



# Family Support 360 and Shared Living Program Assessment

ALVAREZ & MARSAL  
LEADERSHIP. ACTION. **RESULTS.**<sup>SM</sup>





# A&M Team Introduction

A&M's team has experience with developmental disabilities service delivery systems in states across the country, and in working directly with South Dakota.



## **Daniel Harlan – Project Executive**

- 15+ years of experience managing complex projects at the federal and state level
- Expertise in program management, operational and organizational assessments, business process re-engineering, process improvement, stakeholder engagement, strategy development, and financial analysis
- Led multi-year design and implementation of a large-scale developmental disabilities system transformation in Maryland
- Brings familiarity and commitment to services in South Dakota with strong family ties in the State



## **Erin Leveton – Project Lead, Subject Matter Expert**

- 25+ years of experience in disability law and policy, including 7 years in state government
- Expertise in Home & Community Based Services, person and family-centered thinking, stakeholder engagement
- Former Director of the Quality Assurance and Performance Management Administration for DC Department on Disability Services, Developmental Disabilities Administration and Rehabilitation Services Administration
- Charting the LifeCourse certified coach, ambassador, presenter



## **Jillian Salmon – Project Manager**

- Skilled in HHS policy analysis, project management, stakeholder engagement, and communications
- Partnered with multiple states to assess and redesign LTSS programs to improve administrative and operational efficiency, as well as access to services for vulnerable populations
- Led project management office for NH's statewide implementation of a new 1115 Medicaid demonstration authority
- Conducted comprehensive assessment of I/DD services in North Dakota, leading the internal and external stakeholder engagement activities to explore existing services and identify gaps in access



## **AGENDA**

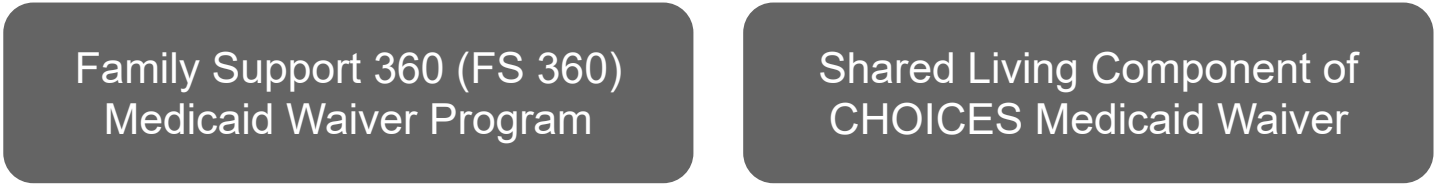
- I. Assessment Approach
- II. Background
- III. Executive Summary
- IV. Recommendations
  - i. Person Centered Systems
  - ii. Access
  - iii. Operations & Administration
  - iv. Sustainability
  - v. Family Support Council
- V. Road Map
- VI. Appendix

# Assessment Approach

# Project Overview and A&M's Approach

A&M partnered with South Dakota to assess the FS 360 waiver and the Shared Living component of the CHOICES waiver, and to issue recommendations to maximize impact of these programs in helping to support South Dakotans with I/DD in the most independent settings possible.

## Programs of Interest



## Assessment Approach



## Study Goals

1. Identify and expand on successful elements of FS 360 and Shared Living programs
2. Highlight opportunities to improve programs and address gaps in access
3. Map out a pathway to enable program stability, growth, and sustainability

# Stakeholder Engagement Overview

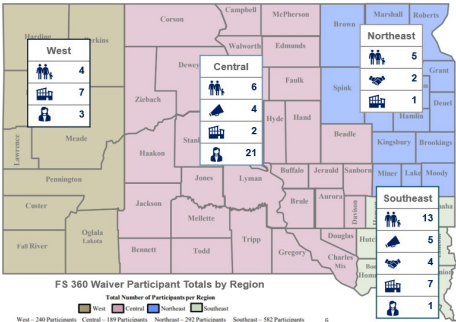
A&M has engaged with stakeholders via a variety of opportunities, including interviews, listening sessions, surveys, and site visits.

A&M has connected with 200+ stakeholders via interviews and listening sessions, in addition to collecting 500+ survey responses



**Interviews: Conducted 85 unique interviews** across all four regions of the State

- Families: 28 interviews
- State agency: 25 interviews
- Provider management: 17 interviews
- Advocates: 9 interviews
- Family Support Coordinators: 6 interviews



**Listening Sessions: Hosted twelve sessions** to connect with legislators, families, and community support providers

- Two legislative listening sessions: 12 attendees
- Eight family listening sessions: 170+ total attendees
- Self-advocate listening session: 13 attendees
- Two provider listening sessions: 28 total attendees



**Surveys: Launched 3 surveys** to collect anonymous feedback from families, provider agencies, and direct care workers

- Family and Consumer Surveys: 362 responses
- Community Support Provider Surveys: 22 responses (across FS 360 and Shared Living)
- Direct care service providers: 117 responses



**Site visits: Total of 8 site visits** across four regions of South Dakota to hear from families, providers, and state agency staff

- Aberdeen, Pierre (x3), Rapid City, Sioux Falls (x2), Spearfish

# Background

# How HCBS Waivers Support Community Integration



## Medicaid funds long-term services and supports (LTSS)

- Medicaid is the primary funder LTSS in the United States
- Medicaid provides LTSS through both:
  - institutional care (i.e., intermediate care or nursing facilities), or
  - home and community-based services (HCBS).



## HCBS waivers provide LTSS in community-based settings

- States develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting



## HCBS Waivers offer medical and non-medical services

- HCBS Waivers provide both medical and non-medical services
- Examples services include:
  - Service coordination
  - In home supports
  - Respite
  - Habilitation services
  - Employment supports, and more.



## HCBS programs must meet federal program guidelines

- HCBS Waiver programs must:
  - Demonstrate that providing waiver services won't cost more than providing these services in an institution
  - Ensure the protection of people's health and welfare
  - Provide adequate and reasonable provider standards to meet the needs of the target population
  - Ensure that services follow an individualized and person-centered plan of care

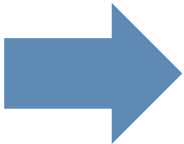


# The Move to Community Integration: From Institutionalization to Family Support

## Institutional Care

Historically, families were encouraged to place children with disabilities into institutions, often far from their homes, that would provide the **supports their child needed across life domains**:

- Education
- Housing
- Medical Care
- Therapies
- Nutrition
- Recreation
- Case Management
- Financial Management
- Guardianship



## Integrated Community Support

People with intellectual and developmental disabilities now live at home with their families. Families must **coordinate integrated supports** to meet their loved ones needs across the life domains. This includes both eligibility-based supports and other natural supports.

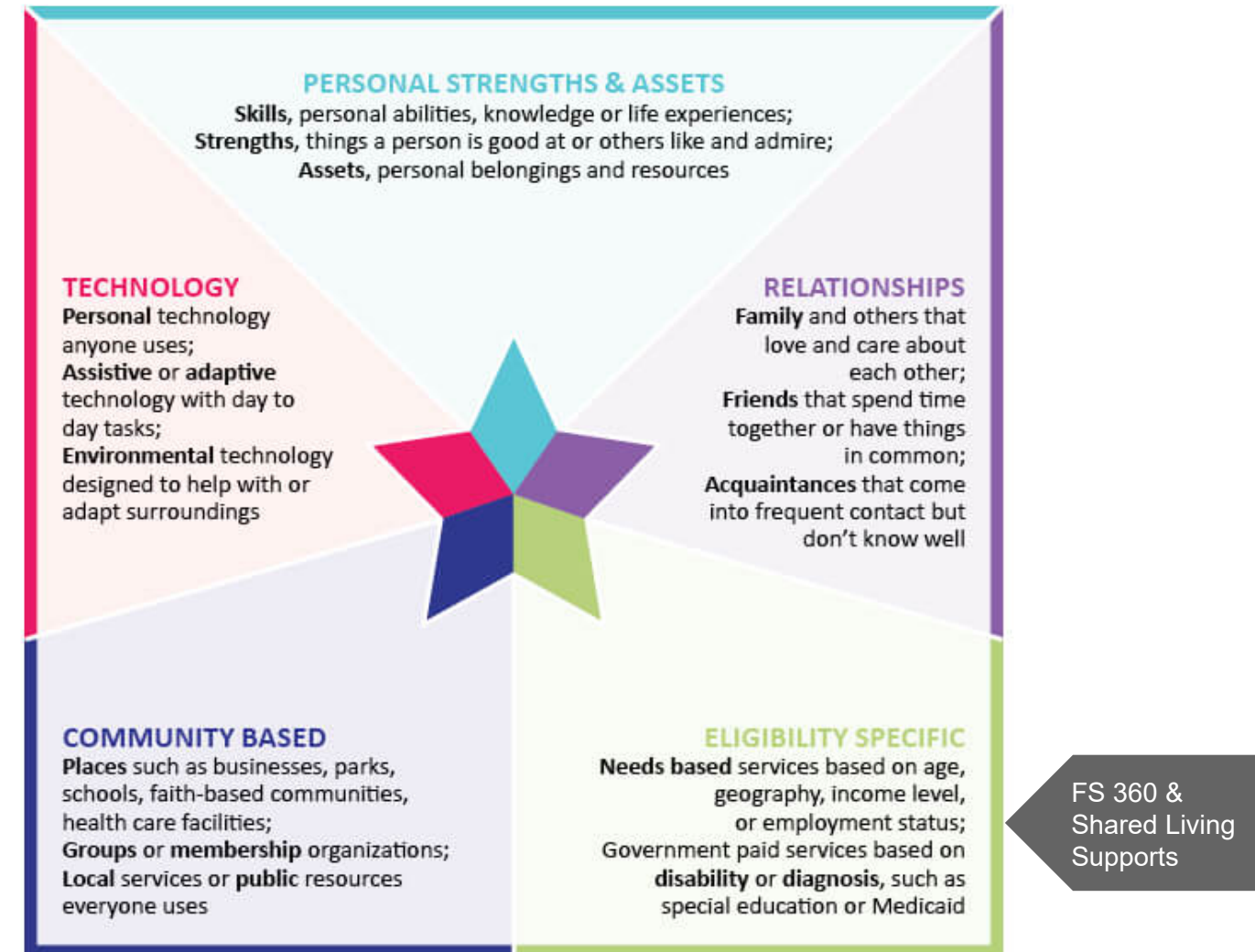


FS 360 &  
Shared Living  
Supports

# Understanding Integrated Supports

People with disabilities and their families need access to a variety of supports to meet their day-to-day needs, achieve long-term and short-term goals, solve problems, and enhance their quality of life.

- Supports work best when they are integrated across an array of options, including both eligibility-based supports and natural supports available in the community
- Focusing only on eligibility-based supports can unintentionally separate a person from their family and natural support system which then can lead to segregation, loneliness, and lack of choice.
- Supports should leverage and be comprised of a mix of:
  - The person and family's strengths and assets
  - Relationship-based supports
  - Community supports and resources
  - Technology
  - Eligibility based options that are publicly or privately funded



# Vision for Family Support 360 (FS 360)



- Family support is not a single service, but rather a flexible constellation of services and supports which are customized to meet the varied and changing needs of each participant and family. A family support program recognizes and values the contribution of natural or informal supports such as extended family members, friends, neighbors, church congregations, and community organizations. In addition to utilizing natural supports, family support programs help participants and families to access existing formalized services such as the Childcare Assistance Program, Children's Miracle Network, Energy Assistance, Children's Special Health Services, Home-Based Services, Independent Living Centers, etc.
- A family support coordinator assists participants to identify and access a broad range of natural and formalized services to meet their identified needs. One of the "hats" frequently worn by the family support coordinator is that of advocate on behalf of the participant. The role of advocacy is best accomplished by someone independent of any agency or entity that might also be providing services for a participant. Otherwise, a family support coordinator might be placed in the precarious position of advocating for the desires of a participant that are in direct conflict with the desires of one's employer.
- Another very essential tenet of a family support coordinator is a pool of flexible funds that can be utilized to purchase services for supports not otherwise available and to assist participants with extraordinary expenses. For example, rather than establishing a formal program to provide for home modifications, the flexible funds might be utilized to purchase the needed modifications from private contractors.
- In lay terms, family support is often conveyed in the phrase "whatever it takes" to maintain and strengthen the participant's ability to remain in their own home. Families receiving family support services often comment that it allows them to be "just a family."

# Family Support 360 and Shared Living: Program Basics

A&M’s study specifically assessed the FS 360 Waiver along with Shared Living, a component of the CHOICES Waiver.

Program	Description	Self-Directed	Participants*	Per Person Annual Spend*
Family Support 360 (FS 360) Waiver	A Medicaid Home and Community Based Services (HCBS) Waiver that helps people with intellectual and developmental disabilities and their families <b>get the services they need to live in their own home and community as independently as possible</b> . Services include companion care, supported employment, personal care, special adaptive equipment, home and vehicle modifications, and specialized therapies such as hippotherapy (horse therapy), art, and music.	Yes	1,502	\$4.2K (\$6.3M total)
CHOICES Waiver**	A Medicaid HCBS Waiver with services for children and adults with intellectual and developmental disabilities. <b>Services include residential services (group homes, shared living, etc.), supported employment, day services, and assistive technology.</b>	No	2,741	\$76.1K (\$209M total)
Shared Living Program (Component of CHOICES Waiver)	A service that is offered as part of the CHOICES Medicaid HCBS Waiver. <b>Shared living is a residential living option where a person with an intellectual or developmental disability lives with someone who wants to share a life and provide supports.</b> The shared living provider can be anyone over the age of 18. The Shared living Host Home and Companion Home providers are very diverse and can include college students, families, single people, couples, and empty nesters. Host Homes provide services to a person in the private home of a community member, friend, or family member.  A person who is using shared living may also access other services through the CHOICES waiver such as supported employment or day services.	No	113	\$68.9K (\$7.8M total)  Compare to average group home service cost: \$84.5K (\$7.8M total)

\*Participants and spending estimates as reported in Waiver Appendix J, 2023 Waiver Year. Costs rounded to nearest tenth of a million and inclusive of both state funds and federal Medicaid matching funds.

\*\*Note that the A&M study targeted only the Shared Living service from the CHOICES Waiver.



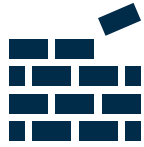
# Evolving Federal Requirements

CMS has proposed a new access rule to build transparency, accountability and reporting, standardization of data and monitoring, and active beneficiary engagement. A&M’s recommendations include steps to help prepare for the potential finalization of this rule and the resulting requirements

Excerpts of Proposed Federal Requirements	Key State Considerations
<ul style="list-style-type: none"> <li><b>Reporting on the waiting list</b> eligibility criteria for inclusion on a waitlist, numbers and average length of time on waitlist (annual)</li> </ul>	<ul style="list-style-type: none"> <li>Determining whether criteria for maintaining a waitlist have been met</li> <li><b>Waitlist management</b>, tracking and reporting</li> </ul>
<ul style="list-style-type: none"> <li><b>Website transparency</b> enhancements for accountability, transparency, and availability of information specific to incident management, critical incident, person centered planning, and service provision compliance data</li> </ul>	<ul style="list-style-type: none"> <li><b>Maintenance of websites</b> that are accessible and in plain language to facilitate access to actionable information</li> <li>Process for quarterly updating of information provided on the website</li> </ul>
<ul style="list-style-type: none"> <li>Annual review of the <b>person-centered plan</b> with revisions only as appropriate to the results of the functional needs assessment.</li> </ul>	<ul style="list-style-type: none"> <li><b>Strengthening the person-centered planning process</b> to promote independence, self-direction, informed choice and individual’s goals</li> </ul>
<ul style="list-style-type: none"> <li>Establish written policies and procedures for a <b><u>grievance process and notification requirements</u></b> for ‘a complaint or expression or dissatisfaction related to the State’s or a provider’s compliance with the person-centered planning and service plan requirements and the HCBS settings requirements. Implementation and management of a <b><u>grievance system</u></b> that includes response, resolution, and the collection and tracking of information</li> </ul>	<ul style="list-style-type: none"> <li>Development or expansion of <b>internal grievance management</b> resources and processes</li> <li>Regulatory and policy changes</li> </ul>

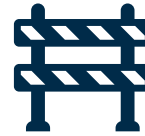
# Executive Summary

# The Big Picture in South Dakota



## Foundational Strengths

- Division for Developmental Disabilities (DDD) leadership has a strong **vision for a person and family-centered system** that supports people to live individualized good lives
- Staff are working on multiple big initiatives to **shift power, choice, and control to families**
- FS 360 and Shared Living are designed to support people to **live in the community in the least restrictive setting that meets their needs** without using facility-based supports



## Challenges

- Past DDD and Medicaid changes to FS 360 **narrowed program flexibility**. A lack of understanding of the reasons behind the change and resulting **denials with insensitive language** have led to **confusion** and some **loss of trust**
- Families are **seeking plain language, responsive communications**, and more opportunities to share their input as experts on how the system operates
- **Lean staffing** impacts timelines for DDD and the ability to share information with people and families routinely



## Keys to Success

- **Partner** with self-advocates and families so that they have opportunities to share input on systems that impact them, from design through to revision. **Respect their context knowledge** as a critical input
- **Share** routine and **plain language updates** on work in progress, status, and what to expect next
- **Revisit decisions made that narrowed flexibility**. While they may have been important in the past, they may no longer serve the system well now



**Critical Takeaway:** There is a **shared vision for FS 360 and Shared Living: to support people and their families to live fulfilling lives in the community**. DDD is investing in systems change to achieve the vision. Achieving this vision will require coming together, building trust, and having hard conversations. DDD and families should work together to reimagine the future of FS 360 and Shared Living services.

# Executive Summary: A&M Recommendations

A&M has five key recommendations. DDD cannot do them alone. They require support from Medicaid, providers, and family members, as well as time, FTE, subject matter expertise support, and funding (as needed).

- 1 Quick Wins to Build Trust:** Restrictions in the service array (for example, no longer allowing fences), along with confusing and perceived insensitive comments and denial letters, have led to **a lack of trust**. Through our listening sessions, we heard **optimistic discontent**. People with intellectual and developmental disabilities and their families believe the system can be better and want to be a part of that change. DDD should **begin work on quick wins from this report to demonstrate a commitment to action based on what A&M heard from families**.
- 2 Flexibility and Investment in Family Support 360:** FS 360 is providing much-needed support for people with intellectual and developmental disabilities so that they can continue to live in the community with their families. Recent changes have increased flexibility around assistive technology and specialized therapies. There is a need for additional flexibility, through services such as an Individual Directed Goods and Services category that would **allow people and their families to determine what would be most helpful to them within the bounds of the Medicaid program** and a limited financial cap on the service. DDD should explore this and other targeted service investments that can help ensure this program remains a sustainable life for families
- 3 Support for Shared Living Families:** Families find Shared Living to be a wonderful service for their children but are struggling to use respite services, and we heard from many families who had not had a break in many months. **Work with families to make respite more available**, for example, through a partnership with the LifeSpan respite program, by sharing a list of certified respite providers, or by allowing Shared Living families to self-direct respite services.
- 4 Continue Efforts to Become a Person and Family-Centered System:** Moving from a government and provider-based system to one that is truly centered around supporting people with intellectual and developmental disabilities to have a good life in the community requires continuous efforts to redesign policy, practice, infrastructure, and rules to increase the presence of person and family-centered practices. This requires closely partnering with and **shifting power from government and providers to people and families**. A good example of this is the work DDD is doing now to support self-direction.
- 5 Partner for Systems Change:** DDD should proactively communicate and **seek opportunities to partner with the people they support, their families, advocates and providers, end to end, in all systems change activities**. A&M understands that the DDD is taking this approach for the changes to the front door. We recommend that they use this practice across the board, including for recommendations within this report.



# Building a Person and Family-Centered System



Strength

# South Dakota's Investment in Person & Family Centered Practices

Person-centered planning is a federal Center for Medicare and Medicaid Services requirement for HCBS. DDD was an early adopter of the Charting the LifeCourse framework created to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.

**In 2016, South Dakota joined the National Community of Practice for Supporting Families of People with Intellectual and Developmental Disabilities** to continue building capacity to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan with the *“overall goal of supporting families with all of their complexity and diversity to maximize their capacity, strengths, and unique abilities to best support, nurture, love, and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life.”*

- South Dakota has continued its participation and is now one of nineteen member states.
- **The state has invested in training in person and family centered practices** for staff, providers, and family members.
- These principles are embedded in recent changes, like the new Individualized Service Plan (ISP) to support good planning with people and families.
- Moving from person and family centered strategies and planning to **becoming a person and family centered system requires a commitment to ongoing listening and learning, and then making changes** when the state finds that their policies and practices are getting in the way of people and families having a good life.



# Shared Vision for Supporting Families

Achieving the vision for Supporting Families in South Dakota will require partnerships and new ways of thinking.



## Core Belief:

All people and their families have the right to live, love, work, play, and pursue, their life aspirations in their community.

## Vision for Supporting Families in SD

Supports to ALL families in South Dakota to live their good life through the following:

- Engaging in open communication and education regarding resources available or needed by families to navigate the DD system
- Gaining a deeper understanding of the needs of people with IDD and their families
- Identifying opportunities for systems change through partnership and feedback from family members and self-advocates as well as by leveraging the resources of the National CoP for Supporting Families, the SD CoP State Team, and the Charting the LifeCourse framework.



**Recommendation:** Continue the **investment in person and family centered thinking, planning, and practices**. Consider **training all DDD staff in Charting the LifeCourse** to reinforce common language, values, and ways of thinking. Make this a part of orientation for new DDD employees. Continue to find ways to **support adoption and the move from awareness to practice**. For example, host a Charting the LifeCourse In Action group for staff, FSCs, and families to share what they are doing, and problem solve together.

# Initiatives to Achieve the Shared Vision

There is a shared vision for people with intellectual disabilities and their families to live good lives in the community. DDD has many initiatives in flight to achieve this vision and become a more person and family centered system.

- A&M understands that DDD has a lot of work in progress - everything from the front door to services to rates. Stakeholders shared confusion about what is happening. Without a way for the public to easily understand the work in progress, it can be hard to build trust that positive change is happening, and common knowledge about what is coming next. **“Information is power.”**
- The number of initiatives in flight, combined with lean staffing means that **there is not strong visibility into DDD’s work**. Combined with a relatively recent history of restrictive system change, for some families, there is a lack of trust or confidence about what is happening. **Proactive, plain language, reliable communication will help bring transparency, understanding, and support for change.**

## Examples of Recent and in Progress DDD Initiatives

- |  |  |
|--|--|
| ✓ New front door process                   | ✓ The new Shared Living tiered model       |
| ✓ Common Law self-directed services option | ✓ The updated website                      |
| ✓ The online case management system        | ✓ Addition of specialized therapy services |
| ✓ The new person and family centered ISP   | ✓ The waiting list portal (in development) |
| ✓ Unbundled rate                           | ✓ Adding a transportation service          |

A&M supports DDD’s initiatives. Our recommendations seek to help families understand the changes and be a part of the change

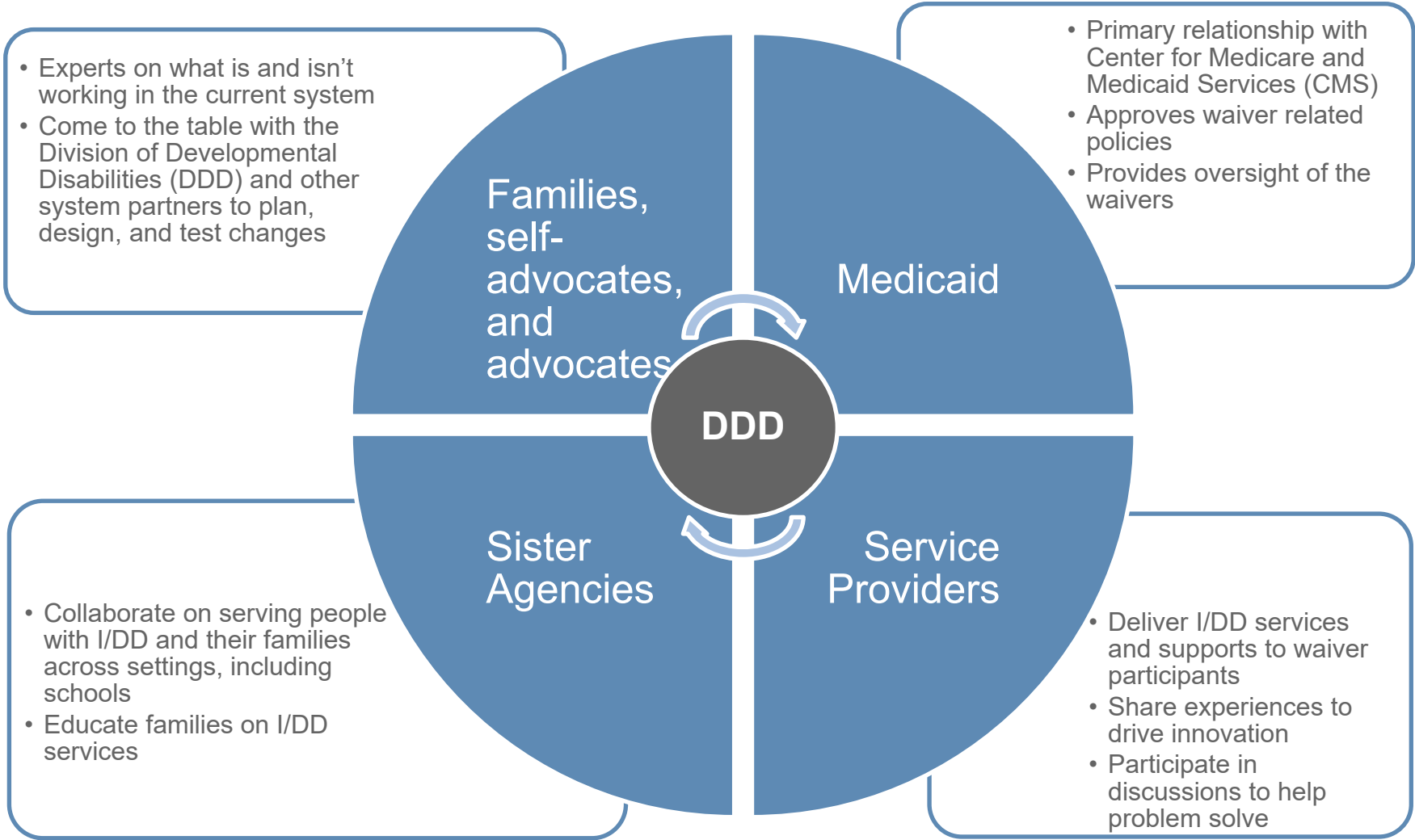


**Recommendation:** The first step in change management is **awareness**. Add a page to the new website for DDDs initiative and let people know what’s happening and what to expect. Use plain language. Update at least quarterly.



# Essential Partners in Designing and Providing I/DD Services

Intellectual and Developmental Disability (I/DD) systems depend on guidance and interaction from core stakeholders to support strong I/DD programs. Regular, active, and meaningful engagement to, with, and by these stakeholders is essential to ensuring successful program operations.



# Partnership between DHS & Families

Change happens at the speed of trust. Partner with self-advocates and families to advance transformational systems change.

- A&M heard that families members want to be a part of systems change initiatives and don't always feel they have an opportunity to participation meaningfully in system design. Some families are frustrated that stakeholder engagement sessions are more informational in nature. **"It has become more information sessions than roll up your sleeves and work sessions."**
- There are opportunities to **seize on this moment of systems change and further involve the people DDD supports and their families** so that they are advising on the system that supports them.



## Tips for Partnering with Families:

Hold meetings at different times of the day, including evenings for families who work during the day. Always include an option to join remotely. Be aware of power dynamics and seek to lift the voices of people with I/DD and their families.



**Recommendation:** Person-centered practices are based on the fundamental principle that **government and service providers must listen to people about what is important to them to create or maintain a life they enjoy in the community**. Review each initiative to check for whether there are opportunities for self-advocates and families to be engaged in through the whole process. Bridge any gaps. Share ways to get involved on the new webpage.



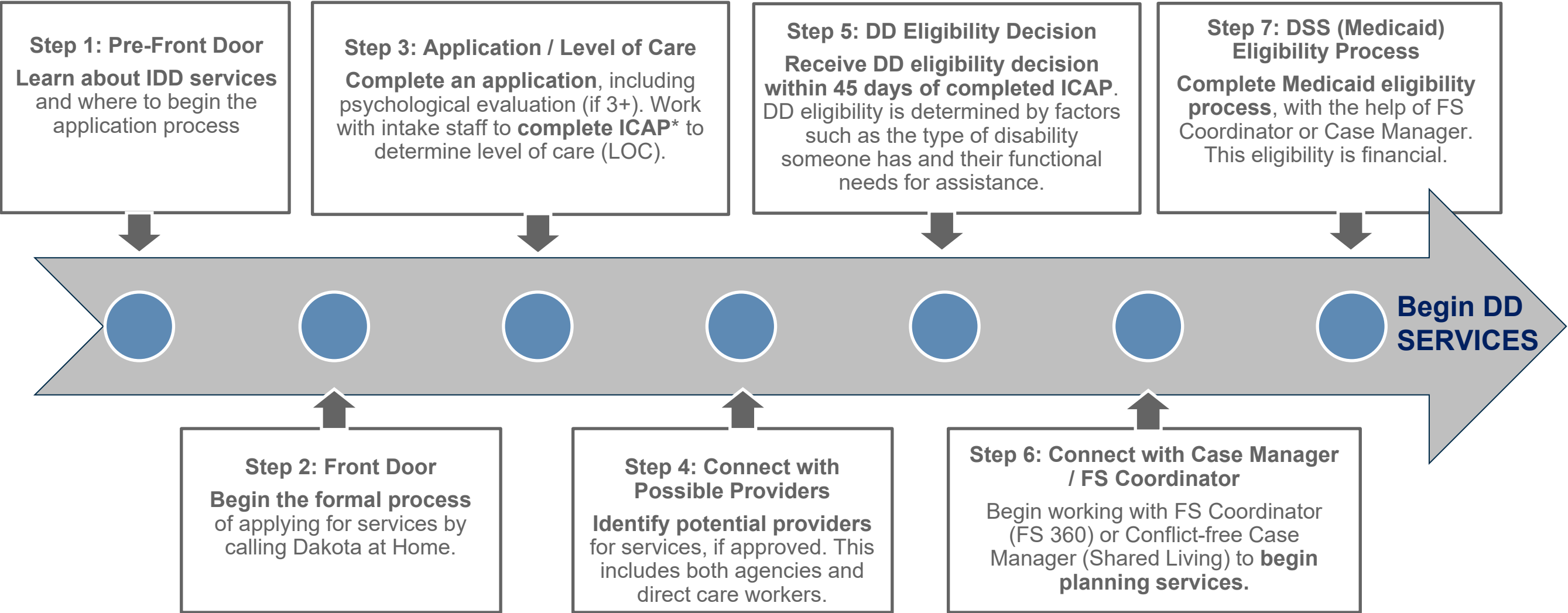
Individuals and families are truly involved in policy making so that they influence planning, policy, implementation, research, and revision of the practices that affect them. Every program, organization, system, and policy-maker must think about a person within the context of family and community.

# Access

*This section covers the front door to developmental disability services, including intake and eligibility, as well as access to the Family Support Coordinators who work with the person and their family to develop a person-centered plan that is a precedent to receiving services from the Division of Developmental Disabilities.*

# Understanding Waiver Access: What Does the Journey to Services Look Like?

To access waiver services, people must go through a multi-step eligibility process that determines whether someone qualifies to receive services. The steps that someone goes through to apply for and begin DD services is called the intake process.



\*The ICAP is a nationally developed tool to measure level of care. This is also the tool South Dakota uses to measure level of care.

# Overview of Core Waiver Access Elements: What Makes a System User Friendly?

Access is about the journey people go through to apply for and receive IDD services. In a person-centered system, access should include both 1) easy to find information about services / the application process, and 2) a family friendly process to apply for services.

## 1. Easy to find information about services and the application process, including:

- Trusted partners and people in the community who understand services and can share information about the process to apply for services
- An agency website (DHS) with information about services and the intake process, including where to begin the application process and how long it will take

## 2. A family friendly application process, including:

- An easy to contact place to start the intake process
- An initial intake conversation that provides information including estimated timelines, an overview of necessary documents, and guidance about choices down the road
- A person-centered conversation that helps people identify supports they can use while waiting
- One central contact throughout the application process
- A way for families to check their application status



People need three buckets of support:

- 1) **Discovery and navigation**
- 2) Connecting and networking
- 3) goods and services.

Information about how to apply for services is part of bucket #1, discovery and navigation. This bucket includes the ability to navigate and access services.

Source: [LifeCourse Framework – LifeCourse Nexus \(lifecoursetools.com\)](#)



# Waiver Access: What's Working Well Today? (Part 1 of 2)

While significant work is still underway, many stakeholders spoke positively about the vision for the future. In general, South Dakota also has an intake process that is accurately identifying the target population for IDD services.



## Positive Stakeholder Feedback

- **DDD staff are highly supportive** of the new centralized front door/ intake process
- Sister agencies such as Early Intervention also **support centralizing the new front door as the “right thing to do”**
- **Eligibility is generally working.** People do not typically hear about denials that surprise them.



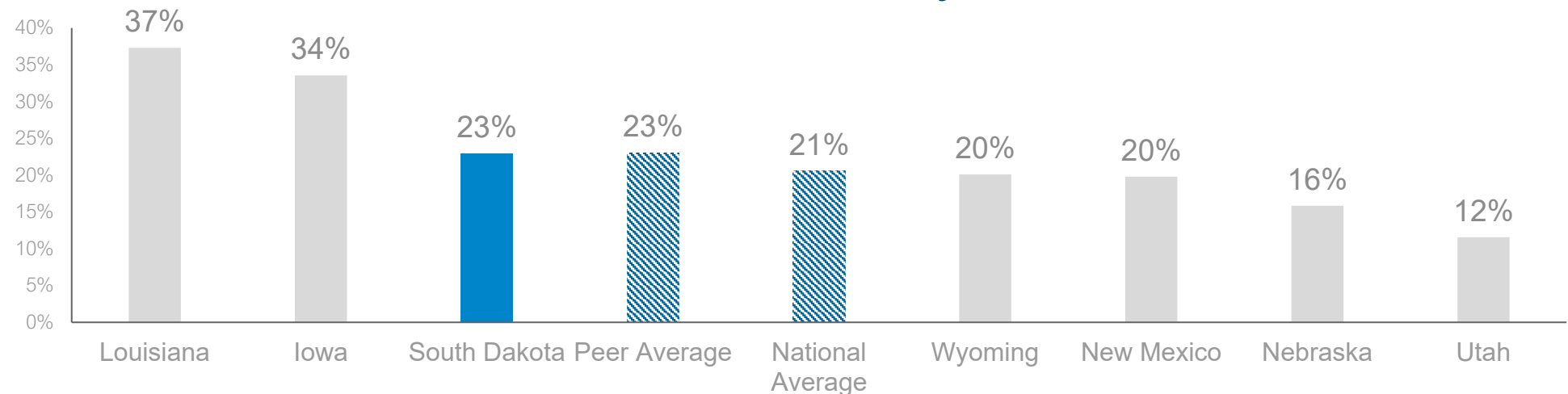
## Foundational Strengths

- **Strong vision** for centralized and transparent intake process
- **End to end stakeholder engagement** to design and test new intake process
- Uses the ICAP for Level of Care, a **nationally used standardized tool** that is valid and reliable

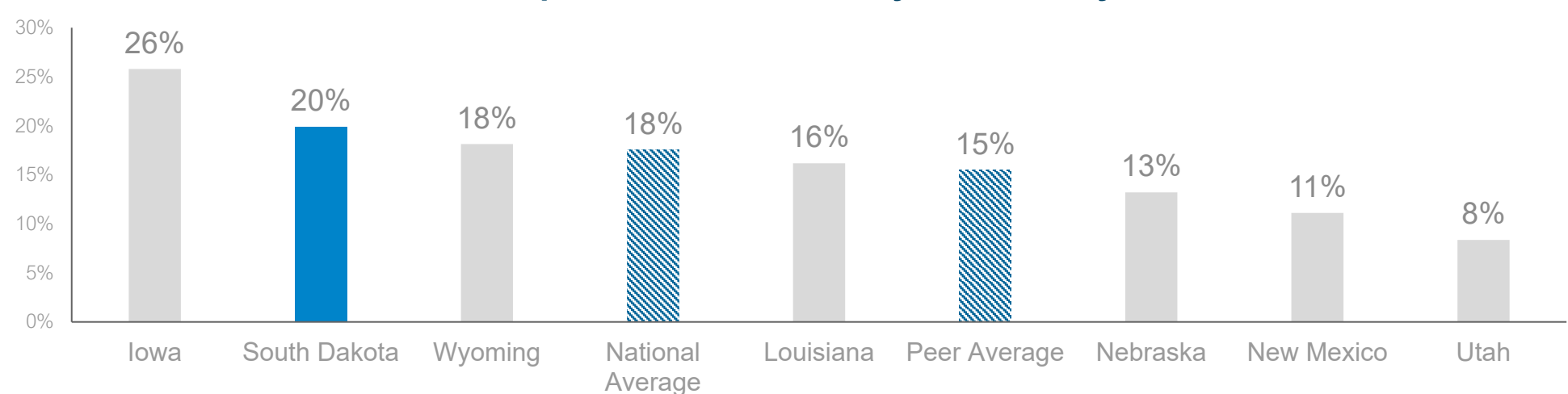
# Waiver Access: What's Working Well Today? (Part 2 of 2)

South Dakota's DDD reaches and serves a higher percentage of its total estimated I/DD population than most peers.

