

Service and Support Recommendations from



Recommendations to the Idaho Department of Health & Welfare, Division of Medicaid

July 18, 2017

Acknowledgements

The following recommendations would not be possible without the efforts of each of the members of Community NOW! The following individuals were essential in the efforts of this group to offer recommendations for how services and supports can be altered to best meet the needs of adults with intellectual and developmental disabilities in Idaho.

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Glossary of Terms and Acronyms

Term	Meaning
	American Civil Liberties
ACLU	Union
AFO	Ankle Foot Orthotics
	The Association of People
	Supporting Employment
APSE	First
	Adult Services Outcome
ASOR	Review
	Community Based
CBRS	Rehabilitation Services
	Center on Disabilities and
	Human Development,
CDHD	University of Idaho
	Certified Employment
CESP	Support Professional
	Center for Medicare and
CMS	Medicaid
DD	Developmental Disability
	Developmental Disability
DDA	Agency
	Department of Health and
Department	Welfare
	Department of Health and
DHW	Welfare
	Home and Community Based
HCBS	Services
	Human Services Research
HSRI	Institute
	Intellectual and
I/DD	Developmental Disabilities

Term	Meaning
	Idaho Council on
ICDD	Developmental Disabilities
ICF	Intermediate Care Facility
	,
	Idaho Employment First
IEFC	Consortium
ISP	Individual Service Plan
	National Association of Dual
NADD	Diagnosis
	National Association of
	Direct Support
NADSP	Professionals
	Office of the Idaho Attorney
OAG	General
	Person-Centered Planning/
PCP	Person-Centered Plan
	Provider Quality Work
PQWG	Group
QA	Quality Assurance
Res Hab	Residential Habilitation
SSP	Support and Spending Plan
VR	Vocational Bohabilitation
VN	Vocational Rehabilitation The Community NOW!
Workgroup	Workgroup
vvoikgioup	Workgroup

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Introduction

About Community NOW!

Community NOW! is a statewide collaborative workgroup (Workgroup) led by adults with intellectual and developmental disabilities (I/DD) and their families, who participate in Medicaid home and community based services. The Workgroup was created so that adults with I/DD and their family members could lead discussions about their experiences with adult developmental disability (DD) services provided under Idaho's Medicaid DD Waiver¹ program. Community NOW! discussions took place at several facilitated meetings held over a six month period, from January to June of 2017. Stakeholders, managers and administrators with the Idaho Department of Health and Welfare (Department), advocacy groups, and others also attended and participated in Community NOW! meetings. The experiences shared by adults with I/DD and their family members at these meetings helped identify what is and is not working with DD Waiver services in Idaho. From this information, Community NOW! attendees developed recommendations about how to improve DD Waiver services, which became the basis and content for this report.

The Workgroup was made possible through the shared resources of the Department and the Idaho Council on Developmental Disabilities (ICDD). Community NOW! meetings and discussions took place as part of implementation of the *K.W. v. Armstrong*² settlement agreement. The Workgroup brought together more than 60 people, including: adults with I/DD; family members who support and spoke on behalf of adults with I/DD; Department managers and administrators; advocacy groups such as ICDD, Disability Rights Idaho, Medicaid service providers; and representatives from the Idaho Attorney General's Office (OAG), the American Civil Liberties Union (ACLU), and Human Services Research Institute (HSRI).

The Workgroup was made up of one large group that met three times from January-June of 2017 in Boise, Idaho. The Workgroup was also, however, broken into three smaller subgroups that met monthly in Boise, Idaho over that same six-month period to discuss DD services specific to Home, Community, and Work. Stakeholders (defined hereafter as service providers, advocacy groups, Department managers and administrators, and representatives from the ACLU, OAG, and HSRI) attended each subgroup meeting. These conversations were facilitated by Marsha Bracke of Bracke

¹ DD Waiver refers to the Idaho Adult § 1915(c) Home and Community-Based Services Waiver administered cooperatively between Idaho and federal Medicaid.

² The case of K.W. v. Armstrong, 1:12-cv-00022-BLW is a pending class action lawsuit brought by adults with developmental disabilities in Idaho. The class action claims were settled pursuant to a Class Action Settlement Agreement approved by the U.S. District Court of Idaho in January of 2016.

and Associates and staff from ICDD. The voices of adults with I/DD and their families were the most important voices in the Community NOW! process.

In addition to the Boise Community NOW! meetings, representatives from the Department, ICDD, the OAG, HSRI and the ACLU also completed an in-person Community NOW! statewide listening tour in each of the seven Health & Welfare regions in Idaho. Each listening tour provided opportunities to meet with and listen to additional adults with I/DD, their families, and other stakeholders, who were not part of the Workgroup, but who had experiences to share about what is and is not working with

DD services in Idaho. During each statewide regional listening session, two parallel meetings were held at each location at the same time: one with adults with I/DD and family members and a second with all other stakeholders, so that both groups could provide their experiences with DD Waiver services.

Services and supports currently available through the Medicaid DD waiver program in Idaho help support adults with I/DD to live successful lives in their communities. The shared stories and real life experiences from adults with I/DD and their families were key to learning what supports adults with I/DD want and need, and what barriers can keep adults with I/DD from living full and independent lives. Through information shared by adults with I/DD and their families, in Community NOW! meetings, barriers adults with I/DD currently face in getting the quality services and supports they want and need were identified. An understanding of these barriers led to the development of seventeen recommendations for improvement. This report shares the Workgroup's findings and recommendations.

Because Community NOW! was asked to develop recommendations, this report focuses on areas for improvement. All information contained in this report was compiled during core workgroup meetings, subgroup meetings, and/or stakeholder listening sessions. Some recommendations were initially developed as part of prior work completed by the Idaho Employment First Consortium (IEFC), but were expressly adopted by the Community NOW! workgroup before being included here. For additional detail on the recommendations initially develop by IEFC please see *Appendix A*.

By the numbers

60+ member workgroup comprised of:

- Adults with I/DD
- Family members
- DHW managers and administrators
- Service Providers
- ICDD staff
- Idaho OAG staff
- ACLU staff
- HSRI

3 meetings over 6 months

3 Subgroups – Home, Community, Work met monthly over 6 months

14 stops on a listening tour across the 7 Department of Health and Welfare regions

2,000+ cumulative hours engaging in the Community NOW process

"...people with developmental disabilities demand respect. And guess what? We are moving forward. Each one of you stakeholders has been charged to help us move forward."

Too often, adults with I/DD have their voices overshadowed when trying to share what they want in their own lives. Community NOW! put adults front and center and gave them decision-making authority. The members of Community NOW! gave a great deal of themselves to this process and believe that the recommendations in this report, if implemented, will help improve Medicaid services so that adults with I/DD can experience more choice and control. With choice and control, adults will be better supported to achieve a meaningful life, as they each individually define it.

Quality of Life Measures

A "quality life" can mean different things to different people; it is unique to each person. Many things can impact the ability of adults with I/DD to achieve a quality life. Community NOW! has identified that quality of life may be measured by identifying the degree to which a person experiences the following:

- Being respected
- Having choices
- Being employed
- Having flexibility
- Having control
- Having community/being part of the community
- Being happy/having fun
- Being connected, loved, and valued



Summary of Recommendations

Community NOW! proposes the following 17 recommendations to best meet the needs of people with I/DD, and to provide the greatest opportunity for a quality life. Recommendations are grouped into three categories, each relying on the others to be optimally effective. Strategies and techniques to realize these recommendations are discussed in this report below.

Generating a Truly Person-Centered System:

- 1. Establish a quality **Person-Centered Planning** (PCP) process based on PCP best practice.
- 2. Use the **Individual Service Plan** (ISP) and **Support and Spending Plan** (SSP) to identify and document how supports (paid and unpaid) are used to achieve the life goals identified in the PCP.
- 3. Establish an early and ongoing expectation and process to understand, develop, and support the adult's most effective and preferred communication method(s).
- 4. Take a proactive role in creating and fostering a culture where rights are known, understood, exercised, and respected. This culture should include an emphasis on understanding and using supported decision-making processes to help adults make informed choices.
- 5. **Emphasize and enforce HCBS rules** related to adults determining where they live, who they live with, and who provides their support.

Fostering Meaningful Access to the Community and Appropriate Support in Response to the Adult's Desires, Interest, and Needs:

- 6. **Create a non-medical service model to support adults with I/DD** to meet their needs and explore their interests in their communities over their lifetimes. Provide flexibility within the service array so services can be matched to meet those needs.
- 7. Provide services that appropriately support adults' overall health, including mental health and substance use.
- 8. Provide services that appropriately meet the needs of adults with dual diagnosis (mental health and I/DD).
- 9. **Include pre-vocational, career planning, and individual supported employment services in the Medicaid benefits package** to support the adult to gain and maintain his or her preferred job in the community at, or above, the prevailing wage.
- 10. Put mechanisms in place that help adults to find, support, and keep **competent**, **consistent**, **capable**, **and quality staff**.
- 11. **Implement a tiered, linguistically and culturally appropriate, training process** that is standardized and person-specific to ensure that all staff draw from best practice, experience, and knowledge.

- 12. Address and resolve issues associated with transitions in all phases of life.
- 13. Provide a mechanism to ensure that information about an adult follows them through systems, providers, and services in a manner that is used on the adult's behalf.
- 14. Provide consistent and effective supports for adults and families through coordination and communication across all relevant state agencies and schools.

Creating and Implementing Ongoing Quality Assurance Processes:

- 15. Use the goals identified in the individual adult's PCP as the ultimate measure of program effectiveness.
- 16. **Formalize QA processes** and implement on an ongoing basis. Use these to assess program effectiveness and to identify and implement improvement strategies.

