HOPE NOTES

A message from Director Kylee Hope

Self-determination is for everyone

The term “self-determination” may or may not be something you have heard before. Self-determination is the idea that all people should be empowered to choose and set their own goals, take the lead in or be involved in making their own life decisions, are supported in being an effective self-advocate and have the opportunity to learn from mistakes.

Self-determination is not the same thing as self-sufficiency or independence; rather it is about making your own choices to the greatest extent with the appropriate supports and accommodations. Self-determination involves many attitudes and abilities that include self-awareness, assertiveness, creativity, pride, problem-solving and self-advocacy. The development of these skills are lifelong and begins in childhood, where choices are given and respected, failure is allowed, and self-advocacy is encouraged.

This concept is not exclusive to one segment of the population. No matter the degree of impact of disability, self-determination is for everyone. The supports necessary may vary greatly but every single person should be afforded the right to have a say in their own life.

Making peer-to-peer connections can be helpful in the process where the older or more experienced individual with a disability or family member can act as a mentor, sharing experiences and ideas, and assisting in problem-solving. At the Division of Disability and Rehabilitative Services, we continuously work to ensure our programs and services allow for and encourage self-determination from early intervention, employment, and independent living supports. A few specific initiatives we are using to continuously embed self-determination principles into our work include waiver redesign, Living Well, Culture of Quality, Community of Practice for Supporting Families and the Community of Practice for Cultural and Linguistic Competency in Developmental Disabilities.

Our goal is that through all of these projects and initiatives we provide purposeful services that support you and your loved ones in living your vision of a good life.

Kylee B. Hope
BUREAU BITS

Bureau of Developmental Disabilities Services

The Bureau of Developmental Disabilities Services is required by the federal government to renew our waivers every five years. This is the year to renew our Family Supports waiver and the Community Habilitation and Integration waiver. This opportunity has allowed us to make some minor changes to our current waivers that we hope individuals and families will find helpful in living their vision of a good life. The following list highlights just a few of the changes, which are scheduled to take effect on July 16, 2020:

- Family and Caregiver Training provides education and support directly to the family caregiver to increase their confidence and stamina. The annual reimbursement rate has been increased to $5,000/year.
- Environmental modifications has been added to the Family Supports waiver. This service allows for physical adaptations to the home which are necessary to ensure the health, welfare and safety of the individual or to enable them to have greater independence in the home. There is a lifetime cap of $15,000 and this service is available outside of the $17,300 budget.
- Community habilitation and facility habilitation have been combined into one service, now called “day habilitation.” This will allow for flexibility and choice in scheduling what activities the individual wants to participate in and where.
- Electronic monitoring has been renamed “remote supports.” Remote supports allow for surveillance systems and onsite response, as well as other options, such as door or bed sensors. This will now be available for youth aged 14–17, in addition to adults. In addition, this service has been added to the Family Supports waiver, where an additional $500 may be accessed outside of the annual cap.
- Paid relative caregivers of residential habilitation or participant assistance and care will now allow for each paid family caregiver to provide up to 40 hours of care.
- Community transition funds are available through the Community Integration and Habilitation waiver as a one-time service for individuals who are transitioning from an institutional setting to their own home in the community for essential furnishings, deposits, set up fees and health/safety assurances. The allowable amount has been increased to $2,500.

For more information about these or any other changes, you may speak to your case manager or email BDDSinfo@fssa.in.gov.

First Steps early intervention program

The vision of First Steps is that all Indiana families have a strong foundation to advocate for their infants and toddler to grow and flourish to their highest potential. While a critical support, First Steps is a small part of making this vision a reality. Therefore, our mission is to come alongside families and fill in the gaps to ensure their children grow and flourish. To accomplish this mission we strive to equip families with the tools and resources to help their child thrive in all aspects of their life and build toward their future where First Steps is no longer needed.

A key aspect to this work is supporting families to advocate for their child by creating outcomes as part of their individualized family service plan that are meaningful to the family and set high expectations for their child. The IFSP is the guiding document for the delivery of early intervention services within First Steps.

A resource that families may find helpful in identifying and advocating for meaningful outcomes is the Integrated Supports Star Divided worksheet, from the LifeCourse Framework. This tool helps families to look at their current strengths and resources, understand how those strengths and resources work to support their child and family, and identify what will be needed in the future to support their vision of a good life. Completing the Integrated Supports Star before an IFSP meeting can empower families to lead the conversation and become their child’s advocate for services and supports.

To learn more about LifeCourse and how to use the divided Integrated Support Star, click here.

Vocational Rehabilitation

Jamie Beck is the first individual in the state of Indiana to use a formal supported decision-making agreement to regain her rights. In 2009, the courts assigned Jamie a guardian after the death of her parents and stepfather. She had no known family. Over the next seven years, Jamie gained access to Medicaid waiver services that provided a new living environment and used Vocational Rehabilitation Services to learn new job skills that resulted in successful employment with full benefits.

Through these experiences, she built her resolve to live a self-determined life and pursue termination of her guardianship. You can read the full story of this remarkable young woman by clicking here.

To sign up to receive text messages and email updates from First Steps, go to this site!
What to know about supported decision-making

New Indiana law makes supported decision-making a recognized option to assist people

By Melissa L. Keyes, M.S., J.D.