**% Known to State DD System**



**% of People with IDD Served by State DD System**

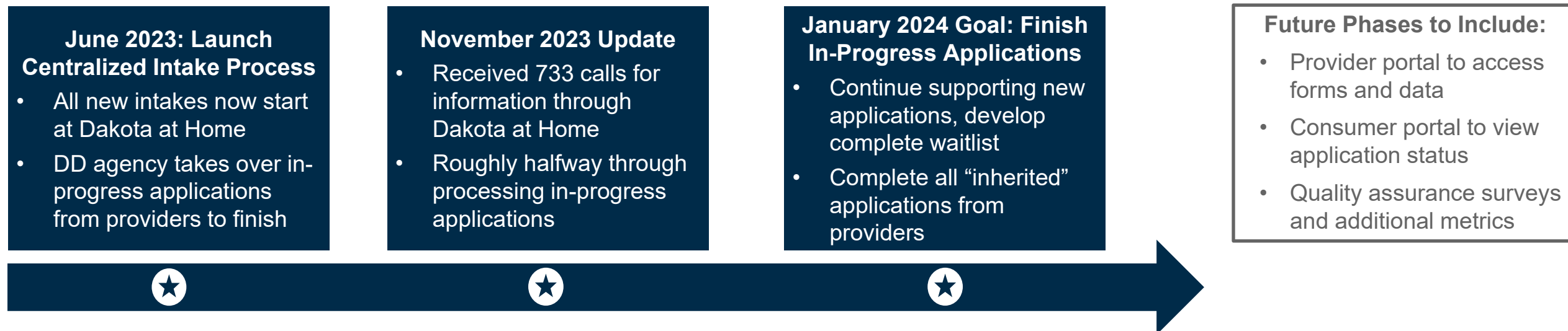


## Key Takeaways

- Generally, **SD performs on par with or better than peer states** when evaluating access to state-provided DD services.
- The estimated percentage of the I/DD population **“known” to the state is 23%**, equivalent to the peer state average and **2% higher than the national average**.
- The estimated percentage of the total I/DD population **served by the State DDD is 5% higher** than the peer state average and **2% higher** than the national average.

# Waiver Access: The Vision for a New, Centralized Intake Process

DDD is currently leading major transformation work to centralize the application and intake process. Below is a summary of what's in progress.

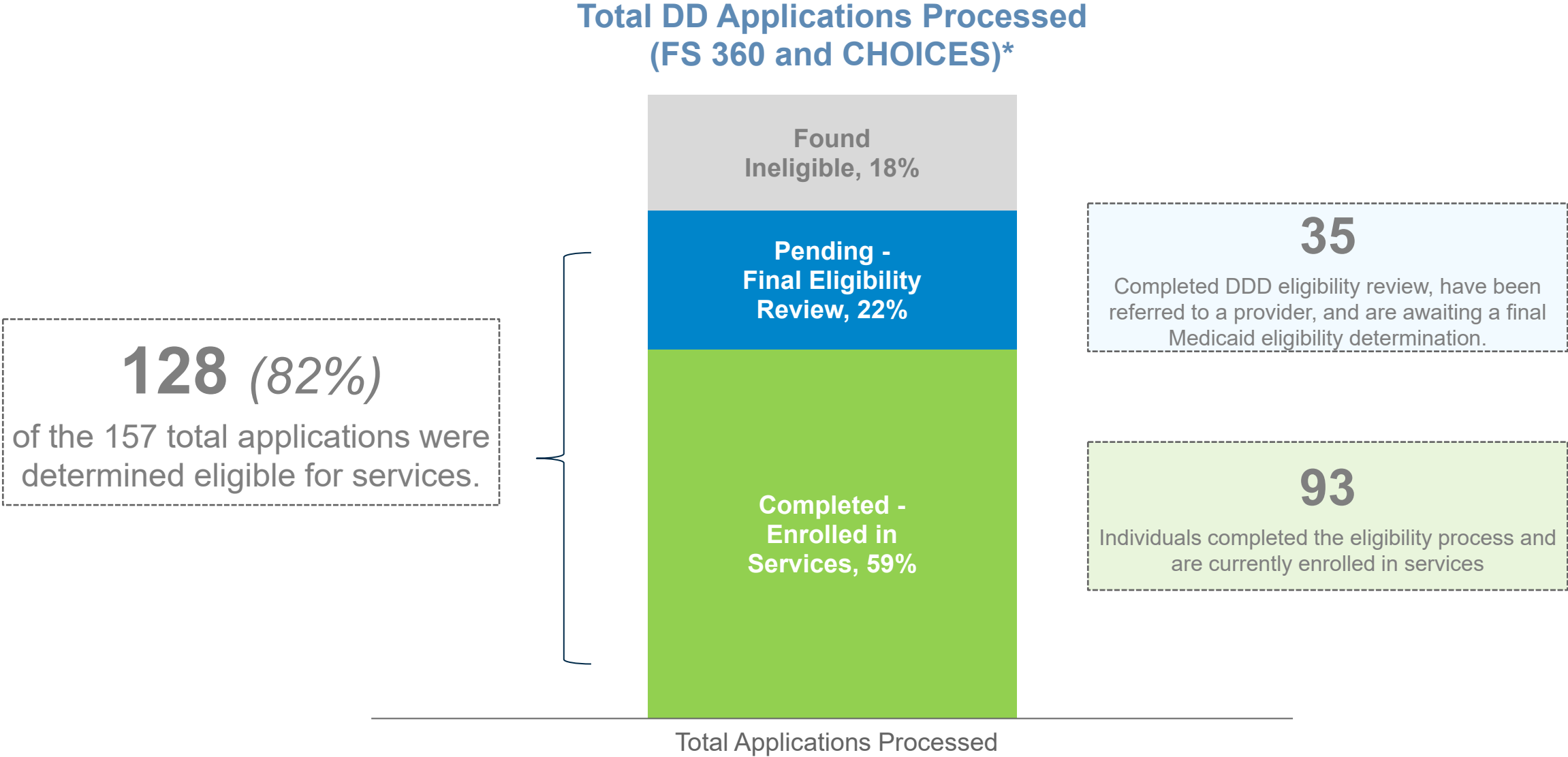


**A&M supports the new intake process and anticipates the following benefits once this work is complete:**

- Increased ability to **prioritize people at risk** of institutionalization: with all applications in one place, they can be evaluated to understand need
- **Equity and fairness:** centralized intake allows applications to be processed in the order they are received (with exceptions for high need)
- **Increased choice** for people and families: once a person has been found eligible for services and there is a waiver slot available, the person may select any provider that has capacity
- **Data-driven decision-making** provides an accurate and up-to-date view into the number of people seeking services and allows the state to project what would be needed to meet the need (waiver slots, funding)
- **Accountability:** Intake now starts with the DDD, and the agency is responsible for processing the applications
- **Transparency:** DDD is working with a national IT vendor to build a user-friendly portal so that applicants can know the status of their application

# Front Door to Supports: Progress Completing Application Processing

DDD launched the new centralized intake process in July 2023. Since this launch, DDD has completed DD eligibility review for 157 applicants.




\*Application data provided by DDD, updated 11.9.23 .


# Waiver Access: Increasing Awareness About the New Application Process

DDD is still rolling out the new intake process. Provide information and regular updates to families and other key partners as this work continues to ensure that people understand the path to accessing services.

- **What A&M heard:** Some people expressed **confusion about how the new intake process works**, especially regarding how long the new application process is intended to take
  - A&M spoke with someone who had gone through the process and thought their application was lost because of how long it took. After speaking with them about their experience, the application was processed within the right timeframe, but they did not understand what the timeframe should be or where they were in the process during any given step.
  - Families shared that they don't understand how the new process is supposed to work: **"It's just a web of confusion"**
  - People voiced that they had difficulty tracking their application through the process: **"You feel blind. You feel helpless"**

-  **Recommendation: Increase people's insight into the application process** by posting the application and an overview of steps / associated timelines on the website, along with **plain language updates on the new process**. Finish building the **new consumer portal** to give people a way that they can follow their application throughout the process.

- 
- **What A&M heard:** Key partners don't yet have a strong understanding of the new intake process.
    - Example: Sister agencies who we spoke with talked about the fact that they did not understand how the new process worked, or how they should refer someone who they considered to be high priority for intake.

-  **Recommendation: Conduct outreach to explain the new intake process to partners**, including sister agencies and common referral sources such as doctors and schools who help spread information.



# Waiver Access: Additional Ways to Enhance the Customer Intake Experience

As DDD implements the new intake process, it will be essential to develop quality assurance measures to ensure a strong customer experience. A&M has also identified a couple of areas where DDD can immediately enhance current practices to reduce barriers in application length and difficulty.

- **What A&M heard:** Some consumers reported difficulty with the new intake hotline, including challenges getting to intake staff and trouble having calls returned. DDD recognizes the need to learn more about how the new process is working for customers and is working to create customer surveys for intake phone calls, as well as hiring staff to support additional quality assurance



➤ **Recommendation:** Expand on the initial quality assurance (QA) efforts already underway and **develop a comprehensive QA strategy** to drive continuous assessment and improvement of the customer intake experience.

- **What A&M heard:** It can take a year+ to complete an application for DDD services because of waiting lists to get required psychological exams. For some people, who are not on Medicaid, this can be cost prohibitive too.



➤ **Recommendation:** Expand the current DHS psychologist contract to **increase access to psychological exams** that are required as part of the application process.

- **What A&M heard:** There is confusion around eligibility requirements for older people who do not have typical intake paperwork
  - Example: We heard stories about adults living in rural communities who had aging caregivers and who had never applied for services before. Both community members and service providers believed these people would need full documentation to apply for DD services, and that this would be a barrier to those who never received formal diagnoses as a child.

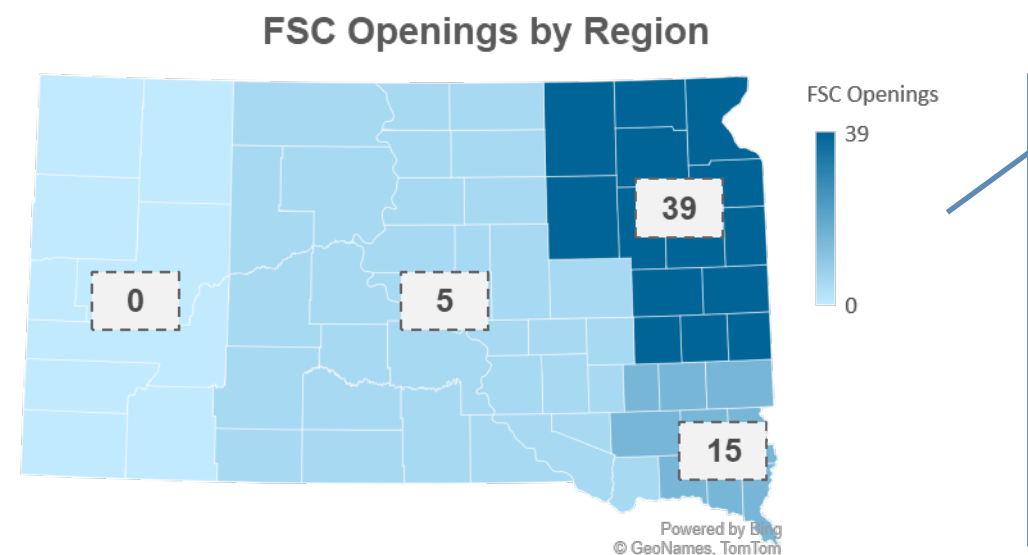
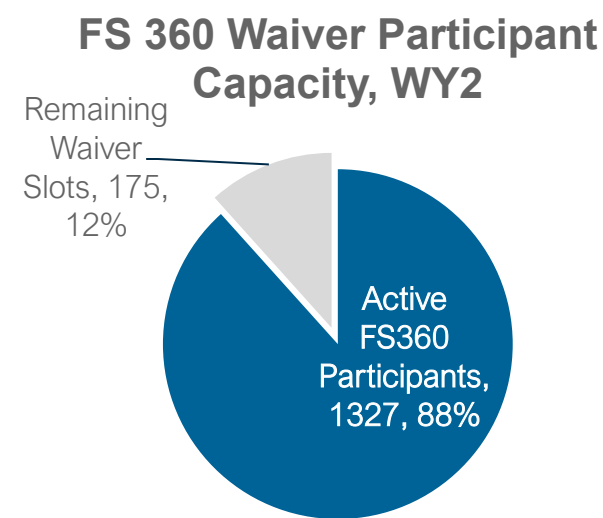


➤ **Recommendation:** **Share information on DDD's flexible and modified application requirements for people without traditional system paperwork**, including options for social histories, by conducting targeted outreach to resources like senior centers.


# Waiver Access: Increasing Family Support Coordinator Capacity

Eligibility is the first step to receiving FS 360 waiver services. Next, a person must be matched with a Family Support Coordinator, who will engage in person-centered planning with them to identify needed services and supports.

- **What A&M heard:** Historically, there have been waiting lists to get a Family Support Coordinator (FSC) and **it is unclear whether there is sufficient capacity for all the people coming through the new front door process to be matched with an FSC**, especially in rural areas. Families are worried that when everyone waiting at the front door moves through the process, there will not be enough FSCs available.



It is possible that small waiting lists may develop in pockets of the state that have less family support coordinator availability. Waiting lists currently are not dependent on waiver slots, but rather on FSC capacity.

 **Recommendation:** Family Support Programs currently use a 1:40 ratio. A provider must open a new program for up to 40 people. Convene a **workgroup with providers and families to develop a path to increase access to FSCs**, for example, **explore options to create a pathway for part-time FSC positions (1:10 / 1:20 ratios)**.  
*Note: A&M heard from family members who would become an FSC if they could do this part time.*

# Summary of Key Access Recommendations

The new centralized intake process is an important initiative that will give DD the ability to plan for and deliver services in a more strategic manner. To support this positive change, DD should prioritize sharing information that will help people understand and successfully navigate the new process.

★ Core Access Recommendations

**Increase awareness and transparency of the new intake process by:**

- **Sharing information** about the process, including timelines, on the DHS website
- Conducting **targeted outreach** to key partners to educate them on the process
- Finishing the **consumer application portal**

**Ensure access to waiver slots and enhance FSC capacity to match demand for services by:**

- Partnering with families and providers to **identify options that can increase FSC capacity**, especially in geographic areas of high need

## Additional Recommendations to Enhance Access:

- Implement an overarching **quality assurance program** to measure and improve the customer experience
- **Resolve known barriers** that can lengthen or impede the application process
  - **Psychological testing** wait times and cost
  - The need for increased **awareness of flexibilities** for nontraditional applicants

# Waiver Operations & Administration

*This section will talk about how the DDD does its work. It includes partnership with Family Support Coordinators, person-centered planning through the new Individual Support Plan, self-direction and the new Common Law option, and how things are handled when things go wrong, as well as interactions with the Family Support Council.*

*DDD and stakeholders have a shared vision and DDD is working hard on initiatives to move to a person and family centered system. A history of narrowed program flexibilities and confusing and perceived insensitive notices have resulted in breakdowns in communications and trust. DDD is making strides to communicate and engage families, but more plain language communication and ongoing opportunities for partnership are needed.*

# Family Support Coordinators



Family Support Coordinators are a highly valued resource for families on the FS 360 waiver. Families truly appreciate the empathy and support they receive from their FSCs.

➤ **What A&M heard:** Family Support Coordinators are the people who do person-centered planning with the person and their families. Family members appreciate that their Family Support Coordinators (FSCs) are family members. FSCs each have a person-centered one-page description that helps families get to know them and helps give families an informed choice of providers. Families and self-advocates shared that when an FSC is not responsive, it is easy to switch. Self-advocates appreciate that control. **“They work for me.”**

- Over 40% of survey respondents mentioned family support coordinators in free text responses about what was worked well in FS 360. Quotes included:

## Survey Results

- **“Having a coordinator handle all the details has made a big difference for us. It was too much for me to try to stay on top of things... Our support coordinator has been wonderful!”**
- **“The ability to get advice from the coordinator, bounce ideas off of and get information about various needs...Our coordinator truly is an extension of our family.”**
- **“Service coordination helps to access services we need to help our child develop”**



People exist and have reciprocal roles within a family system, defined by that individual. Roles adjust as the individual members of the family system change and age. The entire family, needs support to ensure they all can successfully live their good life.



# Individual Support Plan

A&M supports the new Individual Support Plan, which embeds person and family centered planning.

## Key concept: Individual Support Plan (ISP)

- *Definition:* An ISP is the document that defines an individual's goals and the services that will support them in achieving these goals. FSCs and case managers help families and self-advocates put together the ISP using Charting the LifeCourse tools.
- **What A&M heard:** The new Individual Support Plan (ISP) takes longer but has resulted in new understandings and better goals for people with I/DD. We heard from a mom who gained a new understanding of her daughter, who does not speak with words. We heard from FSCs, **"It helps align goals with the person."** **"I love the new ISP"**
- Some family members have not had a good experience with the new ISP. Upon exploration, this appears to be based on having an FSC who may not implement the tool correctly.
  - Family Support Coordinators received training on Charting the LifeCourse when the DDD first became engaged with the National Community of Practice. Since 2019, all new FSCs have gone through Foundational Skills training. This is a good start, but more is needed to move from awareness to practice.
- Person and family centered thinking requires an ongoing investment in capacity building across the system. Training is an important first step to bring awareness of this new methodology. Ongoing capacity building and will help support implementation.



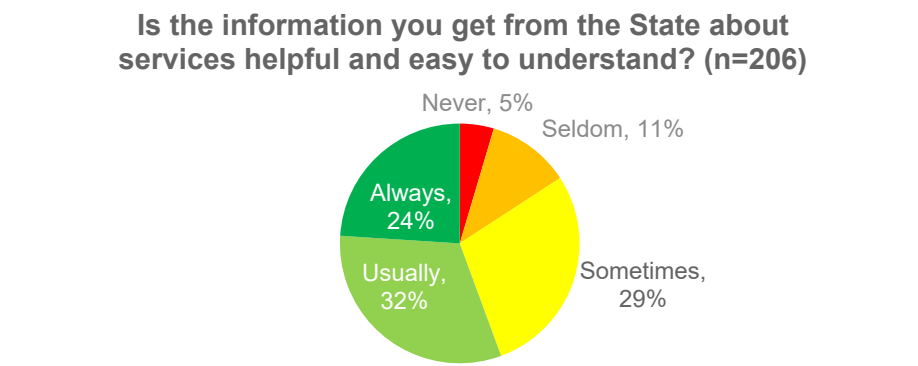
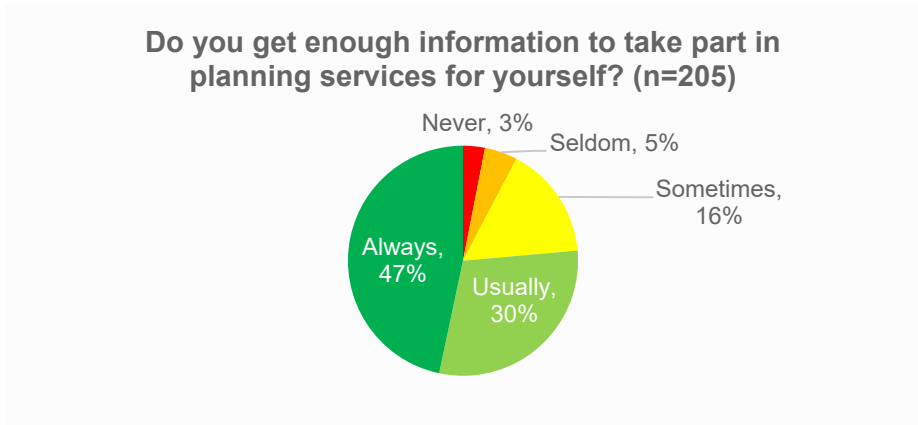
**Recommendation:** Build upon the existing requirement that new FSCs receive training in the Charting the LifeCourse (CtLC) to include a **new requirement that all FSCs receive training in the CtLC framework**. Charting the LifeCourse supports person and family centered planning and is the basis of the new ISP. Talk with providers how to achieve this (eg, what is the impact of training requirements on providers; are there preferred methods; compensation for training time; etc.). Co-create a plan for implementation.

# Service Planning

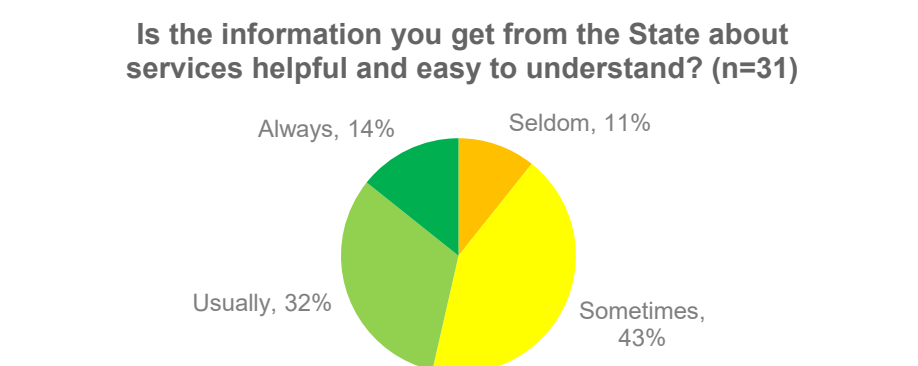
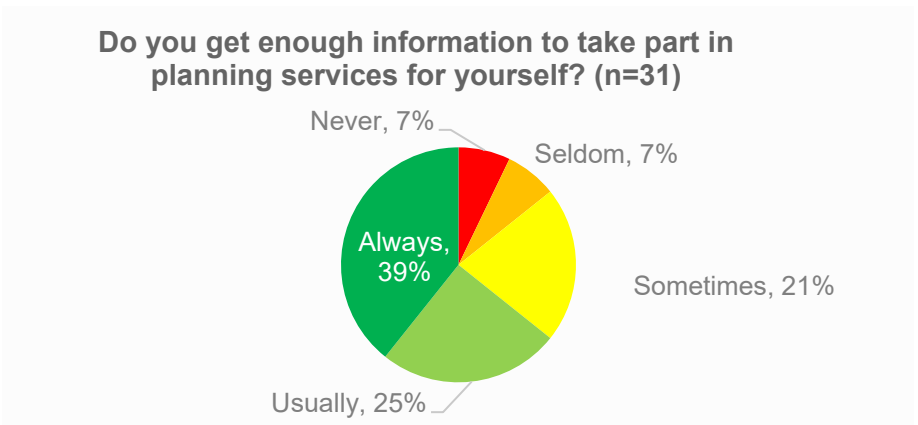
Critical to person-centered planning is having the person lead the process, supported by whomever they choose. To do this, information must flow.

Responses to A&M’s survey for both FS 360 and Shared Living indicate that nearly 25% of respondents don’t have the necessary information to participate in person-centered planning at least some of the time. Approximately half of the respondents find information from the state challenging to understand. **For the new ISP to be implemented with fidelity, plain language communications are needed to help people and their families lead their planning.**

## FS 360



## Shared Living



# Increase Understanding of Service Flexibilities in FS 360

A history of service restrictions, combined with waiver amendments that expand flexibility but have not been adequately communicated, have resulted in Family Support Coordinators and family members not understanding what are and are not covered services.

- **What A&M heard:** Both FS 360 Family Support Coordinators and families are confused about what is and is not covered. There is a sense that items that used to be covered are not any longer. **“We have stopped requesting certain items.”**
- Likewise, we heard that there is some confusion among DDD staff. **“There is a problem with some program specialists approving goals for something when another program specialist would never approve the same goal using very similar verbiage.”**
  - **Example:** DDD has update the FS 360 waiver to include flexible assistive technology services, but some families and Family Support Coordinators did not know about this change. We heard from a family member who was excited to have this service approved for her son, after learning about it from another family member at one of our listening sessions
- DDD has taken some steps to expand program flexibilities, but without a strong understanding of the changes, people may not be able to benefit from them.

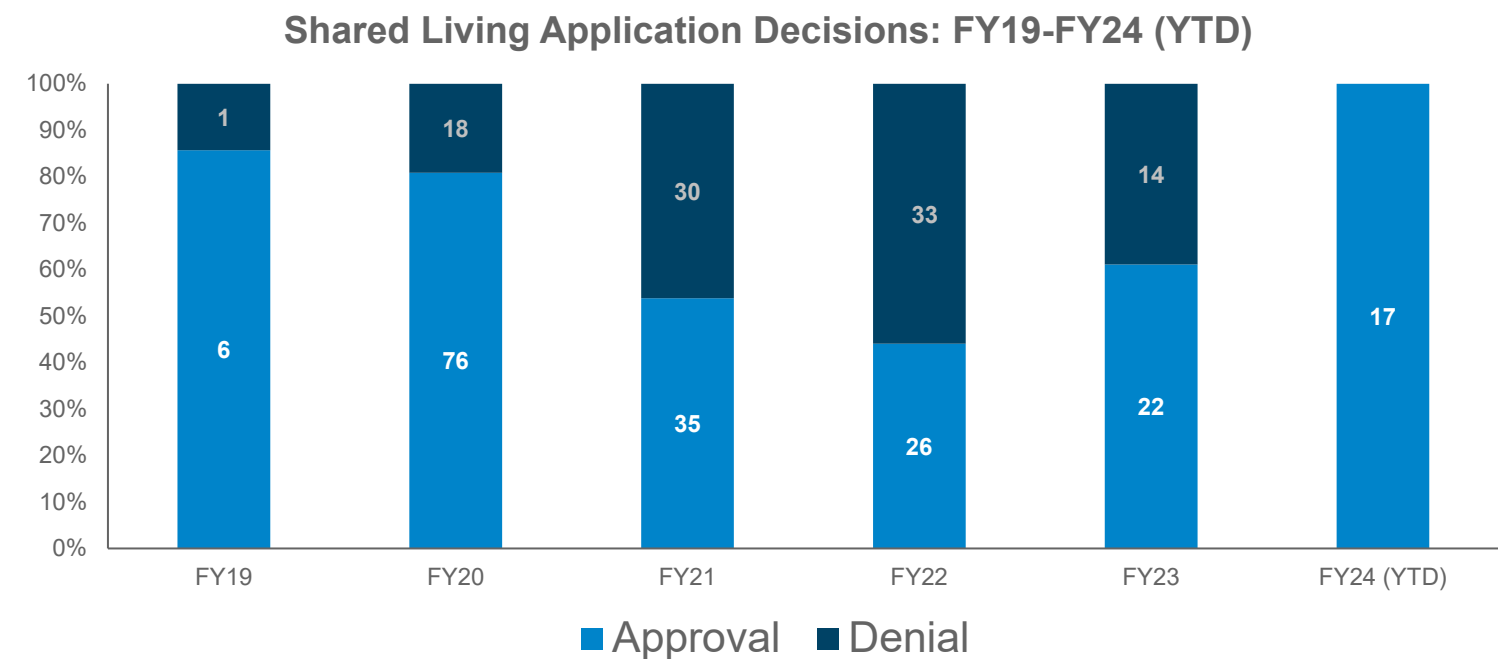


**Recommendation: Develop a plain language version of the financial guidelines** to build a common understanding. Continue to communicate new service flexibilities with Family Support Coordinators and families.

# Service Planning: Spread Awareness of Expanded Shared Living Program

Previously, Shared Living was a program for people with very high support needs. DDD has recently expanded the program by introducing tiers so that those with lower needs can also qualify for the program, but this expansion is not yet widely understood.

- What A&M heard:** We met family members who had applied for Shared Living in the past and were denied. They did not know that DDD had amended the CHOICES waiver to allow many more people to qualify for this service.



**Key Highlight:**

There are 86 people who applied for Shared Living and were denied in the five years prior to the changes in the program to add flexibilities. Since the changes, all applicants have been approved.



**Recommendation:** Review Shared Living denials from the 5 years prior to the change in eligibility. Invite those families to reapply, if desired.

# Service Denials

Denial letters serve an important role in enabling due process, but they must be understandable.

- **What A&M heard: Denial notices are confusing and are perceived as insensitive** and not understanding the lives of people with disabilities and their families. Families talked about understanding Medicaid rules and wanting to be resourceful. Denial letters and comments from DDD staff left them “**feeling shamed.**”



## Denial Letter Examples

Examples included language denying items because

- they were deemed to be **a toy** (weighted stuffed animal, fidget)
- for the **convenience of the family** (Shared Living)
- **not encouraging independence** (adaptive bicycle)
- because **others in the house could use it** (blender for a child who have a pureed diet)




**Recommendation: Develop a plain language versions of the denial notice that helps families understand when something is not covered.**




# Appeals & Problem Resolution

Families are looking for non-adversarial ways to engage with DHS when they think something may be wrong.

- **What A&M heard:** Families are looking for a way to raise issues when something goes wrong, or they disagree with a denial without it becoming an “**adversarial process.**” One family member shared that there is “**No ability to state your case without going to the appeals process. Just want another in between option before going through the process.**”

 ➤ **Recommendation: Develop a complaint/ grievance, or ombudsman process** to help families raise issues and seek resolution. This will also give the DDD information about how people are experiencing their services and understanding rules. Reviewing themes will help DDD understand what’s working and where there are opportunities to improve.

- **What A&M heard:** Some families were surprised when they learned that the Department of Human Services may reject an Administrative Law Judge’s decision in favor of a family member.

 ➤ **Recommendation: Include a full description of the appeal process in the denial notice**, so families have full information when they are deciding whether they want to appeal.

# Self-Directed Services

Self direction lets people with intellectual and developmental disabilities and their families have more choice and control in their lives. The new common law option creates even more opportunities for self-determination.

## What A&M heard:

- Families are curious about the new common law option and want to understand more about how it works and the additional responsibilities that they would be taking on.
- Families are frustrated by the 20 hour/ week limit that agencies with choice have placed upon companion staffing. This creates an alternative.
- The new Common Law option builds upon the strong history of self-direction in the State. Families will need support understanding and getting started with this new option.



Strength

**A&M supports the new Common Law option.** It is rooted in supporting self-determination. It supports people with I/DD and their families to plan their own lives, make their own decisions, determine how resources are spent for supports, plan and choose their own supports, and take responsibility for how decisions are made. It shifts authority for decision-making to the person and their family. It changes the way supports are funded to give people direct control over their funding, putting the person into the center of the relationship between the state and their provider.

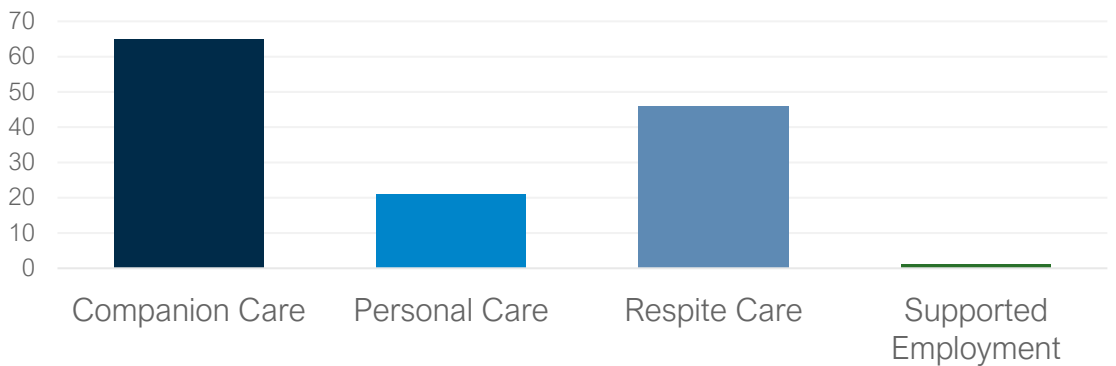


**Recommendation: Provide “Information and Assistance”** services to families who self-direct using the Common Law option. This can be done through a support broker waiver service, through contract, and/ or through a staff person.

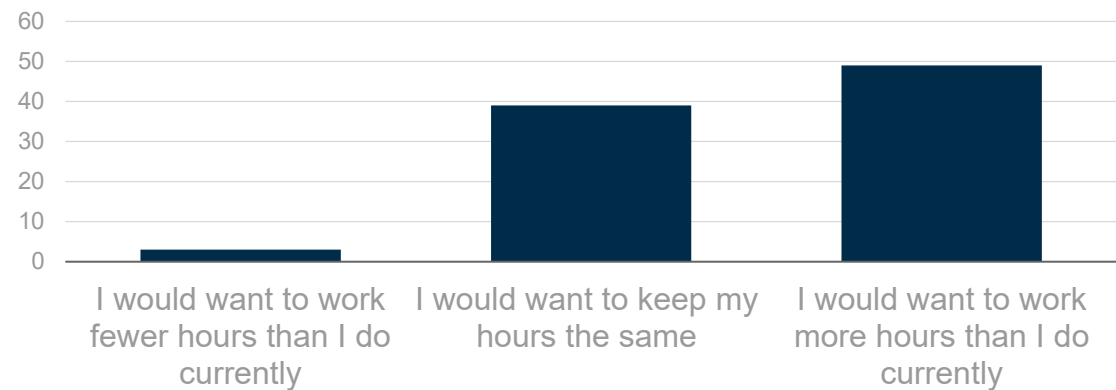
# FS 360 Self-Directed Worker Survey

A&M surveyed FS 360 companion workers. The data shows that families are doing a good job as employers. Workers are getting the training, support and direction they need. Most workers would work more hours, if it were allowable (as it is under the new Common Law option).

What types of FS360 services / supports do you provide? (n=92)

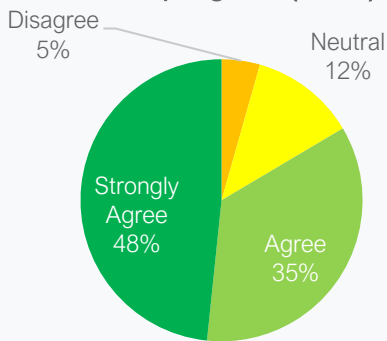


If you had the option, how many hours would you want to work providing FS360 services? (n=91)

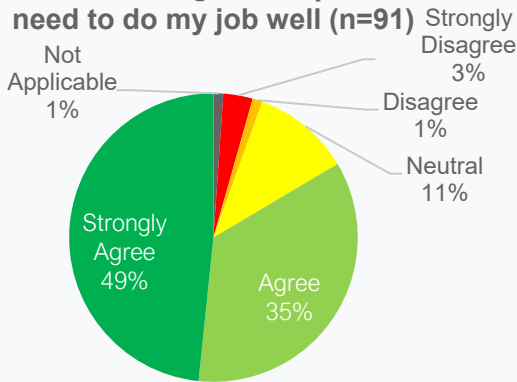


Additional survey data included in the appendix

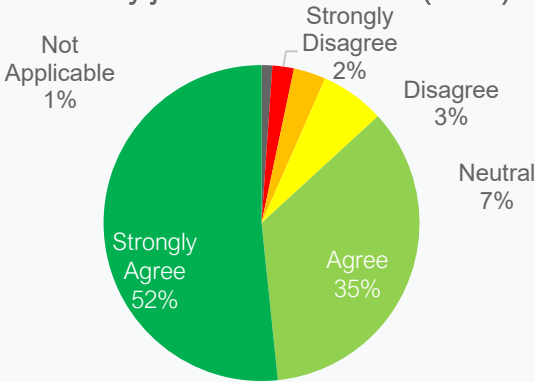
Overall, I am very satisfied with the FS360 program (n=91)



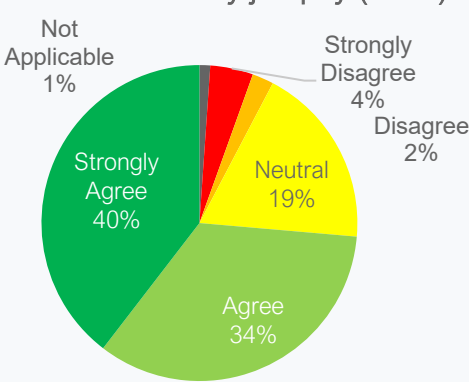
I have the training and supervision I need to do my job well (n=91)



My job duties are clear (n=91)



I am satisfied with my job pay (n=91)



# Self-Directed Services: Additional Recommendations

While the DDD is currently launching this new option for the people it supports and their families, there are some enhancements to help build a strong program.

