

ALLIANCE

Focus Group Report

The Rushmore Group
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Background

Alliance is a nonprofit, statewide association of Community Center Boards and Service Provider Organizations committed to the advocacy of member organizations and the individuals and families they serve. Seeking to take a proactive role in both the design and implementation of system change, Alliance has established Focus on Future, a project guided by a workgroup of representative members who meet weekly via teleconference. Acknowledging people receiving services and families must be the starting point in considering changes that improve the quality and efficiency of services provided to people with developmental disabilities, Focus on the Future solicited the input and feedback of self advocates, families and other local service system stakeholders via regional focus groups. Focus Group findings will be used to guide the work of a group of self advocates, family members, Alliance members and national experts convened to consider necessary changes and formulate recommendations for local and state level implementation. This report presents the findings of five regional focus groups held in 2011:

- Western Slope, Grand Junction, July 11th;
- Southeast, Pueblo, July 12th;
- Northeast, Windsor, July 13th;
- North Denver Metro, Longmont, July 14th;
- Denver Metro, Lakewood, July 14.

Approach

In an effort to understand the depth and breadth of perceptions of system stakeholders absent the influence of preconceived notions created by specific questions, Alliance workgroup members elected to use focus groups as a tool to gather qualitative information to assess the performance of the services available to people with developmental disabilities. Alliance partnered with local Arc chapters to select and host participants for each focus group. Each group was held in a “neutral” location unaffiliated with the developmental disabilities service system. Co-hosts were asked to reach consensus regarding a list of participant invitees comprised primarily of self-advocates and family members of people with developmental disabilities. They were encouraged to recruit people:

- 1) Representative of the designated region;
- 2) Willing to share their experiences and perceptions;
- 3) Who are open and fair minded; and
- 4) Unlikely to polarize others participants.

After committing to participate during a recruitment phone call, participants received a confirmation letter and a follow up phone call reminder. They were offered assistance with accommodations to support their participation. Participants were asked to arrive approximately 15 minutes prior to the designated focus group meeting time to complete a registration form that

included age and gender, and asked them to specify their connection to the developmental disabilities service system. With the exception of the North Denver Metro area which gathered at 11:30 A.M., all groups met at 6:30 in the evening and were provided food and refreshments. Co-hosts were asked to see to the needs of their guests but did not participate in the focus group discussion. Focus on the Future project leader Sally Montgomery was responsible for taking notes for each of the focus group meetings.

Wanda Seiler, Senior Consultant with the Rushmore Group was engaged by Alliance to facilitate each of the focus groups using an interview guide (See [Appendix A](#)) that asked simple and neutral questions regarding participant's experiences with:

1. Service system access
2. Living in Colorado
3. Working in Colorado
4. Health and Wellness
5. Provider Capacity and Quality
6. Community Integration

Participants that did not volunteer information were prompted through probes. Most participants required no prompting. Although the level of participation varied, all participants contributed to the discussion. Following this "autobiographical" phase of the focus group meeting, participants were then asked to assess system performance by identifying:

1. What's working
2. What's not working
3. What should stay the same
4. What must change

Prior to ending each session, participants were given an opportunity to share anything they felt critical that had not been already discussed. Participants were forthcoming and respectful of one another. Each session took a minimum of two hours. The first two sessions ran significantly longer and resulted in modifications to the interview guide to reduce the time needed to cover the topics in the autobiographical portion of the group meetings.

Following each focus group, Wanda Seiler and Sally Montgomery met with the local co-hosts to identify the major themes within and across each of the six autobiographical topic areas. These debriefing sessions were used to develop consensus regarding participants' assessment of the Colorado service system for people with developmental disabilities.

Participants

A total of 84 people attended five focus groups.

- 57 participants or 68% identified themselves as either self-advocates (11 participants) or a family member of a person with developmental disabilities (46 participants).
- The remaining 27 (32%) participants included professional advocates, community leaders, direct support professionals, employers, health professionals, non-profit provider board members, educators, and other service providers.
- 63 participants (75%) were female; 21 participants (25%) were male.
- Participant ages ranged from 27 to 73 with a median age of 50.74.

Regional Trends

Generally speaking, participants' assessment of major issues within the service system was consistent throughout each of the five regions. Variation, however, existed within the extent to which people were able to access services. Participants from areas distant from the Denver metro area reported much longer waits for services and no access to services while they were waiting. They perceived a political bias in decisions-making accountable to the interests of metropolitan areas at the expense of other areas of the state. People outside of the metro area seemed more intent on the pursuit of basic service needs. People living closer to the Denver metro area seemed to have more latitude in looking beyond basic needs in pursuit of an improved life quality for themselves or their family member with a developmental disability.

While the focus group interview guide contained no questions or probes related to the provision of case management and other services by a single provider, the state's ongoing conflict of interest controversy was raised by participants of the Western Slope, Northeast and Southeast focus groups. This issue which questions whether a provider of case management should also provide another waiver service was not raised in either Denver metro area meeting.

Some of the most compelling stories of hardship created by service access barriers were shared by Western Slope focus group participants. This session was the series' longest, lasting almost three hours. Participants had very few positive comments about a service system they find difficult to access and inflexible in the provision of funding. Several people, however, acknowledged leadership provided by a local community center board in the recent outplacement of several people from a regional facility.

In spite of significant travel distances, all areas within the Southeast region were well represented. Many traveled several hours to participate. Some of these folks car pooled, sat

together, and shared similar experiences and perspectives. The Southeast focus group can be distinguished from others in that some participant comments were non-responsive to the questions posed by the facilitator. People seemed to arrive with an agenda and were intent on conveying predetermined information even when pressed to consider the topics contained within the interview guide. Even a uniformed guard reminding participants of an impending closing time did not dampen their enthusiasm in sharing their perspectives. In spite of the unique zeal for participation, major themes emerging from this region remained consistent with those of other regions.

While only slightly perceptible, the tone of the Northeast focus group was more positive than that of its predecessors. As previously stated, this trend continued as meetings closed in proximity to the Denver metro area, presumably due to the increase and availability of resources. In the final three focus groups there was an increased interest in and frustration with employment opportunities and service limitations imposed by Department of Vocational Rehabilitation funding constraints.

The North Denver region was unique in the emphasis that participants placed on the benefits of early intervention and ensuring that resources were available to professionals responsible for the provision of services. This folks also stressed the importance of supporting self advocates and families to make informed decisions. It was at this focus group that participants began to note a variety of service options made available to people on waiting lists.

Participants from the final focus group held in the Denver metro area shared similar experiences with accessing service options such as the elderly and disabled person's (EDP) waiver and reported markedly reduced wait list durations. In contrast to the outlying areas where participants voiced frustration with faceless bureaucrats, Denver metro participants seemed to have more first-hand acquaintance with state leaders. Nonetheless, their frustration with these folks prevailed at an extreme level that was evident statewide.

Common Themes and Issues

A substantial amount of information was gathered in the course of the focus group series. Those themes identified by issues raised in all or the majority of focus group meetings have been given greater emphasis in formulating the findings within this report. See [Appendix B](#) (Focus Group Meeting Notes) for more specific information relative to each of the focus group meetings. Major themes include Service System Access, Systems, Provider Capacity and Quality, Employment, and Advocacy.

Service System Access

System Access can be characterized by the way people enter and navigate within the developmental disabilities service system. Information gathered in the course of the five focus group meetings leave little doubt that the most significant detriment to system accessibility lies

in Colorado's extensive waiting list for services. A waitlist report shared by a focus group participant documents approximately 2,500 people waiting for developmental disabilities waiver services. Focus group participants alleged that the number is much higher and the wait length unpredictable.

Families living in areas outside of the metro area discussed frankly, the devastating impact of waiting for services. One parent told her story of how her daughter was in such dire need of services that she began searching in other states. After locating a reputable program in a state that had no waiting list, she and her children moved. Her husband was forced to remain in Colorado for three years until his employer allowed him to work from their new home. She describes her family's return to Colorado as occurring serendipitously as a result of her periodic calls to inquire about services. Several others described their referral into services as accidental rather than the product of a deliberate attempt to access the services they needed. People used descriptors like "stumbling into services" or "coming across services by chance." Most were referred by parents who had encountered similar difficulties and were generous in sharing advice and support.

