


**FAMILY
BENEFIT
SOLUTIONS, INC.**





Sherrri Schneider

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My Life

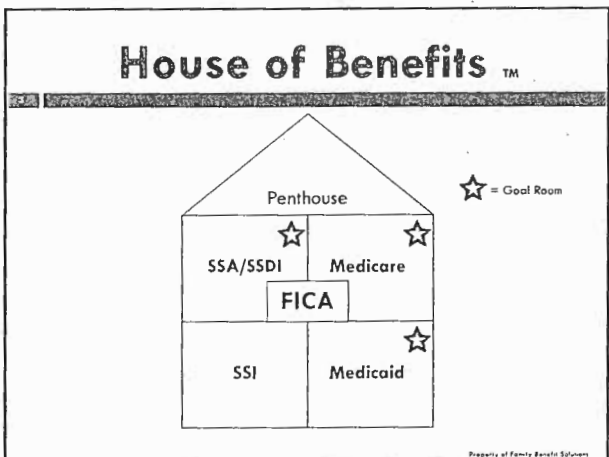
1989

2019

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SSA/SSDI

- Retirement
- Early Retirement
- Widow's pension
- Disabled – Title II

- MUST have paid into FICA
- Quarter: 2019 is \$ 1360
2020 is \$ 1410
- Does NOT look at assets

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Disability Definition Requirements

Different for children than for adults



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Disability for under 18 years old

- Is not working at a job that we consider to be substantial work; and
- Has a physical or mental condition (or a combination of conditions) that results in "marked and severe functional limitations." This means that the condition(s) very seriously limits his or her activities; and
- The condition(s) has lasted, or is expected to last, at least 1 year or is expected to result in death.
- To decide whether your child is disabled, SSI looks at medical and other information (such as information from schools and from you) about his or her condition(s), and they consider how the condition(s) affects his or her daily activities. SSI considers questions such as:
 - What activities is your child not able to do, or is limited in doing?
 - What kind of and how much extra help does your child need to perform age-appropriate activities -- for example, special classes at school, medical equipment?
 - Do the effects of treatment interfere with your child's day-to-day activities?

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Adult Disability – per Social Security

- The definition of disability under Social Security is different than other programs.
 - Social Security pays only for total disability. **No benefits are payable for partial disability or for short-term disability.**
 - "Disability" under Social Security is based on your inability to work.
 - They consider you disabled under Social Security rules if:
 - You cannot do work that you did before;
 - They decide that you cannot adjust to other work because of your medical condition(s);
- And**
****Your disability has lasted or is expected to last for at least one year or to result in death.

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Adult Disability – per Social Security

A. Compassionate Allowance

OR

B. Diagnosis

AND

Functional Limitations

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Disability:

A. COMPASSIONATE ALLOWANCE

- Approved with-in 20 days

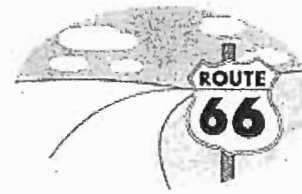
Social Security has an obligation to provide benefits quickly to applicants whose medical conditions are so serious that their conditions obviously meet disability standards.

Compassionate Allowances (CAL) are a way of quickly identifying diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal objective medical information. Compassionate Allowances allow Social Security to target the most obviously disabled individuals for allowances based on objective medical information that we can obtain quickly.

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Compassionate Allowance



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If NOT a compassionate allowance:

Need to **prove** 2 things:

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First: Need to have:

- A DIAGNOSIS on Social Security's list of impairments
- Go to SSA.GOV and Listings of impairments
 - "Sections" for every bodily function
 - Physical, Organ & "Mental"

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What are they looking for??

DEVELOPMENTAL DISABILITY:

- WAIS – full score of 70 or below
- during developmental years

MENTAL ILLNESS:

- 3 inpatient stays within the past 12 months
- compliance with doctor & medication
- clean & sober for at least 6 months+

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What are they looking for Cont'

PHYSICAL DISABILITY:

- affecting 2 limbs

SEIZURES:

- continuing despite medication

AUTISM:

- spectrum

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BUT.

Many people CAN work
having any diagnosis



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Second: Functional Limitations

□ Because I have this diagnosis, WHY CAN'T I WORK?

NEED TO PROVE WITH DOCUMENTATION from a professional – WHY Can't work???

- Concentration, pace, persistence
- Appropriate social functioning
- Activities of daily living
- Understand/Remember/Apply information ☆
- Interact with others ☆
- Adapt or manage oneself ☆

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ALL MEDICAL INFORMATION:

- Best if not older than 3-6 months old
- MUST show **functional limitations** as to why CANNOT work
- Should be consistent
- School records / IEP: Should compare to a TYPICAL child

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Once they get enough medical info:

- Case gets reviewed by a doctor in Springfield.
 - Medically awarded ☺
 - Medically denied – there is some work that can be done ☹ - usually did not prove significant functional limitations
 - Go to a Consultative Examination (CE) ☹

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2nd Definition of Disability

□ Unable to earn:

□ SGA : Substantial Gainful Activity

NOT BLIND	BLIND
2019 = \$ 1220	2019 = \$2040
2020 = \$ 1260	2020 = \$ 2110

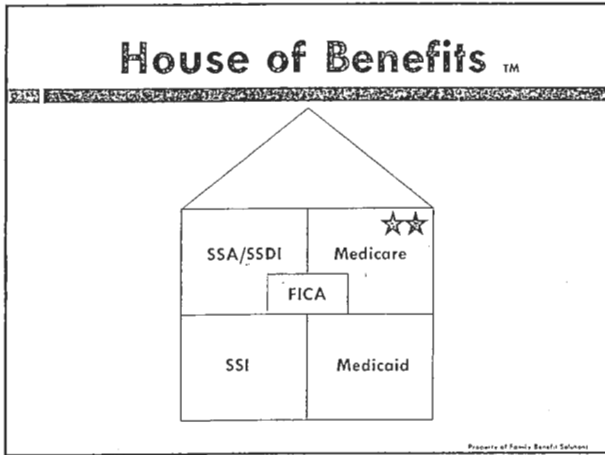
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Working Over SGA??