- **What A&M heard:** Self-advocates and families value the ability to hire their own staff. Like all employers, they are experiencing workforce challenges. This is exacerbated by not being able to offer someone more than 20 hours/ week using the Agency with Choice model.



- **Recommendation:** The new Common Law option allows the person and their family to hire a person for as many hours/ week as they have been approved, based upon their assessed need. **Develop materials for intake staff to share about self-directed options at the front door**, so that families can begin understanding their options and planning early in the process to identify staff select a form of self-direction.

- Agency with Choice remains an important option for people and families who want more support directing their services. Providers have limited the effectiveness of this option for some families with the 20-hour limit on the number of hours that a companion staff can work within a week.



- **Recommendation: Explore options to expand the Agency with Choice provider network capacity.**

- Self-direction is currently only available in the FS 360 waiver.



- **Recommendation: Explore options for people in the CHOICES waiver who use Shared Living services to self-direct to increase access to respite services.** Many Shared Living families started in FS 360 and had a relationship with a self-directed companion or respite worker. Because of the differences in provider qualifications set by the Community Support Providers in the CHOICES waiver and the more flexible qualifications for self-directed workers, the family may no longer be able to use that worker.

- As DDD launches this new program, it will be important to understand how it is working and how it can be improved.



- **Recommendation: Develop a self-direction work group** to: (1) develop a participant promotion strategy; (2) develop metrics to understand satisfaction from the perspective of people and families who are using the service, and their staff; (3) develop quality metrics.

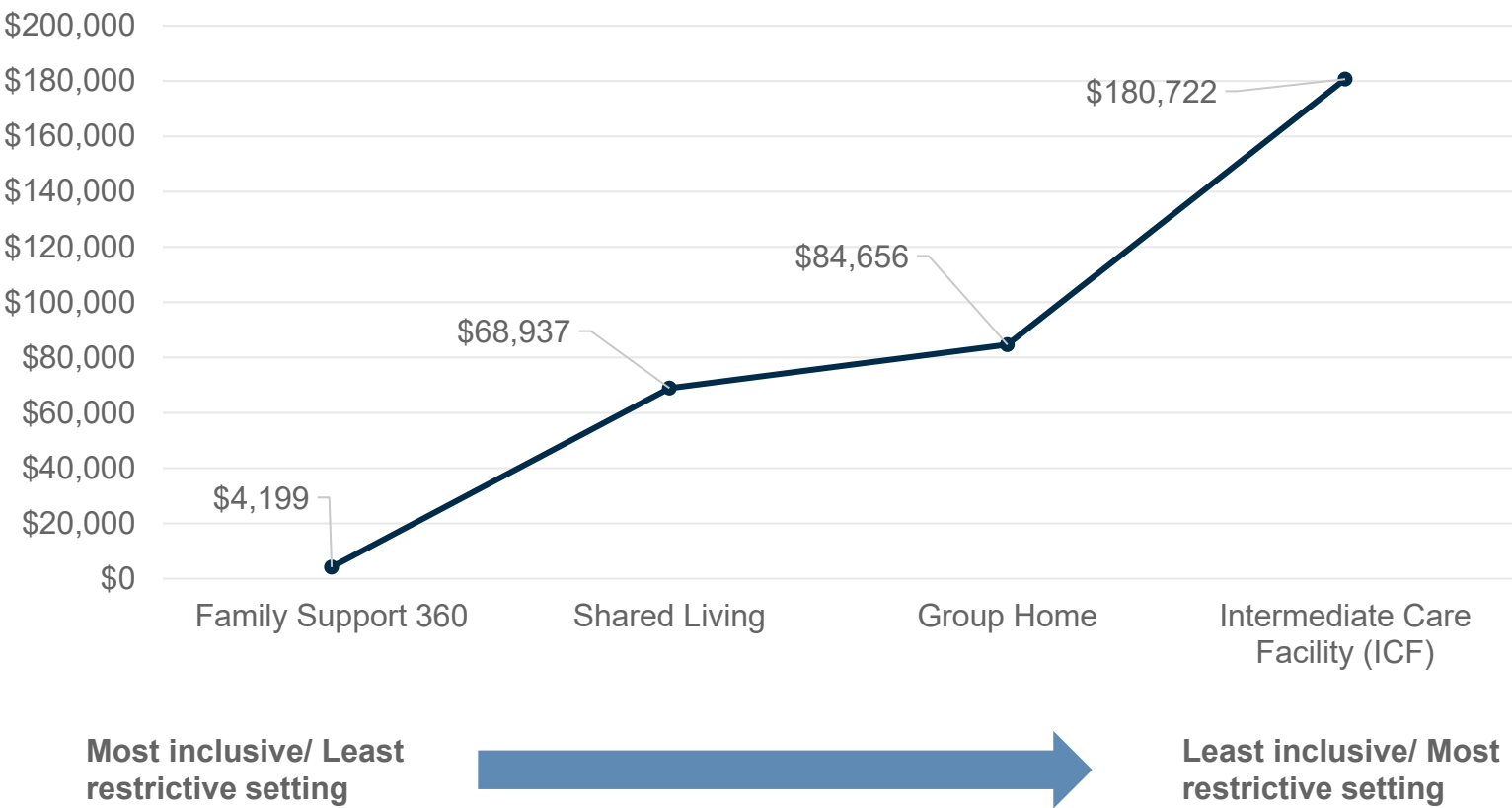
# Sustainability

*This section will talk about the services that the Division of Developmental Disabilities (DDD) offers, the amount it spends to support people with intellectual and developmental disabilities and include recommendations for a limited cost-effective investment to improve the service array that support people to live in the community, with their families; as well as additional staffing opportunities.*

# The Value of Community Based Services

I/DD services exist on a continuum, ranging from lower cost FS 360 supports that wrap around family caregivers, to institutional supports for those with the highest needs. The more effectively the State can serve and keep people in the community, the more people they are able to support overall.

Average Annual Cost Per Person, Compared Across South Dakota I/DD Services



Service	Total Annual Cost Projection	Estimate of Participants
Family Support**	\$6.3 million	1,502
Shared Living**	\$7.8 million	113
Group Home**	\$105.8 million	1,250
ICF*	\$31.8 million	176

To Note: Cost estimates rounded to nearest tenth of a million  
Total cost includes federal Medicaid match

\*ICF cost data sourced from RISP 2018 State Data  
\*\*Group home, Shared Living, and Family Support costs sourced from Appendix J waiver year one projections



# Comparing State Spending on Family Support Programs

Family support waivers are designed to wrap-around family caregivers and provide lower cost integrated supports that make it possible to support people with I/DD in the community. Many of South Dakota’s peer states also provide these waivers, at varying levels of cost.

State	Waiver Participants	Average Spend/Person
Iowa	N/A	N/A
Louisiana – Children*	2,200	\$10.4K
Louisiana – Adults*	2,100	\$6.6K
Nebraska	1,055	\$12.5K
New Mexico**	2,519	\$79.3K
Utah	120	\$24.5K
Wyoming	618	\$15.2k
South Dakota	1,502	\$4.2K
Peer State Average	1,445	\$24.8K

- South Dakota spends less per person on its family support waiver than its peers (peer states as identified by SD leadership) and generally has a more limited-service array
- It is important to manage spending and maintain fiscal responsibility
- However, waivers must also provide families enough support to make family caregiving a sustainable long-term option

*\*Note: Louisiana has two family support waivers – one for children, and one for adults. We have included both waivers in this analysis.*  
*\*\*Note: New Mexico also has a waiver called the Supports Waiver (average spend \$6.8K); however, this is a targeted waiting list waiver not intended to serve people long-term. The Mi Via waiver is the closest match to a self-directed, IFS waiver that provides long-term services.*

Source: Appendix J Waiver Budget Projections Submitted to CMS, for Waiver Years in 2023. Spend rounded to nearest tenth of a thousand  
Additional information on peer state family support waivers included in the appendix

# FS 360 Service Array

FS 360 provides valuable supports to families. A narrow service array and lack of flexibility have limited the effectiveness of the program. A limited investment that adds flexibility would further support people and families.

- **What A&M heard:** People with intellectual and developmental disabilities described integrated lives, where services are appropriately tailored to support them and are just one part of their lives. People described spending their time working, volunteering, playing sports, going to church, etc.
- **What A&M heard:** Families are very appreciative of the FS 360 services they are receiving. **“Family Support has been wonderful for my family.”**
- **What A&M heard:** FS 360 families reported that there has been a restriction in service flexibility over the past five years. Specific examples include fences, weighted stuffed animals, adaptive toys, sensory items, blenders for people who need pureed food, fidgets, mattress encasements for people with incontinence.
  - We heard from a mom who has three sons with autism, **“Getting a fence was life changing. We could go outside in the summer to play.”**
  - **“Everything I want to do, I am told no.”** – from a mom of an adult with intellectual and developmental disabilities who lives with her
  - **“We were asking for a mattress encasement because my child will strip all coverings from his mattress and then soil the mattress or spill on the mattress. We were told that isn’t possible because it’s no different than how any other teenager would use a mattress. That’s a disconnect. Most teenagers who are neurotypical don’t strip their bed coverings and soil their mattresses.”**
  - **My child’s “therapist and doctor and teachers are willing to give recommendations. But the goals are still denied. We want to know how they are better versed in what our children need.”**
  - **“The new ISPs are meaningful, but then leading to denials.”** – from a Family Support Coordinator
- **What A&M heard:** Families also suggested additional services that would be helpful, for example: transportation, a buddy/ safety monitoring service.

# FS 360 Recommendations for Investment

There is an opportunity to work with self-advocates and families on a waiver amendment that adds needed flexibility, while limiting fiscal impact.

The recommendations below are examples of possible service array changes, including potential waiver amendments, that are responsive to what we heard from families. Recognizing limited resources, A&M's overarching recommendation around waiver service array, is that DHS **develop a work group that is majority self-advocates and families**, to discuss the options and policy considerations, and recommend an approach forward for waiver amendments that prioritizes what people and families find to be the most important supports. This would require ***support and engagement by South Dakota Medicaid.***



➤ **Recommendation for Policy Change: Change the financial guidelines to allow fences for people with an assessed need.** South Dakota can put restrictions on who would qualify, for example, from New Hampshire: "For individuals with unsafe wandering and running behaviors, outdoor fencing may be provided under this waiver. Waiver funds allocated toward the cost of such a fence shall not exceed \$2,500."



➤ **Recommendations for Waiver Amendment:**

- **Develop a flexible, capped, "individual directed goods and services" offering** that would meet a person's assessed need, as identified in their Individual Support Plan, and would do at least one of the following (for example): decrease the need for other Medicaid services, promote or maintain community inclusion, promote independence, increase the person's health or safety at home, develop or maintain personal, social, physical or work-related skills, etc. Peer states: IA, NM, UT.
- Explore options to include transportation services. Peer states: IA, NE, NM, UT, WY.
- Add a limited non-habilitative/ buddy/ safety monitoring service (for example, to wrap around work). Peer states: IA & LA.
- Add capped services that support family and peer mentoring, and individual education, training and advocacy supports.

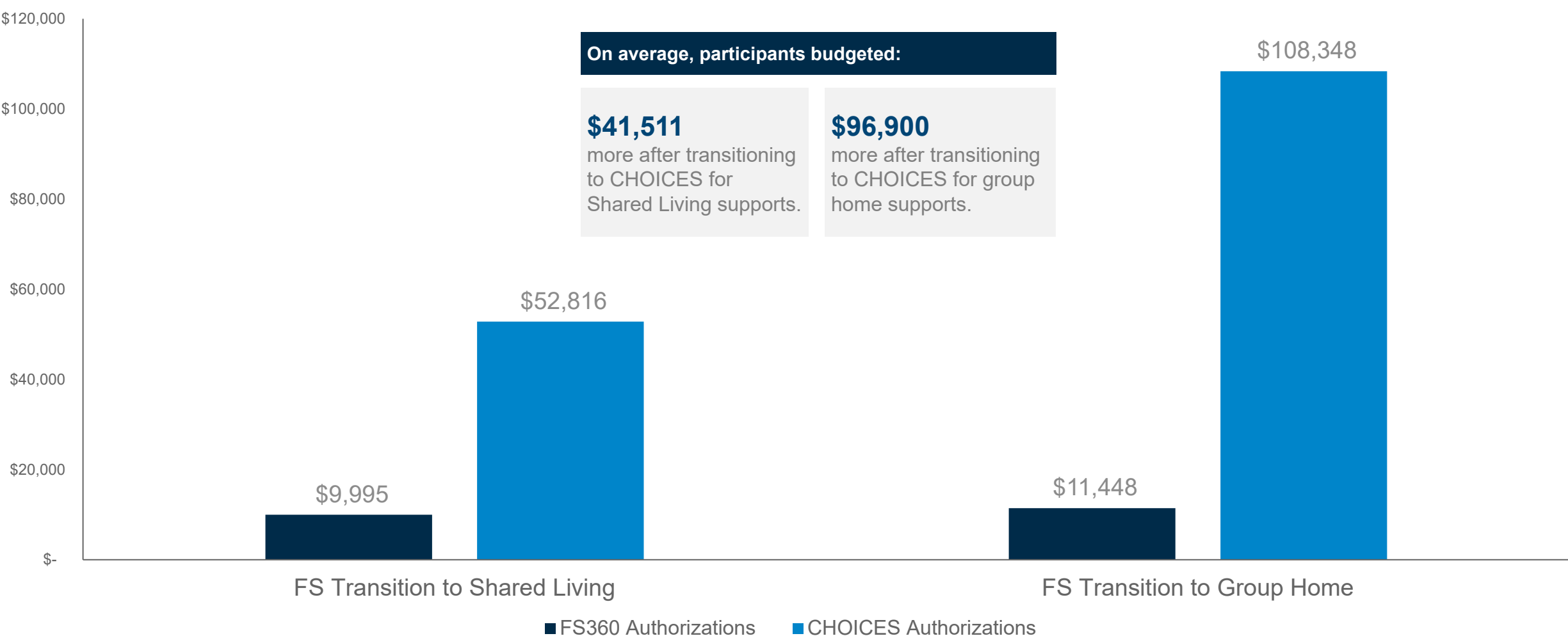


➤ **Recommendation for Partnering with People with I/DD and Their Families:** Use a neutral facilitator, so that the state can come to table as equal partners with people with I/DD and their families, to engage in conversation.

# The Value of Shared Living: Comparison of Sample CHOICES Budgets

DDD provided A&M with a sample of 25 anonymous individuals that previously transferred from Family Support to the CHOICES waiver. This sample included both individuals who enrolled in shared living (n=7), and participants who enrolled in group homes (n=10).

**Average Budgeted Amount per Person**  
*Sample of 25 individuals who moved from FS 360 to CHOICES*



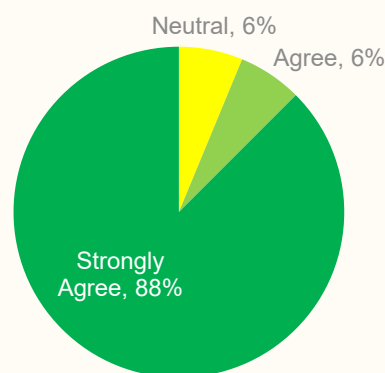


Strength

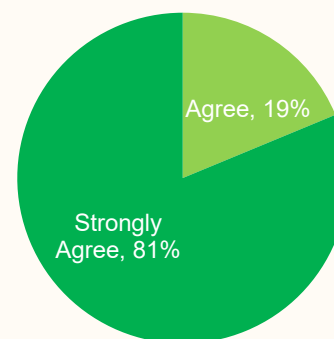
# Direct Service Provider Surveys – Shared Living

Shared Living self-directed service workers, Shared Living Providers (DSPs), are generally satisfied with their training, supervision, clear job duties, and pay.

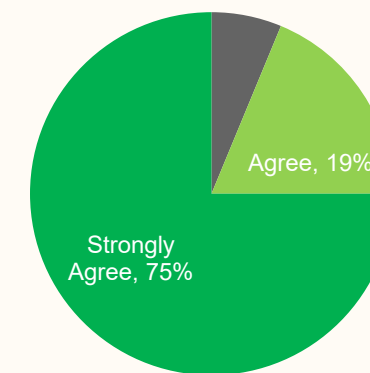
Overall, I am very satisfied with the Shared Living program (n=17)



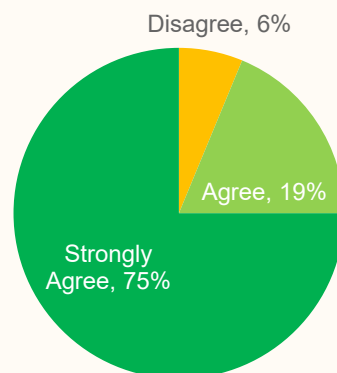
I have the training and supervision I need to do my job well (n=17)



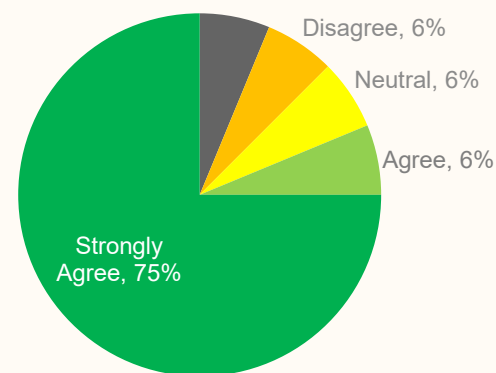
My job duties are clear (n=17)



I am satisfied with the process for billing Shared Living services / time (n=17)



I am satisfied with my job pay (n=17)



**More than 94% of Shared Living providers said they “strongly agree” or “agree” with each of the statements about program satisfaction and job training, supervision, and pay.**

# Shared Living

Shared Living is widely viewed as a great service option. Shared Living providers (often family members) need help getting a break so that they can continue to provide this service.

**Shared Living:** Shared living is a residential living option where a person with an intellectual or developmental disability lives with someone who wants to share a life and provide supports. The shared living provider can be anyone over the age of 18.



Strength

- **What A&M heard:** Shared Living is helping people live their best lives. **“Shared Living is a wonderful, great thing.”** Shared Living is an **“excellent, excellent program. That has been a life saver for us and our sons.”**
- **What A&M heard:** Some families, especially in more rural parts of the state, are struggling to find an approved Respite provider. We heard from several families that they had not gotten a day off in 8-10 months and do not know when they might ever get a break. **“Shared Living is the best life for my daughter. But it is not the best life for me.” “No time to myself for months.”**



- **Recommendation: Help Shared Living families access respite.** DDD has developed materials on integrated respite supports and partnered with the LTSS Lifespan Respite Coalition; share those resources with Shared Living Case Managers and families. Partner with provider agencies to collect and share information on approved individual respite providers. Consider amending the CHOICES waiver to allow Shared Living participants to self-direct respite services.

**Note:** A&M heard questions about rate adequacy from providers organizations. DDD is already engaged in a review of the new rates, using the first six months of data. A&M also heard concerns from Shared Living providers and provider organizations about the 10 hour of service rules (to bill for a day, the provider must provide 10 hours of support). As part of the rate review, consider other options to create additional flexibility for the individual Shared Living Provider (families and roommates). Peer state example: Utah (approach to paid family caregiver compensation).



# Staffing Recommendations

The current DDD team is lean, creating pressure on running the system day-to-day while envisioning and designing the future state with stakeholders.

Below are a list of potential staffing additions for consideration. Recognizing that there will likely need for prioritization. A&M notes that the DDD has also engaged in a staffing analysis. This includes positions that A&M did not assess given our scope, for example, new quality positions, a nurse to support PASSR, etc. **These recommendations should be viewed together with the DDD staffing analysis, as the DDD reviews its resources and determines the highest priority for supports.** Given the size of the state, some of these functions might be able to be combined.



## New Staff Positions for Consideration

- Lead for systems transformation initiatives
- Waiting list manager
- Ombudsman or informal complaint manager
- Nurse who can partner with families to help coordinate and plan for care at critical transitions
- Self-Directed Services lead to grow the program and provide information and assistance support to families


# Family Support Council

*This section shares feedback we heard from past and current Family Support Council members and associated recommendations.*


# Family Support Council (1 of 2)

The Family Support Council (FSC) creates an opportunity for partnership with DHS and families, double loop learning, and information dissemination from peers


- **What A&M heard:** Families recognize and appreciate the value of having a FSC as a path to working with the DHS. Members have suggested that partners should also be at the table.

 **Recommendation:** Medicaid is a key partner in home and community-based services. Include them as a non-voting member. FSC members should invite other partners to the meeting on an ad hoc basis. (Ex: Vocational Rehabilitation, Schools)

- **What A&M heard:** Members and past members mentioned the presence of DHS leadership and their attorney at the table, with a focus on both the number of people they are bringing and how they are engaging with families. **“They have control over the services for our kids.” “They are Erin Brockovich-ing us,” “It’s intimidating. It feels intentional.”** *(With respect to a DHS team of five leaders showing up for the meeting with their attorney.)*

 **Recommendation:** DHS leadership should continue to attend meeting so that they can hear directly from family leaders. Consider having the DD Director attend with other staff, as needed. The Department Secretary might attend a select portion of the meeting that is designated as a listening session to hear from members and the public. DHS staff should bring an awareness of the inherent power they have and seek to share that where possible. Consider options like a neutral facilitator or board training that would help everyone be heard.

- **What A&M heard:** FSC applicants and past participants are concerned that people who have complained about the DHS are not and will not be appointed to serve on the FSC. **“Feels like they are looking for yes people.”**

 **Recommendation:** This is symptomatic of an imbalance of power and/ or broken trust. Engage with families as equal partners in a reciprocal relationship.



## Family Support Council (2 of 2)

The FSC is an opportunity to bring family and DHS/DDD leaders together to problem solve and plan for the future together, based upon what families are experiencing around what is working and not working in the system.

- **What A&M heard:** There is only one self-advocate serving on the FSC.



**Recommendation:** Create space for more self-advocate participation. Update the Executive Order to require a minimum of 3 or more slots for self-advocates (currently only 1 is required). Fill these slots as vacancies occur. Since the time the Executive Order forming the FSC was signed in 2003, there has been research around how to best support self-advocates to meaningfully participate. One finding is that people with intellectual and developmental disabilities participate well when they can support each other.

Please see additional recommendations from the research on inclusive communication practices to the left. Note that it will be important to provide adequate support for self-advocates to participate fully, including support personnel and additional resources / travel assistance, as necessary.



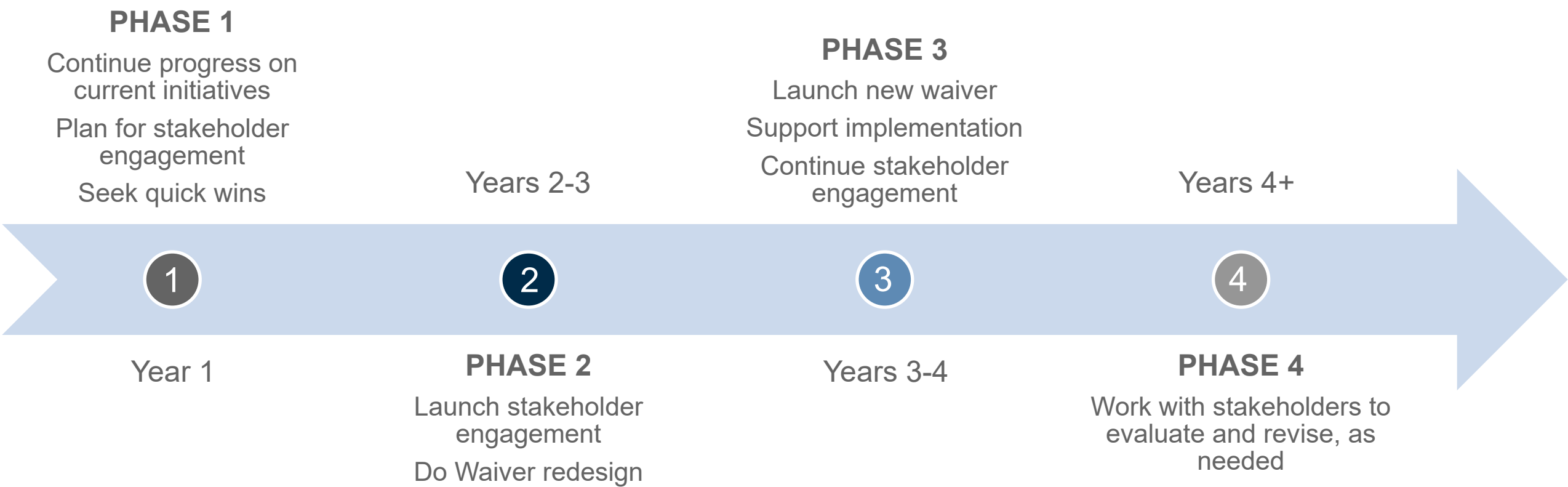
### Inclusive Communication Practices

- ☐ Recruit: Self-advocates tend to participate the most when they can support each other
- ☐ Materials: Share adapted materials at least 10 days in advance of the meeting
- ☐ Pre-meetings: Help people prepare
- ☐ Mentors: Peer supports for people who are new to workgroups and committee
- ☐ Interactive Meetings: The Beyond Tokenism study found that “Interactive meetings were one of the most effective methods for obtaining participation from all members but particularly people with complex needs.”
- ☐ Resources: Consider what additional resources people might need to participate

# Roadmap: The Path Forward

# Roadmap

Implementing these recommendations will bring sustainable and systemic change, but it is a significant lift. It will take time, FTEs, subject matter expertise, and funding (as needed).





# Quick Wins

DDD can start acting immediately to implement these recommendations, improve communications, and rebuild trust.

## > 90 Days

- Host meetings at various times of the day, including evenings and include a remote option
- Post DDD application and guidance with timelines on the website
- Share information on the new flexible AT service
- Share information about the new front door process with sister agencies
- Review Shared Living denials for the past 5 years and begin inviting people to reapply

## 3 – 6 Months

- Work with Medicaid to change financial guidelines to cover fences
- Develop new webpage that provides updates on system initiatives
- Begin meetings with providers to discuss how to increase capacity for Family Support Coordinators.
- Continue to invest in Charting the LifeCourse (training, Charting the LifeCourse in Action)

## 6- 9 Months

- Develop a plain language version of the financial guidelines
- Develop and share plans for partnering with people with intellectual and developmental disabilities for waiver redesign
- Work with the Governor's Office to amend the Family Support Council Executive Order
- Update new webpage

## Up to 1 year

- Pending funds availability, contract with a psychologist to provide examinations, as needed, for people at intake
- Update new webpage

# APPENDIX

# Background

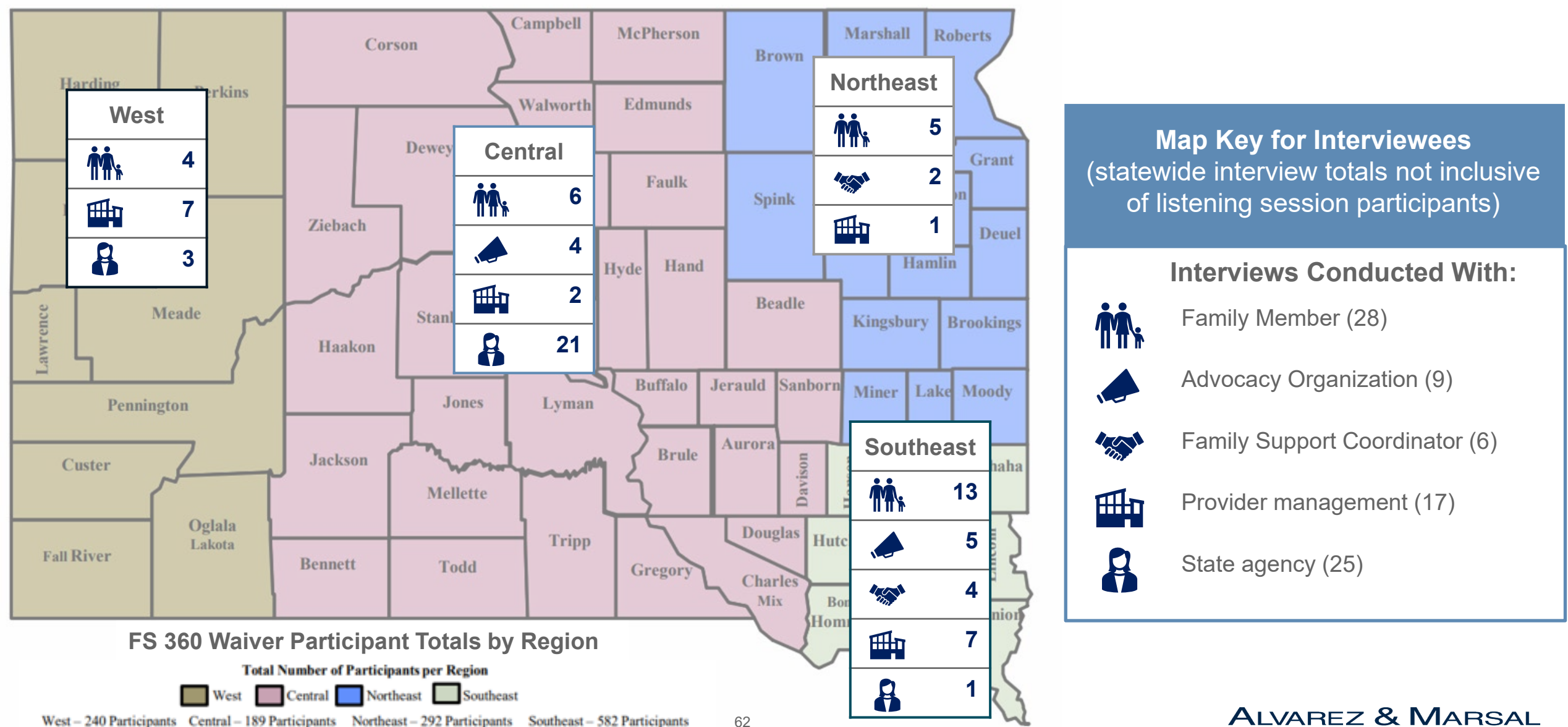
# Acronym Glossary

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1. **AWC – Agency with Choice:** AWCs help individuals to select and manage their own services and direct service providers. AWCs maintain budget and employer authority.
2. **CFCM – Conflict-Free Case Management:** A provision preventing conflicts of interest by requiring that the agency assisting individuals with planning and applying for services be a different agency than the one providing those services.
3. **CHOICES:** A Medicaid HCBS Waiver with services for children and adults with intellectual and developmental disabilities.
4. **CMS – Center for Medicare and Medicaid Services:** Federal agency that oversees and provides healthcare coverage through Medicare, Medicaid, the Children’s Health Insurance Program, and the Health Insurance Marketplace.
5. **CoP – Community of Practice**
6. **CSP – Community Support Providers**
7. **DDD – Division of Developmental Disabilities, part of the South Dakota Department of Human Services**
8. **DHS – Department of Human Services**
9. **DSS – Department of Social Services**
10. **FS 360 – Family Support 360:** A Medicaid Home and Community Based Services (HCBS) Waiver that helps people with intellectual and developmental disabilities and their families get the services they need to live in their own home and community as independently as possible.
11. **FSC – Family Support Coordinator:** Individuals employed at Community Support Providers that assist families with service planning, management, and budgeting.
12. **FTE – Full-Time Equivalent Employees**
13. **HCBS – Home and Community-Based Services:** Person-centered services delivered to individuals in their homes or communities.
14. **ICAP – Inventory for Client and Agency Planning Assessment:** A nationally developed tool to measure level of care. This is the tool South Dakota uses to measure level of care.
15. **I/DD – Intellectual and Developmental Disabilities**
16. **ICF – Intermediate Care Facilities:** An alternative to HCBS, ICFs are long-term care facilities that provide nursing, rehabilitative, and other supports to individuals with I/DD.
17. **ISP – Individualized Service Plan:** A document developed with an FS 360 participant that outlines their goals and specifies services and supports needed to achieve and measure progress towards those goals.
18. **LOC – Level of Care**
19. **LTSS – Long-term Services and Supports:** Encompasses a range of services that assist individuals with daily living activities. LTSS includes both ICF and HCBS.

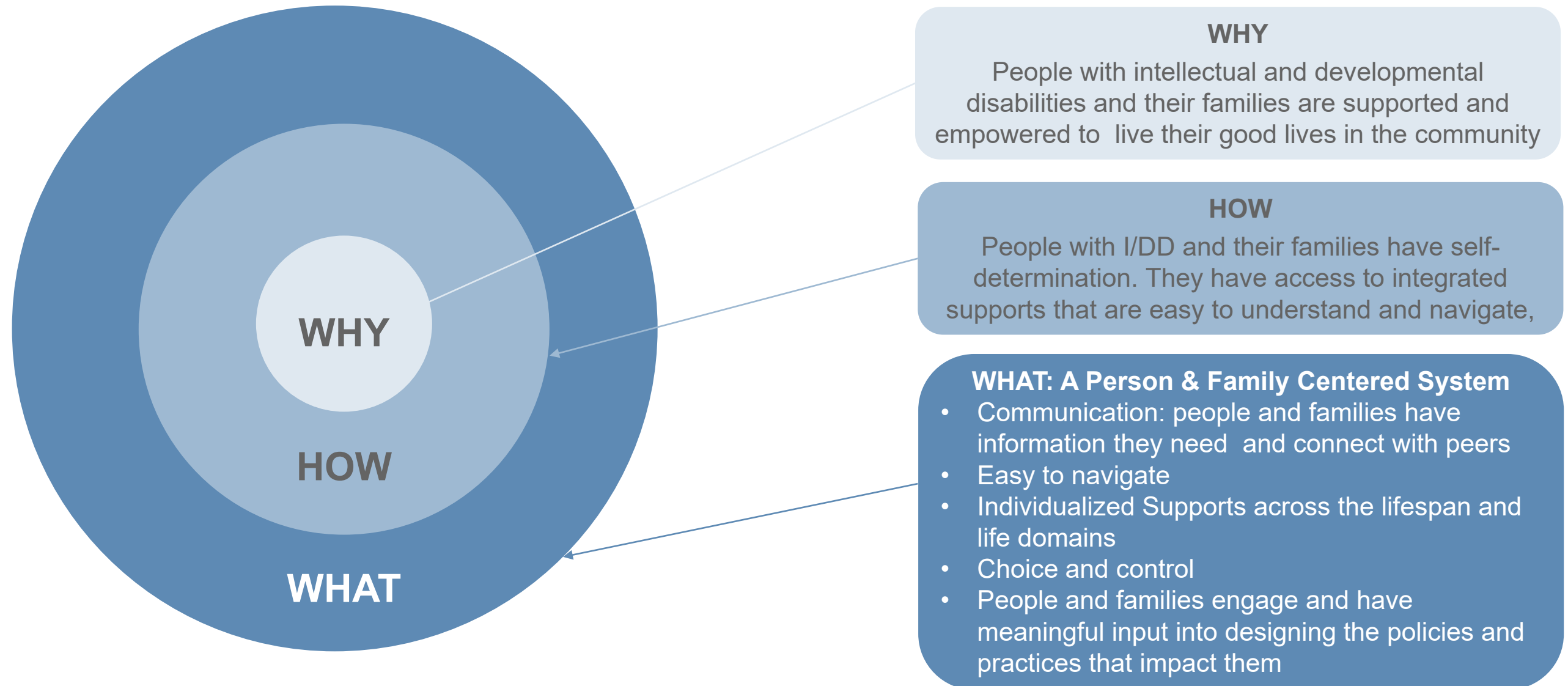
# Mapping Unique Interviews Conducted: A Focus on Regional Representation

A&M collaborated with state leadership to prioritize representation across all four regions throughout various forms of stakeholder engagement, including interviews, listening sessions, surveys, and site visits. The below map specifically highlights the interviews conducted.



