Comprehensive State Plan on Community-Based Services for Persons with Intellectual and Developmental Disabilities (IDD)

A Report to the
Indiana General Assembly

October 2018

Comprehensive State Plan on Community-Based Services for Persons with Intellectual and Developmental Disabilities (IDD): A Report to the Indiana General Assembly

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Written on Behalf of the Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities

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Oct 17, 2018

Indiana Legislative Council
State House
200 West Washington Street.
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Re: House Enrolled Act No. 1102

Dear Legislators:

Hoosiers with intellectual and developmental disabilities (IDD) and their families are vital members of our Indiana community. During my time in the legislature and now in my role as Lieutenant Governor, I have focused on taking all Hoosiers to the next level. All Hoosiers deserve the same opportunities, regardless of background, economic status, or physical and intellectual challenges. There are approximately 100,000 Hoosiers who have an intellectual or developmental disability. These individuals aspire to live and work in a safe, affordable and accessible environment, just like everyone else. While Indiana has taken bold steps in the past, we must remain vigilant in always striving to do better.

Over the last year, I had the honor to chair the Task Force for Assessment of Services and Supports for People with Intellectual and Other Developmental Disabilities, commissioned in 2017 by the Indiana General Assembly in House Enrolled Act 1102. This Task Force, comprised of 17 members including self-advocates with intellectual and developmental disabilities, family members, advocacy organizations, service providers, and state government agencies, met a total of ten times in every corner the state.

Stakeholder input was critical to informing the work of the Task Force. Hundreds of stakeholders, including more than 100 who self-identified as individuals with disabilities; 60 family members of individuals with disabilities; and numerous staff from 26 organizations that provide services to individuals with disabilities, provided comment to the Task Force.

Our goal was to assess our current service and support system and identify ways to improve what we were doing but to also create a system that provided more opportunities for people with disabilities to live independently with access to jobs and their local communities. As part of the assessment, representatives from various state agencies and other stakeholder groups presented data on the number of individuals receiving various services in Indiana, the availability of current services, unmet needs, and services we should consider. In response, Task Force members drafted numerous concept white papers and recommendations regarding modifications to existing services and the addition of prospective services. After countless hours of deliberation, the Task Force developed a vision statement, four overarching goals, and 34 associated recommendations that comprise a comprehensive plan of implementation of community based services provided to people with intellectual and other developmental disabilities.

It is my great pleasure to share with the Indiana General Assembly the Task Force's final report. This plan, with its goals and recommendations, provides information about existing services, identifies gaps in services, and proposes services that will help make people with disabilities more independent. I, along with the members of the Task Force, urge you to implement this plan over the next few years to not only improve services and supports for people with intellectual and developmental disabilities, but to promote greater community opportunities for Hoosiers with IDD.

Sincerely,

Suzanne Crouch
Lieutenant Governor, State of Indiana

Executive Summary

The last state-wide plan in 1998, to modernize community services for people with intellectual and developmental disabilities (IDD), provided a framework for robust systems change, major policy changes, and expansion of best practices. Recognizing the need to develop a more up-to-date strategy to advance community living for people with IDD, the Indiana General Assembly passed House Enrolled Act 1102 in 2017 to create the Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities. This diverse group of stakeholders met 10 times over a 12 month period and was charged to analyze existing community-based services data and develop a comprehensive plan of implementation of community-based services provided to people with IDD.

The result, this report, is a strategic framework for the ongoing evolution of services and supports for persons with IDD. Informed by individuals with IDD, family members, advocacy groups, government agencies, a variety of support providers, and the broader community, this framework is a policy planning tool that provides a values-based vision and path to improve services and supports. The framework is also a tool that Hoosiers can use to hold each other accountable as systems of support evolve.

Findings of Task Force

The Task Force relied on existing and available data to understand the existing community-based services. These data provided a broad picture of the costs, utilization, and services of the existing programs available to people with IDD. Some programmatic data was unavailable and/or more robust analysis was not possible. A summary of the analysis follows.

Medicaid services and supports. In state fiscal year (SFY) 2017, a total of $1.12 billion (66.74% federal and 33.26% state obligation) was spent on Medicaid services, across Home and Community-Based Service (HCBS), State Plan services, and Intermediate Care Facilities for persons with IDD (ICF/IDD, also known as group homes). In total, in SFY 2017, 26,346 people were supported through HCBS Medicaid waivers or ICF/IDDs: 14,261 on the Family Supports Waiver (FSW); 8,963 on the Community Integration and Habilitation (CIH) waiver; and, 3,122 in ICF/IDDs. At present, 1,381 people from across the state are on a waitlist to receive services by way of the FSW. There is no waitlist for the CIH waiver, however, access is limited to those experiencing specific family or emergency situations.

Other Programs that Support Community Living. A number of other programs exist in Indiana that assist people with IDD to live in the community. Data was unavailable at the time of this report regarding the utilization of these services among this population and the costs of these services as it related to people with IDD. Specific programs include: *Aged & Disabled Waiver* – a Medicaid HCBS waiver program designed to provide services to supplement informal supports for people who are aged, blind or have a disability that require nursing facility level of care; *Money Follows the Person (MFP)* – funded through a federal grant, the MFP program assists to move people from institutional settings to home and community-based settings and seeks to prevent future placement in an institutional setting; and, *Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE)* – a program that provides home and community-based services to assist individuals in maintaining their independence in their own homes or communities for as long as is safely possible.

Early Intervention & Education. In SFY 2017, First Steps, Indiana's early intervention program for children birth to three years of age, served 26,426 individuals at the cost of $40.7 million. The most utilized services included speech therapy, occupational therapy, physical therapy, and developmental therapy. Total costs of services ranged from $12.5 million for speech therapy to $9,798 for social work services.

The Indiana Department of Education is responsible for preschool, and primary and secondary education for the state. A total of 13,066 preschool students (with and without IDD) and 128,961 primary and secondary students with mild, moderate, or severe disabilities (with and without IDD) are educated in the state. Funding amounts across these areas that predominately affect students with IDD total approximately $569 million. On a per student basis, these educational costs range from $8,976 for students with severe disabilities to $2,300 for students who have mild or moderate disabilities.

Employment. Vocational Rehabilitation Services (VR) play a large role in supporting people with IDD to obtain and retain competitive integrated employment. In addition, VRS provides pre-employment transition services to youth and young adults transitioning from school to adult life. In federal fiscal year 2017, VR had a total budget of $76.5 million, made up of 78.7% federal share and 21.3% state share. During this time VR served a total of 10,058 people, across all disability groups. Of this group, 33% had a primary impairment of IDD. VR currently has a waiting list for services. Between August 1, 2017 and May 31, 2018, a total of 1,459 people were on this waiting list. Of this group, 5% had a primary impairment of IDD.

Goals and Recommendations of the Task Force

The 34 recommendations responded to public comments from over 200 stakeholders that included people with IDD, family members, and professionals. They are structured around four overarching goals. These goals include:

Goal 1: Prioritize community settings and individualized approaches.
Goal 2: Advance and maximize community and state resources and programs to be inclusive to all Hoosiers.
Goal 3: Respond to individual and family needs.
Goal 4: Include a wide array of supports and services that are sustainable, equitable, and available across all communities.

Additionally, the goals and recommendations are not listed in priority; and, it was the view of the Task Force that achieving these goals in a comprehensive fashion would require the implementation of all of these recommendations. The goals and recommendations can be reviewed below.

Goal 1: Prioritize community settings and individualized approaches.

The Task Force recommends:

1.1 The Division of Disability and Rehabilitative Services develop a Medicaid HCBS waiver system with a full array of services and tiered supports to ensure flexibility of services and systems to meet the unique needs of all individuals served, accounting for age, family and community support systems, behavioral and mental health needs, and health factors.

1.2 An appropriation, to be known as the 1102 IDD Task Force Community Living Expansion Initiative, to fund Medicaid HCBS waiver slots for non-emergency priority placement using criteria developed by the Division of Disability and Rehabilitative Services to allow some level of expansion of individuals seeking to live in the community, away from their family, while creating the opportunity for families to support individuals in making this transition to living away from their family.

1.3 Modifying current legislation dictating waiver placement priority to current Medicaid HCBS waivers.

1.4 The Division of Disability and Rehabilitative Services convene a group of diverse stakeholders to assist with waiver redesign.

1.5 Increasing funding for Vocational Rehabilitation Services to ensure the program can address the fiscal deficit, increase Vocational Rehabilitation Services staffing resources, ensure appropriate reimbursement rates for providers to cover costs and recruit and retain staff, and allow expansion and innovation of Pre-Employment Transition Services.

1.6 It is important that Indiana create an economy and workforce where youth and adults with disabilities, including individuals with significant disabilities, have real opportunities to become competitively employed, use their talents and skills, work alongside other Hoosiers, and earn meaningful, competitive wages, consistent with a person's right to make an informed choice about employment options that meet their needs and preferences. The 1102 Task Force supports the efforts of the Indiana Rehabilitation Commission and DDRS to implement Employment First in Indiana and encourages their efforts to develop policies, practices, and service delivery models to facilitate increased competitive employment options as the first and preferred outcome of services for people with disabilities.

1.7 The development and promotion of public and private sector partnerships that support youth acquiring work experiences, skills, and access to resources and programs that lead to a successful transition from school to competitive employment or additional education. Strong transition partnerships should be considered as part of any new Medicaid HCBS waiver design and services offered.

