What is a concept paper?

A concept paper is a way for the state to share the changes it is considering for the waivers based upon what they have heard from individuals with disabilities, families, providers, case managers, and state staff. It may also summarize the concerns and barriers the changes are meant to address. A concept paper is shared long before anyone sits down to write a new waiver. It is a way of making sure that everyone has an opportunity to provide feedback on the major ideas and path forward.

This is an executive summary of the concept paper. It presents the highlights and main ideas in a condensed version. It can be used on its own or in conjunction with the full concept paper.
# About the Authors

This concept paper was primarily drafted by Alena Vazquez, Brittany Taylor, and Yoshi Kardell of Human Services Research Institute (HSRI). However, the ideas and options detailed within were developed via a collaborative process with a cross-organizational team comprised of national and local experts in HCBS and the Charting the LifeCourse Framework. Throughout this concept paper we refer to this group as the **Project Team**. Below we identify key team members and highlight their specific areas of expertise.

| ![HSRI] | John Agosta, Alena Vazquez, Yoshi Kardell, and Brittany Taylor have aided numerous states in systems redesign efforts specific to the waiver services offered to individuals with IDD. |
| ![UMKC] | Sheli Reynolds of UMKC Institute for Human Development is the primary developer of the Charting the LifeCourse. |
| ![Psi] | Derek Nord and Teresa Grossi of the Indiana Institute on Disability and Community work extensively in the arena of IDD in Indiana and have served as facilitators or evaluators in numerous DDRS projects. |
| ![NASDDDS] | Mary Sowers has offered extensive technical assistance to states on HCBS programs in her role with NASDDDS and served in senior leadership positions during her tenure at CMS. |
| ![Consortium] | Rebecca Wright has worked in the area of IDD policy development and implementation for more than 40 years and drafted the first 1915(j) ever approved. |
| ![Lawrence] | Kristy Lawrance has worked in Indiana public and private health and social services for 20 years providing support in FSSA in various capacities. |
| ![Burns & Associates, Inc.] | Stephen Pawlowski has led more than a dozen rate-setting projects for HCBS programs and aided many jurisdictions in drafting financial components of their waiver applications. |
| ![Grossman] | Gail Grossman, former assistant commissioner for quality management in Massachusetts has worked for over 40 years with a focus on quality management and improvement systems. |
Executive Summary

Introduction

The Indiana Family and Social Services Administration (FSSA), Division of Disability and Rehabilitative Services (DDRS) wants to transform the system of services and supports for individuals with intellectual and developmental disabilities (IDD) and their families. As part of this transformation, DDRS’ Bureau of Developmental Disabilities Services (BDDS) is working to redesign its Medicaid Home and Community-Based Services (HCBS) waivers. To assist with this effort, DDRS sought help from Human Services Research Institute (HSRI) and a team of project experts. The waiver redesign initiative began in the spring of 2019.

Since the spring, the project team worked closely with DDRS/BDDS to understand the current waiver system in Indiana as well as learn about the vision Indiana has for the future of their services. The team has also researched waivers and services used in other states and reviewed feedback that individuals with IDD, their families, service providers, case managers, and state staff that have shared in last few years. This initial concept paper shares the results of these activities and presents possible options for waiver redesign.

This concept paper offers an opportunity to share your thoughts and ideas on these possible options. Nothing presented as part of this concept paper should be seen as a final decision. DDRS is seeking feedback to ensure that changes will have a positive impact on individuals and families.

Key Questions

Throughout the paper, you will see boxes with key questions. The purpose of the key questions is to help you think about the type of things you may want to share in your feedback. You are not limited to these questions and are encouraged to share any and all of your thoughts.
DDRS Vision for Indiana

This waiver redesign effort is a part of a broader transformational change that has been underway at the DDRS. DDRS’ vision and mission statements, listed on the right, help to guide the change that is underway. DDRS primary goal is to create a system of services that supports individuals and families in achieving their vision of a good life.

DDRS goals/objectives

DDRS set out a series of goals for waiver redesign in their original request for outside expert assistance. Those goals were to:

- Increase person-centered planning
- Improve coordination of care
- Increase community engagement
- Enhance member experience
- Maintain qualified providers (and improve capacity)
- Comply with the HCBS rule
- Promote efficiency

A Vision for Redesign

This section describes the types of changes DDRS is considering and provides both broad ideas for possible changes and some specific options for stakeholders to think about. In this executive summary we will discuss possible changes to the current waivers, the possibility of adding a third waiver, ways to enhance current services, and potential new services.

