Choice and Community: Seeking the Voice of Adults with Developmental Disabilities

CENTER ON DISABILITIES AND HUMAN DEVELOPMENT

IDAHO COUNCIL ON DEVELOPMENTAL DISABILITIES

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This study, "Choice and Community: Seeking the Voice of Adults with Developmental Disabilities" was conducted by the Center on Disabilities and Human Development at the University of Idaho and the Idaho Council on Developmental Disabilities in collaboration with the Idaho Department of Health and Welfare from August 2015 - April 2016. After three years, a follow up study will be conducted to see if there are changes in the perceptions of the same respondents.

Purpose of Study

The purpose of the study was to identify the perceptions of adults with developmental disabilities who were receiving Home and Community Based Services (HCBS) (Medicaid Program: State Plan Home and Community-Based Services, 2014) or their guardians regarding the extent to which individuals were integrated into the community, had choices, individual rights, and autonomy within a living setting. The study was designed to provide the Idaho Department of Health and Welfare with information from individuals or their appointed guardians about aspects of the new rules that are currently being implemented and what aspects of the rules are not being implemented.

The study addressed the following four research questions:

1. *How do responses vary among individuals residing in certified family homes and supported living settings?*

2. *How do responses vary among individuals in different regions and geographic designations?*

3. *How do responses vary among individuals who need various levels of support as designated by the Scales of Independent Behavior-Revised (SIB-R)?* (Bruininks, Woodcock, Weatherman, & Hill, 1996)

4. *What are the perceptions of adults with developmental disabilities and/or their guardians who receive Medicaid Home and Community Based Services, regarding the extent to which they are integrated into the community, have employment opportunities, and choices within their living situations?*
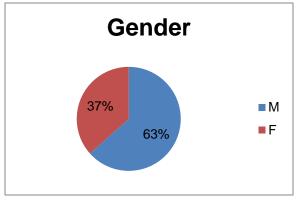
The following sections describe the design of the study including a description of the respondents, interview protocol, and procedures.

Design of Study

Respondents

A random sample of 831 individuals drawn from a list of 3200 adults who receive HCBS were included as possible participants. The sample was drawn from all seven regions of the state. The list of 831 randomly identified names was provided to the Idaho Council on Developmental Disabilities by the Idaho Department of Health and Welfare in August 2014. A total of 112 adult recipients or their guardians agreed to participate. Adult recipients who participated in the study ranged in age from 18 to 68. Sixty-three percent of the adult recipients were male and 37% were female. Forty-seven percent of the

recipients lived in a certified family home, 42% lived in a supported living setting, and 11% lived in what was defined as "other." The "other" category was a person who was directing his or her own services utilizing the "My Voice, My Choice" (self-direction) program. Eighty-five percent of participants lived in an urban setting, 8% lived in a rural setting, and 7% lived in a frontier setting, as defined by the Idaho Department of Health and Welfare (Appendix A).
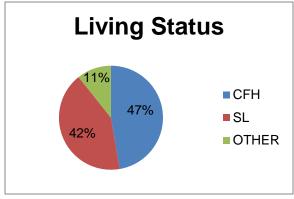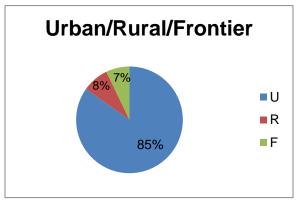

Figure 1

Figure 2

Figure 3

Procedure

Prior to conducting the study, a letter and two consent forms were sent to all the adult recipients on the sample list or their guardians. The study began in region one in September 2015 and ended in region seven in March 2016. One form required the adult recipient or the legal guardian to give his/her consent to participate in the study and the second form required a signature to release the recipient's SIB-R score to the researchers. The signed SIB-R consent forms were sent to the Department of Health and Welfare on a monthly basis and a list of scores was then returned to the University of Idaho.

Following each regional mailing, a phone call was placed to an adult recipient or a legal guardian to confirm receipt of the letter and the consent forms. The recipient or guardian was asked if they would be willing to participate in the study. People who expressed an interest in participating were encouraged to mail in the consent forms. Once the consent forms were received with an authorized signature, the researchers made a second call

to arrange a date, time, and location for an interview. Interviews took place in a recipient or guardian's home, developmental disability agency, or a community setting such as a restaurant or library. Each interview was tape recorded and transcribed for analysis.

Interview Protocol

The interview protocol (Appendix B) was comprised of 20 core questions in categories that were aligned with components of the five standards that all Home and Community-Based Services are required to meet according to federal regulations. These include: a) integration into the community; b) individual choice; c) individual rights; d) autonomy; and; e) choice regarding services and providers. Questions were also aligned with the Department of Health and Welfare's "Person Centered Planning Process and Plan Requirements" (Appendix C).

