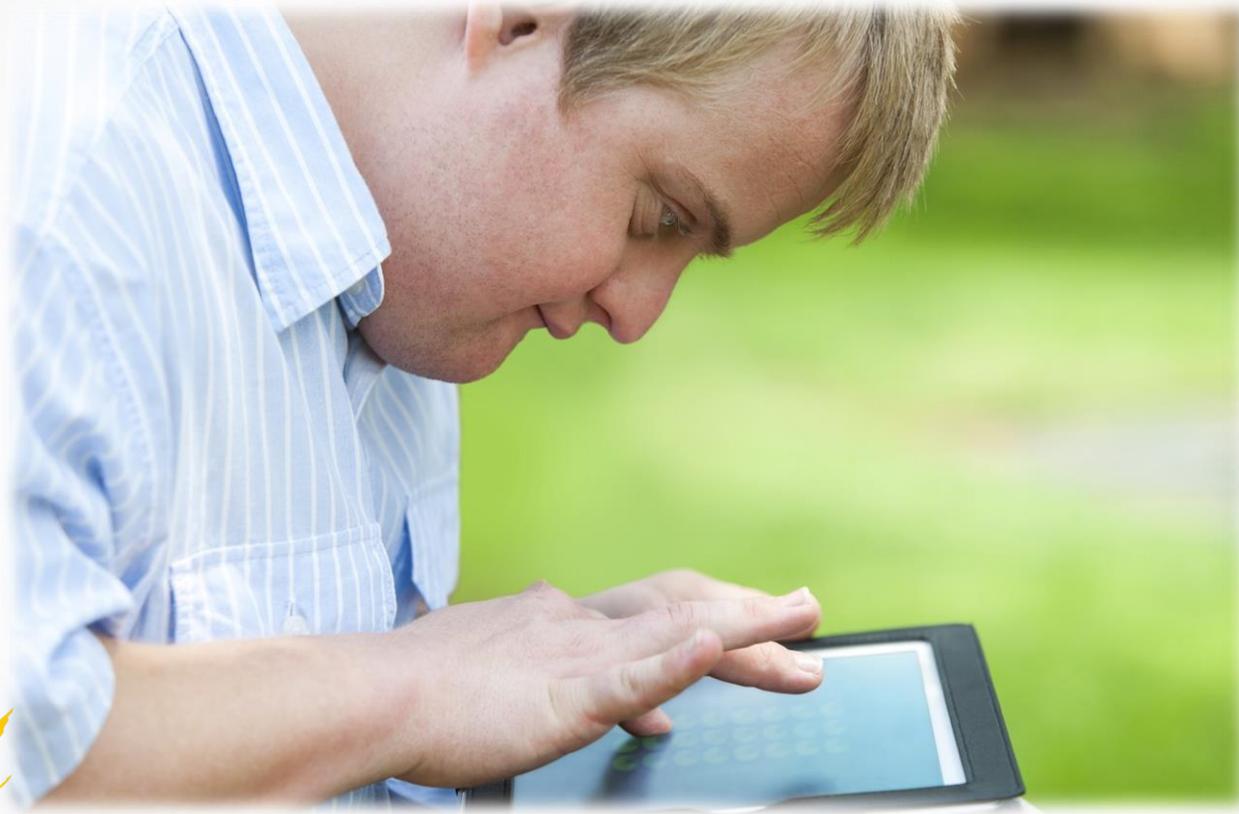


Navigating Disability: Communications and Resources



For people with intellectual
and developmental disabilities

Jennifer Sladen, Program Manager, National Initiatives

Achieve with us.®



Agenda



1. Disability & The Goal of I&R in the Disability Community
2. The Arc's Role in the Disability Community
3. Common Support Needs of People with I/DD and their Families
4. Assisting People with I/DD and their Families with Information and Referral Needs in a Disability- and Culturally-Competent Manner
5. Key I/DD Resources and Referrals
6. Practicing Typical & Crisis Scenarios



For people with intellectual
and developmental disabilities

Achieve with us.

What is Disability?

