

SELF-ADVOCACY AND CDCS SUPPORT PLANNING

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PRESENTERS

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Jillian Nelson

Community Resource and Policy
Advocate, Autism Society of Minnesota
CDCS Participant

Sarah Biddlecome

Executive Director, MNDSA
Former CSG Participant
Parent of 2 CDCS Participants
Sibling of a traditional CADI Participant

Kayla Bertrand

Director of Finance, MNDSA
Parent of CDCS Participant
Spouse of CDCS Participant

Carrie Theisen

CDCS Participant
Parent of CDCS Participant

Julia Biddlecome

CDCS Participant
Sibling of CDCS Participant

OVERVIEW

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What is Self-Advocacy

Jillian Nelson



Support Planning and Self-Advocacy

Sarah Biddlecome



Writing Your Community Support Plan

Kayla Bertrand



Participant and Caregiver Perspectives

Carrie Theisen, Julia Biddlecome



WHAT IS SELF-ADVOCACY?

Jillian Nelson

Self-Advocacy and CDCS Support Planning

What is self-advocacy?


- Speaking up for yourself
- Asking for what you need
- Negotiating for yourself (working with others to reach an agreement that will meet your needs)
- Knowing your rights and responsibilities
- Using the resources that are available to you
- Being able to explain your disability either by the use of written words, pictures or gestures.

What is NOT self-advocacy ?

- Expecting special treatment because you have a disability
- Justification to use your disability as an excuse
- Bullying other people to get your way
- A free pass for others to be Ableist

The Self-Advocacy Umbrella

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- **Self Advocacy is a tool that can be used in many places**
 - Work
 - Home
 - Relationships
 - Law Enforcement
 - Healthcare
 - Friends
 - Family
 - Politically
 - Public Venues
 - Education
 - Service Providers
- This is essentially an endless list. There is no limit to where you can use basic self advocacy!**

Why is self-advocacy important?

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- Defining our needs and wants.
- Protecting our rights
- To have a say in how we receive services and supports.
- To get the help we need:
 - Assistance
 - Clarification
 - Accommodations

Is self-advocacy right for me?

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IT IS THE RIGHT CHOICE FOR EVERYONE!

Self-advocacy is a tool that can direct independence at ANY level, it is important to recognize that independence may look different for different people.



CDCS AND SELF-ADVOCACY

Sarah Biddlecome

Self-Advocacy and CDCS Support Planning

What makes self-advocacy difficult in CDCS?

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Knowledge and Rights

- Accessing information is vital.
What qualifies for a waiver, how are budgets determined, what is a disability related need, what should be included in the Community Support Plan, what is allowable
- Lack of information can lead to decreased confidence
- Process is not strengths-based. Can feel “Othering”.

Lack of Representation

- Very little representation of disabled individuals in the policy making process
- When there is inclusion, can be feelings of tokenization

Sources of Information

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- Community Based Services Manual (CBSM)
 - *Specific policy details with statutory references. First place to find information.*
 - *Searchable and accessible online at https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_000402*
 - *Within this manual is the CDCS Policy Manual. At https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=CDCS_Home*
- Policy Quest
 - *Database of disability services questions and answers that have been submitted by lead agencies*
 - *Searchable and accessible online at <https://policyquest.dhs.state.mn.us/>*

Sources of Information

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- DSD Contact Form
 - *Online form that is submitted directly to the Disability Services Division.*
 - *Usually, a response is received within 3-5 business days.*
 - *Accessible online at <https://edocs.mn.gov/forms/DHS-8168-ENG>*
- DHS Bulletins
 - *Provide timely updates on DHS policy*
 - *Subscribe at <https://mn.gov/dhs/general-public/publications-forms-resources/bulletins/>*
- Elists
 - *Subscribe to a variety of topics at https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_000677*

Self-advocacy in CDCS situations

Frequently

- Requesting the CDCS option
- Budget changes
- Denial of items/services

Sometimes

- Correcting MnChoices
- SMRT referral
- Working with professionals

Correcting MnChoices and SMRT referrals

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Correcting the MnChoices if there are errors

- Sometimes you may simply need to point out the error and it will be corrected. Other times it may take persistence to get it changed. This could be because assessors are hard to get in touch with, they don't believe they made an error, or they think their interpretation of score/answer is correct as opposed to your answer.
 - *Self-advocacy tip: Continue to contact the assessor, don't give up.*
 - *Self-advocacy tip: Make your case. Provide thorough explanations and documentation to support your position.*