In August 2015, a pilot study was conducted with three adult recipients who had various SIB-R scores. Following the pilot, revisions were made to the language of the protocol. Revisions were also made to the protocol following interviews in regions one and two. These revisions included modifying the order of the questions and adding clarifying questions or language to meet the needs and experiences of the respondents. For example, participants confused the terms "roommate" with "housemate." A question was added to the protocol to distinguish between someone who shared a room with the recipient versus some who lived in the home.

Training for Researchers

The interviews were conducted by three researchers from the Center on Disabilities and Human Development at the University of Idaho and one researcher from the Idaho Council on Developmental Disabilities. An initial two-hour training was conducted with the researchers in August 2015. The training included a review of the purpose of the study and initial guidelines for conducting an interview with an adult recipient and/or their guardian. Guidelines included topics such as ways to avoid research bias, pacing of questions, phrasing and rewording of questions, dealing with abstract concepts such as "time," avoiding induced acquiescence, and avoiding response bias. Reliability on the protocol was established with researchers through the initial training and through ongoing regularly scheduled follow up discussions.

Data Analysis

Each interview was transcribed from the audio recording and given a code to identify the region, the date, and initials of the adult recipient. Interviews were then reviewed by the researchers and entered into a data processing software. Totals and percentages were calculated for quantifiable questions (e.g. yes/no) and qualitative data (e.g. individual support plan data) was entered into a word processing program.

Researcher comments were also included as part of the data collection process. Additional comments made but the adult recipient or their guardian were noted in the areas of employment and individual support plans. These comments were then reviewed for themes within a region and statewide.

Respondents

A total of 112 out of 831 adult recipients of HCBS, their guardians or support personnel participated in the interviews.

The adult recipients from the sample fell within all of the SIB-R levels of support with the exception of the "infrequent" level. As such, there were a range of ways that people responded or were able to respond to the interview questions. To provide a clear description of who was answering the questions a coding system was developed to indicate how much of an interview was answered by the adult receiving HCBS and how much had been answered by a guardian or support person. At the conclusion of an interview, the researcher rated the active participation of the focus individual. The interview was rated as a "1" if 90% or more of the interview questions were answered solely by the person receiving HCBS. The interview was rated as a "2" if a guardian or support person assisted the individual with a majority of the questions, and the interview was rated a "3" if the guardian or support person answered 90% or more of the interview questions.

Support Score
N=112

■ Support Score
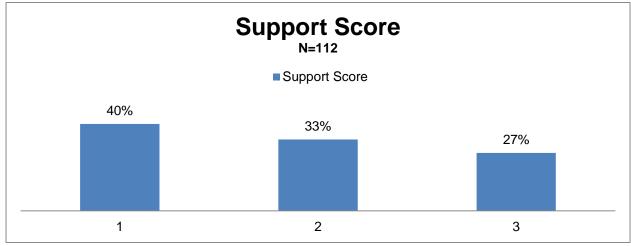
40%   33%   27%

1   2   3

Figure 4

Role of a Support Person

A support person actively participated in 60% of the interviews. A support person was defined as either a legal guardian or designated staff in a living situation who had permission from the guardian to participate in the interview. These people played several roles depending upon the active participation of the focus individual. They might clarify information or expand on an answer. They might reframe a question to help an individual understand the question, or they might explain an answer given by the individual. If a support person answered some or all of the questions for the adult recipient, the researcher verified the answers by asking the respondent such questions as "Why do you say that?" or "Can you give me an example?"

4

Results

The following section details the results of the study for each of the four research questions. As stated above, the categories and questions on the interview protocol were aligned with major components of the rule. These categories included living situation; individual choice; employment; integration into the community; and personalized plan.

1. *How do responses vary among individuals residing in certified family homes and supported living settings?*

The study involved 53 people who lived in a certified family home and 47 who lived in a support living setting. A third setting labeled as "other" was added to the data analysis during the interview process. The "other" category included individuals who were on self-direction and lived with a parent, family members, or by themselves. There were 12 adult recipients in this category.

The study did not find any meaningful differences in responses to the interview questions given for the living, individual choice, employment, integration into the community, or personalized plan category.

2. *How do responses vary among individuals in different regions and geographic designations?*

Of the 112 people who participated in the study, there were no meaningful differences in responses among adult recipients living in the seven regions other than some access to community activities due to rural/frontier settings.

3. *How do responses vary among individuals who need various levels of support as designated by the Scales of Independent Behavior-Revised (SIB-R)?*

The goal of the study was to interview individuals who were receiving HCBS or their guardians as to their perceptions of their current services. The interview process included individuals at support levels as listed on the SIB-R.

Scores on the SIB-R are categorized into six levels of support. Levels include "infrequent/no support," "intermittent," "limited," "frequent," "extensive," and "pervasive." Adult recipients in the study fell within five of the levels. Those receiving "infrequent/no support" were not included in the study. Additionally, individuals deemed "dangerous to self or others" by the Idaho Department of Health and Welfare were excluded from the sample. As noted above, support levels for adults receiving services were provided to the researchers from the IDHW on a monthly basis once a signed release form had been sent to the researchers.