1.8 Developing, expanding, and promoting housing options, especially permanent support housing, for all people with disabilities that allows for informed choice for them to attain affordable, accessible, and integrated housing in communities they choose to live in (rural or metropolitan). As options are being developed, the Task Force encourages the modernization of housing development projects to reflect current technology and the modernization of existing housing resources and programs at both the federal and state levels, addressing the need to continue to use shared service support.

1.9 The Division of Disability and Rehabilitative Services develop and adopt a Shared Living[9] model, as a residential service option, which resembles the most successful Shared Living programs in the United States such as Colorado and Pennsylvania. The current Structured Family Care Giving model used by Indiana does not provide the proper reimbursement methodology to provide the robust supports needed and displayed in the most successful models around the country. Therefore, the Task Force also recommends the Shared Living program use the same algorithm level structure as other Medicaid HCBS waivers versus the current tiered structure of Indiana's current Structured Family Care Giver program. It is also the recommendation of the Task Force that the Shared Living program ensure participants have access to the same services available to people who utilize current residential services such as day services, music therapy, and Wellness Coordination, in addition to the daily rate funding needed for the Shared Living program itself.

1.10 Given the historic trend of reduced use of settings with institutional funding, Indiana review those settings (i.e., ICF/IDDs, nursing facilities, and state operated facilities) with a focus to modernize the system and potentially reduce the number of institutional settings for individuals with IDD. The review will include a group of stakeholders including self-advocates, advocacy organizations, state regulatory agencies, provider organizations and representatives of the 1102 Task Force.

No later than December 31, 2020, the stakeholder group will develop a plan to:

1. Assess the needs of individuals in the system and the needs of individuals not currently in the system;

2. Determine the needs and desires of those individuals currently living in settings with institutional funding and how to transition them out of those settings if appropriate and their desire;

3. Assist providers who choose to voluntarily convert their ICF/IDDs into HCBS settings;

4. Determine the number of settings and type of settings with focus on eliminating unnecessary settings; Based on the above determination, identify the service needs of individuals served in settings with institutional funding and how the Indiana model can improve quality outcomes for those served; and,

5. Ensuring that all living settings are provided with informed choice at every level inclusive of person-centered thinking and principles including living situations, housemates, and types of services.

Goal #2: Advance and maximize community and state resources and programs to be inclusive to all Hoosiers.

The Task Force recommends:

2.1 The Division of Disability and rehabilitative Services and the Indiana Housing and Community Development Authority coordinate and collaborate on improving Indiana 211 for disability-specific information and referrals to ensure information system are accessible, reliable and responsive to the needs of individuals and families when seeking such information. These efforts should be made to improve access and consistency of information for individuals and families regarding disability services and resources across the state.

2.2 The representative of a provider of Vocational Rehabilitation Services for people with disabilities and, a representative of the Bureau of Rehabilitation Services to the Governor's Workforce Cabinet.

2.3 People with IDD, or their interests, are included in the state's initiatives related to the development and use of driverless vehicle technology in Indiana, to ensure it advances freedom and connectivity to community for people with disabilities.

2.4 Developing transportation strategies promoting independence and employment through collaborative efforts of key stakeholders and public-private partnerships across rural and urban areas. This may include addressing multijurisdictional issues; encouraging more funding for public transportation models; working with state and local transportation boards to ensure representation of individuals with disabilities; improving existing infrastructure to be fully accessible; facilitating the use of private ride sharing systems; and encouraging the development of innovative options such as driverless vehicles.

2.5 Maximizing the incorporation of technology in the delivery of services to people with disabilities to increase individuals' access to community services, natural supports, and assist in addressing the direct support professional workforce shortage.

2.6 In collaboration with stakeholders, Indiana shall explore, expand, and promote workforce initiatives to help employers in hiring individuals with disabilities to create an inclusive workforce, which may include access to tax incentives, recruitment and retention strategies, training resources, etc.

Goal #3: Respond to individual and family needs.

The Task Force recommends:

3.1 Since investing in early childhood development is more effective and less costly than addressing problems at a later age and due to increased referrals for early intervention services, the First Steps program receive enhanced funding in order to sustain a high quality early intervention program for the children and families it serves.

3.2 The creation of a services and support system that supports and promotes self-advocacy, independence, and informed choice which leads to a good life.

3.3 The design and implementation of a self-directed care model in Medicaid HCBS waivers administered by the Division of Disability and Rehabilitative Services for individuals to convert their shift model to a version that allows them to hire people they choose via a fiscal intermediary.

3.4 That adults who participate in Medicaid HCBS waiver services be allowed, through informed choice, to receive direct services and supports from one or more family members to meet their assessed needs; and that no individual family member be allowed to provide more than 40 hours of support, within a seven day period.

3.5 The establishment of a statewide IDD crisis response program utilizing all available federal funding (i.e., Medicaid HCBS waiver, etc.) and, as needed/required, State funding with the following crisis best practice components:

1. *24 hour telephone Response/Hotline*;
2. *In-Home Service*;
3. *Temporary Out-of-Home Placement resources for stabilization purposes*;
4. *Telemedicine capacity and coverage*;
5. *Reduction of risk/stabilization*;
6. *Prevention strategy to anticipate/eliminate re-occurrence*;
7. *Program staff/personnel and contractors should include*:

- Psychiatrist
- Behavior Clinicians or BCBAs
- Psychologist
- Direct Support Professionals for temporary staff support
- Registered Nurse consultation

3.6 Encouraging the support of our active duty and veteran military members in Indiana in obtaining services for their children with IDD; and, pending CMS approval, creating a priority status on the Medicaid HCBS waivers for children of active duty and veteran military families.

3.7 The Division of Disability and Rehabilitative Services encourage the use of emerging technology in Medicaid HCBS waiver service delivery.

3.8 Telehealth be approved as a viable and approved service delivery method for services, for example Behavior Management and Wellness Care.

3.9 The inclusion of peer specialists as a Medicaid HCBS waiver service, enabling experienced, trained people with IDD to support their fellow Hoosiers with disabilities.

3.10 Indiana to encourage efforts to increase the use of supported decision-making and other alternatives to guardianship.

Goal #4: Include a wide array of supports and services that are sustainable, equitable, and available across all communities.

The Task Force recommends:

4.1 The First Steps program invest in its workforce to keep pace with demand by increasing the number of service coordinators and providers, and paying service coordinators at a rate that is competitive and supports effective recruitment and retention. This action will also assist in broadening the network of specific services needed in the early intervention system to appropriately serve families and children.

4.2 The creation of an array of living settings that support people with disabilities living in a setting of their informed choice that allows them to enjoy their interests, hobbies, and preferred lifestyle.

4.3 The creation of an array of employment options that leads to a good life with independence and respect for people with intellectual and developmental disabilities and ensures informed choice. The array of options should provide opportunities for people with all abilities to work that provides for growth, respect, preferences, and interests. In developing this array of options, a stakeholders group, led by Self-Advocates of Indiana, must come together to discuss the use of 14c certificates (sub-minimum wage) in Indiana in 2019 and develop strategies to assist provider agencies to transition away from utilizing 14c certificates.

4.4 Developing a plan to enable the Bureau of Rehabilitation Services to serve all Order of Selection priority categories by 2021, or as soon as possible, which would rely upon increased fiscal and staff resources.

4.5 Increasing, as soon as possible, the current state-wide average wage of direct support professionals to a level competitive with other service sector and healthcare jobs using current Bureau of Labor Statistics salary data through funding an increase in base compensation coupled with potential additional compensation tied to completion of a state authorized/approved training that significantly enhances the direct support professional's skills.

4.6 The development of a state approved outcome and competency-based training curriculum for direct support professionals. The purpose of the state-wide training is to ensure consistency of quality training, reduce training replication for providers, and to further professionalize the direct support professional workforce; and, the development of a state-wide registry of professionals who have undergone this training and curriculum.

4.7 The implementation of a public registry listing direct care staff who the Division of Disability and Rehabilitative Services has determined have committed certain offenses that bar them from employment supporting people with developmental disabilities in the state of Indiana.

4.8 Appropriations for DDRS and other state agencies sufficient to develop, plan and implement Task Force recommendations in keeping with timelines specified in this report or, in the absence of a specified timeline, at the earliest date possible.

Conclusion

Indiana has a strong history and commitment to community based services and supports for Hoosiers with IDD, across the lifespan. Indiana is also fortunate to have robust public systems of support that span education, human services, and employment that rely on a dedicated network of service and support providers around the state. These systems provide critical services, across the lifespan, to thousands of individuals and families. The future community-based services and supports for people with IDD will require the skills and growing capacity of this infrastructure. It will also include the full participation and involvement of the broader community. By adopting the Task Force's goals and recommendations, Indiana will provide greater opportunity and community inclusion for people with IDD, through improved, accessible, and sustainable community-based services and supports that meet the needs of individuals and families.

Introduction

Indiana has a lengthy history of providing critical assistance to many people with intellectual and developmental disabilities (IDD) and their families. As a result, today Hoosiers have access to a web of services and supports across the lifespan to facilitate healthy development, equitable education, competative employment, and community integration and inclusion.