- **Four Types of Disability:**
 - Intellectual and/or Developmental Disability
 - Mental Health Condition (also called a Psychiatric Disability)
 - Physical Disability
 - Sensory Disability
- People may experience one or multiple types of disability.
- People may identify as having one or multiple types of disability.
- People may move in and out of disability during their life.
- As people age, disability prevalence increases.
- People may have different experiences of disability based upon the environment they live in.
- People may be perceived as having a disability in one culture and not in another.

Goal of I&R for People with Disabilities

- To provide person-centered information and resources so that people with I/DD can live full and good lives in the community to the greatest extent possible.
- To provide family-centered resources to families of people with I/DD so that the family receives any support it needs to function as well as possible.

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.



For people with intellectual
and developmental disabilities

Achieve with us.®



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>



For people with intellectual
and developmental disabilities

Achieve with us.®



Center for Future Planning

Learn

about future planning

Build

your future plan

Find

a professional

See

how others have planned

Get

help for urgent needs



futureplanning.thearc.org



*For people with intellectual
and developmental disabilities*

Achieve with us.®



Support Needs

What questions have you received from people with I/DD or their families?

What information and support needs do you think are most important to people with I/DD and their families?



For people with intellectual
and developmental disabilities

Achieve with us.



Support Needs - About 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 unpaid support through their families and communities; also called “informal” or “natural” supports
- 71% of people with I/DD (3.5 million+) live with a 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
- More and more families and people with I/DD will need to be aware of and access the resources available through aging services as the family ages together and cares for each other

Support Needs - What The Arc Hears

About Information and Referral Requests We Receive:

- 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., homelessness, 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

Assisting People with I/DD and Families

1. Assess Your Own Bias/Assumptions
2. Understand How Disability Interacts with Family's Cultural Background
3. Practice Good Communication Skills
4. Use Effective Probing Questions
5. Use Disability-Competent Language

Review Assumptions

Myth	Reality
Most people with disabilities use wheelchairs.	Only 10% use wheelchairs, crutches, or walkers. Most have invisible disabilities.
People with disabilities are a drain on the economy.	Majority of people who are not employed want to work, but discrimination maintaining eligibility for public benefits and services often hampers ability to join workforce.
The greatest barriers to people with disabilities are physical ones.	Stereotypes and attitudes are often the greatest challenges to people with disabilities.
People who have disabilities are brave and courageous.	People with disabilities react to situations just like anyone else and have a variety of emotional reactions in adapting to disability.
Government health insurance covers people with disabilities.	Medicaid provides coverage for only a small percentage, usually those with significant disability.

Review Assumptions

- You can test your own implicit biases on disability and host of issues at Project Implicit : <https://implicit.harvard.edu/implicit/>
- Georgetown University's National Center for Cultural Competence provides organization self-assessment and resources on disability and cultural competence: <https://nccc.georgetown.edu/>
- Assumptions on previous slide come from the Community Access Network in Texas (<http://canatx.org>)

How Culture & Disability Interact

- Culture influences how people and families approach I/DD services and disability
 - Whether to disclose a family members' disability
 - Whether to ask for help with caring for family member
 - What services the family wants to use
 - What is expected of the parent and the child
 - How the family is viewed or interacts with their community
 - How the family relates to the formal service system
- Cultural beliefs and traditions vary within and between families as well as generationally
- There can be an “Americanizing” influence on cultural beliefs of different groups in the US

How Culture & Disability Interact

What if....

You receive a call from a young woman. Her older brother has I/DD and a mental health concern and lives at home with her parents, who are both in their 70s. Her parents have both had several health concerns in the last year, and they can't take care of her brother anymore. She knows she will be responsible for taking care of her brother when her parents pass on, and she wants to start moving her brother into a place near where she lives. However, her parents feel it they must take care of her brother - that it is their duty to do so. The parents also mention that they want her to take care of her brother in her home, not in a place nearby.

She wants to help her parents and her brother get the help they need, but she doesn't want to go against her parents' wishes. She also doesn't know what to do about the future; she doesn't want to and can't have her brother in her home, but doesn't want to disrespect her parents.

