

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

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**Division of Specialized
Care for Children**



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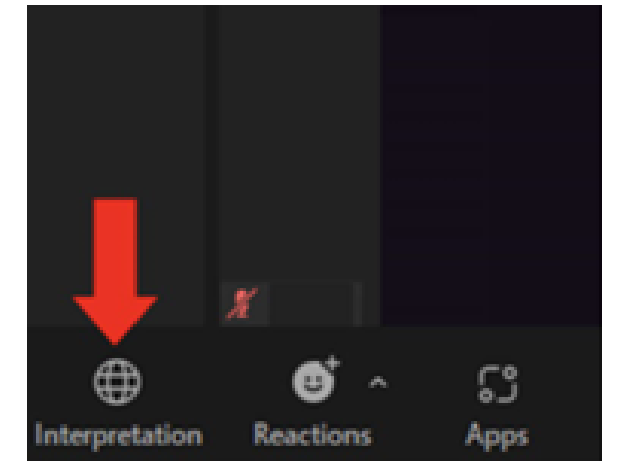
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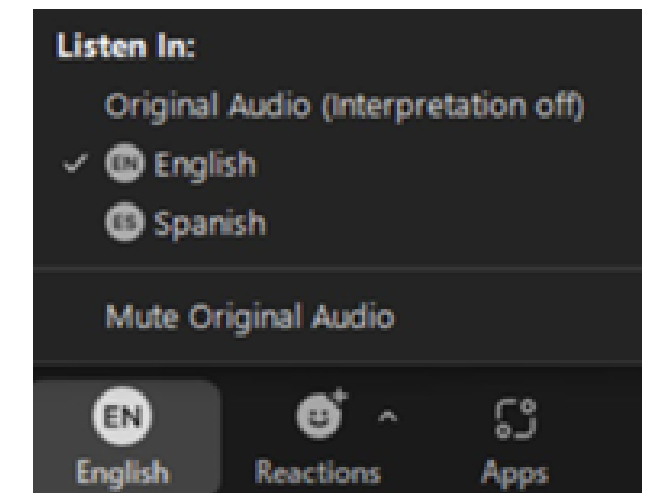
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Presentation Materials

- 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.

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- 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**



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- 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 to understand and use adult services like healthcare, education, employment, housing, and community resources. These systems often require learning new rules and eligibility requirements, which can be challenging for families and young adults alike.

Evolving Family Roles

As young people take on more responsibility, family dynamics naturally shift. Parents and caregivers begin stepping back from daily management and instead take on a supportive role, encouraging their young adult's independence while still providing guidance.

Note: This session focuses on youth ages 12 to 15 years old (middle and junior high school).

Agenda

- 1 Adjusting to Change (Becoming Partners)
- 2 Support Circles
- 3 Navigating Systems and Making Informed Choices
- 4 Planning for the Future
- 5 Bringing It All Together

**“You don’t have to see the
whole staircase just to
take the first step.”**

MARTIN LUTHER KING, JR.

Adjusting to Change: Becoming Partners

"Educated parents become empowered parents."

Suzanne Aaron



Adjusting to Change: Becoming Partners

Goals as Partners

1. **Equip** youth with communication and problem-solving skills to advocate for themselves effectively in adult settings.
2. **Encourage** active participation in decision-making about their healthcare and life choices.

(1) Equip youth with communication and problem-solving skills to advocate for themselves effectively in adult settings.

Steps for youth may include:

- Learning when to ask for help.
- Learning what your body needs to be clean.
- Figuring out what help you need and how to get it.
- Looking into tools and technology that can make daily tasks easier.
- Learning how to ride the bus.
- Preparing for emergencies like power outages and weather events.

[DSCC's Preparing for Adult Living Tip Sheet](#)

Getting The Support You Need: *Molly's Story*

Knowing yourself and understanding how your disability might affect your life and the decisions you make is important. Figuring out what supports you need is the first step.

- **Self-Determination:** Idea that every person has the right to decide how they live their life.
- **Self-Advocacy:** Speaking up for what you need and want. This is self-determination in action!
- **Self-Management:** Your ability to manage your behaviors, thoughts, and emotions. This is also the things you need to do to take care of your physical and mental health, and overall well-being.