In terms of wait length, focus group participants reported wide variation. Isolated reports conveyed little or no wait at one end of the spectrum and a decade long wait and "still waiting" at the other. One father expressed a common fear for many parents in that his child would be forced to transition without his advocacy or support because comprehensive services would be unavailable during his lifetime. Generally, reported waiting periods ranged from one to eight years. Parents were encouraged to place their child on a waitlist for adult services at age 14. Some reported receiving services in time for the transition into adult services. Others described a cliff from which services plummeted until the child's name came up on the adult wait list. This gap was particularly discouraging for families and educators working to support their progress while in school. "You watch them fall off the cliff and you think, what's the use?"

Families also voiced frustration with the lack of a cogent system of information and referral necessary to navigate within a complex service system. Several families reported receiving inconsistent and conflicting information from the state's social service network. With some notable exceptions, physicians and medical professionals lacked service system knowledge and failed to provide useful referrals. Several participants suggested that agencies avoided making referrals to developmental disability services because waiting lists made them an inaccessible service option. Some families also reported inaccuracies in eligibility determinations, an element more common when a person has a co-occurring mental health diagnosis. One educator pointed out that provider agencies possess the knowledge and expertise to direct families, but are inaccessible to people on waiting lists. As an exception rather than rule, a few participants named their case manager as the resource upon who they relied for information. There was some positive feedback on Single Point of Entry organizations that was not supported by group consensus. Most families named other parents as the source most reliable to advise their journey.

Although anecdotal, compelling issues surrounding service access were raised during three of five focus group meetings. Families told stories of how professionals serving the system promoted access to the system by either relinquishing custody of a child or feigning an emergency situation that brought them to the top of the list. A parent shared her emotional dissonance in trying to balance her child's need for services with the devastating reality of "giving her up." Another family told their story of emergency need for services. They were asked to agree to a residential placement and assured a "loophole" would be used to access funding. A year later they received a bill in excess of \$100,000 for the cost of their child's care.

Systems

For the purposes of this report, Systems issues are identified as those that pertain to the infrastructure that undergirds the Colorado DD system. Many of these issues focused on the role of state agencies in carrying out statutory responsibilities. Although the focus group interview guide contained no questions designed to solicit information regarding the performance of state agencies responsible for the funding and regulation of Colorado developmental disability services, focus groups participants consistently brought forward their frustrations with a bureaucracy that from their perspective hinders rather than helps in the provision of services. There are several issues that resonated for participants of all focus groups.

Generally, families describe the Division of Developmental Disabilities (DDD) as "not working" and in need of change. Acknowledging that good people within the Division work "to do their best," many cited changes in leadership and direction as the source of the agency's dysfunction. Participants shared concerns that DDD was no longer "calling the shots" and services were being run by the Health Care Policy and Financing (HCPF) Division, an agency capable in its expertise as a health insurer but without the necessary understanding of services to people with disabilities. Others felt that state agencies have become over-zealous in their efforts to appease the heightened regulatory expectations of their federal partner, the Center for Medicare and Medicaid Services (CMS). "They have created systems that are inflexible and require people's needs to fit funding streams rather than funding streams that fit people's needs." Participants alleged that state leaders are out of touch. "They make decisions from their brick towers without an understanding of how those decisions impact people's lives."

Approximately five years ago DDD moved from a quasi-managed care funding structure to a traditional fee for service reimbursement methodology. While this shift was begrudgingly acknowledged as necessary to retain federal financial participation (FFP) in waiver services, people complained that there were several missteps that occurred in facilitating this transition. Almost every focus group shared concerns with the validity and reliability of the Supports Intensity Scale (SIS) now used to determine service reimbursement levels. While it should be noted that these concerns are difficult to confirm or allay, significant was families' recounting of events and how SIS procedures were first implemented, rescinded, and then revised. Participants used this instance as one of many in which they were forced to accompany state agencies on a roller coaster ride in which initiatives start, stop, and restart but fail to obtain any

substantive or positive change. Participants also cited the Family Caregivers' Act and a legislative mandate authorizing self directed services as important initiatives that failed to take hold because DDD has failed to issue technical guidance necessary to facilitate implementation.

Many people voiced concerns that the transition to a fee for service environment has resulted in unintended consequences with a detrimental impact on service quality. The role of case managers, for example, has morphed into agents for billing and compliance. One self advocate characterized case managers as "too busy" to help people get what they need. As time allows this responsibility falls to other service providers already stretched by funding cuts to fill this gap.

The Supported Living Services (SLS) and Children's Extensive Services (CES) waivers are also credited with unintended consequences of the fee for service transition. People cited complex and time consuming procedures that regulate the authorization and modification of services funding by these waivers. Once approved, the provision of services is extended limited flexibility. As one parent candidly stated, "I think of myself as an honest person. I have learned that I must lie to get my daughter the services I need. When her support person arrived tonight, I listed the tasks that must be completed in order for her to produce billable units. I completed all of those tasks earlier today."

Another parent talked about being authorized for Community Connector services that require her son to go out into the community even though he may prefer spending time with friends at home. A provider shared her frustration with the red tape involved in modifying plan authorizations when a person's needs change significantly. She explained that changes cannot be made in a manner timely enough to support billings for services necessary to meet the change in needs. Another provider described a situation in which parents were relying on Community Connector services to supervise their child while they were absent from the home. Although evident to the service provider that the child was "having a bad day" the provider was forced to weigh the potential for an angry outburst in the community against being able to produce a legitimate billing for services. Without flexibility to move funding between approved services, families have coined the phrase "creative manipulation" to describe the process employed to secure services that address individualized needs.

Many participants shared their concern with what they viewed as a disparate burden of funding cuts borne by developmental disability services and those with the limited ability to sustain the impact of the state's economic challenges. One parent described how funding cuts have reduced her daughter's exposure to the community. "She hasn't left the day program building in two years. She used to be in the community at least two to three times a week." Two of the five focus groups questioned the reasonableness of an increased rate for supported employment at a time when plans are capped and other service cuts are required to cover the rate increase. One self advocate was clearly frustrated by cuts that resulted in the loss of paid employment. "I used to work two days a week and volunteer two days. Now I have to volunteer four days a week so my day staff can be paid for their services. My income is less and I now I am expected to cover copayments on my medical expenses."

Several stories that emerged from the focus group series convey the impression of service system regression. One advocate shared her concern that seniors receiving developmental disability services were not afforded the opportunity for retirement. She illustrated this point with the story of an elderly woman who wished to spend her day at home, but day staff was required to serve her elsewhere in order to produce billable units. The woman was injured in transport to day services and because she could not be supported to convalesce in her own home, she was forced to move to a more restrictive facility based setting. Families spoke favorably of providers willing to embark on initiatives to expand employment opportunities. In one region this meant restoration of a Thrift Store setting more indicative of past rather than present employment innovation. One provider shared their disappointment when a 17 year old was placed at the bequest of state officials in a Regional Center despite their willingness to be both creative and innovative to secure his community based placement.

Beyond funding and service structuring, participants questioned state agency's role in the oversight and monitoring of services. Regulated by three separate and distinct state agencies, providers voiced frustrations regarding inconsistent standards, expectations and technical guidance. Within any single state agency regulatory function, requirements are considered vague and subjective and strain what is described as scarce and diminishing resources. They cited the complexity of each waiver as compounded by the administration of eleven waivers with different services and compliance expectations.

Although not emerging as a common theme identified by all or even a majority of focus groups, two of the groups shared concerns regarding the role and sustainability of Community Center Boards (CCB) within the overall structure of the existing service system. One participant described their role as obsolete with the completion of deinstitutionalization. While this view point did not gain group consensus, it conveyed a perception that some CCB functions were duplicative of state functions, resulting in expenditures that the system could no longer afford. Others cited administrative inconsistencies perpetuated at the CCB level making the provision of services more difficult for service providers working with more than one CCB.

Even when prompted, focus groups participants struggled to identify state systems that were working and should remain unchanged. It should be noted, however, that state officials while informed of the planned focus groups, were not extended an invitation to attend. Neither were they present to respond to participant concerns or offer their perspectives in explanation of situations in which their role in the provision of services was unfavorably conveyed.

Provider Capacity and Quality

Provider Capacity and Quality relates to the competency with which all service providers are able to meet the needs of people with developmental disabilities. Reviews of this capacity were comparatively favorable but fell short of consensus. Many self advocates and families spoke with gratitude of caring staff doing all that they could with limited resources. All focus groups shared their concern with direct support staff salaries. Others voiced their concerns that case

managers were considered by some as entry level professionals charged with responsibilities beyond both their experience and pay grade.

