

# Discovering a Treasure in The Arc Chapter Network



For people with intellectual  
and developmental disabilities

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# Learning Objectives

1. Importance of serving people with intellectual and developmental disabilities and their families
2. Who The Arc is and How The Arc's chapter network serves people with I/DD and their families around the country
3. The Arc of the United States's information and referral process
4. Top requests received from people with I/DD and families
5. Common referrals made by The Arc of the United States



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# Importance of Serving People with I/DD & Families

- There are 4.98 million people with I/DD in the US
  - Only 25% receive any public services or are connected with the “formal” service system
  - The rest receive support through their families and “informal” or “natural” supports
- 71% of people with I/DD (3.5 million+) live with their family caregiver; proportion living with aging caregivers likely to grow
  - 860k+ caregivers over the age of 60
  - 1.2 million+ are aged 41-59
  - 1.4 million+ are younger than 40
- People with I/DD living longer today - needs for and length of time needed for support services have changed as well

# What is The Arc?

- In 1950, a small group of parents came together to act as voices for change. At the time, little was known about the condition of intellectual disability or its causes. There were virtually no programs and activities in communities to help people with intellectual disability or to support families.
- At the outset, the organization was committed to altering perceptions of children with intellectual and developmental disabilities and to educate parents and others regarding the potential of people with intellectual and developmental disabilities.
- Over the last 67 years, The Arc has advocated for the passage of state and federal legislation on behalf of people with disabilities and established a broad network of chapters that range from small volunteer groups to large, professional organizations.



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# What is The Arc?

Today, The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.

Our network includes over 174,000 employees and volunteers that support 1 million people with IDD and family members at 650+ chapters nationwide

Find a chapter:

<http://www.thearc.org/find-a-chapter>



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# About The Arc

Programs at Chapters of The Arc provide services to individuals with I/DD, their families, and the wider community. Services include:

- Public Awareness
  - Parent Support
- Recreational Services
- Day Habilitation Services
- Early Childcare Services
  - Respite
- Education/Transition Services
- Sibling Support
- Grandparent Support
  - Future Planning
- Employment Services
- Transportation Training
- Professional Training
- Therapeutic Services



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# About The Arc

Chapters of The Arc also advocate for system change as well as for individual rights. Common advocacy issues include:

- Health Care Policy and Access to Health Care/Treatment
- Home/Community Based Services
  - Employment Policy and Discrimination
  - Transportation
  - Criminal Justice
- Civil Rights/ADA
- Housing Policy and Discrimination
  - Funding, appropriations
- Public Benefits Policy/Access
  - Education Policy/IEP
- Direct Service Workforce
- Individual Accommodations

# Information and Referral at The Arc

## Inquirers contact The Arc or its resource centers

- Contact us at 1-800-433-5255 or at [info@thearc.org](mailto:info@thearc.org)
- Contact our Center for Future Planning at [futureplanning@thearc.org](mailto:futureplanning@thearc.org) or 202-617-3268
- Contact Autism NOW at 1-855-828-8476 or [info@autismnow.org](mailto:info@autismnow.org)
- Use online forms to request assistance through our website

## Staff dedicated to answering inquiries

- Staff monitor inquiries and respond to inquirers
- Staff research issue and provide customized response and referral by phone/email



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# Information and Referral at The Arc

## Topic Areas:

- Navigating Website
- Services
- Self-Advocacy
- Medicaid
- Housing
- Federal Policy
- State/Local Agencies
- Getting Involved with The Arc
- Physical Donations
- Monetary Donations
- Research Requests
- Other

## I am a.. Areas:

- Self-Advocate
- Sibling
- Parent
- Professional
- Other

First Name \*

Last Name \*

E-Mail

Phone Number

Address

City

State \*

Zip Code

I am looking for something related to... \*

I am a...

I prefer to be contacted by \*

E-Mail  Phone

Please describe your inquiry \*

Yes, I would like to receive email from The Arc.

I am interested in more information about becoming a member of The Arc.

# Information and Referral at The Arc

## About our Inquiries:

- We receive over 10,000 inquiries a year; 6,000 via email and online form
- Callers are often family members of people with I/DD - often parents and siblings - and professionals
- We get calls from people with I/DD but less frequently - usually a call from a supporter

# Information and Referral at The Arc

- Questions range from diagnosis/birth to end of life planning. This includes crises scenarios (e.g., homeless, death of caregiver).
- Top Requests for Assistance:
  - Connection to a local service provider
  - Need assistance with transportation or housing
  - Questions about benefits/services
  - Autism-specific services
  - Future planning assistance
  - Help with the criminal justice system

# Common Referrals Made

## Knowing Common Resources

Our most frequent referral is to a  
Chapter of The Arc:

<http://www.thearc.org/find-a-chapter>

Chapters of The Arc are experts in providing or  
identifying services in the communities they serve.



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# Common Referrals Made

In urgent cases:

<http://www.nasddds.org/state-agencies/>

Every state has different ways of providing services, and the state I/DD agency will identify short and long-term options for the person with I/DD



# Common Referrals Made

When rights may be being violated:

<http://www.ndrn.org/en/ndrn-member-agencies.html>

Protection and Advocacy agencies provide legal representation and other advocacy services to all people with disabilities.

# Common Referrals Made

## Other common referrals:

- **Developmental Disabilities (DD) Councils** - <http://nacdd.org/councils/>
- **Self-Advocacy Organizations**
  - Self Advocates Becoming Empowered (<http://www.sabeusa.org/>)
  - Autistic Self Advocacy Network (<http://autisticadvocacy.org/>)
- **Parent Training and Information Centers and Community Resource Centers** - <http://www.parentcenterhub.org/find-your-center/>
- **Parent to Parent Organizations** - <http://www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx>
- **University Centers for Excellence in Developmental Disabilities (UCEDDs)**- <https://www.aucd.org/directory/directory.cfm?program=UCEDD>
- **Centers for Independent Living** - <http://www.ilru.org/projects/cil-net/cil-center-and-association-directory>

# Common Referrals Made

National Center on Criminal  
Justice & Disability®



We also refer to experts on content areas in our national office around criminal justice, special education advocacy, and future planning.



The Arc@School



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**The Arc.**

Center for Future Planning

supporting adults with intellectual and developmental  
disabilities (I/DD) and their families to plan for the future



The Center provides reliable information and assistance in these areas to individuals with I/DD, their family members and friends, support professionals and the community:

- person-centered planning
- decision-making
- housing options
- financial planning



For more information please visit [futureplanning.thearc.org](http://futureplanning.thearc.org)

# Want to Know More?



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