The available services and supports in Indiana exist in a complex system that crosses numerous state agencies and funding sources that are regularly undergoing policy and programmatic change. The last time the state of Indiana developed a state-wide plan to guide such systems change was in 1998 with the release of the Comprehensive Plan for the Design of Services for People with Developmental Disabilities, also known as the 317 Plan. This plan acted as Indiana's de-institutionalization framework, while laying a vision for a system of community-based services and supports for people with IDD. Since the release of the 317 Plan, there have been major judicial and federal policy developments, including but not limited to:

- ***Olmstead v. L.C. Supreme Court decision (1999)***: Prohibits, per Title II of the Americans with Disabilities Act, the unjustified segregation of people with disabilities. Public entities must "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[1] "The most integrated setting enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible…"[2]

- ***Ticket to Work and Work Incentives Improvement Act (1999)***: Provides greater access to health care for workers with disabilities, enhances work incentive programs, and funds work incentive planning assistance programs.

- ***Individuals with Disabilities Education Act (IDEA) (reauthorized 2004, amended 2015)***: Makes free and appropriate public education available to children with disabilities, and ensures special education and related services to children from birth through 21.[3]

- ***Workforce Innovation and Opportunity Act (2014)***: Brings together education and public workforce systems to assist Americans, including youth and adults with significant disabilities, in obtaining quality jobs and businesses to retain skilled workers.[4]

In addition, in 2014 the Centers for Medicare and Medicaid Services, a major funder of community based services and support for people with IDD, released the regulations to better define the settings in which states can provide Medicaid Home and Community-Based Services (HCBS). The regulations are meant to ensure people with disabilities using Medicaid HCBS services and supports are able to receive them in an integrated fashion and that they support full access to the greater community.

1. 28 C.F.R. § 35.130(d) (the "integration mandate").
2. 28 C.F.R. Pt.0 (addressing § 35.130).
3. Author (2018). About IDEA. Retrieved from https://sites.ed.gov/idea/about-idea/.
4. Author (2018). Workforce Innovation and Opportunity Act (WIOA) final rules. Retrieved from https://www2.ed.gov/about/offices/list/osers/rsa/wioa-final-rules.html.

"This includes opportunities to seek employment and work in competitive and integrated settings, engage in community life, control personal resources and receive services in the community to the same degree as individuals who do not receive HCBS. CMS expects all states to review current HCBS programs and to develop a transition plan providing an assessment, strategies and timelines for compliance with the new rules."[5]

Overview

The purpose of the Comprehensive State Plan is to layout clear values and direction that will guide the future of the community-based services for persons with IDD by reimagining what public systems of support can and should embrace. Kicking off the first meeting of the 1102 Task Force, Representative Edward Clere (R - New Albany), a lead sponsor of House Enrolled Act 1102, reflected on the purpose of this plan and the role of the Task Force by stating:

> ***"This process has the potential to make incremental changes to the system that we have but I hope that's not what we end up with. I hope that folks around this table won't be satisfied with incremental improvement or modest change. You have been given the opportunity… to reinvent and reimagine the entire system."***

As such, this report serves as a strategic framework for the ongoing evolution of services and supports for persons with IDD. Informed by self-advocates, family members, government agencies, a variety of support providers, and the broader community, this framework is a policy planning tool that provides a values-based vision and path to improve services and supports. The framework is also a tool that Hoosiers can use to hold each other accountable as systems of support evolve.

1102 Task Force

The Task Force for Assessment of Services and Supports for People with Intellectual and Developmental Disabilities, also known as the 1102 Task Force, was established by HEA 1102 in the 2017 session of the Indiana General Assembly. The Task Force makeup was statutorily defined and members included a diverse group of stakeholders. Members included self-advocates, family members, advocacy groups, support providers, and state agency representatives. Lieutenant Governor Suzanne Crouch chaired the Task Force, as the Governor's designee. The full Task Force membership roster can be seen in Table 1.

The Task Force met a total of 10 times, from November 2017 to October 2018. Meetings were open to the public and livestreamed for access across the state. Public comment period was provided during each meeting, as well as through written communications in-between meetings.

5. Author (2018). Workforce Innovation and Opportunity Act (WIOA) final rules. Retrieved from https://www2.ed.gov/about/offices/list/osers/rsa/wioa-final-rules.html.

Table 1: Task Force Members	
Name:	**Organization**:
Suzanne Crouch (Chair)	Lt. Governor of Indiana
Jonathan Burlison	Bridges of Indiana, Indianapolis
Steve Cook	Indiana Association of Rehabilitation Facilities
Christine Dahlberg	Governor's Council for People with Disabilities
Kim Dodson	The Arc of Indiana
Trent Fox	Indiana State Department of Health
Shawn Fulton	Self-Advocates of Indiana
Dr. Nancy Holsapple	Indiana State Department of Education
Kylee Hope	Division of Disability and Rehabilitative Services, Family and Social Services Administration
Joe Langerak	Family member, Jackson Kelly PLLC, Evansville
Kathleen McAllen	Family member, Indianapolis
Jason Meyer	Passages, Inc., Columbia City
Kim Milas	Self-Advocates of Indiana
Kevin Moore	Division of Mental Health and Addiction, Family and Social Services Administration
Debbie Pierson	Division on Aging, Family and Social Services Administration
David Reed	Indiana Department of Child Services
Julie Reynolds	Division of Disability and Rehabilitative Services, Family and Social Services Administration
Allison Taylor	Office of Medicaid Policy and Planning, Family and Social Services Administration
Betty Williams	The Arc of Indiana, Self-advocate
Dr. Pam Wright	Indiana Department of Education

A number of concept white papers were developed and presented by Task Force members to frame discussions and inform recommendations. Visit https://www.in.gov/fssa/ddrs/5455.htm for more details on the concept white papers. Meetings also included topical presentations to Task Force members and time for discussion.

Indiana Data

Medicaid Services and Supports

Many people with IDD require assistance that extend over their entire lifetime. The state's Medicaid program provides many of these long-term services and supports to assist across a number of life domains, including daily living, day programs and employment, residential, and health and safety. During state fiscal year (SFY) 2016, Medicaid long-term services and supports for people with IDD cost a total of $1.12 billion. Of these dollars, 24% fund intermediate care facilities for persons with intellectual disabilities, an institutional-based setting. A total of 76% of these expenditures paid for Medicaid HCBS. Specifically, 15% paid for Medicaid State Plan services and 61% funded the Medicaid waiver services. A large percent of the Medicaid State Plan and HCBS waiver costs are paid by way of a federal match. In the most recent SFY, the state was responsible for 33.26% of the total expenditures, compared to the 66.74% federal responsibility.

Medicaid waiver costs and utilization. In SFY 2017, Division of Disability and Rehabilitative Services (DDRS) supported over 26,000 individuals with IDD. Of this total, 23,224 were supported through Home and Community Based Services Medicaid Waivers (14,261 on the Family Supports Waiver and 8,963 on the Community Integration and Habilitation Waiver). There were 3,122 individuals residing and receiving support in group homes, also known as Intermediate Care Facilities for persons with IDD (ICF/IDD). In addition, these individuals receive health care and other services through the Medicaid system.

In SFY 2016 a total of $1.12 billion in Medicaid dollars was spent on the 26,000 individuals served through DDRS programs. These services are funded partially with federal funds (66.74%) and partially with state funds (33.26%). Figure 1 provides a breakdown of these expenditures, ranging from $104,521,550 for the Family Support Waiver (FSW) to $586,424,243 for the Community Integration and Habilitation (CIH) Waiver program. Of the total amount spent on these services in SFY 2016, 52% were for CIH Waiver, 24% for ICF/IDD, 15% for FSW, and 9% for Medicaid State Plan services.

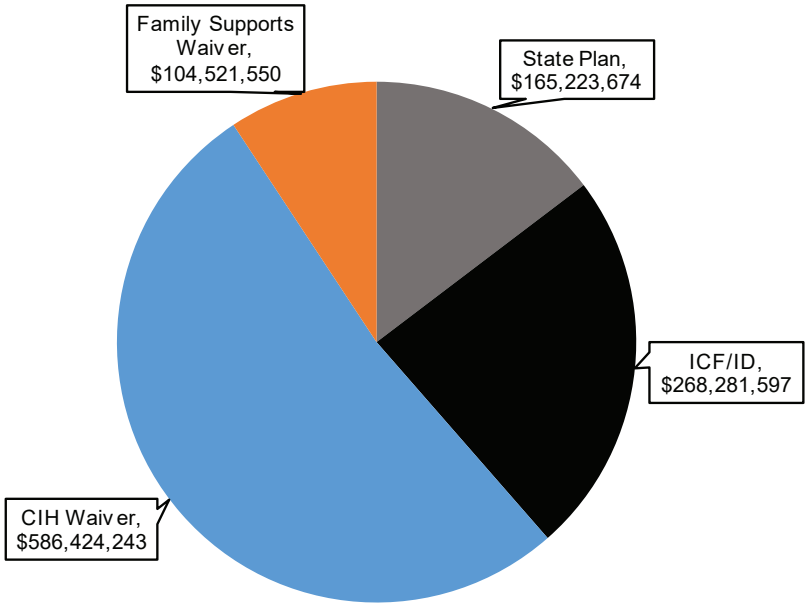

Figure 1. Medicaid Expenditure by Program – SFY 2016.
Source: Medicaid Claims Data

SFY13 to SFY17. As can be seen in Figure 2, over this time period there was an increase of 9,200 waiver recipients. These increases were primarily due to growth of the FSW, from 6,111 in SFY13 to 14,261 in SFY17. More modest growth was realized with the CIH waiver program, where 1,050 new service users were added to the rolls over this time period.