- WIPA- Contact the IATP WIPA Program toll free at (800) 852-5110
- - A federally funded program created to help individuals receiving SSI/SSDI make informed choices about being employed. If you are working, have a job offer or ready to start employment, they will help you understand how working will affect your benefits. They will explain Social Security work incentives in addition to state benefits, such as Medicaid, subsidized housing, TANF, food stamps, etc..
- Work Incentive Planning and Assistance (WIPA) Program will give you the information you need to make the best choice about your future.
-

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- ## Medicare
- Who is eligible?
 - 65 y/o
 - 65 y/o on SSI
 - 65 y/o & Federal Employee
 - Any age - ALS
 - Any age - Renal dialysis for end stage renal disease
 - Any age - Receiving SSDI checks for 24 months
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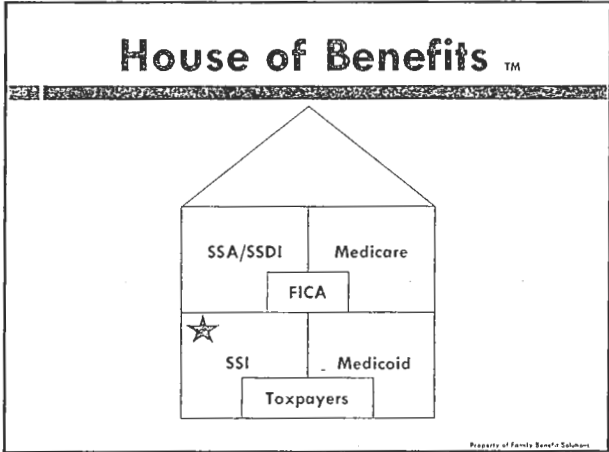
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- ## Medicare
- Parts of Medicare:
 - Part A – inpatient hospital
 - Usually free
 - Part B – Outpatient & doctors
 - Monthly premium
 - Part C – Medicare Advantage Plan
 - Part D – Drug benefit
 - 14 companies selling 42 different plans – each has drug list
 - Call SHIP or 1-800-MEDICARE to determine best plan
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- ## Medicare
- WHO pays first?
 - Coordination of benefits Hotline: Medicare & other insurance: 800-999-1118
 - Medicare Part A – 877-602-2430
 - DME Claims – 800-270-2313
 - Medicare Part B – 800-642-6930
 - Medicare in general – 1-800-MEDICARE
- 
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SSI

- Supplemental Security Income
 - 1 Person Maximum - 2019 in IL = \$ 771
2020 in IL = \$ 783
- MOST STATES ALSO GIVE A STATE CHECK – NOT IL
- Who is eligible?
 - 65 years old or older
 - Blind in both eyes
 - Disabled:
 - Compassionate Allowance
 - or
 - Listing level impairment AND functional limitations

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SSI

- How Process Works
- 3 Decisions –
 - Disabled? (have we proven CANNOT work)
 - Date of onset? – BE CAREFUL - if after age 22, will lose "goodies" later
 - Need payee?
 - THIS IS A JOB !!!!!

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SSI

- LOOKS of income, assets, and living arrangements
 - If over income or asset limit – no SSI
 - Under 18 years old, parents income & assets count (deeming)
 - Spouse's income & assets count

THREE PARENTAL ASSETS ARE EXEMPT FOR A MINOR CHILD:

- Homestead
- One car
- Qualified retirement accounts

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SSI: INCOME – earned & unearned

INCOME:

- Between 18 - 22 y/o & Full time Student exemption
 - 2019= \$ 7550/yr
 - 2020= \$ 7670/yr
- 22 y/o + or Not full time Student - monthly
- First \$85 ok
- then for every \$2 earned, they subtract \$1 SSI

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SSI - ASSETS

ASSETS:

- ◻ One single person – 18 or older, ALLOWED:
 - ◻ Home that you live in
 - ◻ One car – any value
 - ◻ Less than \$2,000 (checking, savings, stocks, bonds, IRA, C/D, money market, 401K, cash value of life insurance – if you are the owner, savings bonds, brokerage accounts)

***** Three year look back *****

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SSI – Living Arrangements

- ◻ Living arrangement = where you live and who pays for your food and shelter items.
- ◻ SSI benefits may be reduced because of the living arrangement when any of the following apply:
 - ◻ You live in another person's home and pay less than your fair share of the food or housing costs.
 - ◻ You live in your own home and someone else is paying for all or part of your food, rent, mortgage, or utility expenses.
 - ◻ You live in a private or public hospital or nursing home for the whole month and Medicare pays for over one-half of the cost of your care.
 - ◻ You live in an institution run by a federal, state, or local government for the whole month.
 - ◻ You are a minor child living in a medical treatment facility for the whole month and private insurance or Medicaid, or both, pays over half your bill.

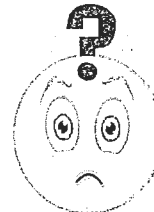
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SSI

Living Arrangements

- Living with another = loss of 1/3 (\$514 in 2019)
- Living in OWN household



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SSI – Living Arrangements Cont'

- Rental arrangement -Needs written rental agreement
- Why wouldn't everyone rent – get more \$\$\$\$?
 - Will the rental income cause a tax issue for the parent?

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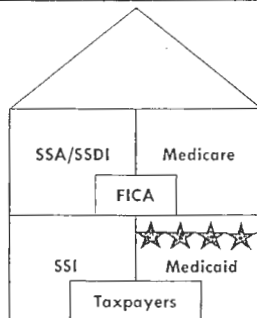
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SSI – Living Arrangements

- FAIR SHARE
 - Get all necessary household bills
 - Divide the monthly amount by number of people in the household
 - If the SSI recipient's share is LESS than \$771, he/she will get \$771
 - If the SSI recipient's share is MORE than \$771, he/she is getting help & will get the reduced amount of \$514

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House of Benefits™



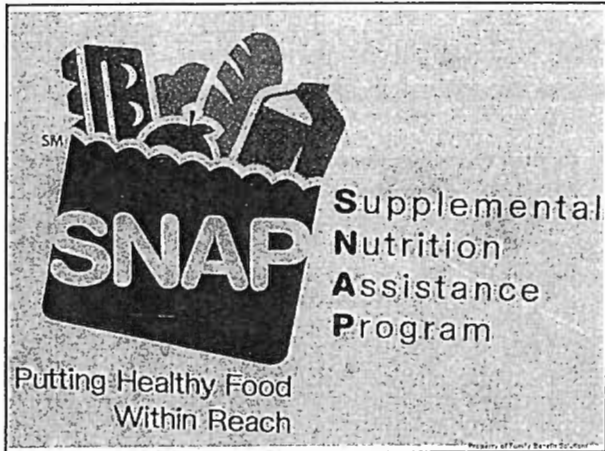
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Illinois Medicaid

- Many names: Illinois Department of Public Aid -vs- Department of Family & Child Services -vs- KidCare -vs- All Kids -vs- Illinois Department of Healthcare and Family Services
- Medicaid office: CASH, MEDICAL & ??