Other Suggestions:

- 17. Develop ways to more systematically engage in the following areas on behalf of the adults with intellectual and developmental disabilities:
 - Financial Limitations
 - Guardianship
 - Housing

- Medical and Non-Medical Transportation
- Other Medicaid Benefits
- Post-Secondary Education



Community NOW! Expectations of Medicaid

Before the Community NOW! process began, Medicaid made a commitment to respond to each of the recommendations brought forward by the Workgroup. The following statement outlines Community NOW!'s expectations for this response.

We, as Community NOW!, have come together over many months, and have given our time, our energy, and ourselves to put forward a series of recommendations to the Department of Health and Welfare, Division of Medicaid. As individuals with intellectual and developmental disabilities and family members, we have expert knowledge regarding the needs, wants, goals, dreams, and barriers experienced by adults using waiver services. We, along with valued providers and advocates, bring to the table our lived experiences with the current system of service and supports, and believe that our input, in the form of these recommendations, can help DHW to make significant and meaningful change in the type and quality of services provided moving forward

Many of us have had prior experiences providing input to DHW, but have found that this input was not adequately reflected in the solutions that were developed. With that in mind, we put forward the following list of expectations regarding the response we will receive from DHW from the recommendations put forth through this process.

- 1. Provide clear information regarding the decision-making process:
 - a. Who, by name, is making the decisions at the Department level regarding which of these recommendations will be implemented?
 - b. What are the criteria you will use to determine which recommendations will be implemented? What factors are considered when deciding which recommendations will not be implemented?
 - When decisions must be made beyond the Department level, what is the chain of decision-making? Clearly delineate what is necessary for recommendations to be implemented.
- 2. Provide a clear timeline for when we can expect an initial response to our recommendations. Include information on how that response will arrive (letter, scheduled meeting, etc.). Is there a point-person or persons that will be in contact with us? How can we best reach this person?
- 3. Provide an opportunity for additional conversation prior to final decision making.
 - a. Allow for clarification. Ensure plans for implementing any recommendations align with our intent.
 - b. Allow for the possibility to meet aims through alternative means. If DHW believes a recommendation is not possible, try to identify other possible solutions to address the underlying issue.
- 4. Provide a timeline for when we can expect a formal response to our recommendations.
- 5. A formal response should address and respond to each recommendation. This includes information regarding how and when this recommendation will be implemented, or why something cannot be implemented now, or at all. Responses to recommendations which will be implemented over a long-period should include information about, and timelines for, benchmarks so that we can see progress.

- 6. Provide information to others affected by impending changes:
 - a. How will the understanding of the purpose behind the implemented recommendations be shared and communicated with regional staff and providers?
 - b. Any communication that goes to support brokers and TSCs regarding these recommendations, and this process as a whole, should also be communicated directly with individuals and families who use services. This communication should be in plain language, and be available through alternative formats, such as video (if possible).
 - c. Explain what will be done to support TSCs and support brokers to have a good understanding of the upcoming changes and so they can share information effectively to help us plan accordingly.
 - d. How will Medicaid help to support understanding and buy-in across the state regarding the purpose behind these new services and/or changes to existing services?
 - e. Explain how everyone potentially affected by these changes will be kept in the loop. How will our recommendations be made publicly available? How will DHW's final response be made publicly available? Special attention should be given to providing this information to parents, providers, support staff, etc.
- 7. Address opportunities for ongoing collaboration:
 - a. Please outline how we can stay connected and involved in this process beyond development of these recommendations.
 - b. Provide information to us on how families and people with disabilities can be helpful in getting through the many layers of implementing some of these recommendations. What advocacy can we do outside of the Department to make sure our recommendations can be effectively implemented? Are there opportunities to influence other decision makers, specifically?
 - c. How will we be included in other parts of the changes that are being made, or are being contemplated around the *KW v. Armstrong* settlement agreement?
 - d. If there are major changes to Medicaid, will there be a process to include people with disabilities and families in the decision making?
- 8. Discuss the process for ongoing check-ins and ongoing quality assurance:
 - a. Please explain how Medicaid will work to maintain the original intent and structure of the changes contemplated by these recommendations.
 - b. Explain how Medicaid will be evaluating the implementation of all accepted recommendations to protect quality and avoid unintended consequences.
 - c. Identify the quality assurance mechanism that will be put in place.
- 9. We understand that Person-Centered Planning is next on the docket. In our experience, the current understanding of Person-Centered Planning varies throughout the state, and we do not have a shared understanding of the definition. How will the differences between what we do now and what the federal requirements demand be addressed, and what is the plan for bridging that gap?
- 10. Please explain how the new assessment tool will provide transparency when budgets change. In our experience, there are currently inconsistencies, inequities, and a lack of clear information.

Quality of Life Measures

Quality of life is reflected by the degree to which one experiences the following:

- Being respected
- Having choices
- Being employed
- Having flexibility
- Having control
- Having community or being part of the community
- Being happy/having fun
- Being connected, loved and valued

Many things can impact the ability of adults with I/DD to experience a life with these elements; however, three interdependent aspects of a service system can have a particularly significant impact on this ability.

By developing a system that is Person-Centered (green), that fosters meaningful access to the community with support (blue), and that engages in ongoing quality assurance (pink), Medicaid has the greatest likelihood of helping adults with I/DD to achieve a quality life.





Recommendations

According to participants in Community NOW!, the true goal of services and supports is to help adults with I/DD achieve a quality life, as they define it. With this in mind, recommendations offered to the Division of Medicaid fall into three categories:



Generating a truly person-centered system



Fostering meaningful access to the community and appropriate support in response to the adult's desires, interest, and needs



Creating and implementing ongoing quality assurance processes

Sixteen of the recommendations to Medicaid fall within these three categories. Each recommendation comes with a series of characteristics, strategies, or specific ideas to help Medicaid as they plan their next steps. The final recommendation is about ways the Department and others can help adults with I/DD in other areas that impact their ability to get the lives they want. All recommendations and guidance have been created, vetted, and approved by Community NOW!

Each recommendation comes directly from experiences and stories shared by adults with I/DD and their families during the Community NOW! process. A small sample of these stories, which highlight both positive experiences and obstacles, is included at the beginning of each recommendation section. A list of just some of the barriers adults and families identified is also included to help provide additional context for the recommendations that follow.





1. Generating a Truly Person-Centered System

"I have programs I don't like. I don't say anything since I don't like conflict, so I just go with the flow. I'd rather not have programs and be able to do what I want, when I want, instead of having to do this, at this time."



Stories and experiences:

"When I would ask my son what he was going to do that day he would say, 'Work on goals.' He never specified what his 'goals' were, but it was clear it was something that he felt was required and he did not want to do. When he moved to self-direction, we brought together a group and did a full person-centered plan. We talked about what he liked, what he didn't like, how he communicated best, everything. We wrote a plan based on what he actually wants to do and he can go out with his support workers and do those things. They are 'his goals' but he doesn't say that anymore. When we go out as a family people I don't even know will come up to him and say hello. There are a couple of places in town that, when he walks in, employees greet him by name and ask if he'd like his regular order. He has become a part of his community all on his own, with support."

"At the DDA, the group decides what activity in the community they will be doing in a given day. My son doesn't use words to communicate so his preference or choices about what activity they are going to do never gets taken into consideration. He uses signs that are unique to him but very few of the staff there know him well enough to know what he's saying. Lately when they go somewhere he doesn't want to go he just sits down on the ground and refuses to get up. Now they say he has to come to the program one less day a week because he's too much to handle and they don't have enough staff."

"Because I used to live in an ICF, I know my rights. But one day a staff at the DDA got mad and tore down the list of rights that were posted on the wall. He said we didn't have any rights but I knew better and went to his boss and told. No one else knew they could do that."

"I was assaulted by my roommate in supported living. He tried to push me down the stairs and he pulled a knife on me. Staff was always there, because he was on intense support, but the staff didn't believe me and they didn't report it. I was fearful for my safety the whole time I lived there. I stayed out of the house from 9am to 9pm and stayed in my room when I was home because I didn't know when he would attack. Roommates have also violated my privacy, come into my room when I asked them not to, and stolen my furniture."

Barriers:

- People in the field do not have a clear understanding of the differences between an Individual Service Plan (ISP) and a true Person-Centered Plan (PCP).
- Many adults aren't given the opportunity to have a PCP.
- The existing service system currently uses Person-Centered Planning (PCP) loosely as a catch-all term for various kinds of support planning.
- Adults with I/DD do not have adequate opportunities or supports to do the things that inspire and motivate them to achieve their goals.
- Programs often have no connection to the person's own identified goals.
- The existing policy is that all services must be directly tied to a need or deficit that is identified in the assessment.
- Behavior is viewed as something to be managed or mitigated rather than as a means of communication.
- Adults regularly have no choice regarding who they share their home with. Roommate matches are made based on availability and provider needs, rather than compatibility.
- Adults with I/DD often do not know what rights they have related to the services they receive.
- Even when adults with intellectual disabilities and their family members know the rights they have, there can be difficulty and fear related to exercising those rights.