While the majority of people agreed with others who stated, “If you are lucky enough to get services, those services are typically good,” only about half of people served from waiting lists acknowledged getting the services they need. Some felt that service providers overstepped boundaries and tended to lead rather than follow. One parent stated, “Each time we get a new case manager, my child’s life changes direction.” This and other comments suggest limitations in person centered approaches to planning.

In consideration of residential options, most people felt that there was a wide continuum of housing options from which people could choose those that best fit their needs. Within those chosen, however, options were limited with people reportedly finding a proper match by luck rather than design.

There appeared to be some regional differences placed on the importance of employment with more concerns raised in and surrounding the Denver metro area. Several participants voiced frustration with the Department of Vocational Rehabilitation. “If they say they can serve someone, we are forced to sit and wait until they are ready.” Several educators stressed the importance employment plays in the lives of young adults. One educator spoke eloquently about “authentic” work as a means to a fulfilling life and his frustration with the aforementioned gaps in the transition from child to adult service systems.

Although some families spoke of their experiences with self directed services, it must be noted that Colorado’s developmental disabilities waivers do not include an election for the provision of self-directed services. These families were referencing instances of provider flexibility and innovation in affording them an opportunity to self-direct their services. Without exception, focus groups promoted self-direction as essential to the evolution of the state’s waiver services.

The final topic contained within the interview guide tested participants understanding of the importance of social roles in making community connections that reduce reliance upon paid supports. While some people demonstrated an understanding of their importance others reflected a more traditional approach to service provision, “In our system we place a greater emphasis on health and safety.” In response, an experienced educator stated, “Our biggest concern is authentic community roles...We tend to make stuff up. Interactions need to be real life.” People noted that the difficulty in establishing and maintaining meaningful social roles was directly related to the extent of a person’s disability. Groups which reached consensus on this issue were also able to identify that supports for social roles tended to be provided by accident rather than any systematic focus.

A common response when focus group participants were asked, “What’s working?” listed the collaboration and coordination that occurs between CCBs, other service providers and other local disability service agencies. They and communities are credited for working together in

providing the services and supports necessary so that people with disabilities can live and work in Colorado.

Health and Wellness

Health and Wellness refers to those supports that are provided so that people can have the best possible health. The concerns most commonly shared in this area were related to the availability of Medicaid providers, medical professionals who had experience working with people with developmental disabilities, and mental health services. In the Northeast region, a parent / advocate indicated that recent changes have imposed limitations on adolescent access to mental health services. While they have access to medication management, mental health counseling services are no longer accessible.

People in rural areas shared their concerns regarding their need to rely on physician assistants and nurse practitioners as well as their need to travel significant distances to receive specialty care. In and around the metro area, people were more likely to raise the specific issue of availability of dentists and dental care under general anesthetic. A participant attending the Northeast region focus group shared information on a pilot project in Larimer County aspiring to improve access to dental care.

Several focus group participants stressed the importance of communication with medical providers and the role of providers in ensuring appropriate follow up. Parents in the group pointed out the importance of medical history in providing appropriate treatment and how this information tends to get lost or pieces fall missing. One participant noted the importance of the person who accompanies her family member to the doctor. In response, we heard from an advocate in the Southeast region who talked about work that had been done to create a standard communication form that captured information medical professionals and providers needed to support health related needs. She also shared some innovative work being done in a local clinic that brings together a team of medical professionals in assessing and meeting the needs of people with developmental disabilities.

In a majority rather than all focus groups, participants explored the importance of staff supports in making sure that people made informed choices regarding their health. Groups discussed the difficulty in allowing a person the right to choose a lifestyle that does not promote good health. Direct support professionals indicated they would like more training to inform and encourage healthy choices. The importance of preventative health was mentioned only in passing to note that little work is being done in this area.

Also noteworthy is what did not come up when this topic was introduced or in the course of other discussions. Other states have faced rather alarming situations in which the health and safety of people have been compromised. Throughout this series of focus groups there was no mention of situations in which people felt that the health and welfare of service recipients was in jeopardy. Because it would be inappropriate to draw conclusions from what was unsaid, the absence of these types of concerns is simply noted.

Advocacy

Focus groups stressed both the importance of and positive influence that advocacy plays in promoting the quality of the Colorado developmental disabilities service system. People were concerned that self advocates and families are excluded from important discussions. “When system changes or planning occur we are not given a seat at the table.” Several participants expressed their gratitude for the support and assistance provided by their local Arc Chapters. Participants also expressed their appreciation for organizations such as the Alliance that collaborate to improve services. Participants consistently recognized the critical role that parents and family play in advocating on behalf of their family member. Several parents felt services for their son or daughter would be dramatically different if not for their persistence and tenacity. These declarations were typically followed by concerns for those in the system that did not have someone to advocate on their behalf. People fear losing the ground they have strived to gain and propose activism should advocacy fail to achieve the progress they seek.

Appendix

Appendix A

Alliance Focus Group Interview Guide

Introduction

Part I

Question 1: Service access/entry (opening question)

Foundation: Define Colorado service system

1. (For all) What was your first contact with / first impression of Colorado services for people with developmental disabilities?

Probes

- a. Was your first impression right /wrong?
- b. Regarding the # of options – Were there too many? Too few?
- c. Did you find a guide (either a person or a resource) upon who you could rely?
- d. Did you get what you needed/wanted?

Question 2: Living in Colorado

Foundation: Participants will list places that people with developmental disabilities live

2. Of these options, where do people with developmental disabilities most commonly live (identify 3-4 of the most common)? Why?

Probes

- a. What are the benefits of these types of living arrangement?
- b. What are the disadvantages of these types of living arrangement?
- c. What/who determines where a person with developmental disabilities lives?
- d. What happens when a child with disabilities becomes an adult?
- e. When/why do people (receiving services) move?

Question 3: Working in Colorado

Foundation: Participants will list the types of jobs people with developmental disabilities have.

3. Of these options, what are the best / worst jobs / places to work?

Probes

- a. How did you get the job you have?
- b. How do people get good jobs?
- c. How might this be different for teens and young adults?
- d. What should you do if you have a bad job?
- e. Who would you ask to help you find a (better) job?

Question 4: Provider capacity and quality

Foundation: Colorado has a variety of service providers – County Community Boards, Service Providers, etc. All are similar in some regards, and very different in others.

4. What are attributes of good/bad service providers

Probes

- a. I have been living in (living arrangement discussed in #2) and working in (good job from #3) in South Dakota and would like to move to Colorado, but need services to live and work here. Where / to whom can I go for assistance in selecting a service provider?
- b. Should I go to someone else if I was seeking services for my 6 year old daughter?
- c. What would prevent you from recommending a service provider to me?
- d. If you had to choose a new/different service provider how would you go about it?

Question 5: Health and well-being

Foundation: Explain the life quality outcome, “People have the best possible health” using the example of Gordon, who was 75 pounds overweight and honored a commitment to his mother to see his doctor. He learned he is pre-diabetic, so he has been on a diet, exercises daily, lost 50 pounds, but is now being treated for skin cancer. Identify how the outcome is now present for him with the supports of family and medical professionals. Participants will list the supports (including people) necessary for people with developmental disabilities to have the best possible health.

5. Which of these supports are accessible / not accessible to people with developmental disabilities?

Probes

- a. Who would identify someone who didn't have the best possible health?
- b. Who should intervene if someone didn't have the best possible health?
- c. Would this be different if we were talking about an adult vs. a child?
- d. What if the person receiving services didn't want to make changes to have the best possible health?

Question 6: Community Connections

Foundation: Community connections make a huge contribution to the quality of life. We connect to our surroundings via social roles that we play within a community. The social roles that are most important to me are wife, a mother, daughter, and employee. For others, it may be church member, volunteer, or bowler. Participants will list and prioritize the community connections and social roles that are important to them.

6. How are people with developmental disabilities supported to establish and maintain the most important connections to their communities?

Probes

- a. Who is responsible for providing these supports?
- b. What should someone do if they need/want these supports?
- c. Are the answers to a. and b. above different for a child vs. adult?

Question 7: Additional Comments (Wrap up)

Part II

Based on your knowledge of the service system:

1. What's working?
2. What's not working?
3. What should stay the same?
4. What should change?

Additional Comments (Wrap up)

Appendix B

Alliance Focus Group, Western Slope, Grand Junction, Colorado, 7/11/11

Participant Demographics

- 14 Participants
- Age range 40 – 66
- Median age 52.4
- 1 self advocate; 8 family; 5 other
- 2 males, 12 females

Service Access

Became connected through a swim therapy program.

