of more than a year with 11 audio/web conference calls, although the largest amount of work done, and time spent was in between the meetings. During this process, the Committee did the following:

1. Reviewed the "Board Roles and Responsibilities" and "Responsibilities of Individual Board Members" and updated them for the 2021-2022 cycle.
2. Developed a Nominating Process Workplan.
3. Reviewed and updated "Factors/Criteria Relevant to Board Composition.
4. Conducted Board Composition Analysis.
5. Developed "Statement of Board Nominating Priorities." Based on the Board Composition Analysis, the Committee identified those Factors/Criteria that were not present in the current board composition and established nominating priorities that included priority factors, including an emphasis on achieving greater gender, ethnic, racial, and age diversity on the board, as well as legal advocacy and financial management expertise
6. Developed "Board Prospectus." The Prospectus included a form that could be used to nominate an individual for the Board or for self-nominations.
7. Developed an "Outreach Plan" and conducted outreach. The Committee first developed an outreach plan and then conducted extensive outreach to identify potential candidates to serve on the Board of Directors. The outreach process included disseminating the Board Prospectus broadly via email broadcast and online to hundreds of people and organizations to see if they could identify other individuals that might be a good fit for The Arc's board. Targeted telephone and email follow-up contacts were made.

8. Developed Potential Candidates Pool. The outreach process, described above, resulted in identifying 121 candidates for the Board. Combined with candidates already on the list from prior nominating cycles, the committee reviewed a total of 189 candidates plus 2 incumbents.
9. Priority Scoring of Candidates. The 189 candidates were scored based on the nominating priorities described in paragraph 5, above, and the list was narrowed to 45 candidates who were selected for further consideration.
10. Preparation of Officers Slate. Simultaneous to the review of candidates for Director, the committee identified current directors to be considered for service as officers, interviewed those candidates, engaged in deliberations and selected the nominees for the office of President, Vice-President, Secretary and Treasurer.
11. Candidate Interviewing. The Committee narrowed the list of 45 potential candidates and selected 21 people to be interviewed; the 2 incumbent members were interviewed as well. The Committee then engaged in extensive deliberations and selected the individuals to be included on
    a. the slate of nominees for election
    b. a recommended list for the incoming President.

The final group of board candidates meets many, but not all, of the priorities we established for this nominating cycle. The BDC made progress in terms of the priorities relating to age, siblings, parents, geographic location, religious diversity, ethnic diversity, legal advocacy, financial management, major donor capacity, corporate connections and celebrity access.

As you can see, this year's nominating process was very comprehensive and the BDC members spent many hours assembling as much information as feasible to make certain the final slate would complement and enhance the future board composition.

I cannot stress enough the amount of time and effort the BDC members expended throughout this lengthy process. Each member was meticulous, conscientious and thorough; they all had provided well-thought out comments and suggestions throughout the whole process. I am honored to have had the opportunity to work with this group of amazing people. It is a pleasure to share with you the results of our work.

Elise McMillan, Chair

Carrie Hobbs-Guiden
Steve McDonnell
Kathy McGinley
Kelly Piacenti
John Shouse
Dan Strick
Nicole Zilmer

The slate appears on the next page.

FINAL SLATE OF NOMINEES

Officers nominated to be elected by Chapters of The Arc

President: Ken Oakes
Vice President: Grace Francis
Treasurer: Laura Kennedy
Secretary: Hugh Evans

Directors nominated to be elected by Chapters of The Arc

Meghan Burke
Jillian Copeland
Debbi Harris
Jasmine Harris
Burt Hudson
Stacy Kray
Guha Krishnamurthi
Meredith Sadoulet
Faye Tate (incumbent)
Jose Velasco (incumbent)

Director recommended to be nominated by President and elected by Board of Directors

Russell Lehmann

DIRECTORS CONTINUING TO 2022

(no action required)

Officers
Fred Misilo, Immediate Past President

Directors
Dena Gassner
Mary Gonzalez
Hussain Ismail
Mitch Routon
Chloe Rothschild
Kathleen Stauffer

NCE Designees
Karen Shoemaker, Immediate Past Chair, NCE Steering Committee
TBD, Chair, NCE Steering Committee

Slate of Candidates Nominated for Election by Chapters of The Arc

OFFICERS

PRESIDENT	VICE-PRESIDENT	SECRETARY	TREASURER
KENNETH OAKES	**DR. GRACE FRANCIS**	**HUGH EVANS**	**LAURA KENNEDY**
Philadelphia, PA	Fairfax, VA	Baltimore, MD	Staten Island, NY

DIRECTORS

MEGHAN BURKE
Champion, IL

JILLIAN COPELAND
Rockville, MD

DEBBI HARRIS
Eagan, MN

JASMINE HARRIS
Davis, CA

BURT HUDSON
Arlington, VA

STACY KRAY
Palo Alto, CA

GUHA KRISHNAMURTHI
Cambridge, MA

MEREDITH SADOULET
Berwyn, PA

VALENCIA FAYE TATE (incumbent)
Denver, CO

JOSE VELASCO (incumbent)
Austin, TX

Additional Candidate Recommended for Nomination by the President and Election by the Board of Directors