One of the early findings of the study was that the SIB-R scores did not always correspond with an individual's ability to be a participant in an interview. For example, there were people who were categorized as "limited" on the SIB-R but were unable to actively participate in an interview, where other people were categorized as "extensive" due to physical needs and were able to fully participate in the interview process. As a result, it was difficult to determine if and how responses varied across support levels.

4. *What are the perceptions of adults with developmental disabilities and/or their guardians who receive Medicaid Home and Community Based Services regarding the extent to which they are integrated into the community, have employment opportunities, and choice within their living situations?*

Category A: Living Situation

1. Do you have a room of your own?

   The results of the study indicated that 96% of adults receiving HCBS had his or her own room. The remaining 4% of individuals shared a room with their spouse or a parent.

2. Do you have a housemate?

   Results for this question indicated that 81% of adult recipients had a housemate(s) and 19% lived alone.

3. Did you choose your roommate/housemate?

   This question was asked of people who were in a "supported living" setting. Of those people asked, 42% of adult recipients indicated that they did not choose their roommate or housemates. Typical reasons for not choosing a roommate or housemate included "the agency chose the home and housemate already lived here," "limited availability of vacancies," or "my family choose for me."

4. Can you be by yourself if you want to?

   Responses by individuals receiving services, their guardians or support personnel indicated that 87% of people were able to be alone. The question was oftentimes clarified to define "alone" as being able to go to another room and "be by themselves" without anyone in the room. Guardians or support personnel were quick to point out that a person might be able to go to another room in the home but could not be left alone in the house. The remaining 13% of adult recipients were not allowed to be alone in the house due to safety concerns. For example, one respondent said, "He can't do anything alone. He doesn't understand concepts so if you leave him alone he could just run out into the street and get hit by a car," or, for health reasons such as the individual had a serious seizure disorder.

5. If you are in your bedroom do people knock before coming in?

   The results for this question indicated that people knocked or said something verbally before entering the room of 83% of the adult recipients. Results showed that people did not knock or indicate their presence verbally for 17% of individuals. Reasons given for not knocking included "I like the door always open," or "we are family so it doesn't matter," "health and safety concerns," and "he is not concerned with privacy."

6. Do you get the privacy you want when you get dressed and use the bathroom?

   Regarding privacy issues, 88% of respondents indicated that the adult recipients have privacy when dressing or using the bathroom and shower. The other 12% of adult recipients were regarded as needing "full assistance" when dressing, showering or using the bathroom and were not physically able to participate in those activities by themselves for safety reasons.

Category B: Individual Choice

7. <u>Are you able to see people that are important to you whenever you want to?</u>

   Results of the study indicated that 89% of adult recipients were able to see people that were important to them. The remaining 11% indicated that they were not always able to see people that were important to them due to distance issues, mileage constraints of support personnel or the lack of "flex staff." In some instances, the adult recipients all had to travel together rather than taking individual trips to visit a particular person.

8. <u>Do you get to eat when you want</u>?

   Respondents to this question indicated that 91% of the adult recipients could eat when they wanted to. People were able to get a "snack" at any time. However, this did not mean that they were able to get a main meal when they wanted to for reasons such as an individual "ate with the family" or the home had "set meal times." The remaining 9% could not eat when they wanted to due to health issues such weight gain, diabetes, or aspiration concerns. Seventy-five percent of those individuals had the restriction noted on their plan.

9. <u>Do you choose what you eat?</u>

   Regarding food choices, 80% of respondents indicated that the adult recipients could choose what they ate during the day. The remaining 20% were said to have had restrictions for reasons that included "gaining weight," "eating too much sugar," "diabetes," or consuming too much of one item like a whole package of cookies or a block of cheese. Of individuals with restrictions, 38% of them <u>did not</u> have the restriction noted on their plan.

10. <u>Who decides what you wear?</u>

    Individuals responding to this question indicated that 89% of adults receiving services decided what they wore each day. The reasons for 11% of people not choosing their clothes included statements like, "does not care what he wears," "unable to make a choice," or "needs to make weather appropriate choices."

11. <u>Do you choose how to spend your money?</u>

    Regarding how money is spent, 93% of the respondents acknowledged that the adult recipient chose how to spend their money with support. According to respondents, a person's money was typically specified as their "allowance." Support for spending was defined as "managing money," "helping to pay the bills first," "requiring supervision when spending money," and staff or agency "keeps or holds the money." Only 7% of the respondents indicated that the adult did not choose how to spend their money. Reasons given included comments like "they don't understand money," "the family chooses based on individual's likes," and that "guardians had to approve spending."

12. <u>Do you have a TV in your house?</u>

    All respondents indicated that there was a television in the house.

