Alliance

December 28, 2011

Dear Stakeholder and Interested Party:

It is our honor to make available to you the Final Report of the Alliance Focus on the Future Project. We especially want to recognize the Focus Group participants, the Project Steering Committee and the Project Workgroup for all their work. We also acknowledge the Alliance Board for their insight and support of the project, and funders for their support as well.

The project consisted of two key phases. In Phase One, five regional Focus Groups met to gather input to identify what's working/not working and aspects of the service delivery system that must stay the same or must change. People receiving services and families were the starting point of the project and composed 68% of the focus group participants. Phase Two was the Workgroup Phase where system stakeholders were invited to join the Alliance Project Steering Committee to formulate recommendations for change. Workgroup participants included people with varied backgrounds and experiences.

The Workgroup analyzed five problems they identified as the root cause of the issues expressed by focus group participants:

1. The System is too complex;
2. Resources are not allocated in a way that meets people's needs;
3. System focus is not first and foremost the person;
4. We don't have formal systematic mechanisms to self direct I/DD services; and
5. We don't have the data infrastructure to assess our system.

The workgroup developed recommendations to address these five problems. Please reference pages 12 to 17 of the Report to review the recommendations. To obtain the report go to www.alliancecolorado.org; there is a link on the homepage to the Focus on the Future Final Report as well as the Focus Group Report.

We would like additional feedback on the report. Please go to www.surveymonkey.com/s/FocusOnFuture and take a quick survey to provide us with additional feedback. Based on input we received, we are issuing clarifications to the report which are highlighted on pages 11, 12 and 17.

This is a time of unprecedented change for services and supports to people with intellectual and developmental disabilities. We look forward to working with you on implementing the recommendations of the Focus on the Future Project.

Sincerely,

Chris Collins
Executive Director, Alliance

Mike Atlas-Acuña
President, Alliance

ALLIANCE

Focus on the Future

Final Report
12/1/2011

Chris Collins, Alliance Executive Director

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Executive Summary

Alliance is a nonprofit, statewide association of Community Centered Boards (CCB) and Service Provider Organizations (SPO) committed to the advocacy of member organizations and the individuals and families they serve. Working within a window of opportunity to play an influential role in shaping the future of community based services, Alliance established a project steering committee to oversee an initiative, *Focus on the Future.* The project's goal was to gather input from self advocates, families and other system stakeholders and use that information to develop recommendations for change.

In Phase I of the project, the Alliance steering committee joined with local Arc chapters to gather input from local stakeholders to identify system strengths and weaknesses. Together they hosted five regional focus group meetings. Over half of the focus group participants (68%) were self advocates and family members.

Generally, participants' perspectives were similar across geographic regions. Participants outside of the Denver metropolitan area, did however, report greater difficulty in accessing services than their urban counterparts. Focus group participants throughout Colorado reported frustration with service system access. They were comparatively positive about provider capacity and competency. Participants in all focus groups voiced dissatisfaction with systems that undergird intellectual and developmental disability (I/DD) services and supports. These systems were described as inflexible, requiring people to "fit funding" rather than funding fitting people's needs. Advocacy was a common topic raised by participants in each of the focus group meetings. Participants agreed that family advocacy plays an essential role in securing services. They expressed concern for those that did not have family or friends to advocate on their behalf.

In Phase II of the project, system stakeholders were invited to join the Alliance steering committee in formulating recommendations for change. The workgroup analyzed five problems they identified as the root cause of the issues expressed by focus group participants:

1. The system is too complex;
2. Resources are not allocated in a way that meets people's needs;
3. System focus is not first and foremost the person;
4. There are no formal systemic mechanisms to self direct I/DD services; and
5. There is no data infrastructure to assess our system.

For each of these problems the workgroup formulated recommendations. The following recommendations were categorized as system redesign initiatives that required authority for implementation beyond that which is vested in work group members.

- Waiver consolidation which may include creation/development of coordinated and integrated services and supports;
- Streamline compliance by designating a single regulatory master; and
- Make self directed services an option that anyone can choose for any service.

The workgroup also made several recommendations they identified as within their authority to initiate and implement. Recommendations the workgroup members have committed to champion are:

- Create online tools to improve system access;
- Develop increased capacity for behavioral supports;
- Leverage employment resources;
- Make person centered planning happen;
- Collaborate with education;
- Identify, gather and analyze data; and
- Identify and measure meaningful outcomes.