Self Advocate – sister helped her get services at MDS. Went to Social Services first and then to MDS

**Was your first impression right/wrong?*

Three people raised their hand as a positive impression

One person indicated they were overwhelmed

Parent – “I ended up managing my son’s services. I know what he likes”

**Did you find a guide (either a person or a resource) upon who you could rely?*

Case manager was the person who guided me. CM was assigned to me.

**Did you get what you needed/wanted?*

Waiting for services; 4 people waiting for over 5 years

No services were available – Parent had to move to ND for services and lived apart from her husband for 3 years so her child could have services.

Daughter had received services in Illinois and moved to Colorado - was surprised to find that the resource did not transfer to Colorado. Does receive SLS, waiting for comp slot

Confused about the waitlist – someone told her if her daughter doesn’t have a home she could be considered an emergency and get services.

**How do you access the waitlist?*

Statewide system for waitlist

Self advocate – go to SSI, HUD and CCB

**Where would you send someone new?*

Send people to ARC and MDS

Call state representative

CCB understands the wait list

**Additional comments*

Host Home Provider – lonely, no support from PASAs, or others in the community.
When clients were in the hospital no one from the PASA even visited

Families can feel lonely and are exhausted

“Often too exhausted from caring for their loved one to really have time to research they system. It can be confusing”

HHP – PASA have too much red tape, not enough support and caring. PASA wants to call the shots but don’t want to know the real situation. Feels it is about the money – it is really about the love.

Living in Colorado

**Where do people with DD most commonly live?*

Children live in the family home

Adults living situations – host homes, group homes, assisted living, in family home with aging parents, nursing homes, on the street, live in their own homes, regional centers

**Who determines where a person with DD lives?*

Family, parent/guardian, courts, choose for themselves, the find something “by luck”,

Choices are limited

“I had the chance to approve or not approve my son’s residential choices, not choose it”

**How do people choose the staff they work with?*

“You don’t get to choose who cares for your child”

5 people raised their hands to say they do direct their family member.

Turnover in staff, home health is tough

Parents end up training people

**What happens when a child with disabilities becomes an adult?*

“Parents hold the primary CM role and are really the primary person who pulls all services together”

“As each CM comes into my daughter’s life her life changes course”

Working in Colorado

**What jobs are available?*

WalMart, Goodwill, Salvation Army, MDS, Self Employed, recreation staff, City Market, the 4-Fs (Food Service, Filth, flowers, folding (laundry)).

**How do people get good jobs?*

There has to be support on the job

Needs to be education for co-workers

**What happens if you have a bad job?*

Quit the job

Individuals are de-hired

Sabotage their job if they don't like it

We need to let people leave a job instead of fixing it

"Fitting the person to the job instead of finding a job to fit the person"

We often create it by providing too much support, we foster dependence

**Is your teen or young adult working?*

2 people said yes

2 said no

1 volunteering

Provider Capacity & Quality

**Attributes of good/bad service providers*

Good: flexible, caring, knowledgeable, listening, good work ethic, interested in client, being on time, doing it as more than just a job, empathic, sense of humor, communication, trained, advocate, stability (low turnover).

Bad: exploited, exhausted, frustrated, PASA – poor communication, shift changes without notice.

**Who would you refer someone to for assistance in selecting a provider?*

Ask the CCB

Talk to other families

You can go outside your area if needed

It is trial and error

Ask support groups/ask others in the community

**Good/Bad provider organization attributes?*

Good – love, energy, thinks outside the box, knows the rules, provides care with a purpose, teach independence, provides care with a purpose, hires to their mission, values and vision.

Bad – over manage the clients, setting, each host home manager should have to do respite for every client on their caseload because they don't have a clue.

Pay is an issue – pay to match the responsibility. "Fast food pays more and if you are flipping burgers and drop one it is not a big issue. If you drop something for the folks we support it can be critical"

"It is not the system that makes it work, it is the person who works in the system that makes it work"

“As each CM comes into my daughter’s life, her life changes course”

What’s working?

Access to medical services

Agencies are willing to step up and fill the void

Strong leaders in provider organizations

CCB is working

Alliance is working (from parent) – working for the common goals in the legislative efforts.

Educational system is working to increase knowledge

Collaboration of all agencies and supports - People communicate in this community

Adaptive sports programs (Durango) are working. They create networks and act as a form of community outreach.

What is not working?

Dual eligibility

No funding for Sports and Rec programs (SLS, CES)

Waivers are not working

Funding

Taking the SEP from CCB functions is not OK. Lumping in w/other services in the identified SEP network is not going to work. If it is centralized it will not work. Needs to be local.

Decisions are not always going to work when they are made in generalized fashion.

Need more self directed services. It needs to be a service option.

System is too complex – Parent quote, “I need to make up a story to get services”

Every law/decision should be required to ask “how will this impact those who cannot help themselves”

CES – too categorized, may not work for an individual. So you make up small stories to get your needs met.

Tell white lies to get the right words to justify the services.

Parent on comp waiting list “to be forced to say your child doesn’t have a home to get comp services is so difficult as a parent”

Systems are not appropriate to get things done.

Parent of an 18 year old “parents were instructed to consider divorce when their child was younger so they could qualify for services”

Additional Comments

Lower funding will impact on concerns being heard

Lot of work to be done – change what you can, but CCB system is efficient.

Be creative

Need to reduce the duplication of services

Grateful for staff

Change is inevitable – we will all be OK

Role of churches in our community needs to be increased.

One agency in a community is enough

Wonderful, caring community (Delta). CCB is key in their town

This focus group information needs to move forward

CCBs working internally on their own depts. Is good

CCB aided her daughter to be more visible and integrated in the community

The wait list is not working – it is a legal obligation of the feds/state to provide services

Thankful for CCBs

Little money and lots of need

Wants to see parents and self advocates at every table

The system does work – it is the time and energy that it takes to learn the complex system over again each time it changes that makes it difficult for parents and providers to focus on the individual's needs.

Parent quote “Caring for the DD child is not the issue - it is navigating the system that is the issue”

Alliance Focus Group, Southeast, Pueblo, Colorado, 7/12/11

Participant Demographics

- 20 participants
- Age Range 19 – 69
- Median Age 49.8
- 2 Self Advocates, 11 Family, 7 other
- 4 Males, 16 Females

Service Access

Six year old son – stumbled into services on accident. Did not get information from Dr or anything and used private insurance. One of her older children was directed to child find for speech issues and it led to her connecting for her younger son. She did get some supports, but found out about more from her friends and moms (informal network).

Self advocate – mom is a board member at Blue Peaks and that has really helped her mom learn about supports and services. Was initially referred to Blue Peaks by her physician – she got the supports she needed. Waited on the list for comp services about 5 years. Mom is concerned about losing resources in Blue Peaks - pulled back to the state. This is causing concerns for families and they see it as a great drain on the rural community. CCB/provider.

When their daughter was born – they were connected with another parent of a child w/Down's syndrome by the hospital.

Had to leave Pueblo to get services for his autistic child – when he returned to his home community the schools did not understand how to support his child.

Priority Areas

Doctors are still not referring folks

Transition planning and collaboration – folks are feeling hopeless “what is the point” since there is a waiting list.

DSS is not hooking folks into the DD system because they are trying to avoid the bureaucracy and it is really doing a disservice to families.

DD system is still struggling to transition to the fee for service and there is a waiting list.

Heard positive things about child find.

If you are lucky enough to get into services they are good. Although some funding blocks are causing problems to get funding – even careful wording and planning is not working to get the things people need.

We have to use creative interpretation (basically lying) to try to get the things folks need. The system is encouraging manipulation.

Several people have lost services or services have been reduced.

Calls to ARC are more focused on people in crisis as opposed to folks who are dissatisfied.

Living in Colorado

Daughter lives at home – doesn't want to leave!

Son lives in a group home – a CM asked their son directly and he said he wanted to move.

They had to let go. Been there ten years – it has been very positive for their son.

Self advocate – lives in a group home

Priority Areas

No significant concerns in this area

There are situations where folks do not get to choose their roommates or where they live.

Working in Colorado

Self Advocate – lost her job at the recycling center due to budget cuts. She also delivered senior meals and used to get a small check. Now she doesn't get any money – recycling is gone and meal delivery was paid.

