

Future Planning for Individuals and Families with I/DD



Jennifer Sladen and Max Daniel



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and developmental disabilities

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Learning Objectives

1. Definition of Future Planning
2. Barriers that Exist Relating to Future Planning
3. How The Arc serves people with I/DD and their families around the country
4. Essential Future Planning Principles
5. How the Center for Future Planning encourages adults with I/DD and their families to plan for the future
6. Tips on how to provide future planning I&R
7. Where to refer people if they need help making a future plan



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What is Future Planning?



Future Planning is creating a guide for a person with an intellectual or developmental disability (I/DD) to lead a good life as independently as possible. A plan is important throughout all stages of life and especially in the future after the parent or caregiver is no longer able to provide support.



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Why Don't People Make Future Plans?

There are 600,000 -700,000 families in the U.S. in which an adult with I/DD is living with aging family members and there is no plan in place for the individual's future.

Barriers to Future Planning:

1. Lack of Information
2. Difficulty addressing emotional issues related to caregiver's mortality
3. Unavailability of appropriate services
4. Difficulty of affording services of attorneys and other professionals

Why do YOU need to know about future planning?

1. Supporting people with I/DD and their aging caregivers to make these plans is going to be increasingly important in the next 15 years.
2. People will likely not call you to ask for resource - you will need to be able to recognize the need for future planning.



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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 60 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 voluntary 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 660+ 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

Future Planning Principles



1. Future plans are made by a team. The person with I/DD, his or her parents, siblings, extended family and friends, and professionals can all play key roles.
2. Every plan is person centered and reflect the wishes of the person with I/DD and other important people in his or her life



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Future Planning Principles

3. You don't need money or a lawyer to create a future plan - but you may want them

4. Planning leads to smoother transitions in the lives of people with I/DD and their families

5. Planning never ends - a plan should always be regularly reviewed and updated as a person's life changes



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Center for Future Planning

The Center for Future Planning aims to support and encourage adults with intellectual and developmental disabilities (I/DD) and their families to plan for the future.

The Center provides reliable information and practical assistance to individuals with I/DD, their family members and friends, professionals who support them and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning.

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



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Audiences

Where to Start?

Who are you?



Parent



Person with I/DD



Sibling



Staff at Chapter of The Arc



Other Family or Friend



Professionals



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Areas of Planning

Learn about these areas of future planning:



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Sharing Stories

See How Others Have Planned

A Parent's Perspective: Kandi's Independent Living

Ginger, Mother of Kandi

Daily Activities

Future Planning 101

Parent



I've always been someone who has wanted things to be better - not only for my daughter but for my community in general. When I first heard about future planning, it made sense to me that as parents, we need to plan for the future. Thinking and planning ahead will help your son or daughter achieve his/her highest potential.

My daughter, Kandi, is a great example of living an independent and good life. Kandi is a 50-year-old woman with moderate intellectual disabilities who lives and works in the community. With the support of a job coach, she has held a job at a grocery store for the last five years. Kandi lives in a townhome that is in a special needs trust I developed and she has the support of an aide who assists her with

daily living. The special needs trust also helps Kandi with expenses that are not covered by her public benefits. As a mother, I'm so happy that planning ahead has helped Kandi reach her highest potential.



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Build Your Plan

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about future planning

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Build Your Plan™

To better support families and individuals with I/DD in future planning, Build Your Plan™ is a tool that enables families to create accounts and begin to build their plans within the Center. Always keep the person with I/DD's interests, preferences, and skills as the main focus of the plan.



[Build Your Plan™](#)



View Your Plan

Create your Build Your Plan™ account and view your future plan at any time. This will guide you on what areas in a person's life to consider when developing a future plan.

[Build Your Plan™](#)

To-Do List

Future planning is important for all families, and it's an ongoing process. The Build Your Plan™ tool will soon have features that will allow you to view upcoming steps or create new steps in your future plan.



[Build Your Plan™](#)



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Quarterly Webinars

Webinar Trainings

The Arc has created the Center for Future Planning™ because we are committed to supporting families and people with intellectual and developmental disabilities (I/DD) as they plan for the future. This means creating a person-centered plan to help guide the person with I/DD to lead a good life as independently as possible. A plan is important throughout all stages of life and especially in the future after the parent or caregiver is no longer able to provide support. A person-centered plan keeps the person with I/DD's interests, preferences, and skills as the main focus.

Upcoming Webinars

The Center offers webinars and other training sessions to help you learn how you can support families in the future planning process. Webinars will be archived and made available online. Please contact The Arc's national office futureplanning@thearc.org to suggest a topic for an upcoming webinar.

[See Upcoming Webinars](#)

Archived Webinars

Completed webinars are recorded and made available for viewing after they occur. View the archived webinars from the Center's webinar series.

[Archived Webinars](#)

Archived Webinars

[What's Next: The ABLE Act in 2016](#)

[Breaking Up is Hard to Do: Divorce and Families that Include a Child with I/DD](#)

[Including Social Connections and Recreational Activities in Future Plans](#)

[Getting There: Including Transportation in a Future Plan](#)

[Planning for a Future in the Workforce: Jobs, Skills, and Supports](#)

[Supported Decision-Making: What Is It and What Do You Need to Know to Get Started?](#)

[SibTips Webinar: Understanding the Alphabet Soup of Future Planning](#)

[Future Planning Stories from Self-Advocates: Successes, Challenges, and How to Make Your Voice Heard](#)

[The Family: Aging and Disability](#)

[Building Bridges: Working with Faith Communities to Support People with I/DD](#)



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Future Planning Resources

Getting the Conversation Started:

<http://futureplanning.thearc.org/file/TipsForSibs.pdf>



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Tips for Siblings:

Getting the Future Planning Conversation Started



Your family needs to plan for how your sibling will live in the future, but starting the conversation can be very difficult. Here are some tips to prepare you to start talking with your family.