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If you ONLY have IL Medicaid

- And no Medicare or no commercial insurance, you will NOT have traditional Medicaid
- You will have to pick an INTEGRATED CARE PLAN – Health Choice IL - has it's own hospitals, doctors & pharmacies.
- If you do not actively pick one, one will be automatically assigned to you



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Illinois Medicaid (Cont.)

- Traditional Illinois Medicaid covers:
 - Most acute care hospitals in Illinois
 - Certain doctors – if accept Medicaid – co-pay is \$3.90 – co-pay may be eliminated
 - *** Pharmacies – co-pay \$2 generic, \$3.90 name brand- co-pay may be eliminated
 - Diapers & bed pads delivered
 - DME – with prior authorization
 - Many nursing homes
 - QMB – if eligible- Part B and Part D Premiums

(There is no co-pay for pregnant women, people enrolled in the Breast & Cervical Cancer treatment program, residents of nursing homes, supportive living facilities and intermediate care facilities)

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BEGINNING JANUARY 1, 2020

IL Medicaid will ONLY pay for prescriptions, referrals, services, etc....

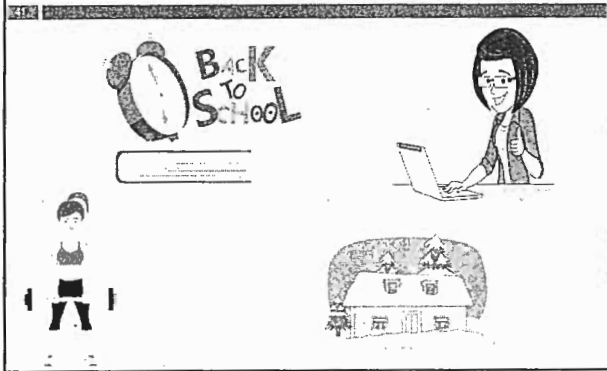
IF THE PRESCRIPTION IS WRITTEN BY AN IL MEDICAID ENROLLED PROVIDER

Need to:

- Find a Medicaid enrolled doctor
- Or
- Ask your doctor to enroll in IL Medicaid

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Medicaid -> NOT JUST FOR MEDICAL



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Medicaid Pays

- PROGRAMMING
-for after 18 years old
(alone or with another payor)
- Day Program
- Supported Employment
- Job Coach
- Residential



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MEDICAID WAIVER PROGRAMS

- HCBS Waiver for Adults with Developmental Disabilities (Home & Community Based Services)
- HCB Support Waiver for Children and Young Adults with Developmental Disabilities
- Residential Waiver for Children and Young Adults with Developmental Disabilities
- Children that are Technology Dependent/Medically Fragile
- Persons with Brain Injuries (TBI)
- Persons with HIV or AIDS
- Supportive Living Facilities
- Persons with Disabilities- DHS - DRS
- Persons who are Elderly
- Behavioral Health – pilot project

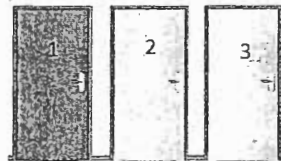
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Department of Human Services

3 "Doors"

- #1
Division of Mental Illness
- #2
Division of Rehabilitation Services
- #3
Division of Developmental Disability



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Division of Mental Illness

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- For any age
- Must have a primary diagnosis of a mental illness
- Pilot project waiver



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Division of Rehabilitation Services

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- Usually for individuals with an IQ over 70 or who have a physical disability
- DON SCORE (Determination Of Need)
- 800-843-6154
- MANY programs
 - Personal Assistant, homemaker services
 - Can help pay for 2-4 year IL state college
 - Respite Services
 - Pre-vocational & supported employment



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Division of Developmental Disability

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- Must have IQ of 70 or below before age 18
- OR
- Have a related condition (before age 22), likely to continue indefinitely, AND have significant life skill deficits in three or more of the following areas of major life activity:
 - Self-care
 - Language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for independent living



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FOR DDD: ALSO NEED PUNS FUNDING

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- Prioritization of Urgency of Need for Services
- There is not enough money to give everyone in Illinois the services they need ☹
- PUNS = List of people in Illinois with developmental disabilities who need services
- No guarantee of services but it is the FIRST step toward getting services in Illinois.
- If you are NOT on the PUNS list, you are NOT on the waiting list for services.

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Division of Development Disability

- Services: day programs, work programs, job coach, group home
- Two things PAY for these services
 - 1) Medicaid
 - AND
 - 2) Be selected from the PUNS (Prioritization of Urgency of Need for Services) list



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PUNS

- REQUIRED for children & adults with Intellectual and Developmental Disability (since 2/08)
- REQUIRED for all Medicaid Waiver Programs for DD
- If under 18, ask for the Children's Waiver
- If 18 or older, ask for the Adult Waiver
 - Home Based services
 - Group home & day program

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More PUNS

- Where to start – ISC Agent (Independent Service Coordination) – see map
- These screeners will ask questions about you & your needs.
- To get on the PUNS list, you must have a developmental disability.
- Urgency of need must be reflected on the PUNS



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PUNS

If age 18 or older - When will I be selected??

dhs.ddd.puns@Illinois.gov

- Name
- Address
- Birthdate
- Social Security number

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Medicaid Facts

- ❑ Medicaid is not very portable
 - ❑ Out of state
- ❑ Medicaid is not accepted at every doctor
- ❑ Medicaid is ALWAYS the payor of last resort

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WHO CAN GET IL MEDICAID?

BEFORE 1/1/14:
MUST BE A CATEGORY
AFTER 1/1/14:
Affordable Care Act (ACA)

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Illinois Medicaid

- ❑ TRADITIONAL CATEGORIES:
 - ❑ Refugee
 - ❑ 65 & over
 - ❑ Blind in both eyes
 - ❑ Disabled (SSDI, SSI, disease ends in death, unable to work for 12 months or more - substantiated with medical records)
 - ❑ Pregnant
 - ❑ Under 19 years old
 - ❑ Parent(s) living with child(ren) who are under 18 years old and that are legally theirs – the entire family is eligible
 - ❑ DCF5 or Foster Child
 - ❑ Breast or cervical cancer – thru Dept of Health

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NEW CATEGORY

- ❑ Now, thanks to the ACA and IL [Public Act 98-101 \(pdf\)](#), more adults are eligible for Medicaid in Illinois and the public is able to apply for Medicaid through a new, online application called the Application for Benefits Eligibility (ABE).
- ❑ Beginning January 1, 2014, all Illinois residents between 19 and 64 years of age, who are U.S. citizens or who have legal status, and who have monthly income less than (2019) \$1,436 for an individual are eligible for Medicaid through the new "ACA Adult" category.

