South Dakota I/DD Continuum of Care Report

ALIGN
BY BENCHMARK

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Introduction

In November of 2019, the South Dakota Department of Human Services initiated a request for proposal in a broad effort to review the continuum of care of services for individuals living with intellectual and developmental disabilities (I/DD) in South Dakota. Four proposals were submitted and the department chose to contract Align by Benchmark to complete an analysis of the current system of care. The project began in January 2020.

During this time, Align worked closely with DHS through a series of meetings, as well as a data and waiver review to better understand the current system. In order to truly appreciate how the system works in practice, Align conducted live stakeholder meetings with individuals and families receiving services, providers, case managers, and guardians. Additionally, surveys were distributed to these same groups in order to get as much feedback on the system as possible. The entirety of the information gathered and reviewed was considered and analyzed to complete this report.

The primary charge to Align was to review the current system and identify the "gaps" in services and to make recommendations to eliminate those "gaps." The intent of this analysis is to identify avenues to improve and build upon that solid foundation. Nothing contained within this report should be construed as a final decision regarding any changes to the continuum of care system. DHS continues to seek potential opportunities to further improve the lives of South Dakotans living with intellectual and developmental disabilities.

South Dakota is a unique state that ranks 17th in square miles and is the 47th most populated state, which is conducive to difficulties in service delivery. While this report addresses those difficulties and others, it should be noted that DHS, providers, individuals, and families have worked together to create a solid system of care that has maximized its existing resources. Every state's intellectual and developmental disabilities (I/DD) system contains gaps in services that differ among each state. *The identification of needs in the South Dakota system is not an indicator of poor quality of services or a lack of oversight, but a dedication to ensuring South Dakotans who live with intellectual or developmental disabilities have the necessary options and resources to live their best lives.*

Feedback received by individuals and families indicates, overall, people are satisfied with the services available. This is a testament to the hard work of providers, the South Dakota Developmental Center (SDDC), and the Division of Developmental Disabilities (DDD) as the South Dakota I/DD system has undergone large modifications over several years due to rule changes mandated by the Centers for Medicare and Medicaid Services (CMS).

Major initiatives include:

- Implementation of the Home and Community-Based Settings rule (HCBS);
- The development of Conflict Free Case Management;
- Transitions from workshop settings due to the Workforce Innovation and Opportunity Act (WIOA), as well as the HCBS Settings Rule;
- Development and Implementation of Shared Living, as a residential service;

- On-going efforts associated with SDDC right-sizing; and
- The introduction of the Life Course Framework.

It is a great accomplishment to be able to maintain quality services for individuals during a time of change. Again, any identification of a gap is an opportunity to strengthen an already viable I/DD system.

Executive Summary

Align, based in Fort Wayne, Indiana, is a division of A.W. Holdings, LLC. Established in 1960, A.W. Holdings, LLC provides services to individuals with I/DD, behavioral health needs, and co-occurring diagnoses, as well as providing consultation and technical assistance for states and provider agencies. Our services span 13 states and the District of Columbia.

This summary will include:

- A review of the data collection activities;
- Overview of the data; and
- Summary of recommendations

As part of our review, meetings were conducted with DHS leadership, the staff of DDD, and the administrative team at SDDC. Data was reviewed regarding available services and programs, administrative rules, policy review, utilization rates, admission and discharges, and other system-wide data that was available. Regional stakeholder meetings were held for individuals and families as well as providers in Pierre, Watertown, Redfield, Rapid City, and Sioux Falls to gather information on the I/DD system. Over 100 individuals, guardians, and family members attended the stakeholder meetings in person, with an additional 75 participating via webinar. The provider meetings were equally well-attended with 95 representatives from providers and case management companies attending in person and 50 via webinar. Surveys were also utilized to gather data on the current system and potential gaps to all individuals, family members, providers, and case managers.

There were three categories of surveys:

1) Individual/Family Survey;
2) SDDC Individual/Family Survey; and
3) Provider Survey

- A total of 331 responses were received for the Individual/Family Survey with an overall satisfaction rating of 4.1 out of 5.0 (1.0 = extremely dissatisfied; 5.0 = extremely satisfied).
- A total of 29 responses were received for the SDDC Individual/Family Survey with an overall satisfaction rating of 3.9 out of 5 (1.0 = extremely dissatisfied; 5.0 = extremely satisfied).
- A total of 38 responses were received for the Provider Survey. Overall satisfaction was not examined as providers do not receive services.

Recommendations

SDDC

1) Create a system of regional crisis diversion centers, either state-owned or privately owned and operated, with SDDC serving as one of the centers; or
2) Continue to incrementally right-size, with the understanding the overhead costs per person supported will continue to increase unless draconian steps are undertaken; or
3) Operate the Developmental Center under contract to a private provider, who contractually agrees to admit all individuals who are committed by the County Review Board or the court system; or
4) Close the South Dakota Developmental Center with the proviso that the gaps in service in the community are adequately addressed and alternative services are established for those individuals who are currently being committed by the County Review Board and the judicial system.

Community Services

State Capacity

1) DHS should consider a complete review of DDD's workload capacity inclusive of a time study, to verify the need for additional employees, and if so, the number required. The review should include a review of the long-term projects required by the Federal government to determine any need to implement these projects and continue the monitoring of requirements, rules, etc. that are created as a result of those projects.
2) DHS should consider the development of an Ombudsman position for individuals living with I/DD in services.
3) DHS should consider creating a Board Certified Behavior Analyst (BCBA), or comparable, level behavior consultation service as a service for both waivers.
4) DHS should continue to work with the Rate Structure Review Committee and Community Support Providers (CSPs) to determine the true cost of providing services with the goals of moving to smaller, congregate waiver settings, expanding provider capacity, and addressing the Direct Support Professional (DSP) workforce crisis.
5) DHS should consider re-examining South Dakota's approach to workshops and Community Exploration and compare it with other states' responses to Federal rule in these areas through continued participation in the State Employment Leadership Network. Additionally, DDD should continue to communicate with, clarify, and educate individuals, guardians, providers, and case managers regarding workshops, Community Exploration, and any other options the state has explored to ensure those involved have a clear understanding of the options in place to address the concerns that were noted.

Communication

1) DHS should consider creating additional opportunities to regularly engage individuals, families, and guardians to provide information, gather input, communicate, clarify, and educate individuals, guardians, providers, and case managers regarding current services and potential changes to service options.

2) DHS should consider developing a waiver manual for both CHOICES and Family Support 360 Waivers as a resource for stakeholders.

Provider Capacity

1) To be consistent with the philosophies of the Life Course Framework, DHS should consider the development of a model in which services revolve around the needs and desires of the individual consumer.
2) DHS should consider the creation of three regional crisis diversion centers.
3) DHS should consider creating a technological assistance service on the CHOICES and Family Support 360 Waivers, allowing for the use of various technology such as sensors, tablets, automatic medication dispensers, Alexa, Google, etc. to provide supports.
4) DHS should consider developing a vision of alternatives to SDDC placement.
5) DHS should consider allowing individuals who lack an established support system to access staffing support from a CSP either temporarily or long term to allow the individual the ability to access the support they need within their home and reduce the likelihood of needing to explore the Choices Waiver option.
6) DHS should consider state-sponsored training to initiate building provider capacity to serve individuals with the most challenging behaviors. Recommended topics are:

   - Behavior support plan (BSP) development;
   - Autism spectrum disorder;
   - Behavior de-escalation techniques;
   - Trauma-informed care; and
   - Sensory Integration.