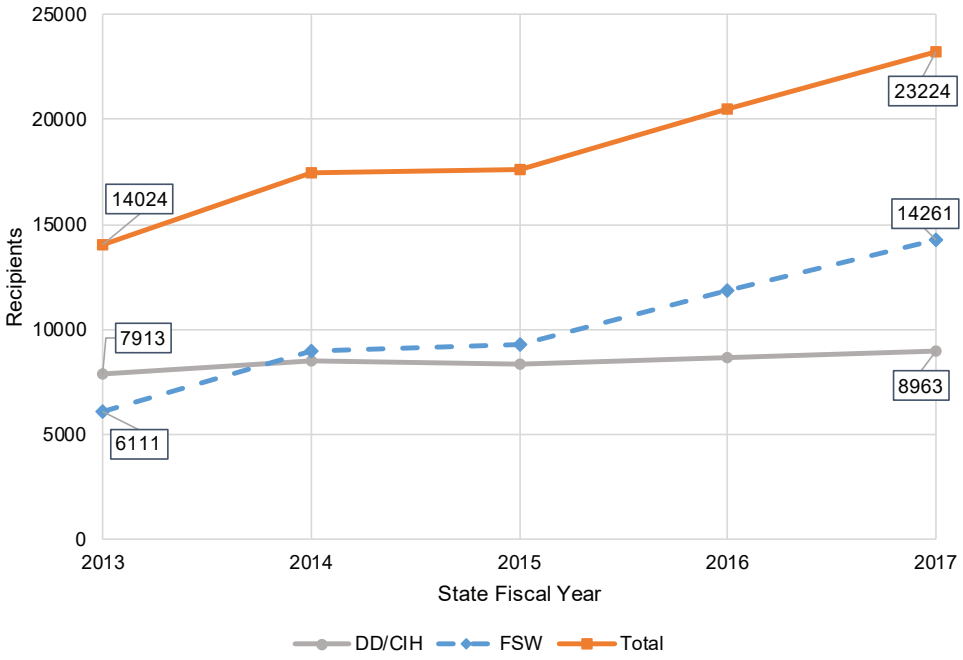

Figure 2. Home and Community-Based Utilization by Waiver, Over Time.
Source: Medicaid Claims Data

Overall costs, inclusive of state and federal contributions, of the Medicaid HCBS waiver programs from SFY13 to SFY17 can be viewed in Figure 3. As can be seen, the total costs rose $228.6 million during this time period. Most fiscal growth was from the CIH waiver program, with an increase of $156.2 million. Whereas, the FSW experienced a $72.4 million increase in this same time period.

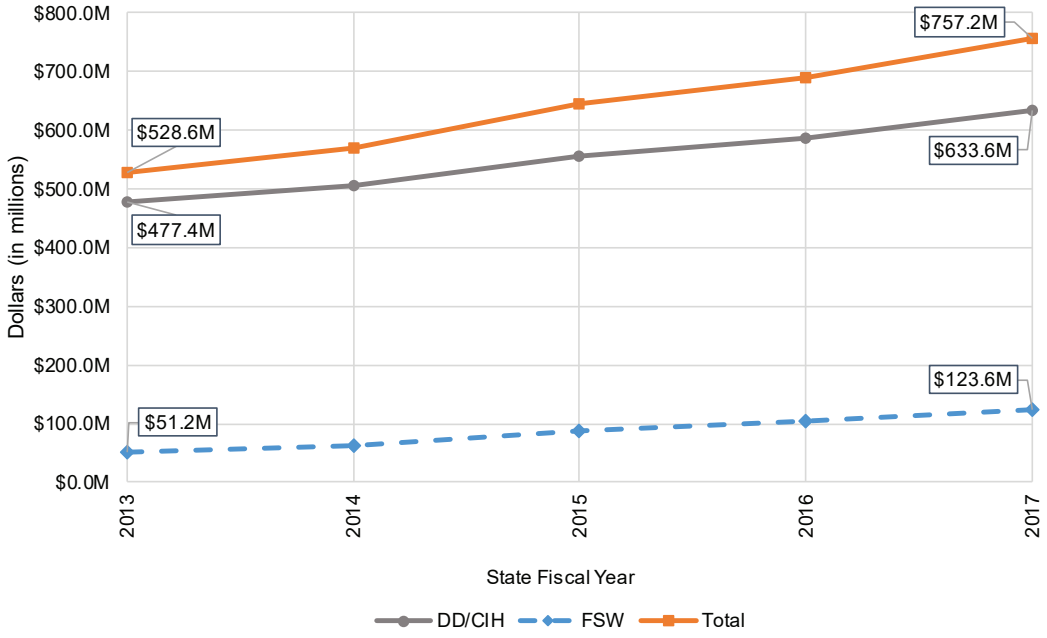

Figure 3. Home and Community-Based Costs by Waiver, Over Time.
Source: Medicaid Claims Data

Medicaid waiver and state plan service utilization. A wide variety of services are made available for people with IDD accessing the CIH waiver and FSW. The five most utilized services for each waiver in SFY16 include the following:

Community Integration & Habilitation Waiver

- Residential Habilitation and Support – hourly (75.4%)
- Behavior Management (62.9%)
- Transportation – all levels (60.0%)
- Community Habilitation (52.8%)
- Behavior Management 10 (49.5%)

Family Support Waiver

- Participant Assistance and Care (25.5%)
- Behavior Management (24.4%)
- Respite (24.2%)
- Behavior Management 10 (17.9%)
- Facility Habilitation Group – all ratios (16.2%)

Medicaid waiver waitlist. The current demand for a FSW extends across the state, resulting in a waitlist (see Table 2). In total 1,381 people are on the waitlist. The largest waitlist is in the Central region, followed by the North Central region. Of the total waitlist, 15% of individuals waiting are between the ages 3-5, followed by 51% for ages 5-17, 20% for ages 18-55, and 2% for those over 55 years. The CIH waiver does not currently have a waitlist, however access to this waiver is limited to family and emergency situations.

Group homes. Across Indiana in SFY17, a total of 475 group home residences existed (also known as ICF/IDDs). These homes served a total of 3,122 people with IDD. Table 3 highlights the county-by-county number of group home residences and people with IDD utilizing such services in SFY17. A total of 75 of Indiana's 92 counties had at least one group home. The highest density of group homes was in Marion County (55), followed by St. Joseph (33) and Allen (31).

Table 2. HCBS Waiver Waitlist by Region

District	#
Northwest (1)	85
North Central (2)	224
Northeast (3)	159
Eastern (4)	103
Central (5)	478
Eastern (6)	143
Southwest (7)	114
Southwestern (8)	75
Total	**1,381**

Source: DDRS DART Data System

Table 3. Number of Group Homes and Utilization by Counties

County Name	# Group Homes	# Served	County Name	# Group Homes	# Served	County Name	# Group Homes	# Served
Adams	4	29	Harrison	4	24	Owen	2	13
Allen	31	203	Hendricks	5	34	Parke	1	8
Bartholomew	4	20	Henry	8	55	Pike	3	20
Boone	2	16	Howard	8	63	Porter	11	62
Carroll	3	11	Huntington	7	38	Posey	1	8
Cass	8	50	Jackson	4	20	Pulaski	2	14
Clark	11	66	Jay	3	17	Putnam	2	12
Clay	5	35	Jefferson	2	16	Randolph	2	12
Clinton	2	14	Jennings	7	29	Ripley	2	13
Crawford	1	7	Johnson	6	47	Rush	1	6
Daviess	2	16	Knox	3	19	St. Joseph	33	192
Dearborn	3	24	Kosciusko	9	67	Shelby	3	20
Decatur	3	16	LaGrange	2	11	Starke	2	15
Delaware	9	63	Lake	19	111	Tippecanoe	6	41
Dubois	3	22	LaPorte	5	30	Union	1	6
Elkhart	14	101	Lawrence	7	48	Vanderburgh	19	136
Fayette	8	51	Madison	11	77	Vermillion	1	6
Floyd	3	23	Marion	55	376	Vigo	16	116
Fountain	1	8	Marshall	4	30	Wabash	6	36
Fulton	1	8	Martin	1	6	Warrick	6	41
Gibson	4	23	Miami	3	24	Washington	2	15
Grant	3	20	Monroe	13	78	Wayne	9	59
Greene	1	8	Montgomery	3	21	Wells	3	13
Hamilton	7	50	Morgan	2	16	White	2	13
Hancock	5	32	Orange	3	18	Whitley	7	54

Source: DDRS DART Data System

Other State Programs. A number of other programs exist in Indiana that serve people with IDD to live in the community. Data was unavailable at the time of this report regarding the utilization of these services among this population and the costs of these services as it related to people with IDD. The specific services include,

- ***Aged and Disabled Waiver***: A Medicaid HCBS waiver program designed to provide services to supplement informal supports for people who are aged, blind or have a disability that require nursing facility level of care. A wide array of services can be made available by way of the program, including but not limited to adult day services, assisted living, homemaker services, respite, structured family caregiving, and transportation. In SFY 2018, this program had $266.67 million in total funding that included $89.01 million in state and $177.60 in federal match.[6]

- ***Money Follows the Person (MFP)***: Funded through a federal grant, the MFP program assists to move people from institutional settings to home and community-based settings and seeks to prevent future placement in an institutional setting. Indiana was approved for the MFP program in 2007 and since that time has focused on assisting eligible persons to leave nursing facilities by providing services for individuals to live safely in their community. To be eligible, a person must reside in a qualifying nursing facility, be Medicaid eligible, and be able to live safely in the community with or without services and supports.