Recommendations for generating a truly person-centered system:

- 1. Establish a quality **Person-Centered Planning** (PCP) process based on PCP best practice. PCP is the foundation upon which a meaningful support system is generated, and outcomes can be measurably achieved. PCP is a process that looks at an adult's whole life before any service planning takes place. In order to do PCP correctly, the entire planning processes, schedule, and mindset must be restructured. While an ICDD/Medicaid Work Group is planned to generate specifics about Idaho's PCP structure during fall/winter 2017, Community NOW! participants identified the following characteristics they expect that structure to accommodate:
 - a. The adult leads the process. No exceptions. "Leading" will look different for different people.
 - b. Each adult has the accommodations he or she needs to lead.
 - c. A PCP-trained specialist, of the adult's choosing, supports the adult to prepare to lead their meeting. Supports include the following: having discussion with the adult about the process and the adult's preferences before the meeting; identifying and preparing the people in the person's circle of support to meaningfully engage in the PCP process, helping to coordinate and facilitate the meeting, and documenting the discussion and results of the meeting.
 - d. The process focuses on identifying the adult's strengths, gifts, interests, dreams and life goals (including their desired employment) instead of listing their deficits or limitations. PCP focuses on leveraging an adult's strengths and abilities to achieve these goals.
 - e. The process features a dedicated and meaningful discussion of rights.
 - f. There are built-in opportunities for checking in on milestones to ensure that progress toward goals is happening with an understanding that some goals are ongoing.
 - g. Materials created as a result of the meeting are provided in accessible formats to help the adult share information and knowledge with people providing their support. There is an expectation that support staff will engage in this information sharing process.
 - h. The PCP process will include an opportunity to discuss the development of relationships within typical community settings, should the adult so choose.
 - PCP-specialists will ask the adult prior to the PCP if they would like to discuss ways and opportunities to have safe discussions about issues related to relationships during their PCP.
- 2. Use the **Individual Service Plan** (ISP) and **Support and Spending Plan** (SSP) to identify and document how supports (paid and unpaid) are used to achieve the life goals identified in the PCP. The ISP and SSP will feature the following characteristics:

- a. The plan connects the life goals identified by the adult in the PCP process, including employment (and how employment may affect disability benefits).
- b. The plan will identify both paid and unpaid supports that are relevant to the adult's goals. Care must be taken to ensure the paid supports don't drive the plan. Life goals, as outlined in the PCP, should drive the plan. This includes giving TSCs the flexibility to pursue opportunities, including activities outside of paid supports, that may support a person's life goal.
- c. Objectives within a plan tie to a goal in a way that is meaningful to the person. If the objective proves ineffective in achieving the goal, a new objective will take its place.
- d. The plan provides evidence that the adult will have the opportunity to practice and share their identified strengths.
- e. Limit skill building requirements to skills the adult wishes to obtain.
- f. The plan and related information is provided to the adult in a way that is understandable to them. This includes providing access to the full list of available Medicaid waiver services to allow for fully-informed choice.
- g. Make supports available to aid adults in pursing academic and life-enhancing opportunities.
- h. Risk is understood and addressed as a normal part of a person's life and learning experience. Limitations based on risk are narrowly defined and regularly reevaluated, with an understanding that people can learn and grow, impacting the scope of those limitations.
- i. The PCP meeting includes a dedicated and meaningful discussion of rights.
- j. Quality assurance is tied to the adult's personal goals. Focus is on determining that the services and supports are helping the person achieve what is important to them.
- 3. Establish an early and ongoing expectation and process to understand, develop, and support the adult's most effective and preferred communication method(s). Attention to communication must start at the earliest possible age and be integrated and maintained within any planning, support, or service provided. Techniques include the following:
 - a. Provide adults the ability to try different methods of communication. Possible need for a different communication, including assistive technology, must be assessed. If a need exists, the ISP/SSP should reflect and address that need.
 - b. Recognize that all behavior is communication. Assist providers and those who work with adults to understand this fact and find ways to foster effective communication with the adults they support.
 - c. Service provision should include paid staff time to review and understand the person's history and communication. Increase capacity for effective communication through training programs, quality assurance processes, and the development and sharing of family and adult expertise of the adult's story.

- d. Assist providers in understanding the use of positive behavioral intervention strategies.
- e. Make interpreter services a paid support available in any setting.
- f. Coordinate a way for communication devices to follow the person from school into adulthood, even when the communication devices were paid for in the school setting.
- 4. Take a proactive role in creating and fostering a culture where rights are known, understood, exercised, and respected. This culture should include an emphasis on understanding and using supported decision-making processes to help adults make informed choices. Strategies include the following:
 - a. Provide training on the rights of adults with I/DD to adults, advocates, guardians, educators, and providers. Highlight times of transition (moving from the children's DD program into the adult DD program, moving from another state, first signing up for DD services, etc.) and life changes (such as when someone initiates guardianship proceedings, when a guardian changes or dies, when an adult experiences significant changes in services, etc.). Rights training should specifically cover what exercising rights looks like in practice in a variety of possible settings.
 - b. Find ways for self-advocates to act as peer trainers regarding how to advocate for rights.
 - c. Make rights information more accessible (video, infographics, screen readers, etc.). Start the rights discussion within the PCP process, continue in the plan development process, and assess through quality assurance.
 - d. Ensure that adults know who to contact, and how, when rights are being violated (e.g. flow chart).
 - e. Establish a myth-busting process (like a hotline to DHW) where adults can ask questions about rules, rights, and restrictions, and report when they feel their rights are not being respected.
 - f. Provide comprehensive training for support staff on the rights of adults, and conduct quality assurance to measure understanding of those rights.
 - g. Develop a standardized process for adults to read, or be read, what staff write about them, making sure information is in accessible formats so that this right can be meaningfully exercised. Whenever possible, staff notes should be written collaboratively with the adult receiving services.
 - h. Develop ways to measure whether rights are being respected. Potential ways could include: asking adults with I/DD, measuring compliance with the HCBS rules, etc.

- 5. **Emphasize and enforce HCBS rules** related to adults determining where they live, who they live with, and who provides their support. Specific strategies to meet the intent of these rules include the following:
 - a. Develop standardized processes that involve adults and family members reviewing and selecting potential roommates, selecting living settings, and interviewing and selecting staff.
 - b. Require that adults and families are informed as soon as possible about upcoming staffing changes (when staff leave, when new staff are hired, and when temporary staff will be used).
 - c. Provide or require that adults and family members have access to the same orientation training as direct staff to aid in keeping staff accountable.
 - d. Make adults, and their guardians as appropriate, primary participants in the staff evaluation process.
 - e. Create a regional infrastructure to aid adults using self-direction in identifying and connecting with qualified providers who may be able to support additional people.



2. Fostering Meaningful Access to the Community and Appropriate Support in Response to Adult's Desires, Interests, and Needs



About services: "It's hard to know what is going to work when all that you know is what you are getting right now."

About staff: "You can have all the skills in the world, but you can't do the job without the heart."



Stories and experiences:

"My son loves to be around people, he is very social and would love a job where he is around people all the time. He goes to a workshop five days a week and has friends there. He would like a job in the community but the provider said they couldn't find him one since he doesn't communicate so well. He would love to do more group activities in the community, more Special Olympics, more parties. Now that it is just us, I can't always help him get to those things even when they happen so he spends a lot of time watching TV and playing videogames."

"I am limited in the things I can do because of where we live. There isn't a day program or ways for me to find friends. There aren't a lot of things available in our little town and I can't get to the things I want to do, like volunteering at the care center or animal shelter in the nearest larger town, because only local miles count. My parents sometimes pay my aides for the miles to get to there but they can't always do that."

"Before I had my job, I didn't know what I was living for. I was depressed, suicidal. I needed something in my life. They were about to shut down the friendship club because it was too dirty. I knew that was something I could do. I volunteered a lot of hours cleaning it up and even won an award. I went to my favorite store and told the boss what I did for the club and he said, "You're hired." Now I work two days a week with a job coach that helps me. My favorite part is getting up in the morning and going to do the day."

"When staff first start, they read all the books, see what all the books say, but don't talk to me at all. I wish my roommate and I got to interview them first, see what they are all about, so we can decide if they are a good fit first. Then when we are finally getting attached to someone the agency pulls them away but don't tell us why."

"We transitioned our daughter from an ICF into Res Hab about a year ago and it was a disaster. I had no idea what we were getting into. We had to move quickly due to a safety issue and the transition process itself, along with some major problems within the supported living setting we moved to, created more safety concerns than we were already facing. Staff didn't provide the structure that she was used to and needed, their focus was on sitting on their phones and taking smoke breaks. Had we known how terrible the transition process would be we would not have moved. Supported Living still would have been in her future, but we would have done a lot more to be ready for a smooth transition and to find the right fit in a provider."

"An adult that I know was fairly independent but had to go into the hospital to have a hip replaced. No one from the hospital coordinated with or notified his case manager or support provider that he had been in the hospital so when he returned to his third-floor apartment there was no support in place because no one was informed."

Barriers:

- The DDA is the only place where some adults with I/DD can obtain support to access the community or see their friends.
- Almost all DDA community support is provided in groups. Groups are rarely built based on interest areas, so consensus on preferred activities or destinations is difficult.

- Time, distance, and programmatic requirements also limit the community locations and activities accessed during DDA hours.
- Adults with I/DD are often given minimal, if any, information, on how to find, develop, and maintain healthy relationships (romantic or otherwise).
- Transportation is a significant barrier to many community activities, including work.
- There is inadequate training and support for the unique needs of adults with I/DD and mental health support needs.
- Obtaining employment is often based on the connections you have. Many adults with I/DD have very narrow social networks to pull from.
- Employment supports, provided in the workplace, are often poorly-matched to the person's specific needs. This could be a failure by providers to appropriately fade supports, a propensity to do the job for the person, or failing to help the person build their own connections with co-workers.
- Good staff may have innate qualities that make them better at their jobs than others. These qualities cannot always be taught or measured, and it can be difficult to compensate for those traits.
- There is high staff turnover. Staff receive training and leave. Particularly for adults with complex medical or behavioral support needs, turnover is more than an inconvenience-- it is a safety issue.
- For adults who use means other than words to communicate, the process of building understanding with new staff can be lengthy and frustrating. In the interim, these adults face not being understood.
- Many adults with I/DD have aging family caregivers and have not had conversations about what happens after their current caregiver is gone.
- Information about transitions in people's services is hard to obtain. Even when information is available, the process is disjointed, and can leave people without adequate support.
- The various systems that impact adults with I/DD often fail to coordinate and leave adults unable to determine where they should go for the support they are looking for, or confused about why the available supports do not align.

