

CREATIVE HOUSING OPTIONS

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The Arc of Massachusetts

Parents have been an undeniable resource for the service system. Parents who provide a life-long home for their son or daughter have made major contributions not only to their family but also to society.



OUR WISH

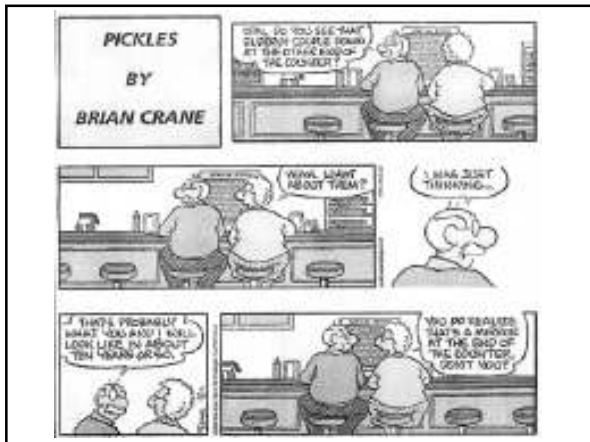
“We all wish that our child with “special needs” will have an enjoyable life, but that we live at least one day longer.”

Brian Rubin



You Are Not Alone


- Over 76% of people with developmental disabilities live at home with their families.
- 1.9 million people with developmental disabilities are estimated to live at home or with a family caregiver.
- Nationwide there are an estimated 475,000 older caregivers of children and adults with intellectual or developmental disabilities.
- Some 25% of these caregivers are age 60 or older.



WAITING LIST

NATIONWIDE, 80,000 FAMILIES
ON A WAITING LIST FOR
GOVERNMENT-FUNDED RESIDENTIAL SERVICES






The average age of an adult with a developmental disability living with parents age 60 and older is 38 years.

Child with MR today – life expectancy of 66.

Fewer than 50% of these individuals have a viable plan for the future after their parents die.

Why Plan?



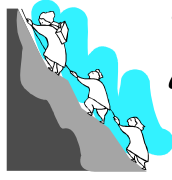
- Resources may diminish with time
- Decisions made in crisis may result in taking what is available, not what is best
- We would like the same freedom from caregiving that other older parents enjoy
- Must find replacement for yourself
- Child may want to live elsewhere

Wish List For Our Children



- A good place to live
- Reliable and compassionate caretakers
- Adequate private financial resources
- Adequate government resources
- Good medical and dental care
- Friends
- A healthy diet


Do you want to act now and voice preferences for your child's future, or leave the decisions to others after you are gone?



Planning is a process, not a problem or solution.

Reasons to Plan

- Change is inevitable for all of us
- We have more control of the outcomes now and can design our own system
- We gain peace of mind
- We can make changes gradually, easing the transition for our son or daughter
- It will be less of a burden to future caregivers because we can help them now



- It is one of the things we all have in common.
- It is going to happen to us eventually.
- Almost all of us avoid thinking about it until it is too late to plan.
- Like sex, no one is comfortable talking about it.



Reasons Given for Not Planning

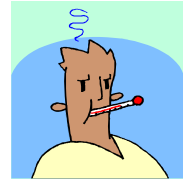


- We do not want to think about our illness or death
- We are not sure that the services will meet our desires
- We assume that others will provide, if the need arises
- My son or daughter contributes at home

HEALTH AND OTHER RELATED ISSUES:



- medical conditions,
- seizures,
- medication,
- behavioral needs,
- dental needs



Planning is Important!

Thinking about the future and trying to plan ahead is an emotional experience which takes courage



Families know that safety of their loved one is directly related to the number and quality of relationships in one's life as well as a system of checks and balances established by the family

SOCIAL RELATIONSHIPS:

How are friends, family, and others going to stay in touch? What are their roles?



Support and Housing Considerations

All the activities of daily living:

- Personal care
- Dressing,
- Food preparation,
- Hygiene,
- Safety
- Shopping

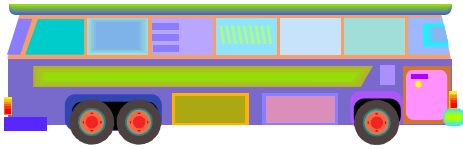


WORK LIFE AND DAYTIME ACTIVIES

Who will be in touch with employer, medical supports, human service agencies, volunteering, community activities?



Considerations: Transportation, money management, food shopping, social activities



DO YOU KNOW?

Studies have reflected that between 12% and 20% of siblings state that they are willing to have their brother or sister live with them.



FEDERAL BENEFITS

ENROLL IN FEDERAL BENEFIT PROGRAMS:

- MEDICAID/MASS HEALTH
- SSI
- SSDI
- FOOD STAMPS
- MEDICARE
- SECTION 8 HOUSING VOUCHERS
- AFC



Parents often don't involve their other children in talking about the present and future needs of the child with a disability.



Roles for Siblings:

- Guardian
- Advocate - write letters, make calls, go to meetings
- Visitor - visit and get to know others in brother's or sister's life
- Friend - connect to family and community
- Trustee
- Caretaker - providing care
- Representative payee

Financial assessment:

How is all this going to be funded?

What public benefits exist:

SSI, paycheck, waivers, SSDI.

Other:

Special needs trusts
Family support



Create a Home



- One that reflects his / her personality and lifestyle
- Avoid crisis with no plan
- Housing alternatives

Housing Alternatives

1. Home Ownership: Gives the individual most control over living arrangement



- Can be financed with family savings, investments, first-time home ownership programs, or special needs trusts
- In-home services provided through health care agency, DDS, roommate, or community and family supports

Housing Alternatives

7. Collaboration with local housing authority and provider agency
8. In-law apartment
9. Purchase of a condo
10. Become a Section 8 landlord
11. Purchase a home, partner with provider agency, rent units



Housing Alternatives

2. Renting or Leasing: Most communities have market rent or subsidized apartments available.

- Information can be obtained from state agencies, housing organizations, human service agencies, friends, relatives, landlords, and realtors.
- Section 8 Housing Voucher.



3. Home Sharing: 2 or more unrelated persons sharing housing and expenses.

HOUSING ALTERNATIVES

12. Purchase multi-family home, rent units
13. Rent in federal-owned 55+ properties
14. Join other families to purchase a house, provider agency, housing authority
15. Find an AFC provider/shared living



Housing Alternatives



4. Supervised Apartments: Agencies support individuals in their own individual or shared apartments. Apartment mate may or may not be an individual with disabilities.

5. Adult Family Care or Foster Care: Individual lives with either a family member or an unrelated family. Family receives monetary support from state agency.
6. Group Homes: Generally certified by government agencies and operated by state or private provider agency.



“The worst thing one can do is not to try, to have a dream and not go for it, to spend the years of our lives in our quiet cocoon fluttering and forever wondering if something could have been – never, never knowing.”

-Alinda Arthur Nelson