What do you want to say to your parents and sibling?

Think about what you want to tell your family about the importance of planning for the future. What role do you foresee playing in your sibling's life in the future? What other obligations do you have in your life that you need to balance? What information do you need to know to support your sibling?

❖ Who Should Be Part of the Conversation?

Think about who in your family should be part of the conversation and whether to start all together or with one or a few people at a time. Would it be best to talk with your parents first, either together or separately? How do you think your sibling with a disability should be brought into the conversation? What about your other siblings and family members? Who could help you start the conversation or join the discussion at another time?

❖ When Is A Good Time to Talk?

Find a time to talk when there are not a lot of activities or events occurring.

❖ Where Do I Feel Comfortable Bringing This Up?

Look for a quiet place where your family can have privacy to talk in a safe environment. If you live out-of-state, start the conversation by phone or via Skype.

For more information, contact:

The Arc
1825 K Street NW, Suite 1200
Washington, D.C. 20036
Phone: 202.617.3268
Email: futureplanning@thearc.org

futureplanning.thearc.org

MISSION

The Arc's Center for Future Planning aims to support and encourage adults with intellectual and developmental disabilities (I/DD) and their families to plan for the future. The Center provides reliable information and practical assistance to individuals with I/DD, their family members and friends, professionals who support them and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning.

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Future Planning Resources

Finding and Choosing a Lawyer:

http://futureplanning.thearc.org/file/CFP_FindLawyer.pdf



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Choosing a Lawyer to Help Plan for the Future



Planning for the future may require specialized legal assistance. When you are looking for a lawyer to help you plan, he or she should have experience in areas of the law such as:

- ❖ *Drafting special needs trusts with expertise in Trust and Estate law in your state and in the federal and state tax provisions related to special needs planning*
- ❖ *Different legal arrangements to support making major decisions, such as a power of attorney, supported decision-making, and guardianship or conservatorship.*
- ❖ *Federal and state law on public benefits for people with disabilities, including Medicaid, Supplemental Security Income (SSI), Social Security, and Medicare.*
- ❖ *The American with Disabilities Act, housing and employment programs for people with disabilities.*

Many families of people with intellectual and developmental disabilities (I/DD) also prefer to work with lawyers who maintain an involvement with organizations in the disability community.

Get Started: Ask for Advice

1. Request recommendations from friends, families who have a son or daughter with I/DD, or trusted professionals.
2. Schedule an interview with the lawyer to make sure you are comfortable with his or her style and approach to the work.
3. Visit www.lsc.gov to find a Legal Aid office that can provide free or low cost legal services if you cannot afford a private lawyer

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Aging Caregiver Outreach Professional Training

Goal: Engage caregivers over the age of 65 who are providing direct support to an adult son or daughter with I/DD in a future planning process.

Target:

- Train at least 60 professional staff in Tennessee and North Carolina

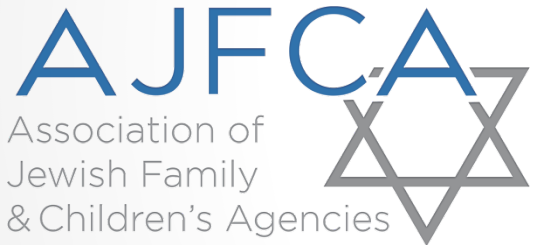
Why:

- Caregivers are often disconnected from online services and service system
- Build future planning skills and knowledge in professional services staff

First time The Arc is going beyond its network and partnering with organizations to reach aging caregivers



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Information and Referral

Information and referrals provided on future planning issues for families, people with I/DD, and professionals.

Email:

futureplanning@thearc.org

Phone:

202-617-3268



For people with intellectual and developmental disabilities

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

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I&R for Future Planning



1. Practicing Good Communication Skills
2. Providing Culturally Competent Assistance
3. Recognizing Future Planning Needs
4. Using Probing Questions
5. Knowing Common Resources



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I&R for Future Planning

Practicing Good Communication Skills

- Future planning calls often come from parents, siblings, and people with I/DD
- People may often be distressed and/or difficult to understand.
- Information may not be presented in a logical manner initially.
 - They may initially direct stress at you.
- Important to practice active listening skills, paraphrase problems and important information back

I&R for Future Planning

Providing Culturally Competent Assistance

- Some people may not mention a family member with I/DD
- Others may be stressed, distrustful or angry based upon their experiences with the service system

I&R for Future Planning

Recognizing Future Planning Needs

Most people are not going to call to say they need to plan.

- Need to find someone to provide legal advice regarding decision-making
 - Moving out of family home
- Needing extra support in home to support family (and caregiver is older)
- Worried about what happens to benefits when moving to a new state
 - Problem relates to need of an adult with I/DD

When chatting, make sure to restate their problem, current assets, and help them think through the whole problem that they have

I&R for Future Planning

Using Probing Questions -

Example, "My son or daughter needs more benefits/services"

- Does your son or daughter receive public benefits?
 - Is your son or daughter connected to your state I/DD agency?
- Do you have a special needs trust set up for your son or daughter? Do you know what a special needs trust is?
- Do you need help connecting to a financial planner to help your develop a plan to make sure your son or daughter has the money he or she needs?
- Have you thought about other things that your son or daughter may need in the future (e.g. more support in his or her home; help getting around in the community)? Have you connected to local community groups to help you make these plans?
- Would you like to learn more about how you can make future plans?



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Future Planning Referral

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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Future Planning Referral

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

Future Planning Referral

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.

Future Planning Referral

The Center for Future Planning is always available to answer future planning questions!

Email:

futureplanning@thearc.org

Phone:

202-617-3268



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Questions?



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