Indiana currently has two Medicaid HCBS waivers for serving individuals with IDD—the Family Supports Waiver (FSW) and the Community Integration and Habilitation Waiver (CIH). The project team has identified two different options, or paths, for organizing the waivers as part of redesign which are presented below. These two paths are only exploring the number and structure of waivers that could be available. The proposed services that will be discussed in the next section can be available in either path.
Path 1

Path 1 would work similarly to the current structure. As part of Path 1, the Family Supports Waiver would be replaced with Waiver 1. On this new waiver, individuals would still have a capped budget but with a refreshed, expanded array of services that would best meet their individual goals and needs. The amount of the capped budget has not been identified at this time. It could remain the same or change.

The Community Integration and Habilitation Waiver would be replaced with Waiver 2. Under this new waiver, the total amount of support they receive would still be determined using the current method (called the Objective Based Allocation, or OBA) and entrance would still be determined by priority criteria. The priority criteria would be analyzed and could be revised based upon feedback received. Individuals on this waiver would also have access to a refreshed, expanded array of services.

If this path is pursued the need for more flexible support options would primarily be addressed through the new and expanded array of services.

Path 2

Path 2 would have the same two waivers as Path 1 but it would include the addition of a third waiver. The third waiver would address the gaps in supports that currently exist between the FSW and the CIH.

Under Path 2, the middle waiver (Waiver 2) would allow for additional supports with an increased annual budget and additional service options. While the annual budget amounts associated with each waiver would still need to be determined, it is expected
that Waiver 1 and Waiver 2 would have their own capped annual budget, with waiver 2 being higher than waiver 1.

In addition to exploring the capped annual budgets for these waivers, the criteria for entrance to each waiver would also need to be determined. It will be important to thoughtfully explore with all stakeholders, including individuals with disabilities and their families, how best to determine the entrance criteria for each waiver so that each person can receive supports that are appropriate and meaningful to them.

**Key Question**

- What waiver path option do you feel would work best in Indiana?

The waivers included in the DDRS waiver redesign will serve both children and adults. It is important to note that FSSA is exploring opportunities to develop an integrated and comprehensive service system for children and families. This is a FSSA wide initiative that is not a part of the current waiver redesign. DDRS will continue to work with FSSA leadership to assist in these efforts while also ensuring that children and families have the supports they need to live their vision of a good life through the current waiver redesign. See Appendix A in the full concept paper for more information.

**Case Management**

Case management and service coordination are critical functions in any service system. Case managers are often the primary point of contact for people with disabilities and their families. Often people with disabilities and families want a case manager who is “a partner in the process”—someone they can rely on to help them navigate a complex service system. The current role of case manager has many different aspects and responsibilities. Those include:

- Assisting individuals to identify their needs and connecting them to services and supports to meet those needs
- Guiding the process of person-centered service planning
- Monitoring health and safety
- Ensuring services are delivered according to the service plan
- Coordinating across an array of paid and unpaid supports
- Addressing complex needs and relationships
- Responding to urgent needs and crises
- Advocating for the people they support
**Self-Direction**

As part of this redesign effort, DDRS plans, for the first time, to begin adding options for self-direction. Self-direction gives individuals and families more control over who and how their services are delivered. Self-direction allows a person receiving services to have complete control over their budget and is responsible for locating, hiring, and replacing their support staff as well as being responsible for all aspects of being an employer. DDRS would like to work toward offering this type of option in the future and developing the infrastructure needed to build this type of program is not feasible on the timeline for waiver redesign. Therefore, the project team has identified two possible options that can be added now that would have elements of self-direction to give individuals and families more control and flexibility. These options are called Participant-Directed Goods and Services and Agency with Choice.

Participant-Directed Goods and Services would allow participants to get services and items that meet their need due to their disability but is not typically covered by Medicaid. Examples of goods would be items you can buy such as special equipment, passes to an event, or products. Examples of services could be gym memberships or house cleaning. The goods and services purchased through this service would assist individuals in maintaining or increasing their independence and be connected to a goal or an identified need recorded in their Person-Centered Individualized Support Plan (PCISP).

Agency with Choice is a model where individuals have greater control over their services by becoming a co-employer with their provider. Individuals and families would have the ability to choose their staff, direct their staff’s day-to-day activities, and train the staff on their own unique support needs. The provider agency would be responsible for the paperwork side of things, including completing background checks, offering standard training, and managing all aspects of paying the employee. This has the benefit of allowing the participant to direct the care they receive without the workload associated with being a solo employer.