Transportation

1) DHS should consider additional funding to support and promote community access. DHS should consider a partnership with public and/or private transportation providers is needed to develop and implement a subsidized fee program for individuals with I/DD. Additionally, DHS should consider additional information and education for individuals, families, case managers, and CSPs on reimbursement to and from medical appointments via the State Medicaid Plan to ensure individuals can access and pay for transportation to needed health appointments.

South Dakota Developmental Center

The South Dakota Developmental Center (SDDC) is located in Redfield, which has a population of 2,333 (2010 census). SDDC is a Centers for Medicare and Medicaid Services (CMS) Intermediate Care Facility (ICF) which provides comprehensive services to individuals with intellectual and developmental disabilities (I/DD). The mission of the SDDC is to provide these comprehensive specialized services to enhance the quality of life and inclusion for individuals with I/DD. Currently, there are approximately 100 individuals receiving services at SDDC with 314.6 fulltime equivalents (FTE) employed at the facility. Nine of the approximate 100 residents are school-aged youth. The rate of individuals with I/DD under 21 years of age and living in long term care with greater than four people declined by 31% in the United States from 1995 to 2016. (Larson, 2018) The generally accepted principle within the I/DD community is children should not be institutionalized, however, roughly 15,000 youth remain in large ICF/IID settings.

The national trend is to move away from large institutions. Between 1960 and 2011, 60% of prominent state-operated facilities for individuals with I/DD have closed. (Li, 2014) As of 2016, only 2% of individuals with I/DD lived in state-run institutional settings. (Larson, 2018) In many cases, those institutions have been under court order to close or the subject of investigations for mistreatment of individuals served. The Americans with Disabilities Act, the 1999 Supreme Court Olmstead decision, and the HCBS rule all accelerated the exercising of rights for individuals with I/DD and the move from institutions to community living. Regardless of the reasons the trend of deinstitutionalization that began in the 1960s continues today.

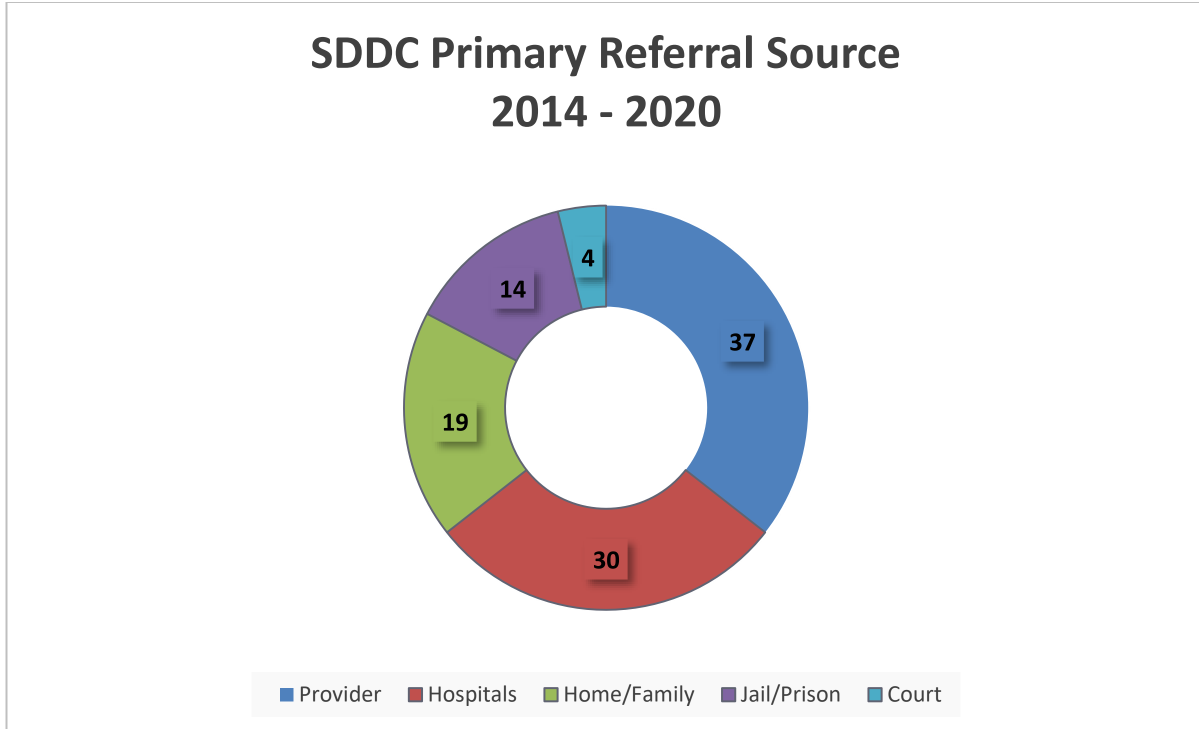
SDDC receives high marks for its service and in its Department of Health survey team reviews. In addition, SDDC is an innovator in meaningful programing with a work development program and a simulated community housing opportunity to prepare individuals for re-entry into the community. Redfield is geographically remote to most of South Dakota and not an easily accessed service. On a per-capita basis, SDDC is an expensive service accessed by very few individuals. Consistent with the national landscape and provider landscape within the state, SDDC has a large number of direct support professional (DSP) vacancies as well.

The segment of individuals who have a dual diagnosis of I/DD and a mental illness is increasing across the country and this trend is expected to continue. Serving individuals with complex mental health and behavioral needs is becoming the “norm.” SDDC is the resource in the state for individuals who are refused by all other providers of service or terminated without recourse from their provider of record. The state law allows private providers to refuse to serve individuals with a history of behaviors or with a legal entanglement. Without SDDC, there are no other placement options within the State of South Dakota.

SDDC admitted 105 individuals between July 1, 2014 and January 14, 2020. Most of those admissions were directly referred by providers (Chart 1 below). Thirty-seven of those admissions for the same time period were readmissions of individuals previously discharged from SDDC. There has been a general downward trend in referrals to SDDC since 2015 with a low of 9 in FY 2017 and increases each year since (FY 2018 – 22 referrals; FY 2019 – 15 referrals). Notably, during years FY 2016 and FY 2017, referrals from community providers decreased significantly to only 3 and 2 respectively, increasing again in FY 2018 and FY 2019. The average length of stay for discharges has trended upwards from 3.47 years in the calendar year 2015 to 5.51 in the calendar year 2019; however, this upward trend is likely an indication that individuals with more complex needs have transitioned into the community in recent years. SDDC

should be commended for their success in substantially reducing the frequency and duration of restraints, including physical holds, between 2014 and 2019.

Chart 1: SDDC Referrals



Twenty-nine individuals and family members completed surveys. Individual and family surveys indicated an overall average satisfaction rate of 3.9 out of 5 with SDDC, where 5 indicates extremely satisfied. Providers also expressed a desire for the ability to utilize SDDC for individuals with challenging behaviors when a community placement may not be appropriate. SDDC serves a population of individuals that have either not been successful in the community or cannot be served in the community under the current system of supports. SDDC currently has some innovative programs in the work development program as well as the simulated community housing to prepare individuals for re-entry into the community.

Large state-operated Intermediate Care Facilities/Intellectually Disabled (ICF/IID) facilities are under scrutiny and expensive to maintain. The national trend over the last several years has been to close state-run developmental centers due to reasons such as Department of Justice (DOJ) intervention, inability to maintain compliance, budgetary constraints, and a shift to community integration. By the end of fiscal year 2017, 13 states and the District of Columbia had no state-operated institutions. (Tanis, 2019) South Dakota is fortunate to be in a position where no outside factors necessitate a hasty change regarding SDDC. Although it is not a service gap, SDDC does represent a social gap when compared to the current direction of CMS and the country regarding providing services to individuals with I/DD. While South Dakota is not compelled to follow the national trend of deinstitutionalization, the state has been working to expand its community services, increase access to the community for individuals living

with I/DD, and championing individual rights to live in the community. These factors appear to lead South Dakota to a social crossroads in regarding to SDDC.

