

**generations  
united**



## Webinar: Grandfamilies Raising Children with Disabilities

Ana Beltran, Special Advisor, Generations United  
Sharon Olson, Vice President and Co-Founder,  
Grandfamilies of America

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# Housekeeping

## Audio

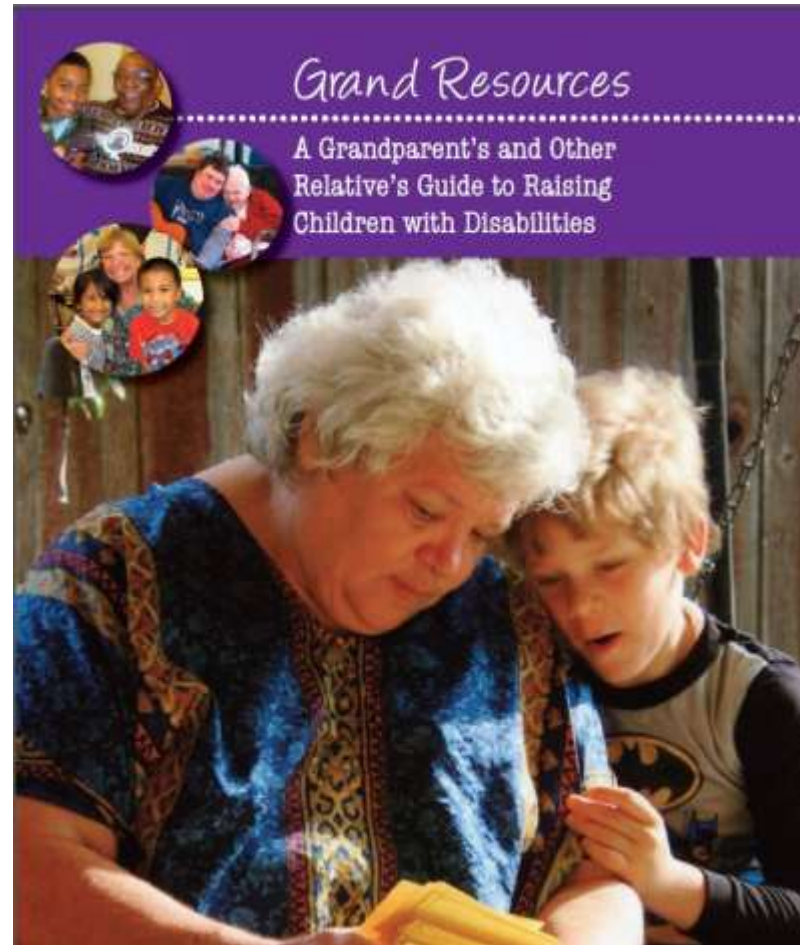
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## Q&A

- There will be time for your questions and comments
- At any time, you can send your questions/comments to the organizers and we will pass them on to the presenters
- Webinar recording and PowerPoint slides will be available early next week on [www.gu.org](http://www.gu.org)
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# Caregiver guide

Available for free  
at [www.gu.org](http://www.gu.org)



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# Agenda

- Where to Start
- Health Care
- Additional Special Help
- The Supplemental Security Income (SSI) Program for Children with Disabilities
- Other Financial Assistance, Food Help, and Tax Credits
- Sharon Olson's story
- Therapies and Educational Services for Children Ages Birth to 3
- Special Education and Related Services for Children Ages 3 to 21
- Children with Disabilities Turning Age 18

# Help for you and your grandfamily

- More than 2.7 million children are being raised in grandfamilies without any parents in the home
- Although we don't know how many, we believe many of the children in grandfamilies have disabilities or special needs
- The guide is intended to help you navigate the questions you have on this journey

# Where to start

- The National Dissemination Center for Children with Disabilities (NICHCY) is a good place to start if you think your grandchild or other relative you're raising has special challenges
- [www.nichcy.org](http://www.nichcy.org) has information about services and programs, and contact information for each state
- They also have staff to answer your questions over the phone at 1-800-695-0285 (Toll-free, Voice/TTY)

# Other resource help

- **2-1-1**- Many communities have these phone lines  
[www.211.org](http://www.211.org)
- **Elder care locator** – 1-800-677-1116 (Toll free)
- **The AARP Foundation Benefits QuickLINK** website at  
[www.aarp.org/quicklink](http://www.aarp.org/quicklink)
- **Kinship navigator programs** - to see if one exists in your area, go to  
[www.grandfamilies.org/KinshipNavigatorPrograms/KinshipNavigatorProgramsSummaryAnalysis.aspx](http://www.grandfamilies.org/KinshipNavigatorPrograms/KinshipNavigatorProgramsSummaryAnalysis.aspx)
- **GrandFacts** –state specific fact sheets for each state and the District of Columbia at [www.grandfactsheets.org](http://www.grandfactsheets.org)