DIRECTOR

RUSSELL LEHMANN
Reno, NV

CONTINUING BOARD MEMBERS

TERMS END IN 2022

DENA GASSNER
Mineola, NY

MARY GONZALES
Chicago, IL

HUSSAIN ISMAIL
Brooklyn, NY

FRED MISILO
Northborough, MA

CHLOE ROTHSCHILD
Sylvania, OH

MITCH ROUTON
Colorado Springs, CO

KATHLEEN STAUFFER
Mystic, CT

NCE DESIGNEES

TBD
Chair
NCE Steering Committee

KAREN SHOEMAKER
Immediate Past Chair
NCE Steering Committee

Board of Directors - Biographies
2020

Officers

Kenneth Oakes - President

Ken Oakes has been involved with The Arc since the 1970s when he joined The Arc of Erie County, PA and the chapter's Youth Arc program. As a college student, he served as President of his local and state Youth Arc chapters and the national Treasurer. Years later he served as President of The Arc of Philadelphia and The Arc of Pennsylvania, remaining an active board member of both chapters. His time as a member of The Arc US board includes serving as chair of the Policy and Positions Committee and a member of the Executive, Strategic Planning and Diversity Committees. His career in special education spans four decades from a teacher to the Special Education Director in the School District of Philadelphia. Now retired, he is currently a member of the graduate school faculty at Chestnut Hill College. His work continues in the field of special education, consulting with public and private school special education programs, and compliance monitoring with the state Bureau of Special Education. Ken has had a long and rich volunteer history with the disability community, including as Chair of the Pennsylvania Protection & Advocacy board of directors, The Arc of PA representative to the State Task Force on the Right to Education, the Governor's Committee on People with Disabilities, and the Governor's Special Education Advisory Committee. His life has been enriched by his family members and friends with disabilities. He lives in Philadelphia with his husband Ed.

Grace L. Francis – Vice President

Grace Francis has been a national board member since 2015. Several members of Grace's blended family experience disability. Positive social change is at the core of her personal and professional endeavors, and, as a result, her work and research focus on family and disability policy, quality of life, family support, and positive post-high school outcomes for individuals with disabilities. She currently is an assistant professor of Special Education Adapted Curriculum at George Mason University. She formally was the director of the SUCCEED program, a residential college program for students with intellectual and developmental disabilities, at the University of Missouri-St. Louis. In this role she partnered with the St. Louis Arc to enhance the program, meet the needs of students and their families, enrich the preparation of University of Missouri-St. Louis faculty and staff to teach and meaningfully include students with disabilities, and participate in community outreach to promote access to college after high school for students with disabilities.

Hugh M. Evans III – Secretary

Hugh Evans has been a member of the board of The Arc of the United States since 2010, and he continues to serve on the Budget, Finance, and Audit Committee. He remains active at the local level through his membership in The Arc of Baltimore. Hugh is a Past President of the Board of Directors of V-LINC, a nonprofit organization that focuses on promoting independence for people with disabilities through the use of assistive technology. He also serves on the Board of Trustees of Catholic Charities of Baltimore. He has extensive experience in investment management, financial management, and organizational development, working with both large and small companies and nonprofit organizations. He is the Vice President of Corporate Development and Ventures at 3D Systems, a leading provider of 3D printing. Hugh is the father of a young daughter with Trisomy 21.

Laura Kennedy – Treasurer

Laura Kennedy has been active in NYSARC at both the statewide and local levels for more than three decades. She is Immediate Past President of NYSARC and the former president of the New York City Chapter of NYSARC, Inc. Deserving winner of numerous awards – including the 2000 Staten Island Woman of Achievement Award – and long active in her community, Kennedy serves as Executive Board Member for the Staten Island Developmental Disabilities Council, Chairperson for the Council's Advocacy and Education Committees, Board Member for Friends of the College of Staten Island, and Board Member for Staten Island Mental Health Society, Inc. Kennedy also serves as Alter Guild Member for Christ Church New Brighton. Kennedy has residences both on Staten Island and in Essex, NY, in the Adirondacks.

Fred Misilo – Immediate Past President

Fred Misilo currently serves as the Immediate Past President of the board of The Arc of the United States. He began his national board career in 2012. He has served as the chair of the Policy and Positions Committee. He has served on the Legal Advocacy Subcommittee and on the Ad Hoc Committee on Planned Communities and Other Residential Alternatives for People with I/DD. He is also the Immediate Past President of The Arc of Massachusetts and a longstanding board member of that chapter. He has a long history of advocacy within the legislative and executive branches of Massachusetts government, including the position of Deputy Commissioner of the Massachusetts Department of Developmental Services. Fred has devoted 37 years to The Arc's mission and looks forward to continuing his service on the national board. Fred is an Officer and Chair of the Trust and Estate Department and Chair of the Elder Law and Special Needs Practice Group at the law firm of Fletcher Tilton PC.

Directors (Chapter Elected)

Meghan Burke

Meghan Burke is an associate professor in the Department of Special Education at the University of Illinois at Urbana-Champaign. Her research examines parent advocacy, sibling caregiving, and families of individuals with disabilities. Meghan is especially interested in designing and testing advocacy training interventions for parents of individuals with disabilities. Meghan has a 26-year-old brother with Down syndrome. She also has a six-year-old son with a disability.

