

Preparing for Adulthood: **A Roadmap for the Future**



Session Two

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**Division of Specialized
Care for Children**



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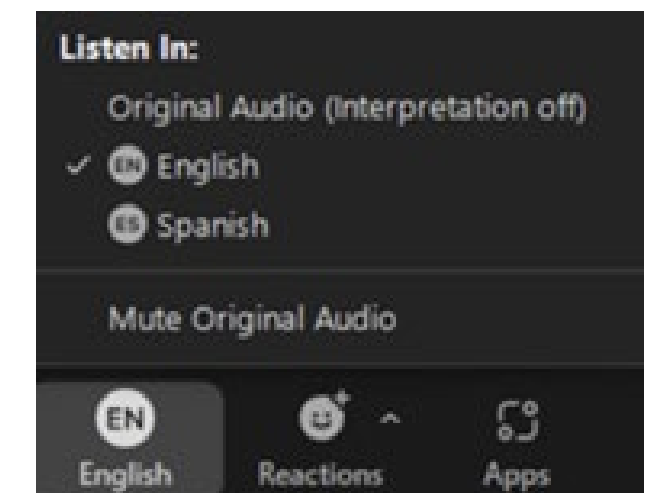
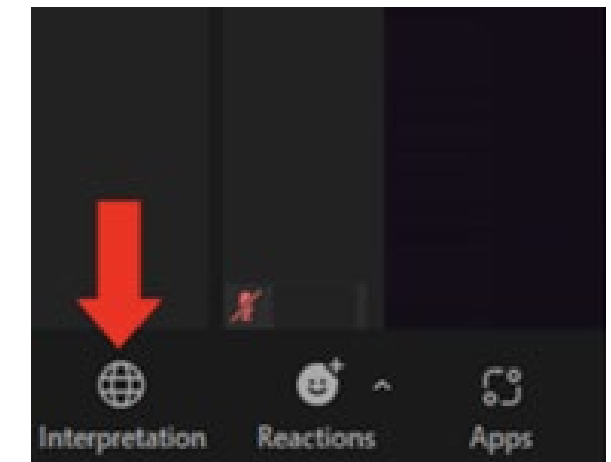
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Presentation Materials

- Information will be presented in English. If you selected Spanish as your language, information will be translated verbally.
- The slides are in English. The Spanish version of all materials are found on the DSCC website.

Claire Cook, MSW

UIC-DSCC, Title V Transition Specialist clairer3@uic.edu

- Helping youth with special healthcare needs make a smooth and successful transition to all aspects of adult life.
- To achieve this goal, DSCC provides transition-focused supports for our care coordination teams and outside providers.



**Title V Transition
Specialist Role**



Suzanne Aaron, CRS-A/D

Illinois Life Span Program, Information and Outreach

Specialist for northern Illinois

Suzanne@thearcofil.org

- For over 70 years, The Arc of Illinois has been advocating with people with disabilities, families, and community organizations to make Illinois a place where people with disabilities can live, work, learn, play, and love in communities across the state.
- We believe people with disabilities should be full participants in community life, and we offer families and individuals the information, resources, family support, and training needed to reach their goals.



**Information &
Outreach
Specialist Role**

How We Help

Our Key Focus

Navigating Adult Systems

We'll explore how, "Educated parents become empowered parents," the role of adult guardianship, health insurance, benefits and programs changes.

Evolving Family Roles

As young people age, family dynamics naturally shift. We'll explore how this may look for parents and caregivers of more complex youth and how their daily management needs impact creating meaningful days. We'll expand on the role of support circles and how to make decisions that support youth and caregivers long-term well-being.

Note: This session focuses on youth and young adults ages 16 and older with complex needs.

Agenda



Part 1: Navigating Adult Systems

- “Educated Parents Become Empowered Parents.”
- Adult Guardianship and Alternatives
- Adult Insurance, Benefits and Program Changes
- Long-Term Care Transition



Part 2: Evolving Family Roles

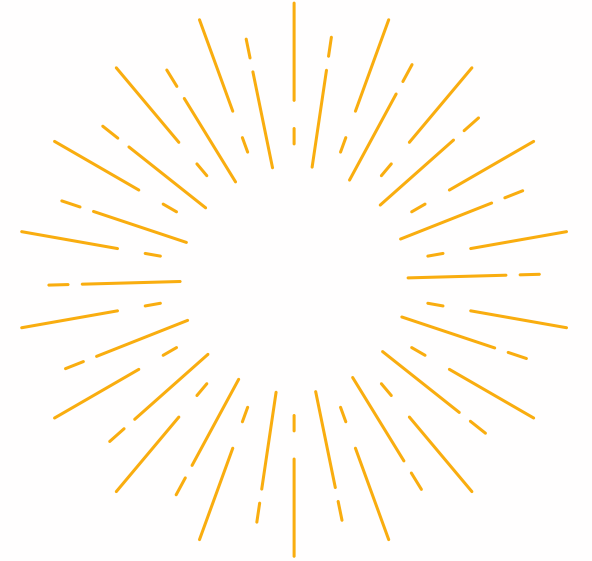
- Planning for meaningful days that benefit everyone
- Dealing with feelings around planning for the future.
- Health Challenges of Parents and Caregivers
- Creating a Plan
- Bringing it all Together

