

Understanding the Funding Maze

A tool kit for public and private funding resources for families raising Children with Glut 1 Deficiency

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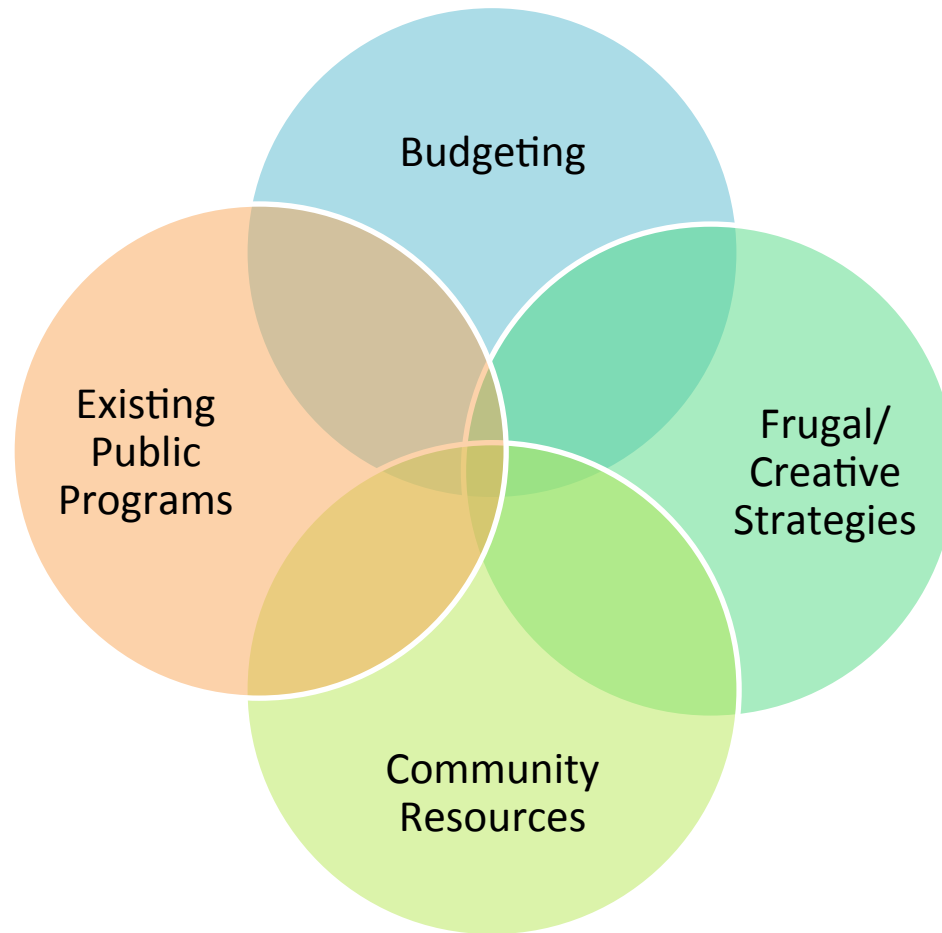
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HELP???





“Rules to live by”

- Leave options open
 - apply now, you can always decline services later
- Expect changes
 - Programs change, link into ways to stay up-to-date
- Ask questions
 - And **MAKE SURE** you have the right answers
 - **DOCUMENT**



How to Stay “up-to-date”