Compounding the societal issue is the cost to maintain SDDC. The current budget is over $25 million per year to serve, on average, less than 100 individuals and maintain a campus that is nearly 120 years old with building usage at less than 50%. From a financial perspective, it is difficult to justify the cost to maintain such a large facility to serve a relatively small group of individuals as a fiscally sound use of funds, in particular when there are gaps in community services as providers struggle with individuals presenting with exceptional behaviors or mental health issues.

It is imperative to understand that any changes to SDDC must coincide with additional services to meet the needs of the individuals currently being served. The simple closure of SDDC and placement of those individuals into the community without the allocation of those funds to develop concurrent, alternative services will result in the expansion of the current gaps within the continuum of care and will also create a void that could destabilize the entirety of the I/DD system of care.

Recommendations:

To improve the system of supports for individuals with I/DD we have suggested several alternative options each requiring the Department of Human Services to invest in certain precedents to fully implement the recommendations. The recommendations are not presented in any specific order.

1) Create a system of regional crisis diversion centers, either state-owned or privately owned and operated, with SDDC serving as one of the centers. These centers would have the capability to provide intensive inpatient psychiatric support for short-term (7-14 day) stays for evaluation and potential adjustment of medications. The emphasis would be a return to the community and the provider of record. In the current system, the provider of the record is not required to allow readmission after stabilization. A number of beds could be set aside at the Redfield Regional Center for any individuals in need of long term placements. These centers could serve as resource centers for providers as well as respite units for those individuals in crisis, reducing the strain on mental health centers, community service providers, families, and direct support staff. Being regionally based, the centers would give access to more individuals as opposed to one large facility within South Dakota.

   Additionally, an enhanced waiver model (4 individuals or less) or small ICF (4 bed) model that is not available in the current continuum of care could be utilized for those individuals who need additional assistance in managing their behavioral challenges. These homes could also serve as transition homes from the regional centers as individuals are preparing to return to their home in the community. Both the regional centers and homes would need to have access to qualified psychiatric and behavior consultant staff and the focus would be community re-integration.

   Geographical clustering of high needs populations should be considered, with the exception for a regional center located in Redfield. While you will see the idea of clustering diverges from another recommendation that people have a choice in the area where they live, this population

has a unique set of needs that would be better served with this approach due to the limited availability of necessary resources. Areas should be considered where community resources are more widely available including behavioral experts, mental health access, psychiatry, and a wider staff base. Training and certification of such services should have strict guidelines to serve the needs of individuals from SDDC.

2) Continue to incrementally right-size, with the understanding the overhead costs per person supported will continue to increase unless draconian steps are taken. The facility will need to continue to meet all CMS regulations for an ICF. This incremental change would allow DHS to muster the resources to fill some of the identified gaps in community service over a period of years.

3) Operate the SDDC under contract to a private provider, who contractually agrees to admit all individuals who are committed by the County Review Board or the court system. There would be contractual incentives to continue to reduce the number of participants who are long term residents. This recommendation could be combined with recommendation number two or be a standalone recommendation, both options utilizing a private provider(s) as the operating entity. As a standalone recommendation, it does not address the need for short term stabilization and medication adjustments.

4) Close the South Dakota Developmental Center with the proviso that the gaps in service in the community are adequately addressed and alternative services are established for those individuals who are currently being committed by the County Review Board and the judicial system.

<u>Barriers</u>:

This process would take a substantial length of time, and the transition could be done in phases. Provider capacity would have to be increased via current CSPs willing to expand or the attraction of external CSP organizations. The State of South Dakota must commit to moving all funding and any saving of tax dollars from SDDC to the community I/DD system to fund the supplemental models.

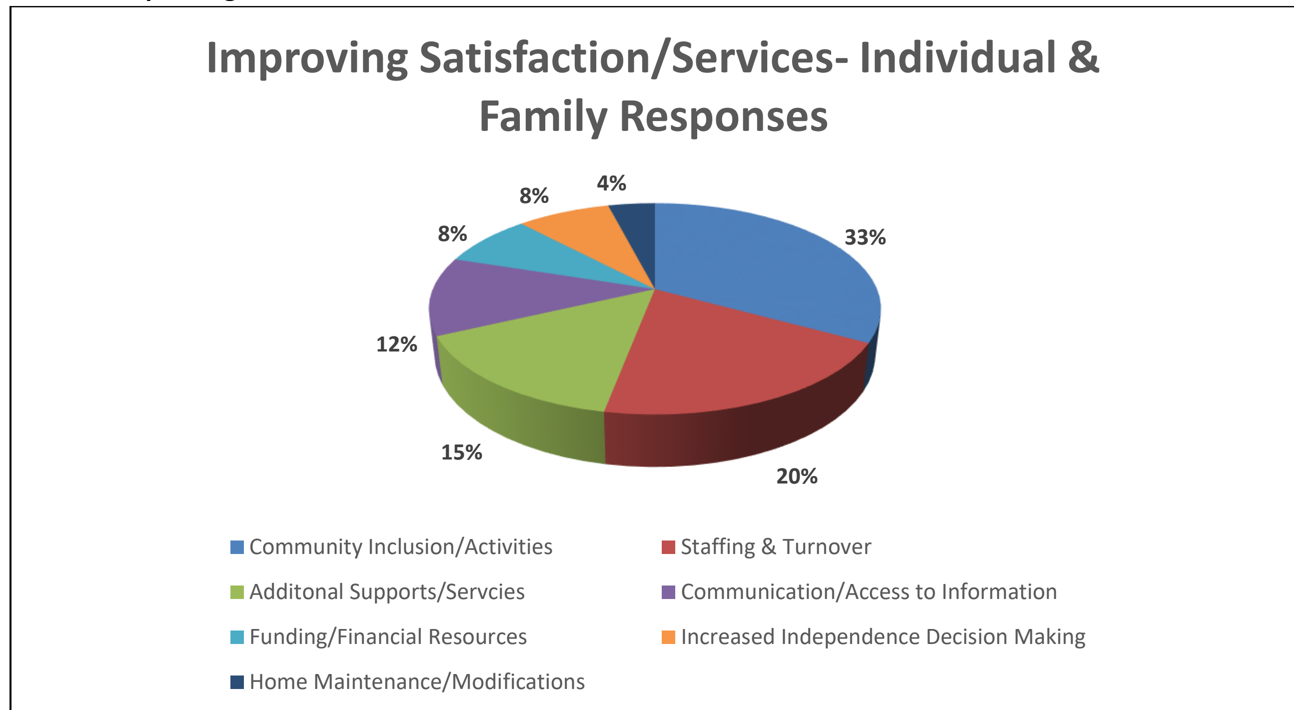
All of the recommendations require current providers of service to change their service model to serve additional individuals with challenging behaviors. The State must provide alternatives contractually for those individuals who are currently refused admission in the community provider system or committed by the County Review Board and the judicial system. In the alternatives for the community system, there is discussion regarding the advantages to the individuals and the state to allow more individuals to stay connected to their home community and natural supports. Breathing fresh ideas into the communities regarding services will better serve the individuals and the taxpayers.