Part 1: Navigating Adult Systems



**“Educated Parents Become
Empowered Parents.”**

Adult Guardianship



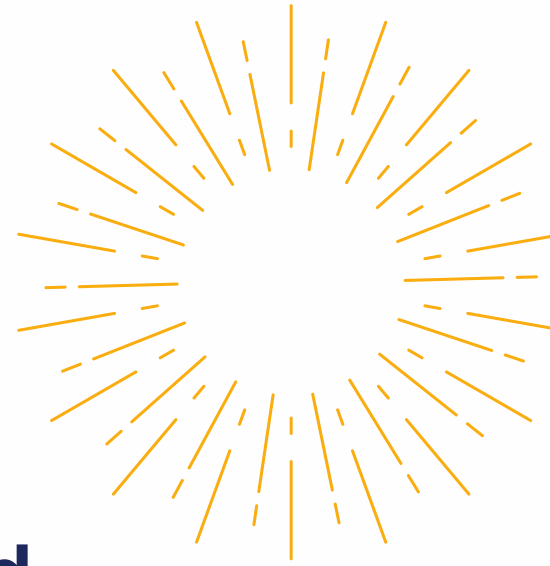
Navigating the difficulties of being your child's guardian

When your child turns 18, you no longer have full authority to make medical or other important decisions for them—even if they are not able to make those decisions on their own.

Guardianship - This means that one person will have the legal power to make decisions for another person, mostly used when a person is unable to make their own decisions.

*You are making the best choice for
your child's well-being.*





First Steps to Guardianship in Illinois

You may need to take legal action to protect your child if they cannot:

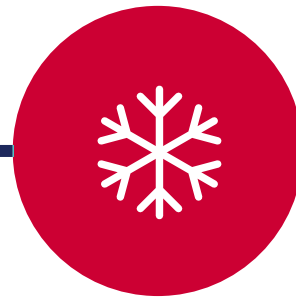
- Recognize when a decision needs to be made
- Think about possible options
- Understand the consequences of decisions
- Express their needs

Guardianship

Questions to Ask Yourself

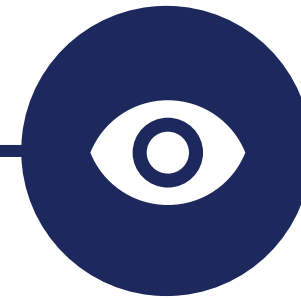


If guardianship is needed, what choices do I have?

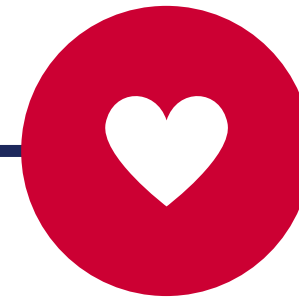


Can I afford to pay for filing and a lawyer?

If not, do I know who to ask for help?



Is there a doctor I trust that can complete the physician's report?



Is there a plan for what happens if the guardian can no longer care for the adult?



**If guardianship is
needed, what
choices do I
have?**

Guardianship can be divided into two main types:

- **Guardianship of the Person:** The guardian helps with things like medical care, living arrangements, education, and daily needs.
- **Guardianship of the Estate:** The guardian manages the person's money, property, and financial matters.

The court decides what kind of guardian a person needs:

- **Limited Guardian:** This guardian can only make certain decisions about the person's care or money, as chosen by the court.
- **Plenary Guardian:** This guardian can make almost all decisions about the person's care and money. This is the strictest type of guardianship.

Court Process

1. To appoint a guardian, a **petition** must be filed in court.
2. A **doctor's report** must also be filed.
3. A **guardianship hearing is scheduled within 30 days** after the petition is filed in court.
4. The person who may need a guardian (called the Respondent) must receive a **summons and a copy of the petition** so they know about the case.
5. When needed, the court will choose a **guardian ad litem (GAL)**, who can be a lawyer or a trained volunteer.

For more information, visit: <https://gac.illinois.gov/osg/guardianship-fact-sheet.html>



**Can I afford to pay for filing
and a lawyer?**

***If not, do I know who to ask
for help?***

Possible Costs:

- **Filing fees** – Cost to submit the guardianship petition to the court.
- **Sheriff's fees** – Cost for the sheriff to deliver court papers to the Respondent.
- **Attorney's fees** – Cost if you hire a lawyer to help with the case.

Contact your local circuit clerk or Illinois Court Help (call or text (833) 411-1121) or visit www.ilcourthelp.gov/hc/en-us to find out the rules in your county.

