



# 2021 Annual Business Meeting

September 28, 2021

THE ARC OF THE UNITED STATES

*Achieve with us.*<sup>®</sup>

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# Agenda

## Section 1

**THE ARC OF THE UNITED STATES**

September 28, 2021



## ANNUAL BUSINESS MEETING AGENDA

Tuesday September 28, 2021

1:45 pm – 3:15 pm

Online via Zoom

- |       |  |   |
|-------|--|---|
| I.    | Call to Order & Welcome<br>-Establishment of Quorum<br>-Review of Business Meeting Operating Rules<br>-Approval of Annual Business Meeting Minutes                                       | Ken Oakes, President  |
| II.   | Proposed Core Values and Guiding Principles  | Ken Oakes, President<br>Kathleen Stauffer, Chair,<br>Core Values Work Group |
| III.  | President's Report   | Ken Oakes, President  |
| IV.   | Chief Executive's Report   | Peter V. Berns, Chief Executive Officer                                     |
| V.    | NCE Report   | Chris Stewart, Chair of NCE   |
| VI.   | Listening Session on Position Statements<br>-Human and Civil Rights<br>-Addressing the Causes and Effects of Intellectual<br>and Developmental Disabilities<br>-Advocacy<br>-Anti-Racism | Laura Kennedy, Chair,<br>Policy & Positions Committee                       |
| VII.  | Legal Advocacy Committee Report  | Jasmine Harris, Chair   |
| VIII. | Diversity (aka Access Equity & Inclusion) Committee Report   | Faye Tate, Chair  |
| IX.   | National Council of Self-Advocates Report  | Chloe Rothschild, Chair   |
| X.    | National Siblings Council Chair  | Grace Francis, Chair  |
| XI.   | National Alumni Council Chair  | Nancy Webster, Chair  |
| XII.  | Announcements & Adjournment  | Ken Oakes, President  |

# Operating Rules and Protocols

## Section 2

**THE ARC OF THE UNITED STATES**

September 28, 2021

## 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	<p>"Mr. (Madam) Chairman" -or- "Mr. (Madam) President"</p>
Making Motions	<p><i>On your own:</i> "I move that..."</p>
Seconding Motions	<p>"Second!" <i>NOTE: you do not need to be recognized to second a motion.</i></p>
Making Amendments	<p>"I move to amend the motion by ... <i>Use one of the three following methods, describing which words to change:</i></p> <ul style="list-style-type: none"> <li>. . .Striking the following words(s): ..."</li> <li>. . .Adding the following words(s): ..."</li> <li>. . .Striking the words(s): - AND inserting the word(s):..."</li> </ul> <p><i>Make sure the motion reads correctly if amended with your proposal.</i></p>
Closing Debate	<p>"I move to close debate on ..."</p>
Voting by General Consent	<p><i>If you object, you do not need to be recognized to say:</i> "I object!" <i>NOTE: you also do not need to give a reason.</i></p> <p><i>If you agree, remain silent when the chair calls for objections.</i></p>
Protecting the Rules	<p>"Point of Order!"</p> <p><i>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.</i></p>
Ask a Procedural Question	<p>"Parliamentary Inquiry!"</p> <p><i>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.</i></p>
Seek Information About the Motion	<p>"I have a question about the motion."</p> <p><i>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.</i></p>

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# Making Motions for Members

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- 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**

September 28, 2021



Minutes of the 71<sup>st</sup> Annual Convention  
 Online  
 Tuesday, October 27, 2020  
 Wednesday, October 28, 2020

<b>Call to Order</b>	The Business Meeting of the 71st Annual Convention of The Arc was called to order by President Fred Misilo.
<b>Welcome</b>	President Misilo welcomed the visitors and guests to the Business portion of the Convention
<b>Credentials Report</b>	Secretary Church read the credentialing report: a total of 2293 of 3897 possible votes had registered at the convention with 35 states being represented.
<b>Establishment of Quorum</b>	Secretary Church declared that a quorum was present.
<b>Review of Business Meeting Operating Rules</b>	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.
<b>Review of Business Meeting Agenda</b>	President Misilo informed the attendees that the meeting agenda has been pre-circulated, and the Chair will follow this order of business.
<b>Appointments</b>	President Misilo announced that Peter Berns was appointed as timekeeper.
<b>Annual Business Meeting Minutes</b>	President Misilo explained the minutes of the 2019 Annual Business Meeting have been published and asked if there are any questions or corrections. Minutes approved as printed.
<b>Proposed Bylaws Amendment</b>	President Misilo explained the Proposed Bylaws Amendment has been pre-circulated prior to the meeting. Converting the Diversity Committee to a Standing Committee passed.
<b>Board Development Committee Report &amp; Election: Presentation of Slate of Nominees</b>	<p>President Misilo welcomed Elise McMillan, Chair of the Board Development Committee. Elise presented the Slate of Nominees. In the absence of any contested positions, President Misilo declared the following elected as officers and directors:</p> <p><u>Officers:</u>          President - Kenneth Oakes          Vice President - Dr. Grace Francis          Secretary - Hugh Evans          Treasurer - Laura Kennedy</p>

	<p><u>Directors:</u>  Meghan Burke  Jillian Copeland  Debbi Harris  Jasmine Harris  Burt Hudson  Stacy Kray  Guha Krishnamurthi  Valencia Faye Tate  Jose Velasco  Russell Lehmann</p>
<p><b>Presentation of Position Statements:</b>  Family Support  Long Term Supports and Services  Self-Advocacy and Leadership  Transportation</p>	<p>President Misilo welcomed Ken Oakes, Chair of Policy and Positions Committee. Ken presented the position statements.  Position Statements passed</p>
<p><b>Listening Session/Input:</b>  Public Policy Agenda</p>	<p>President Misilo welcomed Ken Oakes, Chair of Policy and Positions Committee. Ken led the listening session/input on the upcoming Public Policy Agenda</p> <p>There was no formal voting on the Public Policy Agenda</p>
<p><b>President's Report</b></p>	<p>President Misilo delivered his report.</p>
<p><b>CEO's Report</b></p>	<p>Chief Executive Officer, Peter Berns delivered his report.</p>
<p><b>NCE Report</b></p>	<p>The Chair of the NCE Steering Committee, Karen Shoemaker, delivered her report.</p>
<p><b>Remarks from Incoming President</b></p>	<p>Incoming President, Kenneth Oakes shared some remarks.</p>
<p><b>New Business</b></p>	<p>President Misilo stated that there was no new business submitted in accordance with the rules.</p>
<p><b>Announcements</b></p>	<p>President Misilo asked if there were any announcements before the meeting is adjourned.</p>
<p><b>Adjourn</b></p>	<p>There being no further business, President Misilo adjourned the 71st Annual Convention Business Meeting.</p>

# Proposed Core Values and Guiding Principles

## Section 4

**THE ARC OF THE UNITED STATES**

September 28, 2021



For people with intellectual  
and developmental disabilities

## MOTION – ACTION NEEDED

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**DATE:** July 11, 2021  
**TO:** Chapters of The Arc  
**FROM:** Board of Directors of The Arc of the United States, Inc.  
**SUBJECT:** Motion to Adopt Core Values and Guiding Principles for The Arc

Flesch-Kincaid Grade Level: 8.9 (report, without attachments)

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### Motion

The Board of Directors of The Arc of the United States, pursuant to section 8.1 of the Bylaws of The Arc of the United States, moves for chapters of The Arc to approve the adoption of the Core Values and Guiding Principles set forth below.

