

Labyrinth of Disability Services



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Advocate
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Learning Objectives

- Identify different types of services provided within school systems for children with disabilities from birth to the age of 21.
- Discuss the services and resources available for adults with disabilities while considering the challenges that caregivers/parents experience resulting in distress and burnout.
- Describe how to navigate services for children with disabilities into adulthood to empower caregivers/parents to meet the basic needs, growth, and development opportunities within your practice.

Learning Objectives #1

- ▶ Identify different types of services provided within school systems for children with disabilities from birth to the age of 21.

What are IDD's?

IDDs are differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems.

Intellectual disability starts any time before a child turns 18 and is characterized by differences with both:

- Intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and
- Adaptive behavior, which includes everyday social and life skills.

The term "developmental disabilities" is a broader category of often lifelong challenges that can be intellectual, physical, or both.²

"IDD" is the term often used to describe situations in which intellectual disability and other disabilities are present.³

<https://www.nichd.nih.gov/health/topics/factsheets/idds>



Justin – Self Advocate

I have skills and value. I contribute to my community. I am more like you than different. I have hopes and dreams.

This is Justin. He is handsome, personable, loving, funny, intelligent, a sports fanatic, an Uncle, baseball player and..... he has Down syndrome.

When you use the words 'retard' or 'retarded' as synonyms for stupid or idiot, you are saying that all people with intellectual disabilities are stupid, and that's definitely not true. Regardless if you mean it that way or not, using those terms doesn't just hurt people with intellectual disabilities, but it is also heartbreaking to us, as their family and friends. Next time you have the urge to use those words, look at his handsome face and hopefully it will make you think twice. Thank you

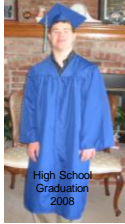
Justin's Business Card

School Services – birth to age 21



3 months old Birth-Age 3 intervention at home.

Justin received an Honorary Diploma in 2008.



High School Graduation 2008



Transition Graduation 2010 with good friend David from early intervention age 3-5

Justin received his Alternative Curriculum High School Diploma at age 21.

Birth to Age 3 – in home

- ▶ Nebraska started education at birth in 1979 – 10 years before Justin was born.
- ▶ Call you local school district to notify them your child needs to be evaluated for early intervention.
- ▶ Contact the Early Development Network at <https://edn.ne.gov/cms/>
- ▶ Get on the Eligibility and DD Registry – better known as “the list”. See “Overall Resources” in Resources PDF.
- ▶ Easy to do if you have a diagnosis of Down syndrome, Cerebral Palsy, premature birth, Fragile X, or Fetal Alcohol Syndrome.
- ▶ The label of a diagnosis and receiving Special Education services.
- ▶ No diagnosis? Just a “gut” feeling?
- ▶ Stages of grief and acceptance.
- ▶ Reach out to like families.
- ▶ Resource PDF includes area school contact information in “Birth to Kindergarten”.

UNMC Munroe-Meyer Institute Programs and Services

- ▶ Genetic Counseling
- ▶ Severe Behavior Program – ages 3-21
- ▶ Physical Therapy
- ▶ Occupational Therapy
- ▶ Recreational Therapy – age 3 and older
- ▶ Speech Therapy – Rite Care Clinics for free; ages 2-PreK; statewide
- ▶ Camp Munroe – age 3 to 21
- ▶ Caring for Champion – dental, vision
- ▶ Early Intervention program – ages 2-10 for Autism Spectrum Disorders
- ▶ Family Resource Coordinators – statewide
- ▶ <https://www.unmc.edu/mmi/services/index.html>

Age 3 up to Middle School

- ▶ Granddaughter Molly.
- ▶ Preschool and Elementary are in your school district, but probably not at your "assigned" school.
 - ▶ Riding a school bus.
 - ▶ When do you fight for your "assigned" school?
- ▶ Be vigilant; trust your gut.
- ▶ Be intentional – try to meet other parents.
- ▶ Attend educational meetings:
 - ▶ Down Syndrome Alliance of the Midlands
 - ▶ Autism Center of Nebraska
 - ▶ United Cerebral Palsy of Nebraska
 - ▶ Autism Society of Nebraska
 - ▶ Olie Webb Center
 - ▶ UNMC Munroe-Meyer Institute
 - ▶ The ARC of Nebraska
 - ▶ PTI Nebraska

