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Indiana Division of Disability & Rehabilitative Services Newsletter

A message from the DDRS director

Focused on systems transformation



DDRS is intently focused on systems transformation to ensure that individuals with disabilities are supported to live their lives as they determine. A key part of achieving this transformation is changing individual, family and societal expectations. This change must begin in childhood. Kids are never too young to start dreaming and the presence of a disability should not prevent parents and children from dreaming about the future. Let's show our children, with and without disabilities, that we think they are the best, most talented people in the world and support experiences to help them understand what it takes to make their dreams a reality.

Your child might dream of flying a magical carpet or flying high like a bird. While we can't make these types of dreams come true for our imaginative little ones, we can help our kids figure out what they're good at, what they actually want and how to get there!

Often, when a child has a disability, we focus on limitations, support needs and services and resources for that disability. We may even form our vision for the future based on our ideas of the limitations that a disability may mean. While planning for current and future needs is important, our focus should be on supporting the dreams, interests and abilities of the child, in the context of their family and community, rather than the disability.

Identifying and exploring interests is a great way to discover what kids may be interested in pursuing as careers or hobbies. When given the opportunity to explore new things, children can discover what they're good at and their unique talents and strengths. The child, family and support network can build upon those talents and strengths to assist the individual in achieving their goals.

Having big dreams isn't silly or indulgent; it's all part of adopting a growth mindset that will help children throughout their entire lives. When we begin to change our expectations, we can work together to identify family, community and eligibility-specific services and resources to support the child and family in achieving their dreams and pursuing what is most important for their lives.

Kelly Mitchell

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STORIES IN THIS NEWSLETTER

- Bureau bits: Updates from your First Steps, Bureau of Developmental Disabilities and Vocational Rehabilitation teams.
- Making the LifeCourse work for you: Using the life stage guides to walk you through planning for your current and future goals.
- News you can use: Opportunities for summer camp options throughout Indiana.
- **Featured story:** Meet Caroline. Giving ourselves and our children the grace to change expectations.
- Events you don't want to miss: The quarterly Building Bridges events create direct avenues for individuals and families to share their feedback.

First Steps

It's never too early to set great expectations!

Think back to your own experiences growing up. What future expectations did your caregivers or teachers have for you? How were these expectations communicated? Are your expectations for your child similar or different?

Research shows a strong link between high expectations for children with disabilities and later outcomes (e.g., employment, college, independent living).

According to Yarbrough, Gretzel and Kester (2014) in their study entitled "expectations of families with young adults with intellectual and developmental disabilities for postsecondary education," parents offered advice to others about the importance of the messages that are communicated to children with disabilities.

Here are three of their suggestions:

- Do not underestimate the abilities of the individual with disabilities. Children should be encouraged to have "can do" attitudes. The supportive adults that interact with the children should display those "can do" attitudes. Finally, adults should also encourage ongoing learning throughout the lifespan.
- Be connected to your community. Parents agreed that being connected to the community was a necessary part of having high expectations of their child. Being active in the community allows opportunities for socializing for both the children and the parents. It also provides emotional support for the parents. Community events and gatherings can provide information for continuing education or employment.
- Post-high school education is important. The college/trade school experience offer many opportunities for continued growth and learning across all areas of development for the student with delays and disabilities, such as daily living skills, social emotional development and communication skills. Besides the opportunity to receive a diploma and/or degree the student also gains a sense of belonging in the community.

How does this translate to setting expectations for younger children? According to Dr. Katie Herron, a researcher at the <u>Indiana Institute on Disability and Community</u> at Indiana University's Early Childhood Center, it is never too early to begin setting high expectations for all children.

Dr. Herron has some recommendations for setting high expectations. They are:

- Ask lots of questions. What are your hopes and dreams for your child? What do you hope to see your child doing in one year? In Kindergarten? In high school? As an adult? When you think about what your child's life will be like, what is most important to you?
- ▶ Withhold judgment. There is no need for expectations to be realistic when children are young. Many young children dream of being astronauts, professional football players, etc. ... Allow yourself and your children to dream big and hope, as those dreams and hopes translate into high expectations. Expectations shift and change as we grow older, gain experiences and gather information.
- Utilize the tools available to you. LifeCourse offers tools for you to be able to set high expectations, goals and a vision for your loved one and your family. Check out the Life Trajectory: Family Perspective planning document, the Life Domain vision tool: family perspective and the mapping relationships worksheet on the family perspective webpage of the <u>LifeCourse website</u>. All these work together to help you and your family set expectations and create pathways to help in realizing those expectations.
- Strength-based language. Focus on what your child does well. Point out progress and successes. Use people-first language strategies. For more information, visit <u>People-First Language</u>.

