

Future Planning

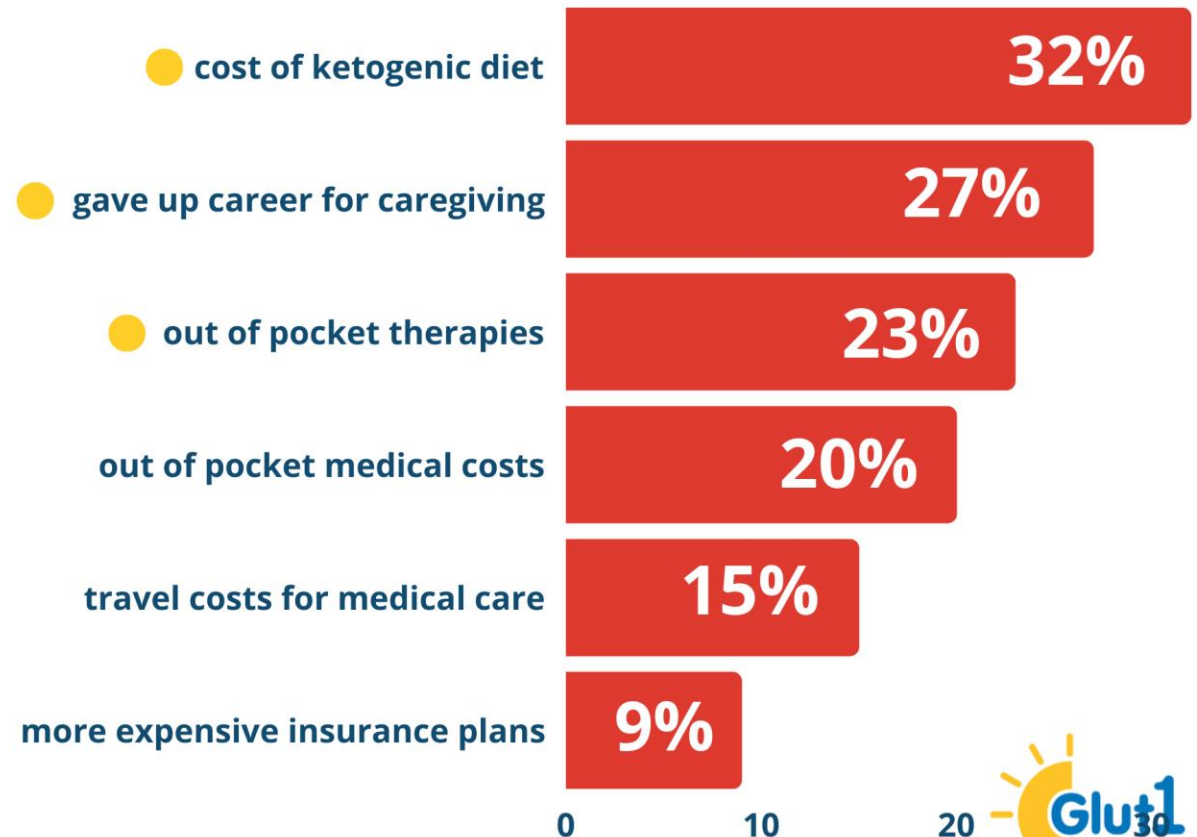
NOW

Why Does This Matter?

- disabilities and disease make life hard
- many additional strains on time and resources
- many financial implications
- good healthcare coverage is essential
- what happens when we are gone?

financial burden

choose top 3



Collective Voices Project

- 27% have disability determination
- 26% receive disability payments
- 13% receive waiver services
- majority have not done any future planning

Disability Definition - SSI

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Supplemental Security Income - through Social Security Administration

Adults:


inability to engage in any substantial gainful activity by reason of any medically determinable **physical** or **mental** impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

Children:

a medically determinable **physical** or **mental** impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months.

Glut1 Deficiency

seizures, movements, cognitive, communication, mobility
severity, combination

 Compassionate Allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits. This initiative helps reduce waiting time to reach a disability determination for individuals with the most serious disabilities.



Application Process

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online - [SSA.gov](https://ssa.gov)
any age eligible

About the Child

- name, SS#, DOB, address, telephone, email
- name, address, phone of someone else who knows about the condition
- a description of the conditions, including when they began and how they limit daily activities

Education and Work History (if applicable)

- names, addresses, and telephone for all schools attended for last 12 months
- type of behavioral or learning tests and when performed
- description of last job (if applicable)

Medical History

- names, addresses and telephone for all doctors, hospitals, and clinics, the dates of and reasons for the visits
- name of any medical tests, when and where done, and who ordered it
- name of each prescription medicine and the doctor who prescribed it
- name of any non-prescription medicine that the child takes

do not have to provide copies of medical records yourself



Determination Process

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- federal program, but state level decisions
- local offices verify information
- Disability Determination Services (state level) makes final decisions
- can take several months
- approvals are retro-active to application date
- appeal process for denials

disability determination is the key that unlocks services and benefits

Disability Benefits

- **monthly SSI payment**

- currently \$794 maximum benefit
- take into account resources you already have (food, shelter, etc.)
- parent resources may make child ineligible
- \$794 income limit, \$2,000 in assets
- over age 18, parent resources don't count directly