Community Services Overview

The State of South Dakota is home to just over 789,000 residents spanning 77,184 square miles, including large frontier areas. There are over 3,700 residents currently supported through one of two 1915(c) waivers for individuals with intellectual/developmental disabilities (IDD), CHOICES or Family Support 360. Unlike many other states, South Dakota does not have a waiting list for waiver services. However, it is notable that the average waiver cost per individual in the State is $32,000 annually versus the national annual average of $49,000. There are currently 20 providers and 4 case management providers serving South Dakotans.

Within the community, there were a number of issues identified by individuals, families, and providers that created barriers to successful transitions and community care. Each major category is discussed in detail in this report, however consistent with the most recent South Dakota Council on Quality Leadership (CQL) 5-year report, many of the challenges were congruent with a broader issue of adequate integrated community living. Rates and workforce capacity were described as major barriers to improving community integration; challenges that were cited by both providers and waiver recipients/caregivers. Overall, of the 331 surveys completed by individuals and caregivers, a high level of satisfaction with care and services was reported, with a mean rating of 4.1 out of 5.0 (1.0 = extremely dissatisfied; 5.0 = extremely satisfied). There were several issues identified by individuals and families that negatively impacted satisfaction with current services and recommendations to improve the system of care; the most salient issues identified are included in Chart 2.

Chart 2: Improving Satisfaction



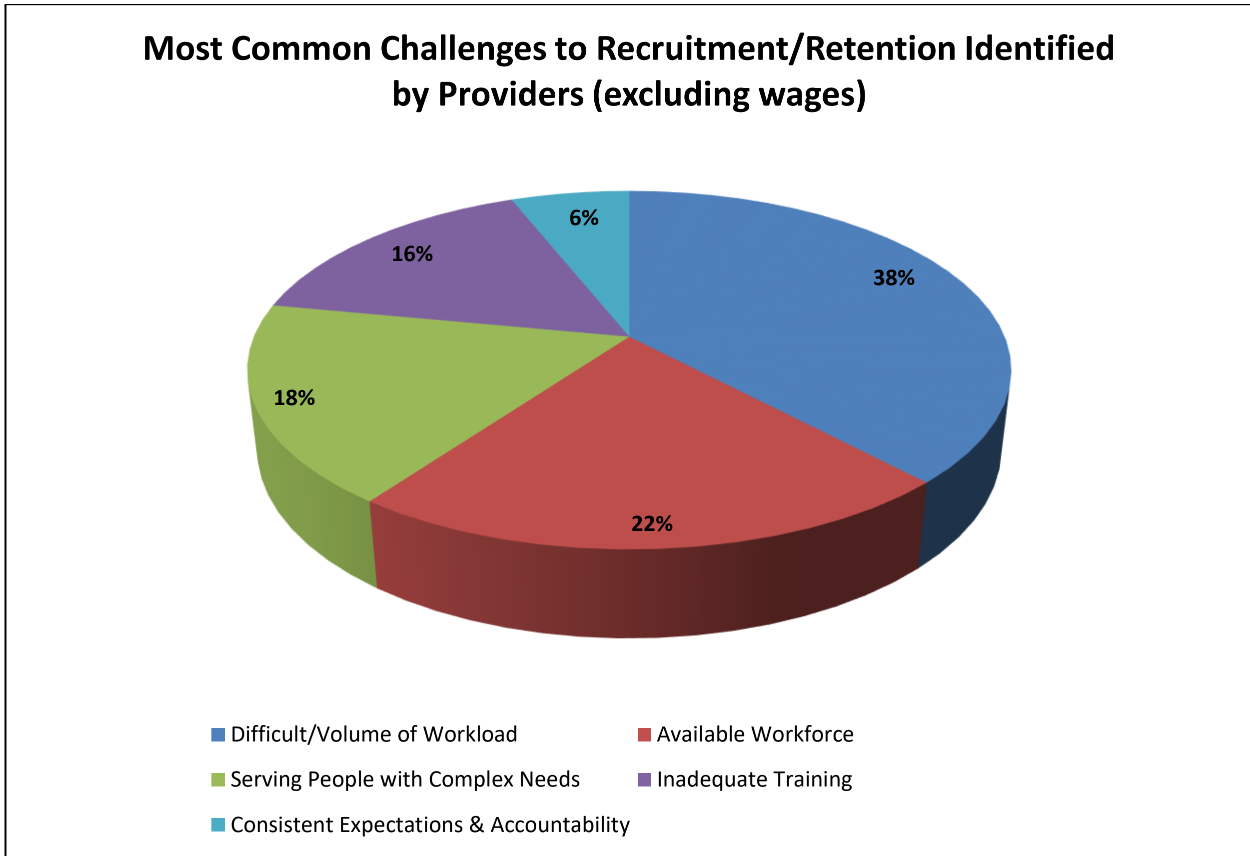
Transportation, behavior analysis, supported employment, personal care services, crisis services, and respite care were some of the specific supports frequently identified by individuals and families as gaps or needs in the system. There were comments from individuals, families, and providers about the need for more comprehensive support options for transition-aged youth. Access to transportation and adequate staffing were identified as barriers to improving community integration. Individuals frequently cited a desire for more employment and recreational opportunities, the ability to consistently attend worship services, meaningful inclusion in decision making, and social activities as needs. Families and caregivers cited communication from providers, funding for current and additional services (limited current service options), inconsistent staffing, high turnover, limited choice of provider, and location as issues impacting satisfaction with services.

There were 38 responses to the provider survey. Providers frequently cited waiver rates, lack of service/support options covered by the CHOICES and Family Support 360 waiver, and too few providers within the market as challenges. Residential rates varied significantly between providers, from $103.35 - $356.69/day with a mean of $159.43/day. The most utilized waiver services were nursing supports and residential services. Interestingly, despite a reported desire for improved employment options and supports, Support Employment was the least utilized service in the Family Support 360 waiver. While Family Support 360 serves a large number of children, it is noteworthy as options for transition-aged youth was identified stakeholders as a gap in system capacity.

The use of technology to provide various remote supports could be an opportunity for the State given limited provider and system capacity. However, the use of technology among providers was extremely varied. Some surveyed providers indicated that technology could or already did play a major role in their services; other providers indicated 5-10% of services were provided using technology solutions, with the mode of responses between 20-25%. Some providers were unfamiliar with technology options.

Community Support Provider (CSP) staff turnover was identified as a major barrier to providing consistent and integrated services. Wages and rates were cited as primary drivers of turnover. In addition, providers also cited a lack of crisis supports as drivers of staffing challenges and admissions to SDDC; 52% of all providers who completed surveys specifically identified a lack of crisis resources as a barrier. In 2019, 57% of dispositions for those referred for crisis services were admission/readmission to an institutional level of care. Nearly 64% of provider respondents specifically identified lack of transportation/transportation funding as a significant barrier to providing supports and community integration. While compensation was identified as the primary issue, providers also identified lack of training opportunities, onerous documentation requirements, limited availability of qualified workforce and inadequate resources to support complex medical or behavioral needs as major challenges.

Chart 3: Most Common Challenges to Recruitment/Retention Excluding Wages



Overall, the available data and survey responses point to a number of gaps within the system of care that impact both the ability to serve people in the community and to providing meaningful community integration: state capacity, information, communication, provider capacity, and transportation. Some of these challenges can be addressed within the context of the current system of care, but funding and service options available through the current waivers create systemic barriers to serving individuals, especially those with complex needs or limited natural supports. Increasing wavier spending could provide better access to community options and expand provider capacity. The topics identified in each category are not meant to be a full accounting of all gaps discovered during this process but are the most prevalent and are interconnected within the continuum of care of services.