# Other resource help cont.

- **Support groups** - The Brookdale Foundation has a national network - [www.brookdalefoundation.org](http://www.brookdalefoundation.org)
- **The National Family Caregiver Support Program** may be able to provide support services through your local Area Agency on Aging. For contact information, visit [www.n4a.org/about-n4a/?fa=aaa-title-VI](http://www.n4a.org/about-n4a/?fa=aaa-title-VI) or call the eldercare locator at 1-800-677-1116 (Toll-free)
- An **eXtension** office in a land-grant university - They also have a lot of information at [www.extension.org/category/family\\_caregiving\\_grandparents\\_raising\\_grandchildren](http://www.extension.org/category/family_caregiving_grandparents_raising_grandchildren)



# Health insurance

- **Private policy** - see if you can add your grandchild
- **Medicaid/CHIP** - <http://insurekidsnow.gov/> or call 1-877-KIDS-NOW
- **Affordable Care Act** – exchanges. Call 1-800-318-2596 (Toll-free), 24 hours a day, 7 days a week to find out how and where to apply [www.healthcare.gov](http://www.healthcare.gov)



# Consenting to health care

- Liability, malpractice, and privacy concerns can cause providers to refuse to treat a child even if the child has health insurance
- Consent through:
  - **Health care consent laws** – about half the states have
  - **Power of attorney laws** – require parents to convey authority to you
  - **Legal custody or guardianship**

# Mental health care

- NICHCY can connect you to resources, [www.nichcy.org](http://www.nichcy.org)
- The National Mental Health Association's Mental Health Information Center 1-800-969-NMHA (Toll Free) or [www.mentalhealthamerica.net/index.cfm?objectid=E422360D-1372-4D20-C8A0285839C8503C&search=yes](http://www.mentalhealthamerica.net/index.cfm?objectid=E422360D-1372-4D20-C8A0285839C8503C&search=yes)
- You can also contact the Federation of Families for Children's Mental Health, [www.ffcmh.org/find-local-chapter](http://www.ffcmh.org/find-local-chapter)

# Additional help

- If you or your grandchild need additional help, like ramps in the house, there are a number of places that may help:
  - **Private insurance**
  - **Medicaid/CHIP**
  - **State Developmental Disabilities office** (contact NICHY for contact information)
  - **Maternal and Child Health/Title V –**
    - Ask whether it serves children living with relative caregivers
    - Ask about the types of help available and how you can apply
    - Contact information for your state at [www.mchb.hrsa.gov/programs/titlevgrants/index.html](http://www.mchb.hrsa.gov/programs/titlevgrants/index.html)

# Supplemental Security Income (SSI)

- SSI provides cash to eligible adults and children with disabilities that seriously limit their activities
- Social Security Administration runs the program
- The average monthly SSI payment is \$632.96 - qualifying children should also get Medicaid and food assistance
- As children get older,
  - special SSI rules may allow them to work and still get cash benefits and Medicaid
  - They may also get long-term care services through Medicaid

# SSI cont.

- To qualify, your grandchild must meet financial and disability rules
- You can use the disability planner on the Social Security Administration website to see if your grandchild may qualify, [www.ssa.gov/d&s1.htm](http://www.ssa.gov/d&s1.htm)
- You can also call the Social Security Administration's staffed toll-free number at 1-800-722-1213 or TTY 1-800-325-0778 if you are deaf or hard of hearing



# To apply for SSI

- You can make an appointment to apply on the telephone or in person at your local Social Security office
- When you have your appointment:
  - Keep your child's Social Security number handy
  - Ask if your state has an extra SSI payment on top of the federal benefit
  - Ask if your grandchild automatically qualifies for Medicaid if he is eligible for SSI or if he needs to apply separately for Medicaid

# Other financial assistance – Temporary Assistance for Needy Families (TANF)



- **Child-only grants**
  - Most children raised by relatives are eligible
  - Usually only child income is considered
  - National average is \$8 per day
- **Family grants**
  - Larger than child-only
  - Work requirements and time limits may apply
- **Short term assistance**
  - For help from utilities to burials



# Social Security

- Your grandchild may be eligible if one of the child's parents
  - is collecting retirement or disability insurance benefits
  - died and was fully insured when he died
- Your grandchild may also qualify based on your work record
- For more information:
  - [www.socialsecurity.gov/kids/parent5.htm](http://www.socialsecurity.gov/kids/parent5.htm)  
or call 1-800-722-1213 (Toll Free)
  - See also Generations United's fact sheet:  
*The Benefits of Social Security for Grandfamilies*,  
[www.gu.org/LinkClick.aspx?fileticket=Vi04p7fvMdl%3d&tabid=157&mid=606](http://www.gu.org/LinkClick.aspx?fileticket=Vi04p7fvMdl%3d&tabid=157&mid=606)