Focus on the Future workgroup members have made a commitment to take these recommendations to self advocates and families for feedback. It is their plan to engage a broad base of perspectives in refining a vision for the future. They are committed to transforming the words of this report into action to affect real and positive change.

Background

Home and community based services (HCBS) provide an alternative to costly institutional care and an enhanced quality of life to people with I/DD and the communities in which they live and work. In 2009, public I/DD spending in Colorado totaled $473.2 million. Of this amount, 68% was used to purchase home and community based waiver services for approximately 7,804 Coloradoans.[1] The average annual cost of community based services was $40,400 per participant.[2] Annual per person expenditures in Colorado's state operated institutions was $197,500.[3]

In comparison to other states, the funding Colorado makes available for I/DD services falls below national averages. Ranking 34th,[4] Colorado's annual average participant cost of community based services is on the low side of the national average. When I/DD funding is put into context of the state's comparative wealth, the state's status is further diminished. Fiscal effort is a ratio that ranks states according to the proportion of total statewide personal income devoted to the financing of I/DD services. While Colorado's fiscal effort rank of 47th[5] is influenced by a variety of factors, the state's significant wait list to access HCBS plays a weighty role.

According to a fiscal year 2010-11 Joint Budget Committee (JBC) briefing document, 8,115 people will need services within the next two years. Anecdotal reports indicate that time spent on the wait list may vary but may extend into several years. The state's ability to address the waiting list issue has been compounded by a weak economy that has resulted in budget cuts at various levels throughout state government.

Colorado's I/DD service system has had an illustrative history of innovation and service excellence. Administered under authority granted to the Department of Health Care Policy and Financing (HCPF) and operated by the Department of Human Services (DHS), the system relies on a network of community centered boards and service provider organizations for the provision of services to participants. Diminishing resources have called into question the sustainability of the system as it is currently structured. As state leaders consider significant reforms, system stakeholders are presented with an important point-in-time opportunity to influence the evolution of services essential to Colorado's citizens with intellectual and developmental disabilities.

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[1] *Source:* Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2011, p. 122

[2] Ibid., p. 25

[3] Ibid., p. 56

[4] Ibid, p. 34

[5] Ibid., p. 60

Approach

Focus on the Future is a two phase initiative that began with planning by a representative group (steering committee) of Alliance members. In Phase I, self advocates, families and other stakeholders were invited to provide input via regional focus groups. Phase II convened a workgroup of system stakeholders and subject matter experts. Together they analyzed issues brought forward by focus group participants and formulated recommendations for service system improvement.

Planning

Initiated on May 16, 2011, the *Focus on the Future* taskforce met weekly via teleconference to design and oversee each phase of the project. The taskforce was also responsible for securing funding to support project activities. (See Appendix B: Listing of steering committee members and Appendix C: Listing of financial contributors.)

Focus Groups

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 I/DD. With this understanding, *Focus on the Future* solicited the input and feedback of self advocates, families and other local service system stakeholders. A total of 84 people attended five regional focus groups.   Fifty-seven participants identified themselves as either a self-advocate or a family member of a person with a developmental disability. Focus group meetings were dispersed geographically:

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

Following each focus group, meeting organizers met to analyze information and identify major themes and recurring issues. This information was compiled by the project's consultant and focus group facilitator, Wanda Seiler and the project leader, Sally Montgomery.   The project's Focus Group Report was distributed to the public in August 2011. (To request a copy of the Focus Group Report contact Alliance 303.832.1618 or go to the Alliance website at www.allianceolorado.org/)

Regional Trends

In comparison to families living in the Denver metro area, participants living in non-urban areas reported longer "waits" for services without being offered service option alternatives. These families reported significant hardships created by limited service access. Within the vicinity of

and in the Denver area, participants reported comparatively shorter waiting periods for services. While they were waiting, they were offered service alternatives and had access to state leaders. These participants were more focused on employment related issues.

Common Themes

The way people enter and navigate the I/DD service system or **service system access** was raised by participants in all five focus groups. The waiting list was identified as the predominant issue and an apparent source of other service system issues. The service system was described as complex and difficult to navigate.

The **systems** that undergird services and supports were described as inflexible requiring that people "fit funding" rather than funding fitting people. Participants asserted that state agencies hinder the provision of services, don't understand the needs of service recipients and were inconsistent in the application of regulatory standards. They contended that change is not well planned and often accompanied by unintended and negative consequences.