State Capacity

Gap 1:

Within DHS, DDD has initiated several projects over the last few years, many being driven by the changes to the Federal Home and Community Based Settings (HCBS) rule. Among these are Conflict Free Case Management and a CHOICES waiver amendment to establish compliance for employment services such as Career Exploration and Supported Employment. DDD also became a member of the Supporting Families Community of Practice and introduced the Charting the LifeCourse curriculum to further support the HCBS rule changes. In addition, the Federal government has directed states to implement

Electronic Visit Verification (EVV) by January 1, 2021. These are monumental changes within a state's system. DDD has been working diligently to meet the requirements set by HCBS and other regulations.

Recommendation: DHS should consider a complete review of DDD's workload capacity inclusive of a time study, to verify the need for additional employees and if so, the number required. The review should include assessment of the long term projects required by the Federal government to determine any need to implement these projects, monitoring of requirements, rules, etc. that are created as a result of those projects. Align realizes there are budget constraints in every state and adding the number of needed positions may come over a period of years.

Barrier: The State of South Dakota may not have the financial resources needed to fund additional positions.

Gap 2:

The current system allows individuals to have choice within their services however it is limited choice, mostly due to low population areas that are geographically separated from larger cities, few providers in certain areas, or limited available case management. This is typical in many of our lives as our choices are driven by such factors as availability or proximity; however, individuals in services or their families may not have the means to resolve conflicts nor feel they have the ability with so few options. The inability for individuals to access an unbiased mediator limits their empowerment to exercise true choice.

Recommendation: DHS should consider the development of an Ombudsman position for individuals living with I/DD in services. This position would be available to help resolve issues that may arise between an individual and a team member, within the team itself, or with DDD. The Ombudsman would report directly to the Secretary for the Department of Human Services, ensuring the position's ability to be completely impartial.

Barrier: The State of South Dakota may not have the financial resources needed to fund the additional position. Administrative Rules of South Dakota will need to be altered to allow for an Ombudsman position in Long Term Support Services.

Gap 3:

Administrative Rules of South Dakota (ARSD) are lacking in support for individuals with challenging behaviors and are vague regarding the professional requirements of an author of a behavior intervention plan. ARSD does indicate criteria that must be included in a behavior intervention plan, however, it does not require the writer of the plan have any specific degree, education, or a specified length of history in creating or monitoring such plans. State data shows 38% of individuals in the waiver programs have behavior issues listed on their Inventory of Client and Agency Planning (ICAP) assessment, which determines the level of care for individuals in waiver services (Appendix 1). There were 97 admissions to SDDC in FY 2015 – FY 2019 (See Appendix 2). Of those admissions, 36 individuals (37%) were readmissions. With the proper level of behavior support, these numbers could be drastically reduced. This data indicates the rule guiding the behavior supports, as well as the application of techniques, are not effective and may have led to avoidable situations and placements in restrictive environments.

Recommendation: DHS should consider creating a Board Certified Behavior Analyst (BCBA), or comparable, level behavior consultation service as a service for both waivers. This would be an add-on service to the daily rate. The potential "add-on" would allow providers the fiscal ability to recruit employees with the required credentials to serve those individuals with more complex diagnoses. Additionally, DHS should consider partnering with state universities to develop a curriculum and/or potential degree for behavior management, BCBA, or similar specialty to help develop the needed capacity within South Dakota over the next several years.

Barriers: This is a long-term recommendation due to:

1. Additional workload for DDD
2. Develop amendments to the waivers and ARSD;
3. Develop funding for the additional add on rate;
4. Recruit professional credentials; and
5. Develop partnership with a state university

Gap 4:

Currently, South Dakota has 20 CSPs throughout the state. Due to the current rate structure, none of the current CSPs appear to have the financial capacity to expand and serve a broader geographical area. Current rate amounts encourage the need for large, congregate waiver settings, which are incongruent with the HCBS Settings Rule. As of 2016, 56% of individuals with I/DD in the United States live in community settings of three or fewer people. (Larson, 2018) As of 2016, the average number of individuals in non-state operated homes (non-ICF/IID) across the United States was 3.4 individuals/residential setting. (Larson, 2018) Large homes have the potential of exacerbating the current workforce crisis, depending on the structure of the home, causing an increase in provider overtime expenses. In 2018, South Dakota had a DSP turnover rate of 62%, which was 11% above the national average that same year. (HRSI, 2018) It is expensive for a CSP to locate, renovate, or build a home to accommodate large numbers of individuals. These factors are disincentives for current CSPs to expand across the state and limit the State's ability to attract new providers into South Dakota. Additionally, the DSP workforce crisis will continue to deepen as CSPs cannot increase wages to be competitive with outside industries due to low rates. The workforce shortage was a sustained theme among CSPs, individuals, and families.

Recommendation: DHS should continue to work with the rate structure review committee and CSPs to determine the true cost of providing services with the goals of moving to smaller, congregate waiver settings, expanding provider capacity, and addressing the DSP workforce crisis.

Barriers: The State of South Dakota may not have the financial resources needed to increase rates.

Gap 5:

Guardians and family members expressed much concern over the closure of sheltered workshops, as well as the current limitations of support within Career Exploration. The frustration appears to stem from concerns that individuals with the most needs will not be able to maintain a community job once workshops are closed and the limitations on the length of time allotted for a loved one in the

Community Exploration service. Parents/guardians stated eliminating workshops would eliminate a paid work option for many of these individuals, leaving day services as their only option.

Recommendation: DHS should consider re-examining South Dakota's approach to workshops and Community Exploration and compare it with other states' responses to the federal rule in these areas through continued participation in the State Employment Leadership Network. We understand much of the changes around sheltered work and Career Exploration are driven by recent federal rules such as HCBS and Work Innovation and Opportunities Act (WIOA), and that South Dakota must operate within the regulations. However, a review of other states may give DDD some additional options it can provide and to eliminate the potential alienation of those individuals who cannot work in a community setting. Additionally, DDD should continue to communicate, clarify, and educate individuals, guardians, providers, and case managers regarding workshops, Career Exploration, and any other options the state has explored to ensure those involved have a clear understanding of the options in place to address the concerns that were noted.

Barriers: HCBS, WIOA, future federal legislation regarding 14c certificates.

Communication

Gap 1:

The families and individuals who attended the stakeholder meetings were very excited about the opportunity to meet and provide feedback and conveyed their desire to have more sessions, particularly when there are upcoming changes within the system. The feedback received suggests there are perceived gaps in the consistency and flow of information among the varying providers as well as individuals, families, and guardians. While many providers and individuals are well versed in the system, there was enough confusion to raise it as a notable gap.

Recommendation: DHS should consider creating additional opportunities to engage individuals, families, and guardians regularly to provide information, gather input, communicate, clarify, and educate individuals, guardians, providers, and case managers regarding services. These sessions would allow information to be conveyed to stakeholders first hand thereby reducing the likelihood of misinformation among those stakeholders. This opportunity builds community involvement, promotes ownership of the services offered, and provides a direct connection with DDD. Offering live webinars with opportunity for questions/discussions that can be recorded to be reviewed at later times is one way to make a connection without the cost or burden of travel.

Barriers: The large geography of South Dakota makes it difficult to host frequent face-to-face meetings. Additional workload added to DDD.

Gap 2:

South Dakota currently does not have a waiver manual for either the Choices or Family Support 360 Waivers. Wavier manuals are excellent resources for providers and individuals regarding services offered, definitions, allowed activities, etc.

Recommendation: DHS should consider developing a waiver manual for both CHOICES and Family Support 360 waivers as a resource for stakeholders. The manual would combine Administrative Rule, approved waivers, and policy memos to ensure consistent information for providers and individuals. This will also clarify the roles of each member of the individual's team (provider, case manager, etc.) and help prevent duplication of work between those members.