Self-Advocacy:

Speaking up for what you need and want. This is self-determination in action!



(2) Encourage active participation in decision-making about healthcare and life choices.

Understanding Consent and Healthcare Rights for Minors

What Does Patient Consent Mean?

Patient consent means you agree to the following:

- You understand the treatment you will get.
- You approve the treatment.
- You know how your private information will be shared.

What is Informed Consent?

Informed consent happens when your healthcare provider talks to you about your care, treatment, and answers any questions you have before it starts. All consent should be informed consent.

178-KNOW YOUR RIGHTS

KNOW YOUR RIGHTS

Minors' Consent & Access to Healthcare Services

DSCC Is Here to Help

The Division of Specialized Care for Children (DSCC) team is here to support independence in your care and health decisions. We can answer your questions and connect you to the right resources.

Are You Puzzled?

As a young person with special healthcare needs, you may have questions about your rights and who can access your health information. This guide will help you understand your rights as a minor, including:

1. Which services you can receive without parental consent.
2. When a parent can access your health information.
3. When a provider needs your consent before sharing your health information.

The infographic features two photographs: one of a healthcare provider in a blue patterned shirt interacting with a young person in a white shirt, and another of a young person in a wheelchair with a dog sitting on a sidewalk.



Support Circles

- **Creating** your “Board of Directors”
- **Building** your Social Capital
- **Networking** within your community
- **Managing Feelings:** Caregiving and Living with Complex Health Needs

Connecting

Creating your “Board of Directors” & Building your Social Capital

1-What is my goal?

Think about what you love to do. For example, maybe you really enjoy drawing and making art. Your goal might be to get better at drawing and to make new friends. But you don’t have a lot of free time.

If your goal has two parts, like building your skills and meeting new people, you could look for an art class just for kids your age. Maybe it only meets every two weeks for a couple of hours, so it fits into your schedule better.



Connecting

2-What is stopping me?

- The class is at 6:00pm on Thursdays and Mom works until 7:00 pm
- The building is not wheelchair accessible.

3-What are my solutions?

Mom works until 7:00 pm

- Ask if there are classes at a different time
- Ask your Aunt to give you a ride to class
- Take the Para-Transit Bus to class

The Building is Not Accessible

- Practice Advocating for Yourself!
- Ask if there is another building that is wheelchair-accessible
- Ask the class organizers if they can make the space easier to get into, like by adding a ramp



Connecting

Networking within your community

Connecting with your local Independent Living Center (CIL) is important!

Here's what to know:

- CILs are run by people with disabilities and focus on helping everyone have equal opportunities.
- They can teach you skills for living on your own, offer peer support and counseling, help with transitions, and provide advocacy and disability awareness.