Visit <u>The Importance of High Expectations for Families</u> to access Dr. Herron's webinar and to learn more about her research on setting high expectations.

Additional resources you may find helpful

Sue Pratt on the importance of a transition plan—National Parent Center on Transition and Employment (pacer.org)

Sue Pratt on <u>parents being the experts</u>—National Parent Center on Transition and Employment (pacer.org)



2023 Indiana Early Intervention Conference

June 8-9, 2023, in Bloomington

Indiana First Steps and Infancy Onward have partnered with the Early Childhood Center at Indiana University to bring together national and local experts to address research and best practices in Early Childhood Intervention. Register today! There is a virtual option for \$25.



BUREAU BITS



Bureau of Developmental Disabilities Services

Over the last two years, the Bureau of Developmental Disabilities Services has been providing a number of trainings to their waiver providers and case managers on the federal home and community-based settings final settings rule. This was in preparation for the requirement for states to be in full compliance by March 17, 2023.

You may have heard some about this through your provider and case manager because the rule is about ensuring an individual's rights, choices, options and opportunities while living in their home and participating in their community. The HCBS final settings rule was developed to ensure that individuals who are using waiver services have the same rights in their home and access to the greater community as individuals who do not have a disability.

You will continue to choose which HCBS waiver services and supports you will receive and who will provide them. This will be reflected in your person-centered individualized support plan.

The rules say that people receiving HCBS deserve the opportunity to:

- Live in the places they want to live and can afford
- Find and keep good jobs
- Be in charge of their own lives
- Choose how they want to be helped and select which supports and services they want or need
- Choose who will help them
- Be part of their community and live life the way they want to live

The HCBS settings rule requires these rights for people with disabilities who are receiving waiver services:

- You have a right to privacy
- You have a right to make choices

- You have a right to choose where you get help and services
- You have a right to be around other people in your community
- You have a right to do the same things in the community that everyone else does
- You have a right to do things in the community with people who do not have a disability
- You have a right to get a job working with people who do not have a disability

When you live in a home that your HCBS waiver provider owns or controls, the HCBS settings rule says you should have opportunities to:

- To be in charge of the things that belong to you including your money
- Be in charge of your schedule and what you do each day
- Decide what to eat and when to eat
- Have visitors when you choose
- To get to all areas of your home
- To leave your home and get back inside
- Decorate your room and personal space the way you want to
- Choose your roommates if you share your home
- Have a lock on your door and have your own key
- Continue living in your home until your lease ends (unless there is a legal reason requiring you to move out sooner)

To learn more about the rule, you can speak with your case manager or visit our fact sheet.

Follow the Bureau of Developmental Disabilities Services on Facebook!

Vocational Rehabilitation

What is your high school student's plan for the summer? Since the school year will be coming to a close in may, now is a great time to start thinking about getting them involved in Pre-ETS so they can make the most of their time off this summer.

What is Pre-ETS? The Workforce Innovation and Opportunity Act amended the rehabilitation act of 1973 and requires Vocational Rehabilitation agencies to set aside federal funds for their statewide provision of pre-employment transition services (Pre-ETS) to "students with disabilities who are eligible for potentially eligible for VR services."

This provides an opportunity to ensure students with disabilities have access to meaningful career planning in order to help with the transition from high school to employment or postsecondary training. A student with a disability is an individual with a disability in a secondary, postsecondary, or other recognized education program who:

- Is between the ages of 14 and 22 years old; and
- Is eligible for and receiving, special education or related services under Part B of the Individuals with Disabilities Education Act (IEP, 504 plan); or
- ▶ Is a student with a disability for purposes of Section 504

Pre-ETS services are provided by both VR counselors and contracted vendors, are available throughout the state, are voluntary and there is no cost to the participant.

Pre-ETS activities include:

- Job exploration counseling
- Work-based learning experiences
- ► Counseling on postsecondary opportunities
- Workplace readiness training
- ► Instruction in self-advocacy

Why is summertime such a great time to take advantage of the Pre-ETS program? Some Pre-ETS contractors offer summer camps, where students meet regularly and are offered opportunities to tour, observe and conduct informational interviews at different facilities, as well as provide opportunities for job shadowing and work experience. Students are also able to participate in fun group activities and outings.