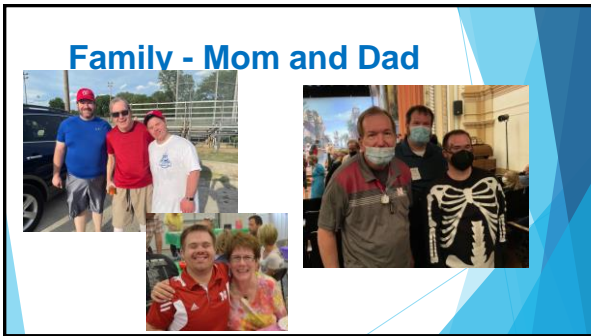
Middle and High School

- ▶ Unified Sports through Special Olympics.
- ▶ Activities with classmates – Homecoming, Prom, football games, basketball games, plays, or choir.
- ▶ Be vigilant, trust your gut.
- ▶ Important to attend meetings on what happens after age 21.
- ▶ The process is long and confusing!
- ▶ Move toward increased independence!
- ▶ What does your child want to do? Start now!
- ▶ Best Guide on what should happen with DHHS from age 14 -21 – Tips for Teachers:
<https://dhhs.ne.gov/DD%20Documents/Tips%20for%20Teachers.pdf>

Transition Program

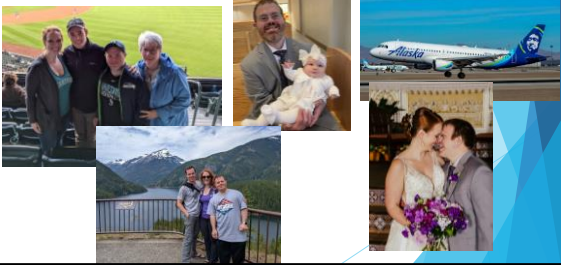
- ▶ Ages 18-21.
- ▶ If you receive a high school diploma at age 18, you cannot receive any services through Nebraska Department of Health and Human Services till age 21.
- ▶ Vocational Rehabilitation – will help with a job.
- ▶ Begin looking at day programs if a job is not in your child's future
- ▶ Best Guide on what should happen with DHHS from age 14 -21 – Tips for Teachers:
<https://dhhs.ne.gov/DD%20Documents/Tips%20for%20Teachers.pdf>

Justin's Story

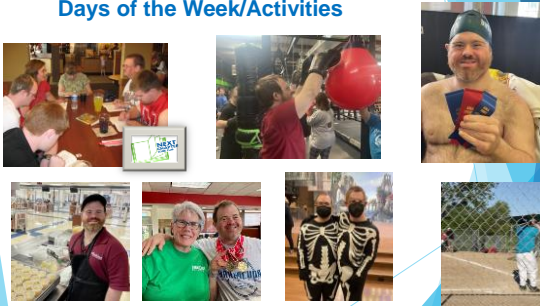




Family- Kristin, JD and Kenna live in Seattle



Days of the Week/Activities



Advocating



Justin speaking at Millard North High School, his alma mater and current employer at age 3 yrs. 8 mo.

Speaking at high schools, groups, businesses since Justin was 10 months old.




Kids on the Block Through Why Arts?

JOBS



11 Years
at Prairie
Life and
Genesis





4 years

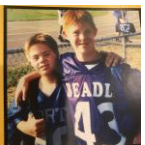
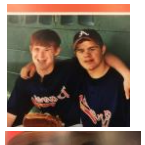






Since
Jan. 2022





Scoopy

Apartment – Roommate is Jerus









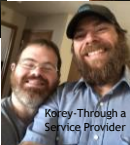
Apartment Staff





Brian
Independent Provider





Korey - Through a
Service Provider

Justin and Jerus just started their 10th year of living in a market rate apartment! This is not a group home.



Learning Objectives #2

- ▶ Discuss the services and resources available for adults with disabilities while considering the challenges that caregivers/parents experience resulting in distress and burnout.



The Labyrinth – age 18-19

- ▶ Should my child do transition?
- ▶ No assets over \$2,000.
- ▶ What are ABLE and ENABLE accounts?
- ▶ SSI – Supplemental Security Income at age 18.
- ▶ Nebraska Medicaid Health Insurance at age 19.
 - ▶ Heritage Health – United Healthcare, Healthy Blue, Nebraska Total Care.
- ▶ Guardianship, Conservatorship or POA (Power of Attorney) at age 19 (In Nebraska).
- ▶ All these acronyms!!

Should my child do transition?

- ▶ If an individual with I/DD graduates from High School at age 18 and does NOT take advantage of the school districts transition program from 18 to 21, they will receive **NO** services from Nebraska DHHS until the age of 21.
- ▶ What will your adult child do every day between the hours of 8 am to 4 pm between ages 18 and 21?
- ▶ Who provides transportation? Can a parent get time off from work?
- ▶ Who will provide job training and coaching?
- ▶ Who will take care of my adult child so I can work?