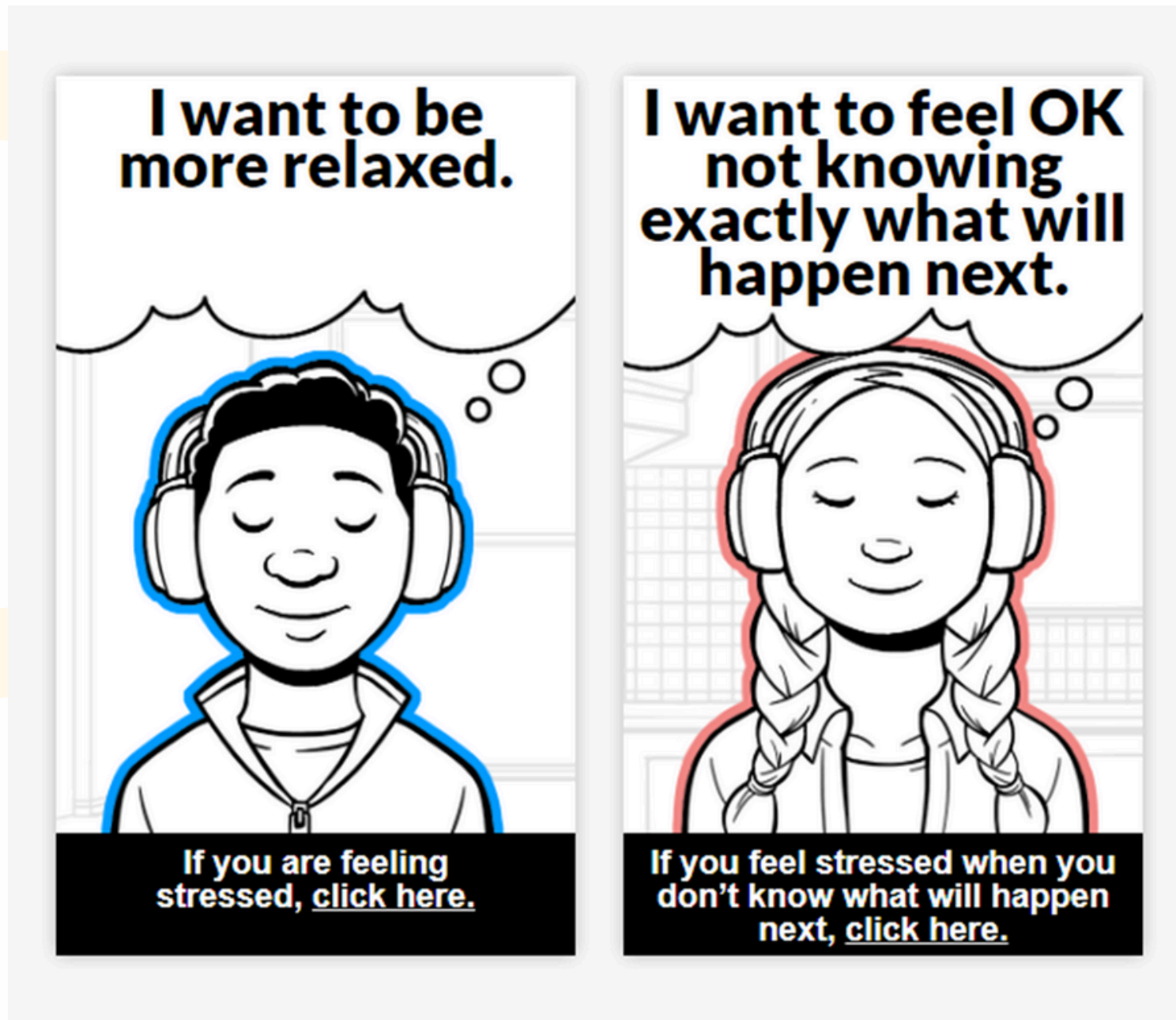
Other ways to get involved!

- Youth Engaged 4 Change (YE4C) is a website that shares resources and opportunities to help young people learn, grow, and make a difference in their lives and communities.



Managing Feelings

Youth Dealing with Burnout



Connecting with others like you:

- Since March 2020, [Generation Patient](#) has facilitated virtual meetings for young adults with chronic and rare conditions.

Using Imagination to Cope:

- [Imagination](#) is a collection of audio recordings that support coping and self regulation skills.

Managing Pain Better:

