

The Power of Advocacy

Tom Baffuto, Executive Director
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Overview of The Arc of NJ

- State's largest advocacy organization representing people with I/DD and their families
- 20 local Chapters providing hands-on support in every county
- MISSION: The Arc of New Jersey promotes and protects the human rights of individuals with I/DD and actively supports their full inclusion and participation in the community throughout their lifetimes; and is committed to enhancing the quality of life of those individuals and their families through advocacy, empowerment, education and prevention.

Programs of The Arc of NJ:

- The Arc of NJ Family Institute
- Mainstreaming Medical Care
- Criminal Justice Advocacy
- Planning for Adult Life
- Self-Advocacy Project
- Project HIRE
- Training and Consultation Services

The Arc of NJ Family Institute

- The Arc of New Jersey Family Institute was created to be the “Go To” place for families caring for someone with I/DD, and to build a strong advocacy network.
- The Arc Family Institute Advocates, Educates and Empowers families while building an effective advocacy network.
- The Arc Family Institute is dedicated to providing timely information, advocacy, support and training to family members of an individual with Intellectual and Developmental Disabilities.
<https://www.thearcfamilyinstitute.org/>



The Importance of Advocacy



- Public Policy works best when family members, self-advocates, professionals and caring citizens work together
- If the voice of the disability community is not heard, the needs we face will be overlooked
- It is particularly important at this time, but really at all times, to make sure individuals and families are part of the dialogue and that this community and the unique challenges we face, are prioritized and at the forefront.

How You Can Help

- Get connected to receive action alerts
- Connect with your legislators
- Connect with the media
- Connect with your local community



The Arc of New Jersey

ACTION ALERT
For Immediate Action
TIME SENSITIVE

Advocating for children and adults with I/DD and their families

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Act Now Tell Congress to Include People With Disabilities in Coronavirus Relief Bill!

Take Action Now!

*** The House of Representatives has passed this bill - it is time for the Senate to act!***

People with disabilities are more likely to have underlying health conditions – this means that they will be disproportionately impacted by the COVID-19 pandemic and need immediate support! This includes expanding access to health care, making sure that direct support professionals (DSPs), who support people with disabilities to live independently, can continue to do their vital work, and much more.

Legislation is quickly moving through Congress to respond to this global crisis. We must ask Members of Congress to include the vital needs of people with disabilities, specifically:

- Increased federal reimbursement for state Medicaid programs to help states respond to the crisis
- Ability to access a 90-day supply of medication and medical supplies
- Emergency requirements for all health insurers to cover testing
- Expanded nutrition assistance
- Workforce support, including paid sick leave and paid leave for all workers

Without this legislation, people with disabilities face possible institutionalization, which would violate their rights and risk their health.

Recent Advocacy Successes – (State)

- Hospitals must permit a Support Person for people with I/DD
- Temporary wage increases for Direct Support Professionals (DSPs)
- Day program funding continued
- Enhanced funding for residential services
- Rationing of care guidance to prohibit discrimination
- Increased testing
- Priority testing for DSPs and people with I/DD

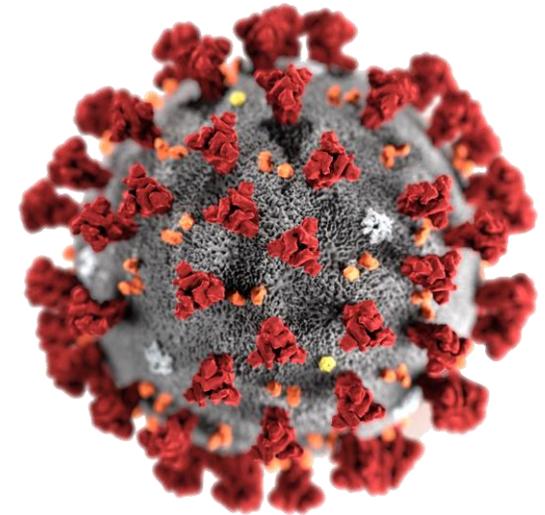


Recent Advocacy Successes – (Federal)

- [HHS Office for Civil Rights Bulletin to prohibit discrimination:](#)
 - “Persons with disabilities, with limited English skills, and older persons should not be put at the end of the line for health care during emergencies.”
- [#FixtheGlitch](#) – This change ensures that people with disabilities on SSI will automatically receive the Recovery Rebate payments authorized by the Coronavirus Aid, Relief, and Economic Security (CARES) Act.
- [Protecting the IDEA:](#) Secretary DeVos Forgoes Waiving Disability Law Amid School Closures
- The House passed (on May 15th) its fourth coronavirus package, [the Health and Economic Recovery Omnibus Emergency Solutions \(HEROES\) Act](#) – the bill includes many elements that will provide critical assistance to people with disabilities, their families and the direct support workforce during this pandemic.