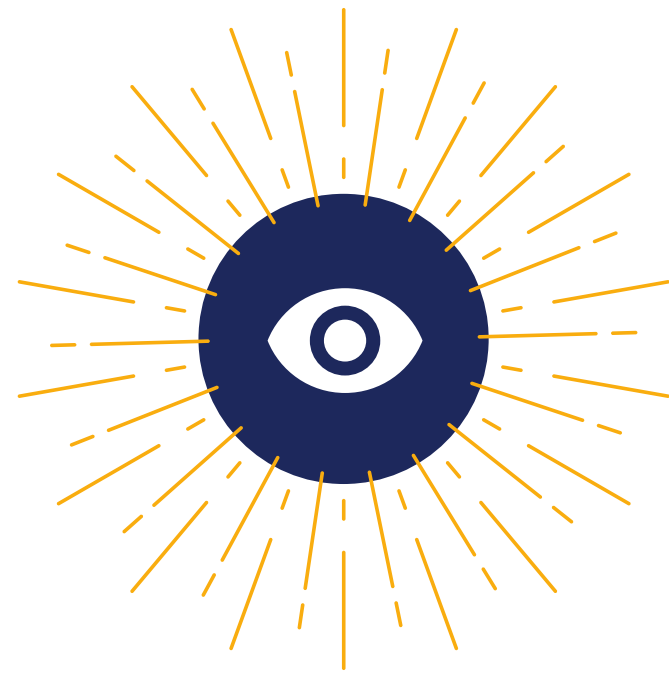
For help with costs:

- [Fee Wavier for Civil Cases](#): *Illinois Legal Aid Online (ILAO)* provides a [guided interview](#) called an Easy Form that will help you fill out the form to file with the court.
- Through [ILAO](#), families may qualify for free or reduced-fee legal help.
- [The Special Needs Alliance](#) offers a special needs lawyer search. These lawyers are experts in the laws that cover disability, special needs, and elder law.

Filing Pro-Se

If you are filing without a lawyer (Pro-Se), there are resources to help you.

- **Illinois Legal Aid Online (ILAO)** has a guide: [How to Start a Case for Guardianship of an Adult.](#)
- **Illinois Guardianship and Advocacy Commission** – Call 1-866-274-8023 for help.
- Some courts have **self-help desks** where you can ask questions, file paperwork, and find guardianship resources.
- Guardianship cases are usually handled by **circuit or probate** courts.



**Is there a doctor I
trust that can
complete the
physician's report?**

The Physician's Letter

- Provides medical evidence to the court about the individual's condition and their ability to manage personal and financial affairs.
- It typically includes diagnoses and medical conditions, level of impairment, a statement on the need for guardianship and the physician's credentials.

Tips:

- You will need to make an appointment with the doctor.
- The doctor must sign the letter within 3 months of your court date.
- Try to schedule the appointment as close as possible to when you are ready to file with the court.

Successor and Testamentary Guardianship



Is there a plan for what happens if the guardian can no longer care for the adult?

It's best to talk to an attorney to find the right options for your family.

Successor Guardianship happens if the guardian passes away, becomes unable to serve due to a disability, or resigns.

Testamentary Guardianship is when a parent names a guardian in their will to take over after they pass away.

Requirements:

- At least 18 years old
- Mentally sound
- Not convicted of a serious crime
- Approved by the court
- Must show they can actively and responsibly handle guardianship

For more information: [Guardianship and Advocacy Commission FAQ](#)

Other Decision-Making Options

Supported Decision Making & Powers of Attorney

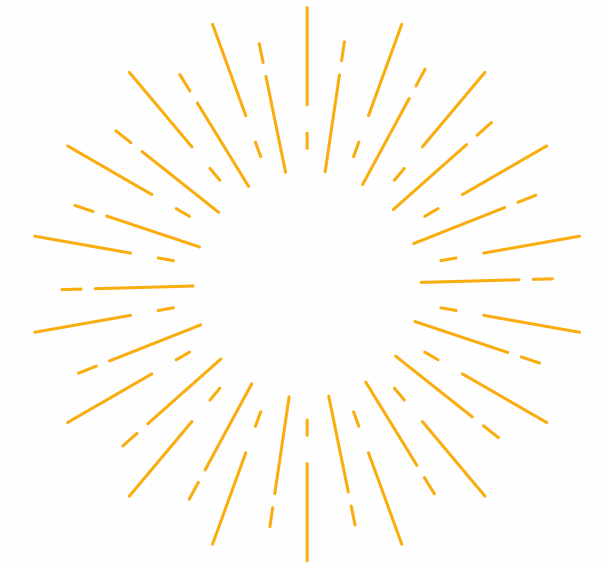
Resources to Learn More:

- [Step-by-Step Guide to Supported Decision-Making](#) – *The Center for Public Representation* provides an easy guide to getting started.
- [Turning 18 Video Series](#) – *The Institute for Community Inclusion* shares videos where self-advocates discuss decision-making, self-advocacy, and alternatives to guardianship.
- *Derek Heard's Story* – A self-advocate shares how his decision-making role grew over time. [Watch here.](#)
- [Power of Attorney for Health Care \(POAHC\)](#) – A simple form to designate someone to help with healthcare decisions when needed.
- [Illinois Legal Aid Online – HPOA Easy Form](#) – This tool helps fill out legal forms with easy steps and instructions.