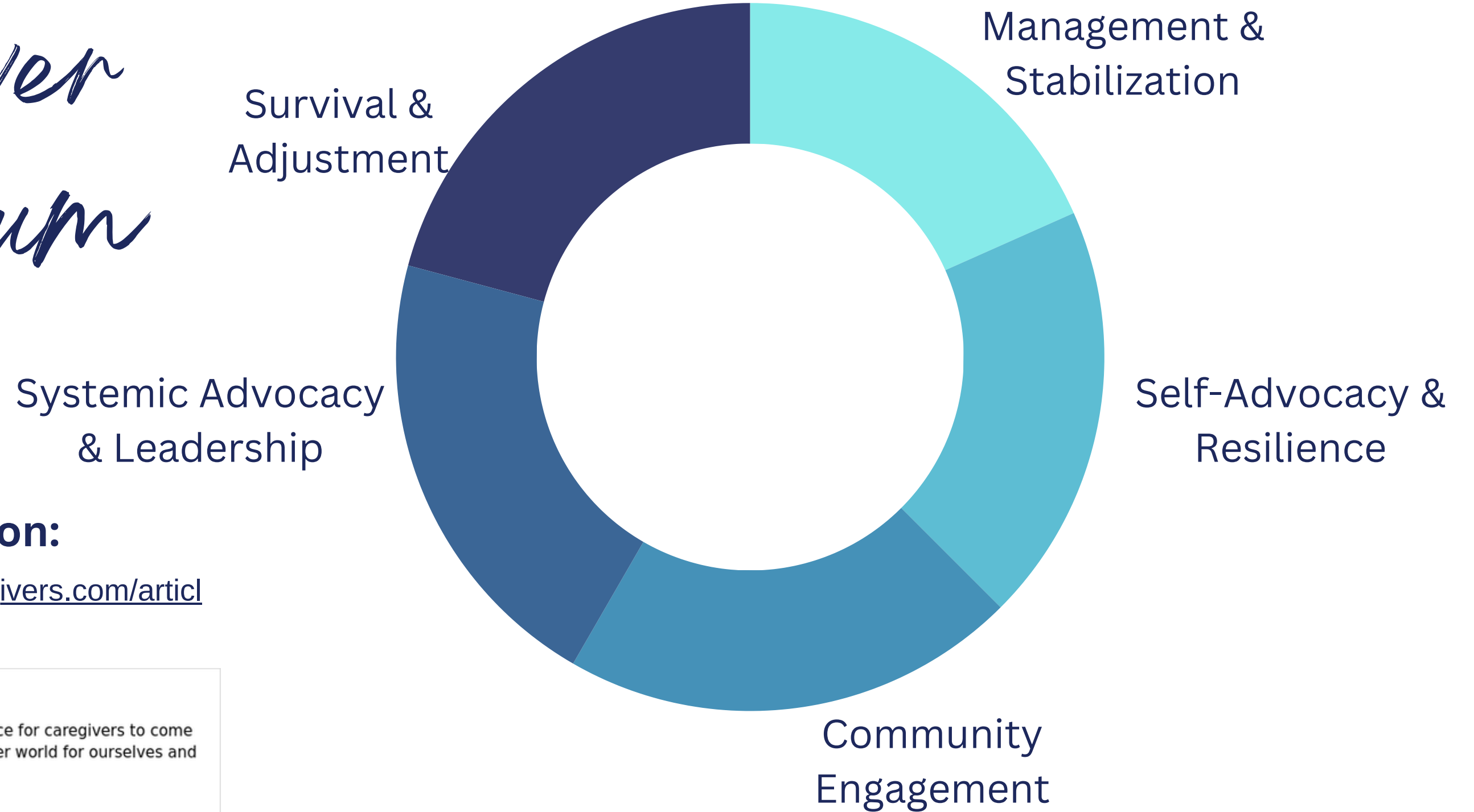
- [The Meg Foundation](#) believes poorly managed pain is about a lot more than a hard few minutes at the doctor's office or a rough few days after surgery.

The background features several abstract geometric elements: a large yellow circle at the top center, a smaller pink circle at the top right, a pink circle at the bottom left, and a large yellow circle at the bottom right. A central orange star-like shape with five arms is positioned on the right side. The text is overlaid on these shapes.

Managing Feelings

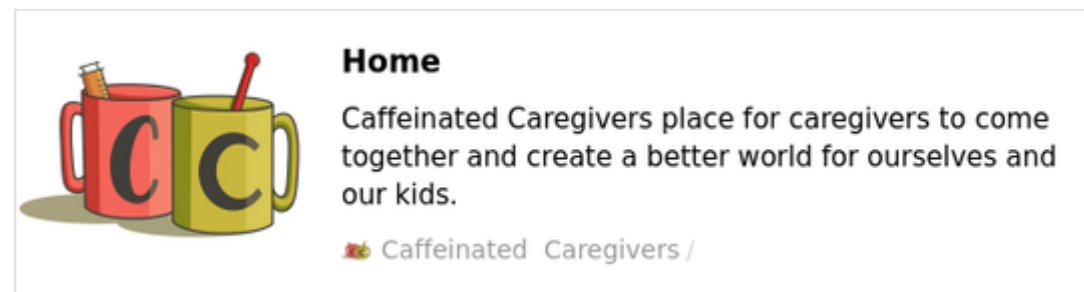
Parent and Caregiver Burnout

The Caregiver Continuum



For more information:

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



Navigating Systems and Making Informed Choices

Learning about complex systems.