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Affordable Care Act Clients

- Illinois Medicaid expansion
- "ACA"
- ONLY LOOK AT INCOME
- DO NOT LOOK AT ASSETS
- CANNOT have MEDICARE
- TODAY – WILL PAY FOR WAIVER PROGRAMS- including nursing homes

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Medicaid

- Redeterminations YEARLY
- Many people get cancelled incorrectly



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If we lose Medicaid:

- We may lose payment for Medicaid waiver programs



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Illinois Medicaid

- INCOME –
 - For all categories- NOT ACA
 - Community
 - If over allowable standard, monthly deductible "spend-down" : 2019=(\$1041 + \$25 = \$ 1066)
 - Long Term Care
 - Resident can keep \$ 30, \$60 or \$90 monthly
 - Resident can pay for Medicare and other health insurance
 - If single, balance of income to facility
 - If married, adhere to spousal rules

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Illinois Medicaid

ASSETS –

- ONLY for Aged, Blind or Disabled
- If over allowable standard = deductible "spend-down"
- Community
 - 1 single person - allowed: house they live in, 1 car and \$2000
 - No look back
- Long Term Care
 - DRA - February 8, 2006
 - SMART Act
 - 60 month look back
 - Spousal Impoverishment



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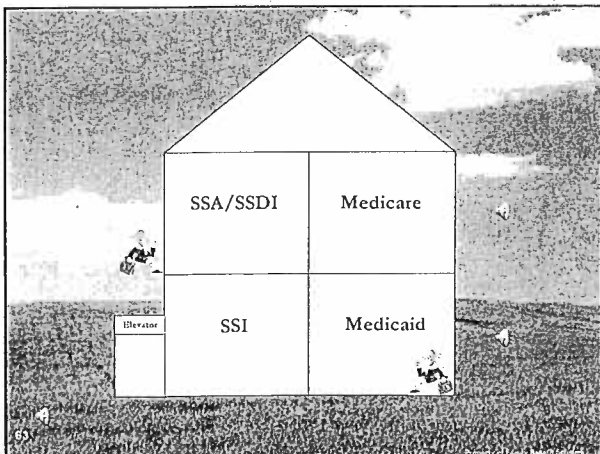
Movin' On Up

- If we are in the "basement", how do we get to the "penthouse"?



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Riding the Elevator

- 1) Works and earns FICA on own but LESS than SGA = monthly (2019= \$1220)
- 2) DAC = Disabled Adult Child
 - CDB = Childhood Disability Benefits
 - a) Onset date that Social Security has is before age 22
 - AND
 - b) Parent with a FICA work record
 - AND
 - c) That Parent either:
 - Becomes retired & collects SSA
 - or
 - Becomes disabled themselves and collects SSDI
 - or
 - Becomes deceased

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Riding the Elevator (Cont.)

Adult Child moves from SSI to DAC (disability)

AND

In 24 months → Medicare



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Riding the Elevator (Cont')

OLD RULE:

- Prove you have enough FICA quarters on your own work record

Or

- Prove your parent has retired & collects, or your parent has a disability of their own & collects or your parent has expired

- AUTOMATICALLY MOVED TO SSDI or DAC

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Riding the Elevator (Cont')

NEW RULE:

A NEW APPLICATION will need to be initiated.

New Medical records will need to be provided to be sent to Springfield's doctors to review to determine if the applicant meets the current rules of disability for their diagnosis.

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What Stops the Elevator?

Marriage

Working over SGA



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How to Lose These Benefits?

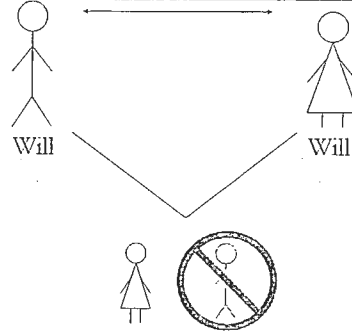


- 1) 10 day rule
- 2) Redeterminations
- 3) Inheritances

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Future Planning



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REAL ANSWER IS- SPECIAL ESTATE
PLANNING TO INCLUDE:

**SPECIAL
NEEDS
TRUST (S)**

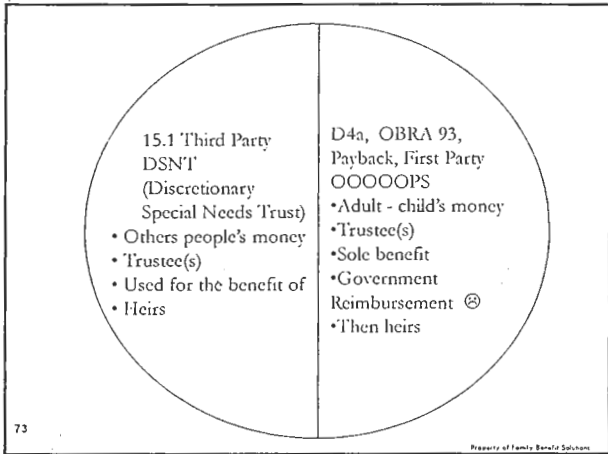
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15.1 Third Party
DSNT
(Discretionary
Special Needs Trust)
• Others people's money
• Trustee(s)
• Used for the benefit of
• Heirs

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WAYS TO SAVE MONEY

- Third Party Trust – private
- First Party Trust – private
- Pooled Trust – already set up
 - Over \$75,000 – Illinois Disability Pooled Trust
 - Over \$6,000 – Life's Plan

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ABLE 529A

- Limit of one ABLE account per person
- 2019 deposit limit is \$15,000
- Cannot exceed \$100,000 or SSI can be suspended
- Strict reporting & record keeping
- Upon death, check for Pay Back to the state for Medicaid waiver services
- Can have in ANY state

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Time for Fun!

TIME FOR BINGO!