13. Can you watch TV whenever you want to?

Respondents to this question indicated that 90% of the adults receiving services were able to watch TV when they wanted to. There were 10% of individuals who had some restrictions. These restrictions included turning off the TV because it was "bedtime" or for health reasons in that "he would stay up all night watching TV."

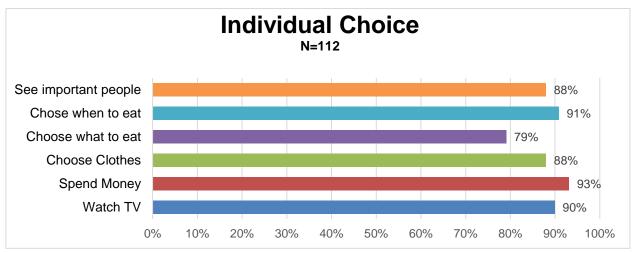None of the individuals had a TV restriction noted in their Individual Support Plan.

Individual Choice
N=112

Category	Percentage
See important people	88%
Chose when to eat	91%
Choose what to eat	79%
Choose Clothes	88%
Spend Money	93%
Watch TV	90%

Figure 5

Category C: Employment

14. Do you have a job?

The results of the study revealed that 72% of adults receiving services were <u>not employed</u>. Of the adults who were employed, 19 were employed in the community between 1-20 hours per week, and 12 were employed in a DD/sheltered workshop between 4-12 hours a week. With regards to paid employment, 52% of people working were paid minimum wage or above, and 13% were paid below minimum wage. The remaining 35% were not sure if they were paid or could not remember how much they were paid. Work settings included cleaning in a hotel, janitorial work in a school or business, tasks at Goodwill, and a detail painter at a sheltered workshop.
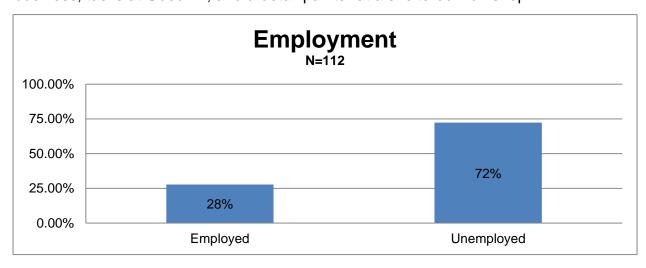
Employment
N=112

Category	Percentage
Employed	28%
Unemployed	72%

Figure 6

Category D: Integration into the Community

15. <u>When you leave your house, what do you like to do?</u>

    Adults receiving services and/or their guardians or support personnel had various answers to this question. The answers were not different across the state. Typical answers included shopping, bowling, going to movies, going out to eat, walking, and going to thrift stores.

    Respondents indicated that 83% of adult recipients made decisions as to what they wanted to do each day. Some individuals received input from family members or support personnel to help create daily and weekly schedules, some of which included an activity that took place in the community. Limitations for community activities might include the issue of "time" in that people needed transportation or support and a family member or support person was not available at particular times of the day or week.

Category E: Personalized Plan

This category focused on the development of an individual's Person Centered Plan. The interviews included core questions regarding the plan but also included follow-up questions to provide additional detail about the process. As with all of the questions, the answers provided were from the perspective of the recipient, a guardian, or a support person.

16. <u>Are you familiar with your person-centered plan?</u>

    The results of the study indicated that 77% of respondents were familiar with their plan and 23% of respondents were not familiar with the plan. The majority of people interviewed did not recognize the term "person centered plan" but rather "individual support plan."

17. <u>Do you attend your annual person-centered planning meeting?</u>

    Responses to this question indicated that 94% of adult recipients attend their person centered planning meeting. Responses for the 6% of people that do not attend included:

    - "The agency goes to the planning meeting."
    - "I know the plan is in my book. I just know mom makes it and they just tell me some stuff I need to follow and that's what I follow. Scheduling and stuff like that."
    - "We have a little meeting without him and we talk over what's going on. Then he is brought in and we go back over everything."
    - "It would be too distressing for him to have to sit for that meeting."
    - "There's so much stuff they talk about, it's mind boggling."

    Respondents were asked a follow up question about how the adult recipient participated in the meeting. The majority of people were asked a series of questions. The process did not appear to be adapted for recipients who had various support needs. For example, adjusting questions for language level, time needed to process information, or the experience of the recipient.

For example:

- "When I'm at (agency name) I attend the meeting but they don't really tell me what my plans are. They just tell me, 'This is what's going to happen'. I go to the meeting, it's just, that they tell me this is what my plan's going to be."

- "He just agrees."

- "She participates by answering 'yes' and 'no' questions."

- "She just listens."

- "Usually I am running the show. I have some chatty Cathy's in my workers and so we'll get lost because I'll get overwhelmed and I'm like 'Okay, I just want this over and done with' and so we'll speed along and kind of forget. But usually on a good day we'll talk about 'Well, what do you think you need help in this area? You have improved in this area. Do you think that needs to be worked on?'"