Finding a Special Needs Planning Attorney

- [For expert guidance, The Special Needs Alliance](#) offers a special needs lawyer search.
- Search for Estate Planning and Elder Law Attorneys
- Contact the [Illinois State Bar Association](#)

Adult Insurance, Benefits, and Program Changes



- Private Insurance
- Adult Medicaid
- Medicare Entitlement
- SSI & SSDI
- Long-Term Care

<https://dsc.uic.edu/family-education-webinars/>

Adult Insurance

Private

Young adults can stay on their parents' private insurance until age 26.

If you have no coverage options, you can purchase insurance through the federal marketplace - Get Covered Illinois.

You can have private insurance and Medicaid as a child or an adult.

Private Health Insurance Plans

Private insurance plans are all different. Understanding how they are different can help you use your health insurance. This can also help you decide which plan is best for you if you have many choices. You should always check the rules of your insurance plan. This is a guide for most plans.

Plan Type	HMO	PPO	OAP	EPO	POS
What Does It Stand For?	Health Maintenance Organization	Preferred Provider Organization	Open Access Plan	Exclusive Provider Organization	Point-of-Service
Primary Care Physician (PCP) Required	✓	✗	✗	✓	✓
Referral Required	✓	✗	✗	✓	✗
Out-of-Network Coverage	✗	✓	✓	✗	✓
Costs	\$	\$ \$ \$	\$ - \$ \$	\$	\$ \$
Provider Network	LIMITED & SMALL	OPEN & LARGE	VARIES BY TIER	LIMITED & SMALL	VARIES
Which Coverage Fits Your Needs	✓ Can only use in-network providers ✓ Cost is lower ✓ Network is more limited	✓ Has in- and out-of-network benefits ✓ Cost is higher ✓ More flexible	✓ Has in- and out-of-network benefits ✓ Cost is low in Tier 1 and higher in Tier 3 ✓ Very flexible	✓ Can only use in-network providers ✓ Cost is lower ✓ Network is more limited	✓ Coverage combines parts of HMO and PPO ✓ Some flexibility ✓ A little higher cost


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Medicaid

Children stay on the family Medicaid case until age 19.

About a month before turning 19, the young adult must apply for their own case as the “head of household.”

After age 19, a prior approval is required if you get more than 4 prescription medications.

<https://dscc.uic.edu/family-education-webinars/>

What Does Illinois Medicaid Cover?

Illinois Medicaid is not a Division of Specialized Care for Children (DSCC) program. DSCC does not decide coverage or eligibility for Medicaid. We provide this information as helpful guide.

Medicaid covers many services, providing full medical, dental, vision and pharmacy benefits. Below are examples of what Medicaid may cover. It is not a complete list.

Some services may have special rules to get them, such as a certain age or medical diagnosis. Some services have limits on how much of the service or item Medicaid will cover. For example, Medicaid will only cover diapers for a child aged 4 and up. The child must have a medical need to get formula.

Medical Services	Medical Supplies
• Doctor appointments • Specialist visits • Lab work • Surgery • Inpatient hospitalizations	• Diapers • Feeding supplies • Formula • Infusion supplies • Oxygen
Durable Medical Equipment	Dental
• Wheelchairs • Commode or bath chairs • CPAP devices and nebulizers • Crutches, canes, or walkers • Hospital beds • Blood sugar meters and strips • Communication devices • Internal home lifts • Stair climbers (only if there are stairs inside the home)	• Oral exams and cleanings every six months • Sealants • Fluoride • Crowns, root canals, etc. • Extractions • Anesthesia and sedation when medically necessary Note: Some services are only available for children through age 21.
Transportation	Medications
• Transportation to appointments • Emergency transportation, such as an ambulance when there is an urgent medical emergency	• Prescription medications • In some cases, over the counter medications and vitamins are covered

Medicare

Medicare is not a program you apply for, It is a program you become eligible for.

Contact the Social Security Administration to see when you/your child might become eligible for Medicare.

You must receive Social Security Disability Insurance (SSDI - this is not same as SSI) for 24 months as a disabled young adult before becoming eligible.

https://dsccl.uic.edu/dsccl_resource/dscclcs-medicare-fact-sheet/

<https://www.ssa.gov>

Medicare Fact Sheet

Medicare is federal health insurance run by the Social Security Administration. You must be a U.S. citizen or legal resident residing in the United States, for five continuous years to qualify for Medicare.

Someone qualifies for Medicare if they are one of the following:

- Age 65 or older
- Any age with End-Stage Renal Disease (ESRD)
- Under age 65 with certain disabilities (Amyotrophic Lateral Sclerosis, also known as ALS or Lou Gehrig's disease) or people with a qualifying disability who have received Social Security Disability Insurance for 24 months.

Medicare Enrollment and Contacts

- You are automatically enrolled if you are already getting Social Security Disability Insurance benefits for 24 months.
- If you are not receiving Social Security benefits, you must enroll yourself in Medicare with Social Security four months before your 65th birthday.
- Visit www.ssa.gov or www.medicare.gov.
- Call the Social Security Administration at (800) 772-1213 or Medicare at (800) 633-4227 or the Illinois Senior Help Line at (800) 252-8966.
- To find a local Social Security office, visit www.ssa.gov/locator/.