Summertime is also a great time to take advantage of other Pre-ETS services, such as volunteering to add experience to their resume, touring area colleges, or participating in paid and unpaid internships.

There are several different ways to get your student started in Pre-ETS. Talk to their school and ask to have them referred. If their school isn't currently receiving services, you can contact the Pre-ETS provider in your area directly or you can contact your local VR office. Help your student make the most of their summer!



Making the LifeCourse work for you

Using the life stage guides

Recently, a young lady and her guardian contacted one of the eight local BDDS district offices. She was looking to leave her supervised group living home and move out into her own apartment. However, she had some concerns. She has never lived in an apartment or been required to maintain her own living expenses. She was worried. So, her team met to work through her concerns and create a plan for the future.

They quickly realized that one of the four-page guides would be most appropriate in this situation. This guide helps walk through some of the questions to ask for each life domain, options to consider and things to discuss as they work together to shape this plan. These life stage guides can help provide a snapshot as they aren't meant to be all inclusive.

The team spoke in detail about how this young lady was going to pay her rent and utilities. Would she be able to afford the rent with her current job or should she start looking for something new? They spoke about what skills she will need to maintain her apartment as well as what area of town she would like to live. How will she find transportation? The team went through each life domain individually to see what sup-

ports she has in place and where she needs some extra assistance. The team commented that they hadn't thought about some of the questions brought up in the four-page guide.

She is still nervous about her next adventure in life but told the district office that she feels much more confident now that she has a plan in place for support.

These four-page guides are available for each life stage. Each guide walks you through planning for your current and future goals. They help you think about what has helped or hindered you in the past and what could possibly work moving forward while also realizing there are setbacks that could occur. We know that each life stage is connected to those from the past and the future. That is why all LifeCourse tools build upon all life expe-

Daily Life and Employment: What a person does as part of everyday life - school, employment, volunteering, communication, routines and life skills.



Community Living: Where and how someone lives—housing and living options, community access, transportation, home adaptation and modification.

Safety and Security: Staying safe and secure-finances, emergencies, wellbeing, decision making supports, legal rights and issues.



Healthy Living: Managing and accessing health care and staying well-medical, mental health, behavior, developmental, wellness and nutrition.



Social and Spirituality: Building friendships and relationships, leisure activities, personal networks and faith community.



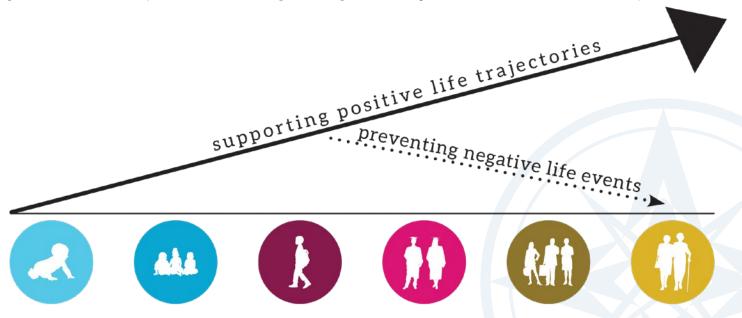
Advocacy and Engagement: Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived.

For more information on the LifeCourse framework and principles, visit: www.lifecoursetools.com.

riences as you move into the next stage of your life. These guides can be used by individuals, caregivers, family members and other supports to help guide the conversation as they move through any change in life stage or transition. In-depth conversations regarding each life domain can help ensure that you are able to live your best life and also work towards future goals.

If you feel like you need more support, you can review the experiences and questions booklet. This breaks down the life stages and domains even further to assist as you dig deeper into planning for your good life.

The guides can be found at the Life Course Library.



2023 summer camps throughout Indiana

There are many opportunities for summer camp options

Looking for summer camp options? There are plenty of opportunities! Check out these links below for more information.

Terra Time Nature Play and Learning

June 12–16; 19–23; July 3–7; 10–14 Albany, Ind.

Terratime.org (Delaware County)

Outdoor enrichment programs are STEM-inspired and designed by a pediatric occupational therapist. Ages 4–11. Registration is open!

Camp Yes And

June 5-9; 12-16 Bloomington, Ind.