People who typically attended a meeting were the adults receiving HCBS, family members, support staff, Targeted Service Coordinators, support brokers, or agency staff. With regards to choosing attendees, 96% of adult recipients answering questions in this category said they had invited the people at their last meeting and knew they could choose the people who attend a meeting.

18. <u>Are you asked about your strengths/abilities during the meeting?</u>

    -and-

19. <u>Are you asked about your preferences/likes during the meeting?</u>

Final Medicaid HCBS rules include changes to the requirements regarding person-centered plans for HCBS waivers under 1915 (c) and HCBS state plan benefits under 1915 (i) and "identifies the strengths, preferences, needs (clinical and support), and desired outcomes of the individual."

The document entitled, "Person Centered Planning Process and Plan Requirements" (Appendix C) is distributed by the Idaho Department of Health and Welfare to reflect the components of the federal requirement for a person centered plan. That document includes the HCBS rule language and states that a plan must "Reflect the individual's strengths and preferences."

To discover how this requirement was currently being met, the interview included a question about strengths and preferences.

The results of the study indicated that only one person out of the 112 recipients was asked about their strengths and preferences to subsequently use in the person centered planning process. The one individual was on self-direction and "loves music" so the plan included music therapy.

There was a pattern across the state on the topics of strengths and preferences. Professionals, individuals, or guardians did not appear to understand <u>why</u> the questions were being asked or how they might be used to develop a plan. For example, when a support person was asked if the individual's strengths were discussed at the meeting

she said, "Yep. Happy all the time for the most part. She loves to socialize." When asked if the woman's likes were discussed she responded, "Yes, she loves animals, Elvis, and she loves to interact with people."

Even though there had been a discussion about this individual's strengths and preferences her goals included "stretches, to be able to cook her food, to use the sign 'toilet,' to go to the YMCA at least once a week, and to 'put away her clean clothes.'"

Another young woman was asked about her "likes" and she responded:

- "I like color. I like music. I like to be socially active. I like being with my friends a lot. I like being with my animals. I like volunteering, doing crafts and helping out with local communities."

This young lady's goals included "meal planning, budgeting, and coping skills."

Other comments included:

- "I think her abilities are - that's one of the things that we're strongly working on is her understanding money and her having some strong life skills. What can she do and what she can't do. I think her abilities are that she can be given three step or five step commands."

- "We have to talk about his likes. That's one of the requirements that they have to fill in for the ISP is things that he likes or does not like."

- "We do, but kind of talk between us usually when we do it. Because if we ask her she'll just answer 'yes' most of the time unless I do a 'yes/no'. So when you ask her what her strengths are its kind of hard because it's not a one or two answers to a question. It's a long list of things she works on throughout the year. We have been working on pain/hurt for the past 24 years. She works on identifying colors and shapes, the basic kind of stuff."

The interpretation of a person's "strengths" from both the professional and family perspective seemed to be defined as an update on how a person was performing on a program rather than reflecting the abilities a person has that could then be used to develop goals on a plan. For example, one young man liked taking pictures and volunteers at the library and food pantry in his community. "He takes pictures all the time and sometimes the local newspaper will publish them," said his guardian, "he does pictures for the county fair and so he's got ribbons and stuff in there for his own pictures."

This young man's goals include "volunteer and making sure he can fill out a timesheet, as well as talking with complete words and sentences."

20. Do you know the goals in your plan?

The final question on the interview asked recipients about the goals on their plan. There were follow up questions regarding community based and work goals as well as how the goals were decided. The results of the study indicated that 34% of respondents did not remember the goals on the recipient's plan.

There were some themes across plans. For example, 25% of people in the study had a "budgeting" or "learning to manage money" goal. Other popular goals included hygiene, cooking, cleaning, safety, living a healthy life, and meal planning.

Respondents also talked about a recipient's participation in community goals in different ways. For example, for some people the community was a place to "build a skill" such as learning how to use an ATM machine. For other people it was about "social interactions" or "learning where different resources are and what they have to offer you." Other community goals included "safety goals like asking help from a clerk", "stranger awareness", or "price comparison."

Not everyone had a specific community based goal or if they did the respondent did not always remember the goal. The definition of community was also defined in different ways depending upon the "support" needed by the recipient. For example, for some people "community" was defined as the day program at the DD agency.

Follow-up questions were also included regarding work and pre-vocational goals. Of the people who were interviewed only <u>two</u> recipients had a work goal on their plan. There was no one who had a "pre-vocational" goal on their plan in any region of the state. Getting a job seemed to be interpreted in a more traditional manner where people work 40 hours a week rather than looking at customizing work experiences to fit the abilities and contributions of the individual.

