

DISABILITY CAMPAIGN

Future Planning for Your Child with a Disability



Image: Mother and son at a Joni and Friends Family Retreat

Caring for a child with a disability can be challenging, especially when considering what the future may hold. According to the *Caregiving in the U.S. 2009* study, approximately 17 million unpaid caregivers provide care to a child with special needs under the age of 18 in the US.

Many of these caregivers are parents or relatives of the child, and therefore express greater concern for the future. Parents of special needs children often worry about what will happen when they pass away, whether their child will be independent or require care, and how their family will be able to afford these expenses. Below are some matters to consider in the planning of the future of your child with a disability.

- 1. Acknowledge that you may not always be there for your child.** A time may come when your health may fail, when you may not be able to provide the best care for your child's changing needs, or when your child will outlive you. No one will ever be able to replace the love, care, and protection you give to your child. But you cannot and should not be in this alone. Accept help as early as possible to prepare yourself and your child for the changes that will come ahead. In doing so, you will provide the best care for your adult child and for your family—even if you are no longer physically there for them.

2. **Do not assume that siblings or other relatives will provide care.** Often, siblings of children with disabilities help around the home or with the special needs of their brother or sister. But each member of your family has his or her own plans and hopes for the future, and the level of care they can offer may not be representative of the amount of love they have for their disabled relative. It's important to have honest conversations as a family on how much each family member is able or willing to contribute to the care of a relative with a disability.
3. **Contact an agency that serves families affected by disability.** If you know one local to you, contact them directly, but sometimes larger organizations are a great place to start. Remember different states and communities offer different services, so get to know what is available in your area. Some of these agencies will offer resources and workshops on how to financially plan for your child's future, and how to coordinate current and future care as a family.
4. **If you are considering a residential facility for the future, begin the search now.** These facilities may have long wait-lists. Furthermore, each facility has different amenities and services, and it's important to give yourself enough time to see which best meets the needs of your child and the finances of your family.
5. **Focus on increasing your child's independence.** Maybe he can learn how to cook a meal or she can practice doing her laundry. Greater independence may mean using a voice activation device or a picture board, performing one's own personal hygiene routines, or moving away from home. Think about enrolling your child in an independence living facility or daycare program.



Photo: ClelianHeights.Org

6. **Foster your child's hopes and dreams.** Allow your child to express her dreams, hopes, and plans for the future. Encourage her to put them into action if the situation permits; if not, help her channel her strengths and talents in ways that contribute to the community and bring her joy. Consider using a vocational coach, searching for volunteering opportunities, and enrolling in educational programs that can accommodate your child's disability.

7. Expose your child to other people.

Does your child spend most of his or her time at home? Introduce your child to others, especially other children of his or her age and adults with disabilities. If you have an intellectually disabled child, you may wish to expose him to a bank or supermarket to introduce activities that he may need to do in the future. If your child is in a wheelchair, think about sending her to a summer camp that accommodates kids or teens with disabilities.



Image: Wheelchair hockey at a Joni and Friends International Family Retreat

8. Focus your plans around your child's needs, hopes, and wishes—not yours.

Take a moment to step into your child's world. What makes her happy? What would stress him out or make him feel ignored? Does your child look forward to leaving the home or does she prefer a home-like setting? Once you've considered what will work for your child, measure how much you can accommodate in consideration of your family's resources.

9. Meet with a financial advisor. To protect your child's future, sit with an attorney and accountant to go over how your money can best serve your child.

Remember that the economy fluctuates, laws vary from state to state, and government benefits are always subject to change. Save money—but don't assume your savings or a special needs trust fund will take care of your child.

Take into consideration if your child will require a legal guardian and who will meet the emotional needs of your child once you are gone. Addressing finances is crucial to planning your child's future, but it won't meet his or her every need.



Image: Huffington Post

10. Don't forget to plan for yourself, your spouse, and your other children. If you want to be there as much as possible for your child, you have to care for yourself and the rest of your family. Do not neglect your needs and that of your other children or your spouse. It may be challenging to find a balance, and not everyone's wants will be met, but at least take them into consideration when making decisions—and if possible, make those decisions as a family unit.

For more information on future planning for your child with a disability, visit <http://www.thearc.org/CFP>. Visit <http://www.joniandfriends.org/family-retreats/> to find a camp for kids with disabilities near you.

Joni and Friends can assume no liability in the recommendation of any product, service or organization, nor does this constitute an endorsement.

© Joni and Friends, 2015

Used by permission of **Joni and Friends**

P.O. Box 3333, Agoura Hills, CA 91376

www.joniandfriends.org