Barriers: Additional workload added to DDD.

Provider Capacity

Gap 1:

The current residential model does not promote opportunities for true consumer choice regarding location of service, type of service, or providers of service. Many individuals must leave their hometowns, away from family and natural supports to gain access to services due to the lack of provider presence in those areas. The burden of service accessibility leans more on the consumer going to the service, rather than on the service provider looking for ways to reach the consumer. Many providers are unable to expand their existing residential housing model either within their current footprint or in other areas around the state. The reasons cited are the inability to recruit and retain staff, lack of financial resources for capital investments, and uncertainty in future state and federal direction. The current CHOICES waiver residential model appears more facility-based than intended within home and community-based services. Although HCBS funding requires individual choice, the choices are limited in the current model, even if in compliance with HCBS. For example, the number of individuals in a home, shared bedrooms, provider-owned and controlled homes, and a single provider for most services, are not consistent with a true supported living experience for individuals served. As noted in 2016, fifty-six percent (56%) of individuals with I/DD in the United States live in settings of three or fewer people (Larson, 2018). The average number of individuals in non-state operated homes (non-ICF/IID) across the country was 3.4 people/residential setting during the same time period (Larson, 2018). Smaller residential sites (3-4) utilizing consumer signed leases of consumer furnished apartments or private residences would reduce the number of staff needed per site, eliminate capital investments from providers, and reduce long term risk.

Recommendation: To be consistent with person-centered philosophies and the Life Course Framework, we recommend the state consider the development of a model in which services revolve around the needs and desires of the individual consumer. Despite HCBS funding, the state lacks a comprehensive care model that creates a true supported living experience for individuals served (# of individuals in a home, shared bedrooms, provider owned and controlled homes, single provider for most services, etc.). This model would also allow for incremental expansion into currently under-served areas of the state.

Barriers: Additional workload on DDD. Funding for increased rates.

Gap 2:

There is a lack of an existing model to serve high or complex behavior individuals throughout the state utilizing best clinical practices. SDDC was primarily spoken well of, but location was the single biggest concern. Thirty-eight percent (38%) of individuals in waiver programs in South Dakota have behavior issues listed on their Inventory of Client and Agency Planning (ICAP) assessment, the tool used to

determine the individual's level of care (See Appendix 1). Fifty-seven percent (57%) of individuals referred to crisis services were placed in an institutional care facility. An additional 9% were placed in jail (See Appendix 4). Currently there are no widely available short-term respite or recovery options for those in crisis. The availability of a model designed specifically to assist individuals in crisis could prevent placements in institutional care facilities or jail and allow the individuals to return to their home or CSP.

Recommendation: DHS should consider the creation of three regional crisis diversion centers. Each center should have the capability to provide intensive inpatient psychiatric support for short-term (7-14 day) stays for evaluation and potential adjustment of medications. The emphasis of the services would be to return the individual to the community as soon as the person has stabilized. Staff from the current service provider would receive training and supports to implement new programming and behavioral supports upon the individual's re-entry into the home. The regional centers would offer in-home supports for pre-crisis analysis and supports for transitions back to the home setting. These centers could serve as resource centers for providers as well as respite units for those individuals in crisis, reducing the strain on mental health centers. Being regionally based, the centers would give access to more individuals as opposed to one large facility within in South Dakota.

Additionally, an enhanced waiver model (4 individuals or less) or small ICF (4 bed) model that is not available within the current continuum of care could be utilized for those individuals who need additional assistance in managing their behavioral challenges. These homes could also serve as transition homes from the regional centers as individuals are preparing to return to their home in the community. Both the regional centers and homes would need to have access to qualified psychiatric and behavior consultant staff and the focus would be community re-integration.

Barriers: This is a long-term recommendation due to:

1. Additional funding for both the center and the 4-bed model homes;
2. Attracting a private provider to oversee both programs;
3. Obtaining CSPs and case managers to buy into the new programs; and
4. Addition workload for DDD

Gap 3:

The DSP workforce crisis has created gaps in the ability of individuals to fully get the services they need. Individuals who receive less than 24-hour services are particularly at risk. The average turnover rate for DSPs across the country was 51.3% in 2018, compared to South Dakota's DSP turnover rate of 62% the same year (HRSI, 2018). The average DSP vacancy rate in 2018 was 14.7% in South Dakota compared to the national average of 11.9% (HRSI, 2018). With such huge turnover, providers run the risk of either losing revenue by not staffing the hours, or paying overtime if there is staff available. There is a need for non-staff options for this category of individuals and technology could fill this void. The use of technology could ensure independence and safety for individuals and give relief to providers who are suffering from the DSP workforce crisis by allowing them to shift their staff resources to those individuals who have the most need.

Recommendation: DHS should consider creating a technological assistance service on the CHOICES and Family Support 360 Waivers, allowing for the use of various technology such as sensors, tablets, automatic medication dispensers, Alexa, Google, etc. to provide supports. Technology is an integral part of contemporary lifestyles; a majority people rely on various devices and applications to assist them in daily life. This new service could allow CSPs to be eligible for remote monitoring implementation and reimbursement when appropriate, as well as the ability to install and train individuals on the various technologies that could improve their lives and safety.

Barriers: Additional workload to DDD to amend the two waivers, administrative rules, and funding for additional services.

Gap 4:

There is an existing process in place for CSPs to access assistance in times of behavior crisis, but the process lacks value for the CSPs because it does not provide the support they are looking for in regards to timeliness, effectiveness, or addressing the immediate health and safety needs of the individual or staff. Seventy (70) individuals were referred to crisis services through SDDC during the fiscal year 2019. Eleven percent (11%) of individuals were repeat referrals. Seventy percent (70%) of individuals were referred for moderate to severe behavior issues (See Appendix 3). Fifty-seven percent (57%) of individuals referred to crisis services were placed in an institutional care facility. An additional 9% were placed in jail (See Appendix 4). CSPs and case managers also seemed to have inconsistent information regarding the available options during times of behavior crisis and how those options are accessed.

Recommendation: DHS should consider developing a vision of alternatives to SDDC placement. Those alternatives need to include clear instructions on how providers or individuals can access specific resources to assist in a time of behavioral crisis. Those resources need to include an array of options including verbal de-escalation techniques, training, temporary in-home support, behavior plan development and implementation assistance, and temporary out of home placement. DHS should consider additional information and training sessions for providers and case managers to ensure they understand and can access the current available options.

Barriers: This is a long-term recommendation due to:

1. Resources to develop the program to include all recommendations; and
2. Potential amendments to the CHOICES waiver, Family Support waiver, and ARSD.

Gap 5:

The Family Support 360 Waiver works well for individuals with an established natural support system, but it is difficult for individuals without that system to identify and secure appropriate caregivers.

Recommendation: DHS should consider allowing individuals who lack an established support system to access staffing support from a CSP either temporarily or long term that would allow the individual the ability to access the support they need within their home and reduce the likelihood of needing to explore the Choices Waiver option.

Barriers: Additional workload to DDD to amend the Family Support 360 waiver and ARSD.