The Process of Developing Goals

Most meetings included someone, either the adult recipient or the guardian, being asked a series of questions. The themes across the state revealed similar goals for adult recipients in every region. Additionally, the goals were developed from a more deficit based perspective "things I need to work on" or "things I'm not good at" rather than reflecting a recipient's strengths and preferences to develop a plan.

- "SIB-R is done at the same time as the meeting. They then ask her to leave the room. Attendees include mostly her staff (Targeted service coordinator, support person, program coordinator). They then sit down and ask her what programs she wants to have. If there's anything new they write it down."

Some plans were developed using previous plans:

- "Well, we usually take the plan from last year. What's worked and what hasn't. Hopefully, like I said I'd like to have some of the staff there that are actually working with him because they can actually say 'this isn't working at all.' But we try and update."

Some plans were developed using other people's plans:

- "I didn't know what I was doing and I didn't get too much direction, so I got a copy of another person's and kind of went with that because I didn't have any idea."

Some plans were based on perceived needs:

- "It's things that I need to work on that I'm not doing so well on. So we try to make that a goal. So after a certain amount of time if I've reach a certain point we can take that off or we can continue with it."

Some plans were developed by other people besides the recipient:

- "No, they just say 'this is what he needs to work on.' They just say to take him to what he likes to do. It's like a reward system."

Some plans were not based on anything in particular:

- "We throw things at the wall and see what sticks."

Respondents said that goals were typically developed from a series of questions that were to be answered by the recipient or their guardian. Goals were also developed from assessments (e.g., SIB-R) that were perceived as skills that people "needed to learn." However, these things appeared to be goals that were not necessarily leading to an outcome. For example, a person might have a goal on their plan to fill out a time sheet but did not have a job or a work or a pre-vocational goal.

The plans of people who had more complex disabilities and were designated at the extensive and pervasive levels of support typically had goals that did not reflect many or few high expectations. People were simply "being taken care of" with little recognition of competency or active participation in work and community activities. The overall sense was that people, both professionals and guardians, did not think about or know how to customize plans to create future outcomes for people at various support levels.

Summary

The study involved a range of people at five support levels on the SIB-R. These were people as young as 18 and as old as 68. They lived in certified family homes, supported living situations, or by themselves or with family. Sixty percent of recipients either had support from another person in answering the interview questions or the questions were answered entirely by a support person with no active involvement by the focus individual. It became apparent as the study progressed that the process of developing the plan was the same no matter the level of support. It was also clear that according to the people who were interviewed, the process was not adapted to accommodate for individual needs. For example, a young man said, "Yes, I don't usually pay attention to those. I usually nod off because they are using a bunch of big words that I'll never understand even if I tried. I go and usually later on have my staff explain it to me in a non-fast paced way because usually they're doing it at a fast pace and I can't keep up."

The results of the study indicated that the format of a planning meeting included gathering information by asking questions and subsequently having recipients make choices about their goals. The challenge of conducting meetings using a verbal format is that people who have a range of disabilities and support levels also range in how they understand and process information. Best practice would suggest that accommodations for a diverse group of people would include variables like pacing of the conversation, language level and terminology, factoring in sensory issues, remembering that people with intellectual disabilities can have issues with the concept of "time," and understanding people's experience well enough to know if they are making an informed choice.

Limitations of the Study

Time

Each interview was conducted in less than an hour. This short period of time did not give the researchers any quality time to get to know the recipient, a guardian, or support person. Researchers did not have an opportunity to conduct any observations to confirm a recipient's experience within a home or community setting.

Missing Data

The list provided by the Department of Health and Welfare contained incomplete and/or outdated information for recipients and their guardians. The researchers were unable to contact 18% of potential participants for reasons including wrong address, disconnected, outdated, or 'wrong' phone numbers, changes in guardianship, and recipients who were now deceased.

"Just another socialist program"

Another limitation of the study was that some guardians and/or professional staff seemed to be wary of the researchers and the interview. Even though they had been given information about the purpose of the study and had signed consent forms there remained a level of skepticism in answering questions. In particular, respondents from certified family homes made comments such as "Why do they want to know that"? or "We don't want to participate in anything having to do with the Department any more than necessary." This attitude may have impacted the validity of a response in that people were afraid their answer would reflect upon them as a care provider.

Verification of information

The researchers did not have access to any of the recipients' person centered plans. They did not see specific goals or any notes made on the document but relied on the perceptions of the individual receiving services, a guardian, or professional staff.

Perception of disability

The complexity of a recipient's disability impacted the research at two points. First, there were guardians who did not want to participate in an interview due to their perception of their son or daughter's disability. Comments such as, "Honey, that would be a waste of your time and mine" or "She is at a three-year-old level" were the kinds of comments that occurred in all seven regions. This perception impacted the number of people who participated in the study.

5 Key Findings

"Choice and Community: Seeking the Voice of Adults with Developmental Disabilities"

1. The perceptions of adult recipients of Home and Community Based Services or their guardians indicate they had adequate choice within their living situations.