Comments regarding **provider capacity and competency** to meet services needs were comparatively positive. Many people expressed gratitude for the services provided by "committed and caring staff." Participants spoke positively about a variety of available housing options and the collaboration that occurs between CCBs, SPOs and other local organizations. They shared concerns about low wages for agency staff, the lack of systemic mechanisms to self direct services, and limited employment options. Some felt that person centered planning approaches were not at a level necessary to achieve self determination.

In the area of **health and wellness**, focus group participants reported a shortage of Medicaid providers. They emphasized a shortage of physicians in rural areas. Participants shared concerns regarding limited access to mental health services and dentistry under general anesthesia. Family members also emphasized the role of staff in supporting healthy lifestyle choices and ensuring good communication with medical professionals. They stressed the importance of ensuring health professionals were aware of patient medical history and how this information sometimes is lost or ignored.

Advocacy was a common topic raised by participants in each of the focus group meetings. Their comments were very positive in expressing appreciation for the support and assistance of local chapters of The Arc. They agreed that family advocacy plays an essential role in securing services and were concerned for those that did not have family or friends to advocate on their behalf.

Workgroup Meetings

Focus on the Future convened a series of three workgroup meetings to analyze the information gathered by focus group meetings and formulate recommendations for system redesign and improvement. Workgroup meetings were facilitated by Wanda Seiler.

Meeting 1	August 2nd & 3rd, 2011	Project Steering Committee System Stakeholders (5) Subject Matter Experts (3)
Meeting 2	September 21st & 22, 2011	Project Steering Committee System Stakeholders (6) Subject Matter Experts (2) State Staff (4)
Meeting 3	October 19, 2011	Project Steering Committee System Stakeholders (6) State Staff (3)

At Meeting 1 the group agreed upon a list of six ground rules to guide their discussions. At Meeting 2, rules 7 - 9 were proposed and adopted by the group:

1. Share all relevant information
2. Use specific examples
3. Agree on what important words mean
4. Explain your reasoning and intent
5. Discuss un-discussable issues
6. Suspend the (above) rules while brainstorming
7. Assume shared values
8. Step into the vantage point of others
9. Ground recommendations in what people want

The workgroup used a basic problem solving model (SADLIE) in formulating recommendations for system redesign and improvement:

- **S**tate the Problem
- **A**nalyze the Problem
- **D**evelop a Solution
- **L**egitimize the Solution
- **I**mplement
- **E**valuate

Meeting 1

The first two steps of the model "state and analyze" the problem were the focus of the first day of Meeting 1. The workgroup analyzed five problems they identified as the apparent root cause of the issues expressed by focus group participants. To assist the group in brainstorming potential solutions to address these five problems, subject matter experts shared professional experiences as well as their knowledge of best practices on a national level. (See Appendix D: Project Consultant and Subject Matter Expert Biographies.)

- Robin Cooper – Federal Perspective on HCB Services
- Ric Zaharia – Managed Care in Developmental Disability Services
- Patti Scott – Participant Self Direction

The group then entered a brainstorming mode in which ground rules one through five were temporarily suspended to allow for a free flow of ideas without consideration of potential barriers. At that juncture, the group's task was to put all ideas on the table for subsequent selection and development during day two. At the close of Meeting 1, workgroup members were asked to take the five identified problems and selected solutions to local stakeholders for input and feedback. Focus group hosts met with local focus group participants to review the workgroup's approach and five identified problems. The group facilitator was tasked with comparing proposed solutions to the issues identified by self-advocates and families in the focus group meetings. This "gap analysis" identified that waiting list and employment issues merited further consideration at the group's next meeting.

Meeting 2

The priority of the workgroup's second meeting was to "legitimize" selected solutions for formulation into specific recommendations. This work began with presentations from subject matter experts regarding their experiences with planning and implementation of system redesign initiatives.

- Robin Cooper – Waiver Consolidation
- Ric Zaharia – Managed Care
- Wanda Seiler – Participant Self Direction

Group members employed a decision matrix to categorize all proposed solutions along two spectrums – impact and effort. This task informed the process of distinguishing solutions as likely components of system redesign decisions requiring authority beyond that of workgroup members from those that could be championed by workgroup members. The group then worked to legitimize recommendations for system redesign and selected solutions they were committed to moving forward. Once again, workgroup members were given the take home task of vetting the workgroup's efforts with local stakeholders and returning to Meeting 3 with their constituents' input and feedback.