Family to Family Health Information Centers

- <http://www.familyvoices.org/states>

- Covering Kids and Families

- <http://www.coveringkidsandfamilies.org>

- Health Reform

- www.healthcare.gov

- State Government Websites

- State name. gov

- Local connections

- Diagnosis Specific Organizations

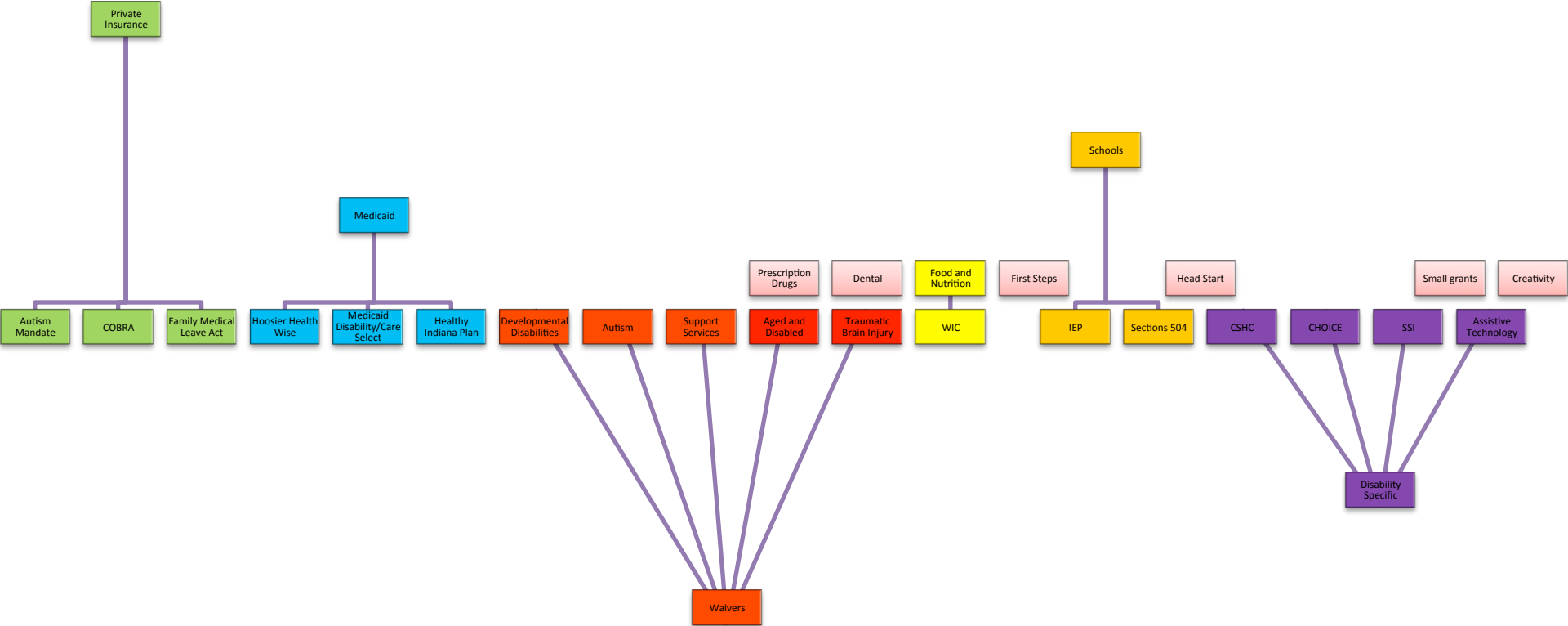
- www.G1DFoundation.org

Federal Poverty Guidelines 2012

Persons in family/household	Poverty guideline
1	\$11,170
2	15,130
3	19,090
4	23,050
5	27,010
6	30,970
7	34,930
8	38,890

For families/households with more than 8 persons,
add \$3,960 for each additional person.

Some Options



***“The Medical Home is
the model for 21st century primary care,
with the goal of
addressing and integrating high quality
health promotion, acute care and
chronic condition management
in a planned, coordinated and
family-centered manner.”***



American Academy of Pediatrics
www.pediatricmedhome.org/

What Does a Medical Home Look Like?