YesAnd.Indiana.edu (Monroe County)

Teens and teachers learn improv as a way to develop social communication skills and transform teaching and learning. Camp registration will open by end of February 2023. Join the fun!

Camp Wy.Not

Runs June through August Bristol, Ind.

ADECinc.com (Elkhart County)

ADEC provides families vital support through meaningful activities for their school-aged children with developmental disabilities. Signups close April 28 or when all spots are full.

Anderson Woods

Runs June and July, Monday through Thursday Bristow, Ind.

Andersonwoods.org (Perry County)

Campers learn self-confidence, trust and responsibility through working together, caring for animals, tending the garden and enjoying the beauty of nature. Registration is now open!

Autism Community Connection

Runs three weeks in June: June 12–16th; June 19–23rd; June 26–30 Greenwood, Ind.

AutismCC-in.org (Johnson County)

A summer program for teens with autism. Registration will open at the beginning of the year.

iD Tech Camp

Butler University and online Runs June 12 through July 21 Indianapolis, Ind.

iDTech.com (Marion County)

Code, game and create. Registration is open.

Camp Millhouse

June 18-23; 25-29; July 2-7; 9-13; 16-21; 23-28; Fall camp: Sept. 16-17 South Bend, Ind.

Dunes Learning Center

Day camps: June 27–29; July 11–13; July 31–Aug. 4 Overnight camps: June 19–23; July 10–14; 17–21; 24–28 Chesterton, Ind.

<u>DunesLearningCenter.org</u>(Porter County)

This camp will build skills and friendships that last a lifetime. Registration is now open!

Virtual Woodwind Academy

Online; join 2023 waitlist at VirtualWoodwinds.com

Provides students with private lessons, masterclasses, music, educational workshops and the chance to collaborate with like-minded peers.

Camp Little Red Door

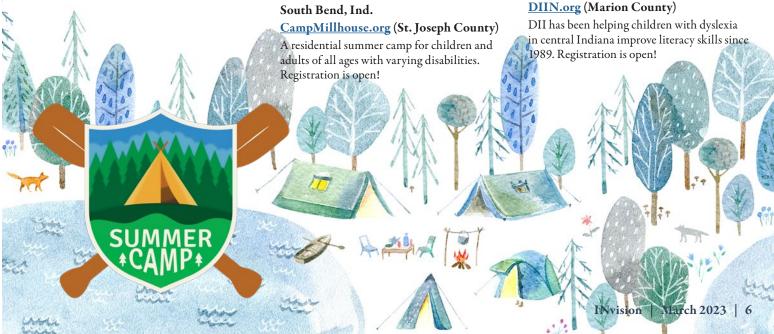
June 11-16; 9-16; July 10-14; Oct. 6-8 Martinsville, Ind.

<u>LittleRedDoor.org</u> (Morgan County)

Indiana's oldest camp for children with cancer. Registration is now open!

Camp Delafield Dyslexia Institute of Indiana Office of Technology

June 5 through July 7 Indianapolis, Ind.



Meet Caroline

Giving ourselves and our children the grace to change expectations

When my husband and I first received Caroline's in-utero diagnosis of osteogenesis imperfecta, we were as surprised as anyone could be, even though we knew there was a 50% chance that she'd inherit my disability. From that point forward, we started a journey,

different from any of our other friends who were pregnant or already had kids. When Caroline was born, she was perfect. I had read as many parenting books, articles and social media as I could and felt as prepared as any new parent. I knew she'd be at risk of breaking bones but wasn't too worried about how that would impact us yet.

It wasn't until she started growing out of the newborn phase and becoming an actual baby with milestones to achieve that I really experienced the stress and anxiety of raising a kid with a disability. All those gross motor skills they talk about she wasn't hitting on time. She wasn't rolling like the other babies her age, then wasn't sitting and certainly was not

crawling. It was at this point that I realized I could not rely on all those baby books I had so diligently read to tell me what "success" looked like. So we quickly pivoted and threw that all out the window.

As a now 2 ½ year old, Caroline is still making her own rules of when she will hit all

those milestones. She's had several setbacks with fractures and surgeries but continues to amaze us each day. We are currently working on walking independently. Every little accomplishment is a huge win and we celebrate it as such, making sure she knows that she is brave,

"My biggest takeaway and advice as a parent with a disability, having a child with a disability, is to make sure that your child always believes in themselves and that you believe in them too."





strong and amazing! We tell her this every day and it certainly has given her the courage to try, try again.