Jillian Copeland

Jillian was an educator, staff trainer and technology coordinator for Montgomery County Public Schools for several years prior to founding The Diener School in 2007. Since Diener's inception, they have worked with over 250 families. Jillian served as the head of school from 2007 to 2013, board of trustee's chair for the following six years and now serves on the board of trustees. Jillian's latest and greatest endeavor, Main Street, is a joint initiative with her husband, Scott. Main Street is a model and a mindset – the first of its kind – an inclusive and affordable apartment building and community center serving people of all abilities. Jillian feels honored and humbled to work with vulnerable populations. She has volunteered in many different capacities for several organizations including CASA (Court Appointed Special Advocates) of Montgomery County, Children's National Medical Center and The Bullis School's 5K Buddy Run benefiting children and adults with special needs in our local community. Currently a member of the board of directors for the Jewish Foundation for Group Homes, Jillian also serves on the disability inclusion committee of The Jewish Federation of Greater Washington, The Developmental Disabilities Administration Task Force and Jubilee's Housing Task Force. Jillian received the 2009 Community Leadership Award from Jewish Women International (JWI), the Abe Polin Humanitarian Award from the Bender JCC in 2016 and the 2018 Bullis School's Community Leadership Award. In 2018, she and her husband, Scott, received the Melvin Cohen Humanitarian Award from The Jewish Foundation for Group Homes and, in March of 2020, they received ADAPT's Humanitarian Leadership Award which was to be presented in New York City. Additionally, Jillian will receive the 2020 Trailblazer award from the VisArts community in October of 2020. She is also a proud graduate of Leadership Montgomery's Class of 2013. Jillian and Scott reside in Rockville, two miles from the exciting Main Street building, and are the proud parents of Danny (25), Jack (23), Nicol (21) and Ethan (19).

Debbi Harris

A self-described purveyor of hope, Debbi Simmons Harris, a Systems Specialist with Family Voices of Minnesota, is committed to helping shape all civic, community, and health systems to seamlessly include people with disabilities and chronic medical conditions, and their families. Having navigated those systems for over 25 years on behalf of her son Josh, who has intellectual and developmental disabilities and complex medical needs, Harris recognized a profound need to ensure that the civil and human rights, and the essential dignity of persons with I/DD is upheld in every aspect of life. To that end, she became a graduate of Partners in Policymaking, which led to over 20 years of civic engagement— publications, hosting home visits with legislators, and speaking on local, state and national platforms. Harris has served on The Arc US Committee on Diversity and is currently a member of the national Work Advisory Group (WAG) for Paid Leave for All. Harris gained experience in Board governance, development, and strategic vision through her leadership as Board Chair of The Arc Greater Twin Cities, which she helped move toward a statewide merger to become The Arc Minnesota. She served on the bioethics committees for two local hospitals for over 10 years, helping medical professionals understand the unique considerations of children with developmental disabilities and their families. A graduate of Hamline University in St. Paul, Minnesota, Harris went on to obtain an M.S. in Health Care Administration, and an M.A. in English and Creative Writing, with a concentration in Nonfiction, Narrative Medicine. She has contributed to various publications, including

Existere : Journal of Literature & Arts, *Kaleidescope*, a literary journal about disability, *Today's Caregiver*, Salon.com, and *JAMA Pediatrics*. Harris also contributes to the Children and Youth with Special Health Care Needs (CYSHCN) Research Network and other medical research study projects. Recently, Harris was one of 100 people featured in 100 Years of Volunteers: Be the Change, a photo book commemorating the 100th anniversary of HandsOn Twin Cities, a leading volunteer nonprofit organization. Harris resides in Eagan, Minnesota, where she and her husband Victor, a retired US Marine Corps officer, care for their son Josh.

Jasmine Harris

Jasmine E. Harris is a Professor of Law and Martin Luther King, Jr. Hall Research Scholar at the University of California—Davis School of Law. Professor Harris is an expert in disability law, antidiscrimination law, and evidence. She writes about the relationship between law and social norms and how laws can be intentionally designed to advance antidiscrimination goals. Professor Harris's research focuses primarily on these questions in the context of disability law. As an interdisciplinary scholar, she draws upon research in the humanities to inform the design of law and legal institutions. Professor Harris's recent articles have or will appear in such publications as the *Columbia Law Review, New York University Law Review, Penn Law Review (print and online), Cornell Law Review Online, American Journal of Law and Medicine, and the Journal of Legal Education*. Professor Harris also writes frequently about disability and equality law for broader popular audiences. Her essays have appeared in the *New York Times, San Francisco Chronicle, Tribune Wire,* in addition to academic blogs such as the American Constitution Society's Expert Forum, Harvard Law School Petrie-Flom Center's Bill of Health, and ImmigrationProf Blog. Professor Harris has been widely quoted and appears in such publications as the *New York Times, TIME Magazine, Forbes, and USA Today*. Harris graduated magna cum laude from Dartmouth College with a bachelor's degree in Latin American & Caribbean Studies. She received her juris doctorate from Yale Law School and clerked for the late Harold Baer, Jr., United States District Judge for the Southern District of New York. She has worked in both private and public interest law. Professor Harris practiced complex commercial litigation, securities, and government investigations as a Senior Associate with WilmerHale. She also worked as a staff attorney at Advancement Project, a national civil rights organization, where she assisted grassroots advocacy campaigns around racial justice in education and juvenile matters.