How Culture & Disability Interact

Questions:

1. What type of information would you like from me that you think can help you best for your family?
2. Has your family connected with services in your community in the past? Would you like to be connected again in the future?
3. What sort of help do your parents need in their home? Your brother? You?
4. We can connect you with local support groups that bring together many different types of families to deal with hard issues. What types of support groups that you want to be connected with most?

Resources:

- Eldercare Locator and Aging Services
- Local I/DD service provider, like The Arc
- Sibling support group
- Service group for cultural group, if the family identifies themselves



Achieve with us.

How Culture & Disability Interact

What if....

You receive a call from a pediatrician. They have just begun serving a new Chinese family - a mom, dad, and a 5-year old son. The doctor notices that the son has many of the indicators for autism, but the family does not have a diagnosis. When the pediatrician mentions the need for the family to do testing and to be connected with services, the family seems to shut down and not want testing or services. The pediatrician is looking for help with resources and to help the family.

What questions and resources would you give this doctor?

How Culture & Disability Interact

Questions:

1. What type of information do you think would be most helpful for this family?
2. We can connect the family with local services and support groups. Do you have an idea of a few groups that you think they may be interested in?

Resources:

- Parent support group
- Organization that represents Chinese Americans
- Local I/DD service provider, like The Arc
- Local Autism Society or Autism Speaks group
- Parent support groups
- I/DD agency - for if the family wants to have services

How Culture & Disability Interact

How I&R Professionals Can Provide Culturally Competent Assistance

1. Be mindful of how different cultural groups view and treat disability and any tensions between the service system and cultural beliefs
2. Listen to what problems are and ask family/caller about what help they want from you
3. Avoid probing questions that have an implicit value judgment about services
4. Provide resources available as accurately and descriptively as possible so that the family can understand the options available to them
5. Pair I&R professionals who are fluent in the language and familiar with the culture to answer families' questions. If not possible, make translation available.
6. Seek out volunteer groups, community organizations, family support groups, and professionals in your community that are families with different cultural groups to customize I&R scripts/recommended probing questions to cultural differences

Use Good Communication Skills

Challenge

Solution

Inquiries often come from parents, siblings, and people with I/DD

- Use probing questions, but avoid value judgments
- Recognize that the issues and needs may be more complex than what is requested initially
- Ask about what the wishes are of the person with I/DD
- And, consider the needs of the *entire* family

People may be difficult to understand or not use appropriate terms

- Ask for as many clarifications as you need to understand what the person is saying and what the need is
- Never pretend you understand if you don't!

Information may not be presented in a logical manner initially

- Paraphrase and repeat information back to person. (e.g., "Here is what I heard you say... Is this right? Is there anything else that I should know about?")

They may direct their stress at you

- Empathize with situation and reiterate solution you can offer
- Don't accept blame for situation you can't control

Using Probing Questions

Example, “My son or daughter needs more benefits/services”

- What public benefits does your son or daughter currently receive?
- Has your son or daughter connected to your state I/DD agency? Is he/she interested in doing this?
- Do you want help connecting to a financial planner or an attorney to help your develop a plan to make sure your son or daughter has the money he or she needs in the future?
- What other things do you think your son or daughter may need in the future (e.g., more support in his or her home; help getting around in the community)? Are you interested in connecting to local community groups to help you make these plans?
- What other support do you and your family need?



The Arc

For people with intellectual
and developmental disabilities

Achieve with us.



Disability Competent Language

Person- First Language Chart

(http://www.inclusionproject.org/nip_userfiles/file/People%20First%20Chart.pdf)

SAY:

People with disabilities.

He has a cognitive disability/diagnosis.

She has autism (or a diagnosis of...).

He has Down syndrome (or a diagnosis of...).

She has a learning disability (diagnosis).

He has a physical disability (diagnosis).

She's of short stature/she's a little person.

He has a mental health condition/diagnosis.

She uses a wheelchair/mobility chair.

He receives special ed services.

She has a developmental delay.

Children without disabilities.