- ***Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE)***: A program that provides home and community-based services to assist individuals in maintaining their independence in their own homes or communities for as long as is safely possible. Recipients must be 60 years of age or have a disability and be at risk of losing their independence. There are no income limits related to eligibility, however, CHOICE funds cannot be used if other funding, such as Medicaid or Medicare, is available. Services include but are not limited to adult day services, home health aide, respite, skilled nursing, and transportation. In SFY 2018, a total of $48.77 million in state dollars was appropriated to the CHOICE program.[6]

Early Intervention and Education

First Steps is Indiana's early intervention program under Part C of IDEA. First Steps serves young children, birth to age three, with developmental delays or disabilities and their families. In the first three years of a child's life, more than one million new neural connections form every second. These early years are a time of great opportunity and great vulnerability, as early experiences literally shape the brain's architecture to support either a strong or fragile foundation for all future learning, health, and success. The purpose of First Steps and early intervention is to promote young children's lifelong success by supporting the optimal development of infants and toddlers and enhancing the capacity of families to meet the needs of their young children.

First Steps is a program of DDRS in the Indiana Family and Social Services Administration (FSSA). The program provides services primarily in a child's home or other natural environments. Services such as assistive technology; developmental therapy; family training, counseling, and home visits; nutrition services; occupational therapy; physical therapy; service coordination (i.e., case management); social work services; speech therapy; psychological services; and vision services – are examples of some of the 17 services required at a minimum by Part C regulations. As a federal entitlement program, First Steps serves families at all income levels; however, more than half of the families served fall below 250 percent of poverty.

6. Author. (2018). Indiana Family and Social Services Administration Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE) state fiscal year 2018 annual report in compliance with IC-12-10-10-11.

The total number of children served in 2017 with an individualized family service plan, or IFSP, was 20,775. As seen in Figure 4, the total number of children served in 2017 regardless of IFSP was more than 26,000.

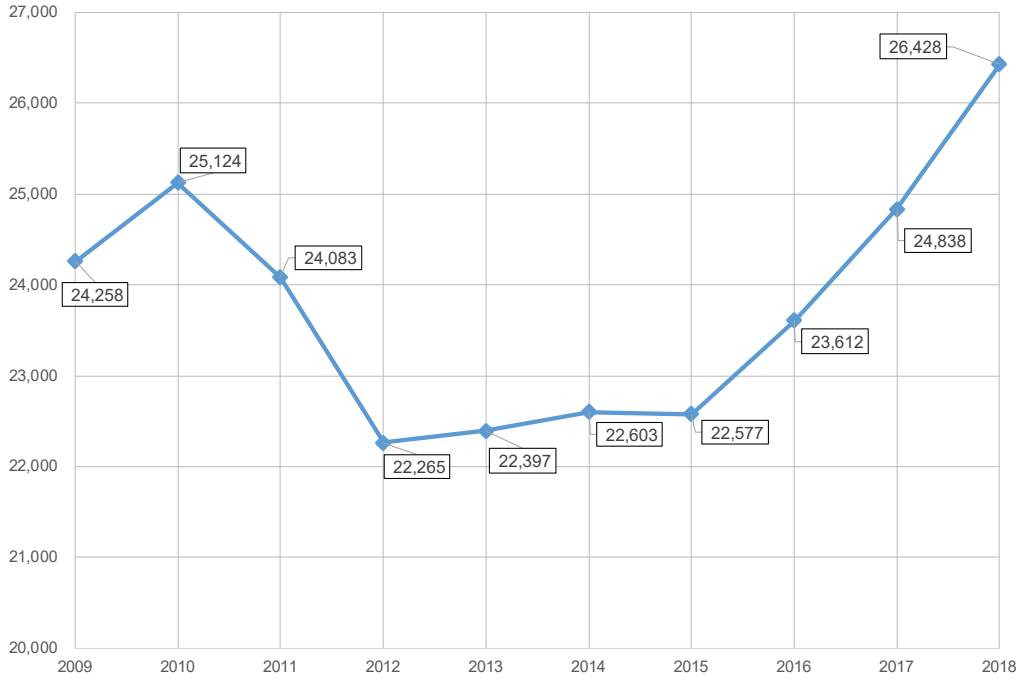

Figure 4. First Steps – Number of Children Served Annually
Source: Social Services Data Warehouse via First Steps database

Figure 5 shows the costs of the First Steps program were $40,720,810 in SFY17. These costs increased by $2.76 million from SFY16 to 17. An additional $2.41 million increase was realized from SFY2012 to SFY2016.

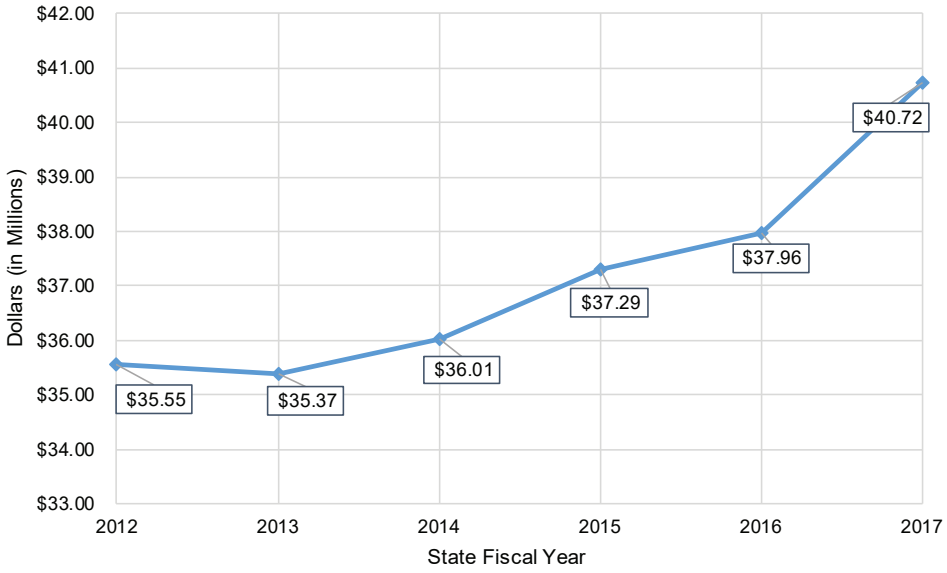

Figure 5. First Steps – Dollars Spent on Behalf of Children
Source: Social Services Data Warehouse via First Steps database

As can be seen in Table 4, there are a wide variety of First Step services available to children and families, ranging from therapeutic to support-related. The most widely used services in SFY17 were speech (17,707 children), occupational (13,507), physical (12,756), and developmental (12,308) therapies. Nursing and vision services were not utilized during the year.

The overall costs of the First Steps services ranged from $12.5 mission for speech therapy to $9,798 for social work services. On a cost-per-child basis, the costs ranged from $825 for assistive technology services to $99 for audiology services.

Table 4. First Steps Services, Costs, Enrollment, and Cost per Child in State Fiscal Year 2017

Services	Cost	Children	Cost/Child
Assistive Technology	$157,503	191	$825
Audiology	$106,865	1,075	$99
Developmental Therapy	$8,355,886	12,308	$679
Interpreter Services	$36,412	340	$107
Nursing	$0	0	-
Nutrition	$131,166	382	$343
Occupational Therapy	$8,901,924	13,507	$659
Other Related Services	$16,875	70	$241
Physical Therapy	$8,953,048	12,756	$702
Psychology	$71,301	155	$460
Social Work	$9,798	39	$251
Speech Therapy	$12,559,846	17,707	$709
Vision	$0	0	-

Source: Social Services Data Warehouse via First Steps database

Preschool, primary, and secondary.[7] The Indiana Department of Education oversees preschool, primary, and secondary education for the state. As seen in Table 5, a total of 13,066 preschool students (with and without IDD) and 128,961 primary and secondary students with mild, moderate, or severe disabilities (with and without IDD) are educated in the state. Funding amounts across these areas that predominately affect students with IDD total approximately $531.5 million. On a per student basis, these educational costs range from $8,976 for students with severe disabilities to $2,300 for students who have mild or moderate disabilities.

Table 5. Indiana Department of Education Funding Amounts (Dec 1, 2017)

Category	# of Students	Cost/Student	Total
Severe Disabilities	29,797	$8,976	$267,457,872
Mild/Mod Disabilities	99,164	$2,300	$228,077,200
Preschool	13,066	$2,750	$35,931,500
Total 3-22	**142,027**		**$531,466,572**

Source: Indiana Department Education

Preschool outcomes are assessed using the Indiana Standards Tool for the Alternate Reporting of Kindergarten Readiness (ISTAR-KR). This instrument assesses the skills of children across three important school-related domains; positive social and emotional readiness, acquiring and using knowledge, and taking appropriate action to meet their own basic needs.

7. Data referenced in this section were presented at the 1102 Task Force meeting by the Indiana Department of Education.

Across these domains, the majority (approximately 75% to 83%) of preschool students made progress in developing in these skills areas. However, the percent of students performing within age expectation was considerably lower: 20% related to social and emotional readiness; 11% related to acquiring and using knowledge; and, 12% related to taking care of their basic needs.

