

Family & Self-Advocate Conversations

Purpose: Foster open and clear communication by providing updates and facilitating feedback from those receiving supports and their families

Meeting Agreements:

- Mute microphone when not speaking
- One person talks at a time
- Be respectful of others' perspectives
- Listen to understand before providing solutions
- Be considerate of other attendees - keep comments brief to give others an opportunity to share

People: Self-Advocates, Families/Guardians, and DDD staff

Date & Time:

July 21st at 7 pm CT/6 pm MT

July 22nd at 12:30 CT/11:30 MT

Location: Zoom

Agenda Item	Owner	I or D Info Decision	Desired Outcome	Come Prepared to...	Time Allotted
1. Welcome & Standing Items <ul style="list-style-type: none"> • Why Family & Self-Advocate Conversations? • Who is invited to these sessions? 	Joey Younie	I	All in attendance understand the purpose of the Stakeholder Collective quarterly sessions, which stakeholders are invited, and how often sessions will occur	Add your name and where you are from in the chat box	5 mins
2. Meeting Overview <ul style="list-style-type: none"> • Review of Agenda & Meeting Agreements • Navigating Zoom • Assigning Roles <i>Timekeeper:</i> <i>Recorder: Julie H</i> <i>Chat Box Monitor: Kayla B</i> <i>Waiting Room: Jaze S</i> • Review summary of April sessions 	Julie Hand	I	We revise agenda to reflect our current priorities and engage team members through roles.		5 mins
3. Getting to know us: DDD Intervention & Support Specialists <ul style="list-style-type: none"> • Dona Deal, Rapid City • Brooke Nelson, Brookings • Kayla Blomme, Brookings • Jenna Hieb, Chamberlain 	Joey	I	All have a common understanding of DDD Intervention & Support Specialist role in supporting people in services and their families to be successful		10 mins
<ul style="list-style-type: none"> • Link to Community Collaboration flyer was shared in the chat box & emailed directly to those who requested it and can be found at https://dhs.sd.gov/developmentaldisabilities/providerresources.aspx under the Family & Self-Advocate Session – July section. Information is also included in slide deck shared during the session. • The Community Collaboration brings together a team to gather and review information regarding identified individuals, in order to provide person-centered supports and/or services to individuals who experience mental and behavioral health challenges and need additional supports to live successfully in the community. • If you are interested in learning more about the Community Collaboration, please contact Jamie Morris at 605.773.3438 or Jamie.Morris@state.sd.us 					
4. Front Door to Supports	Julie H	I	DDD shares our plan to streamline the navigation of available services and		5 mins

<ul style="list-style-type: none"> A brief overview of efforts to create a single point of entry to DDD services 			application process to better service people with disabilities and their families		
<ul style="list-style-type: none"> DDD has worked over the past 6 months to establish an action plan and timeline to create a single point of entry for those seeking services, with an overall goal to improve the experiences of people with disabilities and their families to seek, apply for and secure services. Collaboration with Dakota at Home has occurred – the Dakota at Home toll free number will include a selection option to connect directly with DDD. In the event a caller isn't sure what they need or who to talk to, the Dakota at Home intake specialists will assist the caller and refer them to DDD. DDD hired an Intake Specialist in March and has established training and certification for this position with hopes of having additional staff to fill this role in the future as the volume of calls, applications, etc. increases. DDD plans to solicit feedback from family members who have entered DDD services in the past 12 months through brief telephone interviews in the next several months. DDD will continue to provide updates regarding this process in future meetings 					
5. Family Support 360 waiver renewal	Joey & Jaze Sollars	I	Attendees are aware of the upcoming renewal of the Family Support 360 waiver as well as opportunities to stay updated and provide feedback on proposed changes		5 mins
<ul style="list-style-type: none"> Centers for Medicare and Medicaid Services (CMS) requires renewal of Medicaid/HCBS waivers every 5 years. Renewal for the Family Support 360 waiver expired on May 31, 2022. Renewal application is due to be submitted for CMS review by March 1, 2022. CMS has 90 days to review Family Engagement Strategy: <ul style="list-style-type: none"> The Family Support Council, as a Governor-appointed advisory committee for family support services in SD, will assist DDD to draft and refine service definition language to be submitted to CMS. Family Support Council meetings are open to the public. Each FS Council meeting agenda includes an opportunity for open comment, which provides a format for families to provide general input and recommendations for changes to better support people and families receiving FS 360 services. During these meetings, DDD will provide updates to recommendations shared during the previous meeting 					
6. Open Comment	Joey	D	Opportunity to bring forward questions and topics to build agendas for future meetings	Participate in the conversation – offer suggestions, ask questions	20 mins
<p>Questions/Comments:</p> <ul style="list-style-type: none"> Information about the Family Support Council is VERY difficult to locate – who are Council members, when are meetings, what's on the agenda, how can families participate? <ul style="list-style-type: none"> Currently, information regarding the Family Support Council can be found at: https://boardsandcommissions.sd.gov/boardmembers.aspx?BoardID=40. In follow up to this meeting, we will determine additional ways to increase awareness of the Family Support Council as well as alternative ways to share information about upcoming meetings. Family Support Council members should be a point of contact for other families in SD to share feedback with the expectation that they relay that feedback to DDD. Families don't know what the Council is, who is on it, or how to contact. <ul style="list-style-type: none"> DDD is following up to ensure compliance with the laws and regulations which govern the Family Support Council Efforts to increase the public's awareness of the Family Support Council's role, meeting dates, etc. Recommend this information be sent directly to families – families do not have the time to seek out this information and shouldn't be expected to do so Not all families have access to internet or email – how will communication be shared with them? Can we receive a copy of the Financial Assistance Guidelines? 					