### CORE VALUES

1. Human Dignity.  
People with IDD have human dignity. The lives of people with IDD have value.
2. Personhood.  
People with IDD have varying strengths, abilities and interests. Each person is unique.
3. Choice.  
People with IDD can make decisions about their lives. People with IDD should be supported to do so as requested or needed.
4. Rights.  
People with IDD have human and civil rights which must be protected.
5. Community.  
People with IDD are part of and contribute to the fabric of society. Everyone benefits when people with IDD are present and participate.
6. Support.  
People with IDD have differing support needs. Society must support people with IDD to achieve their full potential. Society should also help families who provide support for loved ones with IDD.

*Achieve with us.*

7. **Equity.**  
Society must remove barriers and correct injustices that limit opportunities for people with IDD. Extra action is needed to help people with IDD, and their families, who face other forms of bias or discrimination.
8. **Diversity.**  
Human diversity is beautiful and powerful. We celebrate, honor, and seek to understand the differences in our identities and life experiences.

### **GUIDING PRINCIPLES**

1. **Advocacy First.**  
The Arc is a disability rights organization. We work with and for people with IDD, their families, and our communities, to achieve change. We use the power of advocacy to improve the lives of people with IDD.
2. **Stronger Together.**  
The Arc unites our chapters to advance the human rights and wellbeing of people with IDD and their families. The success of our advocacy depends on the strength of the chapter network. We are stronger together.
3. **Quality and Excellence.**  
The Arc provides programs and services that people with IDD and their families want, and depend upon in their daily lives. We strive for quality and excellence in all we do.
4. **Shared Leadership.**  
The Arc actively engages people with IDD and their family members, in leading and guiding our work. These voices are the most important. The strong partnership between volunteer, experts, and the people we serve is critical to our mission.
5. **Consensus.**  
The Arc leads by building consensus around a clear vision for the future of people with IDD. We unite and mobilize people behind goals and strategies that will make that vision a reality.
6. **For All People with IDD.**  
The Arc works with and for ALL people with IDD. While our work also helps all people with disabilities, our priority is people with IDD and their families.
7. **Partnership.**  
The Arc works in coalition with other disability, civil rights, and human services groups. We value joint effort and step up to provide leadership when needed.

8. Open and Accountable.

The Arc is accountable to people with IDD, their families, donors, and the public. We are committed to honesty and transparency.

9. Identity and Language.

The Arc respects the rights of people with IDD to decide if or when to self-identify and the language they use when doing so.

### **Background and Process**

1. Under the Bylaws of The Arc of the United States (“Bylaws”), The Arc is to review the Core Values and Guiding Principles (“Core Values”) at least every five years. The review is to determine if the Core Values should be revised.
2. The current version of the Core Values and Guiding Principles (Attachment I) has been in place since 2010. The document is at a 19.2 grade reading level.
3. During the recently completed strategic planning process (2019-2020) resulting in the creation of the new Strategic Framework for the Future of The Arc, the organization gathered input from chapters about the Core Values. Based on that input, the Long-Range Strategic Planning Committee recommended that the Core Values should be revised.
4. In October 2020, the Board of Directors voted to move forward and revise the Core Values.
5. In February 2021, the President of the Board, Ken Oakes, established the Core Values Work Group and charged it to review and revise The Arc’s Core Values and Guiding Principles (“Core Values”). Board member, Kathleen Stauffer, was appointed to chair the work group, which also included four additional board members. The Work Group met four times in April – June 2021.
6. As a first step, the Core Values Work Group reviewed the input about the Core Values collected during the strategic planning process. Based on this review, the Work Group decided to gather more input
  - a. The Work Group conducted a survey of chapters in April 2021. The survey focused on key questions that came up in the 2019 survey and meetings.
  - b. The Work Group led a discussion at the April 2021 Board of Directors meeting.
  - c. Chapter leaders, board committees and councils were invited to participate in the survey or submit comments.
7. Working with all this information, the Work Group developed a new version of the Core Values and Guiding Principles (Version D). This version is at a 9<sup>th</sup> grade reading level.
  - a. The Work Group fielded a second survey of chapters in May 2021 asking for input about the new draft.

- b. Chapter leaders, board committees and councils were invited to participate in the survey or submit comments.
8. The results of the survey showed strong approval for the new draft of the Core Values and Guiding Principles. A summary of the results is included in these materials (Attachment I)
  - a. 93% approved of the new Core Values & Guiding Principles (top 3 boxes: liked them, liked them a lot, love them)
  - b. The 8 Core Values were approved by 87% - 96% of respondents.
  - c. The 9 Guiding Principles were approved by 85% - 97% of respondents.
  - d. A large majority also thought that the language was accessible (69% for the Core Values, 73% for the Guiding Principles).
9. The Core Values Work Group determined that the new draft contained all the ideas that were needed to be included. The group also determined to try to simplify the language a bit more.
10. The Work Group did some more editing and created a new draft, Version E, which is at a 7.2 grade reading level.
11. At the Board of Directors meeting held on July 11, 2021, the Core Values Work Group recommended the new draft of the Core Values and Guiding Principles be approved and advanced for consideration by chapters of The Arc at the next annual meeting.
12. The Board of Directors approved the Work Group's recommendation by unanimous vote on July 11, 2021.

#### ATTACHMENTS

- I. Old version of Core Values and Guiding Principles (2010 – present)
- II. Summary of May 2021 Survey (Version D)

**Attachment I**  
**CORE VALUES AND GUIDING PRINCIPLES**  
**(2010 – present)**

**CORE VALUES**

**People First**

The Arc believes that all people with intellectual and developmental disabilities are defined by their own strengths, abilities, and inherent value — not by their disability.

**Equity**

The Arc believes that people with intellectual and developmental disabilities are entitled to the respect, dignity, equality, safety, and security accorded to other members of society, and are equal before the law.

**Self-determination**

The Arc believes in self-determination and self-advocacy. People with intellectual and developmental disabilities, with appropriate resources and supports, can make decisions about their own lives and must be heard on issues that affect their well-being.

**Community**

The Arc believes that people with intellectual and developmental disabilities belong in the community and have fundamental moral, civil, and constitutional rights to be fully included and actively participate in all aspects of society.

**Diversity**

The Arc believes that society in general and The Arc in particular benefit from the contributions of people with diverse personal characteristics (including but not limited to race, ethnicity, religion, age, geographic location, sexual orientation, gender, and type of disability).