BINGO				
4	19	41	51	●
7	22	44	●	71
10	28	●	56	63
13	●	45	48	75
●	18	31	46	65

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SherrI Schneider
847-279-8506
Benefithelp@aol.com



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ACRONYMS

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ASD	Autism Spectrum Disorders
CART	Clinical Administrative Review Team
CILA	Community Integrated Living Arrangement
CMS	Center for Medicaid & Medicare Services
DCFS	Department of Children and Family Services
DD	Developmental Disabilities
DDD	Division of Developmental Disabilities
DHS	Department of Human Services
DMH	Division of Mental Health
DPH	Department of Public Health
DRS	Division of Rehabilitation Services
DSCC	Division of Specialized Care for Children
DT	Developmental Training Day Program for adults

EI Early Intervention (birth to 3)

FICA Federal Insurance Contribution Act

HBS Home Based Services

HFS Department of Health Care and &
Family Services (Public Aid)

HUD Housing & Urban Development

ICAP Inventory for Client and Agency
Planning

ICD – DD Intermediate Care Facility for
Individuals with
Developmental Disabilities

IDEA Individual with Disabilities
Education Act

IDPH Illinois Department of Public
Health

IEP Individual Education Plan

ISBE Illinois State Board of Education

ISC Individual Service Coordination

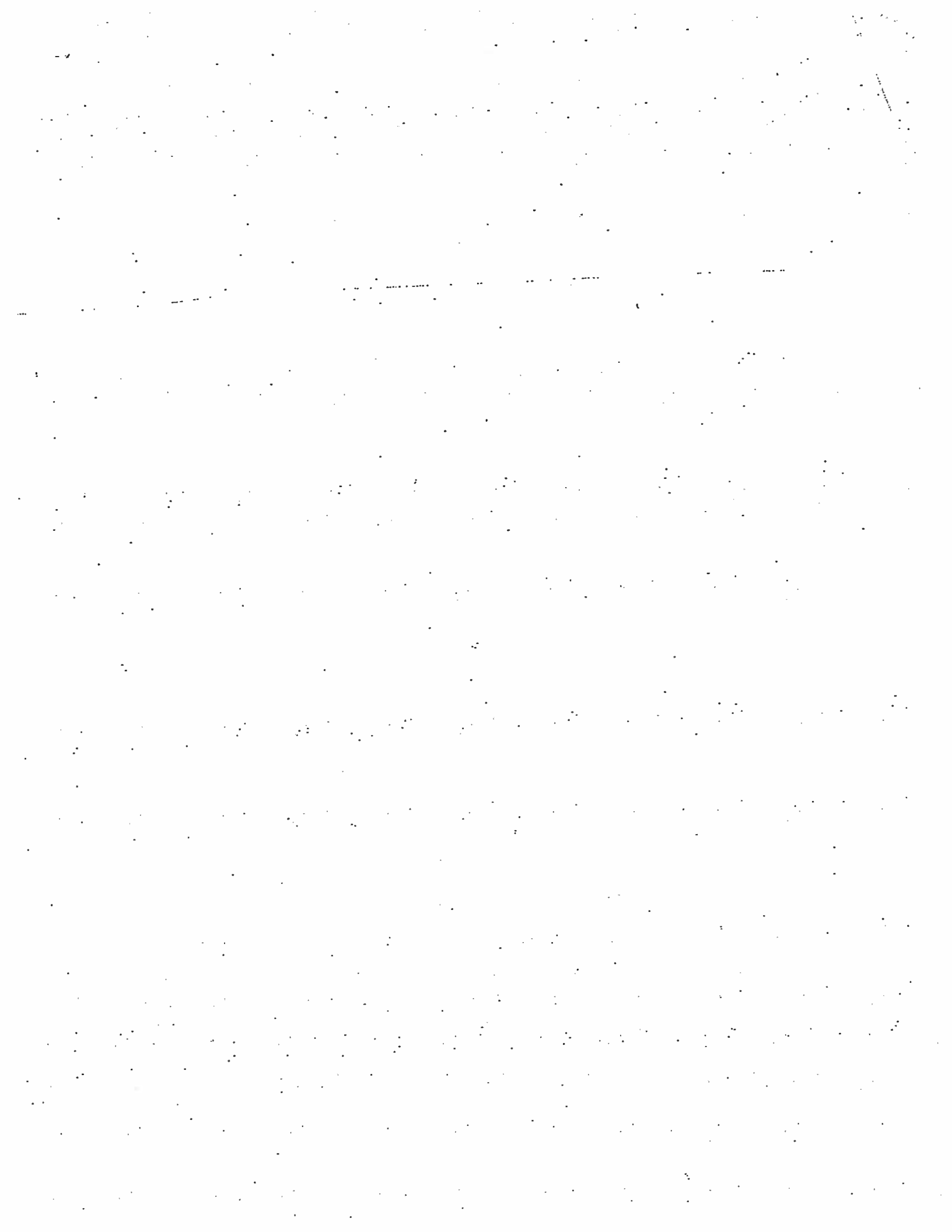
ISP Individual Support Plan

ISSA Individual Service and Support
Advocacy

OIG Office of the Inspector General

PACKET Information on paper going to
Network Facilitator advocating
your need for help

PAS Pre-Admission Screening
PDD Pervasive Developmental Disorders
POS Purchase of Service funding method – fee for service
PUNS Prioritization of Urgency of Need of Services (waiting list)
QA Quality Assurance
QSP Qualified Support Professional
SEP Supported Employment Program
SNAP Supplemental Nutritional Assistance Program (food stamps)
SNT Special Needs Trust
SODC State Operated Developmental Center
SSA Social Security Administration
SSDI Social Security Disability Insurance
SSI Supplemental Security Income
SST Support Service Team
UCP United Cerebral Palsy



EARNING FICA CREDITS FOR SSDI

- The credits are based on the amount of your earnings. Your work history determines your eligibility for disability benefits.
- In 2019, you receive one credit for each \$ 1360 of earnings up to a maximum of four credits per year.
- The number of credits you need to be eligible for benefits depends on your age and the type of benefit.
- How many credits you need for disability benefits depends on how old you are when you become disabled:
 - If you become disabled before age 24, you generally need 1½ years of work (six credits) in the three years before you became disabled.
 - If you are 24 through 30, you generally need credits for half of the time between age 21 and the time you became disabled.
 - If you are disabled at age 31 or older, you generally need at least 20 credits in the 10 years immediately before you became disabled.