- *Financial Assistance Guidelines have been added to the DDD website: <https://dhs.sd.gov/developmentaldisabilities/providerresources.aspx> under the Family Support 360 section.*
- Will you place the Zoom link for these sessions in a more prominent location on the DDD website?
 - *DDD's goal is to create a direct line of communication to people with disabilities and families. Currently, DDD is developing a way to distribute information electronically as well as to those without internet or email access receive timely information as well. DDD welcomes suggestions that will help us reach those who do not have internet or email.*
 - *DDD will consider adding the Financial Assistance Guidelines to the DDD website for easier access. In addition, DDD will send the document to those who requested it during these sessions.*
 - *DDD will add the information for upcoming Family & Self-Advocate Conversations on DDD's home page under "Division Highlights – Upcoming Events" in the future*
- DDD needs to look at the current gaps in services and needs of those receiving services before making changes
- Additional opportunities must be provided for families and people with disabilities to provide input for changes needed– outside FS Council meetings.
 - *DDD has and will continue to consider the feedback received through listening sessions, from individual family members, from the Family Support Council and from Family Support Coordinators over the past several years.*
 - *DDD will outline additional strategies to solicit feedback from families and people receiving Family Support 360 services to provide input throughout the next 6-7 months and will share information regarding the final version before submission to CMS.*
- Family Support Council members in attendance identified themselves and shared contact information through the Chat box
 - *DDD is researching the legal requirements and rules governing the Family Support Council prior to publishing contact information of all Council members*
- Numerous attendees requested to receive meetings notes & handouts shared during the session directly and shared their emails via chat in hopes of connecting with other family members in attendance.
 - *Emails were collected – information will be sent directly to those who requested. In addition, DDD will add these emails to the distribution list in development, as noted above.*
- Families need resources & tools to navigate various aspects of services
 - *DDD has a goal to create short, informational videos targeted to people with disabilities and families so they may be better equipped to advocate and navigate the system effectively. In addition, DDD would like to feature people with disabilities and families in the videos, such as "what is self-direction", "managing conflict with a provider", "what can I expect from my Service Coordinator/Case Manager?" as well as numerous other topics. Suggestions were provided and will be added to the growing list!*
- Future meetings should include updates regarding Agency with Choice and what DDD has explored, worked on as a solution to this issue, and what is the impact to adults?
 - *This topic will be addressed in a future meeting*
- The services and requirements outlined in FS 360 waiver document and Administrative Rules of South Dakota (ARSD) are not the same as what is outlined in the Financial Assistance Guidelines which outlines allowable services and items
- It seems like people at the state are making decisions & they haven't walked in our shoes or been in the same situations as families. Example – previously could receive up-front reimbursement for travel but now have to pay out of pocket and wait for the reimbursement after.
- What is the regulation that prohibits the purchase of fences? Why was this change made without Family Support Council input?
- Seems like people at the state level are on a power trip and only apply their own interpretation of the rules.
 - *CMS provides a framework which states are required to comply with to receive federal Medicaid funding.*
 - *Within that framework, DSS administers South Dakota's Medicaid which includes, among many other services, Home and Community Based Services (HCBS) waivers. Family Support 360 and CHOICES are HCBS waivers.*
 - *DSS authorizes DDD to operate these waivers – which allows us to target services to a specific population of SD Medicaid recipients, specifically children and adults with intellectual and developmental disabilities.*
 - *As the operating agency, DDD must develop specific policies and procedures such as the Financial Guidelines, must be approved by DSS as well as CMS. These policies are procedures act as a guide for Family Support Coordinators as well as for DDD staff.*
 - *The Financial Assistance Guidelines are a resource to families and Family Support Coordinators when discussing and exploring options services and supports.*