## **GUIDING PRINCIPLES**

### **Participatory Democracy**

The Arc acts to ensure that people with intellectual and developmental disabilities, their parents, siblings, family members and other concerned members of the public have meaningful opportunities to inform and guide the direction of the organization’s advocacy, including determining policy and positions on important issues. The Arc strives for diversity in its leadership, as well as in all facets of the work of the organization.

### **Visionary Leadership**

The Arc leads by articulating a positive vision for the future of people with intellectual and developmental disabilities and catalyzes public and private support in realization of that vision through carefully planned and well-executed goals, strategies and actions.

### **Public Interest**

The Arc represents the public interest, supporting and acting with and on behalf of all people with intellectual and developmental disabilities and their families regardless of the type of disability or membership in The Arc.

### **Collaboration**

The Arc works with individuals, organizations and coalitions in a collaborative fashion. The Arc values and promotes effective partnerships between volunteer and staff leadership at all levels of the organization.

### **Transparency, Integrity and Excellence**

The Arc conducts its business with integrity, accountability, and open, honest and timely communication. The Arc is committed to quality and excellence in all it does.

**CORE VALUES AND GUIDING PRINCIPLES, OVERALL**

<b>What do you think about the Core Values and Guiding Principles?</b> 1 – 7 scale: (1) I hate them, (2) I really don't like them, (3) I don't like them, (4) They're OK, (5) I like them, (6) I like them a lot, (7) I love them	<b>Top 3 boxes</b>	<b>Top 2 boxes</b>
<b>Core Values &amp; Guiding Principles in their entirety</b>	<b>93%</b>	<b>63%</b>
<b>Core Values as a group</b>	<b>93%</b>	<b>65%</b>
<b>Guiding Principles as a Group</b>	<b>93%</b>	<b>67%</b>

**CORE VALUES**

<b>CORE VALUES</b> 1-5 scale (Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree)	<b>Should be a Core Value (top 2 boxes)</b>	<b>Language is Appropriate (top 2 boxes)</b>
1. <b>Human Dignity</b> - People with IDD have human dignity. The lives of people with IDD have inherent value.	<b>89%</b>	<b>69%</b>
2. <b>Individuality</b> - People with IDD have varying strengths, abilities, responsibilities, interests, personalities, opinions, values, qualities, and characteristics. Each person with IDD is unique.	<b>93%</b>	<b>81%</b>
3. <b>Self-Determination</b> - People with IDD have autonomy to make decisions about their lives. People with IDD should be appropriately supported in their decision-making as requested or needed.	<b>90%</b>	<b>71%</b>
4. <b>Rights</b> - People with IDD have human and civil rights which must be protected.	<b>96%</b>	<b>88%</b>
5. <b>Community</b> - People with IDD are part of and contribute to the fabric of society. Everyone benefits when people with IDD are present and participate.	<b>92%</b>	<b>75%</b>
6. <b>Support</b> - People with IDD have differing support needs. Society is responsible to support people with IDD to achieve their full potential. Society should also help parents, siblings and other relatives who provide support for family members with IDD.	<b>87%</b>	<b>72%</b>
7. <b>Equity</b> - Society has an obligation to remove barriers and correct past and ongoing injustices that limit opportunities for people with IDD. Extra action is needed to help people with IDD, and their family members, who also face other forms of bias or discrimination.	<b>87%</b>	<b>67%</b>
8. <b>Diversity</b> - Human diversity is beautiful and powerful. We celebrate and honor the characteristics among people, such as disability, race, ethnicity, gender identity, sexuality, age, language, religion, spirituality, geography, citizenship, economic status, and political or personal viewpoints.	<b>94%</b>	<b>82%</b>

<b>CORE VALUES</b>	<b>No</b>	<b>Not Sure</b>	<b>Yes</b>
Are there any important values that guide The Arc's work that are missing?	<b>70%</b>	<b>15%</b>	<b>14%</b>
Overall, is the language accessible to our constituents?	<b>18%</b>	<b>13%</b>	<b>69%</b>

**GUIDING PRINCIPLES**

<b>Guiding Principles</b> 1-5 scale (Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree)	<b>Should be a Guiding Principle (top 2 boxes)</b>	<b>Language is Appropriate (top 2 boxes)</b>
1. <b>Advocacy First</b> - The Arc is a disability rights organization. We work with and for people with IDD, their families, and our communities, to improve opportunities for people with IDD. We use the power of advocacy to achieve change and improve the lives of people with IDD.	<b>97%</b>	<b>84%</b>
2. <b>Stronger Together</b> - The Arc brings local, state, and national chapters together in a unified movement benefitting the human rights and wellbeing of people with IDD and their families. The success of our advocacy depends on the strength of the chapter network. We are stronger together.	<b>94%</b>	<b>79%</b>
3. <b>Quality and Excellence</b> - The Arc is the largest provider of programs, services and supports that people with IDD and their families need, want, and depend upon in their daily lives. We strive for quality and excellence in all we do.	<b>85%</b>	<b>77%</b>
4. <b>Participatory Leadership</b> - The Arc actively engages people with IDD, parents, siblings, and other family members, in leading and guiding our work. These voices are the most important. The strong partnership between volunteer leaders, professionals, and the people we serve is critical to our mission.	<b>93%</b>	<b>83%</b>
5. <b>Building Consensus</b> - The Arc leads by building consensus around a clear vision for the future of people with IDD. We unite and mobilize people behind goals and strategies that will make that vision a reality.	<b>86%</b>	<b>75%</b>
6. <b>For All People with IDD</b> - The Arc works with and for ALL people with IDD. While our work also helps all people with disabilities, our priority is people with IDD and their families.	<b>89%</b>	<b>81%</b>
7. <b>Partnership</b> - The Arc works in coalition with other disability, civil rights, and human services groups. We value collaboration and step up to provide leadership when needed.	<b>91%</b>	<b>81%</b>
8. <b>Open and Accountable</b> - The Arc is accountable to people with IDD, their families, donors, supporters, and the public. We are committed to honesty, integrity, and transparency.	<b>95%</b>	<b>81%</b>
9. <b>Identity and Language</b> - The Arc respects the rights of people with IDD to decide if or when to self-identify and the language they use when doing so.	<b>86%</b>	<b>76%</b>

<b>GUIDING PRINCIPLES</b>	<b>No</b>	<b>Not Sure</b>	<b>Yes</b>
Are there any important values that guide how The Arc operates as an organization that are missing?	<b>65%</b>	<b>24%</b>	<b>11%</b>
Overall, is the language accessible to our constituents?	<b>16%</b>	<b>11%</b>	<b>73%</b>

# Reports

## Section 5

**THE ARC OF THE UNITED STATES**

September 28, 2021



## **Report from the President**

I thought I would be welcoming you to New Orleans from a podium in the Hilton ballroom. Instead, I offer you the warmest welcome to your annual meeting packet, and I will say it aloud at our virtual annual meeting. Making the decision to pivot to a virtual meeting was difficult, but certainly in everyone's best interest. It has been two years since we last gathered together at a membership meeting in Washington D.C. There are two things that I could never have imagined had told me that our world would be turned upside down by a pandemic like we had never seen in our lives, and, that I would become president of The Arc of the United States. Both seemed impossible to me.