Monthly substantial gainful activity amounts by disability type

Year	Blind	Non-blind	Year	Blind	Non-blind	Year	Blind	Non-blind
1975	\$200	\$200	1995	\$940	\$500	2015	\$1,820	\$1,090
1976	230	230	1996	960	500	2016	1,820	1,130
1977	240	240	1997	1,000	500	2017	1,950	1,170
1978	334	260	1998	1,050	500	2018	1,970	1,180
1979	375	280	1999	1,110	700	2019	2,040	1,220
1980	417	300	2000	1,170	700			
1981	459	300	2001	1,240	740			
1982	500	300	2002	1,300	780			
1983	550	300	2003	1,330	800			
1984	580	300	2004	1,350	810			
1985	610	300	2005	1,380	830			
1986	650	300	2006	1,450	860			
1987	680	300	2007	1,500	900			
1988	700	300	2008	1,570	940			
1989	740	300	2009	1,640	980			
1990	780	500	2010	1,640	1,000			
1991	810	500	2011	1,640	1,000			
1992	850	500	2012	1,690	1,010			
1993	880	500	2013	1,740	1,040			
1994	930	500	2014	1,800	1,070			

PUNS - THE BASICS

From The Arc of Illinois

Family to Family Health Information & Education Center

PUNS stands for Prioritization of Urgency of Need for Services.

PUNS is a list of the people in Illinois with developmental disabilities who need services.

PUNS is for everyone who may need help from the government to pay for developmental disability services now or in the future.

PUNS is the first step toward getting services in Illinois. If you are not on the PUNS list, you are not on the waiting list for services.

To get on PUNS, you need to set up a date to meet with a Pre-Admission Screener. These screeners will ask questions about you and your needs. These questions are part of the PUNS survey. All screeners work for Independent Service Coordination Agencies or ISC's. To get on the PUNS list, you must have a developmental disability. If you don't know if you have a developmental disability, the screener will help you.

To find your ISC, you can call Illinois Life Span at 1-800-588-7002. You can also call DHS at 1-888-DD-PLANS.

When your PUNS survey is done, you are on the list. This doesn't mean that you get the services you need. It just means that you have made the first step.

Some of the services that people may need are:

- o In-Home Supports
- o Respite Care
- o Job Coaches
- o Group Homes
- o And many others

There is not enough money to give everyone in Illinois the services they need. Now, many people are working on a fair way to choose who gets services.

Don't forget to update your PUNS form every year. Only people (families) who completed the PUNS - and keep it updated - have a chance of getting "in" to receive services.

If you have questions or need help, you can call Illinois Life Span at 1-800-588-7002.

If you want more information about PUNS or Home-Based Services, go to the Support Network website at www.familysupportnetwork.org

The Arc of Illinois Family to Family Health Information & Education Center



FACT:

Effective 4/1/2020, IL Medicaid will begin to follow the federal regulation that states that IL Medicaid will only pay for prescriptions written by an IL Medicaid enrolled provider. IL Medicaid has been out of compliance since 2012 and now must comply.

WHAT THIS MEANS:

If the prescribing doctor is NOT enrolled with IL Medicaid, IL Medicaid will not pay for the item/service to include: drugs, durable medical equipment, diapers, referrals to another doctor...etc.

WHO DOES THIS AFFECT:

Any person who is eligible for Traditional Medicaid. & MCO Plan.

This does apply to individuals that are "dual eligible" (having both Medicare and IL Medicaid.) The requirement that physicians be enrolled will extend to crossover claims (where Medicare is primary and Medicaid is secondary). To receive the 20% payment from Medicaid, the prescribers will need to be enrolled with IL Medicaid.

EXCEPTION: Drugs filled by Medicare Part D. IL Medicaid does not pay secondary to Medicare Part D, except in a very limited circumstance which is described below. When a pharmacy bills Medicare Part D, the Medicare Part D plan is responsible for the entire cost of the drug, even if the member is dual eligible for both Medicare and Medicaid. IL Medicaid allows Medicare Part D copay only billing for a very small subset of individuals who are not eligible for a waiver, and live in a specific type of supported living arrangement. This policy would apply to those claims.

WHAT HAS IL MEDICAID DONE TO GET THIS WORD OUT:

IL Medicaid has sent Provider Notices to pharmacies and doctor offices. They have updated their provider manual. They have explained that they were able to identify doctors who are not enrolled with IL Medicaid but, in the past, IL Medicaid has paid their prescriptions. These doctors received more notices.

WHAT HAPPENS IF I GO TO THE PHARMACY AND MEDICAID WILL NOT PAY FOR MY DRUG:

IL Medicaid has explained that there will be a one-time (per drug) over ride for the first month. To get an over-ride, one would need to call: 877-782-5565.

NOW WHAT:

This leaves families with several options:

Change to a doctor that is enrolled with IL Medicaid.

As we are aware, there is a lack of available IL Medicaid enrolled doctors.

Many IL Medicaid doctors are not seeing new patients.

It is very difficult for individuals with an Intellectual and Developmental disability or Autism to change to a new doctor.

To find a doctor who is currently enrolled with traditional IL Medicaid, you may call: 800-226-0768

The current non-Medicaid doctor can enroll with IL Medicaid.

A physician can register in Impact to become a Medicaid enrolled provider.

After Medicaid enrollment, this doctor can choose to accept Medicaid patients or choose not to see Medicaid patients but his/her prescriptions will be paid by IL Medicaid for patients eligible for IL Medicaid.



**Important News about Your Medical Benefits
Changes to Copayments**

Beginning September 1, 2019, copayments for doctor visits, prescriptions and other medical services will no longer be required for services provided to children or adults receiving Medicaid benefits under the following programs:

- Family Care
- Seniors and Persons with Disabilities (formerly Aid to the Aged, Blind or Disabled)
- Health Benefits for Workers with Disabilities (HBWD)
- Affordable Care Act (ACA) Adults

HOWEVER, PLEASE NOTE:

Recipients covered by the following programs **are still** responsible for their applicable copayments:

- Children who receive coverage under All Kids Share
- Children who receive coverage under All Kids Premium Level 1
- Children who receive coverage under All Kids Premium Level 2
- Adults covered under Veterans Care

There are no changes to premium requirements for All Kids Premium Levels 1 and 2.