Mom expressed concern that her daughter has had services cut

Daughter is 26. Provider has opened a store and have 13 consumers working in store. The fee for service has really changed services and the 15 min increment billing is ridiculous – creates a mountain of paperwork. They should focus on self determination. Sees the state as being more concerned about compliance with paperwork and not with people's services. Funding for supported employment is so high folks have given up their jobs because it takes up too much of their budget. Quality of services has decreased because they have trouble hiring. Staffing is cut to the bone, so her daughter sometimes doesn't get the services she needs.

Priority Areas

Supported Employment rate requires that something else has to be given up because it eats up so much of the rate

Provider Capacity and Quality

Daughter is 30 and she goes to a day program. Provider is a bunch of compassionate folks who do a great job. He and his wife are growing older. They are on a comp waiting list – doesn't know how long they will sit on the list. They are getting excellent care from the CCB now. He is concerned about the wait and future resources. He got a questionnaire about moving CM services to Denver. It didn't happen because there is no money.

Colorado Springs ARC – only CCB that provides only CM services – no services. She likes the separation and understands that it may not be possible in rural areas. She is concerned about how good it is to police your own services. Separate CM should happen in metropolitan areas.

Priority Areas

Asking folks to do so much for minimum wage

Moving people to more restrictive environments – when someone wants to retire they are basically told they have to go to day program.

Waiting list – worried about how long it will take for their child to get services.

Cherry picking is happening and putting folks in the middle. It happens both in Group Homes and Host Home services.

Health and Well Being

Inspiration Field (LaJunta) - Folks don't have the right resources for the health. They are not getting what they need. Folks have to go to bigger towns to get what they need.

Ways to get better health - it is really up to the individual. Some people do not want to have better health. It needs to start with education. He would go to his doctor and then get referred to a bigger city for services. He did that for services for his varicose veins – he came to Pueblo to see a specialist.

35 year old son and is a nurse. Wants to do something for health care supports – feels like we need to educate health professionals. Dual diagnosis is often misunderstood by doctors. Behaviors are not always handled well (misinterpreted or overreacted to) – shortage in doctors, professionals in rural Colorado. Feels like education for parents and providers is needed. Sometimes the person going with folks to doctor is not the right person – education is so important for everyone.

Parent and provider. As a parent she is required to go to the doctor every 6 months or year. She agrees that doctor needs to be educated and folks don't fit a mold. Many doctors just refuse to see her child.

C-Springs are lucky - Peak Vista is their community health center and through a collaboration they have a health care clinic specifically for folks with DD – they accept Medicaid. They have a doctor, behaviorist, and psychiatrist so that the whole being can be supported. They are also working on a common health form so you can take it to any doctor.

Priority Areas

Lack of Medicaid providers

Not enough doctors – work is being done by PA or nurses

Community Connections

Self advocate – lives in a host home. He is able to make decisions for himself. He would like to see his host home get health insurance benefits. He is a family member. Being independent, making a positive impact on the facility himself.

Self advocate – gets to do things that interest her. Gets to sit on various boards (people first).

Adult protection worker (guardian) – they have wards that are ready to retire. It is not the same as you and I – they don't know what to do. They don't have other social roles so they work.

Provider - provides opportunity for folks to make connections in the community. Goal is to work yours elf out of a role.

Priority Areas

Folks did not really understand this area. It is a red flag that people don't really get this concept.

Community events are not drawing folks because of funding, lack of transportation.

What's working?

Group homes are important for her siblings

Caring compassionate staffing in the field

Family and self advocacy are alive and well in Colorado

HRC works

Has supports for her diet and health

CCBs in general are good (nothing in life is perfect). Let's work to support it and make it better.

CCBs are doing the best they can with what they have to work with – working collaboratively with providers.

CCBs are being creative – opening stores for folks to work with. They are providing jobs and are profitable. Have to find other ways to gain funding.

Rural communities have a greater sense of community and that makes things happen for folks "it is the village".

What's not?

Turnover, recruitment and retention, staffing issues

Funding - no money

Fee for service

SIS tool is being used in a way it was not meant to be used (solely for funding)

SIS is an ordeal for parents to go through

Lack of local control for CCBs

Why do we even need the SIS

Three monitoring agencies – why is there so much? They find conflicting results. The duplication is ridiculous, repetitive

DDD doesn't work the way it is set up right now – no technical support, won't return calls, AMEN Brother!!!

Interpretive guidelines that are not reasonable and don't make common sense. Individual surveyors make different decisions.

HHP have to pay insurance and provide transportation. Also have to buy liability insurance. Son is school system - but is concerned with options. There needs to be more viable options.

There is nothing between 18 and 21.

DDD is always the first one in the line of fire for cuts - it devalues the system, staff are poorly paid – they can get paid more at Taco Bell. We expect so much for so little!

So many things we want to do – but there are so many restrictions

Uncertainty for a parent of a younger person is a problem

\$60 a month for personal needs – how are you supposed to pay the necessary co-pays?
Expected to do more for less.

What needs to stay the same?

Local case management is important

Fee for service standardizes rate across providers and CCBs

Employment opportunities need to stay the same or increase

Collaborative relationships need to continue even though we have so many challenges.

Continue to fight for the consumers – keep going for people. Even though there are issues, billing problems, 15 minutes increments

What needs to change?

Should be separate CM (especially in metro areas)

CCB need to work more with businesses in the community to get more jobs

What works in Metro should work in rural areas

Collaborate more with other organizations for transition age kids (DVR, transition, job coaches, CCB, look at options for adult services)

Waiting list – consensus on this issue

Start integrating high school folks into services – learning about what options they have.

Incorporate a class in school for career exploration.

Slots back to local community. Community needs to be more educated as to disabilities.

Funding cuts have really impacted the exposure to the community. “My daughter hasn’t left the day program building in two years. She used to be in the community at least 2-3 times a week.”

What happens to older people when they retire? They should be able to retire. They should not have to go to day program. It has to change. “Why can’t she stay home and watch the Price is Right and knit?”

Families are filling the gap for things their adult children need.

Additional Comments

Legislators should have been here. They make decisions without understanding who they are impacting.

Elderly parents – no planning process for their loved ones.

Provider – This is my 29th year of providing services. “I want bureaucracy to get out of my way so I can do my job!”

Self Advocate – “it is not fair that consumers have to work for free. They told me that I needed to come to work whether I want to or not so my providers can get paid.”

We need to be careful to not let things go back to the 70s with folks ending up in state hospitals.

“You don’t need to help me just get out of my way”

Get rid of 15 min reporting

The rate for supported employment should be reduced. It takes up too much of an individual's plan dollars.

Reinstitute self determination programs.

Reduction of paperwork

Parent – 33 year old daughter lives at home and requires 24/7 care. She no longer has respite care dollars. She has to pay for it out of pocket. She and her husband have to take separate vacations because they don't have respite.

Parent - Waiting list scares the daylights out of him

Hope this focus group will make a difference

Parent – “we may need to resort to becoming activist to make changes in the system”

Self Advocate – Services have drastically changed his life.

Parent of a six year old – Technology will need to play an important role

Thanks for the opportunity

Peak Center, ARC, Transition services have really helped. These support organizations need to be there to do this work

You can accomplish a lot more with many people than you can with a few. It was a blessing to be here. DD Planning Council has a grant project to get younger families involved

I feel passionate about people with DD. I sit on boards and will continue to be involved in the community (even after I retire) representing the interest of people with disabilities

Churches should be tapped into. Sustaining things locally is the only way we can make it happen

3rd party approval for CES is not working

DVR is not working in C-Springs

No safety net for people with disabilities

“It makes me crazy that people who support folks with disabilities are as devalued as the people they support”

Alliance Focus Group, Northeast, Windsor, Colorado, 7/13/11

Participant Demographics

- 16 participants
- Age Range 26 - 64
- Median Age 47.9
- 2 Self Advocates, 7 Family, 7 other
- 5 Males, 11 Females

Service Access

Started in direct care field with residential services – ADLs

IEP - first learned about the DD services in an IEP. She resented it and it caused her to put off taking advantage of the services. Staff should take separate time to discuss community service options.

Family Support Services - child is again out. She was an advocate in the system so she knew where to go.

Daughter was on the wait list for 6.5 years. Very little information while on the wait list. Almost liked they were shunned. Needs to MRI focus for folks on the waitlist
6 people on wait list 1-8 years.

One parent applied and was denied. Found out through a support group that they should re-apply. Their daughter was on the wait list for 5 years.