I know that we have lost members of our "Arc Family" to COVID. I lost my own brother to COVID in January. I am so sorry for their loss. It just does not seem fair. We dedicate ourselves to their memory and will work even harder to make them proud.

Even though we have cancelled another live convention and Covid 19 still seems to be a great unknown, I am full of enthusiasm and love for The Arc, an organization I have been a part of for 45 years, serving in nearly every volunteer position available. I have enjoyed every minute and have been so proud to tell people about The Arc. What we have accomplished in more than 70 years has changed the lives of countless children, adults and their families. Thank you so much.

In March of 2020, the critical services our 601 chapters and more than 131,000 staff provide to thousands of people with IDD, came to a screeching halt. In a state of emergency, we were all told to stay at home. Without missing a beat our chapter leadership began to face the greatest challenge in our 70-year history. Chapters across the country began to creatively provide virtual services, something many had no experience with. People did yoga and other exercise, art projects, watched videos and movies, practiced skills, talked with their friends, and most importantly stayed connected.

The following statement appears on page two of our 2020 Annual Report:  
*A year of lives forever changed. Perseverance. Commitment. Experience. Determination. Meeting the moment that defined a once-in-a-lifetime crisis.*

Thank you all from the bottom of my heart for all that you have done. I know from serving on my local Arc board during this past year that it has been very hard. But we did it, and I think we are a stronger organization because of it.

The Arc US staff, and board have worked very hard on your behalf this past year. I want to thank all the staff and know that you would agree we have quite a team. Many thanks as well to our CEO, Peter, for holding the national organization together. In spite of all the obstacles that COVID put in our path, The Arc US was a leader advocating across the federal government. Truly amazing, like all of you!

I am very proud of our board of directors. Today, we have the most diverse board ever. Twenty-three directors and officers have worked overtime this past year to strengthen The Arc and serve YOU, our chapters. Our new Strategic Framework is in place and we use the five strategies to drive everything we do. Together with you, we...

Build the Movement  
Speak the Truth to Anyone Who Will Listen  
Advocate  
Extend Our Reach  
and... Innovate

I hope you and your chapter will look closely at the Strategic Framework and consider how it might support your work.

Recently, you should have received via email, the 2020 Annual Report. If you have not had the opportunity to read through it, I ask that you do. It is an amazing document and tells the story of an organization that is ready to meet the moment.

Friends, I am so sorry that we cannot come together this year as planned. We have made the right decision to cancel the in-person convention. We would not risk anyone to this horrible pandemic. It has been a rough year, but we are here.

I am ever hopeful that I will see you at the Spring Disability Policy Seminar in Washington, D.C. Until then, thank you again and please let me know if there is anything I can do to assist you.

Respectfully,

A handwritten signature in cursive script that reads "Kenneth W. Oakes". The signature is written in black ink and is positioned to the right of the typed name.

Ken Oakes  
President

**National Conference of Executives of The Arc (NCE)  
Quarterly Report to the Board of Directors  
September 2021**

Steering Committee Meetings

The NCE Steering Committee met via phone conference in June and July of 2021. Highlights of these meetings follow.

June 2021 meeting:

Welcome

- The meeting minutes from May 26<sup>th</sup> were approved.

Summer Leadership Update

- Abby gave an update on SLI. An email blast was sent out and the website and registration launched on May 17<sup>th</sup>. As of June 23<sup>rd</sup>, there were 90 people registered. SLI has a full program with over 30 live sessions not including on-demand sessions. There is a mix of general sessions and breakout sessions and all details including session descriptions and speaker bios will be available June 14<sup>th</sup>. Abby needs everyone to promote this to their local chapters or nearby disability organizations. The team suggested providing key topics to share with their network. Abby will work with Marketing to get this taken care of.

Task Group Updates

- Regional Rep: The team met to finalize the plans for the happy hour taking place during SLI.
- Silent Auction: The auction team has met, and the site is open with about 10 donations to date. Each Member is seeking to solicit 5 organizations before the next meeting.
- Chapter Resources: Heidi Haines from The Arc of Tennessee will be a co-chair to assist Frank in leading the committee. The team will review the new executive manual to add the NCE component to it and then hopes to get feedback from Regional Rep.
- Awards: The awards application closed on June 18<sup>th</sup>. A total of 15 nominations were received, 2 of which were repeats that have won previously. Reviewing and grading will be ongoing until July 2<sup>nd</sup> and the winners will be decided the following week. Award winners will receive a free ticket to the Awards Luncheon at the National Convention where both the 2020 and 2021 winners will be awarded.

Survey for Core Values and Guiding Principles

- Peter gave a general overview and the background on why the Core Values and Guiding Principles are relevant. After coming up during strategic planning a small committee spent a lot of time working and updating the content, language, etc. before a survey was sent out to get feedback from The Arc Chapters. The results were compiled, and a second survey was sent to get a better idea how people viewed the new core values and guiding principles. The team has gotten the language down from 9<sup>th</sup> grade level to a 7<sup>th</sup> grade level. The board is set to review and approve the updated version of the core values and guiding principles at the next meeting.

Think Tank #1: DSP Workforce Crisis - Next Steps

- The team reviewed list of the possible solutions from the last meeting. Each member of the committee talked about what solutions they have established in their organization including giving bonuses, increasing wages, giving DSP workers benefits such as 401K/403b plans, giving referral bonuses, and refining DSP workers career path through training from Relias products.

Many did exit and “stay in” interviews and determined that many younger workers care about paying off student loans over a retirement plan. Therefore, some of the committee work with staff to get their student loans forgiven and other provide staff a payday loan to help with other small debt.

- Stanford gave the team a review of what his organization does in promoting in diverse markets to recruit DSP workers. The biggest improvement was diversifying the advertising campaign which focused on the heart of the matter: improving the quality of life and wanting to make a difference. These ads are placed all over and the goal is to saturate the market as much as possible, so their organization is everywhere. He also provides \$5000 sign-on bonus spread throughout the year along with other steps.
- Other chapters are doing a surprise bonus for current staff and restructuring work schedules, such as 6 days on and 6 days off to balance the stress of work.
- Besides recruitment and retention, another issue that impacts keeping a DSP worker is the new guidelines that DSP workers must wear a mask regardless of their vaccination status. There are issues with mandated masks being lifted for the public, but not for people with I/DD.
- A few questions remain: how do we get people to want to do this work? How do we make this job more attractive to people we want to hire? How are we addressing that?

#### Policy Update

- Nicole gave an update on policy issues including workforce wages, legislature updates, and 400 billion dollars workforce update.

#### July 2020 meeting:

##### Welcome

- The meeting minutes from June 23rd were approved.

