



Falling Off the Cliff

Disability Life Planning



*Transitioning to
Long Term Living
Not Just Planning*

Facilitator

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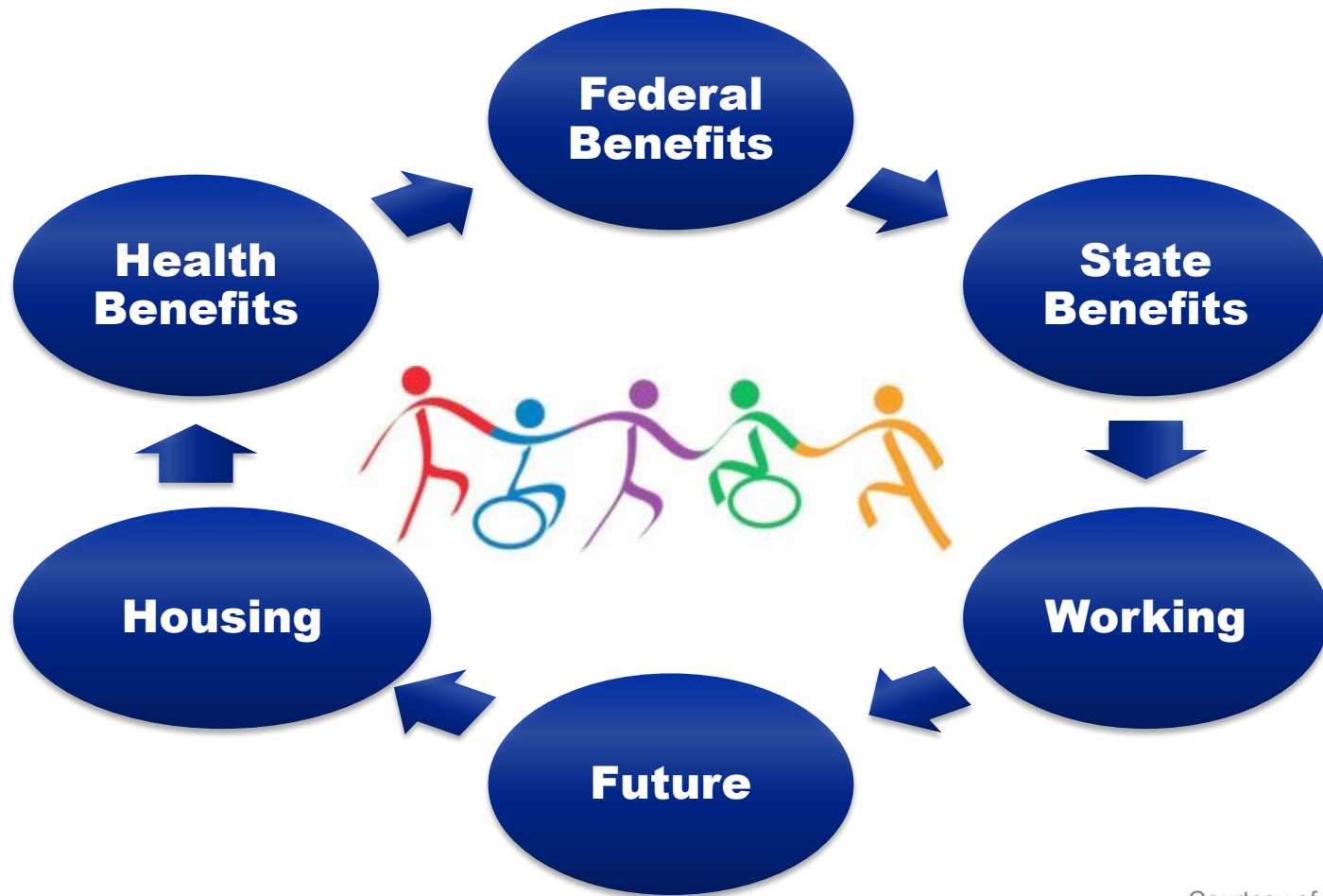
What's Gonna Happen?

- All Income Levels
- Fear
- Assumptions
 - ❖ Siblings
 - ❖ Housing
 - ❖ What about the bills?
 - ❖ Someone will always be there.