Addressing barriers to independence.

Collaborating with others to ensure a
smooth move to adult services.

Learning about complex systems.

Illinois Medicaid Waivers

Health Insurance & Benefits

Illinois Waivers

What is a waiver?

A "waiver" is a program that helps people get services they need to live at home or in their community instead of moving to a care facility.

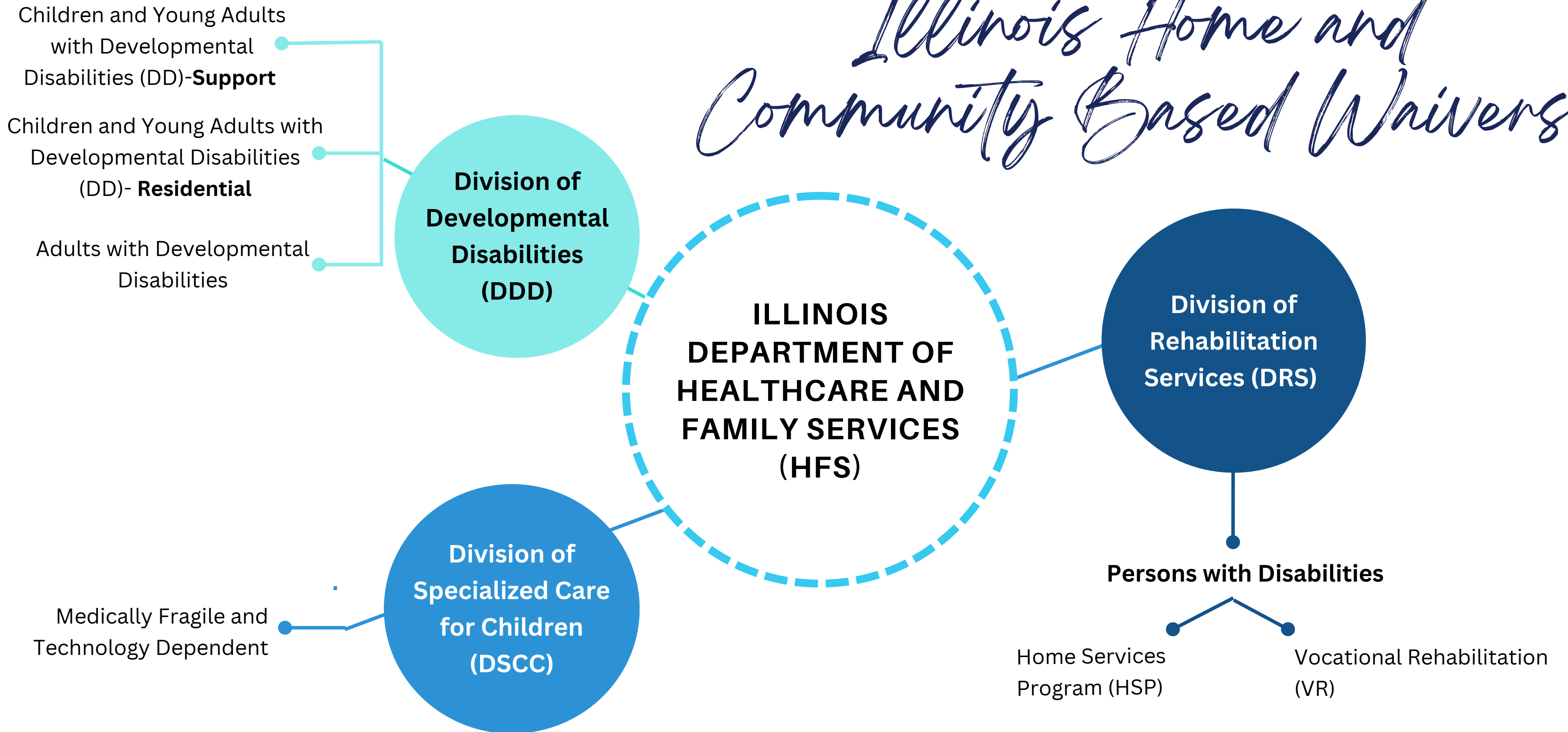
Illinois has 9 Home and Community-Based Service (HCBS) waivers. Some are for kids and young adults, while others are for adults.