##### Summer Leadership

- Abby gave an overview of Summer Leadership Institute. 2021 SLI had 260 people registered. 124 of them were first timers. 20 of the 32 state chapters were represented in attendance. 80 local chapters were represented with 92 CEO's and 23 external organizations. Region 5 is number one with 33% of attendees from that region. Region 3 comes last with the lowest attendees at 7%. 37 chapters sent 2 or more attendees.
- There was a total of 68 speakers (10 were national staff, 24 were chapter staff, 34 were external partners or organizations) not including regional representatives or general session monitors. 18 chapters were represented, and 29 external organizations were represented.
- About 229 registrants attended which is about 88%. Monday had the highest attendance rate of 179 with Wednesday having the lowest at 119. Abby reviewed all the numbers for each session with the opening general session being the highest attended.
- Abby shared testimonies from attendees. Many loved Alonzo and can't wait to attend Professional Development Seminar in New Orleans. Out of the 32 surveys received, 100% rated SLI as excellent or very good.

##### Convention Update/Steering Committee

- Abby gave an overview of where things stand for the National Convention that will be held in the Hilton New Orleans Riverside.
- As of June 26<sup>th</sup>, there were 168 registrants for Convention with 45 for Professional Development Seminar/Reception and 59 for the NCE awards luncheon.
- Abby went over what to do to prepare for the in person Steering Committee meeting and reviewed the schedule for the events taking place that Sunday. Abby reviewed Convention

schedule and heavily emphasized that committee attend the NCE awards luncheon and support and help with the NCE Silent Auction.

#### Agenda for Steering Committee Meeting in September

- These are the things the team came up with for the in-person meeting:
  - Onboarding new members/ice breakers/opening activity/ beach ball toss
  - Update on Policy
  - Review goals and tasks for the steering committee/task group
  - Review convention schedule/seek volunteers for auction monitoring

#### NCE Awards Luncheon Ceremony

- It was discussed how to award 18 winners in 2 hours. One idea is having each category winners (Executive Excellence or Rising Stars) come and collect their awards together or be on stage together. Another option is allowing the master of ceremonies read the nominations which would be about 30 seconds to a 1 minute of each nominee. The nominators will be on stage with the winner to give the award to them and allow for 2-minute acceptance speech.
- There will be some winners not in attendance due to COVID. It was discussed how they should be honored. One option is doing a photo montage of the winners with their awards in the end. Another option is letting those winners do a 2-minute speech pre-recorded video.
- Melanie will be the master of ceremonies. The nominator does not need to be on stage. Jon can hand them the awards. The photos can be taken outside the room with new background.

#### Think Tank #1: DSP Workforce Crisis - Next Steps

- Chris and the team continued the DSP discussion and came up with a list of items that could be expanded on for the NCE Newsletter. There were members working with DSPs on their career paths and new trainings. There was discussion on how this could be spread across the country and what the steps are needed to make that happen. Should we speak with legislatures who do not support nor understand HCBS initiative to have a dialogue with them? Abby will reach out to Nicole for policymaker recommendations that we should be talking to or any connections she has who can talk to us about HCBS expansion initiatives.

#### New Business

- Chris announced the resignation of Jason Meyer due to new responsibilities. His presence on the steering committee will be missed.

Submitted by:

Chris Stewart, NCE Steering Committee Chair

# Listening Session on Position Statements

## Section 6

**THE ARC OF THE UNITED STATES**

September 28, 2021



## Position Statements Listening Session

To: **2021 Convention Attendees**

From: **Laura Kennedy, Chair, Policy and Positions Committee**

### Revisions to Position Statements

The Arc's Policy and Positions Committee, with members from both The Arc and the American Association on Intellectual and Developmental Disabilities (AAIDD), are working to revise three of our current position statements and to develop one new joint statement. AAIDD adopted a new statement in December 2020 on Anti-Racism, which will be the starting point for a new joint position statement. The statements, which follow this memo, are:

- Human and Civil Rights;
- Addressing the Causes and Effects of Intellectual and Developmental Disabilities;
- Advocacy; and
- Anti-Racism (new).

### We Want to Hear from You!

While the Committee is working on the statements, they would like to hear from you about what ideas or concepts you believe should be kept in the statements and what should be changed. Your comments will be considered in developing drafts for the Boards of Directors of The Arc and AAIDD. **Join us for a 30-minute Listening Session on the Position Statements** during the **Annual Business Meeting on Tuesday September 28, 2021**, Hilton New Orleans Riverside Hotel. Come and speak to Committee and Board members who are present.

If you are unable to join us in New Orleans, send any comments to Mike Nagel ([nagel@thearc.org](mailto:nagel@thearc.org)) **by Friday, October 8.**

Later in the year, close-to-final revised statements will be available for comment by the chapters online (from mid-December through mid-January) before the two Boards of Directors vote on them.

## Position Statements for Revision – July 2021

The following position statements have been chosen for revision:

1. **Addressing the Causes and Effects of IDD** (p. 1)
2. **Advocacy** (p. 4)
3. **Human and Civil Rights** (p. 6)

In addition, one current statement from AAIDD has been chosen for development as a joint statement:

4. **Anti-Racism** (p.7)

The up-to-date footnote describing intellectual and developmental disabilities is included in the first statement but has been removed from all other statements simply to avoid repetition.

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### 1. ADDRESSING THE CAUSES AND EFFECTS OF INTELLECTUAL AND DEVELOPMENTAL DISABILITIES<sup>1</sup>

**According to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and other federal legislation, “disability is a natural part of the human experience...”. Prevention activities do not diminish the value of individuals with intellectual and/or other developmental disabilities (IDD), but rather strive to maximize the independence and enhance quality of life for people with IDD. The Nation must continue to investigate the causes, avoid those that are preventable, and limit negative effects of conditions that cause IDD through basic, applied, and clinical research, public awareness, education, advocacy, early intervention, and appropriate supports.**

#### ISSUE

Knowledge about biomedical causes of disability, preventive health care options, and the consequence of exposure to environmental hazards is increasing rapidly, yet practical application of this information is lacking. Supporting the prevention of IDD and valuing the lives, diversity, and contributions of persons with IDD are compatible positions.

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<sup>1</sup> 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.

Despite dramatic advances in our Nation's view of disability and supports and services for individuals with disabilities, quality of life remains elusive for far too many persons with IDD. When individuals with IDD do not receive adequate, comprehensive health care, including access to mental health, habilitative and dental health services across the lifespan, therapies, education, and access to assistive technology, preventable secondary conditions can occur.

## **POSITION**

The Nation must investigate the causes, avoid those that are preventable, and limit the negative effects of conditions that cause IDD through prevention programs, policies, and practices which must include:

### **Research**

- Research on the conditions that cause IDD, including, but not limited to, biomedical causes of disability, preventive health care options, and the consequence of exposure to environmental hazards.