Gap 6:

Many providers, including Case Managers, lack the knowledge and skills necessary to serve the states most challenging individuals. As previously noted, 38% of individuals in the waiver programs have behavior issues listed on their Inventory of Client and Agency Planning (ICAP) assessment, the tool used to determine the individual's level of care (See Appendix 1). Seventy (70) individuals were referred to crisis services through SDDC during fiscal year 2019. Eleven percent (11%) of individuals were repeat referrals. Seventy percent (70%) of individuals were referred for moderate to severe behavior issues (See Appendix 3). A total of 66% of individuals referred to crisis services did not return to their place of residence prior to the referral but were placed in an institutional care facility or jail (See Appendix 4). While admissions and re-admissions to SDDC have trended down in the last five years, re-admission from 2015-2019 represent 37% of admissions. In 2019, twenty (20%) of admissions were individuals who had previously lived at SDDC (See Appendix 2). This data strongly suggests that providers are in need of additional training resources to deal with the most challenging individuals who live in the community.

Recommendation: DHS should consider state-sponsored training to initiate building provider capacity to serve individuals with the most challenging behaviors. Topics to consider would be; BSP development, autism spectrum disorder, behavior de-escalation techniques, trauma-informed care, and sensory Integration. Training that is regionally based would ease access for recipients and a train the trainer model or video produced model would likely bring forth the best results due to the ability to share information with high volumes of people across rural geographical areas.

Barriers: Additional resources and funding to develop the training. The additional workload for DDD to develop a tracking system to ensure training is being offered and completed within given timeframes. Potential changes needed to ARSD.

Transportation

Gap 1:

Individuals, families, and CSPs expressed a concern for a lack of availability and funding to meet transportation needs. The need for additional transportation was identified as a trend as it was noted at every stakeholder session, in every location, spanning both the CHOICES and Family Support 360 waiver participants. In addition to limited community transportation options, the number of individuals living together in community services becomes a barrier to transportation. Based on population density in specific geographical locations, CSPs are the primary or only source of transportation available for individuals.

Recommendation: DHS should consider additional funding to support and promote community access. Because not all consumers are being transported, an add-on rate for a capped number of trips could be a fiscally responsible approach and can be geared toward providing transportation to support true community integration.

Where available, consider a partnership with public and/or private transportation providers is needed to develop and implement a subsidized fee program for individuals with I/DD. The development of options should be explored specifically in geographical areas that public transportation is not available, and a

reimbursement program should be offered within the Waiver. This would be specifically necessary when individuals do not have 24/7 provider supports.

Consider additional information and education for individuals, families, case managers, and CSPs on reimbursement to and from medical appointments via the State Medicaid Plan to ensure individuals can access and pay for transportation to needed health appointments.

Expectations for transportation reimbursement and supplementing community transportation should be clearly defined in the service definition and reimbursement guidelines.

Barriers: This is a long term recommendation due to:

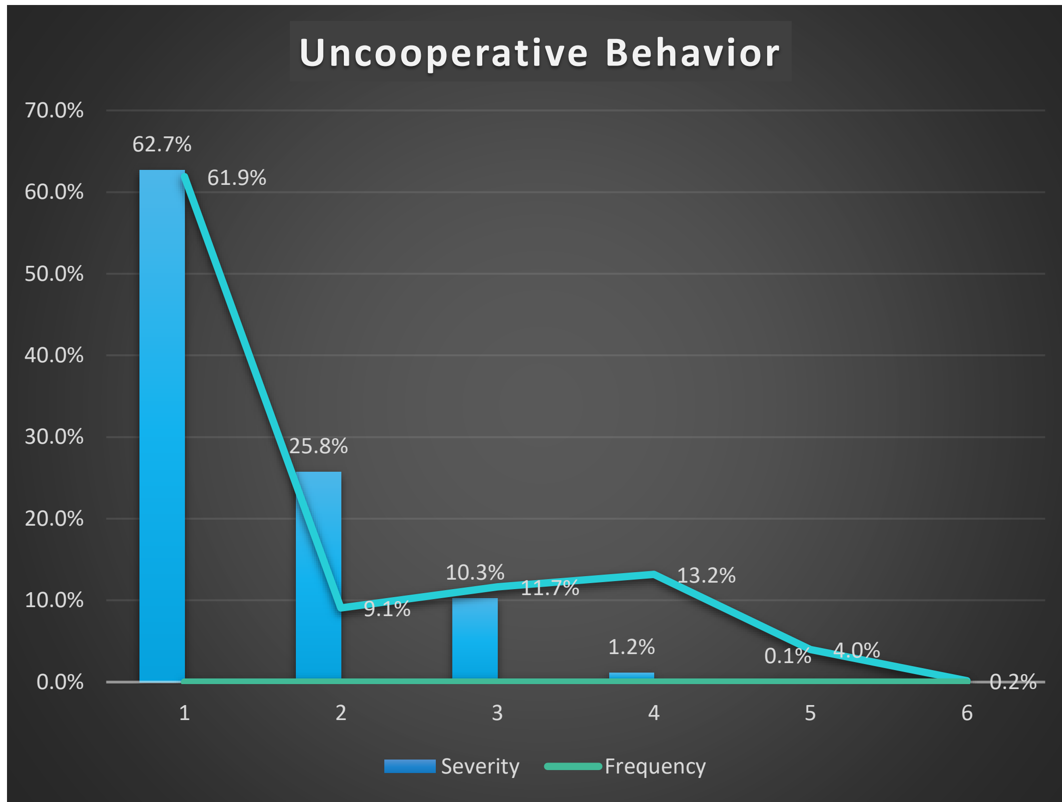
1. Additional funding for the service;
2. Potential amendments to the CHOICES and Family Support 360 as well as ARSD; and
3. Locating potential partners in the public and/or private sector.

Conclusion

South Dakota should be proud of it's I/DD continuum of care system. Despite geographical, fiscal, and personnel challenges DHS, DDD, SDDC, CSPs, and Case Managers have worked together to provide quality services to thousands of individuals living with disabilities with a high rate of satisfaction during several years of rapid change. The gaps and recommendations within this report are designed to highlight additional opportunities to strengthen an already solid system. The recommendations were designed to promote congruency between community services and SDDC. It should be noted that while the recommendations provided for Waiver services can be implemented independently from any changes to SDDC, the opposite is not true.