Recommendations for fostering meaningful access to the community:

- 6. Create a non-medical service model to support adults with I/DD to meet their needs and explore their interests in their communities over their lifetimes. Provide flexibility within the service array so services can be matched to meet those needs. The following strategies support such a model:
 - a. Provide additional flexibility for people to do activities in the community. This should include additional individual adult (versus group) support hours, support outside of set-DDA hours, etc.

- b. Alter existing mileage allowance limits to foster flexibility on a case-by-case basis, particularly for rural areas, to allow for greater community access. An adult's community may be 30 miles away or more depending on where they live.
- c. Find ways to foster additional opportunities for adults to gather with each other organically in their communities. For many, DDAs provide the only opportunity to see friends and be social.
- d. Create and promote services that expand community connections outside of paid supports, like a service which identifies others in the community who have similar interests, not just disability-specific. Services might include:
 - i. Introducing adults and providers to the variety of community resources, activities, and opportunities available.
 - ii. Identifying ways to modify existing opportunities to make them more accessible to adults using services.
 - iii. Gathering information.
 - iv. Resource pooling.
- e. Support the development of peer groups for adults to discuss issues around relationships with each other.
- f. Obtain and/or create and make available a curriculum specifically for adults to learn about creating and maintaining healthy relationships.
- g. Include mechanisms to encourage coordination across provider agencies that help adults connect with other adults using services.

7. Provide services that appropriately support adults' overall health, including mental health and substance use.

- a. Provide adults the option to have a paid support person of their choice available to them while in a medical hospital.
- b. Provide a mechanism to ensure the effective transfer of information between the adult, service providers, direct care staff, and medical or mental health professionals.
- c. Provide access to substance use treatment.
- d. Increase education and understanding by adults with I/DD, families, guardians, targeted service coordinators, support brokers, and plan developers about what types of medical needs (such as glasses, hearing aides, AFOS, etc.) can and should be appropriately paid for through an adult's budget versus via their medical card. This includes increasing understanding of the differences between specialized medical equipment, durable medical equipment, and assistive technology.
- e. Increase integration between the Medicaid waiver services team and durable medical equipment team to clarify and identify how to best support adults with I/DD in getting their medical needs met. [added by Community Now! subgroups]

- 8. Provide services that appropriately meet the needs of adults with dual diagnosis (mental health and I/DD)
 - a. Provide adults the option to have a paid support person of their choice with them when in a psychiatric hospital.
 - b. Find a way to adjust traditional practices, such as one-hour sessions with mental health counselors, to accommodate the communication needs of adults, such as providing for two-hour sessions.
 - c. Restore Community-Based Rehabilitation Services (CBRS) and bridge the gap between CBRS and traditional services.
 - d. Make therapeutic mental health interventions an acceptable service.
 - e. Create capacity of providers to serve adults with a dual diagnosis through the National Association of Dual Diagnosis (NADD) certified provider training.
 - f. Create capacity for direct service providers to provide trauma-informed care.
 - g. Generate a systemic method to transfer mental health information (treatment modalities, medication, coping skills) to appropriate staff.
 - h. Assist mental health providers to obtain skills to effectively communicate with adults with developmental disabilities who may have significant cognitive disabilities or communication impairments.
 - i. Eliminate the practice of authorizing Mental Health Supports based on IQ Score.
- 9. **Include pre-vocational, career planning, and individual supported employment services** (as described in the Idaho Employment First Consortium (IEFC) recommendations [*Appendix A*]) **in the Medicaid benefits package** to support the adult to gain and maintain his or her preferred job in the community at, or above, the prevailing wage. Strategies to achieve this outcome include the following:
 - a. Provide support, learning and work experiences where the adult can develop general strengths and build the skills necessary to perform work. These services should be focused and time-limited.
 - b. Help an adult identify a career direction and develop a plan for achieving competitive, integrated, desired employment. The outcome of this service is documentation of the adult's career objectives and a career plan used to guide additional employment support. Support includes the following: planning time and support for experiential learning opportunities and appropriate exploration activities; support to engage in assessment and discovery processes to learn about career options; and benefits planning and consultation.
 - c. Provide ongoing assistance to adults who, because of their disabilities, need intensive on-going support to obtain and maintain a job that meets their personal and career goals. This can include customized or self-employment support.

- d. Support the addition of opportunities in the adult service system for short-term job experiences.
- e. Promote understanding that the primary function of a job coach is to understand the adult's communication methods, assist the adult in building relationships in work settings, and phase-out their support as appropriate.
- f. Establish quality assurance measures related to job coaching to provide additional focus on success on the job, and appropriate fading of supports.
- g. Establish state-required training that meets ACRE certification for employment support professionals providing career planning and individualized supported employment services. Include nationally identified certification (see detail of IEFC recommendations [Appendix A]).
- 10. Put mechanisms in place that help adults to find, support, and keep **competent**, **consistent**, **capable**, **and quality staff**. Potential strategies include the following:
 - a. Support ways for direct support staff to have a competitive wage, benefits, adequate training, and career growth within the role of direct support. Develop mechanisms to make this possible, including assurances that higher rates are passed on by way of compensation to the direct care provider.
 - b. Create mechanisms that help staff succeed. Staff must have important basic knowledge from the beginning about the person they will be supporting. Create opportunities and expectations for information about the person's communication style, areas of support needs, and preferences to be shared with new staff immediately. Information could be shared by the person receiving support themselves, family, a trusted staff person, etc.
 - c. Increase provider qualifications requirements for employment support professionals to include specific training and certification aligned with best practice and national standards.
 - d. Create ways for adults and family members to have direct influence on incentivizing the long-term and continued employment of quality staff.
- 11. Implement a tiered, linguistically and culturally appropriate, training process that is standardized and person-specific, to ensure that all staff draws from best practice, experience, and knowledge. Strategies for generating such a process include the following:

Standardized training:

 Adopt a standardized training curriculum for direct support professionals. One option would be training from the National Association of Direct Support Professionals (NADSP) or other existing programs. Additional, standardized, Idaho-specific training should be provided by Medicaid.

- b. Support the development of a training curriculum for staff to be provided by paid self-advocates. This could be specific to the concepts of self-direction, rights, thinking outside of the box when providing support, appropriate language, etc.
- c. Encourage and facilitate use of passive training techniques for staff. For example, fridge magnets with rights information, videos with adults talking about rights, etc., opportunities presented within typical daily activities to engage in conversation about rights that make the right relevant.
- d. Require additional education and training for Support Brokers and Targeted Service Coordinators on how to be more effective independent advocates.
- e. Make available additional and more wide-ranging training opportunities for CFH providers, Supported Living providers, direct care staff, and providers serving adults through the self-direction program.
- f. Make training available specifically geared to the competencies needed by employment support providers. This training should include the appropriate methods to fade employment supports over time.
- g. Encourage mentoring opportunities between agencies regarding best practices for supporting adults with I/DD.
- h. Provide training in, and perpetuate the use of, person-first language in all parts of the delivery system.

Person-Specific training:

- i. Encourage the person receiving services, and their friends and/or family members, to be integral in the process of educating staff. This should not be limited to those who select self-direction.
- j. Work alongside adults receiving supports to develop staff training curriculums based on the person's specific support needs and preferences.
- k. On-going and specific training on the needs of each adult should be required and supported.
- I. Train staff to know that they are working for the person receiving support, and expect staff to become experts in asking their permission and respecting their responses.
- m. Measure the effectiveness of the person-specific training that staff receive on a regular basis (providing for a shortened feedback loop to maximize effectiveness). Measures, such as testing over time, should involve the person being served whenever possible.
- 12. Address and resolve issues associated with transitions in all phases of life. Such transitions include: the time between 16 and 21, changes in living situations, changes in levels or types of support (nursing homes, hospital, ICF/IDD, community), moving from children's to adult services, transitions on and off of services, change of guardianship, the death of a family member, etc. Strategies include the following:

- a. Create a position, or positions, for someone with specific expertise on the topic of making transitions. This "systems navigator" would be responsible for helping adults and families navigate the process of making these changes.
- b. Have information about the availability of transition support and expertise available to the people who support the adult.
- c. Allow and educate adults and family members about substitute care so the adult can become more accustomed to receiving support from someone other than mom and dad and to test possible alternative support settings for the future.
- d. Create the ability for adults to test or try out new services, be it a new living setting or a new day support provider, before having to commit to transitioning into that new service or setting long-term.
- e. Create an ability for adults to transition into retirement from certain types of programming, if they so choose. Depending on the adult, this retirement may occur before the age of 65.
- f. Create a step-down process for adults transitioning off of services as a whole. This may occur due to a change in eligibility or by choice, but it should not be a cliff.
- g. Provide tools for adults, family members and guardians to discuss, understand and facilitate end-of-life planning, including:
 - i. A tool to help families have end-of-life conversations with adult sons and daughters.
 - ii. A template or checklist to help families think and plan for all the things to consider.
 - iii. Resources and training about what happens with death and what mechanisms can facilitate changes that occur with death.
- 13. Provide a mechanism to ensure that information about an adult follows them through systems, providers, and services in a manner that is used on the adult's behalf. Possible techniques include:
 - a. Support providers in obtaining comprehensive information about the person they are supporting which can be shared with those people (such as medical and mental health professionals) who help to facilitate health, safety, and wellbeing.
 - b. Require agreements around information sharing between staff and family and/or guardians to be memorialized and enforced. These agreements will vary based on the needs and desires of the adult with I/DD and their guardians and/or chosen support people.
 - c. Require the creation and maintenance of historic living documents, including video and digitized recordings when appropriate, so that those who provide support have an in-depth understanding of the person's needs, even when