**Did you have someone to rely on to help you access services?*

Found out through other parents. No, I did not have anyone, disjointed system. EI - contact at CCB went to preschool at FGI. We had good support from folks in the school district and FGI, parent support group and once in the system, CM helped.

Found out accidentally about putting their child on the wait list. One found out at church.

Another mom found out at an IEP.

Parents have shared information with other families

**Did you get what you needed?*

3 yes

3 in-between

1 still waiting

1 is not getting the right support and gets more from the EBD wavier

Priority Areas

Informal networks for communication

Waiting List

Health and Wellness

Changing doctors has been a real problem - it is tough to get Dr that understand

Dental care is a real issue - folks have to go Denver and C-Springs. Medicaid only pays for dental under GA in a hospital setting.

There are not paid medical services for kids

Health district has been working on getting dental care provided in Larimer County. Started treating folks in Feb. It has been a two year process to get this is in place. HCPF needs to send out a paper explaining how folks can successfully get services while on the wavier. There is a shortage of Medicaid dentist and facilities for dental under GA. Tough to find dentist who are willing to work with someone who has a disability.

DD Nurse for several years. The nursing level of supports for folks is not adequate. CCBs and PASAs are not held accountable to what needs to happen and the direction from the state is not clear. There are not enough nurses!

Mental Health Services - behavioral needs are high. He is worried for families who are trying to deal with behavioral issues. They are not getting the supports and the problems are left for months and years until it is too much for community placement. They end up in the reg center or over medicated. Families are getting hurt - literally!

Adolescents will DD are not offered any mental health services - they can get meds but not counseling.

Priority Areas

Access to health, behavioral support and mental health services are limited

Dental Care is a big problem. Folks have to go to Denver or C-Springs

Finding health care providers who take Medicaid and who are educated in serving people with developmental disabilities

Dual diagnosis is not recognized

Provider Capacity & Quality

**What are the attributes of good/bad service organizations?*

Bad - For profit service providers have a dual role - she worries about the impact on the actual service delivery.

For profit provider- sees his business as being able to manage money directly than a non-profit that may have to go through a board.

Provider likes having the options to work in other CCB areas.

RFP process is an open process and that is good thing. It is open and fair. It is not done in every CCB area. It allows choice.

Good organization pays a living wage. It allows continuity and stability. This population needs this.

Case managers - good providers have knowledge of other services, will brainstorm with other providers. Knowledgeable and innovative are good characteristics.

Has son with autism - CM does not know where to go to get socialization skills for her son. CMs don't know these resources. They don't know the therapies available. Invest now and the person will need less supports later.

Envision provides good services. They want folks safe, happy. They will work with you. Openness and fairness are important.

Is hard to find out where the resources are. Parent used to be involved with Autism Society in Texas. She knew where the resources were there. She doesn't know where they are here.

Priority Areas

CCB are doing things right

RFP process is favorable

CM is favorable, knowledgeable

Good availability of providers - providers are providing a quality service.

Community Connections

**How are people connected to their communities?*

Employment-there is a gap for folks with DD to gain employment. Daughter has had a variety of jobs and there needs to be training for those front line supervisors.

Supported employment works with DVR - it is the main contact for folks looking to get back into the job market.

Biggest concern is authentic community roles - Real work or volunteering in the community. We tend to make stuff up - interactions need to be real life. Really looks to this for the 18-21 year olds he works with. Needs to be pursuing meaningful roles. There were several folks who agreed with him.

Friendship roles - school system did provide a culture where her daughter flourished.

When she left that school to go to middle school it was a very tough transition. That culture was set by leaders in the school community.

Feels school district does a great job with her son. He participating in community and the community embraces him.

Self advocate – She would go to FGI CM and ask for help, her HHP and her work supervisor.

People First provides opportunities for folks to participate in the community.

Special Olympics give the guys he support a chance to be leaders.

Parent - what will happen to their kids when they are not here.

**How do you educate other natural supports?*

Churches

Would like to see ARC or CCBs reaching out and educating others.

Self Advocate - Frontier House - goes to them for help. ARC helps her as well.

Self Advocate - relies on FGI and thinks they are really good at finding her supports.

Priority Areas

Authentic Relationships and roles are key for folks in the community and devoting resources to make that happen will take pressure off the system down the road.

Jobs are important.

What is working?

Recreational program is working

Referral process is working - RFP process is giving folks choice

Got 65 service providers on a list to choose from. It was real choice

The CCB system works. Provides team work and keeps providers working together
CM in CCBs is working

Communication and collaboration is working

Providers are there for her child

The local system is working

What is not working?

Things become more difficult when they have to go to the state level. Information is poor, not great tech support, bureaucracy. Gave example of a dental procedure

Mixed message from CDPHE and DDD about regulations

Large number of people who are out there waiting are utilizing services that are not designed for their needs - ER dumps, assisted living, folks getting into other LTC where they cannot be refused.

Fair system for folks coming off of the wait list

Lack of planning for the aging DD population and aging parents

CCB system does not work in all parts of the state. It is better here.

In the metro there are real issues, cm turnover, excessive admin salaries, low pay for cm and other direct support professionals.

Too many levels of approval for service plans - duplication of services is expensive and wastes resources.

SIS levels are not working for folks with high needs.

Borderline folks are not getting services.

Medical model is a problem. We should be focusing on a social model - integrating the whole person.

Money drives the decision instead of need driving the decision. Colorado spends more money on casinos than people with DD

CMs are asked to do too much - underpaid and undertrained

CCBs are asked to do too much

CMs are required to sit behind the desk rather than meet with families

Communication is not organized and there is often information that is not shared with critical players.

Changes are not well planned and are often implemented before the training and communication plan is thought out

DDD is not working

State depts are not working together even when they are serving the same groups of people.

There is a belief that someone else will take care of issues

Working out funding is not working - you have to keep going back to make minor changes.

Then funding structure is complicated and difficult to accommodate client choice.

What should stay the same?

CM needs to be local

Wants her job to stay the same

Wants her services to stay the same (job, residential and CM)

Want my son to remain in is group home. He is happy and it is home. I want him to keep his day program.

Wants them to continue to let consumers pay for their own activities.

Individualized services are going really well

Collaboration

What must change?

We need more flexibility in funding to encourage client choice. Clients can't choose any variety because it takes too long to go through the service plan process to change to meet people 's need

“Would like to see CCB systems change - it may have been important when folks were coming out of institutions but the landscape is different now”

Transition cliff - the waiting list is long. There is no transition opportunity for kids. There is no opportunity for kids to continue what they are doing when they come out of the district.

More funding for transition services. Need to focus on real life outcomes for kids.

“20 year waiting list for services is unacceptable. We know that if we can get real work options for kids it will take the burden off the system later in their life.”

Additional Comments

Wants to see the possibility for her son for continued education.

Better training for parents (guardianship, trusts, etc)

More residential options for aging folks with DD, need more options for medical needs who need residential options

More awareness of what it is to have a disability

Level of advocacy is so strong and we need to keep that up no matter what

Would like to see a change - easy to navigate system and one that is easy to get information on.

Fiscal perspective - how do we manage a system that has finite dollars

Need to form a system that is coordinated and comes together

One parent works for a Senator and she has her cards with her. She would like to share the focus group report with the Senator

Wants the funding to not be reduced - worried about her SSI ending

OT/PT training having to be done by the current regulation is not paid for to re-train when there is turnover.

Full implementation of FCG act and Self Determination

Mobilizing Families - training for families. Also mentors families who are seeking guardianship and seeking SSI

HCPF - repetitive letters for his daughter's Medicaid status

Colorado is in the bottom 10 for funding and in the top 10 for quality

Children services - big disconnect for county supports. Should be in the CCB services.

Individuals who have criminal records who need to be in a more sheltered environment

It is important for all of us to unite. When resources are tight we tend to fragment. There needs to be more collaboration between all the groups.

Social roles - we need to encourage more relationships for people with disabilities.

Relationships are so important and they are formed by getting people connected to real social roles.

Alliance Focus Group, North Metro, Longmont, Colorado, 7/14/11

Participant Demographics

- 18 participants
- Age Range 27 - 73
- Median Age 51.6
- 4 Self Advocates, 10 Family, 4 other
- 8 Males, 10 Females

Service Access

Works with the school system – school system has lots of challenges. There is a long waiting list for services in the school district

Waiting list

Waited 1.5 years. They moved here from another state and didn't even know they needed to be on a waitlist. They found alternative services through the EBD waiver. They also get CDAS through the EBD waiver.