- Good communication before, during and after office visits
- Coordinating with specialists and other health professionals
- Sharing of health education, family support and community resources
- Avoiding the ER for unnecessary visits
- Preparing for transitions and future health needs

NJ, WA, CO, IL Medical Home Brochures and IN Academy of Pediatrics

Having a Medical Home means your child's care is:

- Accessible
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally Effective
- Family-Centered

“Partnering with your Doctor: The Medical Home Approach” – Region 4
Genetics Collaborative

Families Should Visit Their Child's Doctor Regularly

- Inform their PCP about hospitalizations:
 - ER Visits
 - Surgeries or procedures
- Visits to specialist; may need to facilitate co-management
- Tests and the results
- New diagnosis
- Medications and current dosage
- PCP can write letters to insurance company

Care Plans

- What to expect
- What to do

- Care Plans May Include:
 - Medical Summary and Goals
 - Action Plan
 - Transition Plan
 - Emergency Plan

THE GOOD NEWS IS
THAT WE MANAGED TO SAVE
YOUR LIFE! THE BAD NEWS
IS THAT YOU ARE GOING TO SPEND
IT PAYING FOR THE GOOD NEWS!



MyLemae 08-06

Private Insurance

- Know what you have
 - What is covered
 - Limits
- Make maintaining insurance a priority
 - Preexisting conditions (adults)
 - COBRA
 - FMLA
- Know whom to talk to about issues
 - At insurance company
 - At employer
- Looks at options to supplement
 - Dual coverage
 - Public programs

Health Care Reform

- Patient Protection and Affordable Care Act of 2010 (ACA)
- Phased Implementation from 2010 -2014
- Key provisions for children among first implemented

Pre-Existing Conditions

- Insurers cannot deny policies to children with pre-existing conditions

Health plans won't be able to exclude coverage of pre-existing conditions from their policies. This means that health plans can't refuse to cover your child's treatment solely because s/he already had a health condition when s/he joined the plan.

» September 23, 2010

- Insurers will have to accept everyone who wants to purchase a plan, regardless of their health status.

» Adults over 19 on January 1, 2014

Which Plans?

This new protection will apply to everyone who gets coverage through work and to everyone who buys an individual or family plan after March 23, 2010. This new protection may not apply to those who stay in individual insurance plans that they bought before March 23, 2010, unless that plan has made major changes in its coverage or substantially increased cost-sharing or deductibles.

When did this Start?

- For plan years beginning on or after September 23, 2010, insurers will have to cover all children who apply for a plan, regardless of their health status. However, insurance plans are not required to have new plans available for purchase year-round. Plans may choose to have “open enrollment periods” (that is, periods when they will take new applicants).

What Can they Deny?

Your insurance company can still deny coverage of a particular treatment if your plan does not offer coverage of that specific treatment to anybody enrolled in the plan.

Option for uninsured with pre-existing conditions

- National High Risk Pool
 - Uninsured for at least 6 months
 - Have a problem accessing covering
 - Be a citizen of legal resident

Lifetime and Annual Benefit Caps

- ACA removes annual and lifetime benefit caps for children and adults
- Cannot impose annual dollar limits exceeding specified amounts for “essential health benefits”
 - Until September 23, 2011, this limit is \$750,000;
 - during the following year it is \$1.25 million; and
 - from September 23, 2012, until January 1, 2014, the annual limit can be no lower than \$2 million.
 - After January 1, 2014, no annual limits on essential benefits are permitted.
 - September 23, 2010 no lifetime cap on new individual plans and existing individual and group plans
 - » 2010 no restrictive annual benefit limits on new group plans

Essential Benefits

- The “essential health benefits” listed in the law are:
 - outpatient services
 - emergency services
 - hospitalization
 - maternity and newborn care
 - mental health and substance use disorder services, including behavioral health treatment
 - prescription drugs
 - rehabilitative and habilitative services and devices, laboratory services
 - preventive and wellness services and chronic disease management.

More details about these services will be set forth in regulations

Young adults on Parent's Policy

- Young adults up to age 26 can remain on their parents' health insurance, even if they are not students, don't live at home, and don't live in the same state as their parents!

Who can get this?

