

Consensus of the Fragile X Clinical & Research Consortium on Clinical Practices

Financial Resources for Individuals with Fragile X Syndrome



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Introduction

Many families are faced with financial constraints when raising a child or supporting an adult with fragile X syndrome. Financial resources are drained by both costs which are directly provided in care for the individual, such as frequent and various doctor and therapy visits, medications, access to or purchasing supportive equipment, but also indirect costs to the family including time away from the work place, respite care providers, marriage counseling and more. Families worry about how to provide for the adult child when the parents die. Identifying and addressing this issue can help families link to currently available resources as well as planning ahead to minimize anxieties related to finances. While the resources available will not solve all families' financial woes, any assistance received is worthwhile.

Financial Resources

Medicaid (<http://www.medicaid.gov/>)

- State administered – each state has own guidelines regarding eligibility and services
- Makes payments directly to health care providers
 - May have a co-pay (depends on state legislation)
- Disabled people with limited income and resources are eligible (specific eligibility requirements vary by state)
- SSI recipients are eligible to receive Medicaid
- Eligible to refugees for a period of seven years

SSI (<http://www.ssa.gov/ssi/>)

- Federally funded by taxes
- Provides money to meet basic food, shelter, and clothing needs to disabled people with little to no income and few resources (things you own)
- Based on parents income until the age of 18
- Income level cutoff varies by state
- Must be a US citizen or national
- May get free services to help you work, including counseling, job training, and help finding work
- Children below the age of 18 may qualify for SSI if they are not working and earn less than \$1,000 per month and have a physical and/or mental condition that results in “marked and severe functional limitations” (seriously limits activities)
- Relationship between Medicaid and SSI varies by state
 - In most states, children qualify for Medicaid if they get SSI
 - In some states, Medicaid is automatically tied into SSI
- Amount of money received is the same nationwide, but some states add additional money

Disabled Children's Relief Fund (<http://www.dcrf.com/orderze/default.aspx>):

- Mission is to promote growth and development of children with disabilities
- Provides grants for medical equipment, rehabilitative services, and arts/humanities projects for disabled children up to age 18
- Preference given to physically challenged children
- Specifically focused on children without health insurance
- Applications can be submitted by individuals or organizations
 - Applications available between April and September (<http://www.dcrf.com/orderze/Content/1/Summary.aspx>)

Financial Aid for the Disabled and Their Families 2012-2014 – Gail Ann Schlachter and R. David Weber (<http://amzn.com/158841227X>):

- El Dorado Hills, CA: Reference Service Press. 2012. 510 p.
- Provides current information about more than 1,500 scholarship, fellowship, loan, grant, and award programs established and designed primarily or exclusively for the disabled or members of their families. Entries are grouped under chapter categories: disabilities in general; orthopedic and developmental disabilities; hearing disabilities; visual disabilities; communication and other disabilities; and programs for families of the disabled. Indexed by program title, sponsoring organization, geographic eligibility, subject, and filing deadline.
- There seems to be a new edition published every two years

Angel Flight (<http://www.angelflight.com/>):

- Non-profit organization of pilots, volunteers, and friends
- Arrange free air transportation for medical needs
- Different Angel Flight organizations around the US for different parts of the country
- Coordinates with other organizations to arrange longer distance flights
- To be used in situations where alternative travel is not affordable or feasible

Helping Hand Program (<http://nationalautismassociation.org/family-support/programs/helping-hand/>):

- Must be under 18, live in the US, and be diagnosed with Autism Spectrum Disorder
- Provides up to \$1500 for biomedical treatments, therapy services, and supplements
- Grant application available from June 1-July 15
- Intended for families in serious financial need
- Money goes directly to service provider

ACT Today! Grant (<http://www.act-today.org/act-today-grant-program.php>):

- Provides grants between \$100-5000 for any time of treatment and assessment for Autism
 - Includes ST, OT, PT, meds, biomedical treatments, and more

Financial Resources for Fragile X Syndrome

- Intended to be used for things that insurance or other organizations, like schools and local programs, don't cover
- Preference given to families with multiple children with ASD and with income under \$100,000

United Healthcare Children's Foundation (<http://www.uhccf.org/apply.html>):

- Grants to use for medical services not covered or completely covered by commercial health benefit plans
- Grant pays remaining balance for a given service
- Family submits invoice to UHCF and they pay service provider
- Requirements:
 - Under 16 and live in the US
 - Covered under commercial health benefit plan – excludes Medicare, Medicaid, and any state/federally subsidized health insurance plan
 - Family income less than \$100,000 (depends on number of family members)

Lend4Health (<http://lend4health.blogspot.com/>):

- Non-profit organization that provides community-funded, interest-free microloans for biomedical treatment of Autism Spectrum and related disorders
- Families submit loan request to Lend4Health and Lend4Health posts the information on the blog
- Lenders (visitors to the blog) make donations in varying amounts ranging from \$1 to the total loan amount
- Loans and repayments are made through PayPal
- Organization started by a mother of 2 who realized the need for financial assistance in the Autism community

Special Needs Trust information: NFXF page under development

Respite Care information

Federally funded LifeSpan Respite Care Program

(http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx)

- The Lifespan Respite Care Program was authorized by Congress in 2006. Lifespan Respite Care programs bring together Federal, state and local resources and funding streams to help support, expand and streamline the delivery of planned and emergency respite services while also providing for the recruitment and training of respite workers and caregiver training and empowerment.

The ARCH National Respite Network

<http://chtop.org/ARCH.html>

AUTHORS NOTE: The preceding guideline was authored by Susan Howell, MS, CGC, MBA and was reviewed and edited by consortium members both within and external to its Clinical Practices Committee. It has been approved by and represents the current consensus of the members of the Fragile X Clinical & Research Consortium.

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*The Fragile X Clinical & Research Consortium was founded in 2006 and exists to improve the delivery of clinical services to families impacted by any Fragile X-associated Disorder and to develop a research infrastructure for advancing the development and implementation of new and improved treatments. Please contact the **National Fragile X Foundation** for more information. (800-688-8765 or www.fragilex.org)*