# Help with food

- **The Supplemental Nutrition Assistance Program (SNAP)** – formerly known as “Food Stamps”
  - You can find local offices, the state hotline, and each State's application at [www.fns.usda.gov/snap/applicant\\_recipients/apply.htm](http://www.fns.usda.gov/snap/applicant_recipients/apply.htm)
- **The Women, Infants and Children (WIC) Program** can help meet nutrition needs of children under age 5
  - Children must have certain types of health conditions to qualify
  - For state offices to call, see [www.fns.usda.gov/wic/Contacts/tollfreenumbers.htm](http://www.fns.usda.gov/wic/Contacts/tollfreenumbers.htm)

# Help with food cont.

- **The National School Breakfast and Lunch Programs** provide free or low-cost meals to eligible students - ask your grandchild's teacher or principal for an application
- **The Summer Food Service Program (SFSP)** provides low-income children with nutritious meals when school is not in session.
  - To find a program near you, call 1-866-3-HUNGRY or 1-877-8-HAMBRE (for Spanish speakers) or
  - visit [www.whyhunger.org/findfood](http://www.whyhunger.org/findfood) to locate sites using an online map

# Earned Income Tax Credit (EITC)

- If you don't earn enough to pay taxes, you get a refund check from the IRS - To qualify:
  - your grandchild must have lived with you for more than half the year
  - This credit applies until your grandchild turns 19 (or 24 if a full time student)
  - If your grandchild is totally and permanently disabled, there is no age limit
  - See [www.irs.gov](http://www.irs.gov)



# Adoption tax credit

- If you adopted, this credit can give you a credit for the money you spent to adopt up to \$12,650 per child
- The Affordable Care Act made the credit refundable for 2010 and 2011 – as of 2012, the credit is no longer refundable
- If you adopted a child from the foster care system with special needs, you may be eligible for the maximum regardless of whether you had any qualifying expenses
- If you did not adopt from the foster care system, you must have qualifying expenses like legal fees
- See [www.irs.gov/taxtopics/tc607.html](http://www.irs.gov/taxtopics/tc607.html)

# Additional tax benefits

- SSI payments do not count as part of your gross income
- Tax credits themselves are also not counted as income - they will not be counted when you apply for financial help

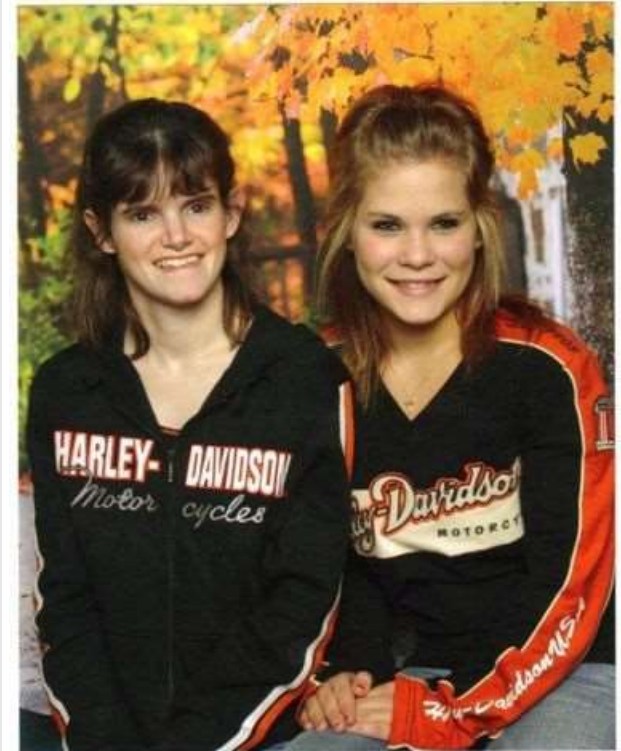


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# Sharon Olson's story

Vice President and Co-Founder,  
Grandfamilies of America

[www.grandfamiliesofamerica.com](http://www.grandfamiliesofamerica.com)



# Young children's development

- Easter Seals has a developmental milestones screening tool that you can use to see if your grandchild ages birth to 5 is typically developing  
[http://es.easterseals.com/site/PageServer?pagename=ntlc10\\_mffc\\_homepageasq](http://es.easterseals.com/site/PageServer?pagename=ntlc10_mffc_homepageasq)
- The Centers for Disease Control and Prevention (CDC) have checklists for typical milestones for children ages 2 months to 5 years old  
[www.cdc.gov/ncbddd/actearly/milestones/index.html](http://www.cdc.gov/ncbddd/actearly/milestones/index.html)