Burt Hudson

Burt Hudson is the Chief Operating Officer of LeadingAge, an association of non-profit aging service and long-term care providers. He is responsible for the association's human resources, business development, finance, and information technology departments. Burt also serves as the Affirmative Action and Chief Compliance Officer. Burt is both a father of and brother to individuals with special needs. "Being both a parent and sibling to these amazing and inspiring people gives me a unique perspective. I have been blessed to witness first-hand their immense generosity of spirit and significant contributions to their communities." In his previous role as Vice President of Insurance Education at America's Health Insurance Plans (AHIP) Burt led the development and implementation of programs which comprised a significant portion of the associations' non-dues revenue. Burt managed relationships with health insurance companies across the country, providing them with timely solutions for a rapidly changing industry. Burt also served as chair of the associations' HR Council, Education Council and IT Curriculum Advisory Group, and as a member of AHIP's Core Values Workgroup. Prior to joining the AHIP, Burt worked for HouseCall, a private technology company based on Capitol Hill that served the United States House of Representatives. As a Business Development and Communications Coordinator, he evaluated the technical and online needs of congressional members for their DC, campaign, and district offices. Additionally, he worked as an Online Producer at CNN in Atlanta where he developed and executed strategies for TV to website content integration. Burt currently serves as Vice President of the board of directors of the Arc of Virginia, an organization he has served since May of 2011. The Arc of Virginia promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community. Burt also serves on the Budget and Finance committee for The ARC of the United States and has done so for the past five years.

Stacy Kray

Stacy Kray is an attorney with more than twenty years of transactional and litigation experience at a leading international law firm. She has coordinated her firm's Bay Area offices pro bono work for more than a decade, and has personally been involved in class action and other legal proceedings to enforce the civil rights of those with disabilities under federal and state law, including the federal Americans With Disabilities Act (ADA) and the Individuals With Disabilities Education Act (IDEA). As a pro bono coordinator, she has been an innovator in change to law firm pro bono, including co-founding a community impact project to educate teens about their legal rights and responsibilities relating to social media use and sexual misconduct, which includes modules on hate crimes, legal consent and bullying (areas of critical importance for the disabled community). She is also a songwriter and former board member of the San Francisco Chapter of The Recording Academy (which runs the Grammy Awards) and the mother of two amazing teenagers, one of whom has special needs. She would be most honored to use her skills and passion for improving the lives of those with disabilities by serving as a board member for the Arc.

Guha Krishnamurthi

Guha Krishnamurthi is a lawyer and law professor at South Texas College of Law, focusing on criminal law and criminal procedure. He was raised in Tulsa, OK, the son of doctors who immigrated from India. He studied mathematics and philosophy at the University of Michigan and University of Texas, and then went to law school at the University of Texas. In his legal career, Guha has worked for three judges and in private practice in Los Angeles, CA. Guha is passionate about human rights, especially with regard to ensuring that those with disabilities can live fulfilling lives as full members of our society. He lives with his wife Charanya Krishnaswami in Washington, D.C.

Meredith Sadoulet

Meredith is a global executive with experience leading human resources and finance functions across media and technology, banking, healthcare, energy and defense industries. She has a proven ability to lead complex, large-scale change across multiple Fortune 100 companies. Meredith is currently VP, Talent Experience at Comcast, where she is leading strategy to deliver outstanding candidate and employee experiences. She has previously held progressive leadership roles at BNY Mellon, General Electric and Lockheed Martin. Meredith and her teams have received numerous awards and external recognition for thought leadership, strategy and business results, and she speaks publicly on a variety of topics. Meredith is a two-time award recipient from Chief Learning Officer magazine, recognizing her with the Talent Management (2018) and Trailblazer (2014) awards. She has also received recognition from Brandon Hall Group for Talent Acquisition (2018) and from several communications and marketing bodies for digital marketing. The Albany, NY Capital Region Chamber of Commerce recognized her as a Woman of Excellence in 2016 for her contributions to her profession and community. A strong advocate for diversity, inclusion and equity, Meredith chairs national and local committees dedicated to elevating conversations, addressing issues and advancing solutions with and for people of all backgrounds. Meredith co-chairs the

National Association of Colleges and Employers (NACE) Inclusion, Equity and Affinity committee, she serves on the Universum Global Advisory Board for employer branding and talent, and she is a member of the Greater Brandywine YMCA Board and Philadelphia's Forum of Executive Women. Meredith earned a B.A. from the University of North Carolina, Chapel Hill, with a portion of her undergraduate studies occurring at the Universidad de Sevilla (Spain). She earned her M.B.A. from the State University of New York, Albany. Meredith has also completed executive education programs at Cornell University and the University of Pennsylvania. Meredith enjoys traveling both near and far to see the world's beauty, learn about varied cultures and practice speaking different languages. She loves a good business book and is motivated by sprint triathlons and bike races. Meredith lives in the greater Philadelphia, PA area with her husband and four children.