# Family Support 360 & Shared Living Golden Circles

Starting with the Why: “The compelling higher purpose that inspires us and acts as the source of all we do.”





# A&M's Approach for Recommendations

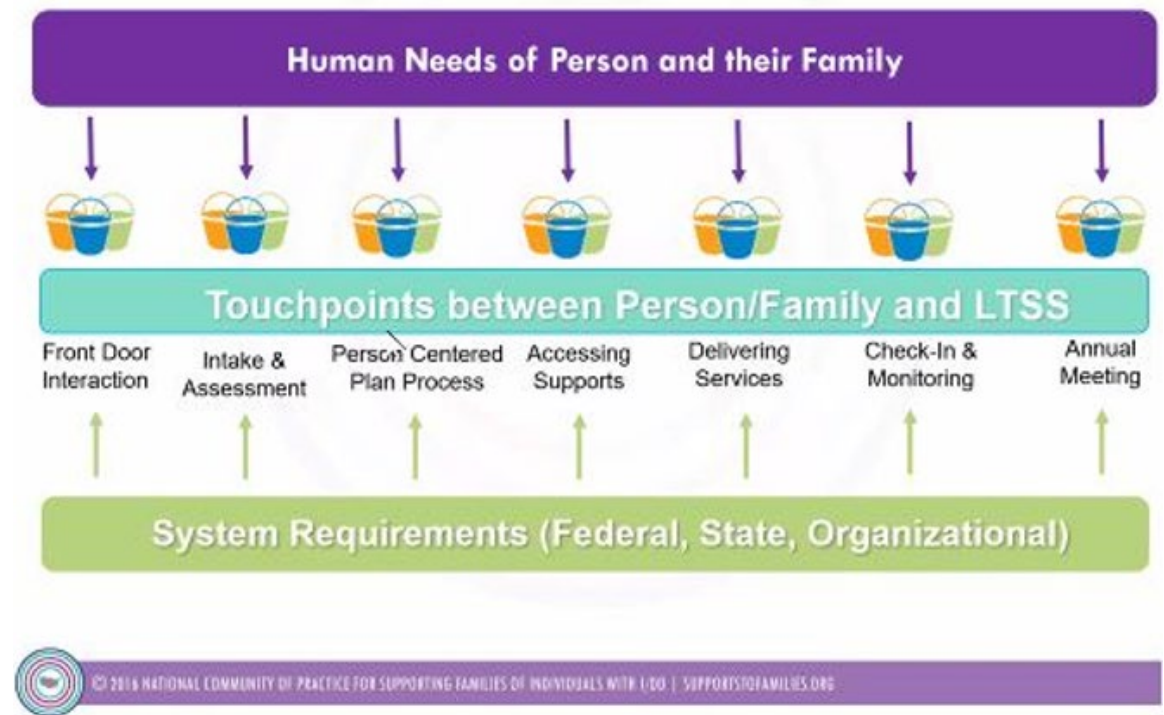
A&M developed recommendations by following the customer journey, reflecting the touch points between a person and their family and the DDD.

As people and families move across the customer journey, they bring human needs for support. Research shows that families need:

1. Discovery and Navigation: information and tools to help understand the situation and make an informed decision
2. Connecting and Networking: connections with other self-advocates or family members who have been in their shoes
3. Goods and Services: these are the services that DDD typically provides to families

At the same time, the DDD has systems needs to meet state and federal compliance. For example, they may need demographic information, to do an assessment, to do a safety monitoring, etc.

Our recommendations, collectively, seek to bridge the gap between human and system needs. Both must be met for a system to function well for people with I/DD and their families.



Source: <https://www.lifecoursetools.com/lifecourse-library/lifecourse-framework/three-buckets-of-support/>

# Understanding Person & Family Centered Systems

DDD has partnered with families to develop a shared vision. Person and family centered thinking, planning and practices are essential for DDD achieve the vision.



*Person-centeredness is a practice that is emerging across a wide variety of fields that work with different people in different settings. Many state and federal policies now mandate person-centered delivery of long-term services and supports.*

## A Person and Family Centered System Requires:

- **Person-centered thinking** focuses language, values, and actions **toward respecting the views of the person and their loved ones**. It emphasizes quality of life, well-being, and informed choice.
- **Person-centered planning** is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it. Person and family centered planning looks at **services and supports in the context of what it takes for a person to have the life they want**.
- **Person-centered practices** are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals. Person-centered practices are **flexible and adaptable**. They encourage informed choice and creativity.

**Sources:** [South Dakota – The Community of Practice for Support Families of Individuals with Intellectual & Developmental Disabilities \(supportstofamilies.org\)](http://supportstofamilies.org); [Person-centered practices / Minnesota Department of Human Services \(mn.gov\)](http://mn.gov); [About NCAPPS \(acl.gov\)](http://acl.gov); [HCBS Training | Making Sure Our Actions Reflect Our Core Values | Institute on Community Integration Publications \(umn.edu\)](http://umn.edu)

# Peer State Individual and Family Support Waivers

# Peer State Support Waiver Approaches (1 of 3)

This table provides detail about each peer state's primary support waiver. If a peer state does not have a supports waiver, their comprehensive waiver is described instead (Iowa).

described instead (Iowa).

					2023		
Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Spend per Person	Total Annual Spend
Iowa – Providers I/DD services on a single comprehensive waiver.							
IA Home and Community Based Services - Intellectual Disabilities (ID) Waiver (0242.R06.06)*	<ul style="list-style-type: none"><li>I/DD</li></ul>	Lifespan	<ul style="list-style-type: none"><li>Intermediate Care Facility for Individuals with Intellectual Disabilities</li></ul>	Yes	14,203	\$36.1K	\$512.2M
Provides adult day care, day habilitation, prevocational services, residential based supported community living, respite, supported employment, home health aide services, nursing, financial management services, independent support broker, individual directed goods and services, self-directed community support and employment, self- directed personal care, consumer directed attendant care (CDAC) – skilled, CDAC – unskilled, home and vehicle modification, interim medical monitoring and treatment, personal emergency response or portable locator system, supported community living, and transportation services							
Louisiana – Provides I/DD services on 4 waivers, including a children’s waiver, utilizing a tiered waiver structure for waitlist management.							
LA Children's Choice (CC) Waiver (0361.R04.00)	<ul style="list-style-type: none"><li>I/DD</li><li>Autism</li></ul>	0-20	<ul style="list-style-type: none"><li>Intermediate Care Facility for Individuals with Intellectual Disabilities</li></ul>	Yes	2200	\$10.4K	\$22.8M
LA Supports Waiver (0453.R03.00)	<ul style="list-style-type: none"><li>I/DD</li><li>Autism</li></ul>	18+	<ul style="list-style-type: none"><li>Intermediate Care Facility for Individuals with Intellectual Disabilities</li></ul>	No	2100	\$6.6K	\$13.8M

**Children Support Services:** Provides center-based respite, support coordination, specialized medical equipment and supplies, financial management services, aquatic therapy, art therapy, environmental accessibility adaptations, family support services, family training, hippotherapy, housing stabilization service, housing stabilization transition service, music therapy, sensory integration, and therapeutic horseback riding services

**Adult Support Services:** Provides day habilitation, habilitation, prevocational services, respite, support coordination, supported employment, specialized medical equipment and supplies, community life engagement development, dental services, housing stabilization service, housing stabilization transition service, and personal emergency response system services

\*Iowa does not have a separate Individual and Family Support waiver. This information is for their comprehensive waiver.

# Peer State Support Waiver Approaches (2 of 3)

This table provides detail about each peer state’s primary support waiver. If a peer state does not have a supports waiver, their comprehensive waiver is described instead (Iowa).

						2023	
Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Spend per Person	Total Annual Spend
Nebraska – Provides I/DD services on 2 waivers, one comprehensive waiver and one supports waiver.							
NE Developmental Disabilities Day Services Waiver for Adults (0394.R04.00)	<ul style="list-style-type: none"> <li>I/DD</li> <li>Autism</li> </ul>	21+	<ul style="list-style-type: none"> <li>Intermediate Care Facility for Individuals with Intellectual Disabilities</li> </ul>	Yes	1,055	\$12.5K	\$13.2M
Provides prevocational services, respite, supported employment – individual, adult day, assistive technology, community integration, consultative assessment, day supports, environmental modification assessment, home modifications, independent living, personal emergency response system, small group vocational support, supported employment - follow along, supported family living, transitional, transportation, and vehicle modification services							
New Mexico* – Provides I/DD services on 3 waivers, including a limited use supports waiver meant for waitlist management (not summarized here).							
NM Mi Via- ICF/IDD Waiver (0448.R03.00)	<ul style="list-style-type: none"> <li>Age or Disabled, or Both - Specific Recognized Subgroups (Medically Fragile)</li> <li>I/DD</li> <li>Autism</li> </ul>	Lifespan	<ul style="list-style-type: none"> <li>Intermediate Care Facility for Individuals with Intellectual Disabilities</li> </ul>	Yes	2,519	\$79.3K	\$20.0M
Provides consultant services, customized community group supports, employment supports, home health aide services, homemaker/direct support services, respite, skilled therapy for adults, personal plan facilitation, behavior support consultation, community direct support, emergency response services, environmental modifications, in-home living supports, individual directed goods and services, nutritional counseling, private duty nursing for adults, specialized therapies, and transportation services							

*\*Note: New Mexico also has a waiver called the Supports Waiver (average spend \$6.8K); however, this is a targeted waiting list waiver not intended to serve people long-term. The Mi Via waiver is the closest match to a self-directed, IFS waiver that provides long-term services.*

# Peer State Support Waiver Approaches (3 of 3)

This table provides detail about each peer state's primary support waiver. If a peer state does not have a supports waiver, their comprehensive waiver is described instead (Iowa).

					2023		
Waiver Names	Target Populations	Age Limits	Level of Care	Self Direction	Maximum Participants	Spend per Person	Total Annual Spend
Utah – Provides I/DD services on 3 waivers, utilizing a tiered waiver structure for two waivers with residential services and maintaining a third supports waiver which is capped and meant to serve individuals on the waitlist for residential services.							
UT Limited Supports Waiver (1886.R00.00)	<ul style="list-style-type: none"><li>I/DD</li><li>Brain Injury</li><li>Autism</li></ul>	<ul style="list-style-type: none"><li>Brain Injury: 18+</li><li>I/DD: Lifespan</li></ul>	<ul style="list-style-type: none"><li>Nursing Facility, Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)</li></ul>	Yes	120	\$24.5K	\$2.9M
Provides integrated community learning, prevocational services, respite, supported employment, financial management services, individual and family peer support, applied behavioral analysis therapy, attendant care, behavioral services, environmental adaptations (home), environmental adaptations (vehicle), individual goods and services, remote support monitoring and equipment, specialized medical equipment/supplies/assistive technology, and transportation (non-medical) services							
Wyoming – Provides I/DD services on 2 waivers, one comprehensive waiver and one supports waiver.							
WY Supports Waiver (1060.R01.00)	<ul style="list-style-type: none"><li>Brain Injury</li><li>I/DD</li></ul>	<ul style="list-style-type: none"><li>Brain Injury: 21+</li><li>Others: Lifespan</li></ul>	<ul style="list-style-type: none"><li>Nursing Facility</li><li>Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)</li></ul>	Yes	618	\$15.2K	\$9.4M
Provides adult day services, case management, community living services, community support services, homemaker, personal care, respite, supported employment, dietician services, occupational therapy, physical therapy, skilled nursing, speech/hearing/language services, behavioral support services, child habilitation services, cognitive retraining, companion services, crisis intervention support, environmental modification, individual habilitation training, specialized equipment, and transportation services							

# Benchmarking



# Benchmarking: Methodology

Our initial benchmarking assessment compares high-level insights regarding access, costs, and potential pain points from the discussed sources. However, due to lags in data update times, these takeaways will be directionally accurate – but not precise.

	Year	SD	IA	LA	NE	NM	UT	WY
Census	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes
RISP	2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes
State of the States	2019	Yes	Yes	Yes	Yes	No	Yes	Yes
NCI-IDD	2020-21	Yes	No	No	Yes	No	No	No
NCI-Workforce	2021	Yes	No	Yes	Yes	No	Yes	Yes
SELN	2020-22	No	No	Yes	No	Yes	No	Yes
StateData (ICI)	2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes



South Dakota did not participate in RISP in 2019 due to COVID

# Benchmarking: Access – Population Served

Relative to comparative states, SD has been able to reach and serve a higher percentage of the estimated I/DD population.

State	Census Population	Est. I/DD Population	% Est. I/DD Pop Known to State	% Est. I/DD Pop Served by State	% Waiting for Services
South Dakota	879,386	5,614	23%	20%	0%
Louisiana	4,664,450	106,349	37%	16%	0%
Iowa	3,149,900	71,818	34%	26%	0%
New Mexico	2,093,754	47,748	20%	11%	10%
Nebraska	1,925,512	42,902	16%	13%	3%
Utah	3,155,153	71,937	12%	8%	4%
Wyoming	579,054	13,202	20%	18%	2%
Peer Average	2,594,637	59,158	23%	15%	15%

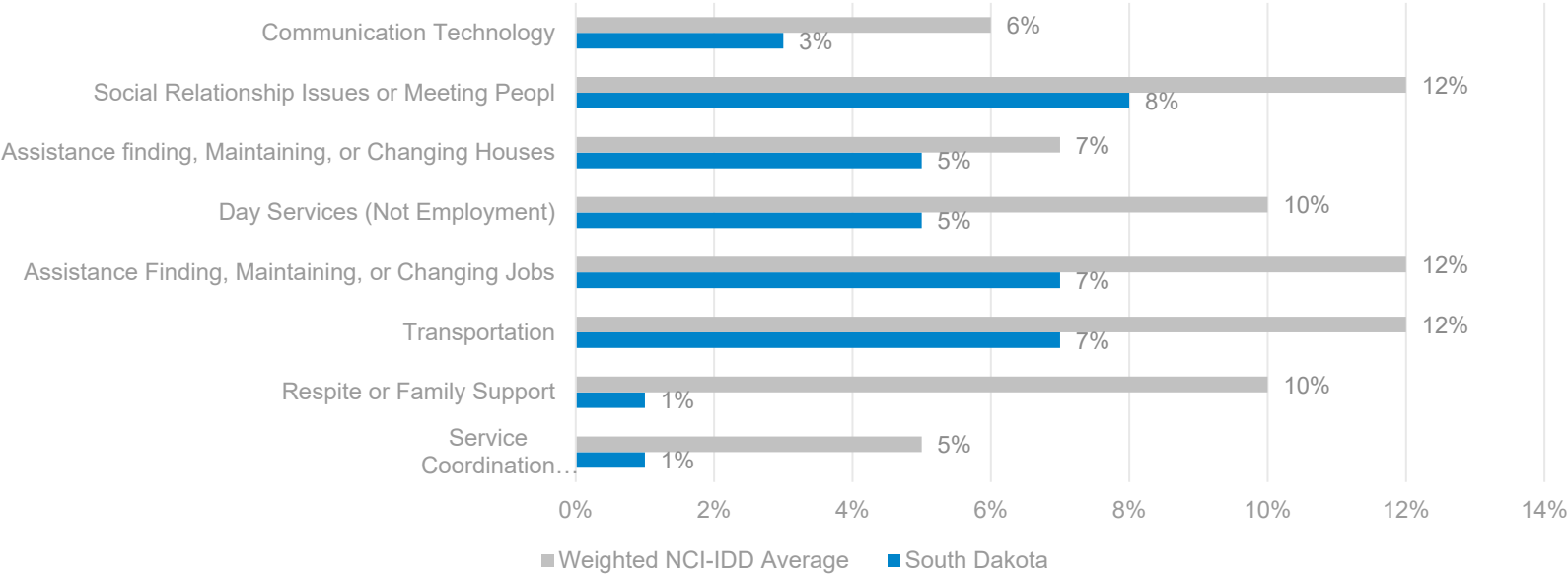
Sources: US Census (2020), RISP (2018)

Generally, SD performs **on par with or better than peer states** when evaluating access from high-level information. The estimated percentage of the total **I/DD population served** by the State DDD is **5% higher than peer state averages**.

# Benchmarking: Access – Services and Provider Workforce

Survey responses highlight services array strengths for consumers and potential opportunities to improve provider supports and trainings.

NCI Consumer Survey Responses: Services Needed (% of “Yes” responses)



## NCI Workforce – Quick Stats

1. The **average DSP hourly wage is 99.7% above the state minimum wage**, 37.5% **higher** than peer states.
2. SD has a **part-time vacancy rate of 29.7%**, 7.6% **higher** than the peer average, and a **DSP turnover rate of 51%**.
3. **75% of providers** surveyed responded that they **received a realistic job preview**, 11% **lower** than the peer average.

## FS 360 Services:

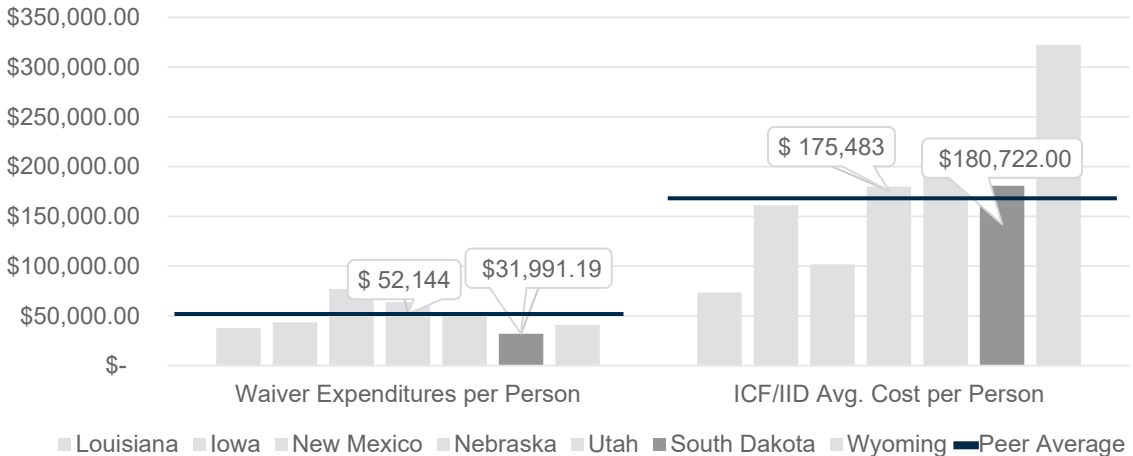
1. Personal Care 1
2. Respite
3. Support Coordination / Case Management
4. Supported Employment
5. Personal Care 2
6. Companion Care
7. Environmental Accessibility Adaptations
8. Nutritional Supplements
9. Specialized Medical Adaptive Equipment and Supplies
10. Specialized Therapies
11. Vehicle Modification

# Benchmarking: Spending on Waivers, ICF, and IFS

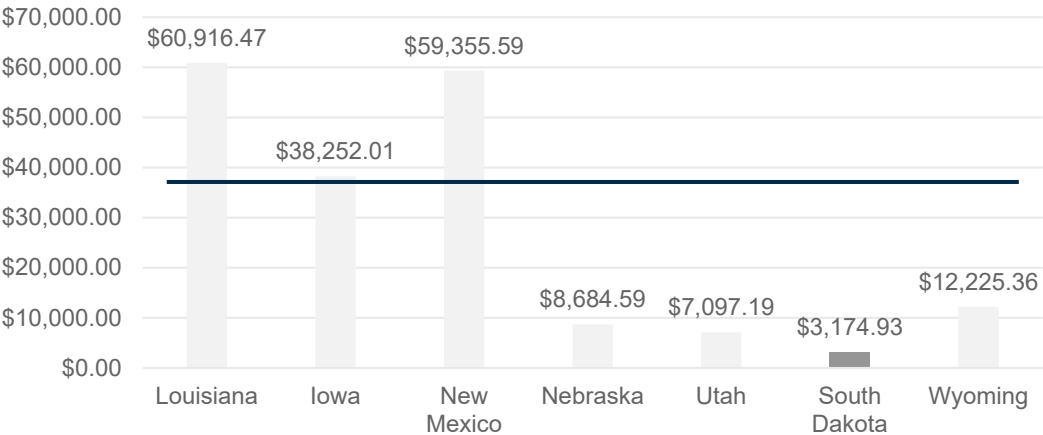
South Dakota reports a higher percentage of individuals using waiver services compared to ICF than both the peer and national averages. However, waiver and individual and family support spending is significantly lower than comparative states.

Peer State Comparison of Average Waiver and ICF Costs per Person (\$)

Source: RISP (2018)



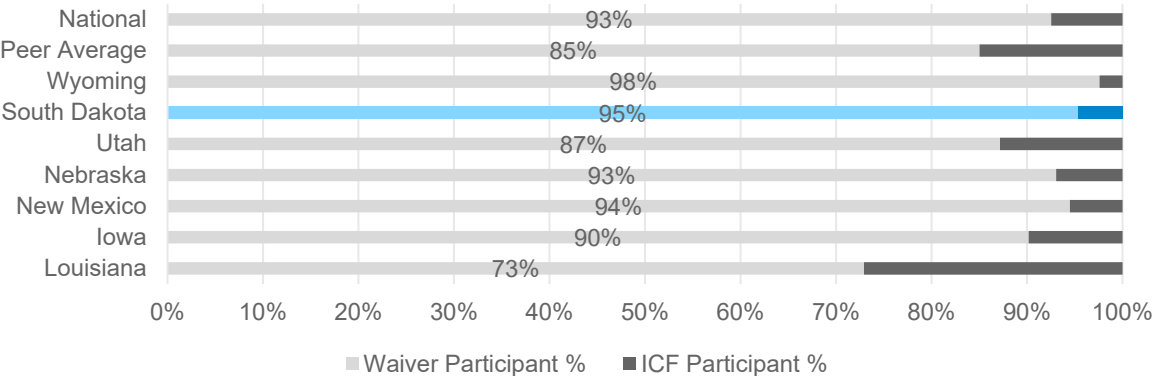
Individual and Family Supports Spend per Person (\$)



Source: National HCBS Waiver Scan, 2022

Waiver and ICF Participants (% of combined total)

Source: RISP 2018

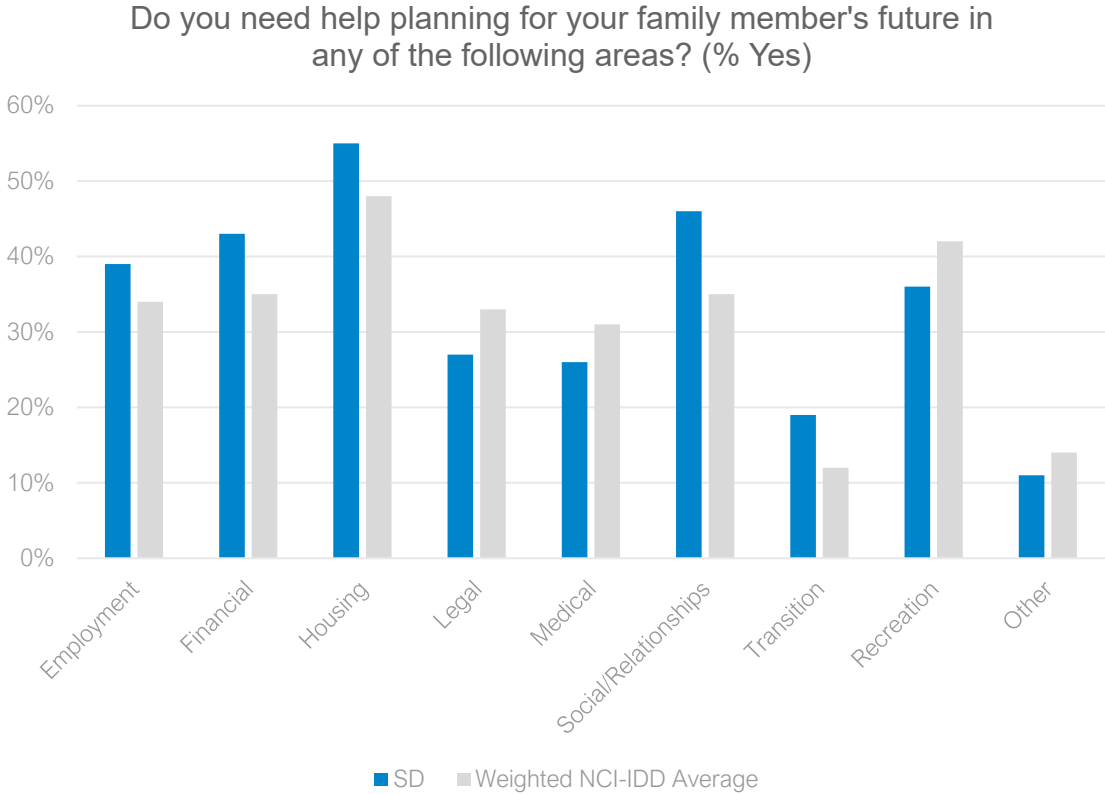


**Waiver participants** represent **10% more** of the population of individuals receiving waivers services and/or ICF compared to the peer state average (85%).

Waiver costs per person and spending on individual and family supports are both **significantly lower than peer averages**.

# Benchmarking: Supporting Successful Outcomes

A focus on future planning in individuals' service plans can support a waiver programs' long-term growth and sustainability. South Dakota has a higher percentage of families that have indicated a need for additional support in employment, financial planning, and housing, amongst other areas.



Source: NCI South Dakota In Person Survey State Report, 2020-21

SD had a **higher** rate of respondents indicate they needed help planning for family members' futures in **employment, finances, housing,** and **social/relationship support** than the national averages.

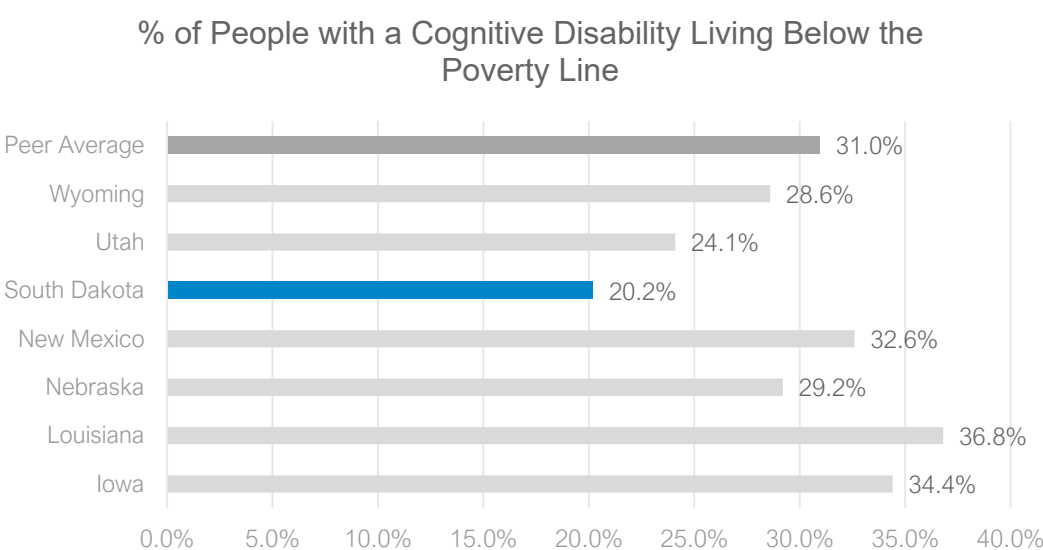
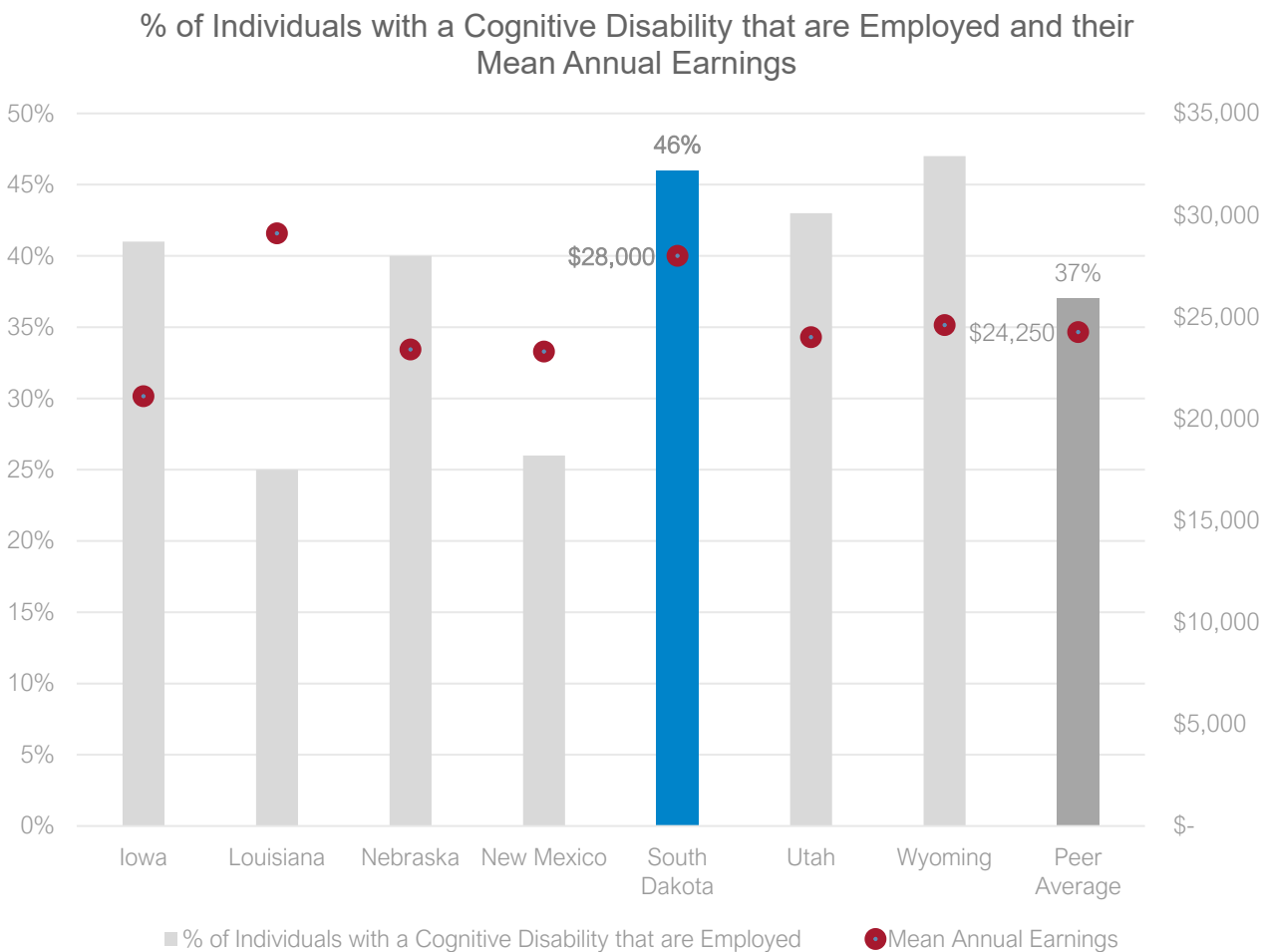
### FS 360 Services:

1. Personal Care 1
2. Respite
3. Support Coordination / Case Management
4. Supported Employment
5. Personal Care 2
6. Companion Care
7. Environmental Accessibility Adaptations
8. Nutritional Supplements
9. Specialized Medical Adaptive Equipment and Supplies
10. Specialized Therapies
11. Vehicle Modification

Ensuring services provided are **adaptable to an individuals' needs** as he/she ages is important for **person-centered planning** and supports **program sustainability** over time.

# Benchmarking: Outcomes

South Dakotans with cognitive disabilities have a higher percentage of employment and report higher annual earnings than peers in comparative states. Compared to peers, South Dakota also has the lowest rate of individuals with cognitive disabilities living under the federal poverty line.



**9% more** of the population of individuals with cognitive disabilities **are employed** in South Dakota than the peer state average. Their **annual earnings** are **15% higher** than peers.

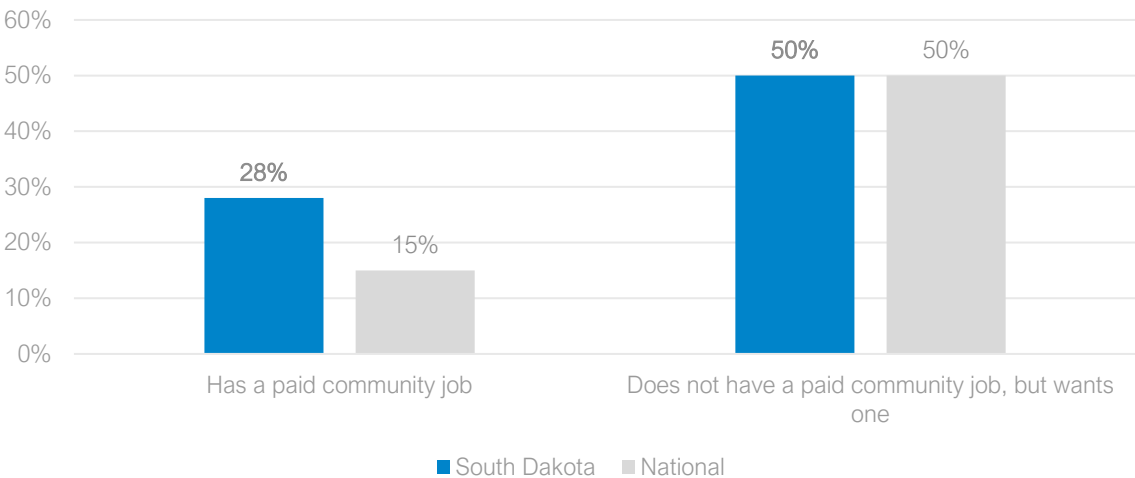
South Dakota also has the **lowest rate** of individuals with cognitive disabilities **living below the federal poverty line** – **over 10% lower** than the peer average.

Source: StateData: The National Report on Employment Services and Outcomes (2019)

# Benchmarking: Supporting Outcomes

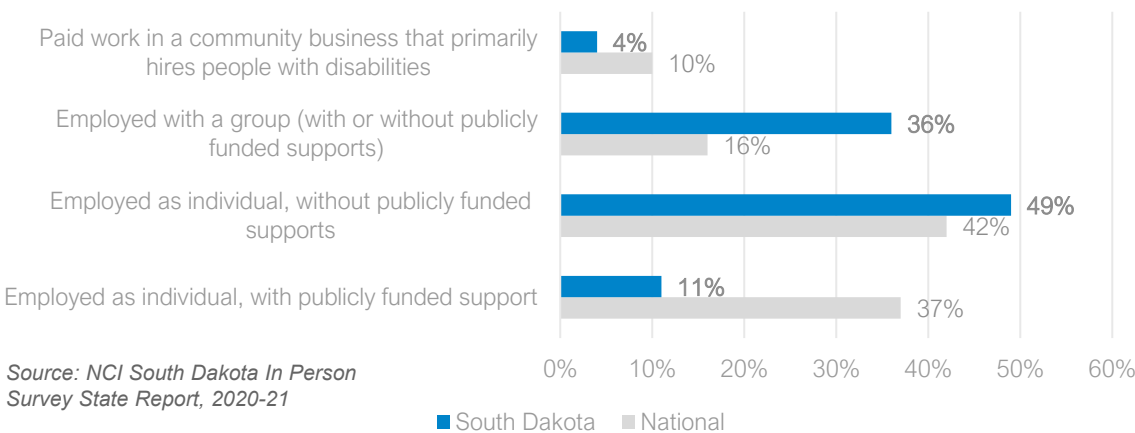
Consistent with data on the previous slide, NCI survey responses also show SD has a higher percentage of individuals with a paid community job. There are fewer individuals employed alone with publicly funded supports, but the rate of group employment is higher than the national average.