Three waivers specifically help young people with disabilities:

Waivers for Children and Young Adults:

- Children and Young Adults with Developmental Disabilities-Support
- Children and Young Adults with Developmental Disabilities-Residential
- People who are Medically Fragile, Technology Dependent (MFTD)
- Persons with Disabilities

Illinois Home and Community Based Waivers



Waivers for Children and Young Adults

Children and Young Adults with Developmental Disabilities (DD)-Support

- For children and young adults (ages 3–21) with developmental disabilities.
- Helps families get services to keep their child at home.
- Offers support like behavior counseling, adaptive equipment, home or vehicle modifications, personal support workers, nursing care, transportation, and respite care.

Children and Young Adults with Developmental Disabilities (DD)-Residential

- For children and young adults (ages 3–21) with intellectual or developmental disabilities.
- Supports those at risk of needing to live in a special care facility (called an ICF/ID).
- Provides services to help them stay in their community.

Medically Fragile/Technology-Dependent (MFTD) Waiver

- For children with complex medical needs who need in-home nursing care.
- DSCC manages this program in Illinois, helping families arrange Medicaid-covered nursing care at home.

Waivers for Children and Young Adults

The Division of Rehabilitation Services' Home Services Program (HSP)

- This waiver, managed by the Division of Rehabilitation Services (DRS), is mainly for adults under 60 but can also help younger people.
- It covers services like personal assistants, nursing care, and respite hours. Unlike some waivers, DRS does not have a waiting list. Families must choose the right waiver if their child is pulled from the PUNS list.
- Legal guardians can be paid caregivers.

Waivers for Children and Young Adults

Getting the Help You Need

Call Your Independent Service Coordination Agency (ISC)

- Children and Young Adults with Developmental Disabilities-Support
- Children and Young Adults with Developmental Disabilities-Residential

Call UIC-DSCC

- People who are Medically Fragile, Technology Dependent (MFTD)

Call or make a DRS referral online

- Division of Rehabilitation Services (DRS) Persons with Disabilities Waiver

Waivers for Adults

Other Waivers:

- Persons who are Elderly
- Persons with HIV or AIDS
- Persons with Brain Injury (BI)

Options for adults with physical disabilities

Division of Rehabilitation Services (DRS) Persons with Disabilities Waiver-

- Under age 60 at the time of application and at risk of placement in a nursing facility.
- Have a medical determination of a diagnosed, severe disability, which is expected to last for 12 months or for the duration of life.
- Medicaid eligible or enrolled in the Health Benefits for Workers with Disabilities (HBWD) program.

Supportive Living Program-

- Persons aged 22-64 who have a physical disability (as determined by the Social Security Administration), or persons age 65 or over.
- Income equal to or greater than current maximum allowable amount of Supplemental Security Income (SSI).

Waivers for Adults

For Individuals with Developmental Disabilities

Adults with Developmental Disabilities HCBS Waiver

- For ages 18 and older, at risk of living in an ICF-I/DD (Intermediate Care Facility for people with Intellectual/Developmental Disabilities)
- Must have Medicaid or be in the Health Benefits for Workers with Disabilities (HBWD) program.
- Cannot need 24-hour nursing care.

This waiver provides services based on the person's needs and choices. To qualify, individuals are chosen from the PUNS waitlist.

PUNS is the waitlist for people in Illinois seeking services from the Division of Developmental Disabilities (DDD).

For more information and helpful tips, take a look at DSCCs PUNS tip sheet and the Arc of Illinois' fact sheets .