The Labyrinth – age 18 – Asset Limits

- ▶ Start immediately on the \$2,000 asset limit for SSI. Has not increased since 1989!!!
- ▶ ABLE Act passed on a federal level December, 2014 changing the tax code.
- ▶ The NE ABLE Accounts, ENABLE, opened July, 2016.
 - ▶ Qualification: Onset of the disability occurs before turning 26.
 - ▶ Qualification: On SSI or SSDI, individual automatically qualifies.
 - ▶ Qualification: Doctor's certificate that onset of disability was before age 26
- ▶ Effective Nov. 16, 2020 Nebraska Medicaid no longer can recapture (claw back) the balance in an ABLE account when the individual passes.
- ▶ \$100,000 total limit before SSI resources are suspended; once you are below \$100,000 in your ABLE account your SSI resumes.
- ▶ \$17,000 is the maximum contribution (from all sources) with the exception of earned income. Earned income deposited in the ABLE account does not count in that limit total
- ▶ See "ABLE Accounts" in Resources PDF.

The Labyrinth – age 18 – SSI



- ▶ Apply for SSI three months before turning 18 (federal age of majority).
- ▶ Must pay rent to parents if living at home.
- ▶ Without a "label" of a disability it can be difficult to qualify. Reapply!
- ▶ Must report any job earnings every month! Penalties can be significant! Plus you get to report earnings **every month the rest of their life.**
- ▶ Representative payee; special bank account.
- ▶ Substantial Gainful Activity (SGA) in 2023- no more than \$1,470 in one month.
- ▶ Parents/guardians are petrified of losing SSI for their loved one.
- ▶ Even with Down syndrome, Justin has had to requalify for SSI.
- ▶ See "Social Security –SSI" and "Social Security –SSDI" in Resources PDF.

The Labyrinth – age 19 – Medicaid Insurance

- ▶ Qualify for SSI – almost always qualify for Nebraska Medicaid Medical Insurance at age 19. Medical insurance is Part I of Nebraska Medicaid.
- ▶ Nebraska Medicaid Medical Insurance through Heritage Health.
- ▶ How do I choose between United Healthcare, Healthy Blue or Nebraska Total Care?
- ▶ Can be your only medical insurance or secondary insurance if individual is on their parent's insurance .
- ▶ Pro's and Con's if Medicaid is your child's only medical insurance.
 - ▶ Cost to carry dependent coverage.
 - ▶ Medical specialists who might not accept Medicaid.
- ▶ Qualify for NE Medicaid every year – 20-25 pages.
- ▶ See "Nebraska Medicaid – Medical Insurance" in Resources PDF.

The Labyrinth – age 19 – Age of Majority in NE

- ▶ Age of majority at age 19 in Nebraska. (Federal level is 18; Iowa is also age 18 as are the majority of states). Individual can make all their own medical and financial decisions.
- ▶ Which is right? Guardianship, conservatorship or POA?
- ▶ Do your homework!
- ▶ Do what is best for your family member, not what anyone else tells you!
- ▶ Guardianship reporting every year – my experience 25-120 pages a year!
- ▶ Office of Public Guardianship was started after a lawyer from Bayard embezzled fund from adults with I/DD in 2013. At the time of her arrest she was the guardian of 216 wards in 36 counties. She had been guardian for up to 600 cases.
- ▶ See "Guardianship/Conservatorship/POA" in Resources PDF.

The Labyrinth – over age 21 CDD Waiver

- ▶ Comprehensive Developmental Disability Waiver
- ▶ The "Cadillac". Don't turn this waiver down!
- ▶ Parents often call this the "Residential Waiver".
- ▶ Justin waited 7 years and 7 days. He was 28 years and 14 days when he received the CDD waiver.
- ▶ Service providers prefer this waiver as reimbursement rates are often two+ times as much as the DDAD or Day Waiver.
- ▶ Only additional services offered are residential and homemaker services.
- ▶ Current wait list is 7+ years.
- ▶ Service providers are having a hiring crisis – sometimes individuals are not coming off the wait list.

The Labyrinth – over age 21 Jobs

- ▶ How does my adult child get a job?
- ▶ This should start in your school districts transition program.
- ▶ Vocational Rehabilitation should also start in transition.
- ▶ Volunteer work at jobs where there is interest.
- ▶ Hard to find, even harder to keep.
- ▶ Family or friend connections.