- family are no longer available. Create incentives for staff to reference these documents with regularity.
- d. Support the development of cooperatives of support for adults with I/DD. This will ensure that understanding of the person is enhanced, and some responsibility for checking in on their quality of life after family is gone will be maintained.
- e. Consider the possibility of a shared, comprehensive database to collect, house, and safely share historical and ongoing information gathering.
- 14. Provide consistent supports for adults and families through **coordination and communication across all relevant state agencies and schools**. The following strategies will help such coordination:
 - a. For people ages 3-21, Medicaid, Public Schools, and Vocational Rehabilitation (VR) need to clarify and communicate roles, responsibilities, and processes.
 - b. Streamline processes across agencies (Medicaid, Public Schools, VR, Housing, Transportation) so it is easier to understand and access services.
 - c. Ensure that school-based Medicaid-reimbursable services integrate the mission of supporting adults to access community employment.
 - d. Create and implement an effective collaboration between VR and Medicaid to ensure continuity of support in preparing for employment and in the workforce. Suggestions include:
 - i. Coordinate and stay current on activities, programs, services, outreach, etc., and provide information to stakeholders and employers.
 - ii. Collaboratively address employment obstacles as they arise.
 - iii. Make sure that all pertinent information about the adult follows them through the employment process, including between agencies. (For example: information from the targeted service coordinator must be transferred to VR, VR's information must follow to long-term supported employment services, etc.)
 - iv. Create a data gathering/reporting process so that employment outcomes can be reported to the public. (IEFC has developed specific data points across systems and recommendations on how this could be implemented.)

3. Creating and Implementing Ongoing Quality Assurance Processes



"If something isn't written in a program and specifically spelled out, it probably isn't going to happen."

Stories and experiences:

"I moved back to Idaho to oversee the care of my family member. There is no one with the same vested interest I have in his care. He is lucky to not have barriers regarding transportation or finances but staff lack the willingness and creativity to help him explore and discover things that he may enjoy. If I weren't here the outcome wouldn't be good. Staff only take him out if I suggest it and am available to meet them, they are waiting for me to make a suggestion of an activity."

"My daughter would prefer to do less. Due to her seizures which are triggered by weather and other environmental factors she would often prefer to stay home. However, because of the need to document completion of all of her programs she sometimes can't stay home even when she really wants to."

"I had to go in and get some medical testing done. I called to get the results and the nurse said she would call me back. Instead of calling me they called my mother who lives out of state. I was terrified that something was really wrong since they only had her number in case of an emergency, I am my own guardian and was waiting for my test results. This is not okay."

Barriers:

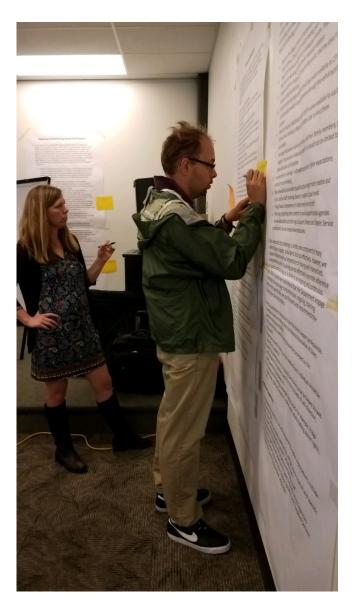
- Quality has a different meaning for each person, making it difficult to measure in a systematic way.
- Some aspects of quality are difficult to describe. "I know it when I see it."
- Lack of visual examples of what quality service delivery looks like.
- Existing quality assurance is reliant on paperwork reviews which does not always clearly indicate the quality of support the person is receiving.
- A general lack of opportunities for those performing quality assurance to have face-to-face conversations with adults receiving those services.
- Few, if any, opportunities for Medicaid policymakers to observe services in action.
- Conflict between wanting to give people notice of upcoming quality assurance in order to respect people's home and privacy and the need to have authentic checks on the adult's wellbeing.

- Family often provides day-to-day quality assurance for adults with I/DD. Unclear how knowledge of the individual, person-specific staff training, etc. will continue if family members are gone.
- Expectations of, and direction for, service delivery can be inconsistent region to region.

Recommendations for creating and implementing ongoing quality assurances processes:

- 15. Use the goals identified in the individual adult's PCP as the ultimate measure of program effectiveness. Strategies include the following:
 - a. Implement the best practice PCP process (as initiated in these recommendations) and review with the adult on at least an annual basis to evaluate its effectiveness.
 - b. Provide information related to quality assurance interviews/activities to adults ahead of time, allowing the adult time to process his or her answers.
 - c. Add quality assurance activities, including interviews with adults, to be conducted by independent, neutral third parties. Include the opportunity for adults to have sufficient interaction with the interviewer to feel comfortable sharing their experiences with them.
 - d. Include additional data points in the employment section of adult's plan to be considered during the plan review process.
- 16. **Formalize QA processes**, and implement on an ongoing basis. Use these to assess program effectiveness, and to identify and implement improvement strategies. Strategies include:
 - a. Continue the use of the existing QA Committee for Self-Direction.
 - b. Establish a duplicate QA Committee for traditional services, soliciting feedback from adults on at least a quarterly basis about program effectiveness.
 - c. Conduct regional outreach meetings with adults and family members on at least a quarterly basis to solicit feedback about program effectiveness and obtain knowledge of regional differences. Include opportunities to meet outside regular business hours.
 - d. Develop better mechanisms to ensure that staffing ratios are appropriate for adults being served in both residential and community settings.
 - e. Identify key places in people's lives where there is risk for control to be lost (especially transition phases). Develop processes and safeguards to limit those losses
 - f. Provide more opportunities for adults to learn and practice self-advocacy skills. Create opportunities for adults to speak up when they want their voice to be heard.

- g. Work to develop an emergent response system to address health and safety concerns as they arise. This could include provision of emergency transportation for adults, emergency respite for families, emergency staffing for those receiving hourly services, etc.
- h. Create a Medicaid DD Program staff position to be a liaison to the DD Community a sustained position with statewide travel included so that this staff is supported to have ongoing conversations with adults and families related to services and quality assurance.
- i. Include employment services quality assurance measures in new and existing service and system evaluation activities.
- j. QA and evaluation of services based on employment outcomes in the Adult Services Outcome Review (ASOR).
- k. Include service and employment outcomes in the provider reporting process.
- I. Implement rigorous quality assurance measures that include collecting data on employment outcomes of adults receiving employment support services.



4. Other Issues That Affect the Ability of Adults with I/DD to Obtain the Lives They Want in the Community

During conversations with the full Community NOW! Group, the three workgroups, and participants of the regional listening tour, a variety of issues came up that fall outside of the DD Bureau's scope. Many of these issues, however, have a significant impact on the ability of adults with I/DD to live the lives they want in their communities, and can limit their ability to meaningfully use Waiver services and supports. The Department of Health and Welfare has the ability to advocate on behalf of adults with I/DD in areas that would typically be seen as being outside of their purview. As one adult in Pocatello noted, "Medicaid doesn't need to put people in boxes. Medicaid needs to be the biggest one to advocate for us getting what we need."

17. We recommend, where appropriate, that the Department, other state agencies, and advocates develop ways to more systematically engage in the following areas on behalf of adults with intellectual and developmental disabilities:

Financial Limitations:

Many of the adults participating in Community NOW! live on very limited incomes. Many adults expressed an interest in participating in community events and activities that have a financial cost associated with them. Furthermore, because most adults are expected to pay the entrance fee for their support provider as well, this becomes even more of a significant limitation for accessing community. Support providers in some circumstances feel that they should pay their own entrance fees, but find that it is not financially feasible for them to do so. Suggestions were voiced that included providers and advocates reaching out to local establishments to try and obtain reduced entrance fees for service recipients and/or free entrance for those providing support. Once established, they could share information about participating establishments with adults and other providers to help expand the array of community activities available. Legal research on this topic may also be warranted, as requirements to allow support providers entrance free of charge may exist.

Guardianship:

Guardianship is a reality in the lives of many adults with I/DD. Concerns were voiced that at times full guardianship is sought and obtained when it is not necessary. Some adults shared positive experiences with guardians, identifying guardians as trusted advocates on their behalf. Others, however, have found that guardianship creates major barriers in exercising choice. One adult described experiences where without express permission from their guardian, which was almost never attainable due to a lack of communication, they were limited from doing activities in their community.

Another example came out during regional listening sessions where an adult was removed from the certified family home they had been happy in for many years, based on the decision of a public guardian who had never met, or spoken to, the adult. It was only when a friend was able to donate the cost of a private attorney that the guardianship transferred to a family member who supported the adult moving back to their previous home. We ask that the Department and advocates support development of methods to implement supported decision making within the guardianship context.

Housing:

A lack of affordable, accessible, housing is a barrier for adults throughout the state. One adult described having to continue living somewhere with rising rent that wasn't affordable because it was the only accessible place they could find. Urban areas can offer more options for quality staff and the most opportunity for community activities; however, living in these areas is very expensive. Living in more rural areas may provide more affordable housing; however, the lack of available transportation supports (described below) means that living in these areas can make accessing the community more difficult.

The lack of affordable accessible housing has also created a situation where those receiving services aren't able to fully exercise their rights. Providers often control and influence the available affordable housing (with homes being owned by a relative or friend of the provider, the provider rents the apartment for the adult, etc.). When a provider has influence over someone's home, and other housing options are not available, it can make it difficult for the adult to change providers or truly choose who they live with.

The Department, other state agencies, and advocates can aid in addressing housing issues by acting as liaison between adults with I/DD and landlords. Medicaid could also consider allowing home modifications even when the adult using services does not own the home, perhaps with a commitment to rent to someone receiving waiver services for a certain term of years.