- **eligible for additional programs and services**

- **eligible for Medicaid in most states**

Medicaid

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Medicaid is a joint federal and state program providing health benefits for those who meet the eligibility requirements. The program provides for millions of United States citizens, including:

- adults with low incomes
- older adults
- people with disabilities
- pregnant women
- children

federal program, state managed
different state to state



Medicaid Eligibility

income limits - Kentucky example

Annual Household Income Limits (before taxes)

Household Size*	Maximum Income Level (Per Year)
1	\$17,131
2	\$23,169
3	\$29,207
4	\$35,245
5	\$41,284
6	\$47,322
7	\$53,360
8	\$59,398

Medicaid Waivers

- allow the federal government to waive rules that usually apply to the Medicaid program
- intention is to allow individual states to accomplish certain goals, such as reducing costs, expanding coverage, or improving care for certain target groups such as the elderly or women who are pregnant
- states can provide services to their residents that wouldn't usually be covered by Medicaid

waiver names, types, and regulations differ state to state

SSI and Medicaid

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- In most States, a child who gets SSI benefits can get Medicaid to help pay medical bills.
- In some cases, a child may be eligible for Medicaid while in an institution, but not be eligible when living at home either because of the parents' income and resources or because of other income.
- At the State's option, children under age 18 who need institutional-level care and live at home may keep Medicaid eligibility while getting home care, if that care is less costly to the government.

Institutional Level of Care

- Three levels are:
 - intermediate care for individuals with intellectual disabilities, nursing facility, or hospital
- Must be appropriate to care for child at home
- Estimated cost of caring for child at home cannot exceed the estimated cost of care in the institution

Will my child need this level of care if something were to happen to me?

diet management, therapies, medical appointments, cognitive challenges, physical limitations



Types of Waivers

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- provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings
- targeted population groups, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses
- some specific to certain conditions such as autism, developmental disabilities, or acquired brain injury
- waiver types, names, and regulations are different state to state

often long waiting lists
can get on more than one waiting list
can transition from one waiver to another



Benefits of Waivers

- prevent and / or delay the need for institutional care
- provides supports for continued learning (living skills, education)
- provides supports for continued social engagement opportunities
- provides support for employment and volunteer opportunities
- paid support compliments unpaid care assistance from family members
- takes some of the pressure off of family caregivers
- allows family caregivers to continue to work outside of the home
- provides a break (respite) from caregiving
- gives peace of mind knowing loved one is safe, supervised, and receiving needed care
- Medicaid waivers more cost efficient than institutional care for the state
- win-win for care recipients, their families, and the state

different waivers = different benefits

Types of Waiver Services

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- service coordination (help with managing care needs and services)
- personal support (assistance with daily living activities, i.e. bathing, dressing, meals, and housekeeping)
- home health services (nursing, home health aide, and occupational, physical and speech therapy)
- emergency response systems
- respite care (caregiver relief)

Examples:

- A home health aide
- Nursing
- Medical supplies and medical equipment
- Chore and homemaking services, such as shopping, laundry, and cleaning
- Hot meal delivery services
- Respite care to relieve a primary caregiver
- Counseling services
- Home and/or vehicle modifications, such as ramps and safety rails, to increase independence
- Support and case management
- Assistance transitioning from a nursing home into the community
- Access to senior centers or adult group day care
- Protected environment for learning living skills, gaining educational experiences
- Supported employment
- Transport to and from non-emergency medical appointments
- Non-medical transportation services
- Personal emergency response systems

Medicaid access - wide range of covered services
use as primary or secondary insurance



Medicaid Services

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Mandatory Benefits

- Inpatient hospital services
- Outpatient hospital services
- Screening, Diagnostic, and Treatment Services
- Nursing Facility Services
- Home health services
- Physician services
- Rural health clinic services
- Federally qualified health center services
- Laboratory and X-ray services
- Family planning services
- Nurse Midwife services
- Certified Pediatric and Family Nurse Practitioner services
- Freestanding Birth Center services
- Transportation to medical care
- Tobacco cessation counseling for pregnant women

Optional Benefits

- Prescription Drugs
- Clinic services
- Physical therapy
- Occupational therapy
- Speech, hearing and language disorder services
- Respiratory care services
- Other diagnostic, screening, preventive and rehabilitative services
- Podiatry services
- Optometry services
- Dental Services
- Dentures
- Prosthetics
- Eyeglasses
- Chiropractic services
- Other practitioner services
- Private duty nursing services
- Personal Care
- Hospice
- Case management
- Services for Individuals Age 65 or Older in an Institution for Mental Disease
- Services in an intermediate care facility for Individuals with Intellectual Disability
- State Plan Home and Community Based Services
- Self-Directed Personal Assistance Services
- Community First Choice Option
- TB Related Services
- Inpatient psychiatric services for individuals under age 21

differs state to state



Waiver Services Care Providers

agency directed

- skilled and trained
- nursing level available
- managed by agency

consumer-directed

- recipient chooses providers
- certain circumstances allow family members
- decide how and when you receive services