If you have questions about this notice, you can call the Healthcare Benefits Hotline at 1-800-226-0768. The call is free. Persons who use a TTY can call: 1-877-204-1012

CN 19.01



**Noticias Importantes sobre Sus Beneficios Médicos
Cambios en los Pagos Deducibles**

Comenzando el 1 de septiembre de 2019, los pagos deducibles por las visitas al médico, recetas y otros servicios médicos ya no serán necesarios para los servicios brindados a los niños o adultos que reciben los beneficios del "Medicaid" bajo los siguientes programas:

- Cuidado Familiar
- Personas de la Tercera Edad y Personas con Discapacidades (anteriormente se llamaba Asistencia para Ancianos, Ciegos o Discapacitados (AABD, por sus siglas en inglés)
- Beneficios de Salud para Trabajadores con Discapacidades (HBWD, por sus siglas en inglés)
- Ley de Atención Médica Asequible (ACA, por sus siglas en inglés) para Adultos

SIN EMBARGO, POR FAVOR TENGA EN CUENTA:

Las personas que reciben beneficios cubiertos por los siguientes programas **todavía son** responsables de los pagos deducibles correspondientes:

- Los niños que reciben la cobertura bajo "All Kids Share"
- Los niños que reciben la cobertura bajo "All Kids Premium" Nivel 1
- Los niños que reciben la cobertura bajo "All Kids Premium" Nivel 2
- Los adultos cubiertos bajo el Cuidado de Veteranos

No hay cambios en los requisitos "premium" para "All Kids Premium" Niveles 1 y 2.

Si usted tiene alguna pregunta acerca de este aviso, puede llamar a la Línea directa de los Beneficios de Cuidado de Salud al 1-800-226-0768. La llamada es gratuita. Las personas que utilizan un Teletipo (TTY) pueden llamar al: 1-877-204-1012

CN 19.01S



SPECIAL NEEDS TRUSTS

THREE TYPES:

--15.1 --- Third Party Trust

- funded with OTHER people's money
- anyone can set this up for an individual who has disabilities
- individuals can be any age
- has a trustee – the individual with disabilities cannot access the funds
- after the individual with disabilities expires, the heirs (or who ever set this trust up can name who can) keep the remaining balance

--D4A, OBRA 93, Payback Trust--- First Party Trust

- funded with the PERSON'S own money
- parents, grandparents, courts or guardians can set this up- IN 2017- NOW THE PERSON WITH THE DISABILITY CAN SET THIS UP FOR THEMSELVES.
- can only be used for the SOLE benefit of the individual with disabilities
- individuals with disabilities must be under 65 years of age
- has a trustee – the individual with disabilities cannot access the funds
- after the individual with disabilities expires, Medicaid is reimbursed for past Medicaid expenses incurred in all states– PRIOR to any other disbursement of the balance.

--D4C, Pooled Trust---

- “pooled” with other people – each person has a separate account
- can only be used for the SOLE benefit of the individual with disabilities
- individuals have to be under 65 - NEW
- already set up – there are several of these in Illinois
- comes with a trustee – the individual with disabilities cannot access the funds
- payback provision
- ongoing fee
- entering fee

QUESTIONS FOR POTENTIAL SPECIAL NEEDS TRUST ATTORNEY

- 1) How many Illinois special needs trusts have you done? Third Party?
D4a/OBRA 93/First Party?
- 2) Do you keep up with the rule changes? If yes, how?
- 3) Do you let your clients know when their trust needs updating?
- 4) Has your trust been denied by SSI or Medicaid? If yes, why?
- 5) If mine gets denied, will you file the appeal and will the appeal cost
me more money?
- 6) Has your trust been submitted with an actual case for someone
applying for SSI and/or Medicaid or have they mostly been prepared
for younger clients?
- 7) Has your trust been pre-approved by SSI? By Medicaid?
- 8) Has your trust been approved by Regional Staff?
- 9) Is your trust compliant with the clarified POMS 1/1/09 and 2010?

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Special Needs Legal & Future Planning

LAW A Professional Corporation

Buffalo Grove • Chicago • Old Orchard
www.rubinlaw.com • email@rubinlaw.com

847-279-7999 • Toll Free 866.To.Rubin

Address mail to 1110 W. Lake Cook Rd., Suite 165, Buffalo Grove, IL 60089-4997

Heard About ABLE Accounts?

The concept is for individuals with disabilities to have a tax-free savings account similar to a 529 College Savings Plan (ABLE accounts will be "529A" accounts).

For information specifically on the State of Illinois ABLE Account program please visit:

<http://www.illinoistreasurer.gov/Individuals/ABLE>

However, Illinois residents can also use many other State's ABLE Account programs. The first State to have an ABLE Account, and many feel, arguably, the easiest to use, is Ohio's found at:

<http://www.stableaccount.com>

To compare the different State ABLE programs got to:

http://www.ablenrc.org/state_compare/

While an ABLE account may be a very useful additional "tool" in some circumstances, an ABLE account may not be as useful as first thought for many families of individuals with disabilities.

First, the ABLE account is limited in terms of the amount of money that can be deposited on an annual basis; the 2018 limit is \$15,000 per year, and there is a limit of one ABLE account per individual. However, in addition, beginning in 2018, due to the December 2017 Federal Tax Bill (the Tax Cuts and Jobs Act), until 12/31/25, an ABLE beneficiary who has income from employment may make an additional contribution of the lesser of the beneficiary's earned gross income from employment for the year, and an amount equal to the Federal Poverty Level for a one-person household (which is currently at \$11,770), if there is no contribution by or for the beneficiary, to an employer retirement saving plan. However, beware; the earned income will still be counted for purposes of eligibility. Additionally, the Tax Cuts and Jobs Act allows, beginning in 2018 until 12/31/25, a designated beneficiary of an ABLE account, to claim the saver's credit for contributions made by the beneficiary to his or her ABLE account, if not a full time student and if age 18 or older. Of note is another new provision regarding ABLE accounts under the December 2017 Federal Tax Bill. That is, in 2018 a traditional 529 college tuition account which has an ABLE beneficiary as the beneficiary, may be transferred to the 529A ABLE Account for that beneficiary, but the amount of the "rollover" is subject to the annual limitation for contributions, again \$15,000 for 2018.

Second, the total value of an ABLE account cannot exceed \$100,000 or the individual will have their SSI eligibility suspended until the account balance returns below that level. Further, the ABLE account is capped at the College Savings 529 Plan maximum in the state in which the ABLE account is open; State limits vary from approximately \$250,000 to \$450,000. Illinois' limit is \$400,000.

Third, ABLE accounts can be used solely to cover disability related expenses or face a penalty.

Fourth, an ABLE account requires strict, complex reporting and record keeping.

Fifth, the individual, unless there is a court appointed Guardian appointed, has full control and access to the Account. That is there is no "trustee" or "custodian".