Medicare and Other Insurance

- If you have private insurance, Medicare is often secondary. It depends on some factors of how you get your private insurance. Talk to your private insurance and Medicare about coordination of benefits.
- If you have Medicaid, Medicare is primary coverage. Medicaid will pay second.

Medicare Savings Program

- The state of Illinois will help people with limited income and resources pay Medicare costs, which include Medicare premiums, deductibles, and coinsurance.
- You can apply for the Medicare Savings Program through the Department of Human Services (DHS) online at ABE.illinois.gov. You can also call the DHS Helpline at (800) 843-6154 or visit a local DHS office. To find the nearest office, visit the DHS Office Locator at www.dhs.state.il.us.

Supplemental Security Income (SSI) & SSDI

- **SSI** can help pay for your food, clothing, and housing needs. After turning 18, Supplemental Security Income (SSI) eligibility is based on the disability rules for adults.
- This is a financial benefit based on financial need.
- It is not a medical benefit and does not mean you qualify for Medicaid in the state of Illinois.
- **Social Security Disability Insurance (SSDI)** is a program that provides insurance payments to people who are no longer able to work because of a significant disability.

<https://www.ssa.gov/>

<https://dscc.uic.edu/family-education-webinars/>

Long-Term Care *Transition*

The Division of Developmental Disabilities (DDD) partners with Independent Service Coordination (ISC) agencies to complete the PAS screening.

- Before someone can move into an intermediate care facility (ICF) or a Community-Integrated Living Arrangement (CILA), they must have a **Pre-Admission Screening (PAS)** through their local **ISC agency**.
- **To locate your ISC agency, go to:** <https://www.dhs.state.il.us/page.aspx?module=12&officetype=7> and select your county. (Note that this is separate from the PUNS list.)
- **IDPH's Office of Health Care Regulation Portal** provides a "Facility Lookup" function to locate facilities licensed by the State of Illinois.

Home and Community Based Living

Waiver Program

If an adult qualifies for waiver funding, they have different living options in the community, such as:

- Group homes
- Community Living Facilities (CLFs)
- Host homes
- Family or part-time support (intermittent/family CILA)

CILA

Someone without
significant medical
or behavioral needs

Intermediate Care Facilities

Note from the Arc of Illinois: Most are large group settings of 9 or more individuals with I/DD. You don't need to be on PUNS to access it.

MC-DD

Someone with
significant medical
needs

- **ICF-DD:** Intermediate Care Facility for individuals who have a developmental disability
- **MCDD:** Intermediate Care Facility for individuals who are medically complex and have a developmental disability