Making sure you receive a SMRT referral if needed

- Usually, if needed, the assessor will make the referral. Other times the MnChoices may be completed and somehow the referral isn't made. This can cause significant delays in services since the SMRT process is lengthy and the MnChoices may need to be repeated after determination.
 - *Self-advocacy tip: Continue contacting assessor, don't give up.*
 - *Self-advocacy tip: Contact county main line or SMRT directly if no response from assessor.*

Requesting CDCS option and budget changes

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Requesting the CDCS option

- The MnChoices assessor and/or case manager should be providing information on CDCS. For a variety of reasons, sometimes this does not happen.
 - *Self-advocacy tip: Know you have a right to choose your waiver service option. Contact your case manager and/or assessor to request more information.*
 - *Self-advocacy tip: Seek out more information through alternative sources, such as community groups or advocacy organizations.*

Budget changes

- Budgets change and this is expected if there is a change in needs or level of care. However, sometimes a budget may change despite there being no differences from your perspective. As with correcting the MnChoices, this could happen for a few reasons. It is important to make sure that everything is entered correctly.
 - *Self-advocacy tip: Request a copy of the full MnChoices to compare each numbered question response year over year. Point out any differences to the assessor.*
 - *Self-advocacy tip: Make your case. Provide thorough explanations and documentation to support your position*

Denial of items/services

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- Speak with your case manager. Sometimes providing additional information or answering questions is enough to have a denial reversed or modified.
 - *Self-advocacy tip: Make sure you are able to provide policy references that support your request*
- Appeal the decision. You have a set number of days to appeal after the Notice of Action. The Notice of Action provides information on appealing.
 - *Self-advocacy tip: If you do not receive a Notice of Action, contact your case manager and/or their supervisor ASAP.*
 - *Self-advocacy tip: Gather all your information to submit as evidence. This could include documentation from professionals, references to policy, etc.*
 - *Self-advocacy tip: Remember to reference policy and cite where you are getting it from (CBSM, PolicyQuest, etc.)*
- Appeals are heard usually via phone by a judge. The county is also present. There are two stages that the appeal goes through. First, the judge will either approve or deny the request. Second, it will go to the judge's superior for final approval or denial. It is not common, but the judge may approve a request and then their superior may override the judge and deny the request.
 - *Self-advocacy tip: Write down key points beforehand to reference during hearing*
 - *Self-advocacy tip: Don't feel intimidated. You have every right to appeal and make your case.*

Working with professionals

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Support Planners

- Support planners are a great resource. However, a support planner should not tell a participant or their caregiver “no” to something or dismiss their ideas. A support planner can advise on rules and allowable expenses based on guidelines and experience, but it is the county or lead agency’s job to approve/deny.
 - *Self-advocacy tip: Remember the support planner works for you. You are not required to use a support planner. Speak up and change planners if needed.*

Case Managers

- There is a high rate of turnover in case managers. Often you may encounter a case manager that has little experience or knowledge of CDCS.
 - *Self-advocacy tip: Understand that most case managers want to help. Provide policy references to help*
 - *Self-advocacy tip: You may need to provide education to a newer case manager. Provide references to rules and guidelines.*

Fiscal Management Services (FMS)

- FMS agencies are required to follow specific state rules related to fund management. However, each FMS has different fees and processes. Similar to case management, staff shortages may impact response times.
 - *Self-advocacy tip: Research FMS fees. You can find a list of FMS and their fees on the DHS website.*
 - *Self-advocacy tip: You choose your FMS. Speak up and change FMS if needed.*

WRITING YOUR COMMUNITY SUPPORT PLAN

Kayla Bertrand

Self-Advocacy and CDCS Support Planning

Description of needs section

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****Most important part of the Community Support Plan****

Plan
Describe yourself When developing your Annual Community Support Plan it's important to tell us about yourself by describing your strengths and needs, likes and dislikes, and how your disability or condition impacts your life. Some people find these questions easy to answer and can do so without assistance. Others have found it helpful to participate in a facilitated person-centered planning process. Information about person-centered planning processes can be found in the DHS CDCS Consumer Handbook, Appendix H. Remember, all goods and services must be directly related to the disability and/or condition and based on the goals you detail in this Community Support Plan.
STRENGTHS
NEEDS
LIKES
DISLIKES
DESCRIBE YOUR DISABILITY OR HEALTH CONDITION AND HOW IT IMPACTS YOUR LIFE
LIST YOUR DIAGNOSIS/CONDITIONS

- The needs section is taken straight from the MN Choices assessment.
- Be as detailed as possible. Items in the plan will directly correlate to the needs section.
- How to start:
 - *ADLs- Bathing, dressing, eating, grooming, toileting, mobility, communication*
 - *IADLs- (Teen or Adult Only) Transportation, Shopping, food prep, laundry, housekeeping, medications, finances*
 - *Communication*
 - *Sensory- likes, dislikes, needs*
 - *Medical- detail out all medical needs throughout the day*
 - *Behavior- talk about all behaviors*
 - *Safety- what are the safety concerns.*

Goal writing

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Utilize the Description of Needs section to write goals.

