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The National Autism
Resource & Information Center

A national initiative of The Arc



The Arc



Future Planning

Though the thought of it may be difficult, parents need to plan for what would happen to their child if they can no longer care for them.

By creating a future plan, parents can effectively organize their thoughts about their son or daughter wants and what they would like for their child's future; work with legal, financial, and other experts to provide for their child's needs; and describe the plan to others who need to know.

What do we mean by "Future Planning?"

Generally, a future plans contain the following characteristics: Comprehension, Participation, and Flexibility.

Comprehensiveness

Planning typically include arrangements for all aspects (financial, legal, living situation, education, employment, leisure, and personal needs) of a person's future. These plans gather as many formal and informal details about the child's current lifestyle as possible and use this information to direct the details of future planning. There is no right or wrong way to organize this information, but generally, having more details is more useful for someone implementing the plan.

Information typically included in Future Plans:

- Individualized Education Programs
- medical documents and lists of medical devices
- doctor contact information
- lists of parents' and child's assets, incomes, insurance policies, and liabilities
- social security and other legal information
- details about a child's personality, interests, behaviors, religion, employment, current living situation
- a letter of intent and vision statement describing the parents' or family's desires for the child's future quality of life and lifestyle.

Participation

Because the future plan provides support for a child to pursue their future life, the child often is and should be actively involved in determining the goals and direction of the future planning. Additionally, future plans often include siblings, friends, and any other people who play a significant role in a person's life. This inclusiveness helps ensure that the plan is followed if needed.

Flexibility

Future plans should be reviewed regularly to ensure they still fit their purpose. This is because the parents' and child's lifestyles, financial and legal standings, and interests and goals change over time.

Questions to Consider When Planning for the Future

Below are 10 questions that parents can reflect upon when beginning the future planning process. This list is not comprehensive but acts as a starting point for further research.



1. If something happens to me suddenly, what would someone need to know to get through the next 24-48 hours with my son/daughter with a disability?
2. If I cannot provide care for my child, with whom and where would my children stay?
3. Will my child have full-time employment after completing school? Do I need to plan for vocational or other employment options?
4. How should I plan for my child to have leisure time, vacation, and contact with family members?
5. Are there steps that I need to take to ensure that my child will have needed medical services or therapies?
6. Does my child have the ability to make important decisions? If not, how do I make sure protective measures, legal or otherwise, exist?
7. How do I find a good attorney? How much will services cost? How can I tell if an attorney is doing a good job?
8. Can my child receive government benefits? If my child receives government benefits that restrict personal income and assets, how do I provide needed financial support?
9. Is my child going to be able to earn a living wage? If not, how can I ensure he/she will have enough money to live on?
10. Can I get a trust to help provide for my child's personal and oversee their financial care?

Resources

Future Care Planning: A Roadmap for Family Caregivers

<http://sonoranucedd.fcm.arizona.edu/caregiverroadmap>

Life Planning: United Cerebral Palsy

<http://www.mychildwithoutlimits.org/?page=life-planning>

Possibilities: A Financial Resource for Parents of Children with Disabilities

<http://www.pacer.org/publications/possibilities/>

The Future is Now: Training Individuals with Disabilities and Families in Future Planning

<http://ici.umn.edu/products/impact/231/15.html>

About The National Autism Resource & Information Center

The National Autism Resource and Information Center is a dynamic and interactive central point of quality resources and information for individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities, and their families.

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The Autism NOW Center

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