ICF-DD

Someone with
significant
behavioral needs

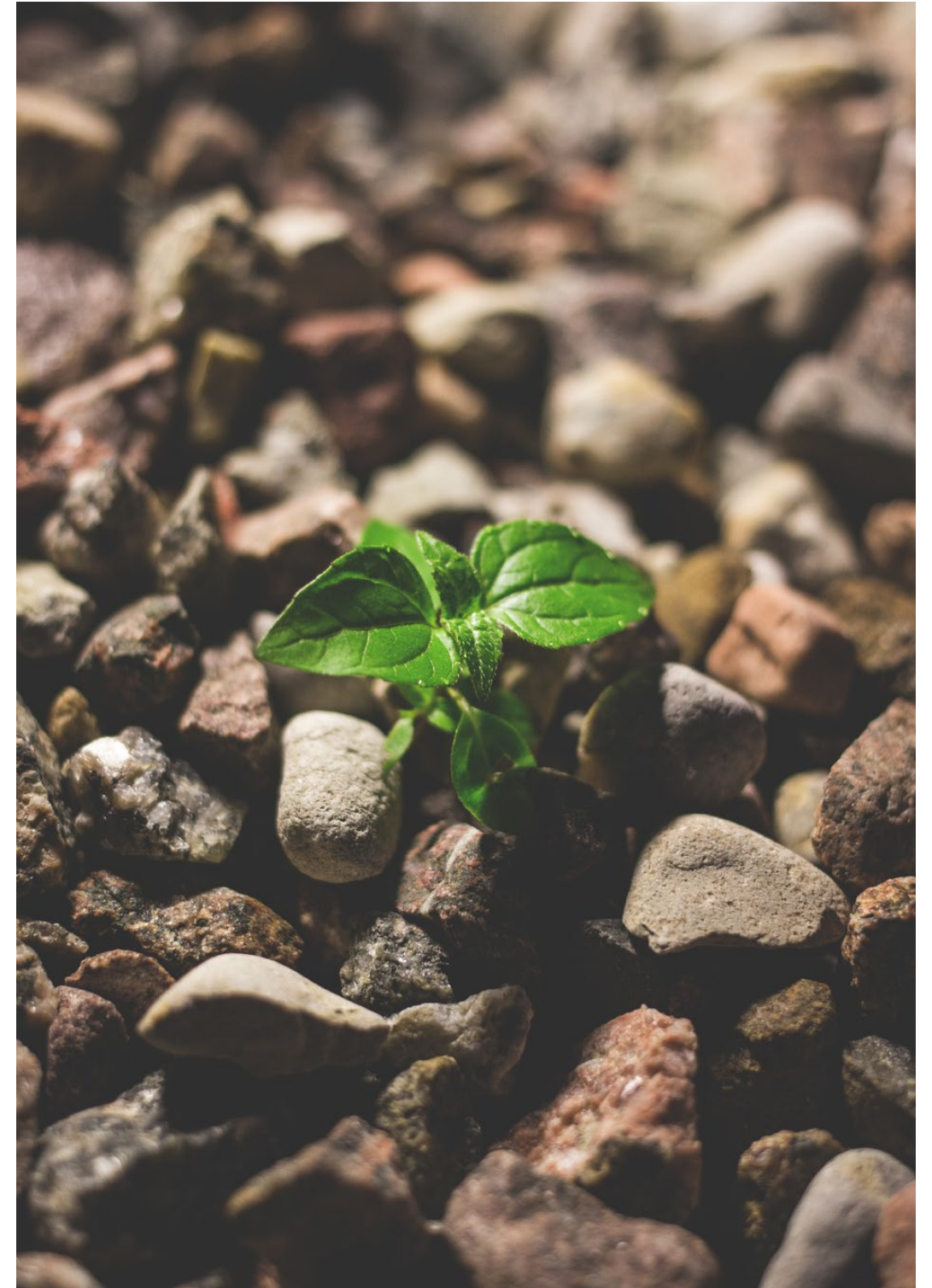
Part 2: Evolving Family Roles

Sam



Supporting Long-Term Well-Being for Young Adults and Caregivers

- **Planning for meaningful days that benefit everyone**
- **Dealing with feelings around planning for the future.**
- **Supporting quality of life and managing health changes**
- **Health Challenges and Considering Your Well-Being**
- **Creating a Plan**



Sam's Thoughtful Day

Begin with your child's preferences

- Sam loves petting Mimi and watching soccer on TV.
- She enjoys moving around and swinging outside.
- She likes cuddling with her Mom and Dad under warm blankets.
- Sam also likes choosing her clothes and deciding if she wants to do certain activities.
- She likes to participate in a young adults group and hang out with her Grandpa Ray.



Sam's Thoughtful Day

Create a Comfortable Routine

Even if it's a special day, keeping some familiar routines (like meals, rest times, or favorite activities) can make it more enjoyable.

Engage the Senses

- **Music & Sounds** – Play their favorite songs, try an interactive music session, or use calming nature sounds.
- **Touch & Textures** – Incorporate soft blankets, water play, sensory toys, or even a hand massage.
- **Visuals & Colors** – Go outside to watch birds, visit a park, or enjoy colorful lights and projections.

Sam's Thoughtful Day

Plan a Fun Activity

- Art & Crafts .
- Adaptive Games and Technology
 - [The Illinois Assistive Technology Program \(IATP\)](#)
[Makers](#) program creates assistive technology devices by using 3D printing, pressure forming, laser cutting, and other easy-to-find materials and tools.
- Including social time
- Going Outdoors (if possible)



Focus on Connection, Not Productivity

A meaningful day doesn't have to be full of tasks—it's about being present.

Sam's Schedule

6:00-7:00 am

Sam gets her morning g-tube feeding. She will press the button to start and stop the feeding.

- On Mondays and Tuesdays, her nurse, Pam, arrives at 6:00 am to help with her feedings.
- On Wednesdays and Thursdays, Sam's Grandpa Ray comes to help and spend time with her.

7:00-10:45 am

- Sam doesn't have another g-tube feeding until lunchtime. During this time, Sam will choose an activity from a picture chart that she can do with Mom, Dad, Pam, or Grandpa Ray.

11:00am-12:15pm

- Sam gets her lunch-time g-tube feeding. She will press the button to start and stop the feeding.

12:30-2:00 pm

- Sam likes to take a nap and listen to music at this time. She will press the button to start her ventilator when she lays down.

2:15-4:30pm

- During this time, Sam and Mom, Dad, Pam, or Grandpa Ray will vote on an activity from a picture chart they can do together.
- On Tuesdays, Sam goes to her local community center where she participates in a young adult group.

5:00-7:30 pm

- Sam gets her dinner-time g-tube feeding. She will press the button to start and stop the feeding.
- Sam, Mom and Dad will sit at the kitchen table together.
- On Wednesdays, Grandpa Ray has dinner with Sam while Mom and Dad go to their church's parent group.