Valencia Faye Tate

Faye Tate is the Vice President of Diversity & Inclusion at CoBank and the former Director for Global Equality Diversity and Inclusion at CH2M. CoBank is a national cooperative bank serving vital industries across rural America. The bank provides loans, leases, export financing and other financial services to agribusinesses and rural power, water and communications providers in all 50 states. She spent six years at Kaiser Hill Company at the Rocky Flats Environmental Technology site. For over fifteen years, Fay has worked in various areas related to Diversity and Inclusion. She is focused on positioning diversity and inclusion as strategic business imperatives. Prior to Working for Kaiser Hill, Faye was employed at Denver Water where she managed water sales and real estate and worked as the Equal Employment Opportunity Officer and Small Business Liaison. She serves on the National Board of Directors for The Human Rights Campaign and the Board of Directors for the Metro Denver Chamber Leadership Foundation, Denver District Our Child Care Center and the Rocky Mountain Minority Suppliers Development Council. She has served on the Board of Directors for the Denver Athletic Club, Colorado Bright Beginnings, The Rocky Mountain Children's Choir and Colorado March of Dimes. She has a Juris Doctor Degree from the Antioch School of Law in Washington, D.C. and a Bachelor of Arts Degree in English Literature from James Madison University in Harrisonburg, Virginia. She is the mother of a daughter with cerebral palsy, who is blind, and has an intellectual disability.

Jose Velasco

Jose Velasco is Vice-President of Operations and Strategy and co-leads the Autism at Work program globally at SAP. Jose has a 30-year IT/Software career that spans public and private sectors in companies ranging from startups to Fortune 50 enterprises. During his tenure of more than 20 years at SAP, he has occupied positions in product management, consulting, development, strategy, go-to-market and HR/diversity functions. He holds a Master Degree in Technology Commercialization from the University of Texas at Austin and B.S. in Computer Science from Tecnologico de Monterrey in Monterrey, Mexico. He is a parent of two children with Autism.Directors Continuing Though 2020

Directors (Board Elected)

Russell Lehman

Russell Lehmann is an award-winning and internationally recognized motivational speaker and poet with a platform of autism and mental health. A graduate of MIT's "Leadership in the Digital Age" course, Russell is a council member for the Autism Society of America, the Youth Ambassador for the mayor of Reno, Nevada, and has also sat on the Nevada Governor's Council on Developmental Disabilities as well as the Nevada Commission on Autism Spectrum Disorders. Russell showed signs of autism as a newborn; however, he was not formally diagnosed until the age of 12 after suffering through 5 weeks in a lock down psychiatric facility. In 2018, Russell was named as Reno-Tahoe's "Most Outstanding Young Professional Under 40". In 2019 & 2020, Russell lectured for the prestigious King's College of London and the Mohammed bin Rashid Center for Special Education in Abu Dhabi, respectively. Russell currently travels the world spreading hope, awareness and compassion in a raw and dynamic fashion, while also setting his sights on erasing the stigma and stereotypes that come with having a disability. Russell's passion is to be a voice for the unheard, for he knows how difficult and frustrating it is to go unnoticed. *For more information about Russell and his work, visit his website at www.TheAutisticPoet.com and follow his journey on Instagram and Facebook.*

Directors Continuing to 2022

Dena L. Gassner

Dena Gassner has been a member of the board of The Arc of the United States since 2014 and serves on the Policy & Positions Committee. She is a Social Worker in Huntington, West Virginia, who has also engaged in public policy advocacy on the local, regional, state, and national levels on topics such as denial of services due to a lack of service providers who can provide systems navigation support. She has also presented to the Interagency Autism Coordinating Committee and to the U.S. House of Representatives and spent considerable time at "Day on the Hill" events in Washington, D.C. She has also served as an advisory board member to the Tennessee Autism Summit. Dena has assisted many clients in navigating transition and vocational rehabilitation and has given testimony before VR National Offices. Dena self-identifies as having been diagnosed with Asperger's syndrome as an adult; she has a 24-year-old son who is on the Autism spectrum as well.

Mary Gonzales

Mary Gonzalez has been a member of the board of The Arc of the United States since 2014 and serves on the Diversity Committee. She is experienced in public policy and an expert in leadership development. Over the years, she has trained many advocates and community organizers through an organization that she co-founded, The Gamaliel Foundation, which is known for its work in training community organizers and advancing social justice causes. She is a former member of the Illinois Governor's Council on Developmental Disabilities. Mary has been involved with many local chapters of The Arc in California and has been a speaker at the National Conference of Executives Summer Leadership Institute and at NCE's pre-conference training during the National Convention. Mary is recently retired. She had a brother with a developmental disability.

Hussain Ismail

Hussain Ismail is a Pakistani-American marketing executive that has spent his career helping brands and non-profits tell their stories. Currently he is the Vice President of Marketing for VaynerMedia located in Brooklyn, New York. He began his career in the music industry, working at Interscope Records and Live Nation, working on artist releases and tours. Hussain was born in Pakistan but moved to the United States at a young age where he grew up in the SF bay area and has a sibling with an intellectual disability.

Chloe Rothschild

Chloe Rothschild is a young adult with autism. She is on a mission to make a difference and help teach others about autism by sharing her own experiences. Chloe advoates through writing, speaking, and social media. She currently serves on various boards in the Ohio area and has been involved with autism advocacy for over five years. Chloe has had the opportunity to be a speaker the Ohio Center for Autism and Low Incidence Conference, the Autism Research Institute Annual Conference, Milestones Autism Resource Conference, and the Autism Society of America National Conference. Chloe has shared her expereinces with parents, schoold districts, health providers, and the larger public.