Primary and secondary school outcomes are assessed using the Indiana Statewide Testing for Educational Progress Plus (ISTEP+) test as a means to measure student achievement in the subject areas of English/Language Arts, Mathematics, and Science in grades four, six, and 10. In the 2016-2017 school year, 54.22% of all general education students passed the ISTEP+ test, compared to 17.52% of students receiving special education services.

Related to dropout and graduation rates in the 2016-2017 school year, special education students experienced poorer outcomes compared to general education students. A total of 4.9% of special education students dropped out of school and 71.7% graduated. Comparatively, 3.9% of general education students dropped out and 91.4% graduated.

One year after graduation, young adults with disabilities experienced a wide variety of post-school outcomes (see Table 6 next page). Of students that exited school in 2017, approximately 50% went on to some form of higher education or post-school training, a number that is about the same or higher than the previous two years. Twenty-seven percent were employed competitively, a figure that is considerably lower than the previous two years. Those unemployed one year post-school was highest for those that exited in 2017.

Table 6. Post-School Outcomes for Young Adults with Disabilities			
One Year After Exiting H.S.	Exited 2015 (n=70)	Exited 2016 (n=122)	Exited 2017 (n=199)
Enrolled in postsecondary	30.00%	31.15%	35.68%
Competitively employed	32.71%	39.34%	27.14%
Other postsecondary/training program	17.14%	5.73%	13.57%
Some other employment	4.29%	9.83%	7.54%
Unemployed and not in school	12.86%	13.93%	16.08%

Source: Indiana Department of Education

It is important to note, since IDD-specific primary and secondary education data was unavailable for this report, these educational outcome data do not explicitly identify the outcomes of students with IDD. As a result, it is unknown how students with IDD fared, compared to other general education and special education students.

Employment

The Day and Employment Services Outcome Systems (DESOS)[8] Report surveyed day and employment programs in Indiana to get individual level data on Hoosiers with disabilities that receive services. In 2017, a total of 63 programs responded (76% of all programs) and data was captured on about 13,317 service recipients, nearly 75% had a primary disability of IDD. After isolating recipients with IDD and their primary service environment, findings show 22% work in individual jobs in the community and 1% work in group jobs in the community; whereas 35% work in facility-based jobs (i.e., sheltered employment). In addition, 42% do not receive employment services (30% receive non-employment services and 12% receive alternative to employment services).

Vocational Rehabilitation Services (VR) play a large role in supporting people with IDD to obtain and retain competitive integrated employment. In addition, VR provides pre-employment transition services to youth and young adults transitioning from school to adult life. In Federal fiscal year 2017, VR had a total budget of $76.5 million, made up of 78.7% federal share and 21.3% state share. During this time VR served a total of 10,058 people, across all disability groups. Of this group, 33% had a primary impaiment of IDD.

Recent changes to federal law require states to shift resources. Specifically, states are expected to allocate 15% of the fiscal resources to pre-employment transition services, increase data collection and reporting, and provide information and referral to people employed at sub-minimum wage. These expectation, among other factors, resulted in a VR waiting list for services. Between August 1, 2017 and May 31, 2018, a total of 1,459 people were on this waiting list. Of this group, 5% had a primary impairment of IDD.

8. Grossi, T. (2017). Indiana Day and Employment Services Outcome Systems report. Bloomington, IN: Indiana Institute on Disability and Community at Indiana University. Retrieved from https://www.iidc.indiana.edu/styles/iidc/defiles/CCLC/DESOS/DESOS2017finalSeptember.pdf

Recognizing the ongoing challenges people with disabilities face in acquiring individual jobs in the community, the Indiana General Assembly passed Senate Enrollment Act (SEA) 390 in 2017, also known as the Indiana Employment First Act. This act added responsibilities to the federally mandated VR Commission to develop a "state-wide plan to support the advancement of competitive integrated employment, including self-employment, as the first and preferred option when providing services to individuals with disabilities." The plan will include identification of barriers to employment; an analysis of federal, state, and local policies affecting people with disabilities related to employment; and, recommendations to advance competitive integrated employment.

Indiana Community-Based Services Strategy

Indiana is committed to ensuring Hoosiers with disabilities have lives of their choosing where they experience being a part of their community, just as people without disabilities. It is about the difference in being a part of the community rather than simply in the community. We envision a future where the rights of people with disabilities include living close to their family and friends with proper and flexible supports, meaningful work, educated in integrated settings, and engaged in community life. These are simple rights, freedoms and choices of every citizen. Key to this future is to partner with families to enhance the support systems and increase the quality of life for their loved one. Flexibility, resources, access to quality services, and a network of supports is central to sustaining family well-being.

Policy changes clearly impact the everyday practice in working with individuals with IDD and their families. The overarching practice of person-centered planning or person-centered thinking share the fundamental principle that services and supports are not driven by available service options or professional opinion, but by the preferences, desires, and wishes of the individuals with IDD and their families within the whole life context.

Indiana is fortunate to have robust public education, human service, and employment systems that rely on a dedicated network of service and support providers around the state. As shown by the data above, these systems serve tens of thousands of Hoosiers with IDD in the community on an annual basis. These systems provide critical services, across the lifespan, to individuals and families. These include services for healthy development and for educational growth and attainment; as well as supports related to daily living skills, community navigation and inclusion, employment, daily supervision, family respite, and many more. The workforce to deliver these services and supports works 24 hours a day, seven days a week. As Indiana looks forward, to the next iteration of services and support, it is necessary to recognize the strong infrastructure that exists by way of public systems. It is also important to recognize that the obligation of Indiana's public systems to effectively serve people with IDD is not the sole responsibility of a single state agency or division. Instead, all public agencies serving Hoosiers have the duty to include people with IDD and provide the population with the highest level of service.

We must also recognize that, to have a robust community-focused life, one must also have full access to their community. As such, the need for equitable access extends beyond public systems to the broader community. Regardless if a person is seeking a place to live, a job to work, a place to recreate, business to shop, or any other community resource, the broader community must be inclusive and accessible for all of its members, including people with IDD.

Vision for the Future

In response to these challenges, the Task Force defines its vision for the future and values from which to draw from during throughout its process (see pages 16-17). The Task Force also approved four overarching goals of the future community-based services and supports for people with IDD. To achieve these goals, the Task Force made 34 recommendations, found on pages 18 through 26. Each recommendation provides a critical direction for the state, as it seeks to improve community-based services and supports for people with IDD. The recommendations, however, are not intended to be isolated strategies to respond to the challenges faced. Instead, the recommendations are to be taken together, as a comprehensive approach to achieve the goals laid out.

Goal 1: Prioritize community settings and individualized approaches.

Goal 2: Advance and maximize community and state resources and programs to be inclusive to all Hoosiers.

Goal 3: Respond to individual and family needs.

Goal 4: Include a wide array of supports and services that are sustainable, equitable, and available across all communities.

Informed by Public Comment

Stakeholder input informed the development of Task Force goals and recommendations of this plan. The public had two outlets to ensure their voices were heard by Task Force members, including: a) 50-minute Listening Sessions prior to each meeting, with the exception of the August 29th meeting, allowing stakeholders to share their views, challenges, successes, and recommendations; and, b) through submitted, written public comments. Nearly 200 individuals provided comment. Table 7 shows each stakeholder group who submitted comments or spoke at the meetings. Many service providers had several staff speak on behalf of their unique programs, however each organization was only counted once. The Task Force would like to thank those individuals who provided public comment. See Appendix A for Listening Session participants.

Table 7: Public Comments by Stakeholder Group

Group	#
Persons with a disability	19
Parents, other family members, or guardian	35
Advocacy organization	10
First Steps providers (only)	2
Support providers (e.g., Day Services, Employment, Residential)	26
Specialized service providers	4
Professional associations	5
School personnel	2

Statement from Self-Advocates of Indiana

The Task Force had a strong commitment to hear from and consider input from people with IDD most affected by the recommendations. During the public comment period at the Task Force's September 19th, 2018 meeting, Self-Advocates of Indiana provided a written statement regarding the future of community services and supports for people with IDD. An excerpt of the statement, where board members were asked what they felt were the most important issues to them, follows:

- We need more choices
- We need more information about our choices so we can make the best choice for us
- Help us learn how to make decisions instead of making them for us
- I need more flexibility so that I can use my services when and where I want to
- Inform us about how our services work so we can use our budget the way we want to
- Recognize that we are independent adults
- Our opinion matters
- Treat us like people not just numbers or clients
- Nothing About Us Without Us – talk with us not about us

We believe a change is necessary to create a system that allows us to have support, choice, and independence.

Let us direct our supports and understand that we each have unique goals and needs, so services should also be unique and flexible. Educate us about all our options, don't just tell us what our options are. Make sure the information you give us is accessible and understandable, so we can make the best choice.

Above all, make sure you aren't making any decisions about us without us. Make sure you are listening to us first. Continue to invite us to the table to discuss these issues and make sure you are valuing us as fellow advocates, community members, and human beings.

– Self-Advocates of Indiana Board of Directors

Topics and Themes from Public Comments

Comments spanned many different topics across various life and support domains. The Medicaid Waiver programs had a high frequency of comments. Concerns included the lack of flexibility of services, limited budgets to respond to service need, limited access to services due to waiting lists and limited provider capacity, challenges due to the complexity of the systems, and inadequate reimbursement rates for service providers.