- Their parent has coverage through their employer or buys family coverage in the individual market
- The plan provides “dependent coverage” (but the young adult does NOT have to be dependent on their parent(s), and does not have to live with their parent(s))
- The young adult doesn’t have a plan that offers health coverage

Preventive Care

Preventive care is covered without co-pays, or other cost sharing.

- Preventative care and screening based on Bright Futures
- Screening based on U.S. Preventive Services Task Force
- Immunizations based on CDC guidelines
 - » September 23, 2010 (new employer based and individual plans)

Medicaid Coverage Expansion

- Individuals up to 133% of Federal Poverty Line
 - » 2014
- All states will use same income eligibility formula
 - Modified Adjusted Gross Income (MAGI)
 - MAGI will also be used for the exchange
- Foster children who age out to age 26
 - » 2014

No Wrong Door

- Simplified application for Medicaid
- All points of entry will accept and process applications on same timeline

2014 and beyond

- An expansion of Medicaid to anyone with a family income less than 133% of the Federal Poverty Level (about \$14,000 for an individual; about \$30,000 for a family of 4)
- Ban on pre-existing condition exclusions for everyone
- Ban on annual coverage limits for “essential health benefits”
- Ban on varying premiums based on health status

Where to Learn More

- www.healthcare.gov
- Families USA: www.familiesusa.org or www.standupforhealthcare.org
- Catalyst Center: www.catalystctr.org
- Community Catalyst: www.communitycatalyst.org
- Kaiser Family Foundation: <http://healthreform.kff.org>
- Commonwealth Fund: <http://www.commonwealthfund.org/Health-Reform/Health-Reform-Resource.aspx>

Medicaid

www.medicaid.gov

Eligibility for Medicaid is based on income and other circumstances. **Each state sets its own Medicaid eligibility rules**, but in general, all states make health coverage available to the following people:

- In general, children in families with incomes up to \$44,100 per year (for a family of four) are likely to be eligible for Medicaid coverage. In many states, families with higher incomes can also qualify for CHIP.
- Pregnant women with family incomes up to \$19,565 for a family of two but many states provide coverage for women with incomes up to \$27,214.
- Parents (income limits vary by state).
- People with disabilities—in nearly all states, Medicaid covers people with incomes up to \$1,868; many states go to \$10,890 FPL.

CHIP

www.insurekidsnow.gov

CHIP provides low-cost health insurance coverage for children in families who earn too much income to qualify for Medicaid, but can't afford private health insurance.

Each state sets its own eligibility rules, but in general, children in families with incomes up to \$44,100/year (for a family of four) are likely to be eligible for coverage. In many states, families can have higher incomes and their children can still qualify.

Medicaid Waivers

Home and Community-Based Services (HCBS) waivers, allow states to disregard family income for children with severe disabilities who are eligible for institutional placement, but who are cared for at home. The HCBS waivers usually provide an enhanced package of services designed to support families in keeping their children in the community rather than in institutions.

- waiver programs restrict eligibility to a pre-determined number of slots, and can limit enrollment to children with specific diagnoses or disabilities such as AIDS, autism, developmental disability, or traumatic brain injury.
- 48 states offer services through HCBS waivers, only a very small number of waiver recipients and waiver expenditures are linked to HCBS waivers that serve only children. Children are often served under general waivers for people with intellectual disabilities, developmental disabilities, or physical disabilities.

Children's Special Health Care Services

<http://mchb.hrsa.gov>

States have Children's Special Health Care Services (CSHCS) programs as part of their Title V block grants, these may be coordinators, direct services, or other supports, eligibility and programs vary from state to state.



Social Security

For application and status of benefits call 800-772-1213 (automated answering resource). Contact website www.ssa.gov/disability/

Social Security Disability Insurance (SSDI): An income disability program that pays benefits to an eligible person with a disability and certain members of the family if the person is "insured," meaning they have worked long enough and paid Social Security taxes .

Supplemental Security Income (SSI): An income disability program that pays benefits to eligible adults and children with disability based on financial need.