Mitch Routon

Mitch Routon, a member of The Arc Pikes Peak Region's Board and The Arc of Colorado's Board of Directors, is a strong self advocate in the Colorado Springs and larger Colorado community. His friendly, laid-back demeanor is paralleled by a quickness to speak out on injustices against those with disabilities. As a current board member for The Arc PPR, Mitch enjoys being involved in the non-profit in a variety of capacities. "I knew about The Arc PPR from growing up; my dad was a former board member and board president from 1994-2000," Mitch said. "I like being involved with The Arc PPR, because it's important to let people know that The Arc (advocacy) makes a difference. I want to do whatever I can to make sure that people who have disabilities have the resources they need."

Kathleen Stauffer

Kathleen Stauffer has been a member of the board of The Arc of the United States since 2014 and serves on the Policy & Positions Committee. She is the Chief Executive Officer of The Arc of New London County in Norwich, CT. She is a recognized leader in public policy advocacy and in individual advocacy for self-advocates. Her leadership skills have contributed to a strong track record for building dynamic teams, supporting people, and working with diverse communities and cultures. In the area of employment for people with I/DD, she advocates "real work for real pay." In the housing arena, Kathleen's chapter serves about 61 people with I/DD in community living homes. Kathleen serves as a member of the Steering Committee for the National Conference of Executives of The Arc. Prior to her involvement in IDD services, Kathleen spent 30 years in media working initially as an editor and journalist and later a group publisher.

NCE Designated Director

TBD, Chair, NCE Steering Committee

Karen Shoemaker, Immediate Past Chair, NCE Steering Committee

Karen Shoemaker has served as the Executive Director of The Arc of Lehigh and Northampton Counties since 1999. As a local chapter of The Arc of the United States and The Arc of PA, The Arc of Lehigh and Northampton Counties provides advocacy and services and supports to over 1,500 individuals with intellectual and developmental disabilities and their families. Karen is invested in the mission of advancing the independence of people with intellectual and developmental disabilities and has a deep commitment to advocating for people with disabilities and their families in all aspects of their lives. She holds a B.A. in Sociology from Muhlenberg College in Allentown, PA and a Master of General Administration in Health Care Administration from the University of Maryland Graduate School in College Park, MD. She has over 34 years of experience in management positions of non-profit disability organizations, with expertise in the areas of programs and services, personnel, development, finance and administration.

Policy and Position Committee

Section 6

THE ARC OF THE UNITED STATES

October 27, 2020

The Arc
For people with intellectual
and developmental disabilities

The Arc
1825 K Street NW, Suite 1200
Washington, DC 20006

T 202 534-300
F 202 534-3731
www.thearc.org

MEMORANDUM

TO: Chapters of The Arc

FROM: Peter Berns, Chief Executive Officer

DATE: August 20, 2020

RE: Notice of Proposed Position Statements

Attached for consideration by Chapters of The Arc are the following proposed, revised Position Statements:

- Family Support
- Long Term Supports and Services
- Self-Advocacy and Leadership
- Transportation

Pursuant to Article VIII, section 8.2.4 of the Bylaws, at a board meeting held on May 21, 2020, The Arc's Board of Directors approved the proposed revisions to the four position statements, listed above, and recommends them for your approval. Adoption of these revisions requires 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.

Extensive revisions were made to these position statements and it is not feasible to provide a redlined copy comparing the prior version to the proposed revised version of each statement. To understand the revisions, we suggest that you compare the revised versions with the originals which may be found on our website using the following links:

- Family Support
- Long Term Supports and Services
- Self-Advocacy and Leadership
- Transportation

Please free to email me at berns@thearc.org or telephone me at 202.534.3701 if you have any questions.

Revised Statement for Chapter Consideration
May 21, 2020

FAMILY SUPPORT

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

ISSUE

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

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

---

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

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

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

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

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

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

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

POSITION

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

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

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

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

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

Adopted: American Association on Intellectual and Developmental Disabilities
Board of Directors
February 12, 2020

The Arc of the United States
Board of Directors
May 21, 2020

Revised Statement for Chapter Consideration
May 21, 2020

LONG TERM SUPPORTS AND SERVICES

All people with intellectual and/or developmental disabilities[1] (IDD) have the right to full lives in communities of their choosing where they can live, learn, work, and enjoy life. To achieve this, people with IDD need access to comprehensive, person-centered and self-directed high quality long term supports and services (LTSS). Robust, reliable, and immediately accessible funding sources that include Medicaid are needed. There must be a flexible public policy framework that emphasizes self-direction, is well-funded, responsive, and nimble, and is developed with—and not for—people with IDD. Waiting lists for home and community-based supports and services must be eliminated.

ISSUE

A variety of barriers to ensuring that people with IDD receive the LTSS required to live their fullest life in communities of their choice continue to exist. These include:

- Insufficient Medicaid funding;
- Institutional bias in the Medicaid program;
- Continued and worsening crisis of unmet need; and
- Persistent and worsening workforce crisis.

Insufficient Medicaid Funding

Medicaid has been the major funding source for all LTSS for people with IDD for decades. Medicaid is also under constant political threat, creating anxiety, confusion, and compromising the well-being of people with IDD and their families.

The persistent lack of a system of comprehensive community LTSS is a crisis requiring immediate solutions. Individuals and families are forced to navigate a patchwork of systems of supports and services that are complex and frequently uncoordinated; are limited and often diminishing in scope and relevance; and, are

---

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

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

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

difficult to access and offer no clear path to assistance. Medicaid is means-tested, is not portable across state lines, differs—often dramatically—from state to state, and does not meet the demand for community-based LTSS for people with IDD of all ages.