Path to Independence

Understanding the “Why”



Entitlement vs. Eligibility

■ Entitlement

- ❖ Instituted right by law.
 - IDEA, 504, IEP, Bill of Rights/Amendments

■ Eligibility

- ❖ Meet a set of criteria
 - Acceptance into college/programs, SNAP, OVR

Assumptions

- Medical Assistance/Medicaid doesn't end when the student leaves the school
- Services/waivers are guaranteed to those with IQ Below 70
- There are no services/waivers for those with IQs Above 70
- Vocational Rehab (VR) is ongoing
- Guardianship is the “way to go”



Social Security Administration Income Support Programs

- Supplemental Security Income (SSI)
- Social Security Disability Insurance (SSDI)
 - ❖ Social Security Childhood Disability Beneficiary (SSCDB)

SSI & SSDI Eligibility

- Incur Severe Impairment That Will Last 12 Months or Longer (Disability Determination Services)
- Inability to Achieve Substantial Gainful Activity “SGA” monthly
 - ❖ CY 2023 Non Blind SGA is \$1,470/mo.
 - ❖ SSI – SGA is Irrelevant After Application
 - ❖ SSDI – Fiscal Cliff w/o Work Incentives
- Re-determination @ 18 years old
- Continuing Disability Reviews

What's In a Name?

- Realistic goals and progress in IEP & Evaluations
- Acceptance of function/diagnosis
- Language is extremely important
- Environmental supports
 - ❖ Natural and Structured
- Difference between obtaining or being rejected for adult services

Supplemental Security Income (SSI)



- Continual Limited Assets
<\$2000
- Medicaid (No Wait)
- Payments Immediately
- Unearned & Earned Income
- State cash supplement
- Work – 2 for 1 dollars
 - ❖ Use of work incentives increases income
- In-Kind Support

SSI – In Kind Support

- Food & Shelter
- Divorce
 - ❖ Child Support
- Financial Support
 - ❖ Inheritance
- Assets & Resources
 - ❖ Requires careful planning



Medicaid

- Automatic When Receiving SSI
- Cash Benefits/Medicaid are 2 Separate Items
- < Age 18 Resources are Irrelevant
- Cooperative Between State and Federal Government
- Waiver Eligibility is Based on Disability/Income



Social Security Disability Insurance (SSDI)



- Based on Work History
- Medicare (2 year Wait)
- 5 Month Wait Period
- Childhood Disability Benefit (SSCDB)
 - ❖ Benefits Can be Tethered to the Parents' Benefit
- Work – Fiscal Cliff
 - ❖ Use of Work Incentives Increases Income

Qualifiers for SSDI for Disabled Adult Child

- Child Must Have Been Diagnosed With the Disability Before Age 22
- Parent Meets One of the Following Criteria
 - ❖ Disabled
 - ❖ Retired
 - ❖ Deceased
- Child Must be Above the Age of 18

Medicare



- Federal Benefit
- Must be Receiving Retirement or Disability Benefits
- Monthly Contributions
 - ❖ May be Waived if Medicaid is Triggered
- Supplements Available
- Waiver Eligibility not Guaranteed Due to Income Limits

Representative Payee

- Person who is Responsible for the Fiscal Record Keeping of the SSI/SSDI Cash Benefits.
 - ❖ SSA's Main Contact
 - ❖ Overpayments/Underpayments
 - ❖ Reporting/Tracking
 - ❖ Age of Person with Disability is Irrelevant
 - ❖ Changes in Household and Life Events
 - Work/income changes
 - Living arrangements

20 Hours



Impact of Work on SSI (CY 2023)