### **Public Health Programs**

- Promotion of folic acid supplementation among women of child-bearing age, with emphasis in communities where the incidence of neural tube defects is higher;
- Efforts to prevent accidental childhood injuries, such as programs to promote the use of car seats, seatbelts, and bicycle and other sports helmets;
- Compliance with state laws on immunizations of children for preventable contagious diseases associated with IDD to achieve public health objectives and optimal health outcomes;
- Encouragement of immunizations for women of child-bearing age for preventable contagious diseases that are associated with IDD;
- Programs to ensure that prospective parents and pregnant women have coverage for and access to comprehensive prenatal care to support the best possible birth outcomes. In the case of mothers with IDD, such care must meet the mother's disability and communication needs;
- Disability sensitive information and supports for post-natal care for mothers with IDD;
- Programs to ensure that pregnant women (including those with IDD), infants, and children receive adequate nutrition and healthcare;
- Information and care before, during, and following birth, including frequent physical/developmental checks, and referral to community resources, if appropriate;

- Programs to ensure that children who live in poverty have access to adequate health and development support;
- Education of professionals and the public on the risks of prenatal and childhood exposure to agents that may harm brain development, such as alcohol, drugs, tobacco, polychlorinated biphenyls (PCBs) and environmental hazards such as lead and mercury. In addition, professionals, families, and self-advocates should be made aware that individuals with IDD who experience compromised health or limited access to healthcare may be uniquely vulnerable to environmental hazards;
- Reduced exposure to and protection against infectious agents and environmental hazards known to cause or contribute to IDD, such as insect-borne diseases like the Zika virus, and lead, mercury, and polychlorinated biphenyls (PCBs), as well as improved workplace safety initiatives;
- Programs and education to reduce the incidence of disabilities resulting from child abuse, particularly Shaken Baby Syndrome;
- Expansion of newborn screening and early childhood developmental screening programs to identify conditions that require specialized medical treatment at birth or soon after, and to provide for timely referral to early intervention services. Such programs should be modeled on the highly successful efforts to prevent IDD resulting from PKU and hypothyroidism; and
- Enforcement of existing public policies designed to prevent IDD.

### **Quality of Life**

Investigating the causes, avoiding those that are preventable, and limiting negative effects of conditions that cause IDD will contribute to individual and family quality of life. It is also imperative that individuals with IDD engage in person-centered and self-directed services and supports that are appropriate and affordable in order to improve quality of life, as well as to address secondary conditions through the following:

- Appropriate funding for interventions, preventive health care, habilitation services, educational services, community-based supports, and assistive technology to maximize independence and lessen the development of preventable secondary conditions in people with IDD who often are at greater risk for health problems that can be prevented;
- Proactive efforts in policy development and program design to identify and prevent health disparities and the development of secondary conditions in persons with IDD;
- Continued research into and application of promising interventions, best practices, and community-based supports that maximize independence and enhance quality of life for individuals with intellectual and/or developmental disabilities; and

- Dissemination of knowledge about research-based best practices.

Rev'd 2016

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## 2. **ADVOCACY**

**Advocacy on the individual or systems level is acting with or on behalf of an individual or group to resolve an issue, obtain a needed support or service or promote a change in the practices, policies and/or behaviors of third parties. Advocacy is essential for promoting and protecting the civil and human rights of people with intellectual and/or developmental disabilities and for establishing, maintaining or improving their quality of life.**

### **ISSUE**

Without strong advocacy at all levels, people with intellectual and/or developmental disabilities may not have access to needed supports as well as opportunities to exercise inherent civil and human rights. Additionally, strong advocacy may be required to prevent and/or address abuse, neglect and exploitation that people with intellectual and/or developmental disabilities may experience. Persons with intellectual and/or developmental disabilities may need the support of advocates to become effective self-advocates.

### **POSITION**

Advocacy is vital in improving and sustaining quality of life for persons with intellectual and/or developmental disabilities. To be effective, advocacy must take place at both the individual and system levels. Advocacy can be aimed at public officials, support systems and the general public.

### **Individuals**

Advocates, including self-advocates, should be trained and knowledgeable about the rights and dignity of children and adults as set forth in the position statements of The Arc.

Advocates must communicate effectively with individuals they assist, encouraging them to express and act on their thoughts, choices and feelings about issues and proposed solutions to problems. The advocate and the individual must be able to understand each other. The advocate should exercise great care to ensure that the person with intellectual and/or developmental disabilities fully understands the benefits and risks of any decision. When making decisions, individuals should be encouraged to consult with the important people in their lives.

Advocates have an ethical obligation to represent the desires and needs of the person they represent, regardless of their own personal opinions on matters under consideration.

Self-advocates should:

- Know about, understand and assert their rights;
- Obtain support to be effective self-advocates;
- Practice self-determination and advocacy;
- Learn and develop the skills necessary to advocate for one's self;
- Practice self-protection;
- Obtain needed services; and
- Fully participate in their community.

In certain circumstances, parents, other legal representatives or other supporters may need to be involved in making decisions with and on behalf of the individual. At such times, advocates must represent the interests of the individual. Advocates must be careful to recognize and set aside their own personal desires or points of view that may conflict with those of the individual for whom they are advocating. If there is a conflict of interest, the advocate should withdraw from the decision-making.

## **Systems**

Systems change advocacy can provide tremendous benefit for people with intellectual and/or developmental disabilities.

The goal of systems advocacy is to enhance public awareness of the rights, strengths, needs, and interests of people with intellectual and/or developmental disabilities and influence law and policy to improve public and private systems of support and services. Family members and self-advocates should play a meaningful role in systems change. Agencies providing supports to individuals should also advocate for system change that will improve the quality of life for all individuals, whether supported by the agency or not.

Individuals should have access to Protection and Advocacy systems and other entities mandated by state and federal laws that:

- Have the flexibility to respond to issues raised at any time during an individual's life;
- Are independent of conflicts of interest, undue influence and government control;
- Are adequately funded and staffed;
- Provide advocacy on their behalf even though a formal complaint has not been filed;
- Have appropriate government or other oversight of quality, cost effectiveness, efficiency, and high standards to ensure the health, safety and well-being of individuals being served;
- Use multiple advocacy strategies, such as information and referral, mediation, legal action, and legislative and regulatory solutions; and
- Provide means for appealing unfavorable decisions.

### 3. HUMAN AND CIVIL RIGHTS

**The human and civil rights of all people with intellectual and/or developmental disabilities must be honored, protected, communicated, enforced and thus be central to all advocacy on their behalf.**

#### ISSUE

Today, as throughout history, the human and civil rights of people with intellectual and/or developmental disabilities have been unjustifiably limited or denied based on a lack of understanding of their humanity. These rights include the right to autonomy, dignity, family, justice, life, liberty, equality, self-determination, community participation, property, health, well-being, access to voting, freedom from unwarranted and unjustifiably extensive guardianship, equality of opportunity and other rights recognized by law or international declarations, conventions, or standards.

Though freedom from discrimination is a basic human right accepted as part of the fundamental law of the land, advancing the human and civil rights of people with intellectual and/or developmental disabilities presents particular challenges.