Many individuals and families experience extraordinary hardships due to a lack of services and supports. Many people with IDD are living at home with a caregiver of retirement age. Family caregivers play a critical role in providing uncompensated supports and services. Many family caregivers are forced to leave employment to provide services that their family member may need because that is their only option. Relying on families to provide support cannot be a substitute for creating a systemic solution to ensure that everyone with IDD who needs LTSS receives them.

Institutional Bias of Medicaid

Making choices and self-directing one's life with the assistance they may need should be an expectation for all people. However, most individuals with IDD are not given opportunities or supports to make and/or execute choices and decisions, or their choices have been ignored. It is important that self-direction includes the ability to select and dismiss the people who provide supports and services, and to have control over funding. Ensuring the system of LTSS is self-determined and person-centered and directed is critical to having a system of individualized supports for people with IDD. Too often decisions about supports and services are based on availability and cost, not on the person's choices made independently of the self-interests of the funder and/or service provider. Many people either accept supports and services that are available but inappropriate and/or inadequate, or receive no supports at all.

While most LTSS for people with IDD are community-based, a Medicaid institutional bias, based in the antiquated medical model of care, continues to exist. This means that institutional services (such as nursing homes) are mandatory under federal law, while community-based supports and services are optional. In addition, in many states, existing Medicaid services fall short of meeting the full needs of people with IDD, requiring continued advocacy to ensure ease of access to necessary, community-based services and supports.

To become or remain eligible for vital Medicaid-funded LTSS, most people seeking services are forced to impoverish themselves and remain poor for a lifetime. Program changes designed primarily to reduce costs rather than improve or expand supports and services are emerging in greater numbers of managed care state LTSS systems. This shift has, in a number of states, resulted in greater barriers to accessing LTSS.

Continuing and Worsening Crisis of Unmet Need

People waiting for LTSS is unacceptable. Individuals with IDD remain on waiting lists for years—in some states for a decade or more—after requesting and being determined eligible for necessary supports and services. If ongoing supports and services are not available to young adults with IDD transitioning out of the education system, educational gains are lost, as are opportunities to launch careers and achieve independence.

People with disabilities often must experience the death of a parent, a medical emergency, or other tragic event to obtain the supports they need. They are thus thrust into a new situation without planning at a time of crisis.

As people with IDD continue to seek supports in their communities, access to affordable housing in safe neighborhoods has emerged as an urgent need. Because Medicaid eligibility for individuals with IDD often requires them to impoverish themselves, even generally available affordable housing programs are frequently inaccessible to them.

Direct Support Professional Workforce Crisis

The quality and effectiveness of LTSS for people with IDD depends upon qualified providers of supports and services with adequate skills and training. Inadequate compensation hampers both recruitment and retention of direct support professionals (DSP). Insufficient funding to support livable wages for DSPs, and for training of DSPs and their supervisors, negatively impacts the quality of supports available to people with IDD, as well as the success that individuals have in living the life they choose in the community.

POSITION

A comprehensive system of LTSS must include the following:

- An LTSS system that is sustainable and enables all eligible individuals to obtain LTSS whenever needed;
- A system that includes private and public funding mechanisms for LTSS, as a shared, societal responsibility;
- Elimination of the need for individuals or their families to impoverish themselves to receive supports and services;
- Services which are portable and allow people who move from one state or political jurisdiction to another to receive uninterrupted, self-directed supports;
- Medicaid as a viable funding option for individuals who need LTSS and have no or limited access to private insurance options;
- Medicaid buy-in options that are available in all states to allow people to preserve their eligibility for Medicaid-financed supports while encouraging careers, savings, and wealth-building;

- Medicaid programs that enable people to participate fully in their communities, experience a quality of life they define, and achieve economic security and personal independence;
- Medicaid funds that are controlled, to the fullest extent possible, by the person;
- Medicaid funding that is redirected from institutional care to person-centered home and community-based supports that are delivered in natural community environments;
- Improvements to Medicaid to ensure access to self-directed and determined LTSS, consistently deliver better outcomes for more people with IDD, and eliminate waiting; and
- Medicaid service delivery system redesign that is transparent and involves meaningful input of all stakeholders.

Self-Direction

Access to adequate and appropriate supports and services needed to live in the community is a basic human right. To achieve this:

- Individuals must design and direct their own services, to the fullest extent they wish and with the assistance they want;
- Services must be person-centered and based on the unique needs and desires of the individual, accompanied by measured progress toward person-centered outcomes to which the person aspires;
- Individuals with IDD who wish to employ DSPs must have access to timely and relevant information, technical assistance, and training;
- Services must be delivered promptly to meet individual needs and desires in the most integrated setting, with flexible funding to meet changing circumstances; and
- Outcome measures, defined in substantial part by the person, and outcomes consistent with state-defined value based reimbursement systems should be used to measure the individual and systems outcomes of LTSS in every state.

Continuing and Worsening Crisis of Unmet Need

- Individuals who are eligible for and want LTSS should not have to wait to receive services;
- Public systems must actively reach out to individuals and to families with un- and under-met 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 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 person-centered and self-directed supports and services immediately.