We make hundreds of decisions every day; some more complex than others. Regardless of the decision, each involves a similar process: understanding the issue; gathering information; identifying choices; determining a course of action; making or implementing your choice; and evaluating or observing the outcomes. Sometimes these steps happen instantaneously; for example, when deciding what to wear or what to have for lunch. Other times, we are much more deliberate. No matter what choice we make, as adults with presumed capacity, those decisions are generally respected. We have self-determination, or control, over the direction our lives are taking. Unfortunately, not everyone has the same right. People with disabilities or others who have difficulty making decisions, may be prevented from exercising self-determination and independence to the greatest extent they choose.

One way to enhance self-determination is to embrace the concept of supported decision-making. In its most basic understanding, supported decision-making is a way to accommodate the decision-making process. The core principle of supported decision-making is that the person uses “supporters”—generally trusted friends, relatives, or caregivers—to help them through the decision-making process, but the person retains the ultimate decision-making authority. The concept itself is not new. Indeed, most of us talk to friends, family members or professionals when faced with a complex decision. Thanks to a new law in Indiana, supported decision-making is now a recognized option to assist people who need help with the decision-making process.

Formalization of supported decision-making means writing a person’s decision-making supports into a document called a supported decision-making agreement. In formalized supported decision-making, the person chooses the areas where they need and want support—for example, finances, health care, housing or employment. The person also chooses who they want to serve as supporters and how they want their support to be given. The agreements are flexible and are under the control of the person using them. They can provide structure to the person’s relationship with their supporter and the agreements can be used to show providers who may be questioning a person’s ability to make a decision that they can, in fact, make decisions using their identified supports.

Supported decision-making is one of many options available to support an adult in the decision-making process. Anyone interested in learning more about what options are available is encouraged to contact an attorney or visit Indiana Disability Rights’ resource page for supported decision-making.

1Ind. Code §29-3-14 et seq.

LIFE DOMAINS AND STAGES

Making the LifeCourse work for you

Using the Tool for Exploring Decision-Making Supports

The LifeCourse Framework offers many tools to assist you in living your vision of a good life. One tool that may be helpful in exploring what types of supports you need when making decisions is called the Tool for Exploring Decision-Making Supports. This is a great way to look at what level of support is needed in each life domain.

Each life domain has a number of questions to help you think through the number of things that may be important in your life. With each question you mark if this specific item is something that you can do with no extra support, you need some support with the decision or you need someone to make the decision for you. Keep in mind that everyone, no matter if you have a disability or not, needs some supports to make many of the decisions in their life.

Whether you are buying a house, creating a budget, maintaining a healthy diet, or choosing a new doctor we all use supports to help us make those decisions. Those supports can be friends, family, professionals, technology, the internet, smart phone apps and community programs. It is important when filling out this tool that the individual is involved in the discussion and is giving input as to where they think they need support.
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Don’t forget! It’s time for the 2020 U.S. Census
It’s important, and you count!

Information gathered through the census is important in determining state government representation. For example, the census counts the number of people in each state and that number is used to determine the number of seats a state gets in the U.S. House of Representatives. Indiana officials can also use the information to redraw the boundaries of your congressional and legislative districts.

Additionally, the census can affect you, your family and your community through the distribution of federal grants and support that each state receives. These grants provide funding for many state and local programs including Medicaid, TANF, SNAP, childcare assistance and public education.

The census also allows your local government to plan appropriately for public safety and emergency readiness. From May to July, census takers will begin visiting homes that haven’t responded to the 2020 Census to help make sure everyone is counted.

You can respond online, by phone or by mail. If you’re worried about your privacy, your privacy is protected, as it is against the law for the Census Bureau to publicly release your responses that could identify you or your household. Responses can only be used for statistics.

For more information about the census, visit this site. It’s important and you count!

NEWS YOU CAN USE

Resources to help develop a plan that works for you
COVID-19 guidance as Indiana enters the final stage of reopening

As Indiana enters the final stage of reopening, you may still be struggling to determine what is right for you and your family. COVID-19 is still present in our community and it remains important that we all take the proper precautions to keep ourselves, our families and our community healthy.

We all have unique circumstances that we have to consider as we figure out our own personal re-entry plan. Some of us are taking care of young children, some of us are taking care of children or loved ones who have underlying health conditions, some of us are taking care of our aging parents, some of us have an underlying health condition ourselves, and many of us are juggling a number of these types of circumstances that we have to consider. Following are some resources that may be helpful as you develop a plan that works for you:

Governor Holcomb’s Stage 4.5: What’s Open, What’s Closed provides guidelines for all Hoosiers as well as information on what is open with any recommendations or restrictions.

The Indiana State Department of Health Public Resources webpage provides links to several resources and information on topics such as testing information, public Wi-Fi sites in Indiana, health equity and COVID-19, long-term care resident information, childcare, schools, universities, and community organizations.

The Centers for Disease Control & Prevention has developed a number of resources specifically for individuals with disabilities, including those with developmental and behavioral disabilities.

COVID-19 guidance for DDRS Stakeholders contains information, updates and policy guidance on any of the DDRS programs and services you may be utilizing. This page also contains resource toolkits and webinars that are specifically for families and individuals with disabilities.
EVENTS YOU DON’T WANT TO MISS

Following are the current commission, councils 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.

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 SPIL’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. 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. For more information, visit the DDRS Commissions & Councils webpage.

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.