Many individuals, businesses, federal, state, and local government agencies and other entities remain unaware of or ignore the human and civil rights of people with intellectual and/or developmental disabilities. As a result, people with intellectual and/or developmental disabilities face unique challenges, including the following:

- A history of discrimination and exclusion from meaningful choice and participation in employment, housing, voting, transportation, and other programs, activities, and services provided by the public and private sectors of society;
- Social and cultural attitudes of devaluation and fear;
- Unfounded beliefs that people with intellectual and/or developmental disabilities cannot and/or do not contribute to society;
- Societal failure to provide the supports wanted and needed for full community participation, equal opportunity, independent living, and economic self sufficiency;
- Overprotection without freedom to exercise individual rights;
- Under-payment for labor and services and denial of the means of economic self-sufficiency;
- Forced impoverishment;
- Prejudice that views people with intellectual and/or developmental disabilities as unworthy of progressive public policies and related public funding; and

- The presence of other factors that, in combination with intellectual and/or developmental disabilities, expose them to increased risk of rights violations. These factors include: age; gender; race/ethnicity; sexual orientation; cultural, linguistic, geographic, or spiritual diversity; economic status; severity of disability; intensity of needed supports; and others.

## **POSITION**

All people with intellectual and/or developmental disabilities are entitled to human and civil rights. Given that all people with intellectual and/or developmental disabilities are complex human beings with varying attributes and living circumstances, and many experience multiple risk factors for human and civil rights violations, we emphasize that all are entitled to human and civil rights regardless of age, gender, race/ethnicity, sexual orientation, cultural, linguistic, geographic, and spiritual diversity, economic status, severity of disability, intensity of needed supports, or other factors that expose them to increased risk of rights violations.

These rights include the rights to autonomy, dignity, family, justice, life, liberty, equality, self-determination, community participation, property, health, well-being, access to voting, and equality of opportunity and others recognized by law or international declarations, conventions, or standards. All people with intellectual and/or developmental disabilities must have the right to supports they need to exercise and ensure their human and civil rights. Local, state, federal, and international governments must strongly enforce all human and civil rights.

Rev'd 2015

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## **4. ANTI-RACISM**

*(Current Position of AAIDD)*

The AAIDD community is grieving the deaths of George Floyd and Breonna Taylor as well as Sandra Bland, Eric Garner, Freddie Gray, Tanisha Anderson, Deborah Danner, Ezell Ford, Alfred Olango and Keith Lamont Scott and the murder of Black people due to violence, including police violence. We condemn all violence and discrimination resulting from structural racism. As a professional organization, we are committed to supporting the eradication of barriers within policies and practices that are grounded in systemic and structural racism that form inequities for Black people in our country, including Black people with intellectual and developmental disabilities. As an organization, AAIDD does not condone racism or discrimination and recognizes that these issues have unfairly impacted the education, health, justice, and dignity of Black people in our country. In view of that, to AAIDD's Black members we say—your lives matter! To Black people with intellectual and developmental disabilities—we see you—we support you—and your lives matter!

AAIDD reaffirms our commitment to promoting diversity and understanding that racism is at the forefront of this oppression. We acknowledge that racial inequities contribute to the persistent income and wealth gap, unemployment rate, education bias, housing discrimination, healthcare inequality, social exclusion, and violence that has impacted Black people throughout the history of our country—and has sparked outrage for many individuals across the globe. We as an organization pledge to take action against these injustices by advancing an antiracist agenda that includes leveraging our resources and supports to combat issues of racism. We must also illuminate how racial oppression for Black people with intellectual and developmental disabilities impacts their human rights in ways that it does not impact other groups. Thus, AAIDD pledges to promote anti-racist policies, research, and practices that prioritize equity for Black people with intellectual and developmental disabilities.

We are saddened by the multidimensional forms of racism that leads to the death of Black people in this country. This violence against Black people is a reminder of the action that must happen against oppressive forces. Therefore, we call on our AAIDD community to embrace efforts to eradicate unjust forces that particularly impact the lives of Black people. We call on our AAIDD community to identify tangible steps to implement an antiracist agenda and address racist policies that creates trauma for Black people with intellectual and developmental disabilities. We also recognize that institutional discrimination targets many groups beyond Black people, and we strongly denounce all such forms of hate that produce inequities and violence. As our nation continues to listen and learn lessons, we are dedicated to working as an organization and with allies to support social justice and antiracism.

December 9, 2020

# Reports

## Section 7

**THE ARC OF THE UNITED STATES**

September 28, 2021



# The Arc of the United States Annual Business Meeting September 2021 Access, Equity, & Inclusion (AEI) Committee Report

## Board Committee Leadership and Contact Information

<b>Faye Tate</b> (she/her)	<b>Chair</b>	<a href="mailto:ftate@cobank.com">ftate@cobank.com</a>
<b>Ariel Simms</b> (she/her or they/them)	<b>Staff Liaison</b>	<a href="mailto:simms@thearc.org">simms@thearc.org</a>

## Summary

- 1) Committee leadership has met many times. At these meetings, we talked about the work we are doing this year. We talked about creating a new plan to advance AEI. We planned for our Committee meetings and Board meetings.
- 2) We changed the name of our Committee. We used to be the Board Diversity Committee. We are now the Board Access, Equity, & Inclusion (AEI) Committee. We will make this change in the bylaws.
- 3) Since October 2020, we welcomed new members of the Committee. We currently have 15 members.
- 4) In April 2021, we had our first Committee meeting. We talked about our work for this year. We talked about strategic planning.

We reviewed our plan and timeline for this. Our process includes three phases.

- 5) In June 2021, we had our second Committee meeting. We talked about our strategic plan for AEI and The Arc's revised Core Values.
- 6) In May and June, we sent a survey to the Board. The survey asked about identity. Identities describe who we are. The survey also asked about people's experience on the Board. We shared the results with the Committee and Board in July.
- 7) In July 2021, we had our third Committee meeting. The focus of this meeting was the AEI strategic plan. We discussed the plan and then voted to move to Phase 2 of strategic planning.
- 8) In August 2021, we had our fourth Committee meeting. At this meeting, we discussed the Board survey. We also talked about the AEI strategic plan.
- 9) Looking ahead, we plan to wrap up AEI strategic planning by September 26<sup>th</sup>. However, we are prepared to extend the work into 2022 if needed.

## **Our Work in 2021**

Since October 2020, Committee leadership has met several times. At these meetings, we prepared for our work this year. Our highest priority has been creating a new AEI strategic plan for The Arc. The Arc's [Diversity Strategic Action Plan](#) ended in 2020. Leadership had an opportunity to reflect on our past diversity work. We have brought lessons learned into the strategic planning process this year.

The name of our Committee is changing. We were formerly the Board Diversity Committee. After reflection and discussion with the Board President, we decided to change our name. We want our Committee's name to parallel the AEI Team at the national office. We are now the Board AEI Committee. We are working to make this change official. This will involve updating the bylaws.

Since the 2020 Board elections, we welcomed our newly reformed Committee, which now includes 15 members. This is the largest our

Committee has been. We have many wonderful Committee members who bring passion and excitement to our work.

In April 2021, we held our first Committee meeting. At our meeting, we discussed the past and current work of the Committee and The Arc's AEI Team. We reviewed the recommendations of the 2020 Board Diversity Committee. These have informed our work this year. We reviewed the process and timeline for AEI strategic planning. This effort is being co-led by the Committee and The Arc's AEI Team and involves the full Board.