Note – why is there never a waitlist for EBD waitlist and there is for DDD services?

Self advocate – has been on the waitlist for 11 years to get services

Self Advocate – waiting for 1 year

Moved back to Colorado in 1984 – took five years to get services for his son.

Daughter was on a waiting list for GRSS when she was 5. When she turned 18 she came back to Boulder and it was really difficult to find the services she wanted. She went to the top of the waiting list since she was the only person needing that type of service.

Daughter got SLS and is on the comp list for 10 years, but he doesn't ever expect to get services.

**Does anyone know how the waiting list works?*

They put you on the wait list and you just wait.

You can go on the waitlist for adults at 14. Then you come up on the list based on your application date

Daughter – did get emergency services due to the level of services their daughter needs.

No one would serve her so they are in a pilot for in-home care.

**Are you getting the services you need?*

Yes we are getting the services in our home and it is the best situation they can imagine. She is very aggressive and could end up in the state hospital. She has been charged with assault and if she has one more incident she will go to the state home.

No – 4 people are not getting what they need.

Getting SLS services for their son and he does have a job. SLS cuts have put much more burden on the parents.

**Did you have someone who helped you find services or guide you through the system?*

Uses Imagine and ACL (ARC) – parents call her all the time and it is difficult and confusing

Got help from ACL (ARC)

Self Advocate also got help from ACL (ARC)

Got referred to ACL and things started to happen for their family. They did know a lot of people because their child has such a history and it was still difficult. It wasn't until they got to ACL

Priority Areas

Lack of knowledge of resources and other services available to them

Waiver issues

Waiting list – when you are on the wait list cannot access the mental health services

Health and Wellness (best possible health)

Need a good health provider. It is tough to find someone who is willing to deal with behaviors or needs. Also tough to find someone who will take Medicaid.

Mental Health Providers do not understand dually diagnosed

It goes beyond the providers – it is also the staff and whether they will support the person's needs. Need staff support to go for a walk, get exercise.

Choice vs. Healthy Lifestyle

Self Advocate – is type II diabetic. He has to exercise and there are programs available through community support programs like ACL

Peoples clinic – pediatrician. Doctor's office needs to talk folks through the process of identifying issues, set goals and working through the issues

It really works to have a nurse who works as part of the IDT and then you can call them when something comes up. Providers contract with nurse for supports and to have them on a team is so helpful

IP process – it is great to have a nurse there

Health history often gets lost – as folks move from agency to agency pieces get lost. People end up not getting those things attended to.

Priority Areas

Planning – support to learn about their health care and choices

Dual diagnosis – bringing mental health and health care together

DDD is not working

What makes a good or bad service provider organization?

Imagine and Day Spring – both good. It is the first person you meet as your CM, therapist. Strong CM is important.

Imagine could be better if they could provide more information about alternative services
Public Forums – it is good when providers hold open forums. No one shows up, but they should. It is important to encourage collaboration.

Even links on a website – no resources. They ran into someone at church who showed them

Googles for information

Good quality - cultural awareness

Good providers in foster care are paid well – bad that bio families can't get those resources

Service access is tough – even at the state level

CHIRP – no flexibility makes it a bad provider/service

No collaboration between DDD and child welfare

Bad service provision puts people in boxes – everyone is so nervous about giving parents a few dollars. There is an assumption they will misuse dollars.

How did you get into your services?

5 - by accident

6 - deliberate

Priority Areas

Strong service coordination

Complex service requirements

Staff retention

Community Connections

Employee, Family member, Friends, Connection with Service Provider, Church Member, Neighbor, Citizen, Building a social network, Daughter, Boyfriend/girlfriend, Husband/wife, student

**Who supports folks to build social roles?*

Parents and care providers

ACL – provides forums to bring people together

Talking and asking for help – taking responsibility for reaching out

Recreation programs – special programs for DD

Provider can help someone meet others

Family members or friends

Visibility is important – it is tough because his daughter is not easily taken into the community. No neighbors relate to her, she just doesn't have any friends

It really is parents and staff who are their friends

The more serious your disability is the fewer opportunities you have for social roles
Parents are really in charge of building the opportunities – what happens when you are not around.

ACL does training around how to structure a social network.

This is a paid system and auditors

“No one is healthy and safe without relationships and this does not matter in our system.
It doesn’t get the attention it deserves”

Providers are pigeon holed by rules and regs and are not allowed to support people in social aspects. Extracurricular activities are getting cut.

Depends on who is involved – but funding models do not support it

Group homes are outdated. Host homes offer more opportunity.

Due to situations people have to be moved – when they had to move they lost their social network because it is connected to their provider.

If you build strengths for folks then the SIS drops and the funding drops. Folks then lose the connections.

What’s working?

CCB as service providers

ACL

In home model of service is working

Medicaid state plan is working – mixed with Imagine services

State funded SLS is working – allows him to work as a dishwasher (26 years on the job)

Special Recreation program is working

Employment is working

Employment program in school district has really worked

What is not working?

Pigeon holed in a type of program

Parents have to advocate for children to get a job

People are not treated as individuals

DVR is not funding people with disabilities very well

CHIRP is not working (too challenging and no flexibility)

Funding cuts are limiting options

Goal for school district is not employment – there is not a priority for true independence. They are not preparing them for real life. These are damaging system problems in the schools.

Integration is not the model and we do not start day 1 building the culture of acceptance

Transition program is cookie cutter and they do the same thing every week.

What needs to change?

The school district needs to change how they work with kids with disabilities

There needs to be more funding

Mailing list state wide to be able to share new resources

Need to have more information about available resources

Develop a flow chart of options for everyone to use (families, providers, Drs)

More information at Dr office for families when they first find out what is going on with their kid

Need to pay more to providers

More education for health care providers – where to send them

State needs to give providers more training to get more help for the people

School district needs to work more on basic reading and writing skills

Dollars need to be closer to the person – self direction

Need to recognize that families do know best – (several nods)

Stop making decisions based on the problem situations.

People in color community are not being represented and outreach needs to be improved

Increase state sales tax to help education

Need self determination from the start – teaching kids from the beginning to understand their disability, self determine. Nothing about me without me

Waitlist – you are either in the system or out of it

Parent need to teach their children to be independent

Get ACL, Imagine together on the same page to help the general public understand the needs of folks with disabilities. More collaboration in the community

What needs to stay the same?

Imagine!

Child Find

Services should stay the same (just need to be expanded) – Services +

It is working when the state give resources to families.

Additional Comments

Thank the people who put this together. It is important to have these conversations

School districts – we have to start when they are young to teach folks. Vote taxes in!

Everyone is an individual and needs to be addressed

Medical Home – pushed by CDPHE. You should ask your Dr is they are trying to be a medical home

Parents getting more funding because they know what is best – has worked with people who don't have families or families are not working in their best interest. We shouldn't push families into the care provider role.

Self advocate – paid employment. He has been looking a job for 2.5 years.

Climate in this country – poor people and people with disabilities are overlooked. People need to fight for this.

School districts need to know what their responsibilities are

More funding

More funding and take responsibility as citizens

Elected officials should go on the health care the rest of us have.

DHS and HCPF have lost their way. The SIS level has turned into a tool to cut resources as opposed to assessing needs.

The one thing that needs to change is the transition from C to B as it causes kids to have gaps in services. Deadline for applying for a preschool is prior to your child find visit. They need to figure out a way to work together.

Every comment impressed her – she was

More access to the resources.

Surprises: no one mentioned the inconsistency in the system and how the SIS system is not really working.

Alliance Focus Group, Denver Metro, Lakewood, Colorado, 7/14/11

Participant Demographics

- 16 participants
- Age Range 34 - 72
- Median Age 52.6
- 2 Self Advocates, 10 Family, 4 other
- 2 Males, 14 Females

Service Access

Parent – first access was for her daughter. It was confusing. She heard language she had never heard before and had to figure things out for herself. It was overwhelming. Confusing is the word she would use to describe her experience.

Parent – came from Ca. Told her to take her daughter Fletcher Miller. She had to take her to a different school. It was a positive experience.

Parent - EI was referred to the CCB by the school district. The pre-school is not good. They don't follow testing protocols – it was upsetting. She was a teacher so she had a good idea of what was supposed to happen. The EI support was good. Will enter Part B in September

Parent of child with TBI and had excellent supports for her son through Cherry Creek school district. She had been a teacher and did have to fight to assure her son's services. Had to battle the process to get services. Her DP Case Manger was wonderful and helped her through the process of moving into adult services. Smooth transition process and now he is getting SLS, but is on the waiting list for comprehensive services.