- case worker, social worker assigned
- annual plan of care developed, implemented, tracked
- timesheets, payroll, unemployment, training, background checks

Special Considerations

- periodic eligibility review
- waivers differ by state - moving to a new state
- must notify of income changes for SSI payments
(penalties and repayment)
- estate recovery rule
("payback" for benefits)
- asset protection/estate planning
\$2,000 asset limits/\$794 month
Special Needs Trusts, ABLE accounts

ABLE Accounts

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Achieving A Better Life Experience

tax free savings account for individuals with disabilities

Qualifications:

- eligible for Supplemental Security Income (SSI) based on disability or blindness that began before age 26;
- entitled to disability insurance benefits (DIB), childhood disability benefits (CDB), or disabled widow's or widower's benefits (DWB) based on disability or blindness that began before age 26; or
- someone who has certified, or whose parent or guardian has certified that he or she met the criteria for a disability certification before age 26.

ABLE Accounts

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Achieving A Better Life Experience

recognizes the extra and significant costs of living with a disability and provides a savings tool to address it

How Does It Work?

- contribute up to \$16,000 per year into the account (more if employed)
- only assets above \$100,000 count toward SSI limits
- interest earned on account savings or investments is not taxable
- qualified distributions are not taxable
- can make qualified distributions to support many types of living expenses
- can set up in a state other than your own
- can allow person with disabilities to have some control over account

ABLE Accounts

Achieving A Better Life Experience

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Drawbacks:

- self-administered accounts are more susceptible to be taken advantage of
- subject to "Medicaid Payback"

Learn More:



NATIONAL RESOURCE CENTER
ACHIEVING A BETTER LIFE EXPERIENCE ACT

STABLE 
ACCOUNT



SPECIAL NEEDS TRUSTS

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Special Need Alliance

The Special Needs Alliance (SNA) is a national organization comprised of attorneys committed to the practice of disability and public benefits law. Individuals with disabilities, their families and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena.

The screenshot shows the homepage of the Special Needs Alliance (SNA). At the top right, there is a "Contact Us" link. The main navigation bar includes "FIND AN ATTORNEY", "SPECIAL NEEDS 101", "INFORMATION CENTER", "PUBLIC POLICY", and "ABOUT US", each with a dropdown arrow, followed by a search icon. The SNA logo is on the left. The main content area has a blue background with the headline "WE ARE A NATIONAL ALLIANCE OF ATTORNEYS FOR SPECIAL NEEDS PLANNING". Below this are three columns: "Maximize & Preserve Benefits", "Protect Assets", and "Assure Lifelong Care". A paragraph of text follows: "Over the past two decades, we've seen remarkable growth. So many talented, accomplished and committed attorneys have joined us to advocate for individuals with disabilities and their families, and provide the resources, counsel and education they need to live good lives."



GUARDIANSHIP

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Guardianship, also, referred to as conservatorship, is a legal process, utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence.

Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after alternatives to guardianship have proven ineffective or are unavailable.

- Representative or substitute payee
- Case/care management
- Health care surrogacy
- Trusts
- Durable powers of attorney for property
- Durable powers of attorney for health care
- Living wills
- Community advocacy systems
- Joint checking accounts
- Community agencies/services
- Supported decision-making networks

Learn
about future planning

Build
your future plan

Find
resources

See
how others have planned

Get
help for urgent needs

Future Planning 101

Who Are You?

Where to Start?

Webinars

About

Future Planning 101

What is Future Planning?

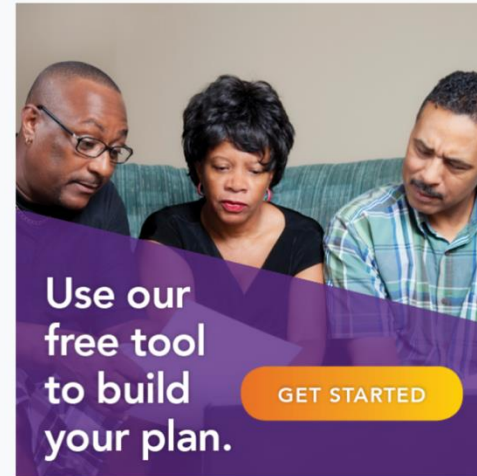


Why Future Planning is Important

Share

Watch on  YouTube

Learn more about what is included in a future plan.



Use our free tool to build your plan.

GET STARTED

Future Planning: It's Possible

Future planning is possible regardless of income.

futureplanningthearc.org

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The Arc

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities (IDD).

Take-Aways

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- apply for SSI disability when you have enough "evidence"
 - even if you think you won't need it (situations change, long wait lists)
 - even if you think you won't qualify for any help (Waiver programs)
 - apply at SSA.gov
- collect and save supporting documentation
- disability determination is key
 - appeal if necessary, hire outside help if necessary
- don't qualify for monthly SSI payments - may get other help
- find out about Medicaid Waivers in your state and how to apply
- protect your assets and their inheritance
- tools and resources are available
- plan for the future...now!

Thank you!