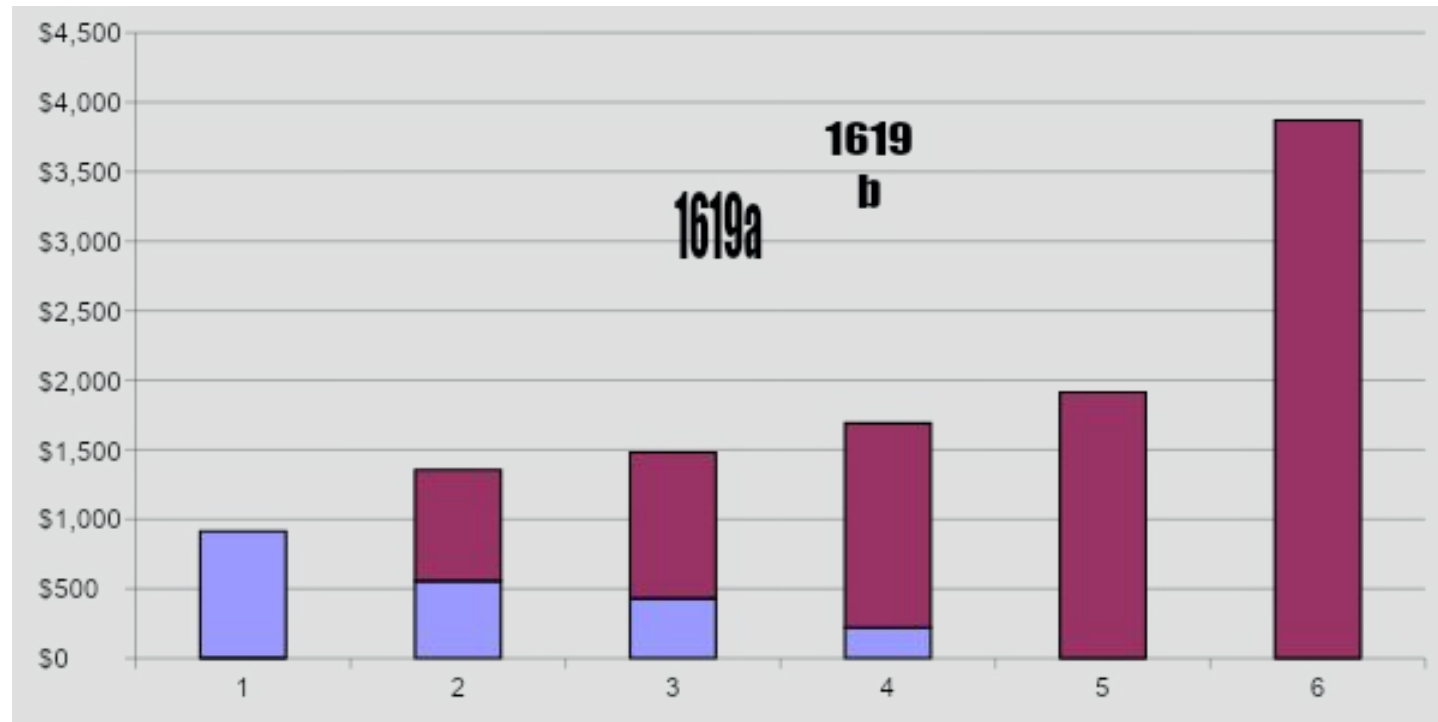


Table courtesy of AHEDD www.ahedd.org

With monthly earnings of \$1,470 in CY 2023, the person has continuation of benefits under 1619(a). Even when cash benefits are suspended, 1619(b) allows for continuation of Medicaid until they reach \$36,000+/yr depending on the state they live in(CY 2023). with cash assets under \$2,000.

Concurrent Beneficiary

- Receiving Both SSI & SSDI
- Possibly Eligible for Medicaid & Medicare
- SSDI \$1 for \$1 of SSI Benefit
- Employment Allows for SSI Recipients to Earn Quarters – Will Gain Eligibility for SSDI & Retirement Benefits
- If You are Working or When a Parent Dies Your SSI Benefit May be Stopped. At this point, You May Receive SSDI Only
 - ❖ Eligibility for Medicaid Depends on Monthly Amount and Assets
 - ❖ Medicaid Buy-In May Be an Option

Work Incentives – Must request!

- Plan for Achieving Self Sufficiency (PASS)
- Student Earned Income Exclusion (SEIE)
- Subsidy – SSDI only
- Impairment Related Work Expenses (IRWEs)

Work Incentives – Must request!