Meeting 3

Prior to Meeting 3, workgroup members received a draft copy of *Focus on the Future's* recommendations. Organized around the project's five identified "root causes" each problem was introduced by a narrative description of major themes and listed consequent recommendations. Unable to support some of the project's draft recommendations, one organization represented on the workgroup withdrew from participation. This organization provided written feedback that the group considered in addition to other feedback in making revisions to the draft recommendations. Meeting time was also used to outline implementation plans and identify champions for project recommendations. The remainder of the final meeting was devoted to strategizing implementation of the project's recommendations.

Results

Focus on the Future results are presented in a format that reflects the basic problem solving model – SADLIE - adopted by group members. Results state the underlying problem or issue the group seeks to address, provides a brief analysis of the problem, and seeks to mitigate the problems through proposed recommendations. Recommendations are categorized into one of two categories – system redesign initiatives beyond the authority of workgroup members and recommendations that are within the authority of workgroup members working with other system stakeholders. Each of the latter has been assigned workgroup member champions responsible for the recommendation's implementation and evaluation.

Problem 1: The system is too complex

Under authority delegated by HCPF, Colorado operates 12 HCBS waivers. Four of the waivers relate to services for people with developmental disabilities. Each has a unique service configuration, and distinct administrative requirements.   HCBS waivers for adults with developmental disabilities and most of the HCBS waivers for children have lengthy waiting lists that confound service access and make movement between waivers extremely difficult. Beyond the complex funding mechanism of HCBS waivers there are a variety of non-federal funding sources that result in geographic variation of service accessibility. People are confused by what is available, feel forced to take "what they can get," mold their needs to fit the services available, and stick with what they have even if it is not what they need or want.

Twenty community centered boards serve as the single point of entry to community services for people with developmental disabilities. County social services offices determine Medicaid eligibility. Families report frustration with this bifurcated system's capacity to produce consistent and accurate information. Challenged by a complex array of service options and funding streams with limited access, people are forced to "cobble together" services. This complexity makes it difficult for them to understand what they're eligible for and advocate for what they need.

Navigating a service system comprised of multiple waivers presents additional challenges. While there are technical experts with critical pieces of service system knowledge, they are typically housed within separate silos.   Fragmentation limits the broad information and knowledge of the entire array of services and supports that could be employed to best meet a person's needs.

In addition to HCPF and DHS, the provision of waiver services is also monitored by the Department of Public Health and Environment (DPHE). Each department maintains rules and requirements that are often inconsistent and redundant.   While compliance is a provider responsibility, the administrative burden created by a triple layer of regulatory bureaucracy diminishes the already scarce resources available to meet participant service needs. Inconsistent and contradictory requirements create an aura of uncertainty and wariness within the provider community that can stifle creativity and innovation.

Beyond the complex maze of waivers and waiver services is a multi-tiered service infrastructure in which state agencies, CCBs and SPOs play different and sometimes conflicting roles. Lack of standardization at the CCB level exposes SPOs and people receiving services to an additional layer of inconsistency and, in some cases, inequitable services and supports. The overall service system complexity conceals service gaps and makes it difficult to accurately assess provider performance. When the system fails to respond to individual situations, complexity masks responsibility for both the problem and the solution.

Recommendation 1a (System Redesign): Consolidate/Modernize Waivers

- Combine existing I/DD waivers into two waivers, one for adults and one for children. The children's waiver should include all children and focus on family preservation. The adults' waiver should be designed to serve only people with I/DD and emphasize employment and community integration.

- Waiver eligibility should be based on a standardized tool.

- Planning processes must identify individual needs and abilities, and prioritize personal preferences. Professional discretion must be used in conjunction with standardized assessments. Service plans must include an array of supports that balance what is important to and important for the individual.

- Service definitions must allow flexibility to meet individual needs.

- Ensure there are distinct processes which prescribe the coordination of Medicaid state plan services with those available in the HCBS waivers.

- Emphasize flexible services and natural supports that allow people to lead normal lives.

- As needs and individual situations change, so should supports and services.