In May/early June, we sent an inclusion and identity survey to the Board. The survey asked about identity and people's experiences on the Board. We want to make sure Board members feel valued, welcomed, and respected. We shared the survey results during the July Board and Committee meetings.

In June 2021, we held our second Committee meeting. At our meeting, we discussed the current work of the Committee and The Arc's AEI Team. We reviewed the latest draft of the AEI strategic plan. We also discussed the proposed revisions to The Arc's Core Values.

In July 2021, we held our third Committee meeting. At this meeting, we discussed the latest draft of the AEI strategic plan and the Board's feedback. We voted to move to Phase 2 of our strategic planning process.

In August 2021, we held our fourth Committee meeting. At this meeting, we discussed the Board survey results. We also discussed AEI strategic planning.

### **What's Next for the AEI Committee?**

The AEI Committee will meet monthly until strategic planning has concluded. We plan to wrap up AEI strategic planning by the September 26<sup>th</sup> Board meeting. However, we are prepared to extend the work into 2022 if needed. In addition to strategic planning, we will continue work related to the Board Inclusion & Identity Survey.

## The Arc's National Council of Self Advocates (NCSA)

### 2021 Business Meeting Report

#### About Us

The Arc created the NCSA to actively engage people with intellectual and developmental disabilities in our work. Our NCSA is led by people with intellectual and developmental disabilities, and all our members are people with disabilities.

The NCSA meets many times each year. We meet online as well as in-person at our national convention. During our meetings, we share about big issues that our members are interested in. We also provide feedback and advice to staff at The Arc to guide their work.

#### 2021 Efforts

- We expanded our NCSA leadership for 2021-2022 from six to ten leaders. We did this to make sure that our leaders reflected the diverse experiences of people with IDD, particularly reflecting people from communities of color, with diverse gender identities, and who come from the LGBTQIA community. Our new leaders shared about themselves and their advocacy passions via social media in summer 2021.
- We provided guidance on many issues, including The Arc's Strategic Framework for 2020-2030; The Arc's Core Values and Principles; and the strategic plan for advancing Access, Equity, and Inclusion. Our members will also be providing feedback on changes to four of The Arc's position statements in the fall and winter of 2021.
- Our members also met to learn more about key COVID-19 recovery issues and learned how they can advance grassroots advocacy efforts in their states.
- NCSA volunteers have also shared about other opportunities to give feedback to partner organizations around accessible technology, criminal justice, health disparities, and other issues.

How do I join the NCSA? Sign up here: [thearc.org/join-the-national-council-of-self-advocates/](https://thearc.org/join-the-national-council-of-self-advocates/)

Questions? Contact us at [NCSA@thearc.org](mailto:NCSA@thearc.org).

**National Sibling Council 2021 Business Meeting Report**  
**Grace Francis, Chair**  
**Liz Mahar, Arc Staff**  
**October 2020- August 2021**

**The National Sibling Council engaged in the following key activities:**

- We received 70 applications for the 2021-2022 National Sibling Council and welcomed eight new members to our 2021-2022 National Sibling Council:
  - Acrystal Pugh, CA
  - Hannah Roundtree, TX
  - Ilknur Eren, NJ
  - Karah Ley, MI
  - Nayma Guerrero, CA
  - Paul Giordano, NY
  - Shane Janick, PA
  - Wendy Parkin, PA
- Sibling Council members, in addition to Grace Francis, Liz Mahar, and Nicole Jorwic, held quarterly meetings to:
  - Receive an Arc advocacy & policy update (e.g., HCBS)
  - Receive an update on Arc initiatives (e.g., policy movements)
  - Discuss advocacy strategies and needs observed across the country
- Sibling Council members were also invited to provide feedback on Arc initiatives (e.g., core values, strategic framework)
- Sibling Council members contributed their stories to enhance The Arc's outreach, including The Arc Sibling E-newsletter and social media (<https://www.facebook.com/media/set/?vanity=thearcus&set=a.10161688240372715>)
- Current sibling list size: **2,731**
  - The **first** email in 2020 (on 3/1) was delivered to 1,646 people
  - The **last** email in 2020 (on 12/14) was delivered to 2,315 people
- Average email open rate in 2020: **23.47%** (includes a four-email average)
- Average email open rate in 2021: **24.75%** (includes a two-email average)

Respectfully submitted,

Grace Francis  
Vice President, Arc Board of Directors  
National Sibling Council Chair

Liz Mahar  
Director, Family & Sibling Initiatives



## The Arc Alumni Council

The Arc Alumni Council is for:

- ◇ The Arc lifetime disability rights activists who want to continue to advocate with and for people with IDD
- ◇ Experienced nonprofit professionals and volunteer leaders who want to give back by sharing their knowledge and expertise with current and emerging leaders
- ◇ Valued colleagues who wish to maintain enriching professional and personal relationships
- ◇ Parents, siblings, family members, self-advocates, professionals, and supporters who are committed to the ongoing success and sustainability of chapters of The Arc and the federation as a whole.
- ◇ The Alumni Council will advance The Arc's mission to promote and protect the human rights of people with intellectual and developmental disabilities and actively support their full inclusion and participation in the community throughout their lifetimes.

**PLEASE JOIN US!**

With Marty Ford staffing our committee, we meet quarterly to hear about and discuss the progress and the challenges facing The Arc, and to learn how the staff and volunteers are tackling them; to hear about new ideas and exciting ventures:

In **March** we met with *Chris Stewart, President/Chief Executive Officer, The Arc of Central Alabama*; and Chair, NCE Steering Committee to learn of the impact of COVID on Individuals and Chapters around the country.

We also heard from *Nicole Jorwic, Senior Executive Officer, State Advocacy for The Arc US* for an update on the Federal COVID Relief.

How about a lively discussion?! In **May** we met for a great discussion and to give feedback to the Strategic Framework planning group about the Revisions of the Core Value and Guiding Principles.

*Shira Wakschlag, Senior Director, Legal advocacy and General Counsel at The Arc* gave us an overview of The Arc's legal advocacy work, including discussion of our COVID-19 advocacy work, voting rights litigation, education class actions, and other initiatives in **July**.

This is also a time to reconnect with colleagues and friends who have joined The Alumni Council and value staying connected with The Arc.

**PLEASE JOIN US!**

# *The Arc Alumni Council*

As The Alumni Council progresses, we hope to have our members also participate in a number of other volunteer opportunities such as:

- \* Self-Advocate Support: serving as a mentor to self-advocates;
- \* Chapter Mentoring: providing technical assistance to chapters, for example in governance, management, development, transition, etc.;
- \* Future Planning Facilitation: for individuals with IDD and their family;
- \* National Committee service: serving on a committee, or work force, or task group for the national organization, for example;
- \* Outreach: visiting local chapters or other disability organizations to strengthen connections;
- \* Speakers Bureau: making presentations about The Arc.

Stay connected and involved with The Arc! And with its chapters and families.

**PLEASE JOIN US!**

Nancy Webster, Chair  
August 2021