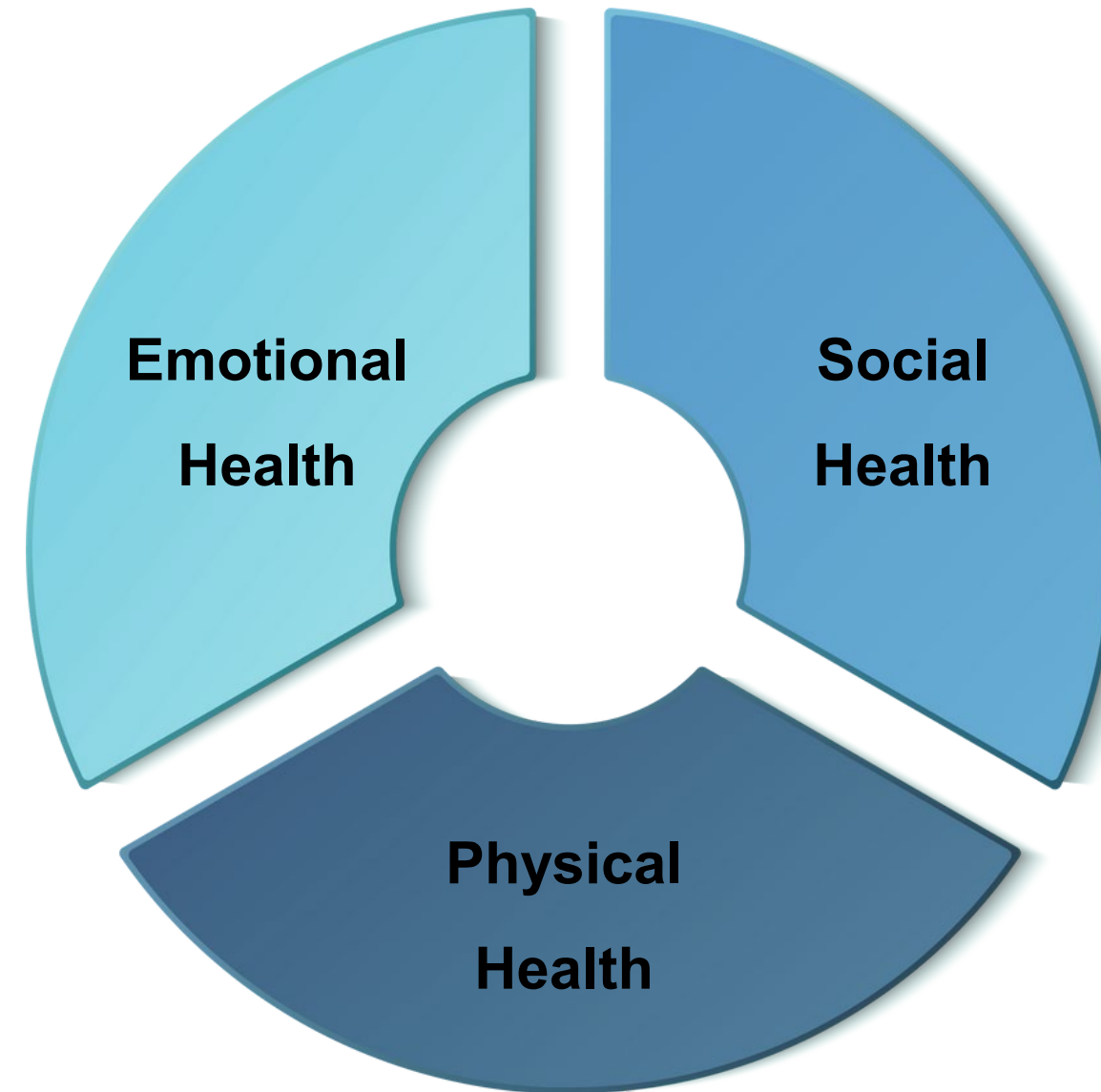
Dealing with Feelings around planning for the future

Grief, guilt, anger, helplessness, isolation, and a sense of paralysis

Shahali S, Tavousi M, Sadighi J, Kermani RM, Rostami R. Health challenges faced by parents of children with disabilities: a scoping review.

BMC Pediatr. 2024 Sep 30;24(1):619. doi: 10.1186/s12887-024-05104-3. PMID: 39343886; PMCID: PMC11440903.

Health Challenges of Parents and Caregivers



Shahali S, Tavousi M, Sadighi J, Kermani RM, Rostami R. Health challenges faced by parents of children with disabilities: a scoping review. BMC Pediatr. 2024 Sep 30;24(1):619. doi: 10.1186/s12887-024-05104-3. PMID: 39343886; PMCID: PMC11440903.

Planning for the Future When Life is Overwhelming

Sam's Board of Directors



- **Dr. Suki-** Sam's Adult Primary Care Doctor
- **Evelyn Foremister-** Mom's Church Friend
- **Grandpa Ray**
- **Cousin Sylvia**
- **Bill Richards-** Independent Service Inc. Case Worker
- **Suzanne Aaron-** Arc's Lifespan Program
- **Cindy Taft-** Special Needs Law Lawyer
- **Rachel Sims-** DSCC Care Coordinator

Supporting quality of life and managing health changes

Considering Your Well-Being

Sam's Dad, Phil

Considering Your Well-Being

- **The Division of Rehabilitation Home Services Program (HSP)** provides services to individuals with severe disabilities so they can remain in their homes and be as independent as possible.
- For those under age 60
- Complete a web referral here:

<https://wr.dhs.illinois.gov/wrpublic/wr/dynamic/referral.jsf>

Those over age 60 should contact the Illinois Department on Aging's

[**Community Care Program**](#)



Sam's Mom, Abby

Self-Advocacy and Resilience

Taking Care of Yourself as a Caregiver

- **Self-Care Matters:** Caregivers begin to view self-care as a must.
- **Setting Boundaries:** It's okay to say no. Protect your time and energy so you don't get burned out. A healthy you means better care for your child.
- **Seeking Support:** Connect with support networks, whether through therapy, peer groups, or respite care.