- Plan for Achieving Self Sufficiency (PASS)
 - ❖ Two forms of income – SSI required
 - ❖ Work goal required
 - ❖ Savings account for work goal
- Student Earned Income Exclusion (SEIE)
 - ❖ SSI required
 - ❖ Proof of school attendance
 - ❖ Earnings not exceeding
\$2,200/mo. or \$8,950/yr. for CY 2023

Work Incentives – Must request!

■ Subsidy

- ❖ SSDI only
- ❖ Extra amount of wages an employer pays for services over the reasonable value of the actual services performed (ie, job coaching)

■ Impairment Related Work Expense (IRWE)

- ❖ Out of pocket expenses to enable work
- ❖ Receipts required

Long Term Work – Navigating w/Benefits

- Be aware if company offers Part Time employees ESOP or other cash incentives
- Increase in hours or wages (yearly increases)
 - ❖ Impact of federal benefits and/or waivers
- Re-engaging VR services for new job tasks
- Opting in/out of different Employer sponsored health plans (cherry picking)

Medicaid Buy In Programs

- State specific (5 states are not a part of this program)
- Disabled Per SSA Guidelines, Except Earnings and Income
- Asset and Income Limit vary by state
- Primary Residence and One Vehicle Not Counted as assets
- Monthly Premium 5% of Countable Income
- Must be Working at Least 10 Hours a Month
- Eligible for Waiver Services!

State Waiver Programs

- Independently Living in Community
 - ❖ Waivers – (Waives Funding from Institutional Care)
 - ❖ Highlight greatest need of support
 - ❖ Be sure to update EVERYTHING yearly
 - ❖ Don't decline assessments because you think "it's all okay"
 - ❖ Provides Additional Supports Throughout Lifetime
- Must be Deemed Eligible
 - ❖ Disability and Financially
 - Limited assets – it's why special needs trusts are crucial



Protecting the Future

■ Primary Issues

- ❖ Maintaining Government Eligibility
 - Assets
 - 5 year look back
 - Waiver eligibility asset level is different
- ❖ Identify Financial Resources
- ❖ Establish Special Needs Trust



Courtesy of Leahy Life Plan, LLC

ABLE Act

(Achieving a Better Life Experience)

- Regulated by each State differently
- 401K/ESOP Not Applicable
- Cannot exceed \$100,000 without penalties
- Expenses need State approval
- Limited to one per person
- Gifting is \$17,000 annually

Now & Later Planning

■ Lifetime Guidance

- ❖ Circle of Support
- ❖ Housing while parents are living
- ❖ Budgeting separately
- ❖ Employment/Daily Activities

■ Succession Planning

- ❖ Who becomes Rep Payee/ISP contact
- ❖ Circle of Support
- ❖ Budgeting

Now & Later Planning

- Supplemental Funding to Assure a Meaningful Lifestyle
 - ❖ Prior to primary caregiver death
 - Are they living their best life? Have autonomy?
 - Active interdependence with outside support
 - Money – separate budgeting of living expenses
 - Alternative supports actively involved?
 - Individual Support Plan realistic?
 - ❖ After Parent's Death
 - Lifestyle changes (geographic, expenses, employment)
 - PWD retirement
 - Services Point of Contact (Rep Payee, POA, etc.)
 - Money (Special Needs Trust, other resources)

Legal Considerations

- Prepare Will(s) & Living Wills,
- Establish Special Needs Trust
- Choose Trustee(s)
- Divorce
- Identify Financial Resources
- Review Plan Annually



Power of Attorney/Guardianship

Letter of Intent

- Power of Attorney
 - ❖ Medical
 - ❖ Financial
 - ❖ Preserves Rights as an Independent Adult
- Guardianship
 - ❖ Total Decision Maker
 - ❖ Determined Incompetent
 - ❖ Cannot be “willed” or “intent”



Divorce

■ Landmines

- ❖ Child Support Can Negate Cash and Medical Benefits
- ❖ Extended Child Support
- ❖ Legal Obligation – Letter of Intent

■ Beneficiary Planning

- ❖ Spousal Change
- ❖ Additional Children

■ Co-Parenting Issues

- ❖ Medication
- ❖ Therapy
- ❖ Schooling/IEP



Identify Financial Resources

- Family Supplements
- Gifts and Inheritances
- Investment Earnings
- Legal Settlements
- Real Estate
- Life Insurance



Be Careful How Beneficiaries Are Listed!