1. Individuals that have or want a paid community job

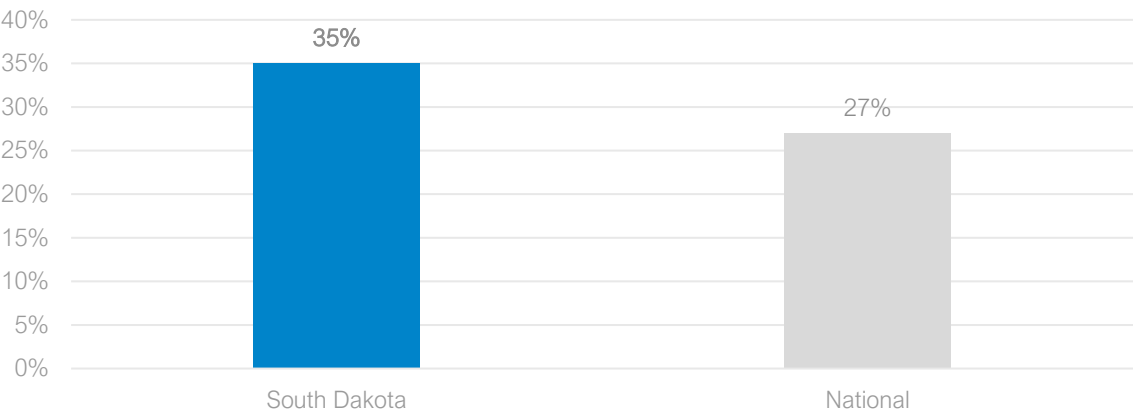


- 1. Compared to the national average, **13% more** of the IDD population in SD **has a paid community job** compared to the national average.
- 2. Of the employed population, the proportion of **individuals employed in groups** (e.g., work crews) is **20% higher** than the national average. The percentage of individuals **employed with publicly funded supports** is **26% lower** than the national average.
- 3. Of the population of individuals that are not employed, **35% have community employment as a goal** in his/her service plan.

2. Type of Paid Community Job (of those with paid community job)



3. Has community employment as a goal in service plan (of those that want a paid community job)



Source: NCI South Dakota In Person Survey State Report, 2020-21

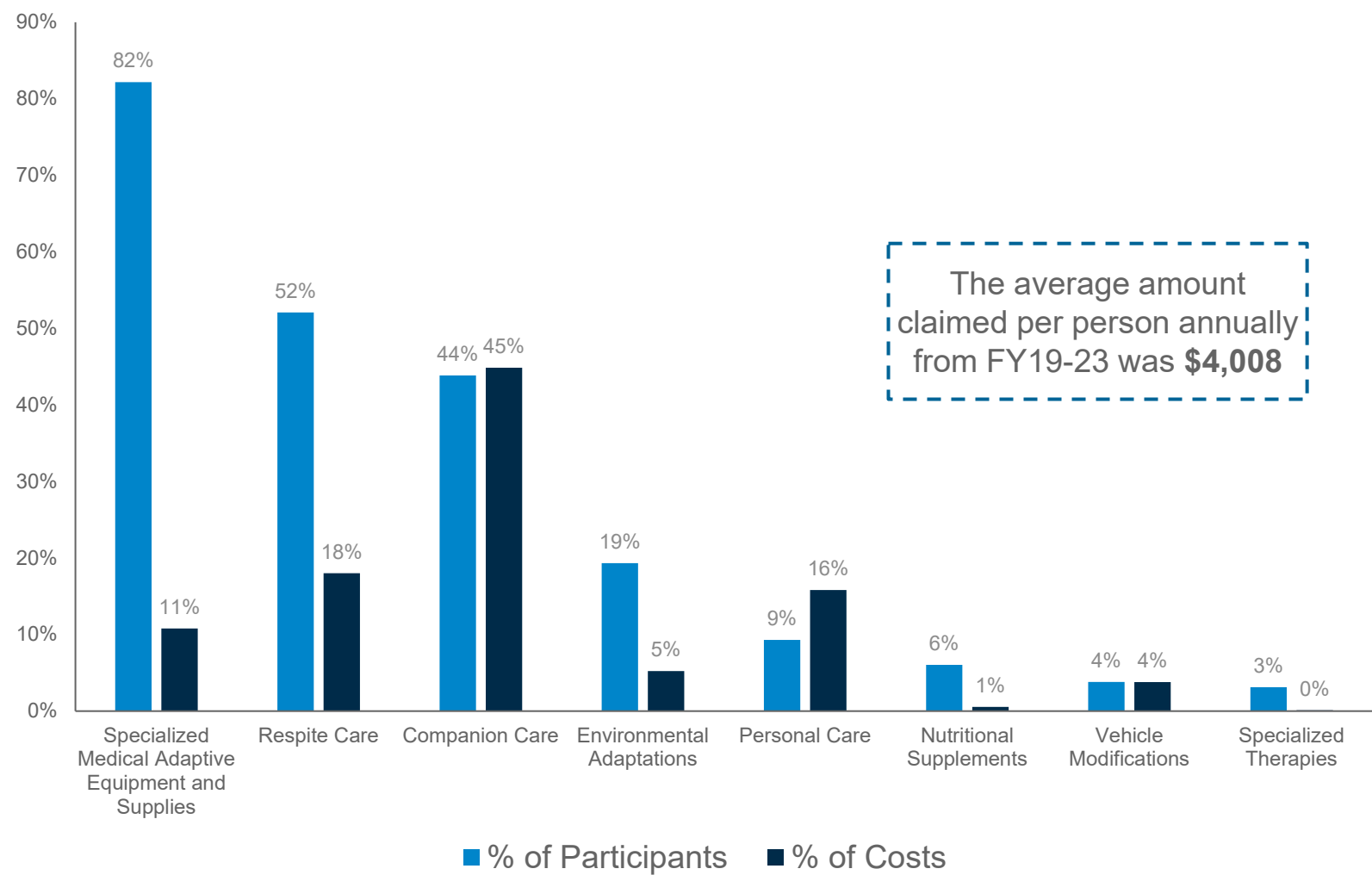


# Analysis of Waiver Claims Data

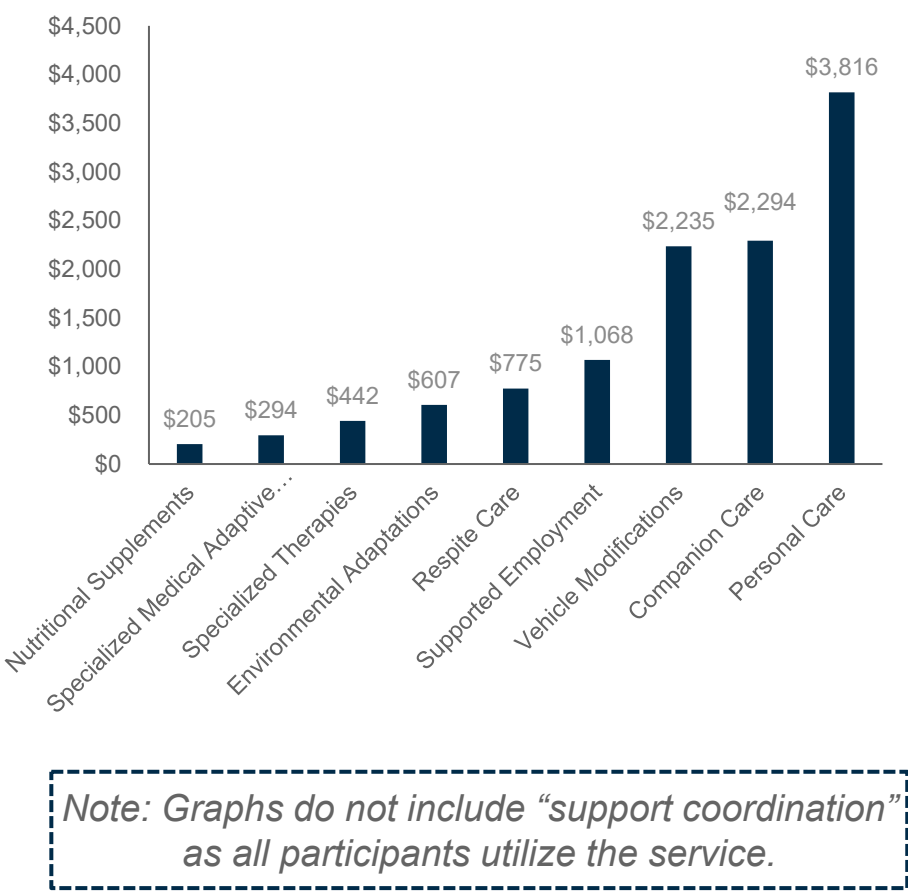
# FS 360 Waiver: What Waiver Services Do Participants Use?

A&M analyzed Medicaid claims data to assess the most utilized waiver services by participation percentage and total claimed amounts..

Participation Rate and Percentage of Total Claimed Amount by Service  
FY19-23

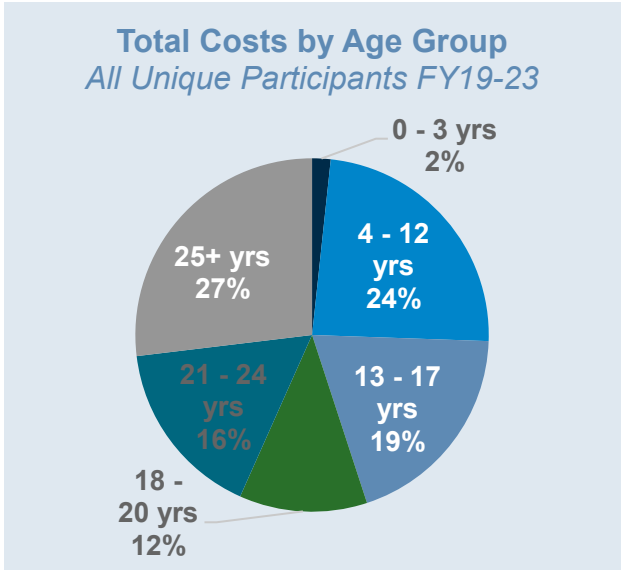
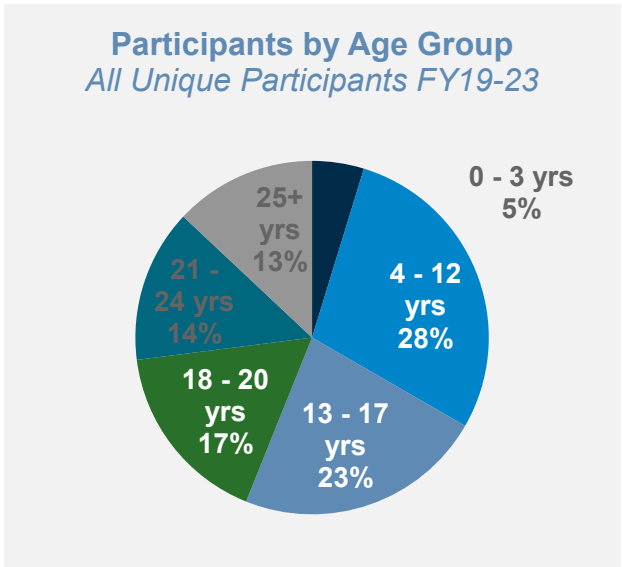
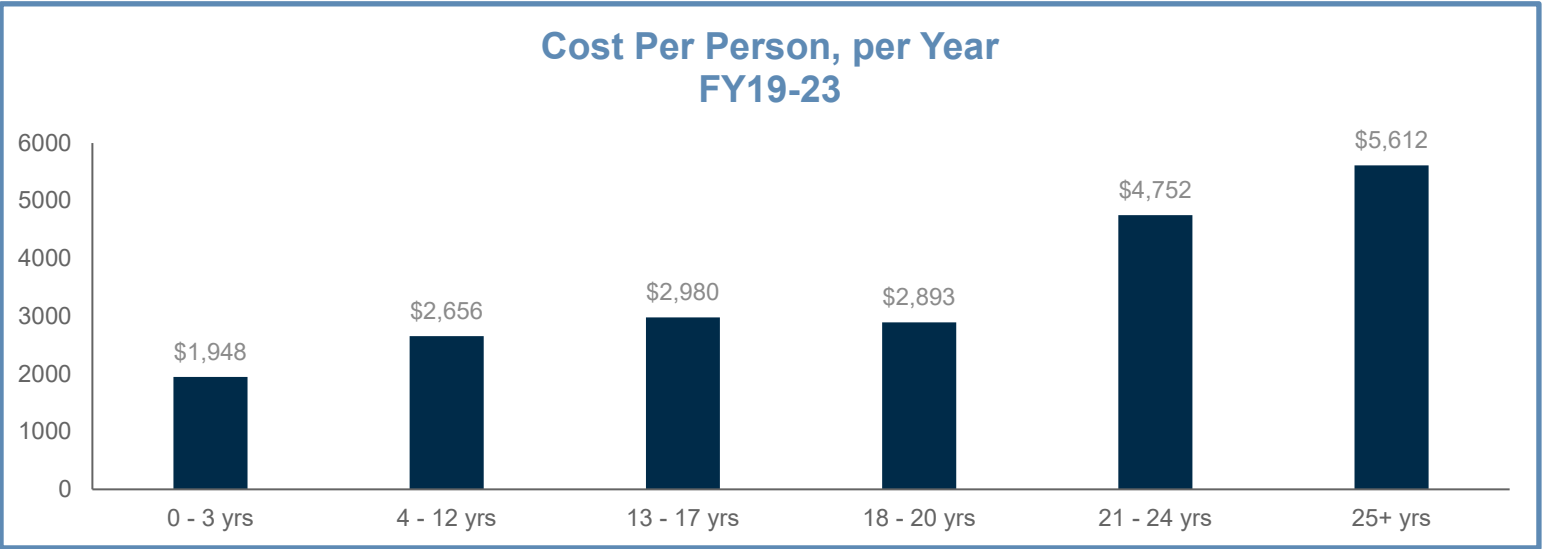
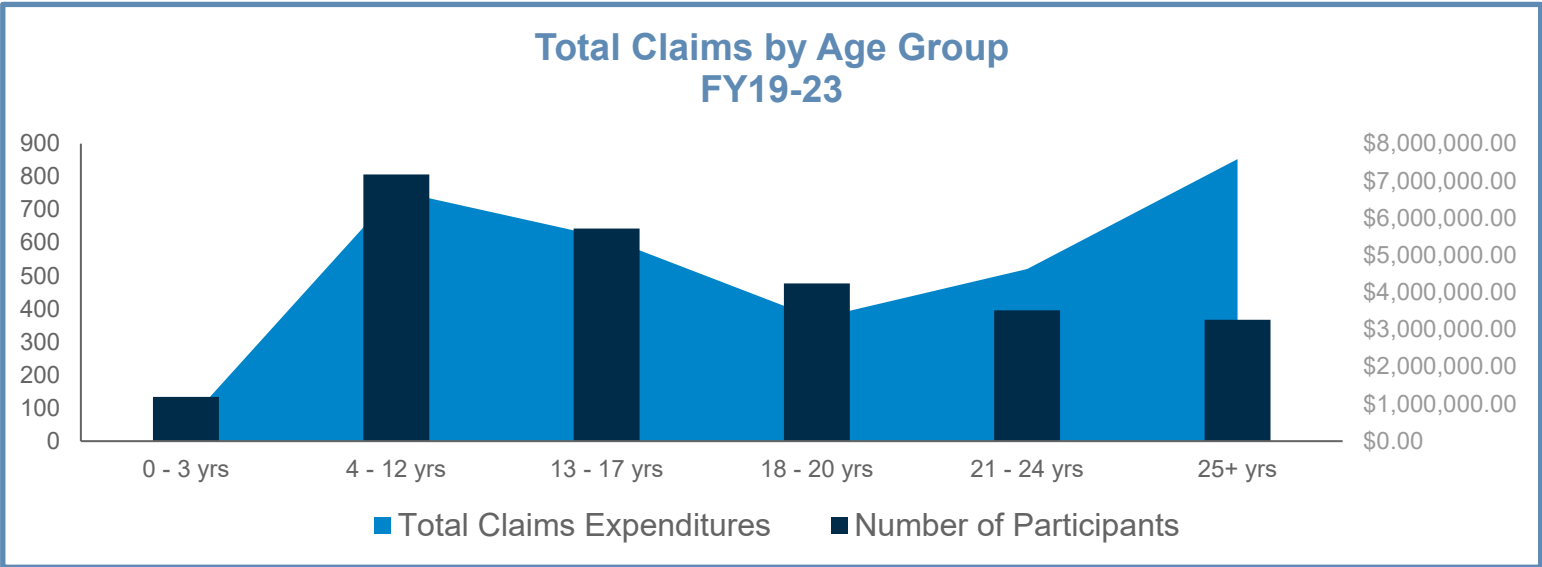


Claimed Amount per Person per Service  
Annual Average from FY19-23



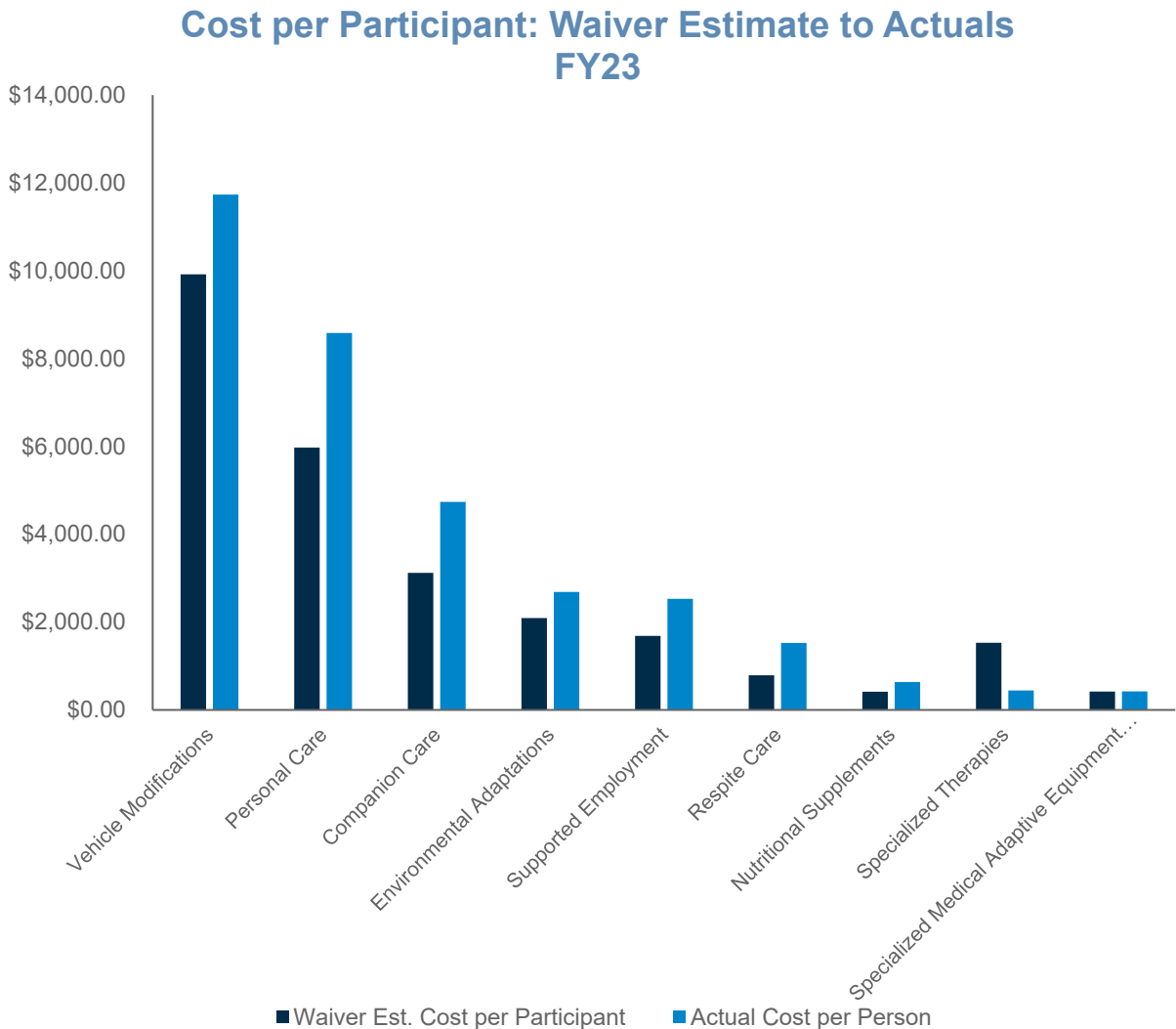
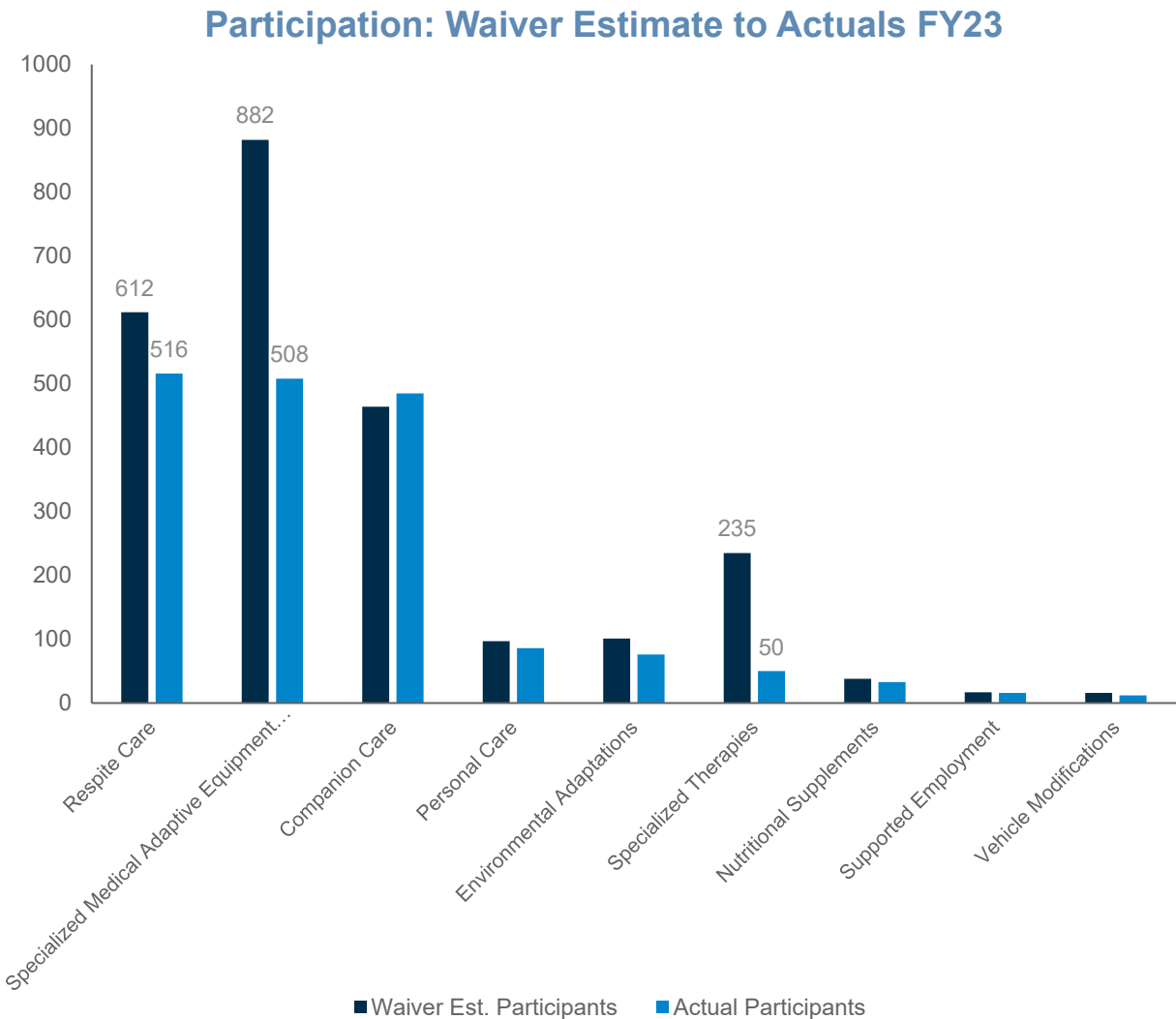
# FS 360 Waiver: Participation and Costs by Age Group

Around 68% of the FS 360 waiver program participants in the last five years were between four and twenty years old. This age group accounts for only 55% of total claims.



# FS 360 Waiver: Waiver Predictions and Actuals

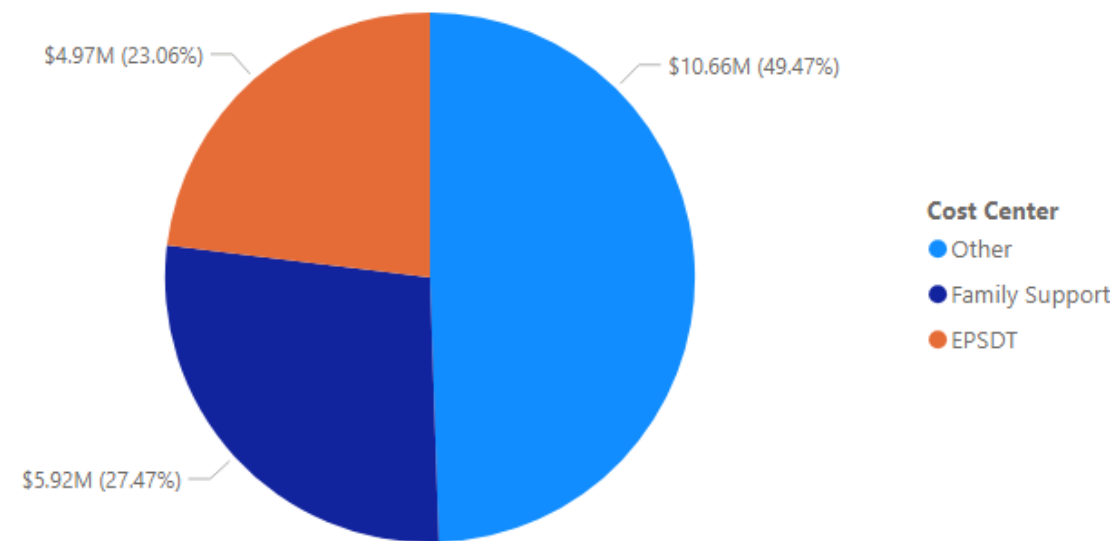
A&M compared the estimated utilization (by costs and participation) from waiver documentation submitted to the Center for Medicare and Medicaid (CMS) to actuals. In FY23, participation in respite care and SMAES was significantly lower than predictions.



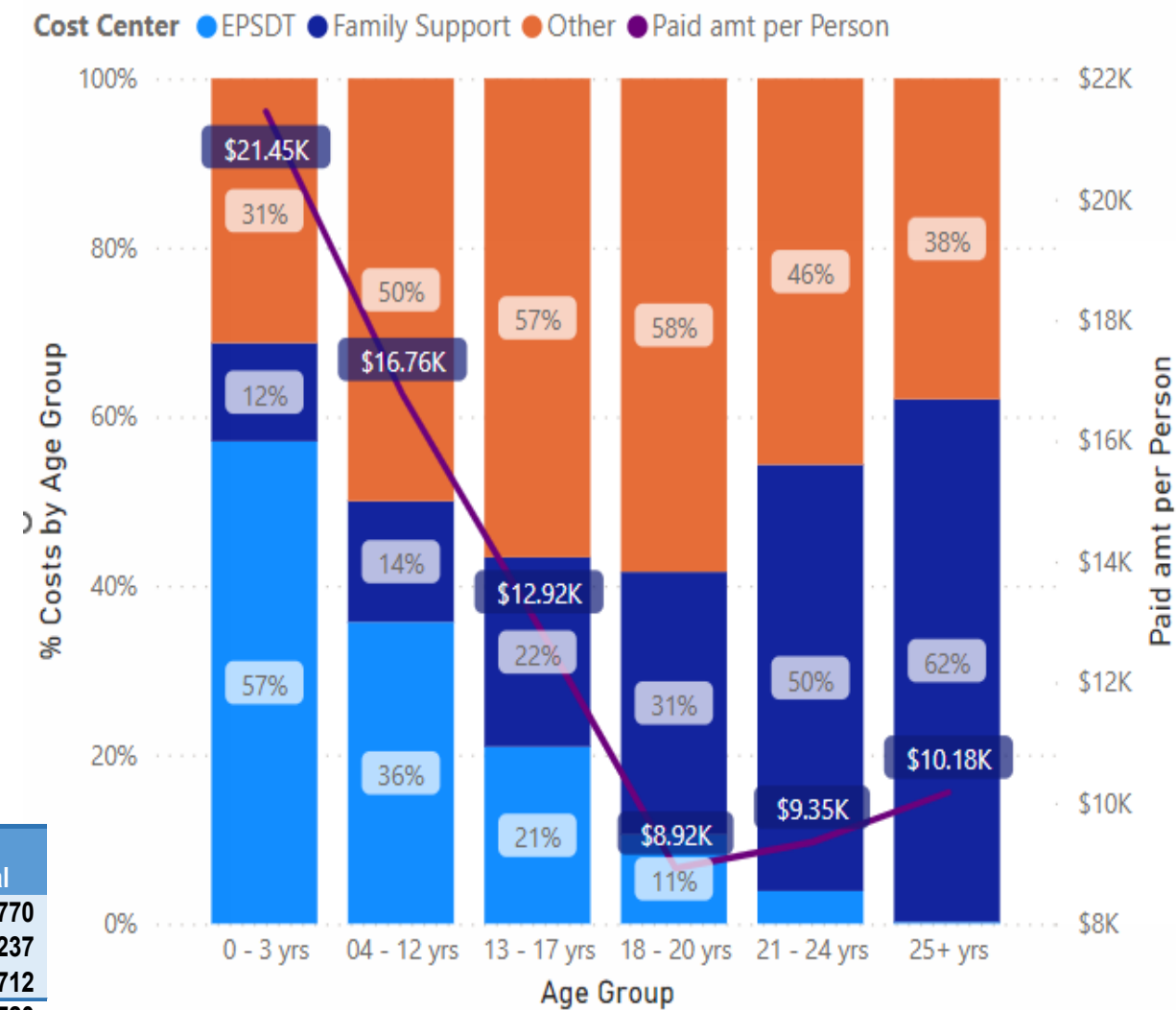
# FS 360 Waiver: Participant Program Costs

Across all active FS 360 participants in FY23, family support claims accounted for about 27% of their total claims. When viewing total claims by age group, the average amount claimed per person decreases over 58% from ages 3 to 20.

Claims Amount Paid  
BY COST CENTER



Total Claims Row Labels	SFY	2019	2020	2021	2022	2023	Grand Total
Family Support	\$	4,559,565	\$ 5,175,866	\$ 5,660,063	\$ 5,919,624	\$ 6,880,653	\$ 28,195,770
EPSDT	\$	3,897,999	\$ 4,714,264	\$ 4,842,305	\$ 4,970,882	\$ 5,779,786	\$ 24,205,237
Other	\$	6,618,955	\$ 7,484,544	\$ 11,727,727	\$ 10,661,482	\$ 11,636,005	\$ 48,128,712
Grand Total	\$	15,076,519	\$ 17,374,674	\$ 22,230,095	\$ 21,551,988	\$ 24,296,444	\$ 100,529,720



# Access: Process Maps

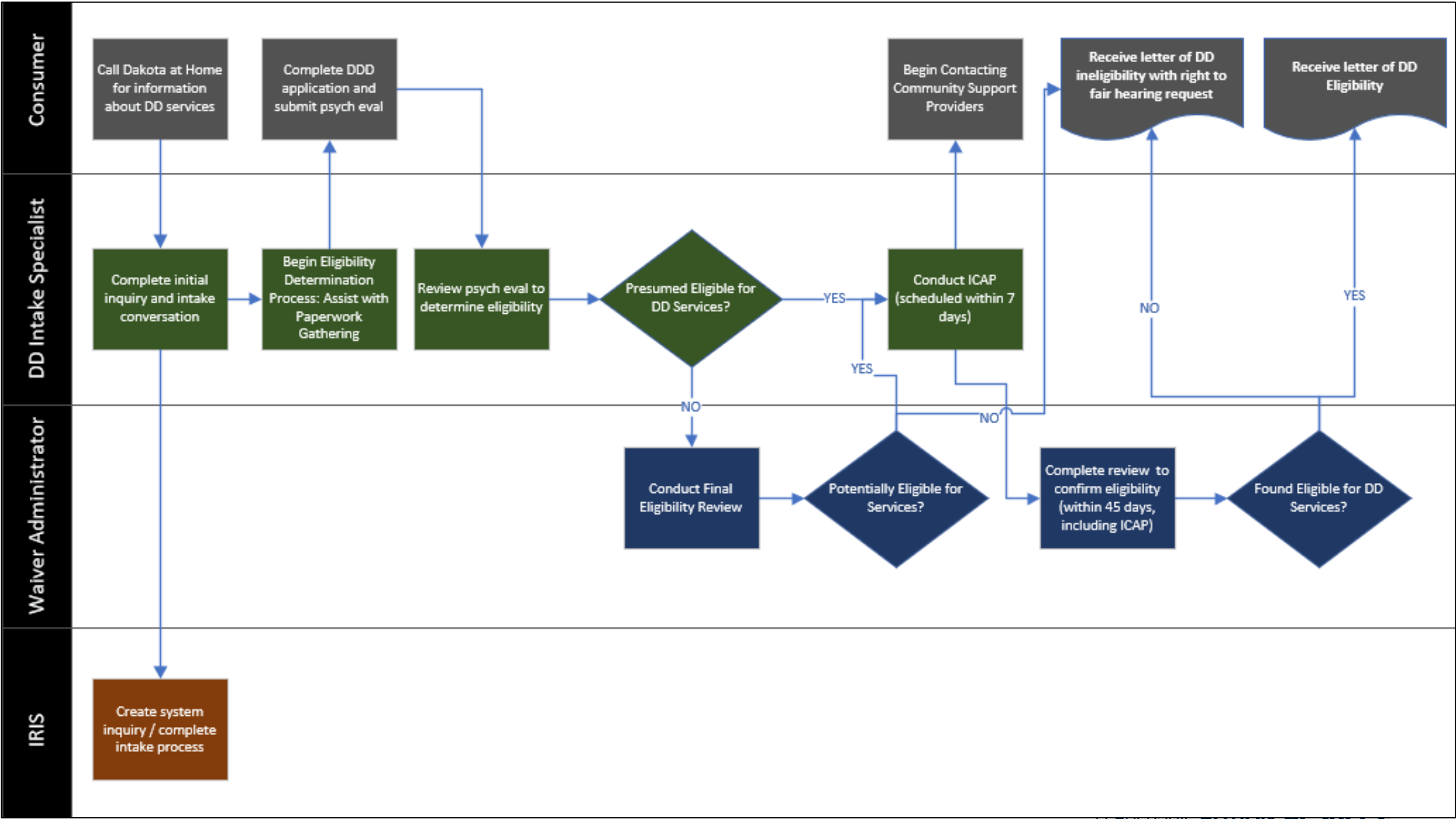
# Understanding Waiver Access: Terms to Know

Term	Definition
Intake Process	The intake process describes the steps that someone looking for IDD services goes through to apply for and begin State services. This is also known as the application process.
Pre-Front Door	Pre-front door refers to peoples' experience before they reach the official front door. This includes how someone learns about services and how they discover the official front door to begin the process.
Front Door	The front door is the official start of the intake process, where people can begin the formal process of applying for IDD services.
Level of care	Level of care (LOC) is a measurement of an individual's physical, mental, social, and/or emotional status. This information is used to assess DD eligibility.
ICAP	The ICAP is a nationally developed tool to measure level of care. This is also the tool South Dakota uses to measure level of care.
Eligibility	Eligibility is whether someone qualifies to receive services. To receive DD Waiver services, you must be both DD eligible and Medicaid Eligible For DD eligibility, this is determined by several things including the type of disability someone has and their functional needs for assistance. For Medicaid, eligibility is financial.