Communicates with her eyes/device/etc.

Customer

Congenital disability

Brain injury

Accessible parking, hotel room, etc.

She needs... or she uses...

INSTEAD OF:

The handicapped or disabled.

He's mentally retarded.

She's autistic.

He's Down's; a mongoloid.

She's learning disabled.

He's a quadriplegic/is crippled.

She's a dwarf/midget.

He's emotionally disturbed/mentally ill.

She's confined to/is wheelchair bound.

He's in special ed.

She's developmentally delayed.

Normal or healthy kids.

Is non-verbal.

Client, consumer, recipient, etc.

Birth defect

Brain damaged

Handicapped parking, hotel room, etc.

She has problems with...has special needs.

Using Disability Competent Language

- The disability field commonly uses person-first language (e.g., person with autism, person who has low vision or is hard of hearing)
- But, some people with disabilities prefer to use identity-based language to refer to themselves (e.g., autistic, blind, or deaf)
- BEST PRACTICE: Use person first language initially, and then use the same type of language that the caller uses to identify their or their family member's disability or health condition

NEVER use the “R” word!



For people with intellectual
and developmental disabilities

Achieve with us.



Review - Assisting People with I/DD with I&R

1. Review and check any assumptions you may have about people with disabilities
2. Learn how and be sensitive to how different cultural groups in your community think about disability BUT don't assume that the family may adhere to all of the beliefs of the group
3. Practice active listening and good communication skills when interacting with family
4. Use effective probing questions to identify complex needs or the needs of the whole family
5. Use disability-competent language and use the same terms as the family, if appropriate, when providing support



For people with intellectual
and developmental disabilities

Achieve with us.



Common Referrals

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.

Other service organizations to connect with that are experts in local resources include Easter Seals or disability-specific organizations.

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>

Practice Scenario

56-year old woman calls. Her mother - who has been taking care of her sister with TBI - has just been placed into hospice. She thinks that she will be asked to take care of her sister when her mother passes, and she says she doesn't know what she should be doing.



*For people with intellectual
and developmental disabilities*

Achieve with us.®



Practice Scenario

Identified Needs:

- **Education:** Sister needs education on caregiving and disability community
- **Future Planning:** Sister who will be caregiver needs support to discuss issue with her mother and sister while there is still some time, and sister will need assistance to take stock of current situation and ensure care continues uninterrupted once mother passes
- **Grief and Loss Support:** Both sisters will likely need help with grief and loss after mother passes
 - **Sibling support/Caregiver support:** Sister who is likely to become caregiver may need support once she becomes a caregiver

Practice Scenario

Questions to Ask:

- Have you talked with your mom and sister about expectation for caregiving once mother passes?
- Do you know the details of your sister's daily life is like right now?
 - How familiar are you with disability services and benefits?
- Does your mother need additional resources that I can help you with?
 - Do you and your sister need more support to help your mother?

Information and Referrals/Resources:

- State Disability Agency
 - Chapter of The Arc
 - TBI-specific provider
- Sibling Support Group (Sibling Leadership Network)
 - Center for Future Planning
 - Local counseling agency
- Elder care services (as needed)
- Centers for Independent Living



For people with intellectual
and developmental disabilities

Achieve with us.



Small Group Practice

1. What needs can you identify in this scenario?
2. What questions would you ask this caller to probe the issue that they have?
3. Based upon what you can tell from the scenario, what information and referrals would you provide to the caller?
4. What additional resources do you think they may need?

Final Takeaways

When working with people with I/DD and their families:

1. Review any assumptions you have about people with disabilities
2. Be sensitive to how different cultural groups think about disability
3. Practice active listening and good communication skills
4. Use effective probing questions to identify complex needs or the needs of the whole family
5. Use disability-competent language and use the same terms as the family as appropriate when providing support
6. Make as comprehensive a referral as possible to family - don't hesitate to reach out to local/national disability resources!

Questions?



Jennifer Sladen
sladen@thearc.org
(202) 600 - 3490



For people with intellectual
and developmental disabilities

Achieve with us.®