Breadwinner vs. Caregiver

- Calculate hours of care needed
 - ❖ Transportation
 - ❖ Doctor's appointments
 - ❖ At home care
 - ❖ Financial care (bill paying, etc.)
- Replacement
 - ❖ Hourly wage
 - ❖ Time available



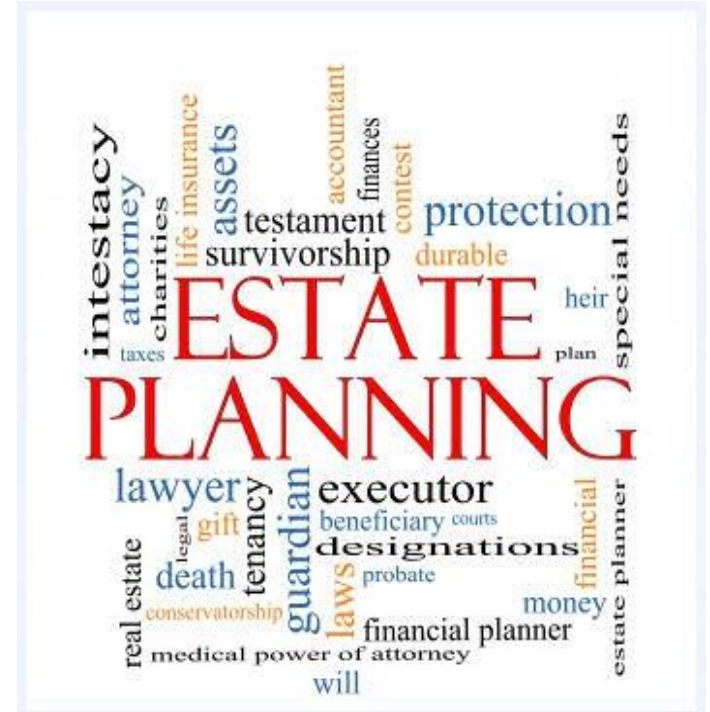
Choosing the Right Trustees

- Agencies
 - ❖ Can be Responsible for Social Security as Well
 - ❖ Care Planning
- Family Members
 - ❖ Personal Experience
 - ❖ May Not be Familiar with Gov't Programs
- Co Trustees
 - ❖ Checks and Balances
 - ❖ Agency & Family Member

Types of Trusts

- Pooled
- First Party/Self Funded
- Third Party/ILIT

Remember that a Supplemental Needs Trust is a living legal document that is meant to not only maintain benefits eligibility, but also to bring enjoyment and new, positive experiences to the beneficiary.



Person Centered Planning (PCP)

- Natural and Paid Supports
 - ❖ Written (Short, Mid, Long Term) Goals
 - ❖ Team of Accountability
 - ❖ Waiver team (support staff)
 - ❖ Family/friends
 - ❖ Follow up with Meetings
 - ❖ Disperses responsibility

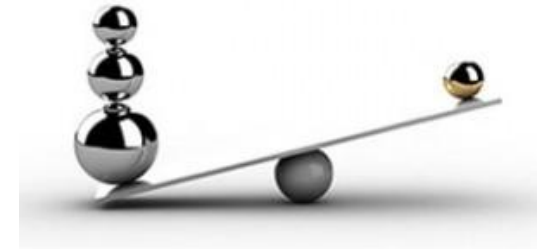


Microboarding

- Formal Person Centered Planning
 - ❖ Formal Team with a Non Profit Status
 - ❖ Assignments
 - ❖ Brings Assistance to the Nuclear Family



Succession Planning



- Personal Strategic Planning
 - ❖ Who is Going to Handle the Person's Care?
 - ❖ Where are They Going to Live?
 - ❖ What Will Their Daily Schedules Look Like?
 - ❖ Future Life Plans?
 - ❖ Who is Going to be There for Holidays and Birthdays?
- Fair is Not Always Equal

Horizon Planning

- Think 10, 20 even 50 years in the future
- Living Arrangements
- Work life
- Social life
- Religious life
- Passing the baton
- Quality of life – To Live, not just survive!