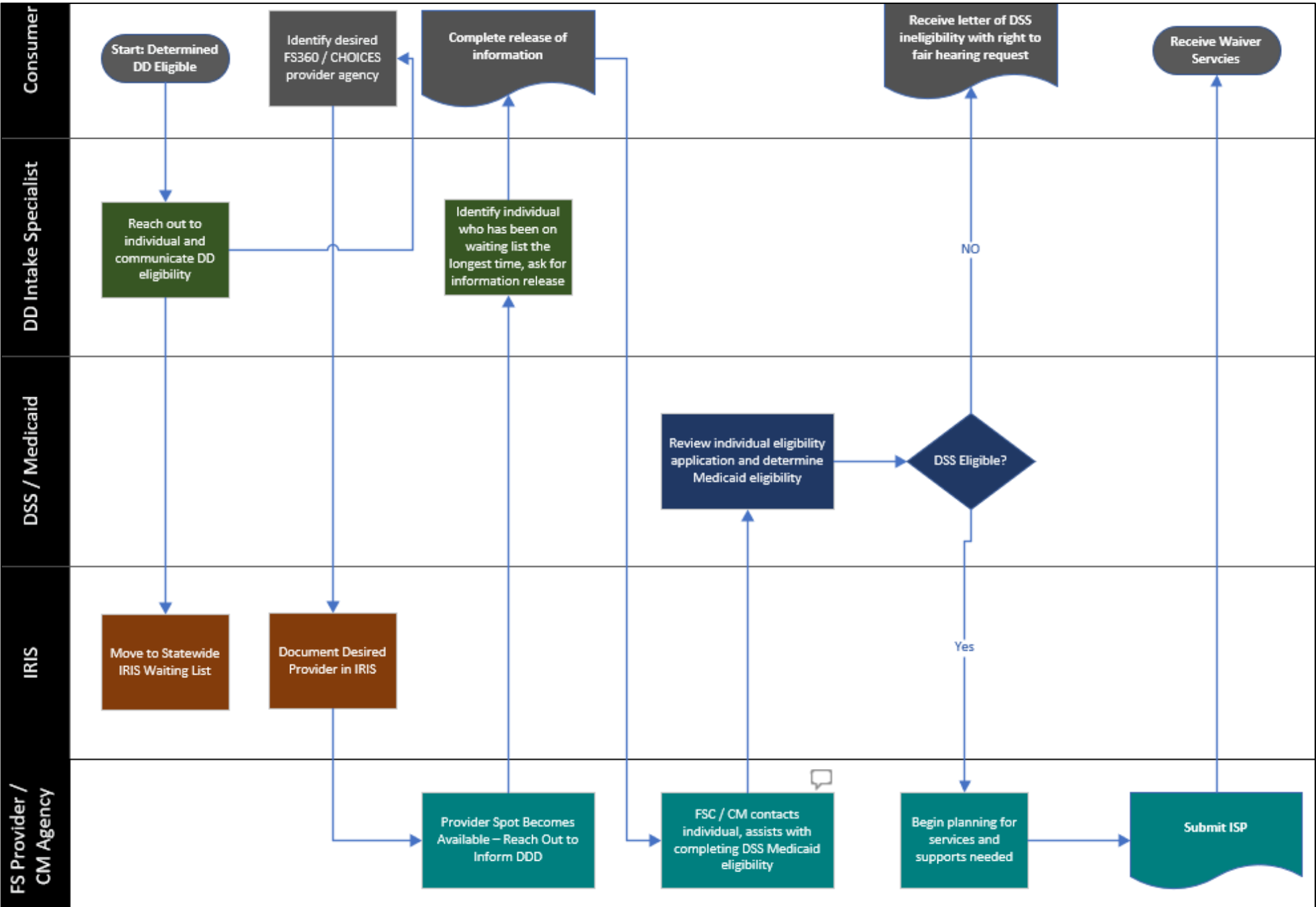
# Intake and Eligibility Process for DD Services, Part 1

This process map depicts the customer journey from calling Dakota at Home, through eligibility for DD services



# Intake and Eligibility Process for DD Services, Part 2

This process map depicts the customer journey from the time when DD eligibility is determined, through the time that waiver services begin.



# Access: Level of Care & the ICAP

# Introduction to Tools to Measure ICF LOC

There is great variation in states' approaches to determining level of care, with most states using at least one homegrown/ state specific tool.

- There is no federally mandated standard, formula, tool, or set of factors to measure ICF LOC
  - Variation in LOC definitions and tools used to collect and analyze information on a person's condition and functional limitations.
  - Variation in who completes the LOC assessments:
  - Different assessment instruments for different populations.
  - Variation in length and complexity.
  - Paper-based, electronic, or web-based.
  - Homegrown, customized, or standardized.

*“Nearly every state (49 of 51) used at least one tool for either eligibility determination or care planning that was state-specific. Only two states used independently developed tools exclusively. However, 28 states used one or more tools developed independently, such as the Supports Intensity Scale (American Association on Intellectual and Developmental Disabilities) and the interRAI Home Care Assessment System (interRAI), alongside the state-specific tools. Another five states used a combination of nationally used tools and tools adapted by the state from existing tools.” – MACPAC Study*

*Source: MACPAC Report to Congress on Medicaid and CHIP, Ch 4: Functional Assessments for Long-Term Services and Supports (2016)*

# LOC Tools Can Be Standardized or Home Grown

At the same time that homegrown tools are frequently used, there is also interest in and movement towards use of a standardized tool across states.

## Standardized Tools

- 28 states are using one or more tools that are developed independently
- Easier to implement: User manuals and training materials available
- Electronic data collection
- Pros/Cons: Reliability and validity testing / higher cost, customization limits
- May be **cross-disability**, like the interRAI Suite of Assessments and the Functional Assessment Standardized Items (FASI), **or designed for the I/DD systems** like the Supports Intensity Scale (SIS) and the **Inventory for Client and Agency Planning (ICAP)**

South Dakota uses a **standardized instrument** to determine the level of care for the waiver and for institutional care under the state Plan: the Inventory for Client and Agency Planning

## Home Grown Tools

- Widely used: 49 of 51 states
- Pros/Cons: Aligns with LOC criteria, low cost / limited testing for reliability and validity

# Standardized LOC Tools

There is interest at the federal level, and in some states, in developing a single cross-disability assessment tool that can be used across populations to determine level of care, as well as supporting care planning, resource allocation, and more.

*“A universal, standardized assessment is a critical tool for streamlining access to care for people seeking services. A well-designed assessment instrument can be used to not only determine eligibility for public programs, but may also provide other functions such as care planning, data collection, rate setting and quality assurance. A universal assessment can also: promote choice for customers when the assessment determines eligibility for multiple programs; reduce administrative burdens by decreasing the need for staff to perform multiple assessments; promote equity by using the same assessment criteria for all individuals in need of services; and capture standardized data that will help policymakers analyze program effectiveness.”*

- The Kansas University Research and Training Institute on Independent Living

# The Inventory for Client and Agency Planning

The ICAP is a comprehensive, standardized tool, designed to assess adaptive functioning and gather additional information to determine the type and amount of services that people with disabilities may need.

- Used in 14 states, including South Dakota, for determining eligibility, planning services, evaluating, reporting progress, and/ or for use in resource allocation.
- Compiles demographic information, diagnoses, and other information relevant to determining service needs.
- Needs-based assessment: it measures how a person would do if they had no supports in place
- Measures and identifies information about a person's ability to function in four categories of adaptive skills: Motor Skills, Social and Communication Skills, Personal Living Skills, and Community Living Skills
- **Strength:** strong psychometric properties (reliability and validity) for measuring adaptive and problem behavior, a normative sample across the lifespan, straightforward administration and scoring, and sensitivity to differences among individuals with varying degrees of behavioral functioning. Beyond the standardized data obtained from the ICAP, the instrument also compiles demographic information, diagnoses, and other information relevant to determining service needs.
- **Weakness:** the tool was published in 1986 and is no longer being updated. While the ICAP is still in use in thirteen states and readily available, at some point the tool's publisher may elect to retire the tool and cease distribution.



# Peer State Tools to Measure ICF LOC

The majority of South Dakota’s peer states are using homegrown tools to measure Level of Care for people with intellectual and developmental disabilities

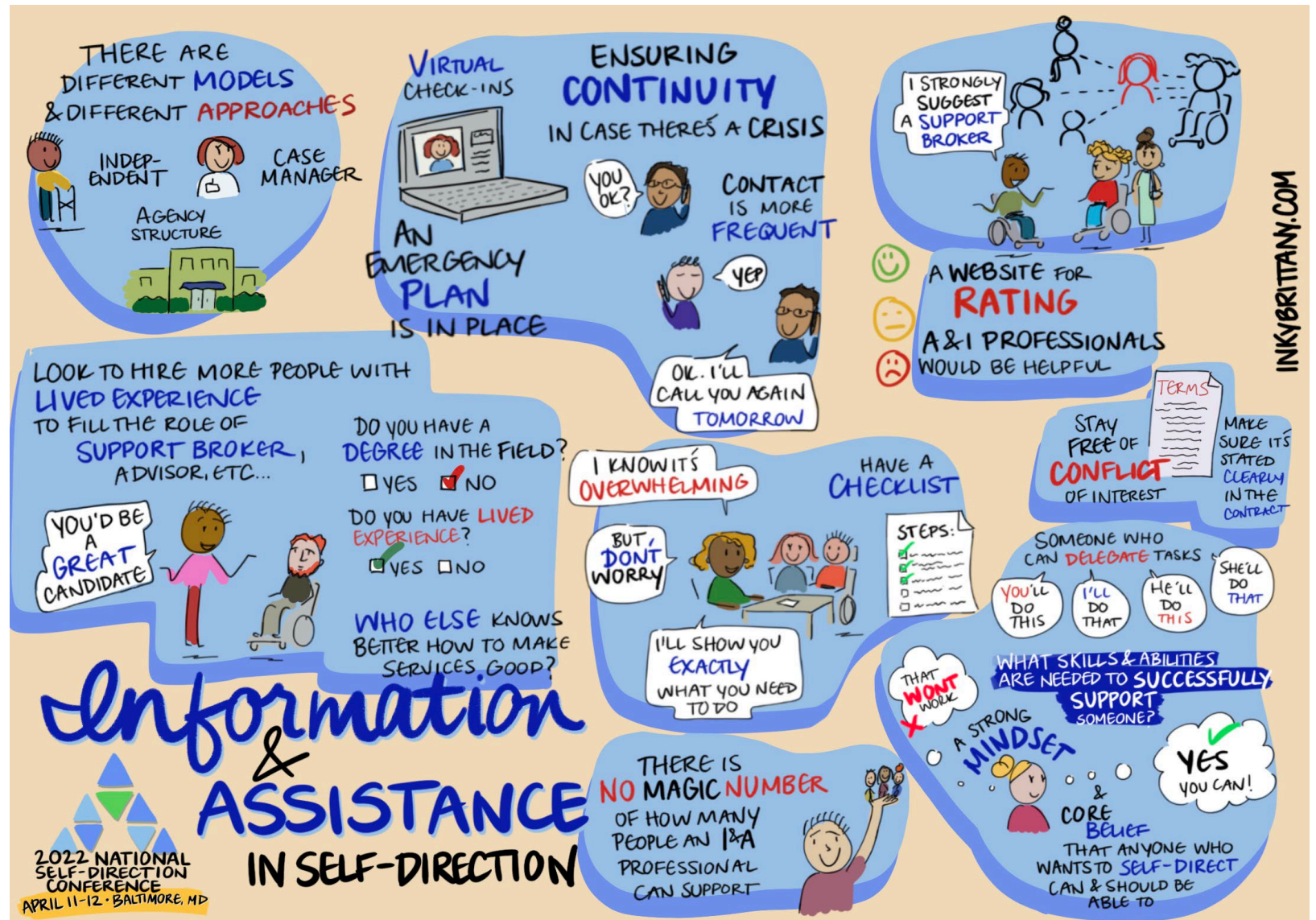
State	Type	Assessment Tool
Iowa	Standardized	Ages 0-4 Case Management Comprehensive Functional Assessment Tool (Form 470-4694) Ages 5-15 Supports Intensity Scale® for children (SIS-C) assessment tool Ages 16+ Supports Intensity Scale® for adults (SIS-A) assessment tool
Louisiana	Homegrown	The Office for Citizens with Developmental Disabilities (OCDD) form 90-L is used to determine the ICF/DD Level of Care.
Nebraska	Homegrown	The ICF/IID level of care assessment tool for waiver evaluation and reevaluation, known as the Developmental Index, is used for all ages
New Mexico	Homegrown	New Mexico ICF/IID and Developmental Disabilities Home and Community Based Services Waiver Long Term Care Medical Assessment Abstract.
Utah	Homegrown	The level of care determination screen in the Utah Systems for Tracking Eligibility, Planning, and Services (USTEPS) functions as the State’s level of care tool.
Wyoming	Homegrown	The LT-104 form gathers information on the individual’s conditions that indicate the person may have an intellectual or developmental disability, according to the Wyoming definition, and is used to identify determine that an individual meets the ICF/IID LOC. The LT-104 is performed annually to reevaluate ongoing need for the ICF/IID LOC.

# Self Directed Services: Information & Access

# Information & Assistance is a Critical Success Factor

A well-designed approach to Information & Assistance is critical to successfully scaling a participant directed services program

- According to the Center for Applied Self-Direction, without robust Information & Assistance, states struggle to scale self-direction
- People typically decline participation in self-direction if they feel they have not received enough support to understand the model
- Part of strong Information & Assistance is program monitoring, and having safeguards in place



# Defining Information & Assistance

## CMS Core Service Definition

- Service/function that assists the participant (or the participant's family or representative, as appropriate) in arranging for, directing and managing services.
- Serving as the agent of the participant or family, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services.
- Practical skills training is offered to enable families and participants to independently direct and manage waiver services.
- Examples of skills training include providing information on recruiting and hiring personal care workers, managing workers and providing information on effective communication and problem-solving.
- The service/function includes providing information to ensure that participants understand the responsibilities involved with directing their services.
- The extent of the assistance furnished to the participant or family is specified in the service plan.
- This service does not duplicate other waiver services, including case management

# Components of Information & Assistance

## Key components of the core service definition

- An Information & Assistance service should assist the participant and their family in:
  - Arranging for, directing and managing services.
  - Identifying immediate and long-term needs
  - Developing options to meet those needs, and
  - Accessing identified supports and services.
- The program should provide the participant and their family:
  - Practical skills training so that they can independently direct and manage waiver services.
    - Examples: information on recruiting and hiring personal care workers, managing workers, effective communication, and problem-solving.
  - Information to ensure that participants understand the responsibilities involved with directing their services.
- The Individual Support Plan should indicate the extent of assistance the person and their family needs

# Components of Information & Assistance

Key components of the core service definition

## Information

- Person centered planning and how it is applied
- The range and scope of individual choices and options
- The process for changing the plan of care and individual budget
- The grievance process
- Risks and responsibilities of self-direction
- Freedom of choice of providers
- Individual rights
- The reassessment and review schedules
- Other subjects pertinent to the person and/or family in managing and directing services

## Assistance

- Defining goals, needs and preferences
- Identifying and accessing services, supports and resources
- Practical skills training (e.g., hiring, managing and terminating workers, problem solving, conflict resolution)
- Development of risk management agreements
- Development of an emergency backup plan
- Recognizing and reporting critical events
- Independent advocacy, to assist in filing grievances and complaints when necessary
- Other areas related to managing services and supports



# Information & Assistance Models

Information & Assistance can be offered through Service Coordination, a waiver service, a vendor Fiscal Management Service & Support Broker, or any combination thereof. States take different approaches to the model

States have taken different approaches to offering participants in self-direction programs the Information & Assistance they need to be successful.

Options include:

- The **support coordinator** provides information and assistance, along with their typical responsibilities
- There is a specific **waiver service** for information and assistance.
  - Agency model: For example, the provider may be a support broker agency, a Center for Independent Living,)
  - Individual/ independent model: any who meets the provider qualifications for the service
- **Contracted** information and assistance as part of the Scope of Work of the Financial Management Services (FMS)
- States may **combine** these options

There is a range in provider requirement around the skills and experience required to provide I&A support:

- Minimal initial training with little or no ongoing training
- Some states allow lived experience in lieu of professional training
- Professional credentials and offer rigorous opportunities for further training

# Examples of Peer State Approach: Iowa

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Iowa provides technical assistance, including training, to people who self-direct and those that support them as an administrative activity

- Iowa provides Information and Assistance through case managers, waiver services (Independent Support Broker and Financial Management Services, as well as training as an administrative activity.
- Through a contract with the Iowa Medicaid Enterprise (IME) the HCBS Quality Assurance and Technical Assistance Unit provides support and assistance to service workers, case managers, health home coordinators, community-based case managers, members, providers, Independent Support Brokers, and others needing information about HCBS waiver programs. This includes the self-direction program.
- The technical assistance provided includes developing and conducting regularly scheduled webinar trainings, developing and implementing required ISB training and answering questions from the field about the Consumer Choices Option (self—direction) program.



# Family Support Council

# Promoting Inclusive Participation by People with I/DD

The Beyond Tokenism National Study identified the best practices to support individuals with complex and/or high needs in leadership roles and found five elements that support inclusion on a board/advisory committee.

Elements of Inclusion	Descriptors
Authentic Membership	People are recruited, treated and respected as full members of the advisory council
Deliberate Communication	People receive and share information in formats that can be understood and are included in ongoing dialogue
Full Participation	People are provided with means to be present and are engaged in carrying out their responsibilities in roles and activities that reflect their interests and preferences
Meaningful Contribution	People provide input and assistance that is important to the advisory council in ways that leverage their gifts, talents and experience
True Influence	People enhance or alter the substance, direction and outcomes of advisory council in ways that positively impact the lives of people with disabilities

# Promoting Inclusive Participation by Families

Inclusivity requires full participation of diverse members, including people with disabilities and families. Here are five recommended practices to promote full inclusion of family members in an advisory council.

Elements of Inclusion	Descriptors
Onboarding	Have a clear onboarding process, so family partners understand the rules of engagement and are comfortable participating
Meeting Preparation	Engage families in creating meeting agendas, so their priorities and goals inform the meeting’s structure. Send upcoming meeting documents to families in advance of meetings, so they can prepare and fully
Elevate Expertise	Ask family partners about their specific interests and expertise, and then match their role on the project with their interest
Ask for Feedback	Ask families for their feedback on how to improve meetings to better respect and incorporate their ideas and insights
Appreciate	Regularly tell families that they are valued, respected and heard. If possible, provide a stipend or a token of appreciation that recognizes participants’ time

Source: [Five Strategies for Building Diversity in a Patient Family Advisory Council \(nichq.org\)](https://nichq.org/five-strategies-for-building-diversity-in-a-patient-family-advisory-council)

# Family Support Council

Update text of executive order to say: At minimum three members of the council shall have an intellectual or developmental disability.

**Note:** A&M would recommend this change in composition occur over time, through vacancies.

STATE OF SOUTH DAKOTA  
OFFICE OF THE GOVERNOR  
EXECUTIVE ORDER 2003-06

WHEREAS, Family support services enable families with children with developmental disabilities to raise their children at home, which is in the best interest of the children, the families and all citizens of South Dakota; and

WHEREAS, Family support services extends to adults with developmental disabilities the opportunity to remain in their home communities by building upon naturally occurring support systems; and

WHEREAS, Families and communities are the greatest natural resource available to people living with disabilities. As with all individuals, those with developmental disabilities need families, communities and relationships in order to develop to their fullest potential, and families and communities are the major providers of support, care and training for these individuals; and

WHEREAS, The input of individuals with developmental disabilities and their families is critical in the development of family support services;

IT IS THEREFORE, BY EXECUTIVE ORDER, directed that the South Dakota Family Support Council be authorized to function in compliance with the following sections of this order.

General Provisions

Section 1. The name of this council is the South Dakota Family Support Council.

Section 2. The membership of the council consists of 15 members as follows:

- (a) Members of the council shall be immediate family members of a person with a developmental disability or have a developmental disability themselves;
- (b) At minimum, two members of the council shall be Native American;
- (c) At minimum, one member of the council shall have a developmental disability.
- (d) Members of the council shall be appointed by the governor. Five members will initially be appointed for 1-year terms. Five other members will be appointed for 2-year terms and the remaining five members will be appointed for 3-year terms. Any appointments to replace members whose terms have been expired will be for 3 years. Any member appointed to fill a vacancy arising from other than the natural expiration of a term shall serve only for the unexpired term, but may be reappointed to a full term.
- (e) The council shall annually choose from its membership a chairperson, a vice-chairperson, and a secretary.

Section 3. Duties of the Family Support Council shall include but not be limited to:

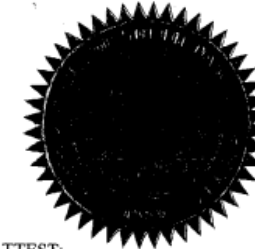
- (a) Defining the principles and philosophy of family support services;
- (b) Advising the Department of Human Services, Division of Developmental Disabilities in the Department's planning, policy, goals, implementation and evaluation of family support services; and
- (c) Providing an annual report to the Governor and Legislature.

Section 4. The Division of Developmental Disabilities of the Department of Human Services will provide staff assistance to the council.

Section 5. Meeting expenses for the Family Support Council will be paid from the Division of Developmental Disabilities of the Department of Human Services funds.

Section 6. The effective date of this order shall be Sept. 27, 2003.

Dated in Pierre, South Dakota, this 27th day of Sept., 2003.



  
M. Michael Rounds, Governor of South Dakota

ATTEST:

  
Chris Nelson, Secretary of State

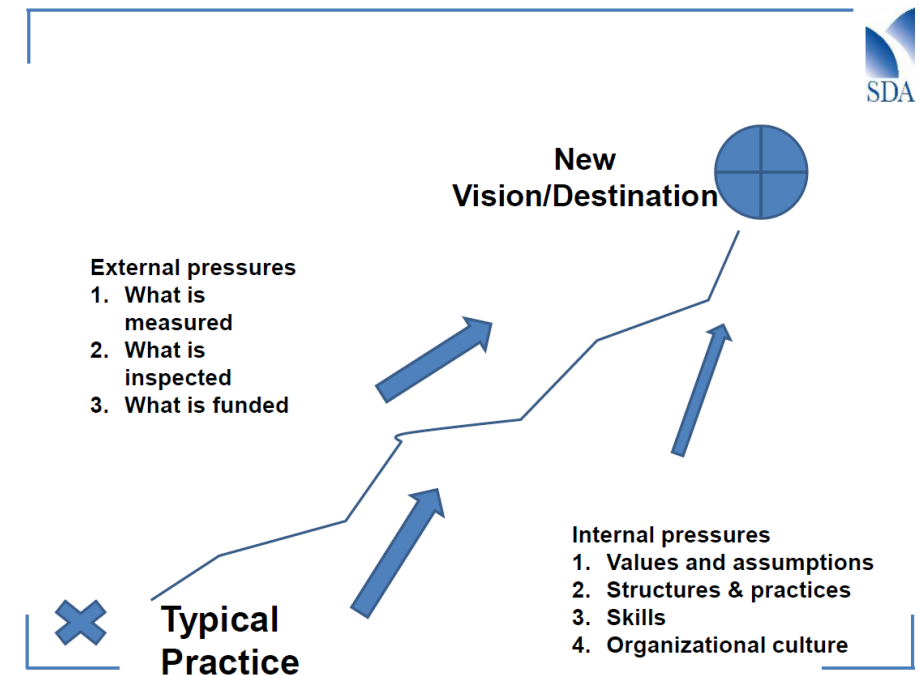
New Sec: FSC members may invite agency partners, including Medicaid, to attend meetings to share information and hear input.

# Pressure Mapping

# Introduction to Pressure Mapping

Systems transformation requires understanding and impacting the various influences to the service delivery system

- Achieving South Dakota's vision for supporting people with intellectual and developmental disabilities and their families requires applying pressure that make it easier for state staff, providers, partners, and families to do things that implement that shared vision (and tougher to do things that may not)
- An example of this is the federal HCBS Settings Rule. CMS is exerting pressure to support meaningful community integration through the rule requirements. Places in which HCBS is offered must meet minimum criteria around access to the community, choice, autonomy, etc.
- Typical external pressures include what is funded, authorized, required, and measured
- Typical internal pressures include values, practices, skills, and culture
- Even with the best intentions, people tend to do what they know. For example, if Family Support Coordinators are not comfortable with person-centered planning, they may not readily implement new tools
- The idea is to change pressures – eg, what the DDD funds, what skills Family Support Coordinators are required to have, what the quality system measures – so that state staff and providers find it easier to achieve the vision



# DHS Mission & Principles Are Foundations

Transformational change to support people with intellectual and developmental disabilities and their families is guided by DDD's mission and principles

## Mission

The mission of the Division of Developmental Disabilities is to ensure that people with developmental disabilities have equal opportunities and receive the services and supports they need to live and work in South Dakota communities.

## Principles

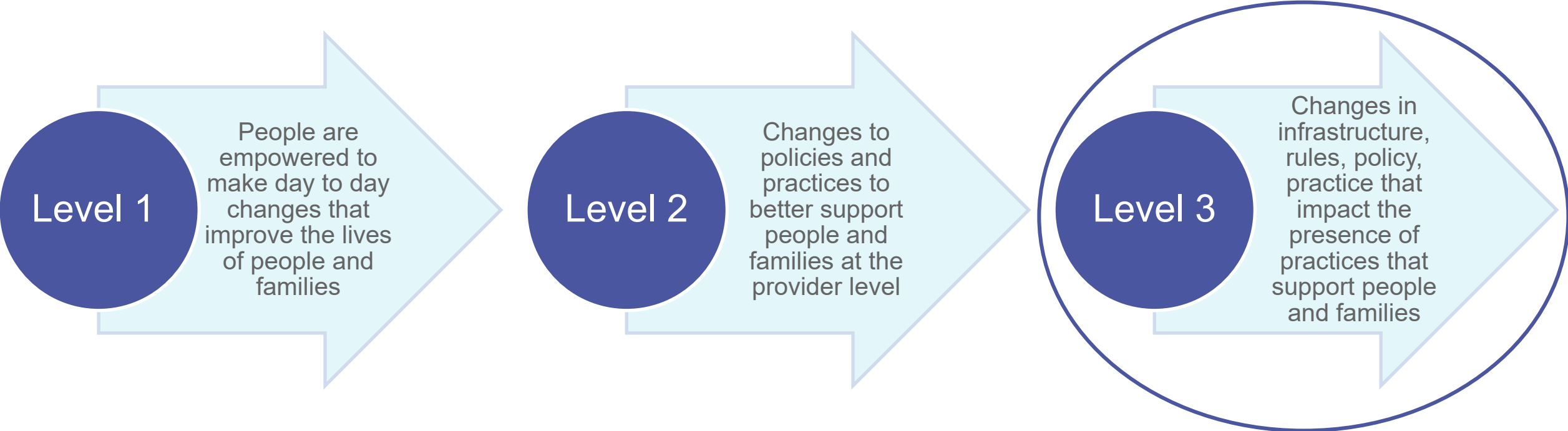
1. We will support people to participate in the life of their community.
2. We will honor the importance of relationships with family and friends.
3. We will ensure that quality services are available and accessible.
4. We will work with providers to enhance services while respecting the dignity of risk and the importance of health and safety.
5. We will respect and value cultural diversity.
6. We will be good stewards of public funds.



**DEVELOPMENTAL DISABILITIES**

# Changes Will Need to be Supported at All Levels

Successful transformation requires integrating person and family centered thinking and values into the fabric of DDD

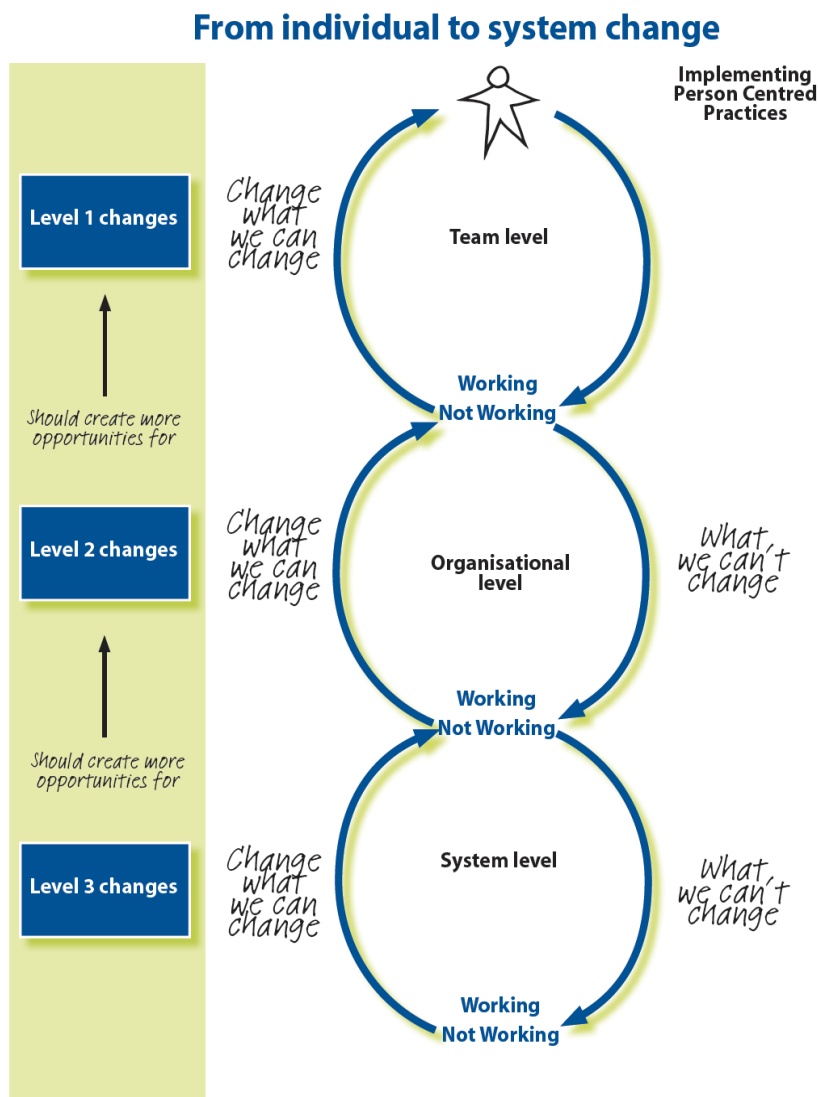


Source: Adapted from *Organizational Change | The Learning Community for Person Centered Practices (tlcpccp.com)*



# Levels of Change

Successful transformation requires integrating person and family centered thinking and values into the fabric of DDD



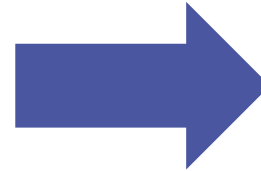
Source: [Organizational Change | The Learning Community for Person Centered Practices \(tlcpccp.com\)](https://www.tlcpccp.com/)

# Achieving the Vision will Require Transformation Change

Transformational change requires an evolution of DDD structures, including strategy, culture, processes.

## Transitional or Adaptive Change

- “Retooling” the system and its practices to fit the new model
- Mergers, consolidations, reorganizations, revising systematic payment structures,
- Creating new services, processes, systems and products to replace the traditional one



## Transformational Change

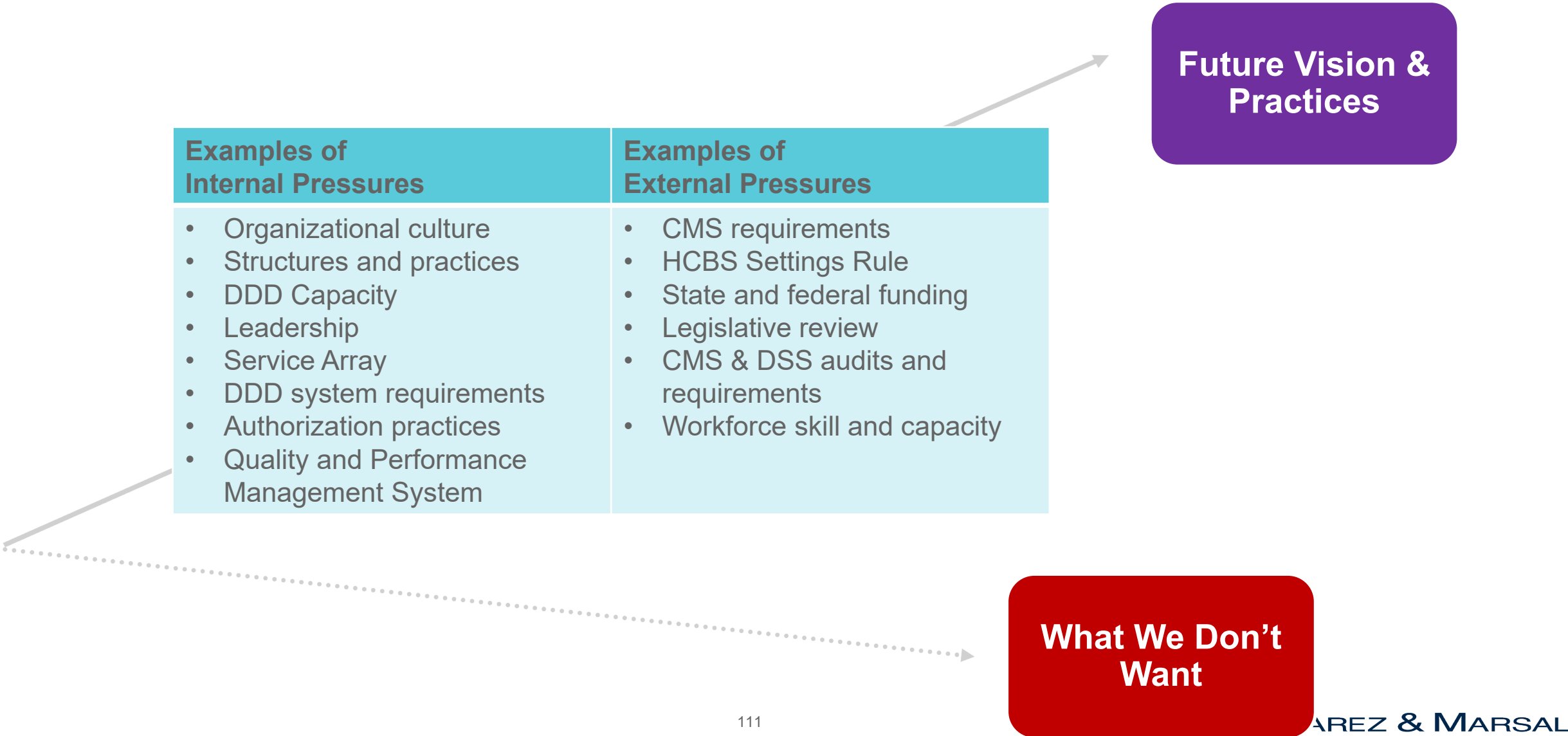
- Fundamental reordering of thinking, beliefs, culture, relationships, and behavior
- Turns assumptions inside out and disrupts familiar rituals and structures
- Rejects command and control relationships in favor of co-creative partnerships

By naming and mapping system pressures and understanding how they interact, the DDD can begin to change pressures, nudging the system towards transformational change

Source: [Types of Organizational Change & How to Manage Them | HBS Online](#), LifeCourse Nexus, citing *Creating Blue Space*, Hanns Meissner, 2013

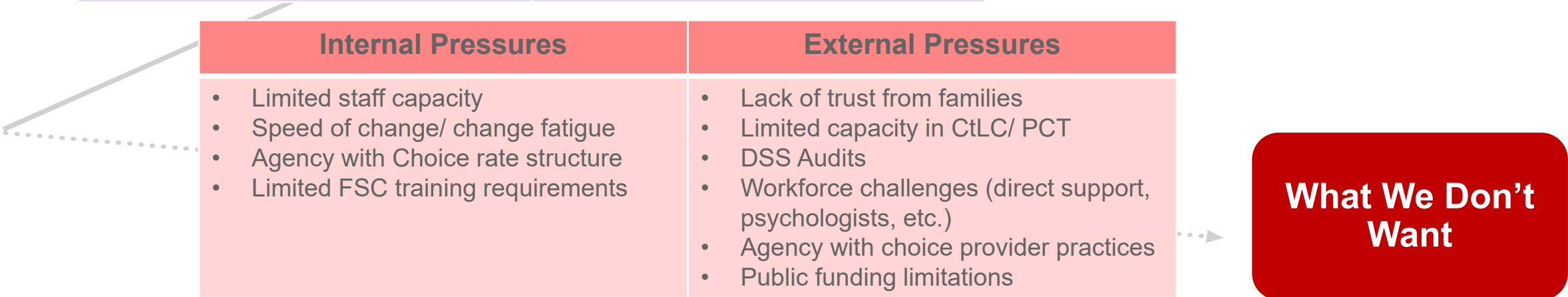
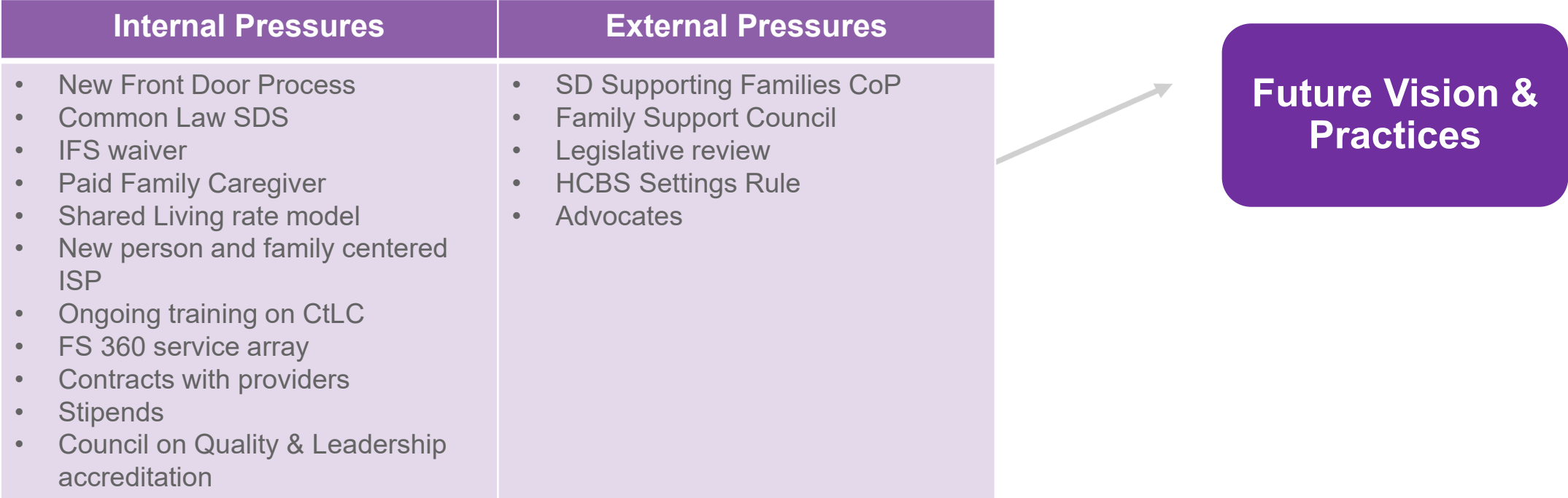
# Pressure Mapping: Internal and External Systems Pressures

Pressure mapping supports transformational organization change by identifying the internal and external pressures that affect how the South Dakota developmental disability system operates. Use pressures to create a new path of least resistance.