Being a strong advocate means making sure both you and your child get the support you deserve!



Caffeinated Caregivers

<https://www.caffeinatedcaregivers.com/articles/the-caregiver-continuum/>



Creating a Plan

Considering the young adult's long-term needs

Financial Planning- means making a plan to ensure your child and family are financially secure now and in the future.

Naming a Testamentary Guardian – In your will, name who will care for your child if you are no longer able to. This could be family, friends, or an organization.

Letter of Intent – Write a document outlining your child's needs, preferences, and routines to guide future caregivers.

Emergency & Backup Plans – Prepare for unexpected situations, such as a caregiver becoming unavailable or a sudden change in health.

Financial Planning



**Do I have a
financial plan
for my child's
future?**

- [The Arc's Center for Future Planning](#) provides a series of videos to help individuals save money and protect public benefits.
- [Illinois ABLE \(Achieving a Better Life Experience\) accounts](#) make it possible for people with disabilities and their families to save and invest for expenses related to living with a disability.
- [PACER Center's Financial Planning for Parents of Children with Disabilities](#) discusses using your life and disability insurance to ensure your child's care after you are gone.
- [The Academy of Special Needs Planners website](#) offers helpful information and connections.

Special Needs Planning Experts

Help families navigate:

- Estimating the future cost of your child's care
- Identifying available financial resources, programs and benefits
- Establishing a special needs trust
- Balancing planning goals for your child and for yourself
- Estate Planning

To find a planner near you: <https://specialneedsanswers.com/USA-special-needs-planners>

A Letter of Intent is writing down your goals and wishes for your child's future after you are gone.

All About Me

My name is...

My birthday is...

My important people...

My favorite movie is...

My favorite animal is...

My favorite color is...

My diagnoses are...

My medication list...

My favorite activities...

What works for me...

What doesn't work for me...

My goals...

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Health and Healthcare Topics

Medical Care

- What potential health complications could arise?

Health Insurance

- How can I ensure continuous coverage?

Medications & Equipment

- Do I have a list of medications, medical devices, and assistive equipment?

<https://dsc.c.uic.edu/all-about-me-pages/>

Letter of Intent

Daily Living Topics

Housing:

- Will my child live at home, in a group home, or nursing home?

Daily Support :

- What help is needed for dressing, eating, bathing, and mobility?
- Who will step in if I'm unable to?

Transportation

- How will they get to appointments and activities?

Emotional Well-Being

- How can you prevent social isolation and include activities they enjoy?

Sam's Letter of Intent

Sam's Family: Mom, Dad, Grandpa Ray, Cousin Sylvia

Local Resources:

- **Independent Service Inc.-** Sam's case worker is Bill Richards
- **Unity Church-** She attends a young adult group on Sundays.
- **Park District-** Sam participates in a monthly bowling team.
- **Hope Day Program-** Sam helps here on Tuesdays and Thursdays between 2-4 pm.

Care Needs:

- Sam has quadriplegia and muscular dystrophy and needs help with bathing, eating, brushing her teeth, and moving around. She enjoys picking out her own clothes but may need help choosing based on the weather.
 - *See her equipment and supply list.
- She communicates by using a switch to answer questions. She takes showers three times a week using a bath chair and board and prefers warm water. Sam will decide which days of the week to shower.
- Sam eats through a G-tube four times a day.
 - *See her medication list and schedule.

Sam's Letter of Intent

Educational Information:

Sam graduated from the Special Education Program at Southeast High School this past Spring.

Important Relationships:

Sam is closest to her Grandpa Ray and enjoys watching soccer with him the most.

A typical Day:

Sam is happiest petting her cat Mimi and spending time in Unity Church's young adult group. She likes being active and prefers if you speak to her directly. When Sam is frustrated Mom helps her calm down by rubbing her back and turning on soft jazz music.

Mom and Dad want Sam to know how much they love her and how proud of her they are. They want Sam to know that she lights up every room she is in and has a big heart. They want Sam to continue to have a choice in where she lives and in what she does daily. It is important for her to be as independent as possible and to remain connected to her community.

<https://www.specialneedsalliance.org/the-voice/letter-of-intent-4/>

Bringing it All Together

Part 1: Navigating Adult Systems

“Educated Parents Become Empowered Parents.”

Adult Guardianship

Adult Insurance, Benefits and Program Changes

Long-Term Care Transition

Part 2: Evolving Family Roles

Planning for Meaningful Days

Dealing with Feelings Around Planning for the Future

Health Challenges and Considering Your Well-Being

Creating a Plan

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THANK
you