Comparison of Adult Services : IL Division of Rehabilitation Services (DRS) Medicaid waiver Home Services Program or the IL Division of Developmental Disabilities (DDD) Home-Based Services Program/Community Integrated Living Arrangement (CILA)

Individuals with disabilities can receive funding for services through only one Medicaid waiver. Some people with I/DD selected from the PUNS have been receiving services through the DRS Adult Waiver Home-Services Program for Persons with Disabilities/ Persons with Brain Injuries(TBI) must make a choice whether to remain with the DRS waiver or begin the application for services through the Adults with DD Waiver. Please note two key differences: The DRS waiver offers funding that can increase as the complexity of the disability increases. DRS Home Services are mostly offered in one's home. Whereas, DDD home-based services can be offered outside of the home and are based upon a fixed funding award of 3 x SSI monthly program allotment.

DRS Medicaid Waiver www.illinois.gov/hfs/MedicalClients/HCBS/Pages/disabilities.aspx	DDD Medicaid Waiver – HBS www.dhs.state.il.us/page.aspx?item=52665	DDD Medicaid Waiver – CILA www.dhs.state.il.us/page.aspx?item=52665
Home Services Program Union membership that offers health care for personal assistant (PA); union sets PA hourly wage	Home-based services from monthly allotment of 3 X SSI (Adult) Employer and personal support worker (PSW) negotiate an hourly rate for the PSW to be paid.	Community Integrated Living Arrangement Group or Host Family (24/7 care) or Intermittent/Family CILA (<24/7); DDD sets amount of individualized award
Eligibility: Under age 60 with severe disability lasting at least 12 months or life, imminent risk of health facility placement	Eligibility: IQ of 70 or below before age 18 OR related condition before age 22 with significant life skill deficits in 3 of 6 major life areas (self-care, language, learning, mobility, self-direction, capacity for independent living); PUNS waiting list	Eligibility: IQ of 70 or below before age 18 OR related condition before age 22 with significant life skill deficits in 3 of 6 major life areas (self-care, language, learning, mobility, self-direction, capacity for independent living); PUNS waiting list
Services include: PA/In-home Service -PA hours based on determination of need (DON) score. <ul style="list-style-type: none"> - Electronic Home Response System - Home-Delivered Meals - Adult Day Care (ADC) - Assistive Equipment - Environmental Modification - Respite - Homemaker - Nursing/Intermittent - Nursing - Therapies (PT/OT/ Speech) - Home Health Aide - Specialized Medical Equipment - Supported Employment (SEP)* <p><i>NOTE: No Community Day Services Programming and/or residential services</i></p> <hr/> Non-Waiver Specialized services: 12 week Vocational Training (Blind/ Visually Impaired) • Employment Assistance (Deaf/Hard of Hearing) • Bilingual Staff Assistance (Hispanic/Latino)	Services include: <ul style="list-style-type: none"> - Individualized Service and Support Advocacy - Supported employment (SEP)* - Behavior Counseling (Individual and Group) - Behavior Intervention and Treatment - Psychotherapy - Support Services Team - PT/OT/Speech Therapy* - Adaptive Equipment* - Assistive Technology* - Home Accessibility & Vehicle Modifications* - Self-Direction Assistance - Personal Support - Temporary Assistance - Nursing - Emergency Home Response Services - Transportation (non-medical) - Training and Counseling for Unpaid Caregivers - Out of home respite - Adult Day Care* - Community Day Service (CDS) program - Temporary Intensive Staffing (in CDS program only)* <p>(** when unpaid caregiver is unable to provide support due to a temporary absence.)</p> <p><i>The SSI monthly allotment is determined by Social Security. This amount is generally updated in January of each year.</i></p>	Services include: <ul style="list-style-type: none"> - Individualized Service and Support advocacy - Residential Habilitation - Community Day Service (CDS) program - Temporary Intensive Staffing* - Supported Employment (SEP)* - Adult Day Care* - Other Day Program (formerly sheltered workshop)* - PT/OT/Speech Therapy* - Behavior Counseling (Individual and Group) - Behavior Intervention and Treatment - Psychotherapy - Adaptive Equipment* - Assistive Technology* - Home Accessibility Modifications* <p><i>*Services that require both authorization and prior approval are marked with an asterisk. *See DHS DDD comparison chart offered at https://www.dhs.state.il.us/page.aspx?item=101181</i></p>

Note: There are 9 waivers in IL. Only 2 are being compared in this document.