**Key Questions**

- Would the addition of a Participant-Directed Goods and Services service and Agency of Choice help individuals to have more choice and control in getting their needs met?
Service Changes

A number of the changes that individuals and families would like to see with the waivers relate to the services available. When considering potential service changes the project team identified four ways to enhance service options.

1. Clarify service names

For the current services that stakeholders felt were working well or that would only need minor changes the project team identified ways to make the service names and definitions more clear. This will make it easier for individuals and families to identify which services best meet their needs. For example, Extended Service offers ongoing job-coaching to individuals who need help at their place of work after supports from Vocational Rehabilitation have ended, or when they have found a job through other means. This service could be called Supported Employment to better describe what the service entails.

2. Group or simplify services

The project team looked to see if there were similar services that could be grouped together as a way to simplify the service offerings. To do this, we considered people’s experiences when selecting services. For example, when being asked to choose from “Residential Habilitation and Support” and “Residential Habilitation and Support Daily” how does an individual know which to pick? Combining these services into “Residential Habilitation and Support” would reduce confusion and simplify the services to choose from. It would also allow individual and family to work with their case manager to identify which billing and payment structure is best for them.

3. Change or remove services

Based on stakeholder feedback the project team identified services that need more significant changes. For example, Family and Caregiver Training has been a service that is underutilized and often misunderstood. First, the project team suggests renaming this service to Family/Caregiver Supports. In addition to enhancing the opportunities for training that this service provides the project team proposes adding a peer support and peer training element that would provide opportunities for families to connect to other families.

Another example would be to make significant changes to the Structured Family Caregiving service. Some of these changes would include: Changing the name of the service from Structured Family Caregiving to Shared Living to better reflect the spirit and goal of the service; requiring a robust matching process for individuals and families prior to placement to make sure personalities and lifestyles are a good fit together; and limiting Shared Living settings to no more than two individuals, unless for the benefit of the individuals.
Finally, the project team explored services that could be added to meet the needs of individuals and families and provide supports that are holistic, comprehensive, and individualized. New services under consideration include:

**Housing Support Services.** The goal of this service is to assist individuals with IDD find good and affordable housing, and to keep that housing once they have it. To accomplish this, DDRS could partner with agencies and community organizations with specific housing expertise to expand the system of support and opportunities for people with IDD.

**Healthy Living Services.** This service could contain many different options which provide flexible opportunities to obtain support that promotes physical and emotional health and wellness. Within this service someone could receive nutrition education, bereavement counseling (counseling for when a loved one has died), education on safe and healthy relationships, or other services that promote overall health and wellbeing.

**Expressive Therapy Services.** This service would contain many different creative therapy service components like therapeutic riding, art therapy, music therapy, drama therapy, dance and aquatic therapy.

**Peer Support and Community Connection.** This service would help find opportunities for individuals to get out into the community and form relationships with people who are not paid to support them. This service would help participants build new skills and support their full participation in community life. For example, as part of this service a peer connector could help an individual who loves researching their family history find a group for people who are interested in genealogy. They could help them figure out when the group meets and how to get there, and attend the group with them a few times to get acquainted.

**Key Questions**

- Do you think these suggested changes could help meet some of the needs in your life that aren’t currently being met?
- Which of these new services described as potential changes are most important to you? Do you have suggestions of other services that should be considered?
- Could any of these changes make it more difficult for you to find or use services?
Quality Measures

All of the changes being considered as part of this waiver redesign are aimed at improving the quality of services and supports. Recently changes were made to the current performance measures as part of two waiver renewals. The new performance measures now include:

- The percentage of sampled individuals who report that their services and supports are helping them to live a good life.
- The percentage of sampled participants who responded that their case manager asks what they want as part of their service plan
- The percentage of waiver participants who do not feel afraid or scared in their home or day program

DDRS is working to change the way it measures the quality of services and plans to add person-focused quality measures—both as part of the waiver redesign project and more broadly. We would like to hear quality measures you could suggest. We have provided some examples of measures of quality of services and supports:

- Number of individuals who feel connected to their communities
- Number of individuals who have valued social roles
- Number of individuals who chose where they live and work
- Number of individuals who have friendships with people other than paid caregivers
- Number of individuals who are actively involved in self-advocacy groups
- Number of individuals who have access to the same resources in the community as individuals without a disability

Getting consistent and trustworthy information on the quality of life of individuals is a long-term process. DDRS is committed to this process. Changes to the waivers are the very first step in that process.