Direct Support Professionals Workforce Crisis

- System funding must provide for living wages and benefits to DSPs;
- Wages, benefits, and professional development opportunities remain consistently insufficient and must improve 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;
- National, state, and local private and public entities must engage in policy initiatives to recruit, train, and retain a high quality DSP workforce;
- Federal and state quality assurance programs must incentivize DSP retention and competence as part of licensure, in order to recognize positive performance and to direct assistance to those programs with unacceptable performance; and
- States must utilize a Nation-wide system for criminal and related background checks, including a system for tracking people for whom abuse, neglect, and exploitation charges have been substantiated, for all public and private DSPs working in the state.

Adopted: American Association on Intellectual and Developmental Disabilities
Board of Directors
February 12, 2020

The Arc of the United States
Board of Directors
May 21, 2020

Revised Statement for Chapter Consideration

May 21, 2020

SELF-ADVOCACY AND LEADERSHIP

People with intellectual and/or developmental disabilities[1] (IDD) have the right to advocate and/or be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves and others, with whatever supports they need. Self-advocates must have a meaningful role in decision-making in all areas of their daily lives and in public policy decisions that affect people with IDD.

ISSUE

People with IDD have been isolated and segregated from their communities, and presumed incompetent, resulting in loss and denial of basic human rights and discrimination in almost all areas of personal and community life. Through self-advocacy, people with IDD will have more impact on their own situations and on the public policies that affect them.

The self-advocacy movement has been critically important in supporting people with IDD to learn about self-advocacy skills and other topics, including:

- Civil rights, including the right to vote, the right to integrated services and supports, and self-determination;
- Self-confidence and development of leadership skills;
- Successful story-telling;
- Public speaking;
- Problem-solving techniques;
- Participation in group decision-making; and
- Involvement on boards and task forces and with policymakers at the local, state, and national level.

---

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

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

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

There are many ways for people with IDD to act as advocates, including individual self-advocacy for the individual services and supports that they or another person with IDD needs, as well as policy advocacy for the funding, services, and rights that impact people with IDD at the local, state, and national level.

POSITION

People with IDD must have the right to advocate for themselves and others. People with IDD have the right to speak or act on their own behalf and alongside other people with disabilities, whether the issue is individual or related to broader public policy. Recognizing these rights in a respectful partnership between people with and without disabilities can lead to better outcomes and better lives for everyone.

Self-advocates provide important knowledge, experience, and skills that individuals, organizations, and government agencies need in order to effectively support the needs of and enhance the lives of people with IDD. To promote this participation, it is critical to acknowledge the important role that self-advocates 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 IDD must have the power to make informed decisions about their own lives and the services they receive, including those who need support and those who have legally-appointed guardians.

- People with IDD have access to necessary accommodations and supports in order to meaningfully participate in meetings, conferences, task forces, boards, and other forums when issues and policies that are important to them are discussed ("Nothing about us without us" principle). These accommodations include but are not limited to:

    - Extra time planned for meetings to ensure the participation of each person;
    - Enhanced and alternative communication methods, such as communication devices, sign language, or interpreters;
    - Availability of technology supports and access through technology to ensure participation;
    - Materials provided ahead of the meeting for review;
    - Meeting materials written in plain language;
    - Support from direct support professionals, when needed; and
    - Funding for transportation and travel-related costs, including support staff.

- When communicating with or about people with IDD, it is important to respect the way that people with disabilities prefer to be identified. In most circumstances, person-first language is most appropriate, e.g. person with IDD. However, some people with IDD prefer identity-first language, e.g. autistic person. In addition, people's self-identified pronouns for gender identity must be respected.

- Policy development must include self-advocates and be regularly evaluated to ensure that self-advocates are actively and meaningfully participating.

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

- Self-advocacy organizations and individual self-advocates must be supported to develop and sustain the self-advocacy movement, including mentoring youth and young adults with IDD to become self-advocates.

- 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 IDD have accessible information, training, and education in self-advocacy, and (2) providers have the information they need to deliver person-centered services that address self-advocate-led trends in policy and design.

- Children and youth with IDD must be supported by families, schools, direct service providers, and other entities to learn self-advocacy skills and put these skills into practice. Children and youth with IDD should have opportunities to use advocacy skills in educational planning, including Individualized Education Programs (IEPs), transition plans, and all decision-making.

- Adults with IDD can be effectively supported by peers, self-advocates, families, direct service providers, and other entities to learn self-advocacy skills and put them into practice. In order to continually use these skills, adults with IDD should have opportunities to use self-advocacy skills in service planning and daily decision-making.

- Self-advocates must be afforded the same dignity of risk that all people have to make informed decisions and learn from any mistakes that impact themselves and others in the community.

- Self-advocates must be included on boards and other advisory bodies for disability advocacy organizations, service providers, and agencies who serve people with IDD, as well as encouraged to meaningfully provide input on the policies, programs, and evaluation methods of those organizations and agencies.

Adopted: American Association on Intellectual and Developmental Disabilities
Board of Directors
February 12, 2020

Revised Statement for Chapter Consideration

May 21, 2020

TRANSPORTATION

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

ISSUE

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

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

POSITION

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

---

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

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

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

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

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

Adopted: American Association on Intellectual and Developmental Disabilities
Board of Directors
February 12, 2020

The Arc of the United States
Board of Directors
May 21, 2020