Housing services and supports was of concern for the pubic. Comments included concerns about the lack of affordable housing, the limited flexibility within existing models, and the desire to maintain group homes.

The topic of employment supports also had numerous comments. These comments fell into to two broad categories, sheltered work and community-based employment. Related to sheltered work, many commenters were concerned that the service option would be eliminated and many others advocated for modernization of these settings and the elimination of sub-minimum wage within these settings. Related to community-based employment, comments included a recognition of the transportation barriers related to work, as well as the need for effective transition from school, greater funding, and to end to the VR waiting list.

Other topics addressed by public comments included the need for service systems to be individual and family-centered, the need for accessible and affordable transportation options, the importance and challenges of sustaining direct support professional workforce, the need for quality special education, and the importance of accessible early intervention services.

Emerging from the numerous topics that were commented on by the public were a number of themes for the Task Force to address. Many of these themes crossed constituency groups. They included:

- Self-determination and choice
- Support families
- Access to Medicaid HCBS waiver
- Access to early intervention
- Provide quality housing options
- Improve employment outcomes
- Effective transition to adulthood
- Improve transportation options
- Expand technology-based supports
- Stabilize direct support workforce
- Utilize public-private partnership

It was important to the Task Force to respond to the needs of its many stakeholders. As presented in each of the forthcoming sections, a table is presented to reflect how each goal and accompanying recommendation responds to these major themes.

Vision for the Future

To guide the work of the Task Force, a vision statement was defined and approved at an early stage. This vision was meant to provide members and the broader community a clear articulation of the value and importance of people with IDD in Indiana. The vision reads:

All Hoosiers are included, recognized, and supported as equal citizens, including people with intellectual and developmental disabilities.

All Hoosiers with intellectual and other developmental disabilities have opportunities to use their gifts and talents and live a good life, with choice and control.

Hoosier Values

A strong values statement was also produced by the Task Force. This statement was to provide a focus and direction as the Task Force produced recommendations for future services and supports for people with IDD. The values statement reads:

Future community-based supports and services for Hoosiers with intellectual and other developmental disabilities will:

- Be based on strengths and respond to individual abilities and dreams.
- Respond to individual and family needs.
- Respond to individual and cultural differences.
- Recognize legal, civil, and human rights and responsibilities as citizens.
- Prioritize typical community settings and individualized approaches to support peoples' lives.
- Ensure individuals drive and control supports and resources to make informed choices[9] about life and honor the choices they make.
- Nurture and support family and natural supports.
- Advance and maximize community and state resources and programs to be inclusive to all Hoosiers.
- Include a wide array of supports and services that are sustainable, equitable, and available across all communities.
- Focus on employment as the outcome of all services, if that is the choice of the individual.

9. Informed choice is defined as a voluntary, well-considered decision that is made on the basis of available options, information, experiences, and understanding.

1 Community Settings and Individualization

Advancements in support practices and service delivery over the last twenty years have provided greater access to community-based supports for people with IDD than ever before. Today, individualized, strength-based support models exist to facilitate full community lives, allowing Hoosiers with IDD to live, work, and play in their communities. As such, it is a goal of the Task Force to prioritize where and how people with IDD participate and how services and supports should be delivered across the state. Task Force recommendations provide actions across a variety of topics (see Table 8) that can move the state to achieving this goal.

Goal #1: Prioritize community settings and individualized approaches.

The Task Force recommends:

1.1 The Division of Disability and Rehabilitative Services develop a Medicaid HCBS waiver system with a full array of services and tiered supports to ensure flexibility of services and systems to meet the unique needs of all individuals served, accounting for age, family and community support systems, behavioral and mental health needs, and health factors.

1.2 An appropriation, to be known as the 1102 IDD Task Force Community Living Expansion Initiative, to fund Medicaid HCBS waiver slots for non-emergency priority placement using criteria developed by the Division of Disability and Rehabilitative Services to allow some level of expansion of individuals seeking to live in the community, away from their family, while creating the opportunity for families to support individuals in making this transition to living away from their family.

1.3 Modifying current legislation dictating waiver placement priority to current Medicaid HCBS waivers.

1.4 The Division of Disability and Rehabilitative Services convene a group of diverse stakeholders to assist with waiver redesign.

1.5 Increasing funding for Vocational Rehabilitation Services to ensure the program can address the fiscal deficit, increase Vocational Rehabilitation Services staffing resources, ensure appropriate reimbursement rates for providers to cover costs and recruit and retain staff, and allow expansion and innovation of Pre-Employment Transition Services.

1.6 It is important that Indiana create an economy and workforce where youth and adults with disabilities, including individuals with significant disabilities, have real opportunities to become competitively employed, use their talents and skills, work alongside other Hoosiers, and earn meaningful, competitive wages, consistent with a person's right to make an informed choice about employment options that meet their needs and preferences. The 1102 Task Force supports the efforts of the Indiana Rehabilitation Commission and DDRS to implement Employment First in Indiana and encourages their efforts to develop policies, practices, and service delivery models to facilitate increased competitive employment options as the first and preferred outcome of services for people with disabilities.

1.7 The development and promotion of public and private sector partnerships that support youth acquiring work experiences, skills, and access to resources and programs that lead to a successful transition from school to competitive employment or additional education. Strong transition partnerships should be considered as part of any new Medicaid HCBS waiver design and services offered.

1.8 Developing, expanding, and promoting housing options, especially permanent support housing, for all people with disabilities that allows for informed choice for them to attain affordable, accessible, and integrated housing in communities they choose to live in (rural or metropolitan). As options are being developed, the Task Force encourages the modernization of housing development projects to reflect current technology and the modernization of existing housing resources and programs at both the federal and state levels, addressing the need to continue to use shared service support.

1.9 The Division of Disability and Rehabilitative Services develop and adopt a Shared Living[10] model, as a residential service option, which resembles the most successful Shared Living programs in the United States such as Colorado and Pennsylvania. The current Structured Family Care Giving model used by Indiana does not provide the proper reimbursement methodology to provide the robust supports needed and displayed in the most successful models around the country. Therefore, the Task Force also recommends the Shared Living program use the same algorithm level structure as other Medicaid HCBS waivers versus the current tiered structure of Indiana's current Structured Family Care Giver program. It is also the recommendation of the Task Force that the Shared Living program ensure participants have access to the same services available to people who utilize current residential services such as day services, music therapy, and Wellness Coordination, in addition to the daily rate funding needed for the Shared Living program itself.

1.10 Given the historic trend of reduced use of settings with institutional funding, Indiana review those settings (i.e., ICF/IDDs, nursing facilities, and state operated facilities) with a focus to modernize the system and potentially reduce the number of institutional settings for individuals with IDD. The review will include a group of stakeholders including self-advocates, advocacy organizations, state regulatory agencies, provider organizations and representatives of the 1102 Task Force.

No later than December 31, 2020, the stakeholder group will develop a plan to:

1. Assess the needs of individuals in the system and the needs of individuals not currently in the system;

2. Determine the needs and desires of those individuals currently living in settings with institutional funding and how to transition them out of those settings if appropriate and their desire;

3. Assist providers who choose to voluntarily convert their ICF/IDDs into HCBS settings;

10. Shared Living denotes, "an arrangement in which an individual, a couple or a family in the community and a person with a disability choose to live together and share life's experiences… [Shared Living includes] mentor, host family or family home, foster care or family care, supported living, paid roommate, housemate and life sharing" (National Assoc. of State Directors of Developmental Disability Services (2013), retrieved from: https://www.nasddds.org/resource-library/general-information-on-administering-state-programs/family-living/shared-living-brief/

4. Determine the number of settings and type of settings with focus on eliminating unnecessary settings; Based on the above determination, identify the service needs of individuals served in settings with institutional funding and how the Indiana model can improve quality outcomes for those served; and,

5. Ensuring that all living settings are provided with informed choice at every level inclusive of person-centered thinking and principles including living situations, housemates, and types of services.

Table 8: Goal #1 Themes by Recommendation

Goal 1: Prioritize community settings and individualized approaches.

Recommendations	Self-determination	Family support	Medicaid HCBS waiver	Early intervention	Housing	Employment	Transition	Transportation	Technology	Direct support	Public-private partnerships
1.1			x								
1.2			x		x	x					
1.3			x								
1.4			x								
1.5						x	x			x	
1.6	x					x	x				
1.7			x			x	x				x
1.8	x				x			x			
1.9			x		x						
1.10	x				x						

2 Inclusive Resources and Programs

Information about resources available across the state is necessary for people with IDD and their families to make quality decisions regarding healthcare, education, disability-specific supports, and other services available in their communities. Like the general population in Indiana, people with IDD and their families are a geographically, culturally, and linguistically diverse community. As such, it is important for these constituents to have access to information and programs that are respectful to their individual and familial backgrounds. Additionally, to ensure the needs of people with IDD and their families are being heard, state and local entities and programs should include these constituents in important advisory roles. Recognizing these needs, it is a goal of the Task Force for the state to provide inclusive resources and programs to Hoosiers with IDD and their families. The Task Force also recommends specific steps to achieve this goal across a number of topics (see Table 9).

Goal #2: Advance and maximize community and state resources and programs to be inclusive to all Hoosiers.

The Task Force recommends:

2.1 The Division of Disability and rehabilitative Services and the Indiana Housing and Community Development Authority coordinate and collaborate on improving Indiana 211 for disability-specific information and referrals to ensure information system are accessible, reliable and responsive to the needs of individuals and families when seeking such information. These efforts should be made to improve access and consistency of information for individuals and families regarding disability services and resources across the state.