Key Questions

- What kinds of quality measures can DDRS use to make sure Hoosiers are living a good life?
- To better monitor safety, DDRS may need to seek information from individuals who use HCBS waivers more frequently. How often should this occur?
- Would you be comfortable sharing your thoughts directly with DDRS so that it could get the kinds of information it might need to answer some of its quality indicators and performance measures? If so, who would you like to ask you those questions (a case manager, your staff, a DDRS staff, someone else?)
Other Improvement Efforts

Individuals with disabilities, their families, providers, case managers, and others have expressed a desire for changes that cannot be made through waiver redesign. DDRS is committed to assisting in transforming other areas of Indiana’s systems to support individuals and families in living their best life. For more information on these other improvement efforts visit section 2.4 of the full concept paper.

The Path Forward

DDRS is seeking public input on the options presented in this concept paper. There will be several ways to stay informed about progress and offer feedback. You can choose the one that works best for you.

- **Public communication channels:** DDRS will provide information about waiver redesign through the DDRS website, DDRS Announcements, INvision newsletter, and BDDS Facebook page.
  - All information on the waiver redesign can be found at [https://www.in.gov/fssa/ddrs/5733.htm](https://www.in.gov/fssa/ddrs/5733.htm)
  - To sign up for DDRS announcements, the INvision Newsletter and to follow the BDDS Facebook page visit [http://www.in.gov/fssa/ddrs/2639.htm](http://www.in.gov/fssa/ddrs/2639.htm)

- **Public meetings:** Updates will be provided at the DDRS Advisory Council and 1102 Taskforce meetings. For information on the DDRS Advisory council visit [https://www.in.gov/fssa/ddrs/3355.htm](https://www.in.gov/fssa/ddrs/3355.htm) For information on the 1102 Task Force visit [https://www.in.gov/fssa/ddrs/5455.htm](https://www.in.gov/fssa/ddrs/5455.htm)

- **Stakeholder and advocacy group meetings:**
  - DDRS and the project team will meet with key partners such as the Arc of Indiana, Indiana Governor’s Council for People with Disabilities, Self-Advocates of Indiana, and Indiana Association of Rehabilitation Facilities. These meetings will allow these groups to share their thoughts and include what they have heard from the individuals, families, and other interested parties they work with.
  - The Indiana Institute on Disability and Community at Indiana University, in collaboration with Self-Advocates of Indiana, will host a series of six public meetings around the state to give self-advocates a chance to learn about what is proposed in the concept paper and provide feedback from their point of view. Information on the time and location of these meetings will be shared once they are scheduled.
  - The Bureau of Developmental Disabilities Services (BDDS) is hosting additional Building Bridges meeting throughout the state as an avenue
for families and individuals with disabilities to learn more about the waiver redesign project, the initial concept, and share their feedback.

- At the request of any group impacted the waiver redesign project, DDRS will meet with them directly and/or provide materials for groups that wish to meet on their own. These materials will help groups to think about the possible waiver changes so they can submit their own feedback.

- **Electronic survey.** You are also welcome to share your thoughts through our web survey. The key questions that were highlighted throughout this paper are included in the survey, but answering those questions is optional. The survey also includes a blank area where you can provide any feedback you would like. To access the survey please visit:
  
  [https://iu.co1.qualtrics.com/jfe/form/SV_6qXBDMKLzCxZDYq](https://iu.co1.qualtrics.com/jfe/form/SV_6qXBDMKLzCxZDYq)

To access the survey available in Spanish visit:

[https://iu.co1.qualtrics.com/jfe/form/SV_3yLAqmr2NaO8QZ](https://iu.co1.qualtrics.com/jfe/form/SV_3yLAqmr2NaO8QZ)

Following are the next steps in the waiver redesign project. These dates are approximate and are subject to change.

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<tr>
<th>Milestone</th>
<th>Dates</th>
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<tr>
<td>Initial concept paper released</td>
<td>January 2020</td>
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<tr>
<td>Public input period on initial concept paper</td>
<td>January 2020 – April 2020</td>
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<tr>
<td>Concept paper expanded</td>
<td>April 2020 – June 2020</td>
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<tr>
<td>Final concept paper released</td>
<td>June 2020</td>
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<tr>
<td>Public input period on final concept paper</td>
<td>June 2020 – July 2020</td>
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As Indiana moves to transform the system of supports for people with IDD and their families, we must work together to achieve the results we wish to see. The time is now for Indiana to build a system that can support people with disabilities in living their best life.