# Evaluating your grandchild

- First you may want to talk to your grandchild's doctor and/or teacher about your concerns
- **If your grandchild is under age 3**, call your state's early intervention coordinator – NICHCY can tell you who to contact, [www.nichcy.org](http://www.nichcy.org)
- **If your grandchild is between ages 3 and 5**, you can ask your neighborhood school to evaluate. The program for children ages 3 to 5 is often called "Section 619" - the Section 619 coordinator for your state can be found at <http://ectacenter.org/contact/619coord.asp>
- **If your grandchild is already in elementary school or a higher grade**, ask the school to evaluate

# Early intervention, birth to age 3

- Each state's early intervention program has different rules
- Some states serve infants and toddlers who have **disabilities**
- Others serve infants and toddlers who have **“developmental delays”** - a more general category that covers more
- Other states also serve infants and toddlers who are **“at risk” for developmental delays**



# Individualized Family Service Plan (IFSP)

- For birth to age 5, if your grandchild qualifies for services, she will get an IFSP
- The IFSP describes the services that can help her
- As her caregiver, you will develop the IFSP along with a group of people who know what services can help
- You do not need legal custody or guardianship to help put together the IFSP or to get services
- You may be charged fees for a child ages birth to 3, but no fees for ages 3 to 5

# Types of early intervention services

- Occupational, speech, and physical therapy, hearing or vision services, mental health services
- special training for you to help your grandchild
- A “service coordinator” who can help you keep track of services and appointments



# Special education, ages 3 to 21

- To qualify, your grandchild must have specific disabilities that negatively affect her ability to perform in school
- Schools may also serve children ages 3 to 9 who have “developmental delays”



# Individualized education plan (IEP)

- If your grandchild qualifies, she will get an IEP
- The IEP should set annual goals
- The IEP should specifically describe the education and related services she will get
- You will help put together the IEP
- You do not need legal custody or guardianship and should not be required to become a “surrogate parent”
- You should be charged no fees

# Special education and related services

- The Individuals with Disabilities Education Act (IDEA) entitles eligible children with disabilities to get a “**free and appropriate public education**” (may be referred to as FAPE) and related services
- **Related services** may include speech-language, physical and occupational therapies, mental health services, and an instructional aide
- **Reasonable accommodations** may also be made, things like priority seating close to the teacher
- May also include **assistive technology** -- special computers or learning devices

# Suspensions/expulsions

- Schools have the authority to suspend or expel children with disabilities, but they must follow special rules
- The IEP team must first review the situation
  - Are his IEP and placement appropriate?
  - Do his emotional disabilities limit his ability to control his behavior and understand its consequences?
- Generally, students with disabilities must continue to get the educational services in their IEPs



# Medications

- Federal law is very clear that schools cannot require students to take medications
- The school cannot require it as a condition of attending school, getting an evaluation or receiving special education and related services



# Getting ready to leave high school

- Federal law requires schools to provide two different types of transition statements as part of a child's IEP:
  - Beginning at age 14, the IEP must include the different courses of study that will prepare each child for what he will do after high school
  - Beginning at age 16 or younger, the IEP must provide for transition services that will help each child move to the next phase of his or her life

# “504 Plan”

- If your grandchild does not qualify for an IEP, call your local school district and ask to have him evaluated for a “504 plan”
- Federal law requires that all school districts have a 504 coordinator and identify all students who may qualify
- A 504 plan describes accommodations and services the school will provide to help your grandchild learn



# Help



- You can talk with your state's Parent Training and Information Center - to find your state's Center, [www.parentcenternetwork.org/national/aboutus.html](http://www.parentcenternetwork.org/national/aboutus.html)
- You can also call your state's Protection and Advocacy office and ask if they can help you - to reach this office, contact NICHCY or look on their website, [www.nichcy.org](http://www.nichcy.org)

# Accommodations in College

- The college must provide accommodations, aids, and services if the college receives federal funds - almost all do
- Might include things like note taking help, assistive technologies or additional test taking time
- The college is not required to make the same accommodations as a high school



# Before your grandchild turns 18

- **Decision making issues**
  - Adult guardianship
  - Power of attorney
- **Child support**
- **Supplemental Security Income (SSI)** – disability and income rules change when become 18
- **Other financial assistance**
- **High school, vocational training, and higher education -**  
The federal special education laws cover youth until turn age 21
- **Trusts**

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For more information, email

[gu@gu.org](mailto:gu@gu.org)

for a free copy of the caregiver guide, visit

[www.gu.org](http://www.gu.org)

For additional resources, see

[www.grandfamilies.org](http://www.grandfamilies.org)