- Monthly payments for children under 18 who meet Social Security's definition of disability and has income/resources within eligibility limits (@3,000 not including home a car)
 - Resources of family members living in house are considered if child lives at home or returns home from school for visits



Prescription Drugs

- **NeedyMeds**- Provides information on Patient Assistance Programs (PAPs), state programs, local programs, and disease specific programs.
www.needymeds.com
- Stores that offer reduced price
- Communicate with Physician



Dental Care

- Community Health Centers
- Dental Schools
- Give Kids a Smile
- Maximize coverage



Food and Nutrition

- Food Stamps (SNAP)
- Emergency Food Assistance Program
- Free and Reduced Price School Meal Program
- Community Resources
- Creative and Careful Shopping

WIC

- at or below 185% of the federal poverty level
- serves prenatal women, post-partum breastfeeding women within a year of the infant's birthday, post-partum non-breastfeeding women within six months of the infant's birthday, infants through the month of their fifth birthday.
- provides: nutritious foods (including formula and liquid nutrition as appropriate), nutrition counseling, referrals to other programs
- local offices To find the clinic nearest you or to learn more about, WIC, call 1-800-522-0874

Child Care Voucher

www.naccrra.org

- A voucher (also called a "certificate") is payment issued by a State or local government directly to or on behalf of a parent for child care services.
- Voucher systems vary by State
 - Being an "eligible family" means children must be under the age of 13 and must reside with a parent who is working or attending a job training or educational program and whose family income does not exceed the State's limit for eligibility.

Early Intervention (Part C)

www.nectac.org

- The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families.



Head Start and Early Head Start

- Head Start is a federal funded program that provides comprehensive services for low income Hoosier children and their families. Head Start programs are available in every area and serve children ages three through five. Early Head Start programs serve pregnant women, infant and toddlers (ages birth to three). All programs provide early childhood educational, social, medical, dental, nutritional and mental health services to enrolled children and families.

A cartoon illustration of a yellow school bus with a face, arms, and legs. It has "SCHOOL BUS" written on its side and is holding a red octagonal stop sign in its right hand. The bus is smiling and has a small 'x' mark above its head.

Special Education (Part B)

Special Education: IDEA (Individuals with Disabilities Education Act) a federal program that provides a free appropriate public education in the least restrictive environment to **special education** students up to age 22 Free and Appropriate Public Education

- May bill Medicaid
- Medical services needed to provide access to education (nursing services at school– IHP as part of IEP)
- Extended school Year (ESY)
- Evaluations including independent
- Transition Planning

Section 504

- Section 504 is federal civil rights legislation which prohibits discrimination against people with disabilities. Children who are not eligible for special education and related services under IDEA, but who have a disability within the meaning of Section 504 may be able to access some services under Section 504.



Assistive Technology

- Any item, piece of equipment, or systems that is used to increase, maintain or improve the functional capabilities of an individual with a disability.
 - Who pays?
 - Learn more
 - Get Help



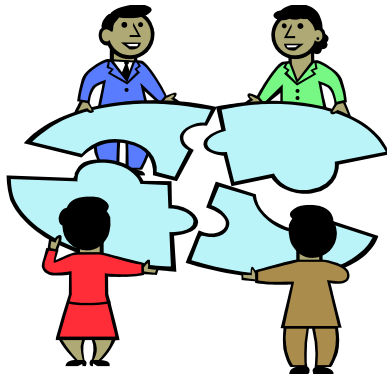
Grants



- www.aubreyrose.org/grants.htm
- www.mesa-angels.com/apply.asp
- www.joniandfriends.org/CFD_Application.pdf
- www.challengedamerica.com/index.html
- www.hannahandfriends.org/grants.html
- <http://www.uhccf.org>

Community Resources

- Township Trustee
- Food Banks
- Service Organizations
- Community Foundation
- Faith Based



Creativity

- Barter
- Partnerships
- Negotiation
- Asking!!!!

Questions??

Tips to share?