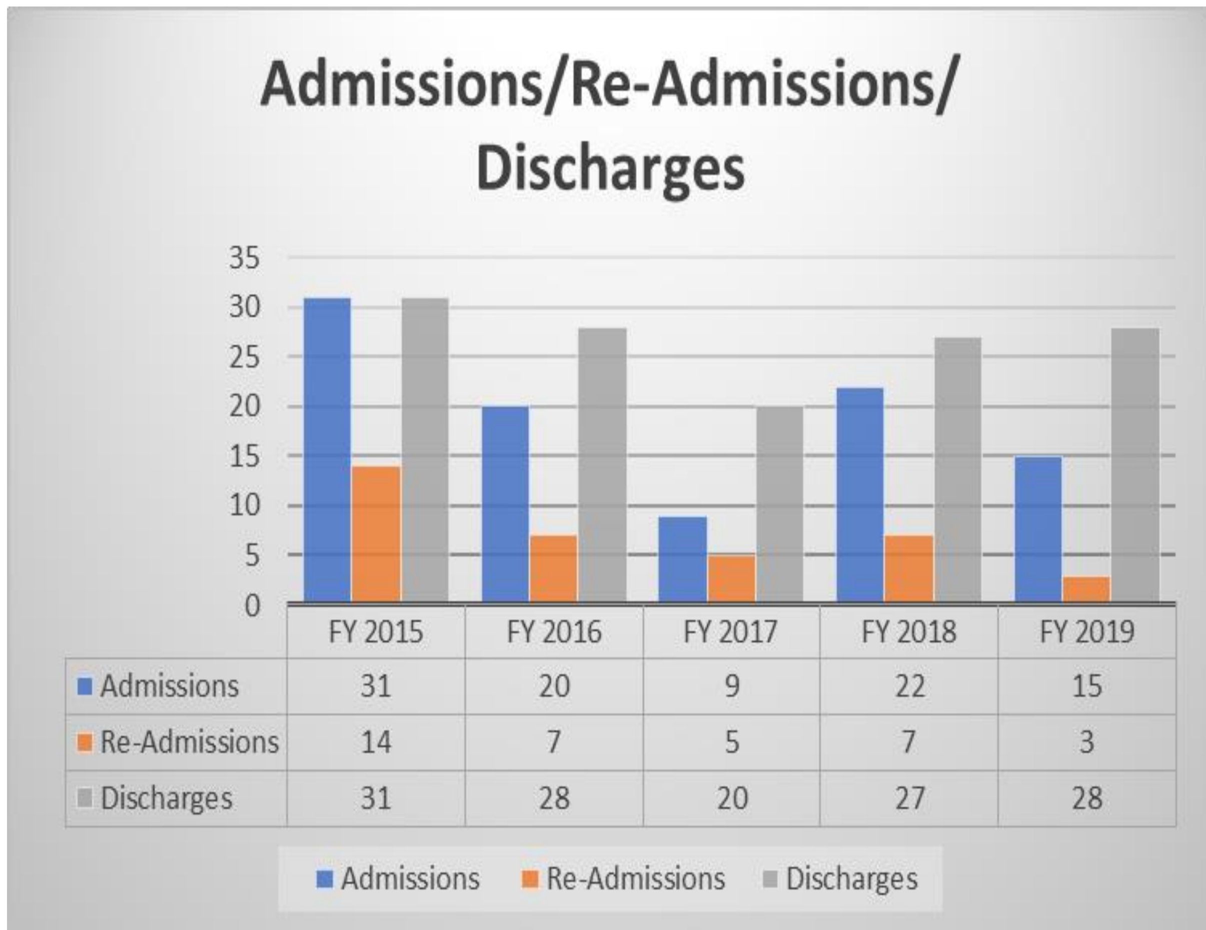
ALIGN
BY BENCHMARK

Appendix 1



Uncooperative Behavior Frequency					Uncooperative Behavior Severity			
Frequency	Counts	Total	Percentage		Severity	Counts	Total	Percentage
None	3638	5877	61.9%		Not Serious		3685	62.7%
<1/month	533	5877	9.1%		Slightly Serious		1514	25.8%
1-3x/month	686	5877	11.7%		Moderately Serious		604	10.3%
1-6x/week	775	5877	13.2%		Very Serious		68	1.2%
1-10x/day	234	5877	4.0%		Extremely Serious		5	0.1%
1, >1x/hour	10	5877	0.2%					

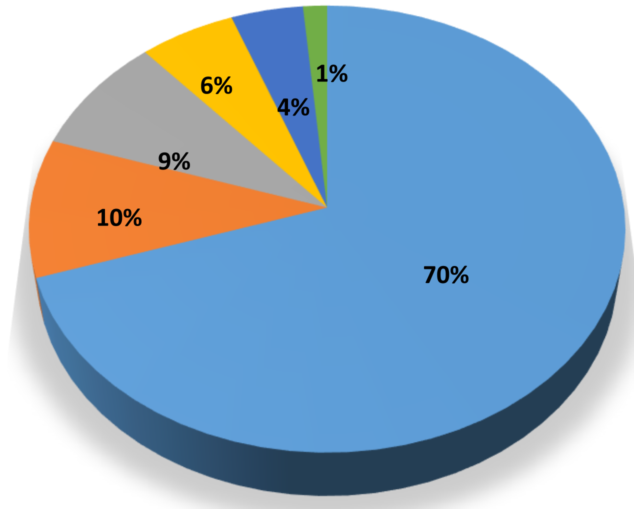
Appendix 2



	FY 2015	FY 2016	FY 2017	FY 2018	FY 2019
Admissions	31	20	9	22	15
Re-Admissions	14	7	5	7	3
Discharges	31	28	20	27	28

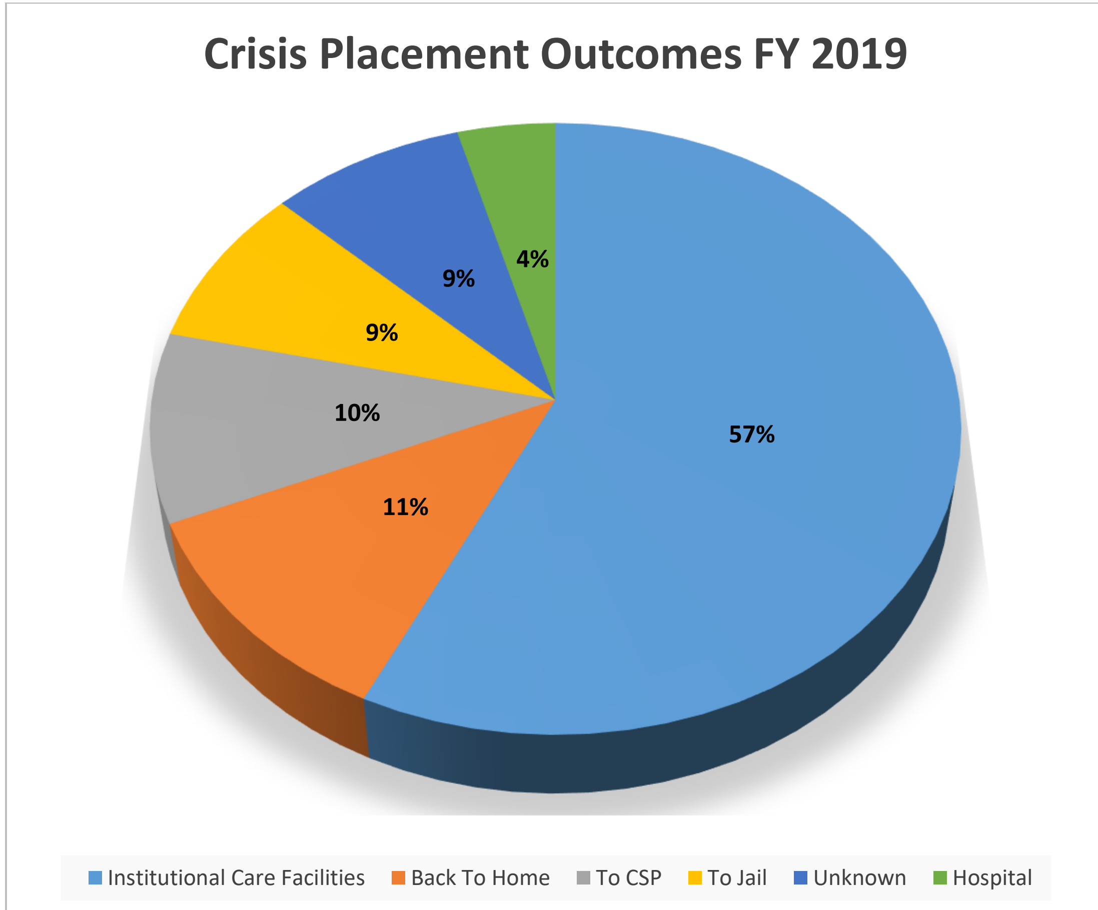
Appendix 3

Crisis Data Fiscal Year 2019



- Behavior (aggression, property destruction, uncooperative behavior, moderate to severe)
- Mental Health Episode
- Alleged Crimes (Very Severe)
- Family Disfunction
- Medical Needs
- Aging Parents

Appendix 4



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