As it relates to expectations this is all we can do. Encourage our child to be the best version of themselves and make sure that whatever they accomplish is wonderful, even if

it's outside of what is considered the "normal" timeline or expectation. As parents, we have worked really hard to push out the noise of people who mean well and comparing her to other children, instead focusing on Caroline's strengths and how much she has accomplished

in her few years of life.

Moving forward, I can only hope we will continue doing so as she continues to grow. As parents with disabilities ourselves, we know that everyone's journeys are different and unique and we are encouraging Caroline to make her own path. There are always going to be setbacks, struggles and hard times, but as long as she believes in herself and feels supported by her parents, that's all that matters.

My biggest takeaway and advice as a parent with a disability, having a child with a disability, is to make sure that your child always believes in themselves and that you believe in them too. Being flexible and adaptable to change makes a huge impact. We cannot stress about the expec-

tations we once had and how it has changed. Instead, we must give ourselves and our kids grace to change expectations, be amazing in their own ways and allow ourselves to love and fully experience the uniquely wonderful new expectations and experiences our children bring to us.



Indiana Family and Social Services Administration Division of Disability and Rehabilitative Services 402 W. Washington St., W453/MS 26 Indianapolis, IN 46204

You can sign up to receive this newsletter by clicking here.

For updated meeting information, as well as agendas and past meeting minutes, visit the DDRS Commissions & Councils page.

The Division of Disability and Rehabilitative Services is a program of the Indiana Family & Social Services Administration. If you have questions about DDRS programs and services, visit us online.

Did you know that families can sign up to receive text messages and email updates from First Steps? Families will learn more about policy issues, how to become an effective advocate, how to be involved in your local planning and coordinating council, how to connect to events and groups, how to tell your family story and more. Go to this site to sign up!

EVENTS YOU DON'T WANT TO MISS

Following are the current commission, council and public meetings that you may be interested in learning more about and/or attending in the future. To find the most current information, including next meeting dates and locations, please click here.



Building Bridges

These meetings are an opportunity for families and self-advocates to meet and speak with the Bureau of Developmental Disabilities Services state staff. These sessions are an important part of the Bureau's efforts to create direct avenues for individuals and families to share their feedback. These meetings are solely for families and individuals with disabilities to provide a forum for constructive and valuable conversations on successes or concerns, as well as suggestions or input regarding BDDS programs and services. For more information on upcoming meetings, please visit the DDRS Announcements web page.

INSILC public meeting

The Indiana Statewide Independent Living Council provides oversight of the Indiana State Plan for Independent Living and assists the Centers for Independent Living with the plan's implementation and coordination of services. For more information, visit the Statewide Independent Living Council webpage.

DDRS Advisory Council

The DDRS Advisory Council was established to assist the Division of Disability and Rehabilitative Services in ensuring that individuals with disabilities are as independent and self-sufficient as possible. The council meets at least six times a year and the meetings are open to the public. For more information, visit the DDRS Commissions & Councils webpage.

ICC meetings

The Interagency Coordinating Council for Infants and Toddlers with Disabilities is the state's federally mandated early intervention council. The council is charged with advising and assisting DDRS in its responsibility to develop an early intervention system of the highest quality, balancing family-centered services with fiscal responsibility. The council is comprised of parents, state agency groups, early intervention service providers, legislators and others. The meetings are open to the public.

Members of the public are encouraged to attend. A link will be made public prior to each meeting. Should a member of the public need access to the meeting link, special accommodations or interpretative services, please contact Janet Ballard at Jaeball@indiana.edu at least two weeks prior to the scheduled meeting. The 2023 meeting dates are as follows:

March 8, 2023, 10 a.m. ET May 10, 2023, 10 a.m. ET July 12, 2023, 10 a.m. ET

Sept. 13, 2023, 10 a.m. ET Nov. 8, 2023, 10 a.m. ET

Commission on Rehabilitation Services

The Commission on Rehabilitation Services works with the Bureau of Rehabilitation Services' Vocational Rehabilitation Services on matters such as the effectiveness and customer satisfaction with the services provided to individuals participating in the VR program. The commission is also involved in matters affecting VR policies and procedures, goals and priorities, and the state plan. For more information, please visit the <u>DDRS Commissions & Councils webpage</u>. Check the <u>2023</u> Indiana Commission on Rehabilitation Services meeting schedule to find the upcoming meetings.