2. The majority of recipients who had some kind of restriction related to what they could eat or when they could watch television did not have that restriction listed on their plan.

3. Recipients of Home and Community Based Services were not employed. They did not have a work or pre-vocational goal listed on their plan.

4. The person centered planning process developed goals that did not reflect a recipient's strengths and preferences.

5. The person centered planning process did not accommodate the diversity of recipients of Home and Community Based Services.

Appendix A

County Number	County FIPS	County	Region	Region Num	Geo Density	2015 Population	Land area sq miles	Population per Sq miles
1	1	Ada	Region 4	4	Urban	434,211	1,053	412.4
2	3	Adams	Region 3	3	Frontier	3,843	1,363	2.8
3	5	Bannock	Region 6	6	Urban	83,744	1,112	75.3
4	7	Bear Lake	Region 6	6	Frontier	5,922	975	6.1
5	9	Benewah	Region 1	1	Rural	9,052	777	11.6
6	11	Bingham	Region 6	6	Rural	44,990	2,094	21.5
7	13	Blaine	Region 5	5	Rural	21,592	2,644	8.2
8	15	Boise	Region 4	4	Frontier	7,058	1,899	3.7
9	17	Bonner	Region 1	1	Rural	41,859	1,735	24.1
10	19	Bonneville	Region 7	7	Urban	110,089	1,866	59.0
11	21	Boundary	Region 1	1	Rural	11,318	1,269	8.9
12	23	Butte	Region 7	7	Frontier	2,501	2,232	1.1
13	25	Camas	Region 5	5	Frontier	1,066	1,074	1.0
14	27	Canyon	Region 3	3	Urban	207,478	587	353.5
15	29	Caribou	Region 6	6	Frontier	6,770	1,764	3.8
16	31	Cassia	Region 5	5	Rural	23,506	2,565	9.2
17	33	Clark	Region 7	7	Frontier	880	1,764	0.5
18	35	Clearwater	Region 2	2	Frontier	8,496	2,457	3.5
19	37	Custer	Region 7	7	Frontier	4,087	4,921	0.8
20	39	Elmore	Region 4	4	Rural	25,876	3,075	8.4
21	41	Franklin	Region 6	6	Rural	13,074	664	19.7
22	43	Fremont	Region 7	7	Frontier	12,819	1,864	6.9
23	45	Gem	Region 3	3	Rural	16,852	561	30.0
24	47	Gooding	Region 5	5	Rural	15,284	729	21.0
25	49	Idaho	Region 2	2	Frontier	16,272	8,477	1.9
26	51	Jefferson	Region 7	7	Rural	27,157	1,094	24.8
27	53	Jerome	Region 5	5	Rural	22,814	597	38.2
28	55	Kootenai	Region 1	1	Urban	150,346	1,244	120.9
29	57	Latah	Region 2	2	Urban	38,778	1,076	36.0
30	59	Lemhi	Region 7	7	Frontier	7,735	4,563	1.7
31	61	Lewis	Region 2	2	Rural	3,789	479	7.9
32	63	Lincoln	Region 5	5	Frontier	5,297	1,201	4.4
33	65	Madison	Region 7	7	Urban	38,273	469	81.6
34	67	Minidoka	Region 5	5	Rural	20,461	758	27.0
35	69	Nez Perce	Region 2	2	Urban	40,048	848	47.2
36	71	Oneida	Region 6	6	Frontier	4,281	1,200	3.6
37	73	Owyhee	Region 3	3	Frontier	11,310	7,666	1.5
38	75	Payette	Region 3	3	Rural	22,896	407	56.3
39	77	Power	Region 6	6	Frontier	7,648	1,404	5.4
40	79	Shoshone	Region 1	1	Frontier	12,432	2,630	4.7
41	81	Teton	Region 7	7	Rural	10,564	449	23.5
42	83	Twin Falls	Region 5	5	Urban	82,375	1,921	42.9
43	85	Valley	Region 4	4	Frontier	10,103	3,665	2.8
44	87	Washington	Region 3	3	Frontier	9,984	1,453	6.9

| | 2015 | | | |
Cnty Type	Number of Sq Miles	Population Count	Percent of Sq Miles	Percent of Population
Frontier	52,572	138,504	64%	8%
Rural	19,897	331,084	24%	20%
Urban	10,176	1,185,342	12%	72%
Total	82,645	1,654,930	100%	100%

Geo Density Criteria:
Urban counties have a population center of at least 20,000.
Rural counties have at > = 7 people per square mile and no population centers larger than 19,999.
Frontier counties have < 7people per square mile and no population centers larger than 19,999.