Medical and Non-Medical Transportation:

The current mileage restrictions for non-medical transport was brought up by many adults and families, particularly in rural areas. Adults who live in rural parts of the state reported needing to travel upwards of 30 miles each way to access their nearest community resources. While some families identified being able to supplement the mileage reimbursement to providers out of their own pocket, those without that ability are limited to 1,800 miles a year, which can have the effect of limiting community access.

Transportation was also identified as one of the major barriers related to employment. Adults reported being unable to take or keep jobs because there was no public transportation available near the workplace, or they were given shifts when public transportation was not available. In most areas of the state, public transportation is not available at all. Family members identified that in order to support an adult with I/DD to have and maintain a job, they had to be available to meet all transportation needs. While some providers do offer transportation support related to employment, the need for ongoing support to get to and from work made some adults fearful of fading support even though they felt ready to do their jobs independently. Identifying ways to meet employment-related transportation needs is one way the Department and other advocates can help to increase the number of adults with I/DD with community employment.

Concerns with the medical transportation contractor were widely reported. Because of the way the contractor is administering the services, many adults experienced a change from having local, consistent, drivers who knew them well, to drivers who were constantly changing and knew little or nothing about adults with I/DD. Dispatch was also cited as a problem due to inconsistencies between the caller's request and the outcome of the ride itself. One person identified losing their medical provider due to being dropped off late for their appointments on too many occasions while another conveyed a circumstance where someone who required supervision to remain safe was dropped off at their DDA before it was open, and while the doors were still locked. A parent expressed concern about the ineffective use of state resources when their adult child had to have a specialized vehicle sent to North Idaho from Boise in order to be transported for medical appointments with a reported cost of thousands of dollars per trip.

Other Medicaid Benefits:

During the listening sessions, many adults and family members expressed concerns regarding Medicaid benefits outside of waiver services. Medicaid's failure to pay for glasses was identified as a real hardship for some, with one adult relaying that their certified family home provider paid for his glasses out of their pocket since he couldn't see without them. Dental care was also a major issue for many in these sessions. The minimal amount of dental care that is authorized by Medicaid was discussed, as was the quality of care. Several families mentioned that they avoid dentists that take Medicaid in some places because they feel the dentists simply want to "pull teeth," rather than correct issues. When people were willing to see dentists that accept Medicaid, the extreme distance that those in rural areas have to travel was described as problematic. One parent questioned why Medicaid couldn't simply provide her with the amount they were willing to pay for dental care and she, in turn, could provide proof that she used those funds, alongside supplemental funds, to access a local dentist.

Other family members identified that the quality of the adult briefs Medicaid would cover was so poor that it acted as a barrier for their loved one to access the community for fear they would leak. Again, families inquired why Medicaid did not allow them to purchase higher quality briefs and reimburse the family the amount Medicaid was willing to pay. Other medical equipment such as bath chairs, etc. were also discussed. In general, adults and families felt that if Medicaid would simply allow the family to pay the difference for a superior product, or would take into account the extended usability of a slightly more expensive piece of equipment, people's needs could be better met.

Post-Secondary Education:

A number of the adults that attended the regional listening sessions expressed great desire and interest in accessing continuing education and post high-school learning opportunities. Multiple adults expressed going to college as their biggest personal goal, but described an inability to continue formal learning due to only receiving a certificate of completion for high school and limits on the kind of activities someone can work on with a support provider or at the DDA. Several parents described their adult children losing reading, writing, and math skills they had acquired in school due to an inability to continue practicing those skills. Other adults identified a desire to participate in continuing education courses, but could find no resources to help pay for such classes and needed supports because they were not degree-seeking. One possible way that Medicaid could support adults in reaching these education goals is through use of a community connector as described in recommendation 6.d.



5. Conclusion

Many of the adults who participated in Community NOW! were initially fearful of this process. Some had worked in the past to make recommendations to Medicaid that they felt never went anywhere. Others had never talked so openly about what is working and not working in the services they receive. As one adult exclaimed during the final Community NOW! full group meeting, "I've never been in an environment where I could voice my opinion and my opinion has been heard!"

This process was also unique for the other stakeholders involved. Multiple providers noted that never before had they been asked to sit quietly back and just listen to the experiences of adults and families. While providers and Department staff were involved in developing this series of recommendations, their suggestions for improvements were made directly in response to the experience and stories they heard first-hand. As one workgroup member identified, "Adults and families had to be courageous to share so much of themselves in this process, Department staff and providers had to have the humility to accept the status of what people were experiencing and commit themselves to helping move forward."

The seventeen recommendations proposed by the Community NOW! Workgroup represent the culmination of thousands of hours of joint effort by adults with I/DD, their families, and other stakeholders. All members of this process took the mandate given to them seriously. As one self-advocate noted, "Not only the stakeholders but also, we, the people you serve, have a job. That job is moving Medicaid forward, not backward."

Each of these recommendations has a direct link back to the stories and experiences shared by adults with I/DD and their families. These stories outlined the barriers they have faced, and the ways they have seen success. Each recommendation can stand alone as a way to move forward in helping adults with I/DD to live the lives they want in their communities. However, when taken as a whole, these recommendations provide the blueprint for helping adults with I/DD to achieve the quality life outcomes they most desire, from the perspective of the people who know them best—adults and families themselves.

All members of Community NOW! understand that this series of recommendations is just the first step in a long process. They are excited and hopeful at the prospect of continuing to help the Division of Medicaid as they move down the path of making these recommendations a reality.



Appendix A



Idaho Employment First Consortium

Recommendations for Medicaid Employment Services

Employment First means that having a job in the community should be expected and planned for people with developmental, intellectual, and other disabilities. It is a national movement and many states have changed their policies, services, and systems to align with Employment First principles. The Idaho Council on Developmental Disabilities established the Idaho Employment First Consortium (IEFC) as part of its Employment First Initiative. This Consortium has been meeting over the past 4½ years to review national and state-specific data, Idaho policy and systems and develop recommendations for needed changes to agency services/procedures and state policies.

Because adults with disabilities who experience significant barriers to employment often need additional services and supports to gain and maintain integrated employment, the Consortium has determined that enhancements to the Idaho service system for adults with intellectual and developmental disabilities are necessary to ensure employment outcomes for Idahoans with disabilities.

The Consortium proposes expanding the choice of services that support employment, as allowed by the Center for Medicare and Medicaid Services (CMS), to encourage an effective and productive use of Idaho Medicaid service dollars towards the goal of employment and enable Idahoans with disabilities to become more independent, contributing members of their communities.

The Consortium also proposes the development of specific provider qualifications related to recognized core standards for the provision of employment support services by supervisors and direct support professionals. The Idaho Council on Developmental Disabilities and members of the Consortium are committed to supporting and facilitating a coordinated effort to identify provider qualifications and develop a standardized, state-approved training curriculum for related professionals.

In addition, the group proposes implementation of rigorous quality assurance measures that include collecting data on employment outcomes of individuals receiving employment support services.

The Idaho Employment First Consortium makes the following recommendations related to the implementation of employment support services under the Idaho Medicaid service system for adults with intellectual and developmental disabilities who are eligible under the 1915c HCBS DD waiver and the 1915i DD State Plan option.

Recommendations

- Add additional service options to the Idaho Medicaid benefits package.
- 2. Increase provider qualifications requirements to include specific training and certification aligned to best practice and national standards.
- 3. Improve the person-centered planning process by training service coordinators, support brokers, support personnel, participants, family members and other members of their circle of support to have the skills needed to:
 - a. Engage in an employment discussion with individuals to focus on consideration of a work goal. Help individuals (and circle of support) picture a different day for themselves with a variety of services that lead to an integrated employment outcome
 - b. Discuss how income from employment may affect the individual's disabilityrelated benefits
- 4. Include employment services quality assurance measures in new and existing service and system evaluation activities.
 - a. QA and evaluation of services based on employment outcomes in the Adult Services Outcome Review (ASOR)
 - b. Include additional data points in the employment section of the Individual Support Plan (ISP) to be considered during the plan review process.
 - c. Include service and employment outcomes in the provider reporting process.
- 5. Create a data gathering/reporting process so that employment outcomes can be reported to the public.
- 6. Engage in discussions with Vocational Rehabilitation to determine best process/protocol to enable the most effective use of both program's services and a smooth transition for the individual to ensure continuity of support in preparing for employment and in the workplace.

As Idaho moves forward to help individuals with disabilities become employed and contributing members of their community, the Consortium realizes that some policy and system changes to build capacity in our current service system may require a request for additional funds to make system enhancements possible. The Idaho Council on Developmental Disabilities and Consortium members are committed to working with policymakers to secure support for needed resources to make this more positive future a reality.

Depending on the work to be done, our efforts may include: facilitating workgroups to develop information, gather data, and develop recommendations; drafting and supporting legislation that, upon passage, would allow additional funds for fiscal impact of system enhancements; collaboratively drafting rules and program procedures; collaboratively developing educational materials/training for a variety of stakeholders related to the implementation of those rules and procedures; facilitating the development of interagency agreements as needed; and other strategies as identified.

Contact: Tracy Warren, Idaho Council on Developmental Disabilities Email – tracy.warren@icdd.idaho.gov Phone: 208-334-2178



Idaho Employment First Consortium

PREVOCATIONAL SERVICES

Description (following CMS Informational Bulletin 9-16-2011)

Services that provide learning and work experiences including volunteer work where the individual can develop general, non-job-task-specific strengths and skills that contribute to employability in paid employment in integrated community settings.

Services are provided over a defined period of time (not to exceed one year) and with specific outcomes to be achieved as determined by the individual and their planning team through an ongoing person-centered planning process.

