Future Planning for Individuals and Families with I/DD

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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
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.
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.
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.
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
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
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.
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
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.
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Center for Future Planning

[futureplanning.thearc.org](http://futureplanning.thearc.org)
Audiences

Where to Start?

Who are you?

Parent

Person with I/DD

Sibling

Staff at Chapter of The Arc

Other Family or Friend

Professionals

The Arc

For people with intellectual and developmental disabilities

Achieve with us.
Areas of Planning

Learn about these areas of future planning:

- Expressing Wishes for the Future
- Deciding Where to Live
- Financing the Future
- Employment & Daily Activities
- Supporting Daily & Major Life Decisions
- Making Social Connections
Sharing Stories

See How Others Have Planned

A Parent’s Perspective: Kandi’s Independent Living

Ginger, Mother of Kandi

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.
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™
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

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:

Finding and Choosing a Lawyer:

http://futureplanning.thearc.org/file/CFP_FindLawyer.pdf
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.
Information and referrals provided on future planning issues for families, people with I/DD, and professionals.

Email: futureplanning@thearc.org
Phone: 202-617-3268
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
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?

The Arc
For people with intellectual and developmental disabilities
Achieve with us.
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.
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:


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