# Pressure Mapping: SD DDD

What internal and external pressures that currently exist make achieving the future vision possible? What pressure should be changes or mitigated? Align internal and external pressures to support SD DDD’s vision, mission, and values, and to build capacity and skills needed for implementation.



# A&M Surveys

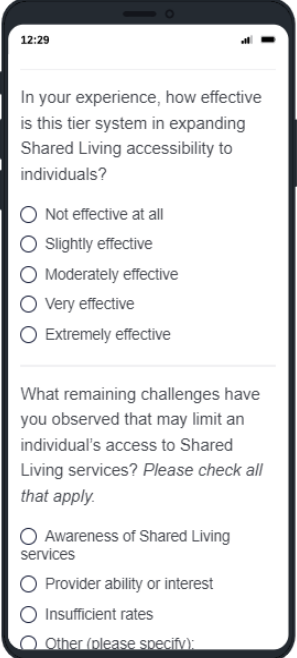
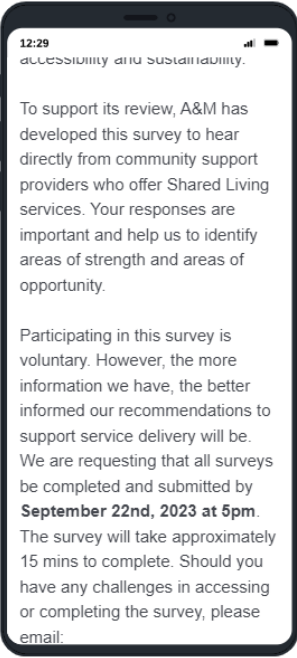
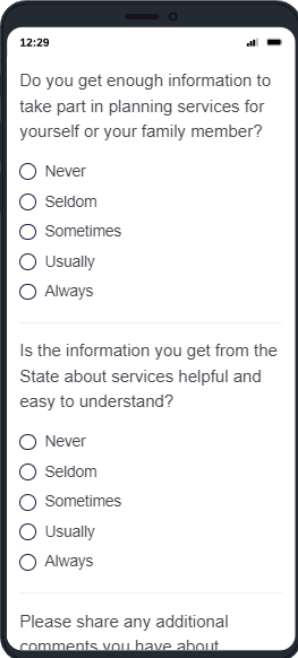
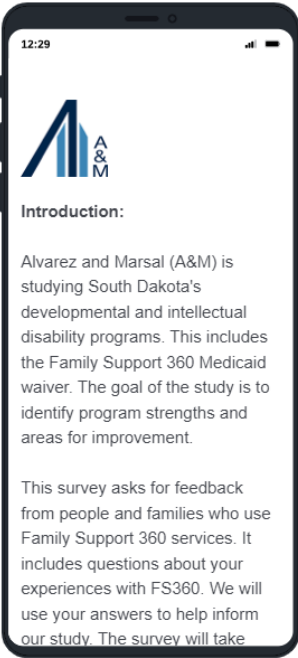
*A&M created three surveys to solicit direct feedback from key stakeholders. This section shares consumer, direct service provider, and Agency with Choice survey responses.*

# Stakeholder Survey Overview

A&M created three surveys to solicit anonymous feedback from key Family Support and Shared Living program stakeholders. This section shares consumer, Agency with Choice (AWC), and direct service provider (DSP) survey responses.

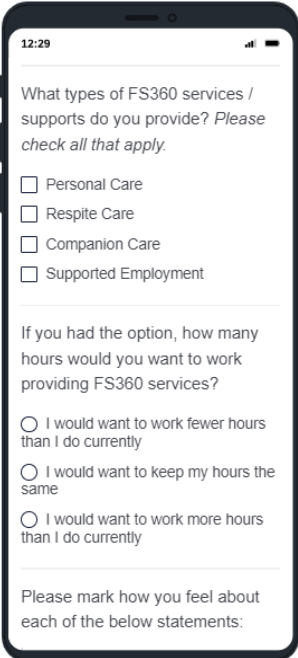
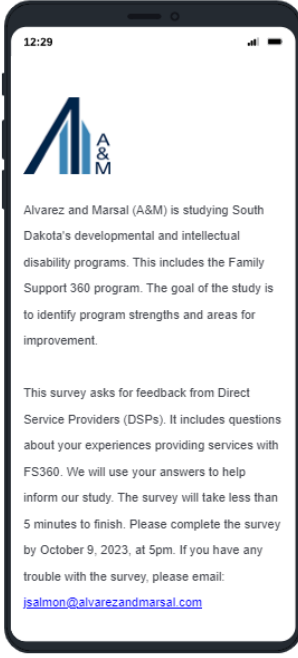
## Consumers

Self-Advocates, FSCs, Family Members



## DSP's

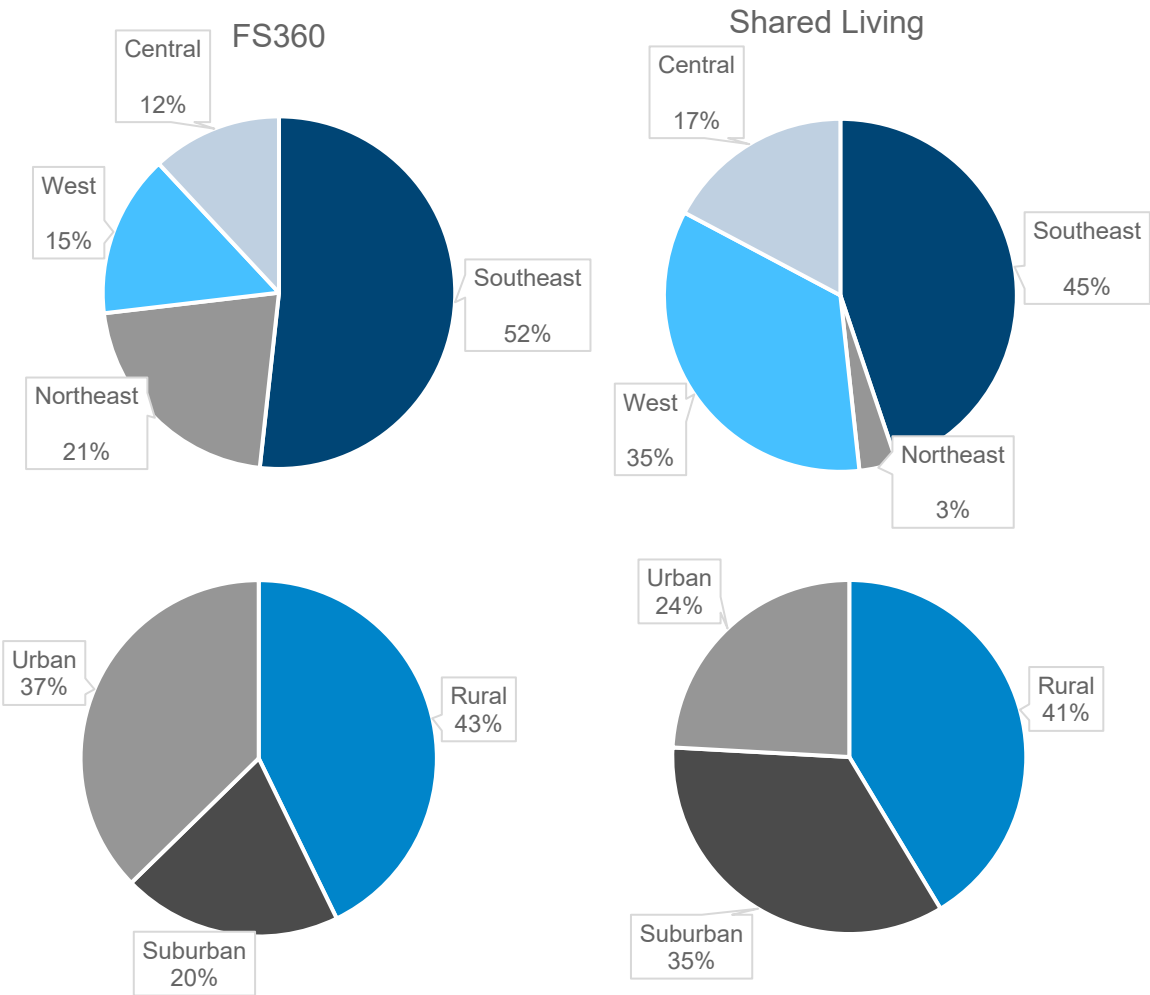
Companions, Shared Living Providers



# Consumer Survey Overview: Respondent Demographics

We received over 210 responses to the FS 360 survey and nearly 30 responses to the Shared Living survey. Compared to FS 360, Shared Living respondents were more likely to be based in the West and Central regions.

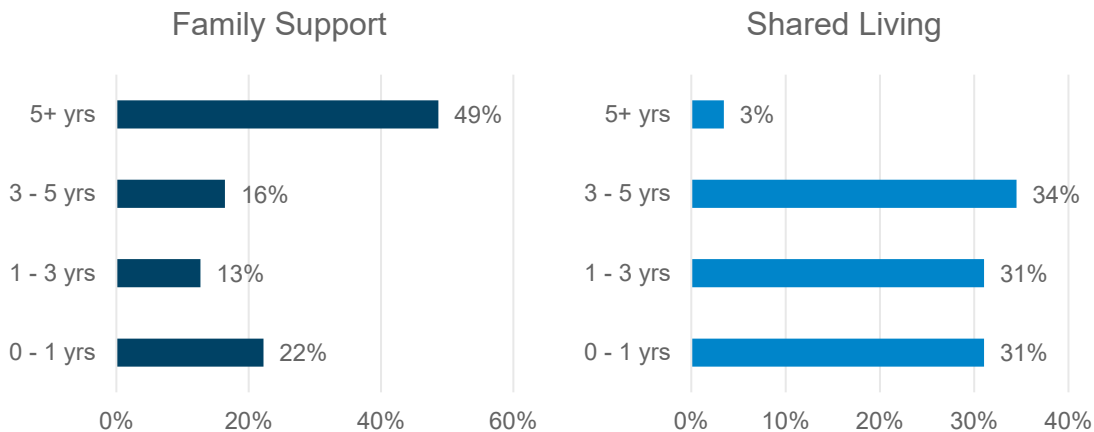
Where Respondents Are



Who Respondents Are

Relation to Individual	FS 360	Shared Living
Parent/Primary Caretaker	86%	62%
Other (companion, sibling, etc.)	5%	24%
FSC or CM	5%	3%
Myself	3%	10%

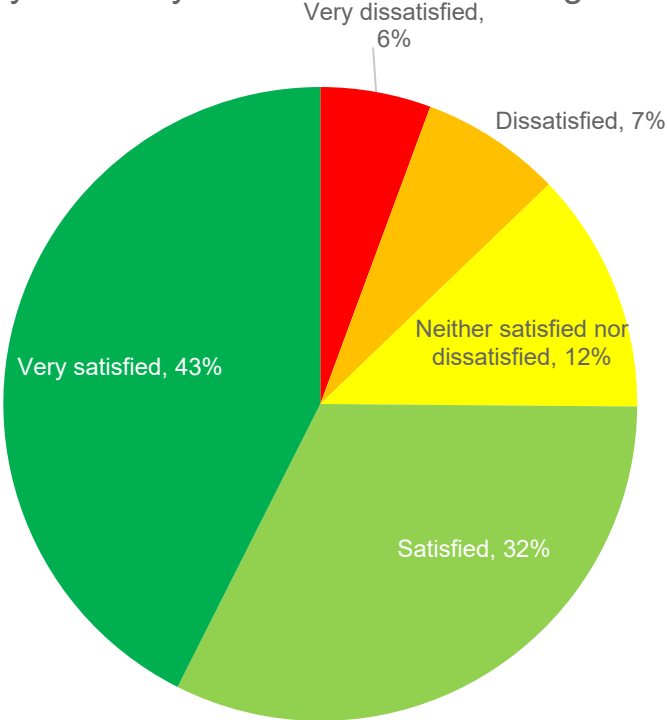
How Long Individuals Have Received Services



# Family Support Consumer Survey: Access

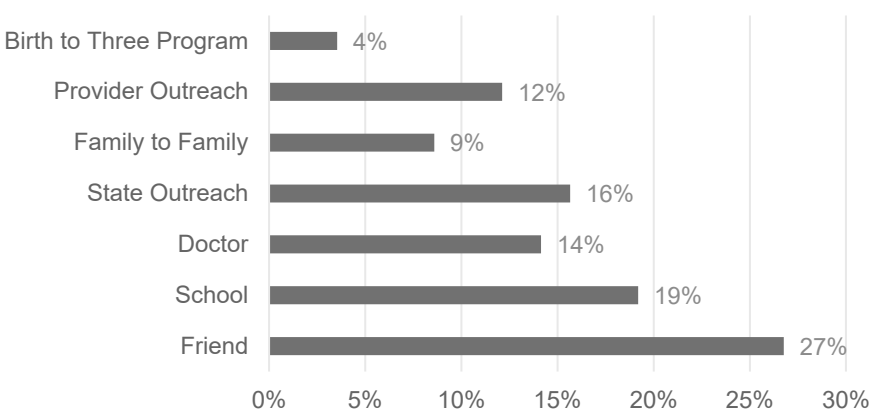
The majority of individuals receiving services through FS 360 are satisfied with the support they receive through the waiver program and receive enough information to partake in their service planning.

How satisfied are you with the service(s) / support(s) you or your family member receive through FS360?



Over 75% of FS 360 survey respondents indicated that they were **very satisfied or satisfied** with the services and supports they receive through FS 360.

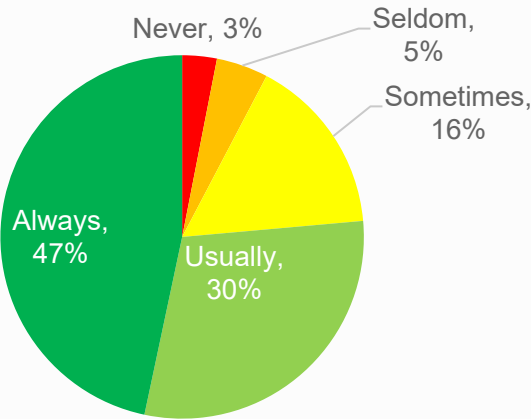
How did you find out about the FS360 program?



The most **common channels** survey respondents learned about FS 360 were: **Friends** (27%), **Schools** (19%), and **State Outreach** (16%).

Over 75% of FS 360 survey respondents indicated that they “**usually**” or “**always**” receive enough information to partake in their service planning.

Do you get enough information to take part in planning services for yourself?

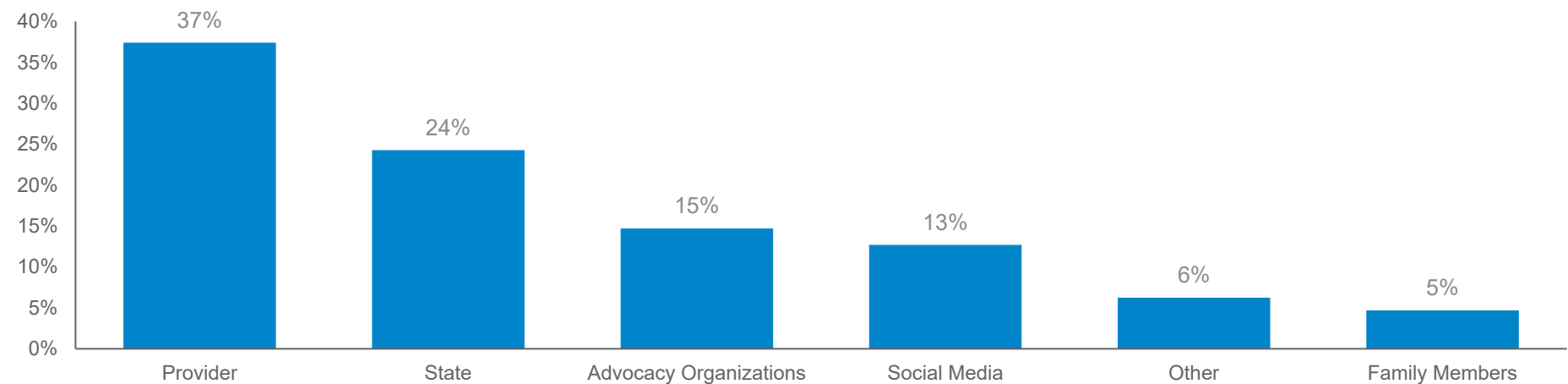




# Family Support Consumer Survey

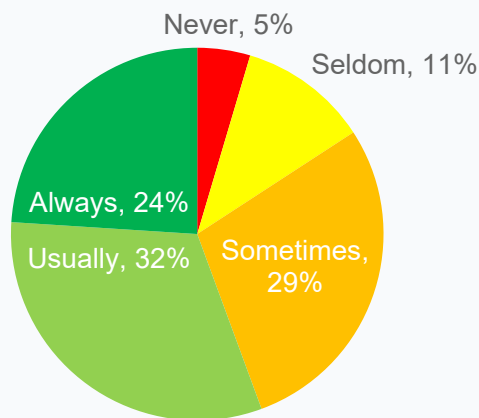
The majority of individuals receiving services through FS 360 are satisfied with the support they receive through the waiver program and receive enough information to partake in their service planning.

Where would you like to go to receive information on FS360 services?

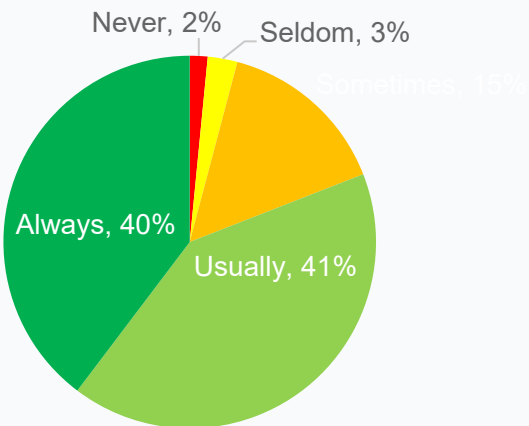


Individuals who selected “other” mentioned receiving information via **schools, paper mail, therapists, and periodic State listening sessions.**

Is the information you get from the State about services helpful and easy to understand?



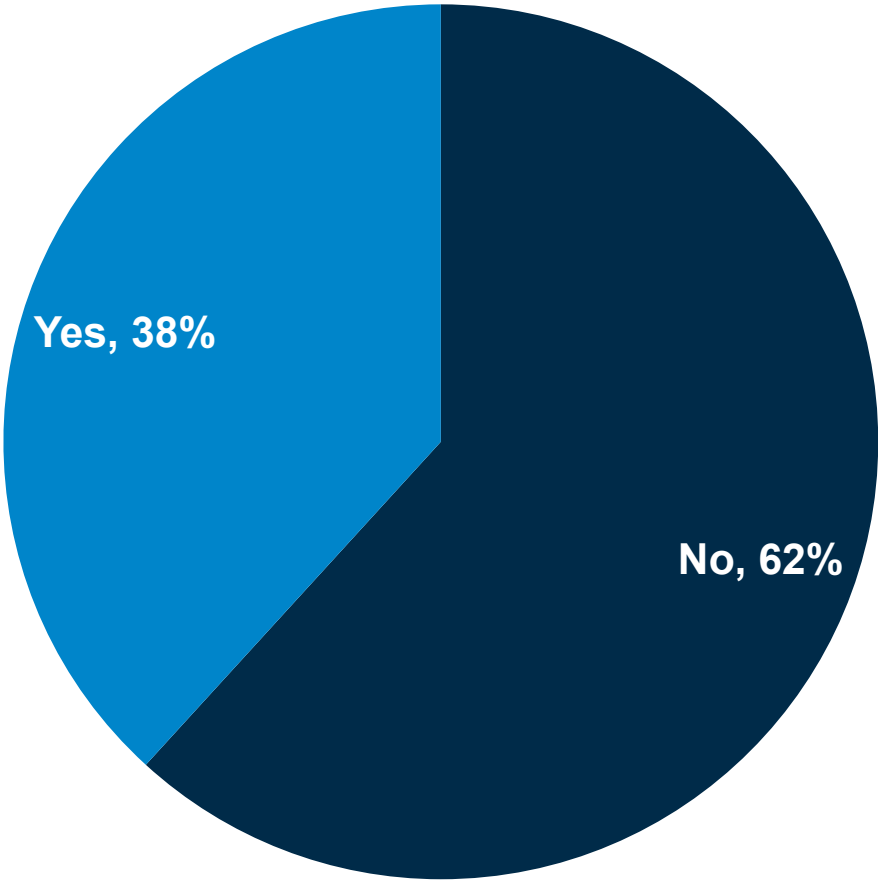
Is the information you get from your provider about services and supports helpful and easy to understand?



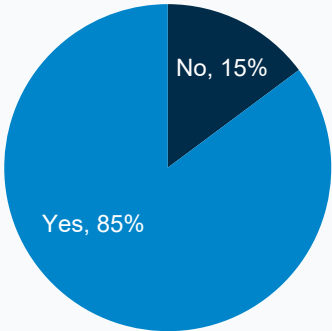
# Family Support Consumer Survey: Appeals

The majority of survey respondents had not had a service request denied. Of those that had been denied services, only 17% elected to go through the appeals process.

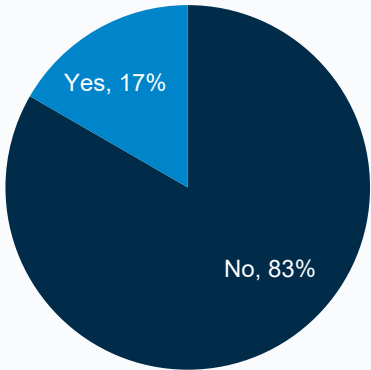
Have you ever had a service request denied?



Do you know what to do when you disagree with a decision about your services?



Have you gone through the appeals process?



# Family Support Consumer Survey: Service Access

Over 75% of FS 360 participants receive all the services listed in their service plans. Individuals that do not receive all the services / hours requested on their service plans frequently mentioned difficulties finding respite care providers, especially in rural areas.

Do you receive all the services listed in your service(s) plan?

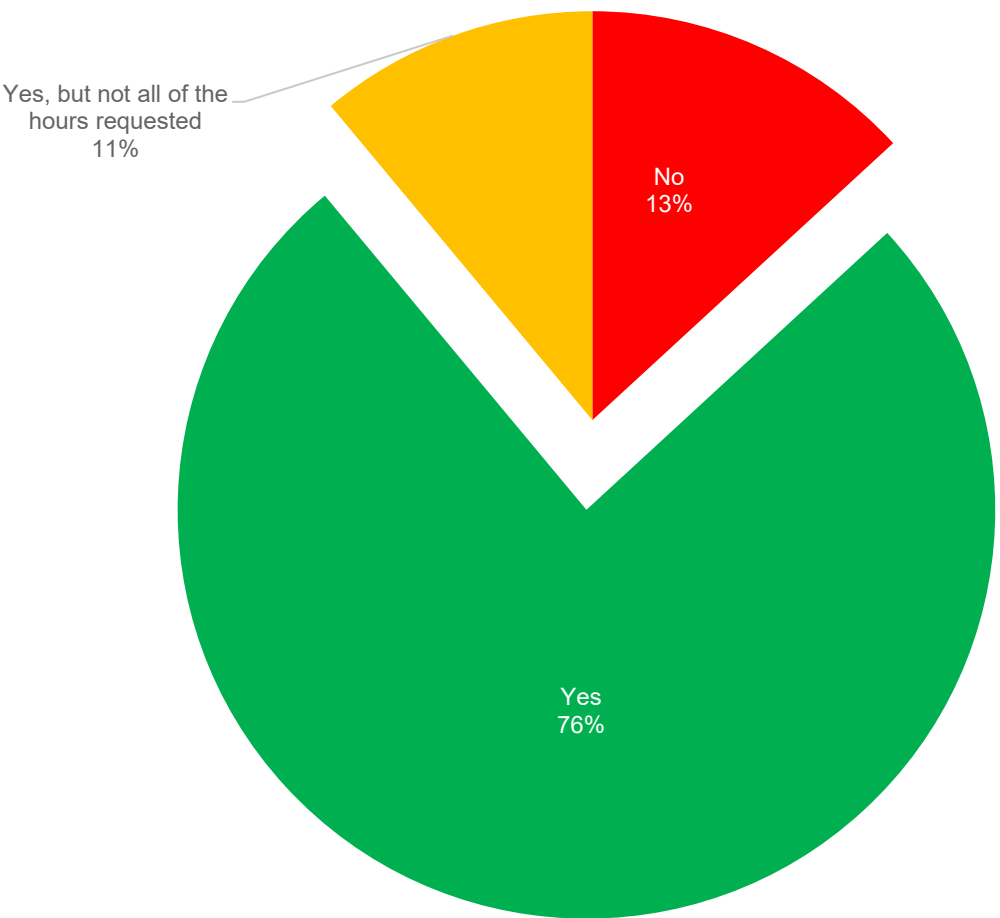
Please share more about what services you haven't been able to get all your hours for, and why.

**Provider Availability (56%+ mentioned):**

- "difficult to find providers in rural areas"
- "hard to find people to hire"
- "Hiring care providers is so difficult."

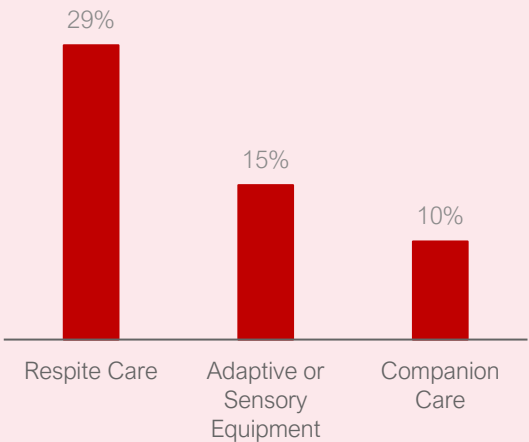
**Budget Limitations:**

- "Amount of money allotted for recreation services doesn't cover what it should"
- "The state set therapy stipend only covers one monthly therapy a year."



What services haven't you been able to receive, and why?

**Most Common Services Mentioned**

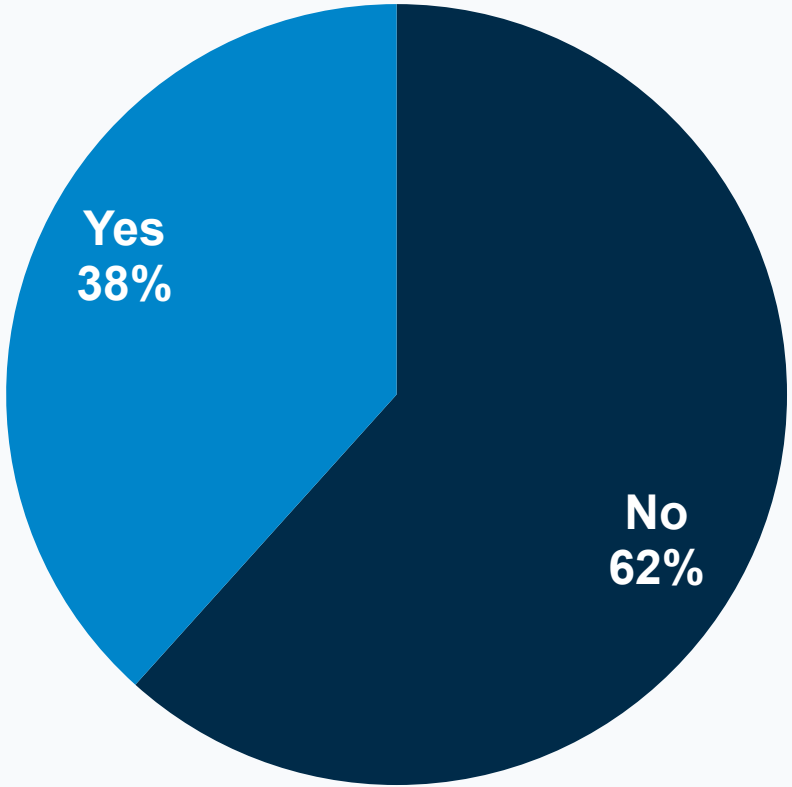


Survey respondents mentioned several obstacles to receiving services: **difficulties finding respite and companion care providers** and **long approval wait times**.

# Family Support Consumer Survey: What Can Be Improved?

Nearly 40% of respondents felt there should be additional services added to the FS 360 waiver. Daycare services and transportation were most frequently mentioned, but families also asked for more education and training around the existing waiver services.

Are there any additional services that you feel should be included in the FS360 Medicaid waiver program to better support your family's needs?



What additional services should be included in the FS 360 Medicaid waiver program to better support your family's needs?

*Families Most Frequently Mentioned:*

- **Daycare or supervision services** for children that are too young for or have aged out of companion care
- **Transportation** Support / Reimbursement
- Increased budget for **specialized therapies** and **recreational activities**

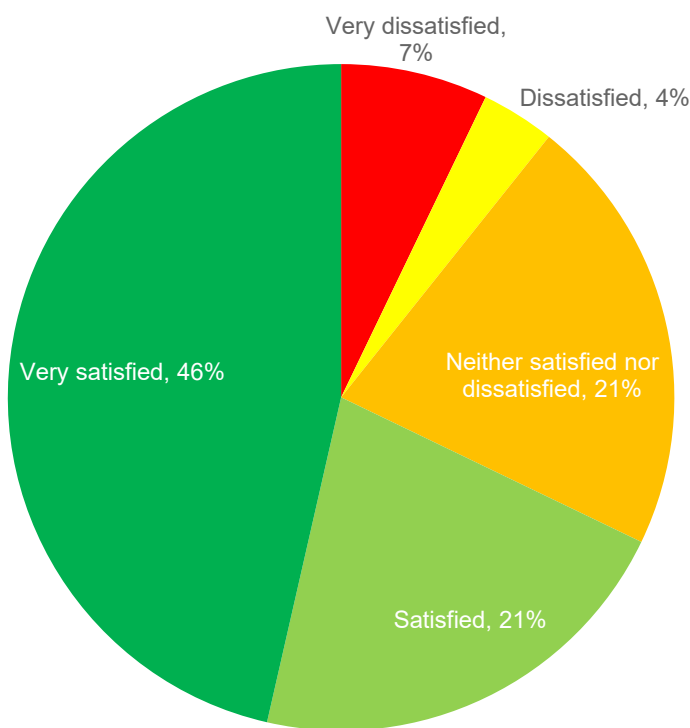
In response to the question above about additional waiver services, respondents also frequently asked for additional waiver education and training support for participants and their families.

- *"I'd like some sort of educational support to understand how it all works"*
- *"I am not entirely sure that I know what is available."*

# Shared Living Consumer Survey: Access

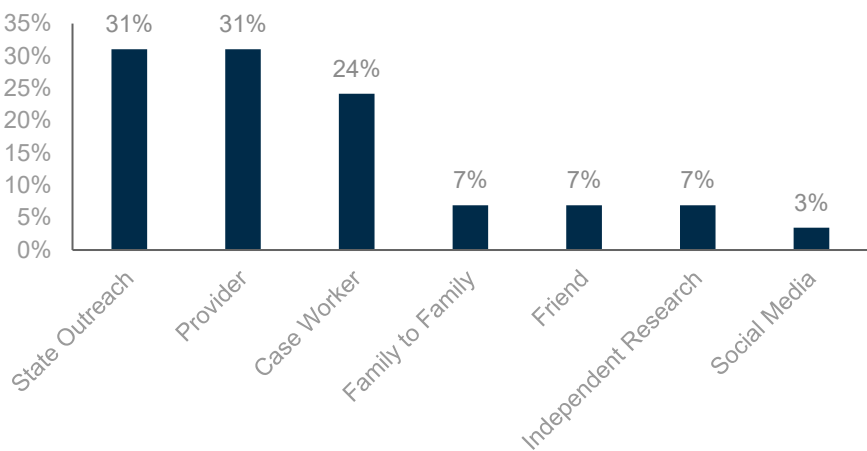
Shared Living participants are generally satisfied with the services and supports they receive through the shared living program and receive enough information to participate in planning services for themselves.

How satisfied are you with the services / supports you or your family receive through Shared Living?



**67%** of FS 360 survey respondents indicated that they were **very satisfied or satisfied** with the services and supports they receive through FS 360.

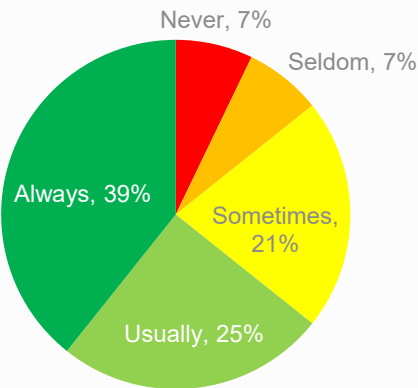
How did you find out about shared living program?



The most common marketing channels for Shared Living respondents were **State Outreach (31%)** and **Provider Outreach (31%)**.

**Over 35%** of Shared Living survey respondents indicated that they **receive enough information** to take part in planning services for themselves **only some of the time**.

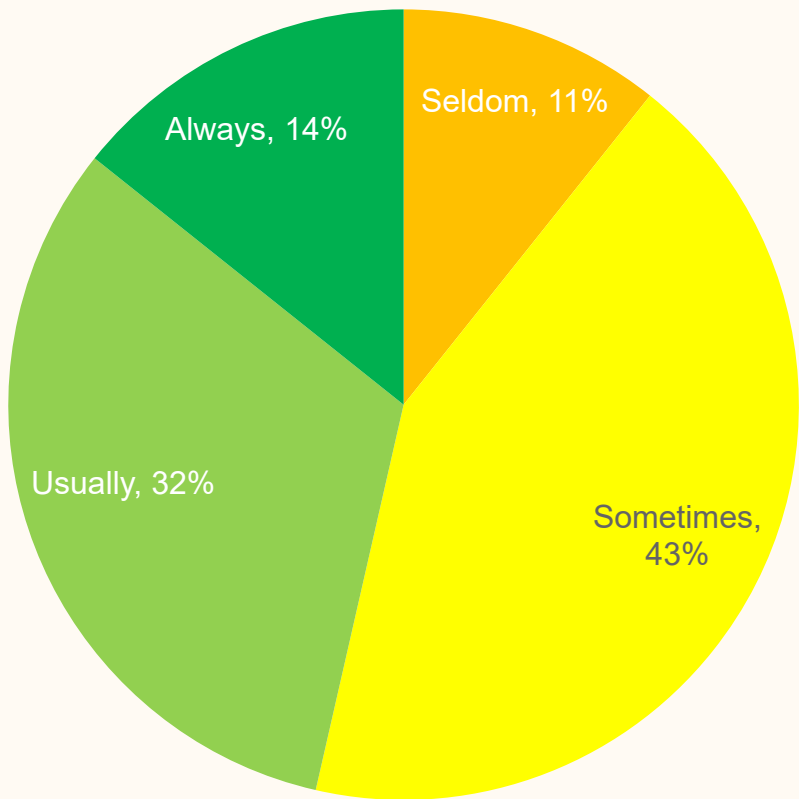
Do you get enough information to take part in planning services for yourself?