2.2 The representative of a provider of Vocational Rehabilitation Services for people with disabilities and, a representative of the Bureau of Rehabilitation Services to the Governor's Workforce Cabinet.

2.3 People with IDD, or their interests, are included in the state's initiatives related to the development and use of driverless vehicle technology in Indiana, to ensure it advances freedom and connectivity to community for people with disabilities.

2.4 Developing transportation strategies promoting independence and employment through collaborative efforts of key stakeholders and public-private partnerships across rural and urban areas. This may include addressing multijurisdictional issues; encouraging more funding for public transportation models; working with state and local transportation boards to ensure representation of individuals with disabilities; improving existing infrastructure to be fully accessible; facilitating the use of private ride sharing systems; and encouraging the development of innovative options such as driverless vehicles.

2.5 Maximizing the incorporation of technology in the delivery of services to people with disabilities to increase individuals' access to community services, natural supports, and assist in addressing the direct support professional workforce shortage.

2.6 In collaboration with stakeholders, Indiana shall explore, expand, and promote workforce initiatives to help employers in hiring individuals with disabilities to create an inclusive workforce, which may include access to tax incentives, recruitment and retention strategies, training resources, etc.

Table 9: Goal #2 Themes by Recommendation

Goal 2: Advance and maximize community and state resources and programs to be inclusive to all Hoosiers.

Recommendations	Self-determination	Family support	Medicaid HCBS waiver	Early intervention	Housing	Employment	Transition	Transportation	Technology	Direct support	Public-private partnerships
2.1	x	x									
2.2						x					
2.3								x	x		
2.4						x		x			x
2.5									x	x	
2.6						x					x

3 Individual and Family Need

For individuals and families, supports and services play an important role in facilitating a wide variety of life outcomes. Regardless if its early intervention services, support during times of crisis, job development support, or supports in a stable home environment, there is a demand for services across the lifespan that are flexible to individual and familial circumstances, responsive to the varying needs of culturally and linguistically diverse service users, and adaptable as life goals change. In response, it is a goal of the Task Force to make Indiana community-based services individual and family focused. The Task Force also specifies recommendations to achieve this goal across various topics (see Table 10).

Goal #3: Respond to individual and family needs.

The Task Force recommends:

3.1 Since investing in early childhood development is more effective and less costly than addressing problems at a later age and due to increased referrals for early intervention services, the First Steps program receive enhanced funding in order to sustain a high quality early intervention program for the children and families it serves.

3.2 The creation of a services and support system that supports and promotes self-advocacy, independence, and informed choice which leads to a good life.

3.3 The design and implementation of a self-directed care model in Medicaid HCBS waivers administered by the Division of Disability and Rehabilitative Services for individuals to convert their shift model to a version that allows them to hire people they choose via a fiscal intermediary.

3.4 That adults who participate in Medicaid HCBS waiver services be allowed, through informed choice, to receive direct services and supports from one or more family members to meet their assessed needs; and that no individual family member be allowed to provide more than 40 hours of support, within a seven day period.

3.5 The establishment of a statewide IDD crisis response program utilizing all available federal funding (i.e., Medicaid HCBS waiver, etc.) and, as needed/required, State funding with the following crisis best practice components (continute next page):

1. *24 hour telephone Response/Hotline*;
2. *In-Home Service*;
3. *Temporary Out-of-Home Placement resources for stabilization purposes*;
4. *Telemedicine capacity and coverage*;
5. *Reduction of risk/stabilization*;
6. *Prevention strategy to anticipate/eliminate re-occurrence*;
7. *Program staff/personnel and contractors should include*:

- Psychiatrist
- Behavior Clinicians or BCBAs
- Psychologist
- Direct Support Professionals for temporary staff support
- Registered Nurse consultation

3.6 Encouraging the support of our active duty and veteran military members in Indiana in obtaining services for their children with IDD; and, pending CMS approval, creating a priority status on the Medicaid HCBS waivers for children of active duty and veteran military families.

3.7 The Division of Disability and Rehabilitative Services encourage the use of emerging technology in Medicaid HCBS waiver service delivery.

3.8 Telehealth be approved as a viable and approved service delivery method for services, for example Behavior Management and Wellness Care.

3.9 The inclusion of peer specialists as a Medicaid HCBS waiver service, enabling experienced, trained people with IDD to support their fellow Hoosiers with disabilities.

3.10 Indiana to encourage efforts to increase the use of supported decision-making and other alternatives to guardianship.

Table 10: Goal #3 Themes by Recommendation

Goal 3: Respond to individual and family needs.

Recommendations	Self-determination	Family support	Medicaid HCBS waiver	Early intervention	Housing	Employment	Transition	Transportation	Technology	Direct support	Public-private partnerships
3.1		x		x							
3.2	x										
3.3	x	x	x							x	
3.4	x	x	x							x	
3.5			x							x	
3.6			x								
3.7			x						x		
3.8			x						x	x	
3.9	x		x							x	
3.10	x										

4 Sustainable, Equitable, and Available

Full and equal access to community-based services and supports for people with IDD is important to ensure all Hoosiers with IDD can live of their choosing, regardless of where they reside. A skilled, stable, and robust direct support workforce is imperative to this outcome. Therefore, it is a goal of the Task Force to ensure the state provides a variety of services and supports in a manner that all Hoosiers with IDD can access them throughout the state. The Task Force recommends specific actions over numerous topics to achieve this goal (see Table 11).

Goal #4: Include a wide array of supports and services that are sustainable, equitable, and available across all communities.

The Task Force recommends:

4.1 The First Steps program invest in its workforce to keep pace with demand by increasing the number of service coordinators and providers, and paying service coordinators at a rate that is competitive and supports effective recruitment and retention. This action will also assist in broadening the network of specific services needed in the early intervention system to appropriately serve families and children.

4.2 The creation of an array of living settings that support people with disabilities living in a setting of their informed choice that allows them to enjoy their interests, hobbies, and preferred lifestyle.

4.3 The creation of an array of employment options that leads to a good life with independence and respect for people with intellectual and developmental disabilities and ensures informed choice. The array of options should provide opportunities for people with all abilities to work that provides for growth, respect, preferences, and interests. In developing this array of options, a stakeholders group, led by Self-Advocates of Indiana, must come together to discuss the use of 14c certificates (sub-minimum wage) in Indiana in 2019 and develop strategies to assist provider agencies to transition away from utilizing 14c certificates.

4.4 Developing a plan to enable the Bureau of Rehabilitation Services to serve all Order of Selection priority categories by 2021, or as soon as possible, which would rely upon increased fiscal and staff resources.

4.5 Increasing, as soon as possible, the current state-wide average wage of direct support professionals to a level competitive with other service sector and healthcare jobs using current Bureau of Labor Statistics salary data through funding an increase in base compensation coupled with potential additional compensation tied to completion of a state authorized/approved training that significantly enhances the direct support professional's skills.

4.6 The development of a state approved outcome and competency-based training curriculum for direct support professionals. The purpose of the state-wide training is to ensure consistency of quality training, reduce training replication for providers, and to further professionalize the direct support professional workforce; and, the development of a state-wide registry of professionals who have undergone this training and curriculum.

4.7 The implementation of a public registry listing direct care staff who the Division of Disability and Rehabilitative Services has determined have committed certain offenses that bar them from employment supporting people with developmental disabilities in the state of Indiana.

4.8 Appropriations for DDRS and other state agencies sufficient to develop, plan and implement Task Force recommendations in keeping with timelines specified in this report or, in the absence of a specified timeline, at the earliest date possible.

Table 11: Goal #4 Themes by Recommendation

Goal 4: Include a wide array of supports and services that are sustainable, equitable, and available across all communities.

Recommendations	Self-determination	Family support	Medicaid HCBS waiver	Early intervention	Housing	Employment	Transition	Transportation	Technology	Direct support	Public-private partnerships
4.1				x						x	
4.2	x		x		x						
4.3	x		x			x					
4.4						x				x	
4.5										x	
4.6										x	
4.7										x	
4.8	x	x	x	x	x	x	x	x	x	x	x

Implementing Indiana's Community-Based Services Strategy

This comprehensive plan put forth by the 1102 Task Force, is meant to be a guide for the state. By adopting the Task Force's goals and recommendations, Indiana will provide greater opportunity and community inclusion for people with IDD, across the lifespan, through improved, accessible, and sustainable community-based services and supports that meet the needs of individuals and families.

The Task Force recognizes that the successful implementation of this plan will require time, leadership, advocacy, and action. This includes from the Indiana General Assembly at present and in the future, as well as from other stakeholders including persons with IDD and their family members, service and support professionals, and state agency leaders.

Appendix A: Listening Session Participants

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Cami Berkav
Tammy Blackman
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David Block
Ella Boyd
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Megan Burger
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Kelsey Cowley
Teri Culter
Max Danko
Lisa Danko
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Bitta DeWees
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Bettye Dunham
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Jeff Frady
Karen Freeman
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Leslie Green
Jennifer Greenlee
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Patti Sebanc
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Savannah Smith
Heather Sorrells
Joe Spoelker
Kevin Steele
Diane Stevens
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Jim Stewart
Kirk Stoltzfus
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Cathy Summers
David Terrell
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Amelia Williams
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