- Goal writing is extremely important in getting items approved in CDCS plan.
- Four parts to goal writing:
 - Need- writing a narrative as to why the request is needed
 - Goal- what is the request going to achieve
 - Action- what is the request
 - Measure- how will the request be measured to the goal of the request.
 - Additional Justification- some goals require more explanation so adding a section at the end for additional justification is helpful to reduce the number of questions and further explain the need and goal of the request.

Goal example #1

What are your goals and outcomes?

Goal
<p>Describe (include how to implement and measure results)</p> <p>Need: Participant needs to have adaptive bedding that zips. He is working on completing chores. Having bedding that is easy and will help him make his bed will increase his independence with that chore. Doing chores independently also helps Participant feel accomplished and successful which in turn decreases his behavior.</p> <p>Goal: Participant will be Independent with making his bed.</p> <p>Action: Adaptive bedding will be purchased.</p> <p>Measure: Participant will be 100% independent with making his bed and will complete this chore 3 out of 7 days. Outcome will be measured by paid parent.</p> <p>Additional Justification: Participant struggles with motor planning with tasks. Multi-step tasks are also difficult for him due to his Autism. As is typical with people with Autism the task of making his bed is difficult due to the multi-step process along with the need for it to be perfect. He is wanting to further his independence. When Participant is struggling with multi step processes or motor planning he has behaviors like yelling, screaming, kicking and hitting. His goal is increase his independence and decrease his behaviors. Typical bedding is not a solution for Participant because of the multiple layers. First you have the fitted sheet that needs to go over the corners of the bed. Next you have the flat sheet that needs to be tucked in and lined up properly. Finally you have the top blanket that also needs to be lined up and even on both sides of the bed. Due to his disability Participant is unable to complete this multi-step process. Utilizing zip-up bedding will allow Participant to be more independent with the chore of making his bed. This will eliminate the multi-step process of making his bed by allowing him to zip up the blanket to the sheet.</p>

Goal example #2

What are your goals and outcomes?

Goal
<p>Describe (include how to implement and measure results)</p> <p>Need: PARTICIPANT needs staff trained to meet her specific health and safety needs. Support staff need to be trained to respond in emergency situations and complete life sustaining interventions until emergency medical professionals arrive. Emergency protocols related to PARTICIPANT'S health needs are detailed in the Health and Safety section of the CSP.</p> <p>Goal: All support staff will be trained in basic life support and CPR to provide optimal care during an emergency situation.</p> <p>Action: All support staff will complete a CPR/First Aid class.</p> <p>Measure: By the end of the year plan, support staff will have successfully completed a CPR/First Aid emergency course. Outcome will be monitored by client.</p>

Goal example #3

What are your goals and outcomes?

Goal
<p>Describe (include how to implement and measure results)</p> <p>Need: Participant has issues with anxiety. She is working on coping skills to help her with her anxiety. These kits are used to help her deal with her anxiety while also teaching her the fine motor skills she is needing. Participant was able to utilize these while on her CSG and would like to put them back in her plan. This has become a great coping skill for her. Craft Kits allow her to work through her anxiety. Using them in the past has also helped with decreasing her behaviors.</p> <p>Goal: Participant will reduce her behaviors from her anxiety.</p> <p>Action: Craft Kits will be purchased.</p> <p>Measure: Participant will reduce her behaviors and times of anxiety by 25%. Outcome will be measured by paid parent.</p>

Finding items for your plan

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- Check your county expenditure guide (if available) and unallowable items.
- When looking for items make sure to look at least costly alternatives. Sometimes if you select an item that isn't least costly, it may also be necessary to explain in your goal why something that costs less isn't the most effective.
- Look at different options. (Example: making your own visual schedule vs. buying one pre-made)



PARTICIPANT AND CAREGIVER PERSPECTIVES

Carrie Theisen, Julia Biddlecome

Self-Advocacy and CDCS Support Planning

Personal stories of self-advocacy

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- Tell us about yourself
- How have you self-advocated during the CDCS process?
- What out of the box items have you put in your plan?

QUESTIONS?

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THANK YOU!

Self-Advocacy and CDCS Support Planning

www.mndsa.org

www.ausm.org