Individuals receiving prevocational services must have a goal to become employed identified in their person-centered services and supports plan and the general habilitation activities must be designed to support such goals. Services are provided to individuals who, without these services, are not expected to join the general workforce within one year.

A person receiving prevocational services may pursue employment opportunities at any time to enter the general work force. Participation in prevocational services is not a prerequisite for receiving other supported employment services.

Prevocational services may be furnished in a variety of locations in the community in situations that enable the individual to transfer employment-related, but not job-task-specific skills learned to a work environment. This differs from general skill-building that may happen under developmental therapy and/or residential habilitation because of the employment-related focus of the skills learned.

Examples include but are not limited to:

Prevocational services include activities that are not primarily directed at teaching skills to perform a particular job, but at underlying habilitative goals that are associated with building skills necessary to perform work.

- Focused, time-limited instruction for general "soft skills" for employment including:
 - ability to communicate effectively with supervisors, coworkers and customers
 - generally accepted community workplace conduct and dress
 - o ability to follow directions
 - o ability to attend to tasks
 - workplace problem solving skills and strategies
 - o general workplace safety and mobility training
- Personal care/assistance can be a component of prevocational services

Transportation to and from the site where prevocational services are being furnished.

Prevocational Services - Provider Qualifications

People who provide this service need a level of expertise in employment-related communication and general workplace skills.

Completion of standardized training and assessment (to be identified) that documents core competencies and includes the following topics:

- person-centered planning process and practice
- instruction of soft skills development: communication support, ability to communicate
 effectively with supervisors, coworkers and customers; generally accepted community
 workplace conduct and dress; ability to follow directions; ability to attend to tasks; workplace
 problem solving skills and strategies; general workplace safety and mobility training
 (underlying goals for skills necessary to perform work).

CAREER PLANNING SERVICES

Description (following CMS Informational Bulletin 9-16-2011)

Person-centered, comprehensive employment planning and support services that provide assistance for individuals to obtain, maintain or advance in competitive employment or self-employment.

Focused, time-limited service engaging an individual in identifying a career direction and developing a plan for achieving competitive, integrated employment at or above the minimum wage. The outcome of this service is documentation of the participant's stated fields of interest and career objective and a career plan used to guide individual employment support. This information could be shared with a Vocational Rehabilitation Counselor to inform the Vocational Rehabilitation process.

Includes planning time and experiential learning opportunities for the appropriate exploration, assessment and discovery processes to learn about career options as one first enters the general workforce.

Individuals receiving prevocational services or day habilitation services may use career planning to develop experiential learning opportunities and career options consistent with the person's skills and interests.

If an individual is employed and using supported employment services, career planning can be used to explore advancement opportunities or find other employment more consistent with the individual's skills or interests.

Examples include but are not limited to:

- person-centered, comprehensive employment planning and discovery process to determine individual interests, skills and preferences
- experiential learning opportunities for the appropriate exploration, assessment and discovery processes to learn about career options including: situational (community-based) assessments (job sampling); job preference inventories; identification of career options/job matches
- Social Security and other public and private benefits education and planning
- assistive technology (assessment and training)

(Services listed could be included in the individual's Medicaid service plan if not otherwise available to the individual through Vocational Rehabilitation.)

Career Planning Services - Provider Qualifications

Completion of standardized training and assessment (to be identified, see recommendations) that documents core competencies and includes the following topics:

- discovery process
- person-centered planning process
- setting up experiential learning opportunities
- assistive technology assessment and training
- Social Security and other public and private benefits education and planning
- understanding of the Vocational Rehabilitation process
- understanding of additional resources to support employment

INDIVIDUAL SUPPORTED EMPLOYMENT SERVICES

Description (following CMS Informational Bulletin 9-16-2011)

Supported employment services are ongoing supports to individuals who, because of their disabilities, need intensive on-going support to obtain and maintain an individual job in competitive or customized employment or self-employment, in an integrated work setting in the general workforce compensated at or above the minimum wage. The outcome of this service is sustained paid employment in an integrated setting in the general workforce, in a job that meets personal and career goals.

Services must be provided in a manner that promotes integration into the workplace and interaction between individuals with and without disabilities.

Services and training activities are provided to the individual in regular business, industry and community settings. May also include support to establish or maintain self-employment including home-based self-employment.

Individual employment supports does not include facility based, or other similar types of vocational services furnished in specialized facilities that are not part of the general workplace. It is not intended for people working in mobile work crews or small groups of people with disabilities working together in the community.

In Idaho we will focus this service on a customized employment approach and process that differs from typical Vocational Rehabilitation practices that aim first to successfully place job seekers within the context of competitive hiring processes and then provide supports as needed to maintain employment.

Examples include but are not limited to:

Individualized services that may include any combination of the following services:

- Job search planning; utilize information from discovery process; develop plan that includes list of potential employers
 - Social Security and other public and private benefits education and planning
 - o asset development and career advancement services
- Customized job development and negotiation with prospective employers
- Post-employment support
 - o job analysis; training and systematic instruction; job coaching

- development of natural support in the workplace, communication with supervisors/coworkers
- o ongoing support and monitoring of satisfaction in the employment relationship
- o transportation
- o personal care assistance to prepare for work and in the workplace

(Services listed could be included in the individual's Medicaid service plan if not otherwise available to the individual through Vocational Rehabilitation.)

Individual Supported Employment Services - Provider Qualifications

People who provide this service must have a range of competencies within the four components of customized employment: discovery, job search planning, job development and negotiation, and post-employment support.

Completion of standardized training (to be identified) and assessment that documents core competencies and includes the following topics:

Employment Specialist

- discovery process; observational skills evaluation activities; documentation of information
- job search planning; development of strength-based portfolio or resume; development of a CE plan; benefits support, training and planning
- Vocational Rehabilitation process and services
- understanding of additional employment resources
- customized job development; negotiation with prospective employers; job analysis, training and systematic instruction
- Post-employment support; monitor satisfaction of individual and employer, evaluate performance and resolve problems; asset development and career advancement services; transportation; development of natural support in the workplace; communication with supervisors/co-workers

Job Coach (paraprofessional level)

 Post-employment support including: job analysis; training and systematic instruction; development of natural support in the workplace; communication with supervisors/coworkers; monitor satisfaction of individual and employer; evaluation of employee performance; support of problem-resolution processes with employer and employee; assist individual to access transportation.



Idaho Employment First Consortium

Employment Support Services - Provider Qualification Recommendations

Quality employment support services can make the difference for an individual with intellectual/developmental disabilities in achieving a life that includes competitive integrated employment with community engagement. The Idaho Employment First Consortium (IEFC) has been working over the last 5 years to address barriers for individuals to achieve employment and build capacity in our systems and communities to ensure the opportunity to have a job in the community is possible. (See list of IEFC members on page 16). One barrier identified by the Consortium was lack of access to employment support services provided by trained and qualified staff. Without detailed state policy related to provider qualifications and training for employment support professionals, there is wide variation in the amount of training provided by agencies to staff providing community supported employment services. It is the intent of the IEFC to not only expand the array of employment support services available but also increase the expertise of direct employment service providers. It is imperative that Idaho make an investment in staff competencies and a commitment to quality and best practice in service provision to ensure that services are effective in helping individuals achieve and keep competitive integrated employment.

Following the Consortium's submission of recommendations for new employment support services for the Idaho Medicaid benefits package in December 2015, the IDHW Division of Medicaid requested the IEFC develop information for the Division on which to base fiscal impact of the recommended services. The Consortium convened a Provider Qualifications Work Group in February 2016. The Workgroup was tasked with identifying and recommending the desired qualifications direct service providers will need to ensure consistent quality of services statewide. Recommendations from the PQWG begin on page 4.

The report that follows is based on current data collected by the IEFC. It is intended to inform Medicaid staff of desired provider qualifications to help determine possible reimbursement rates for the new services. These rates will help the IEFC develop a report with estimated fiscal impact to the Idaho Legislature. Our intent is to gain legislative approval for the Division of Medicaid to move forward in policy development activities to establish the new services.

The Provider Qualifications Work Group (PQWG) began meeting in February 2016 and was tasked with identifying and recommending the desired qualifications direct service providers will need to ensure consistent quality of services statewide. In addition to this goal, PQWG members expressed a desire to address the growing problem of access to the service. One contributing factor that needs to be addressed is turnover of direct service staff. The PQWG recommends that services are designed with the intent of developing and retaining highly skilled professionals. It is hoped, through measures to improve the value of the service provided, these professionals will continue their careers in the field. The group believes that professional skill development will positively affect the quality of service and ensure access.

The PQ Workgroup was comprised of individuals currently working in the field, representatives from the Idaho Dept. of Health and Welfare, Dept. of Labor, Division of Vocational Rehabilitation, and the Council on Developmental Disabilities for a total of eleven individuals. The majority of work was completed through teleconferences over several months. One face-to-face work meeting was conducted.



Idaho Employment First Consortium

The table below contains information on the three proposed Medicaid vocational services the Idaho Employment First Consortium presented to the IDHW Division of Medicaid in December 2015. A summary of the desired skills, characteristics, education, work experience and training options is available as well by contacting Tracy Warren, ICDD.