**How many have been on a waiting list?*

10 people are on the waiting list.

Son is 12 – first waiver wait was 4 years, second wait was 3 years. He received early intervention services, but no other services while on the wavier. He is currently receives CES wavier.

Came in 1969 – told that he should go to Jeff co. He got services immediately.

On a waiting list for wavier services - about a month at this point. Think it might be a long time

Waited for 5 years – is now on SLS. Went in on comp, but did not meet her needs

**How does the waiting list work?*

Geared to your date of application – 14 years is when you can go on. They have been in crisis and it has been difficult to find out where you are on the list.

One person is on a waiting list and not receiving any services.

Daughter got services off a lawsuit – off of the King lawsuit

**Who did you find that you could rely on for good information to access services?*

ARC advocate

Other parents

Myself

Information is confusing and conflicting so it makes it difficult. She just spoke to a family yesterday that the county DD services told them they were not eligible for the EBD waiver. They were eligible.

You have to keep asking to find your way

Trainer – he trains providers, families and youth in the DD system. You have to use certain words, terms and need to learn what to do to get into the system. Providers know how to work in the system but parents don't have the same information. Service providers are not necessarily available to families if they are not in services. People get bits and pieces from the different agencies.

It just can be overwhelming – parents find it difficult to complete. Even if you know the system it is tough. One parent who has a disability herself has to get help to complete the paperwork.

Priority Areas

Waiting list – no services while on the waiting list

Information is inconsistent and confusing

Health and Wellness

**What supports do people with DD need to have best possible health?*

Behavior intervention and training – DDRC has a mill levy and set up their own clinic

Finding a health care provider who understands the disability. You have to see so many doctors – one for this problem, another for that problem.

Lack of mental health services for intellectual disabilities

Have mental health services been available? Kinda of mixed response

Mental health services are not necessarily accessible to folks with DD

Hard to find doctors that take Medicaid and know about

Parent – has been very happy with Kaiser- Medicaid

Many folks are using clinics that have residents – good but you always have a different Dr.

Behavioral services are limited. The availability is not good.

Medical care for kids – Children's Hospital is really good but as kids age out it becomes different.

The real problems are when you go into the adult system

Dental services are a nightmare!

You have to find someone who is willing to treat the whole family – not just the patient.

Payment rules are a barrier. Different waivers have different services that are available and that is so confusing for parents.

Health supports that are provided by the non-medical community

Health club – the access for transportation and supports is limited. A few people.

Self Advocate – he has had his services reduced and has to work with his provider to try to figure out how to get everything done.

Priority Areas

Lack of information for health care providers

Health care providers need to educate the family

Access to Medicaid providers

More success when their children were younger

Provider Capacity and Quality

**What makes a good/bad service provider organization?*

Good – well trained staff

Bad – high turnover rate. Self advocate described how he really does the training for his provider and then in a few months they go.

Caring staff

Bad – assumes she is clueless. Don't tell her how to parent her son. Ask her some questions about why she does the things she does. She knows her son.

Good – the parent would be treated as a team member. Value and respect the family – be a team with the family. Don't leave me out

Good – would look at each person as an individual and focus on abilities

Good – be responsive. Call back

Good agency has a large number of parents on their board.

How would I select a good provider for my daughter? Get her involved with Down's Syndrome assoc, DP, talk to other parents, DDD, google it, tell them first of all – don't move to Colorado! The wait list is too long. Send you to PADCO and Parent to Parent. Contact the local ARC chapter

Priority Areas

Services are good if you can get them

Well trained staff

Parents want to be a part of the team

Changing role of Case Management

Community Connections

Employee, Church member, Family member, Neighbor, Team member, Student, Homeowner, Employer, Volunteer, Citizen, Girlfriend/boyfriend

Friend – it is tough to find friends. It is often paid staff who takes him places. There have been cuts. One person has places where she is known and enjoys going, but does not have typical friend. Friends are often in the same group of folks they hang out with at Special Olympics, but not in the “outside” world. When younger is easier, but when they get older it is hard.

How do people establish these roles?

Family

Knights of Columbus – Service groups

Paid staff – provide transportation, training, keep you safe, introducing you to people

Schools

Create environments where folks can meet each other. Example is DS Football Camp – once introductions are made parents have to plan it and sustain it.

Spontaneity in doing things with others is lost when you need support.

Priority Areas

Lack of Friends and relationships

People believe they need intentional and organized support

What is working?

Paid staff is working – funding cannot go away. Need to maintain the level of service

Sheltered workshop has been a saving grace

Keep the choices for families – need to have a spectrum of services.

Family Caregiver is a positive thing

What is not working?

Cut backs

Not flexible as it used to be. It is horrible

Inconsistency – the information from the state is so inconsistent. It is confusing and inconsistent.

The ups and downs are so difficult. She is getting this information from HCPF.

One parent took them to court because it was so inconsistent.

Information is different from CCB to CCB. One CCB may tell you to end a service and another tells you to continue (don't worry about it).

System is such a state of flux

When the governor changes then dept staff change.

There is not a single point of contact – you have both DHS and HCPF

Rules and regulations are constantly changing – it is as confusing for providers as it is for families

Term limits are causing problems

The waiting list

The SIS is a joke – self advocate did his SIS interview and the more independent he appears then his services get cut.

The SIS is not administered consistently from one area to the other. Interviewers run the assessment differently.

Self Advocate had difficulty getting new crutches because he had to prove he needed them. He had to keep calling his supplier and she called Medicaid to get them.

CM and staff in the system used to be able to advocate, but now they are so tied up with paperwork they can't advocate. Folks have to do that for himself. Admin requirements have dramatically increased. Everyone has experienced this change in Case Management and Service Coordination.

The annual plan has changed from hopes and dreams to just what they can't do. Families who have lost services have to stay home and do it themselves.

What should be the same?

Collaboration

Access to other supports (organizations and community supports) that are available for families in their communities

Want to keep their current services

What needs to change?

The waiting list

We need Self Directed Services! It is in the wavier but you can't access it yet

The SIS needs to change

Need to put back the SLC

Parents need to stand up and fight. When one parent tried to do that folks (ARC, Denver Options) told her it was not a good idea. "I am going to fight for every right my daughter has, if I don't they will continue to take her services and she won't have anything left"

Additional comments

Lack of information from the state level – parent to parent is great

State of Colorado needs to simplify the waivers – there are too many and too confusing.

Employer – this was enlightening

Problem in Colorado is when HCPF got involved five years ago. The people at the state level at DDD were impacted by the threats made by HCPF. DDD is like a deer in headlights. HCPF is running the show and now DDD doesn't have much power and has been taken out of it.

Positive EI services were usable and tailored to her son's needs

The system is too rigid and the caps within caps is a problem. Right now you cannot make decisions to work within a cap – too much control.

Things are not very positive right now. The system is killing us as advocates because they get tied up in managing the inflexibility and so they can't advocate as a group.

Doesn't see the younger parents around this table

Lack of leadership at the state levels – the right people are not in the right positions. Gov, legislators

State of Colorado 6 in the US for wealth and 43rd in the state for service funding. Tax base needs to be looked at.

The accessibility of services – rewording the application for services so folks can understand it and have access to it. There should be some place they can go and get support. Need more supports for Spanish speaking and need to be culturally competent.

Self advocate – would like to have more funding because he has had to cut his services so far back. If more cuts happen it would impact his independence. If he could have more funding - he would like more provider time to assist him access the community because physically he cannot do that.

Transportation – para transit is not geared for folks with disabilities and their families to get where they need to go. It is not user friendly.

Inconsistency and lack of information available. Consistent information between CCBs would be great.

Lack of communication prevents folks from getting out to candidate events. It is so important to come to events and speak out.

Three things – grateful and please with what services they have. They are fearful these will be cut. The comp waiver is providing good supports. Need more flexibility with employment dollars – maybe employer incentives. With caps in supported employment folks have had to cut back the time they can work

Frustrated when there isn't a protocol to get something done. Guide for parents would be so helpful. Parent was asked to sign a form for "alleged" Down Syndrome. Wants single entry for coordinating insurance and other events. More user friendly information. Repetition of paperwork is ridiculous.

Would like to see forethought when they are going to implement changes. Would like systems change based on what people need and that the departments talk to people.

Additional Projects/pockets of excellence – Down's Syndrome Clinic