Finally, be aware that the States that provided medical assistance and/or Medicaid waiver services during the life

"payback" or reimbursement, for all such amounts (including medical and Medicaid waiver) which were provided to the individual after the establishment of the ABLÉ account.

There are several circumstances in which an ABLÉ account may be very useful. For example, in situations where an individual with disabilities wants to save excess work earnings or Social Security money so that it may be used in the future, as this money cannot be accumulated over \$2,000 in their own name (under SSI and "traditional" Medicaid rules) but they can place up to \$15,000 a year into an ABLÉ Account.

An ABLÉ account might also be useful where a relative has left an inheritance of less than \$15,000 directly to the child who is on "traditional" Medicaid and/or SSI and mistakenly did not leave it to a 3rd party Special Needs Trust.

Another possible use for an ABLÉ account might be to receive "adult" child support ordered by a court, in order not to impact SSI or Medicaid.

ABLÉ accounts could also be used to avoid the 1/3 reduction to SSI for family contributions to the individual for food and shelter. If the family contributes the funds for food and shelter to the Able Account, its use will not cause the 1/3 reduction to SSI as it would if such funds came from them directly or through a special needs trust.

Lastly, it might be the perfect vehicle for small litigation settlements.

However, due to the "payback" or reimbursement to the State(s) on death for Medicaid use, it is definitely not an appropriate vehicle for gifts or inheritances from others for the benefit of the individual with disabilities, unless there is the strong belief that all funds gifted will be spent for disability related expenses before the individual with disabilities dies. In that situation a Third Party Special Needs Trust is the only appropriate option and with a Third Party Special Needs Trust's favorable income tax rules, that is, being taxed as a Qualified Disability Trust with a \$4,150 exemption in 2018, and with the beneficiary's 2018 standard deduction of \$12,000, the Trust can shelter potentially (subject to the beneficiary's earned income) more than \$16,000 in annual investment income.

In short, the ABLÉ account has some use for the individual's own savings, but generally not for gifts or inheritances from others due to the pay-back on death of the individual.

Many believe that the most beneficial provision of an ABLÉ account is that it grows "income tax free", at least for Federal Income Tax purposes. However, if you "do the math" you will see that, that fact is really of little benefit. If the individual is receiving SSI, the ABLÉ account cannot have more than \$100,000. The individual can use their 2018 standard deduction of \$12,000 to shelter their earned income and any income on ABLÉ account investments. Further, if you add the average individual's (receiving SSI) annual earned income to the current possible return on \$100,000 in ABLÉ account investments, you will see that more than likely than not there wouldn't be any income tax anyway on those funds, even if they were "taxable".

It is important to remember the benefits as well as the shortcomings of ABLÉ accounts as you consider them as one of the savings tools for an individual with disabilities.

Before considering an ABLÉ account, when they become available, you should consult with an experienced special needs planning attorney. To find such an attorney we suggest visit <http://www.specialneedsalliance.org/find-an-attorney/illinois/> (the national not-for-profit association of experienced special needs planning attorneys, membership by invitation only).

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Special Needs Legal & Future Planning
Buffalo Grove • Chicago • Old Orchard
www.rubinlaw.com - email@rubinlaw.com - 866.to.rubin

TIME LINE FOR ILLINOIS PARENTS WITH A SPECIAL NEEDS CHILD
DIAGNOSED WITH DEVELOPMENTAL DISABILITIES OR AUTISM

(As seen in Chicago Parent Special Parent Magazine, The Daily Herald, and Special Olympics Newsletter)

Written by Sherri Schneider of Family Benefit Solutions

- If, at birth, your infant remains in the hospital for some time, apply for Supplemental Security Income (SSI) for this child. As long as the child remains in the hospital, parents' income and assets will not count. To apply, call 1-800-772-1213 and indicate that you are applying for SSI. If your child has no or limited health insurance, think about applying for Illinois Medicaid.
- At any age, the sooner the better, you will need to do some special needs estate planning to include (but not limited to): wills, special needs trust(s), powers of attorney, and change of beneficiary. It is vital that you use an attorney whose practice is limited to these issues and who keeps up with the ever-changing rules. To find an attorney in your area, you may reference the Special Needs Alliance website. Doing this planning will help to ensure that your child can obtain and maintain benefits for now and in the future.
- From birth to age 3, have your child evaluated for early intervention programs. There are several agencies that provide this program. To locate the agency for your area, you can call 217-782-1981.
- Do not open any assets in your child's name. Let others know this as well.
- At age 3, seek as much help from the school district as possible. You may need to hire a school advocate or attorney to get what your child needs.
- Continue to keep no assets in your child's name.
- If your child has the diagnosis of developmental disability or on the Autism Spectrum, you must do a PUNS (Prioritization of Urgency of Need for Services). Because there is not enough money to give everyone in Illinois the services they need, this is Illinois' waiting list for services that Illinois maintains. To do a PUNS, you will need to call your Independent Service Coordination Agency (ISC) which can be found by calling 1-800-588-7002 or 1-888-DDPLANS. You can request funding for services such as: respite, children's waiver, Home Base Service waiver, job coaches, and group homes.
- If your child is under 18 years old, most benefit programs will count the parents' income and/or assets against the child. Some programs do not. To find some programs that do not deem parents' income and assets, you may call: Case Management under Division of Specialized Care for Children 773-444-0043

- Attend as many conferences you can to obtain information for your child's future. The schools have presentations. The ARC of Illinois lists their presentations on their website. If you would like support from fellow parents, you can reference IPADD Unite on Facebook. You can attend a work group in your area. www.iacdd.org

- When your child turns 14 ½, the school should be starting transition planning. Ensure your child's IEP reflects realistic goals. Consult School Attorney or Advocate if necessary.

- Between 17-18, have your child take a WAIS test and, if not already selected from the PUNS list, a Vineland test.

- In Illinois, special education can end the day before your child turns 22. One year before this, do your due diligence to look at programs (day, residential) for where your child may attend when the school district is finished.

- At 18 years old:

- Apply for SSI
- Apply for Medicaid
- Consider the need for Guardianship –vs- Powers of Attorney for your child – The same attorney doing your special needs planning may be able to do this
- Get a school Power of Attorney executed and given to the school
- Get an Illinois Disabled Identification Card
- Look into RTA Reduced Fare Permit and/or ADA Paratransit Service
- Males – Register for Selective Service
- Register to vote – if applicable

- ONGOING – establish and update a Letter of Intent