Waivers for Adults

Questions to Consider:

What services does my adult child need to funding for?

- ☐ (ie. Personal Support, Community Day Services, Residential Services, etc)

Where will the majority of services take place?

- ☐ In the home and the community
- ☐ At a residential setting
- ☐ Must take place in Illinois; waiver funding is non-transferable to another state

How does each waiver provide my adult child with an amount of service?

- ☐ DRS assigns each individual a fixed number of personal care service
- ☐ DDD provides a fixed monthly amount to be allocated for personal support and other services

Location of services:

- ☐ A Personal Assistant (PA) paid through DRS Home Services Program enrolled in the persons with disabilities waiver provides some services exclusively within the home, which can include some community hours.
- ☐ A Personal Support Worker (PSW) paid through DDD can provide services in the home, in the community, and in an agency setting. (Note: if a person is being supported by a CDS provider, they're not allowed to receive and bill for PSW services during that time.)

The Arc of Illinois, Ligas Family Advocates
9980 190th Street,
Suite C Mokena, IL 60448

Ligas Family Advocate Line: 708-331-7370

815.464.1832 ext 1032
www.thearcofil.org

Disclaimer- This is a broad explanation. More specific information can be provided by DDD, DRS, or Ligas Family Advocates.



Health Insurance & Benefits

1

DSCC's Illinois
Medicaid Programs and
Eligibility Guide

2

Transitioning Health
Insurance Benefits to
Adulthood slides

DSCC's Guide to Adult
Benefits, Services and
Resources

3

DSCC's Medicare Fact
Sheet

Addressing barriers to independence

Step 1: Gradually transition responsibilities to young adults, ensuring they are prepared and confident in managing their own lives.

Step 2: Address barriers to independence and find practical solutions.

Step 3: Work together to make the move to adult services easy.

Step 1: Gradually transitioning responsibilities to young adults

Caregiver/Parent: How does my role differ as my child ages? How can I continue to support them without doing it for them?

Youth: How will my role change as I get older? What supports will I still need from my parent/caregiver?



Step 2: Address barriers to independence and find practical solutions.

Transportation

- Teaching youth how to navigate public transportation
- Exploring transportation programs in your area (county, township, etc)
- Practice, practice, practice! Start small and have youth take short rides with help.

Access to Technology

- Enroll in basic technology classes or online tutorials
- Explore devices or software designed to support individuals with disabilities, like screen readers or voice-to-text tools with your local college or the Illinois Assistive Technology Program.
- Your school may be able to provide AT assessments

Step 3: Work Together to Make the Move to Adult Services Easy.

You are not alone in this journey.

You are not the first family to navigate this.

You can turn to community and state resources to help guide you:

- Special Education professionals
- Transition specialists
- Disability-specific advocacy groups
- DSCC Care Coordinator
- The Arc of Illinois

Planning for the Future

Introduction to managing your health and
financial future

Important Financial Decisions to Make Now

- Navigating the ins and outs of Trusts
- ABLE accounts
- Social Security Income (SSI)
- Funding sources when you have a limited income
- Life and Disability Insurance

Planning Tools

The Arc's Center for Future Planning

- Build Your Plan[®]Tool

LifeCourse Nexus

- Charting the Life Course

Managing My Health

Matteo's Story

- What should I think about for my care as I grow up?
- Do I know how to take care of myself and make my own choices in life?
- What might my body and mind be like in 10, 15, or 20 years?

Matteo's Daily Needs

1. Matteo needs to check his blood sugar before he eats breakfast, lunch and dinner.
2. If Matteo's blood sugar is high, he will use insulin to lower it.
3. If Matteo's blood sugar is low, he will pick something to eat and/or drink that will help raise it.
4. If Matteo's blood sugar is high or low, he will re-check it in half an hour.

Bringing it all Together

1. Adjusting to Change (Becoming Partners)
2. Support Circles
3. Navigating Systems and Making Informed Choices
4. Planning for the Future



**Division of Specialized
Care for Children**



THANK YOU!