Housing – Options in Nebraska

- ▶ Your adult child does not just move out at age 18 or age 21!
- ▶ Continuous Home (group home) – must be on the CDD (Comprehensive Developmental Disabilities) Waiver - 7+ year wait.
- ▶ Shared Living Provider – live with another family who is supervised by a Nebraska Service Provider. Need the CDD Waiver. Wait list.
- ▶ Market Rate apartment.
 - ▶ Private pay for help in the apartment using SSI funds or parental funding.
 - ▶ DDAD (limited help).
 - ▶ CDD Waiver (wait list).
- ▶ Sibling or Family member – do not need a waiver, but to have any help during the day the DDAD (Developmental Disability Adult Day) Waiver is needed.
- ▶ Sheltering Tree – a consumer-controlled, safe, affordable, and community-centered apartment community that has amenities that are desirable for adults with developmental disabilities. Wait list.
- ▶ Low Income Housing in City of Omaha, Douglas or Sarpy County. Wait list.

Learning Objectives #3

- ▶ Describe how to navigate services for children with disabilities into adulthood to empower caregivers/parents to meet the basic needs, growth, and development opportunities within your practice.

How does a parent or guardian find their way out of the labyrinth?

- ▶ No one knows all the answers. Low pay causes turnover which causes parents to receive incorrect answers at DHHS, Social Security, Medicaid and Medicare.
- ▶ Along the Way resource guides are some of the best summaries available. Included in the "Overall Resources" of Resources PDF.
- ▶ DHHS listing of state & federal resources – <https://dhhs.ne.gov/Pages/DD-Resources.aspx>
- ▶ Newsletters of various organizations – DSA of the Midlands, ARC of Nebraska, Olie Webb Center, MMI United Cerebral Palsy of Nebraska, Autism Center of Nebraska, Autism Society of Nebraska.
- ▶ Facebook Groups.
- ▶ Attend training seminars through the above organizations.
- ▶ Other parents are your best weapon and best source of knowledge.
- ▶ Group Therapy? What is it?
- ▶ Give yourself grace; have a good cry.
- ▶ See Resource Information included as part of this presentation.

Employees of UNMC – what can you do?

- ▶ Prefill forms if possible. Especially if a particular wording is needed to get services. Email in advance so parents can try and fill out before appointments.
- ▶ Refer IDD parents to the Family Care Enhancement Project at UNMC Munroe-Meyer Institute for a Parent Resource Coordinator Contact mmifcep@unmc.edu or 402.559.5735
- ▶ <https://www.unmc.edu/mmi/family-resources/community-services/fcep.html>
- ▶ Parent Resource Coordinators are located at UNMC-MMI, Boys Town Pediatrics, One World Community Health Center, Charles Drew, CHI, Kearney, Lincoln, Norfolk and Scottsbluff.
- ▶ Help is available for all ages.
- ▶ Encourage the parents to join the MMI Caregivers Corner on Facebook at <https://www.facebook.com/groups/mmicaregiverscorner/>
- ▶ **Never say Never!**

For everyone - Interaction with Families

- ▶ Parents try to the best of THEIR ability!
- ▶ Exhausting and will not end till we are 6 feet under!
- ▶ Is their extended family in town to help? Can you babysit for a couple of hours?
- ▶ Marriage and Divorce – Usually women bear the brunt of the work. ☹
- ▶ Other siblings – don't say you can't do things because of sibling with a disability!
- ▶ Need to belong to a parent organization or other parents. Might need babysitting.
- ▶ Chronic sorrow.
- ▶ Dealing with medically fragile and/or wheel chair users. Limited services ☹
- ▶ Can the child/adult stay by themselves for any length of time?
- ▶ Battles with schools, insurance companies, Medicaid, Medicare, Nebraska DHHS and Social Security.

What can you do?

- ▶ We don't want your pity. Have empathy instead!
- ▶ Use People First Language
- ▶ Never use the "R" word. Tell your friends/families not to use
- ▶ Can your department or employer provide job opportunities?
- ▶ Thank employers when you see an individual with I/DD working at their business
- ▶ Have your typical children volunteer at Camp Munroe at MMI; Special Olympics; Unified Sports at local public schools.
- ▶ Adults can volunteer as a Next Chapter Book Club Facilitator.
- ▶ Contact your state or federal representatives about I/DD services. ARC of Nebraska will keep you abreast of issues.
- ▶ <https://www.arc-nebraska.org/>



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Welcome to Holland
by Emily Pearl Kingsley
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Thank you

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Questions via the Chatbox