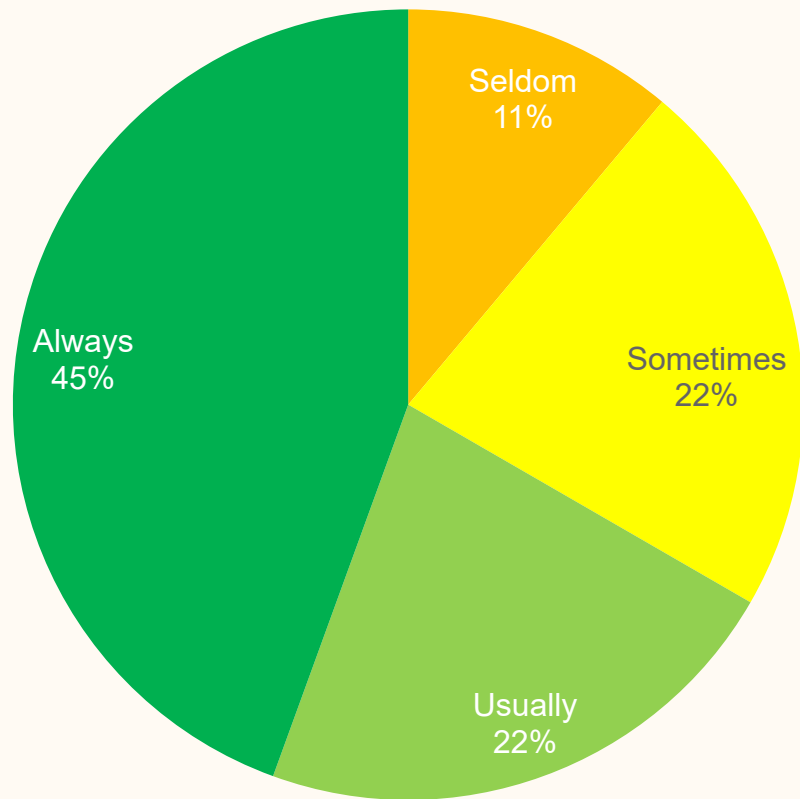
# Shared Living Consumer Survey

54% of Shared Living survey respondents said information about services received from the State was only sometimes helpful and easy to understand. In comparison, only 33% of respondents indicated information received from providers was only sometimes helpful.

Is the information you get from the State about services helpful and easy to understand?



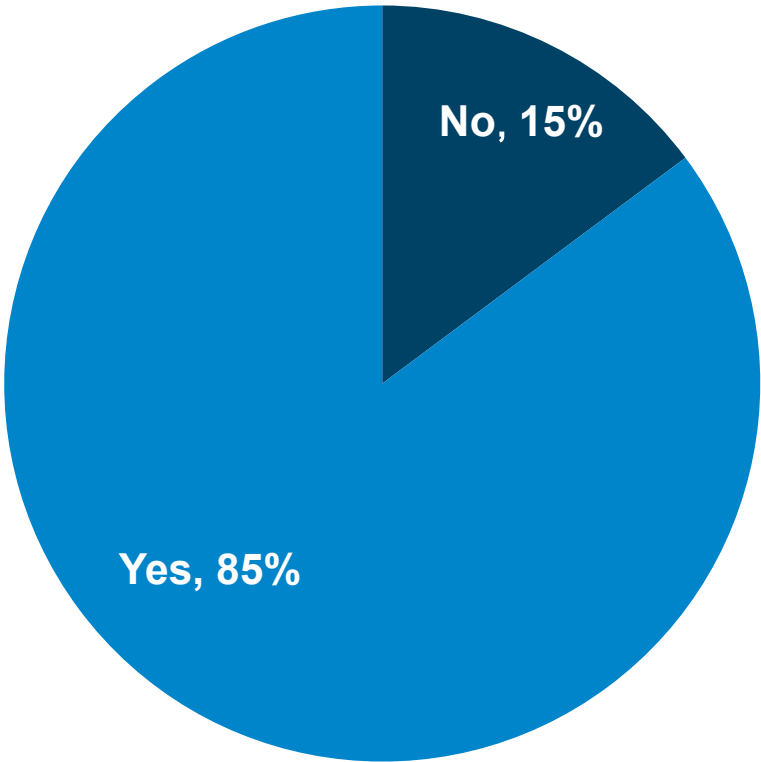
Is the information you get from your provider about services and supports helpful and easy to understand?



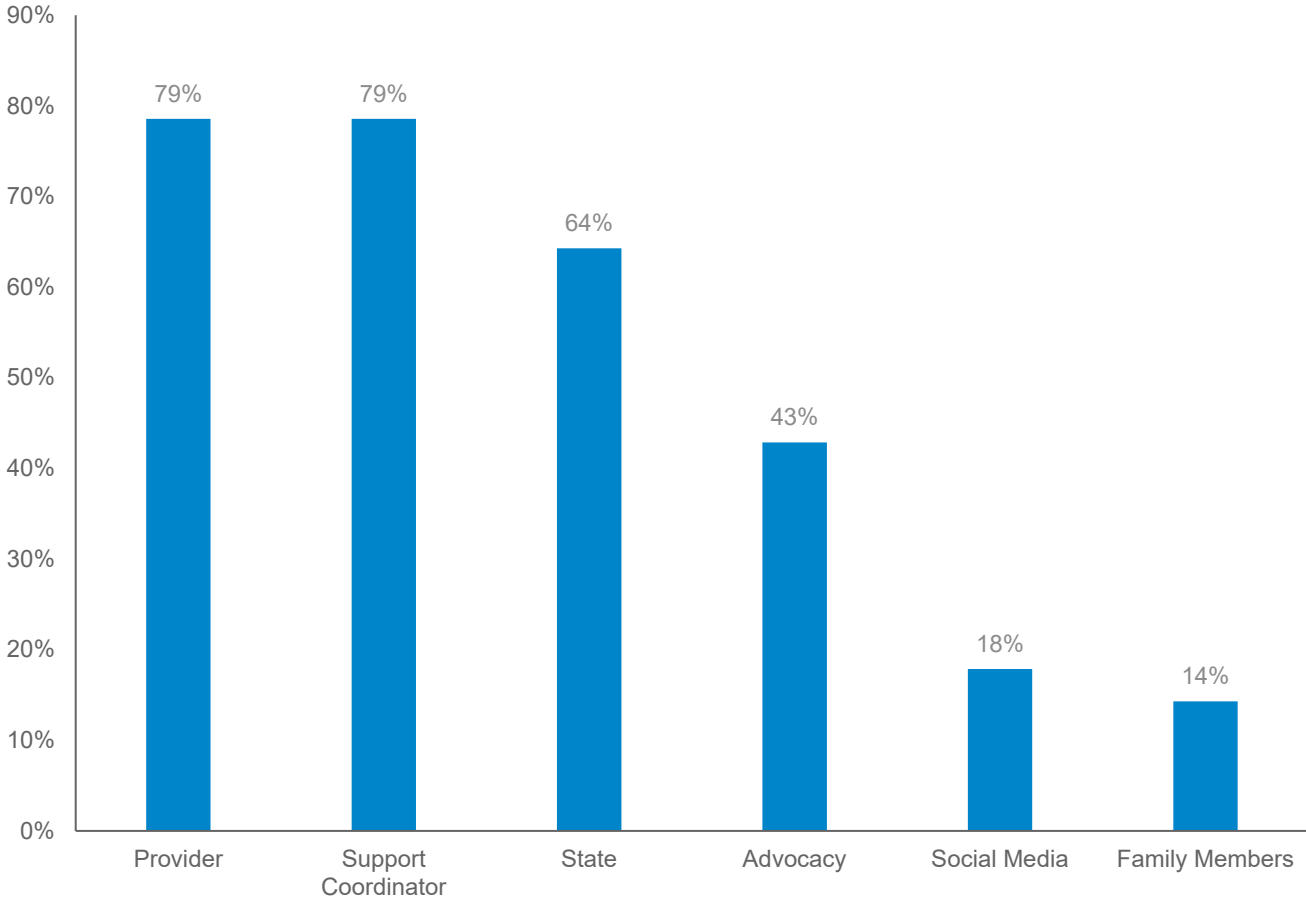
# Shared Living Consumer Survey

85% of Shared Living survey respondents said they know what to do when they disagree with the State’s decision about their services. Going forward, participants indicated they would prefer to receive updated information about Shared Living from their provider, case worker, or State communications.

Do you know what to do when you disagree with a decision about your services?

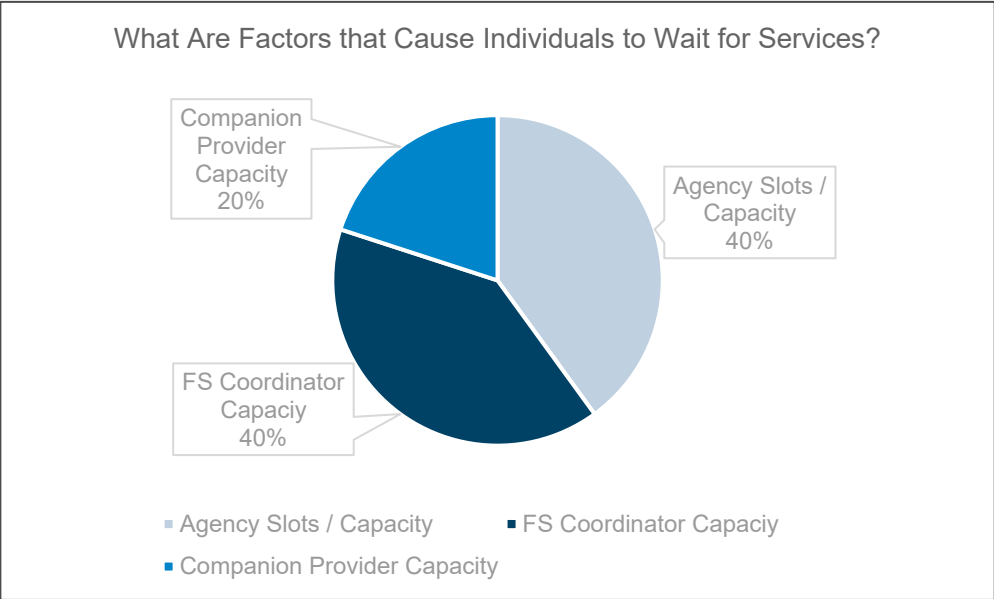


Where would you like to go to receive information on Shared Living services?



# CSP Survey: FS 360 – Access and Communication

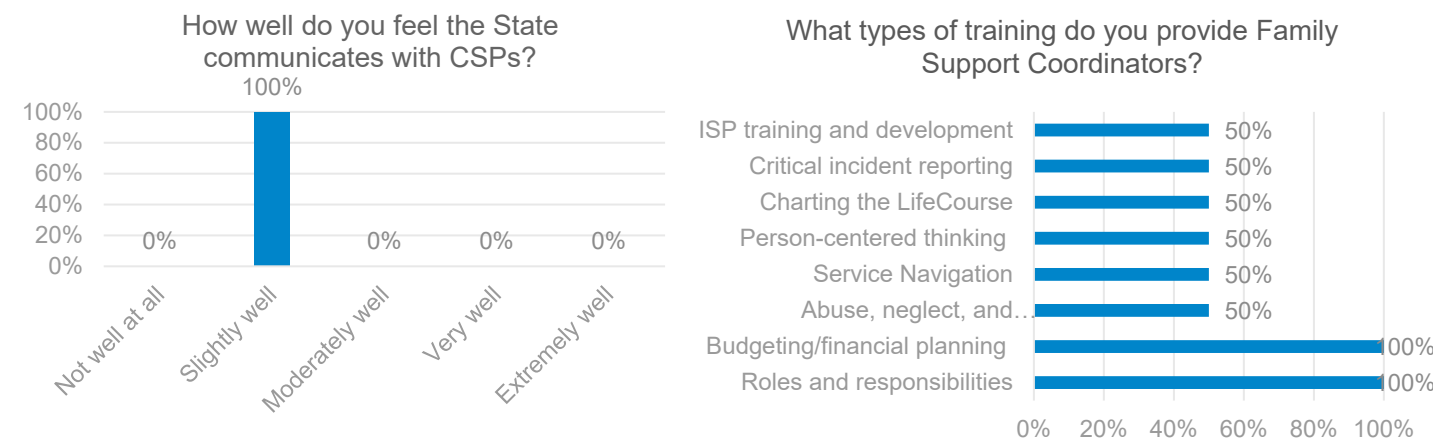
CSP respondents cited challenges related to communication from and with the State, long authorization times, lack of capacity, and other pain points that may inhibit program changes, expansion, and sustainability.



Across all survey responses, there were a total of **71 individuals** reported to be ready to access FS 360 services but are **waiting to be served** by the agency.

80% of these individuals are waiting due to agency capacity and / or Family Support Coordinator capacity.

**A third of respondents** indicated they **would expand their organization’s capacity to offer FS 360 services** by adding 1 additional program and noted that state reimbursement has been an obstacle to program expansion.



**100% of Provider respondents said that the State communicates with CSP’s only “slightly well.”**

**Key Challenges:** Lack of **collaboration between the State and CSP’s**, long authorization times for FS 360 services and approval of funding requests, and **inconsistent communications with Program Specialists**,

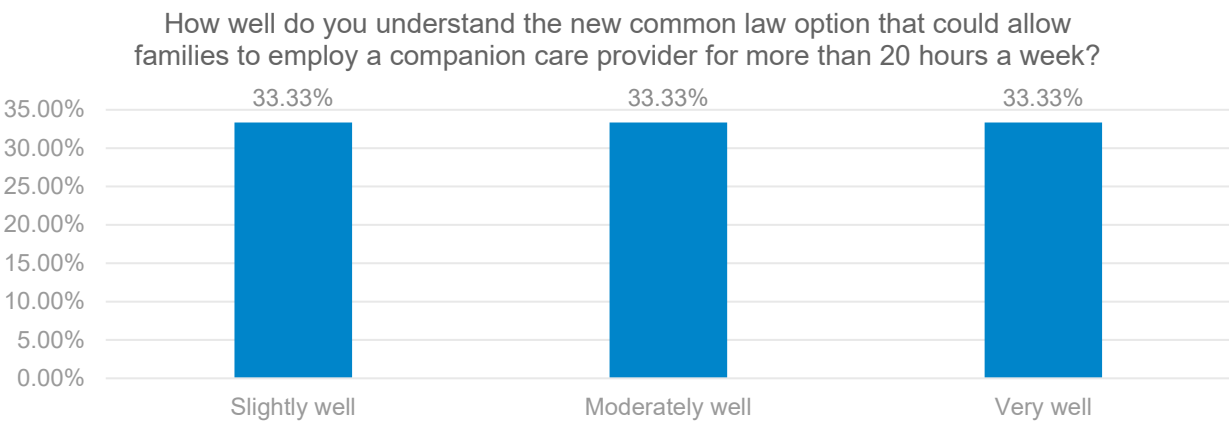
*Challenges may contribute to inconsistent service delivery, training, and preparedness amongst CSPs.*

- “DDD does hold monthly zoom meetings with Family Support staff to share information, but there is **not a lot of back and forth dialogue...** It is taking months to get new participants approved for Family Support, to receive a response on funding requests, and our current Program Specialist at DDD has not been very responsive in returning phone calls or emails.”
- “[There is a] lack of direct communication and partial disclosure. Changes are rolled out without adequate preparation or planning. “



# CSP Survey: FS 360 – Opportunities for Improvement

Survey respondents generally feel positively about the new common law option’s ability allow families to employ companion care providers for more than 20 hours a week. However, there is a gap around day service / support options for children and adults that may be addressed with future waiver adjustments.



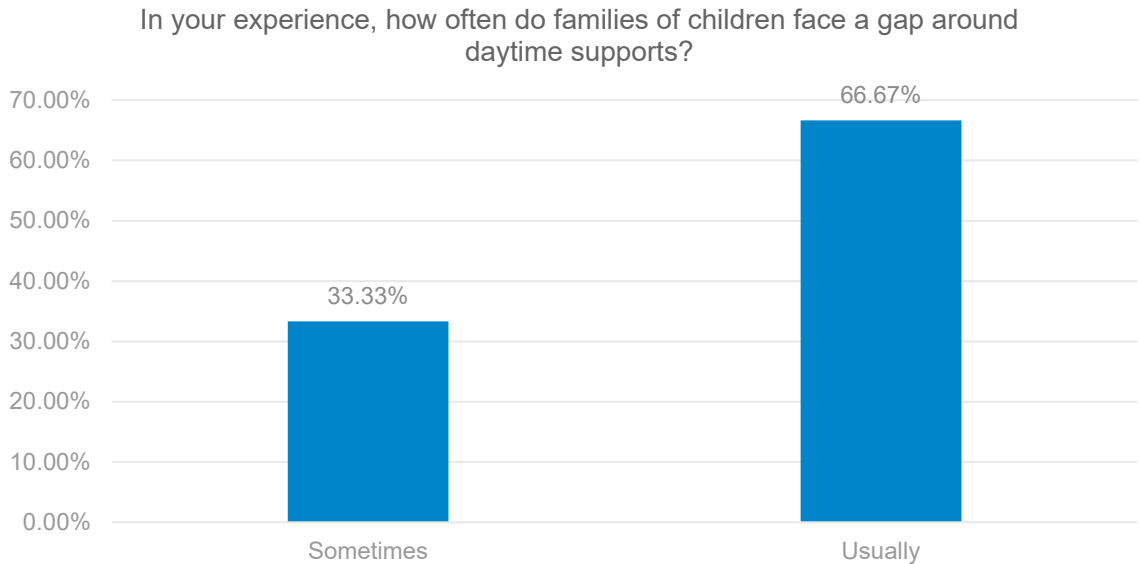
**100% of Provider respondents said that they limited companion care services to 20 hours a week.**

**Rationale included:**

- 1. Fear of creating workforce liability:** employees may put the provider at risk of labor liability under DOL national standards and requirements.
- 2. Reluctance to provide additional benefits:** 100% of agencies were not willing or able to provide 401k, overtime, or other fringe benefits even with additional State support.

*However, these providers generally feel positively about the new FMS / Common Law option for families to employ a companion care provider for more than 20 hours a week.*

*“Our goal is to move all employment for this program over to the FMS which is specially designed to provide this resource.”*



**100% of respondents indicated that families of children face a gap around daytime supports.**

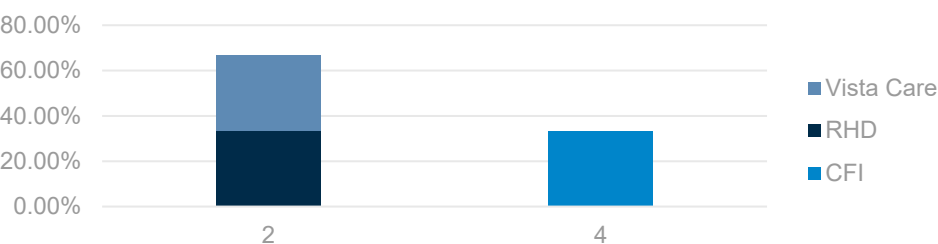
Challenges are related to provider availability, service limitations (cannot provide services during school hours), and providers cite a desire for a new service line to **support individuals that may need supervision support** that fits the circumstances and needs of these families, but may not match what is offered through companion care and respite.

These supports were noted to be especially needed for older individuals that are too old for childcare but need daytime supports while caretakers are working.

# CSP Survey: Shared Living – Access and Communication

CSP’s highlighted pain points in the timeliness and consistency of communications from the State. Providers have called for more standardized communications to all CSPs to ensure individuals interested in or already participating, CPSs, and SLPs in the program are adequately supported.

Once a CHOICES case manager identifies the desire/need to include Shared Living in an individual’s services and begins the authorization process, approximately how long does it take to receive final State approval for these services? (months)



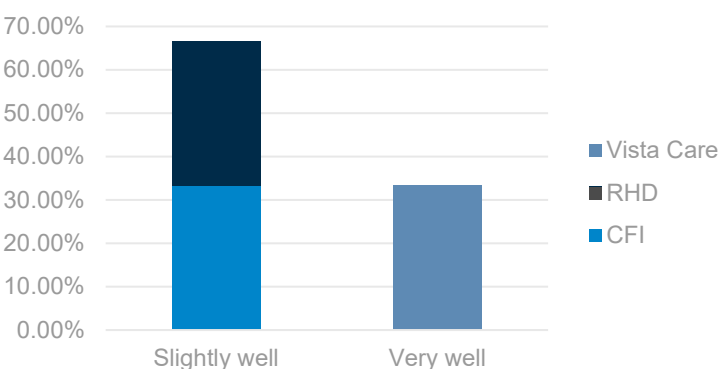
On average, SL providers indicated a **2.6 month wait time** to receive final approval from the State.  
**CFI** reported an estimated wait time that is **two times longer** than other providers.

A respondent called for an improvement in the referral process by **ensuring all CSP’s in the area are aware of a family’s interest** in receiving the service.

**Only one provider reported** there were individuals that authorized for services that **were still waiting to receive services**.

Reasons included a lack of agency slots / capacity, lacking an SL provider, and challenges with the Front Door to Supports Process

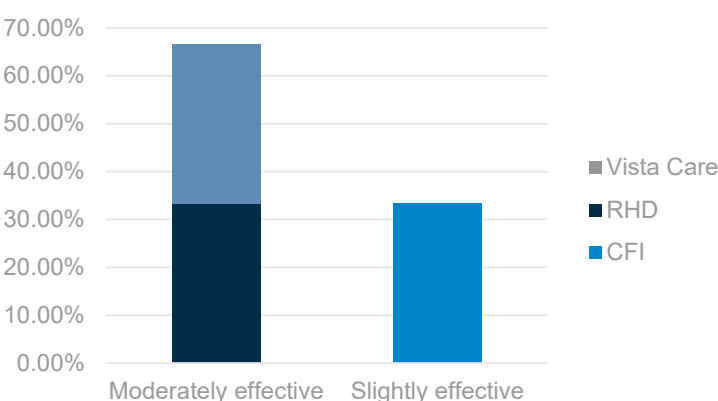
How well do you feel the State communicates with Community Support Providers?



Responses from providers highlight challenges in the **timing and consistency of communications** from the State.

- “Division staff give different answers ... Their training is surface level and does not give the necessary information...”

Are the state-provided trainings and materials given to your organization effective?

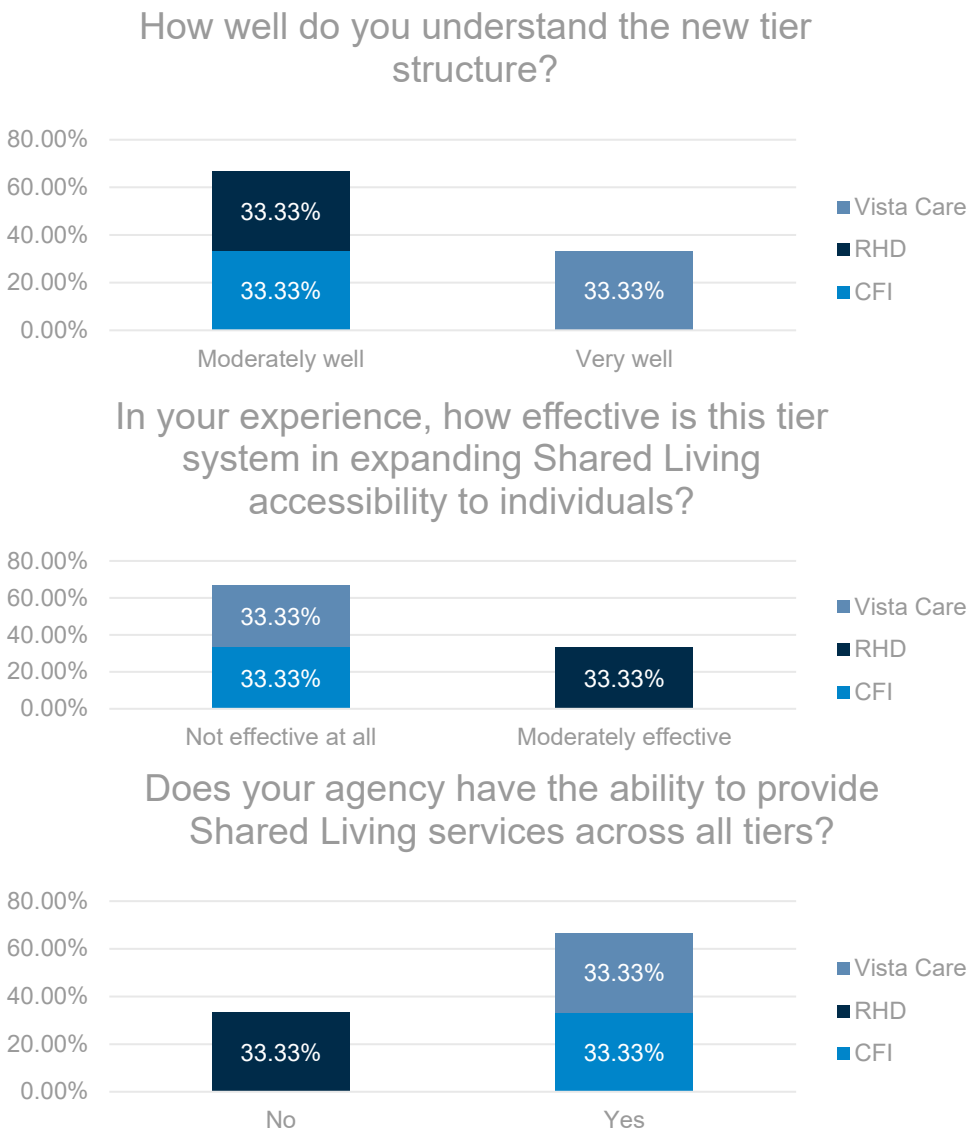


Providers highlight **challenges in comprehensive trainings**, especially in **accompaniment of new processes** from the State.

- “state trainer usually has pretty detailed materials. ... other materials don't always help. Rights restrictions are always fuzzy....”
- “Rollout of the new system for EHR and/or billing wasn't ready for the changes to the rate methodology...no training”
- Unsure of why there was a change to require documentation of 10 hours ... many issues for SL and Respite Providers”

# CSP Survey: Shared Living – Tier System, Rates, and Program Sustainability

While most CSP survey respondents indicated they can provide access to additional tier levels, expansion of the program may be inhibited by provider rates and other requirements.



**100%** of survey respondents responded they **understand the new tier structure moderately or very well**.

However, there have been challenges observed in how effective this system has been in **expanding access to more individuals**. Some of these challenges have **overlap with the provider rate-setting methodology**.

*“With the new rate structure, we cannot support a Tier 6 (highest needs)”*

## Provider Quotes: Supports Needed to Expand Program:

*At a high level, providers commented on a **lack of equivalent incentive (through rates) to support higher tiers**.*

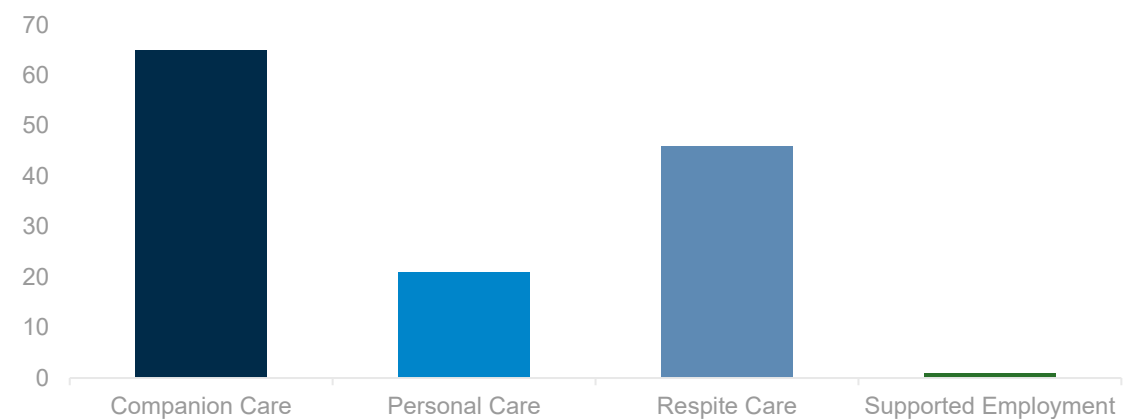
*Providers asked for a **reassessment of the rate methodology** due to decreases in pay for SLP’s and CSP’s. They also noted challenges and perceived **inflexibility from the 10-hour billable day requirement for SLP’s***

- “Higher tiers present a larger risk to our agency, higher levels of support needed for the person served and the Shared Living Provider.... The amount left over for higher Tier levels is almost equivalent to that of the lower Tier levels,.. **In short, the rates left for agencies doesn’t support taking on higher Tiers.**”
- **“We have the ability** [to provide services to higher tiers] - **just not any incentive**. At \$64 dollars a day, that barely covers the admin cost of the services.”
- **“Reassess the 10-hour billable day methodology** - many **Shared Living Providers are finding this problematic:**”
- “Understand that it is ok to have grey areas and make decisions that are helpful to that situation.”

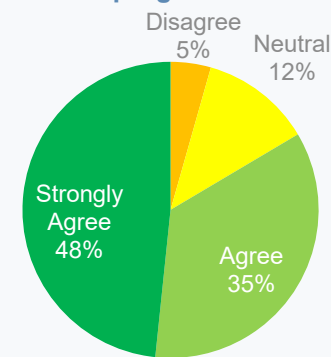
# FS 360 Self-Directed Worker Survey

A&M surveyed FS 360 companion workers. The data shows that families are doing a good job as employers. Workers are getting the training, support and direction they need. The majority of workers would work more hours, if it were allowable (as it is under the new Common Law option).

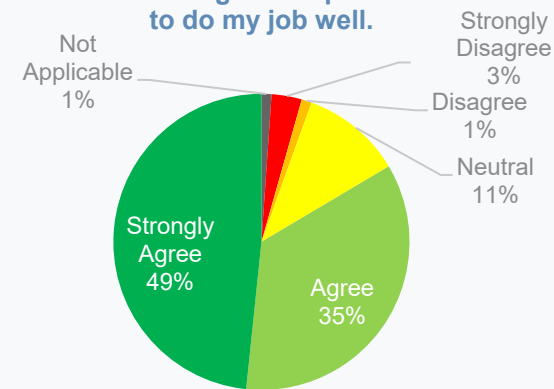
What types of FS360 services / supports do you provide?



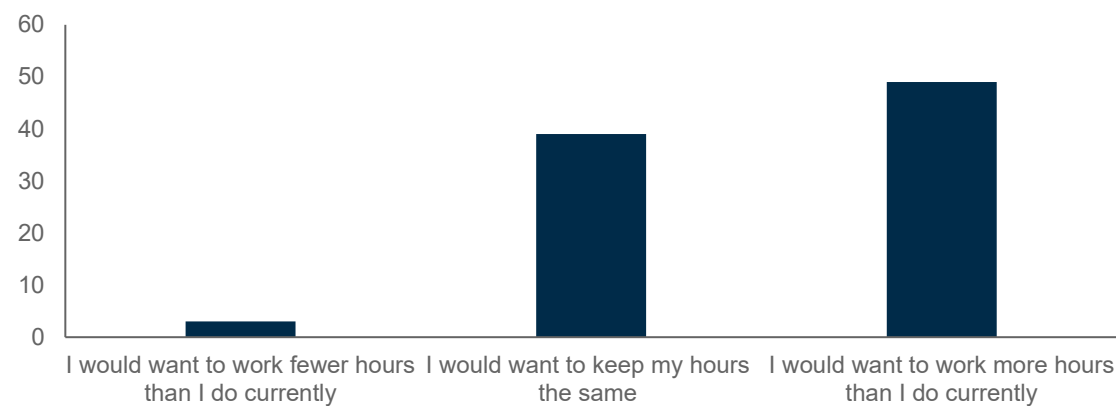
Overall, I am very satisfied with the FS360 program.



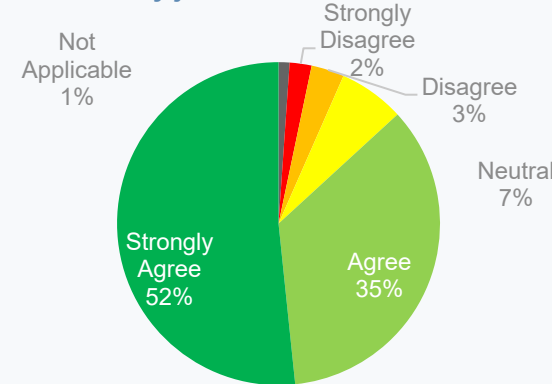
I have the training and supervision I need to do my job well.



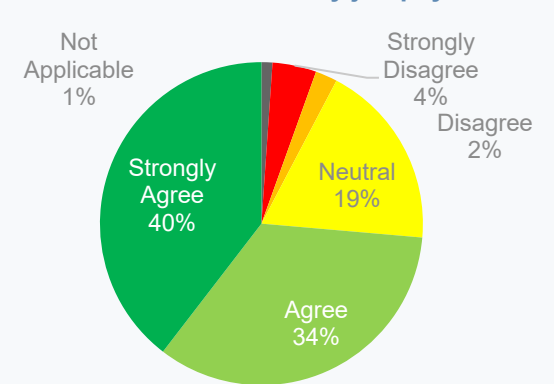
If you had the option, how many hours would you want to work providing FS360 services?



My job duties are clear.



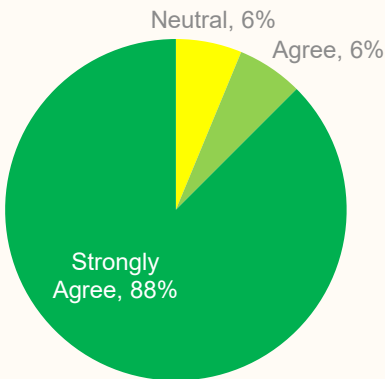
I am satisfied with my job pay.



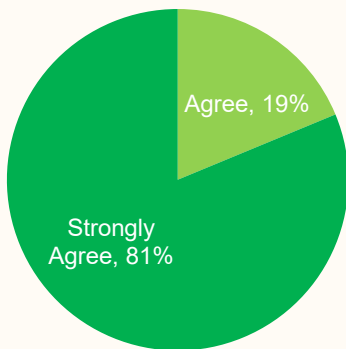
# Shared Living Direct Service Provider Survey

Shared Living self-directed service workers, Shared Living Providers (DSPs), are generally satisfied with their training, supervision, clear job duties, and pay.

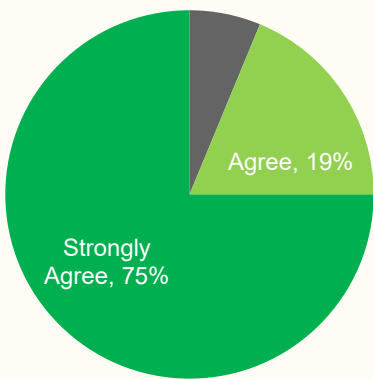
Overall, I am very satisfied with the Shared Living program



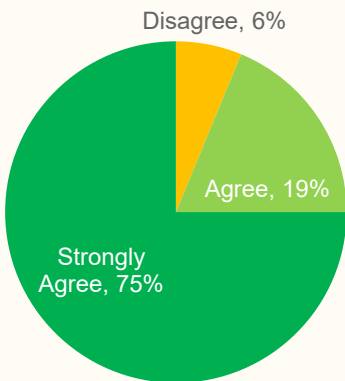
I have the training and supervision I need to do my job well



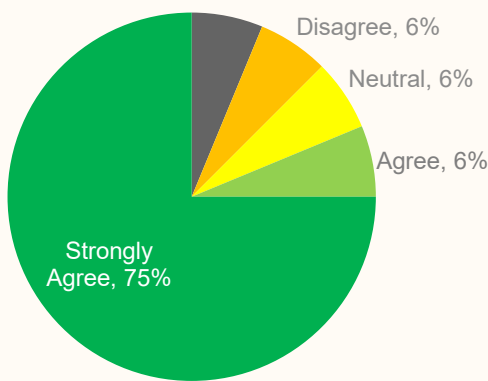
My job duties are clear



I am satisfied with the process for billing Shared Living services / time



I am satisfied with my job pay



**More than 94% of Shared Living providers said they “strongly agree” or “agree” with each of the statements about program satisfaction and job training, supervision, and pay.**

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8. [Five Strategies for Building Diversity in a Patient Family Advisory Council \(nichq.org\)](#)
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