Counties w population center of 20,000 or more	CountyN	NAME	POPESTIMATE2014
1 Ada	Ada	Boise City city	216282
2 Bannock	Ada	Eagle city	22502
3 Bonneville	Ada	Meridian city	87743
4 Canyon	Bannock	Pocatello city (pt.)	54278
5 Kootenai	Bonneville	Idaho Falls city	58691
6 Latah	Canyon	Caldwell city	50224
7 Madison	Canyon	Nampa city	88211
8 Nez Perce	Kootenai	Coeur d'Alene city	47912
9 Twin Falls	Kootenai	Post Falls city	29896
	Latah	Moscow city	24767
	Madison	Rexburg city	27094
	Nez Perce	Lewiston city	32482
	Twin Falls	Twin Falls city	46528

Appendix B

Interview Protocol

Date:

Place:

Interviewer

Interviewee Information

- Age
- Sex
- Living situation (Certified Family Home/Supported Living/Self Direction/Other)

(Describe the (a) purpose of the study, (b) individuals and sources of data being collected, (c) what is being done with the data to protect the confidentiality of the interviewee, and (d) how long the interview will take.)

Questions:

Category A: Living Situation

1. Do you have a room of your own?
2. Do you have a roommate or housemate?
3. If you have a roommate, did you get to choose him/her?
4. Can you be by yourself if you want to/Can you be alone if you want to?
5. If you are in your bedroom, do people come in without asking first?
6. Do you get the privacy you want when you get dressed, use the bathroom, or shower?

Category B: Individualized Choice

7. Are you able to see people that are important to you whenever you want to?
    a. People who matter to you, etc.
    b. Reasons… scheduling problems? Distance?
8. Do you get to eat when you want to?
9. Do you choose what you eat?
    a. If no, is the diet restriction included in your personalized plan?
    b. If meal planning, are you a part of the weekly planning?
        i. If no, are you aware it should be?
10. Who decides what clothes you wear?
11. Do you choose how to spend your money?
12. Do you have a TV in the house? Where is it?
13. Can you watch TV whenever you want to?
    a. If no, is the restriction included in your personalized plan?
        i. If no, are you aware it should be?

Category C: Employment

14. Do you have a job?
    a. If yes, where do you work?
        i. What do you do?
        ii. Are you paid?
            1. How much?
        iii. How many hours a week?
    b. If no, would you like a job or has anyone talked to you about working?

Category D: Integration into the Community

15. When you leave your house, what do you like to do?
    a. How do you decide what to do?
    b. Who decides when you do those things?

Category E: Personalized Plan

16. Are you familiar with your person centered plan?
17. Do you attend your annual person centered planning meeting?
    a. Do you participate?
        i. How?
    b. Who attends those meetings?
        i. Did you choose those people?
            1. Are you aware you can choose who is in attendance?
18. Are you asked about your strengths/abilities during the meeting?
19. Are you asked about your preferences/likes during the meeting?
    a. *****What are you good at? Vs What do you like to do?*****
20. Do you know the goals in your plan- what are they?
    a. Do you have any community-based goals?
    b. Do you have a 'work' goal?
        i. If no, is there a pre-vocational goal?
    c. How were they decided?

Appendix C

Person Centered Planning Process and Plan Requirements

Person-Centered Planning Process The individual will lead the person-centered planning process where possible. The individual's representative should have a participatory role, as needed and as defined by the individual, unless State law confers decision-making authority to the legal representative. All references to individuals include the role of the individual's representative. In addition to being led by the individual receiving services and supports, the person-centered planning process:
• Includes people chosen by the individual
• Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.
• Is timely and occurs at times and locations of convenience to the individual.
• Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.
• Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.
• Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS. In these cases, the State must devise conflict of interest protections including separation of entity and provider functions within provider entities, which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process.
• Offers informed choices to the individual regarding the services and supports they receive and from whom.
• Includes a method for the individual to request updates to the plan as needed
• Records the alternative home and community-based settings that were considered by the individual.

Person-Centered Service Plan The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver, the written plan must:
• Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
• Reflect the individual's strengths and preferences.

• Reflect clinical and support needs as identified through an assessment of functional need.
• Include individually identified goals and desired outcomes.
• Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.
• Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed.
• Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.
• Identify the individual and/or entity responsible for monitoring the plan.
• Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.
• Be distributed to the individual and other people involved in the plan.
• Include those services, the purpose or control of which the individual elects to self-direct.
• Prevent the provision of unnecessary or inappropriate services and supports.
• Document that any modification of the additional conditions, under paragraph (c)(4)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:
(A) Identify a specific and individualized assessed need.
(B) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
(C) Document less intrusive methods of meeting the need that have been tried but did not work.
(D) Include a clear description of the condition that is directly proportionate to the specific assessed need.
(E) Include a regular collection and review of data to measure the ongoing effectiveness of the modification.
(F) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
(G) Include informed consent of the individual.
(H) Include an assurance that interventions and supports will cause no harm to the individual.

Review of the Person-Centered Service Plan.

The person-centered service plan must be reviewed, and revised upon reassessment of functional need as required by § 441.365(e), at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of the individual.

References

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