Issues We Continue to Face – (State)

- Continued funding for day programs
- Enhanced money for residential providers
- More PPE
- Advocacy with NJ Department of Education to ensure:
 - Students with I/DD have technology they need to participate in virtual learning
 - Compensatory services will be available should they be necessary when schools re-open
 - Extended School Year (ESY) for students with I/DD is available – even if the only option is virtual



Issues We Continue to Face – (Federal)

- #WeAreEssential Campaign - we need the Senate to pass legislation that includes the critical needs of people with disabilities, their families, and the direct support professional workforce. Looking to address the following items:
 - HCBS to keep people with I/DD in their homes and communities
 - Access to PPE for direct care workers
 - Ensure paid sick days and paid leave provisions
 - Economic impact payments for all people with disabilities



Current Advocacy Challenges

- Engaging the grassroots. Families are dealing with extra challenges brought on by the pandemic
- Legislators are flooded by issues and constituent groups
- Disability community faces a myriad of issues
- Limited funding to support all of the vulnerable populations
- Legislative offices are mostly working remotely
- In-person meetings not possible at this time
- Uncertainty about the future

Ways you can still advocate:

1. **Writing**
2. **Calling (May take extra time to connect)**
3. **Media (Letter to the Editor)**
4. **Social Media (Facebook, Twitter)**



Tips for Advocacy



When responding to an action alert (Email/Letter)

- Address your letter directly to the Senator/Assemblyperson/Congressional Representative
- Use People First Language
- State that you are a constituent (this means you live in the geographic region the legislator was elected to represent)
- State the issue clearly
- Include additional materials: fact sheets, statistics, etc., if you have them
- Ask for a response: “I look forward to hearing how you will work to address this issue.”
- Always be polite even if you don’t agree with your legislator’s political party or stance.

Tips for Advocacy

When responding to an action alert (Phone)



- State that you are a constituent and calling about an issue or a Bill that is up for vote.
- Use People First Language
- Provide your contact information so they can respond and/or keep you up to date about the issue you're calling about
- Clearly state the issue & keep your message short and simple
- State why the issue matters to you
- If you are asked something, and you do not know the answer, be honest. Let them know you will get back to them with the information.
- Ask for a commitment. Example: "Can I count on the Senator to vote yes/no?"
- Always be polite

Tools for Advocacy

- How to find who represents you in Congress and on the State Level:
 1. [Disabilityadvocacynetwork.org](https://disabilityadvocacynetwork.org) (Will provide national and state representatives)
 2. www.njleg.org (Will only provide your state legislator info)

These sites list phone numbers and email addresses for your representatives

Your most important tool is your personal story!

- Relating that story in an effective way is the most impactful way of advocating.
- How is the COVID-19 pandemic or whatever the current advocacy issue of the day, affecting your loved one with I/DD?
- A personal story is the best means for getting and keeping someone's attention. It has the biggest effect and leaves the most lasting impact.

Why do stories matter?

- Stories educate people about important programs and services
- Personal stories make policy "real"
- Stories motivate people to act

What's Ahead?

FY21 State Budget

- COVID-19 will have a tremendous impact
- The original proposal from the Governor in early March included a number of great things, including: DSP wage & day program funding
- We will continue to advocate for the inclusion of those items in addition to our pre-COVID advocacy campaign to increase Early Intervention rates

Work to protect Medicaid

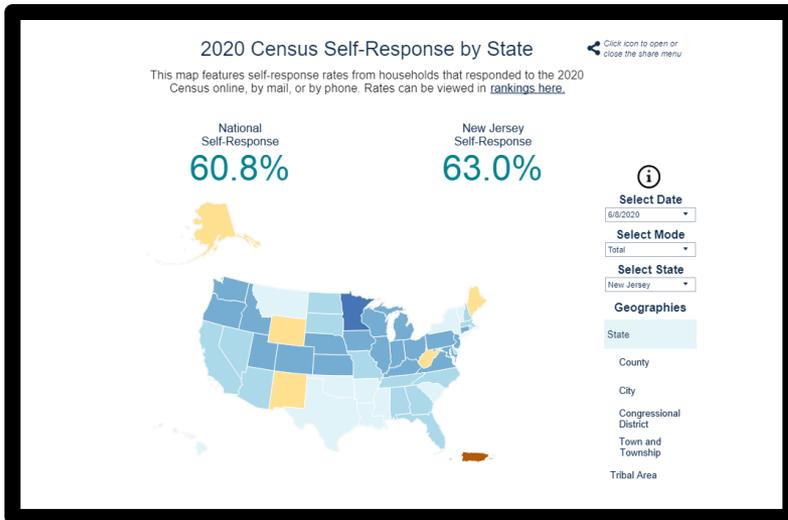
- There will be a significant strain on Medicaid and funds for this critical program in light of COVID-19



Weighing in on NJ's Re-opening

- Governor's Restart and Recovery Advisory Council – Social Services and Faith Subcommittee
- DDD Reopening Committee
- CEArc Internal Reopening Committee

Census 2020



- ***The numbers above are accurate as of June 9, 2020***

- Every 10 years, everyone in the United States is counted through the census.
- Data determines how much money state and local governments receive
- Due to COVID-19 the US Census Bureau has extended the self-response phase deadline for the 2020 Census to October 31st.

Resources:

- **The Arc US census page:**
<https://thearc.org/census/>
- **The Arc of NJ Family Institute Census Page:**
www.thearcfamilyinstitute.org/spcial-campiangs/census-2020.html

Contact

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