- *DDD recognizes that the Financial Assistance Guidelines do not account for every individual circumstance or request we may receive and work diligently to gather additional information to make a fair determination when reviewing requests.*
- What's the difference between Medicaid waiver funding and "general" funds?
 - *Medicaid waiver funding = federal funds received from the Centers for Medicare and Medicaid Services. Services funded must comply with CMS regulations, DSS authority and DDD policy & procedures for HCBS waiver services*
 - *State General funds = state funds (generated by SD citizen taxes). A portion of State General funds are used to provide "matching funds" for each waiver services and must also comply with CMS regulations, DSS authority and DDD policy & procedures for HCBS waiver services*
 - *DDD operates several services paid strictly by State General funds – in these instances, DDD has more flexibility and autonomy in determining what is and is not allowable; however, these also are subject to related ARSD, policy and procedural requirements which must be met*
- How can we advocate for a change to this (fences not allowable) limitation?
 - *By attending these sessions, Family Support Council meetings. You may also contact your local legislator or the Dept. of Social Services at **1.800.597.1603***
 - *You may appeal a denial of services by contacting <https://dss.sd.gov/medicaid/rr.aspx>*
 - *To request a fair hearing if you disagree with any decision about your application. Hearing requests must be made within 30 days from the date the written notice was received. To request a hearing contact the Office of Administrative Hearings, Kneip Building, 700 Governors Drive, Pierre, SD 57501, by phone at 605.773.6851 or by fax 605.773.6873. The request must indicate what action is being appealed.*
- What is happening with the regional centers? There will be one east river and one west river?
 - *DHS has selected providers through the Request for Proposal (RFP) process and is currently in the process of negotiating contracts. When contract negotiations are completed, the providers and locations of the regional intermediate care facilities for adults will be announced publicly.*

<p>7. Wrap Up:</p> <ul style="list-style-type: none"> ● Online survey regarding informational videos on DDD website ● What's one thing you appreciated about our time together today – <i>use Chat</i> ● Respond to poll questions to give feedback on today's meeting ● Next meeting dates – <i>September 15th & 16th</i> ● Meeting summary shared on DDD website 	Julie	I	<p>Attendees provide feedback to DDD to assist in planning future sessions</p> <p>Date of next sessions & location of information provided today is shared</p>	<ul style="list-style-type: none"> ● Mark your calendar! ● Look for notes & slides: https://dhs.sd.gov/developmentaldisabilities/providerresources.aspx ● Share one thing you appreciated about today's meeting in the Chat ● Answer poll questions 	5 mins
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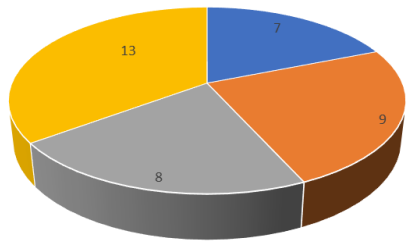
Closing Suggestions/Comments:

- In future meetings, you could ask people to rename themselves and their role behind their name
- I appreciated learning about the different resources and contacts shared in this meeting. Thank you!
- Thanks for having today's event
- I appreciate connection of contacts and resources.

*See below for results of poll questions

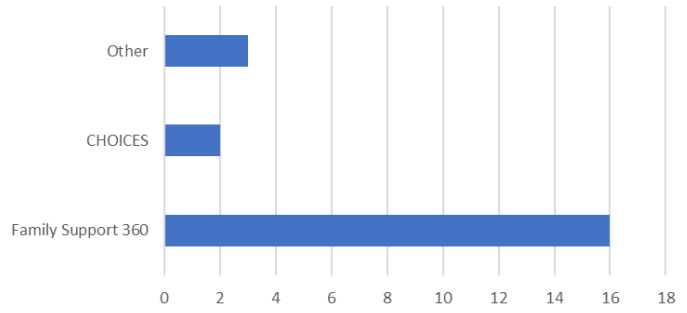
**Closing poll was not completed for 7/21/21 session due to time constraints.

What is your Role?

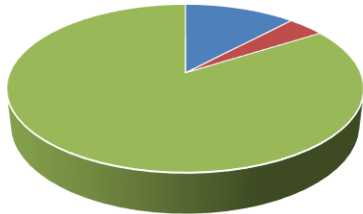


■ Guardian of a person over 18 years old ■ Parent of a child under 18 years old
■ Person with a disability ■ Unknown - No Response or Other

Which services do you/your family member receive?

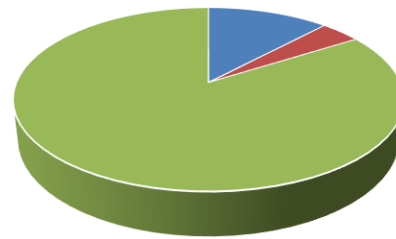


Meeting Time Allowed for Maximum Participation



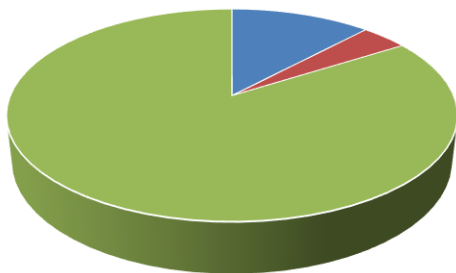
■ Yes ■ No ■ No Reponse

Information Provided Was Helpful



■ Yes ■ No ■ No Reponse

Purpose of Session was Clearly Communicated



■ Yes ■ No ■ No Reponse