PREVOCATIONAL SERVICES	CAREER PLANNING SERVICES	INDIVIDUALIZED SUPPORTED EMPLOYMENT
Service Description	Service Description	Service Description
Individuals receiving prevocational services must have a goal to become employed identified in their personcentered services and supports plan and the general habilitation activities must be designed to support such goals. These focused, and timelimited services are provided to individuals who are not expected to join the general workforce within one year. Services that provide learning and work experiences including volunteer work where the individual can develop general, non-job-task-specific strengths and skills that contribute to employability in paid employment in integrated community settings.	Focused, time-limited service engaging an individual in identifying a career direction and developing a plan for achieving competitive, integrated employment at or above the minimum wage. The outcome of this service is documentation of the participant's stated field of interest, career objectives, and a career plan used to guide individual employment support. Includes planning time and experiential learning opportunities for the appropriate exploration, assessment and discovery processes to learn about career options.	Supported employment services are ongoing supports to individuals who, because of their disabilities, need intensive on-going support to obtain and maintain an individual job in competitive, customized, or self-employment, in an integrated work setting in the general workforce compensated at or above the minimum wage. The outcome of this service is sustained paid employment in an integrated setting in the general workforce, in a job that meets personal and career goals. In Idaho we will focus this service on a customized employment approach and process that differs from typical Vocational Rehabilitation practices that aim first to successfully place job seekers within the context of competitive hiring processes and then provide supports as needed to maintain employment.

PREVOCATIONAL SERVICES	CAREER PLANNING SERVICES	INDIVIDUALIZED SUPPORTED EMPLOYMENT
Recommended Provider Qualifications	Recommended Provider Qualifications	Recommended Provider Qualifications
 High School Diploma 18 years or older Twelve months paid work experience HW criminal history check Valid Driver's license - insurable First Aid and CPR Training within the first six months: Person Centered Planning Strength-based service delivery Understanding disabilities Understanding employer "soft skills" expectations Advocacy Instructional techniques Self-advocacy, self-determination, and high expectations 	 High School Diploma 18 years or older Two years of paid employment – preference that this include job coaching experience HW criminal history check Valid Driver's license - insurable First Aid and CPR Computer skills – keyboarding, general knowledge of Word, Excel Successful completion of ACRE approved training that includes the following components: Person Centered Planning Strength-based service delivery Intro to Motivational Interviewing Advocacy Assistive Technology – Job Accommodations Customized Employment Techniques Understanding disabilities Career Counseling – Labor market information Understanding VR service delivery system Understanding Social Security and other benefits i.e. Medicaid, housing, etc. Fundamentals of job search/business expectations Knowledge of assessment tools/techniques 	 High School Diploma 18 years or older Two years of paid employment – preference that this include job coaching experience HW criminal history check Valid Driver's license - insurable First Aid and CPR Computer skills – keyboarding, general knowledge of Word, Excel Successful completion of ACRE approved training that includes the following components: Person Centered Planning Strength-based service delivery Intro to Motivational Interviewing Advocacy Assistive Technology – Job Accommodations Customized Employment Techniques Understanding disabilities Career Counseling – Labor market information Understanding VR service delivery system Understanding Social Security and other benefits i.e. Medicaid, housing, etc. Fundamentals of job search/business expectations Knowledge of assessment tools/techniques

PREVOCATIONAL SERVICES	CAREER PLANNING SERVICES	INDIVIDUALIZED SUPPORTED EMPLOYMENT
Preferred but not required skills:	Preferred but not required skills:	Preferred but not required skills:
Previous experience with people with	Bachelor's degree	Bachelor's degree
disabilities (volunteer, paid, family	Previous experience with people with disabilities	Previous experience with people with disabilities
member)	(volunteer, paid, family member)	(volunteer, paid, family member)
	Marketing experience	Marketing and Sales experience
Desired Characteristics	Desired Characteristics	Desired Characteristics
Positive Attitude	Positive Attitude	Positive Attitude
Creative	Creative	Creative
Desire to teach/coach to success	Desire to teach/coach to success	Desire to teach/coach to success
Patient	Patient	Patient
Friendly	Friendly	Friendly
Energetic	Ability to develop rapport quickly with a variety of	Ability to develop rapport quickly with a variety of
	customers	customers
	Flexible – adapts to variety of environments	Flexible – adapts to variety of environments
	Energetic	Energetic
Recommended Certification Requirement	Recommended Certification Requirement	Recommended Certification Requirement
None	Certified Employment Support Professional (CESP)	Certified Employment Support Professional (CESP)
	– pass national exam	– pass national exam
Training options considered	Training options considered to achieve certification	Training options considered to achieve certification
Classes through College of Employment	CTAT LLC	CTAT LLC
Services	Virginia Common Wealth University	Virginia Common Wealth University
	APSE - College of Employment Services	APSE - College of Employment Services
State designed training	Training Resource Network	Training Resource Network
	Workplace Inclusion and Sustainable Employment	Workplace Inclusion and Sustainable Employment
	IPS Dartmouth Supported Employment Center	IPS Dartmouth Supported Employment Center
	Utah State University	Utah State University
	Griffith-Hammis and Associates	Griffith-Hammis and Associates
	Open Futures Learning	Open Futures Learning



Additional Recommendations for Provider Qualifications:

- 1. All direct staff have experience working with people with disabilities and a minimum of one-year paid work experience.
- 2. Required training for provider staff is a critical component of the new services.
- 3. Training should be formatted to allow for anytime and anywhere access; internet-based in all likelihood. This is important given the rural nature of the state and remote areas where services are accessed.
- 4. Training is ACRE certified for professionals providing career planning and individualized supported employment.
- 5. Training must be completed within 6 months of employment and includes structured clinical supervision, mentoring and demonstration of competency.
- 6. The time of supervision will need to be factored into the training cost. This supervision should include: supervision of service elements of the agency, including face-to-face supervision of agency staff providing direct support services; observation and review of the direct services performed by all staff on at least a monthly basis, or more often as necessary, to ensure staff demonstrate the necessary skills to correctly provide the services; documentation of observation of skill competency and satisfaction of service recipient.
- 7. A checklist or observation record is developed for use by supervisors for assessing skills and competencies of direct support staff similar to the current requirement by IDHW for quarterly field observations of direct support staff providing waivered supported employment. A standardized checklist to be used by all providers would need to be developed.
- 8. All providers of Career Planning and Individualized Supported Employment obtain professional certification through completion of the CESP Examination and maintain certification through completion of 36 continuing education credits in three years or pass the examination again. Current cost for this examination is \$159.00 per applicant with an additional cost of \$125.00 every three years for recertification. CESP testing sites could be established across the state and proctors trained to avoid people having to travel to exam sites in other states.
- 9. Total cost of training during the first six months of employment for Career Planning and Individualized Supported employment will include the cost of completing formalized training, CESP examination fees, and 200 hours of supervision for the first six months on the job. These should be considered and factored into the rate setting formula.
- 10. All professionals providing Career Planning and Individualized Supported Employment sign and adhere to the Employment Support Professional Certification

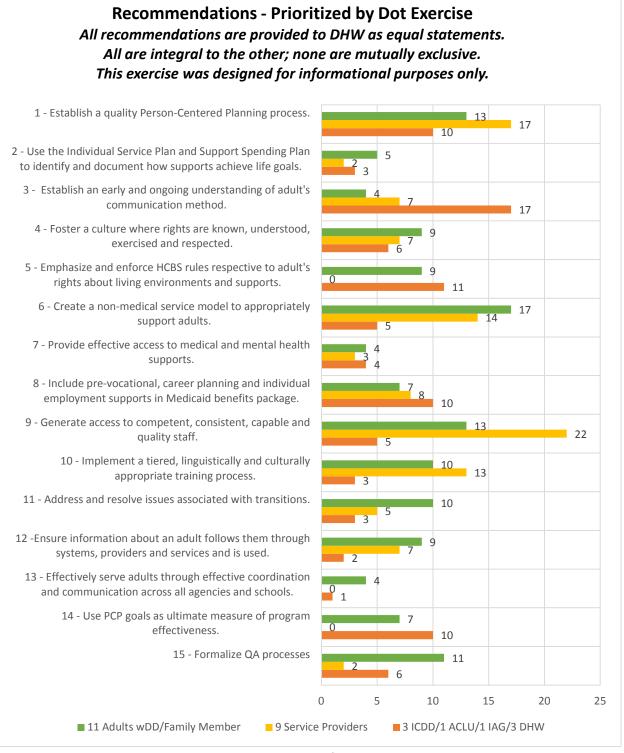
- Council's (ESPCC) Code of Conduct at time of the CESP examination and every three years thereafter.
- 11. Given the lack of training or certification specific to Pre-Vocational Services, it is recommended that training be customized or created through individualized training classes that are available through the College of Employment Services and the College of Direct Support. The PQWG has identified several of these they believe will meet the training expectations.
- 12. The State of Idaho should develop and adopt a code of conduct for Pre-Vocational Services in the event professionals offering this service have not passed the CESP examination.
- 13. Given the intent that these services will be designed to meet the needs of a variety of individuals, including those with the most significant disabilities, customized employment training is important. The PQWG recommends consideration of onsite technical consultation from an ACRE certified trainer in customized employment to aid implementation. It is recommended this training would supplement training modules/core curriculum of the Colleges of Employment Services and Direct Support. This will require a significant investment.
- 14. The State or the Employment First Consortium continue to work with a post-secondary educational institution toward establishing an accredited training option that would lead to an Associate's degree and provide a building block for those professionals who desire to further their education and develop a career in the field.

Other Considerations:

- 1. Identifying "comparables" from other occupations or professions in the state is difficult given the diversity of skills desired.
- Group values importance of networking and peer-to-peer mentoring during training and suggests an ongoing component that supports shared knowledge between staff in similar positions and peer support in finding solutions to unique situations.
- There is value in structuring service delivery similar to other Medicaid services
 where general provider qualification requirements are in place prior to providing
 any of the services.

Medicaid Employment Services Recommendations - originally submitted 12/16/2015 Provider Qualifications Recommendations - 8/10/2016

Appendix B



All individuals participating in this dot exercise were part of the entire Community NOW! process. Each was provided 12 dots to contribute across the 15 recommendations, and were asked to use as many dots on each recommendation as they saw fit. They were asked to distribute the dots based on those areas they would like Medicaid to initially focus its attention. It appears not all individuals used all the dots available to them.