Recommendation 1b (System Redesign): Streamline Compliance

- When multiple departments conduct regulatory activities, each department's responsibilities must be clearly delineated and expectations must be clearly defined. To ensure consistency and eliminate redundancy, all information must be funneled through a single agency.

- Regulatory efforts must be focused on outcomes identified during the person centered planning process.

- All of these efforts must culminate in a "big picture" approach to continuous improvement.

Recommendation 1c: Create Online Tools to Improve System Access

- Inventory and review existing resources for application, accuracy, accessibility and efficiency.

- Engage system stakeholders to identify information needs, current gaps and the key components of an ideal solution.

- Identify financing options and expenditure parameters.

- Outline plans for a feasible solution.

- Vet plans with prospective users.

- Automate, test, revise, implement and then evaluate online tools to support system access.

Problem 2: Resources are not allocated in a way that meets people's needs

While the adequacy of Colorado I/DD funding is subject to debate, there is general consensus that available resources are not allocated in a way that meets people's needs. The most obvious example of this problem is the lengthy wait for services during which families receive limited or no support. Contrast this with people receiving comprehensive services when they may prefer and need services that could cost much less. Until that paradigm shifts, there can be no certainty in responding to the question of adequate resources.

Children sent to live in out of state placements illustrate how systems elect costly alternatives over adapting existing community based services. In spite of overwhelming evidence that the most efficient and consistent source of services and supports is family, parents may be forced to relinquish custody to get their child the services he or she needs. While community re-integration for people living in institutions is a shared goal, success hinges on deliberate planning and access to community based services. A greater investment in preparation and flexible resource allocation can yield high returns and avoid both the emotional toll and financial cost of transition failure.

Recommendation 2a (System Redesign)

Create/develop a system of coordinated and integrated services and supports that meets individual needs, acknowledges personal preferences and enhances family and community support. System redesign must support the ability to project and manage costs, streamline enrollment, simplify administration, integrate care, offer flexible services, and incentivize the cost effective allocation of resources. System redesign of this magnitude will require a radical reconfiguration of infrastructure and roles as well as significant planning and effort.

- Data must be meticulously mined to formulate a design and assess feasibility – the devil is in the details.

- Savings derived by controlling costs must be used to reduce/eliminate waiting lists for services.

- Care must be taken to ensure that vital functions upon which local communities rely - fund-raising, the deployment of local tax dollars, local planning and coordination and emergency response, etc. - are not lost.

- Acute care, dental and behavioral health services should be integrated with long term services and supports.

- Resources should be adjusted to meet people's changing needs and family situations. Giving up resources when they are not needed means they are available when they are needed.

- Create a robust system of case management that seeks to balance person/family choice with the Center for Medicare/Medicaid Services (CMS) views around conflict free case management.

- Design must hold true to the mission and values of self-determination. Prioritize what's good for people and maximize opportunities for local control.

- Solicit stakeholder input throughout design and implementation.

Recommendation 2b: Develop Increased Capacity for Behavioral Supports

- Assess current funding of behavioral supports to identify service gaps.

- Develop a plan to address service gaps to include cost projections, a plan for recruiting and training professionals, and timelines.

- Solicit/identify funding for plan implementation.

- Implement and evaluate against established benchmarks.

Recommendation 2c: Leverage Employment Resources

- Build upon the opportunity created by the state's investment in the Supported Employment Leadership Network (SELN). Establish a task force to review and assist implementation of the recommendations of the Colorado SELN assessment.

Problem 3: System focus is not first and foremost the person

In a service system comprised of stakeholders that agree system focus should be first and foremost the person, it is widely acknowledged that this focus commonly evades practice. The State commits to person centered practices within their waiver application responses. People clearly seek to lead self-determined lives. Where in this journey has this objective been derailed? The most frequently cited reasons are changes in leadership, increased regulatory requirements, and financial constraints.

Like other states, Colorado has experienced frequent changes in I/DD leadership. Accompanied by significant time gaps, these transitions take a toll. System demands never cease and oftentimes decisions are made without consideration of the big picture. Fixes that occur to appease the moment result in layers of unintended consequences that must be peeled back in order to begin the process of positive change.

In 2005, the Colorado I/DD system came under the close scrutiny of their federal partner, CMS. In rectifying these concerns, DHS made several decisions that went beyond CMS expectations. The result was impractically narrow service definitions and billing increments. The role of case

manager was propelled towards that of compliance monitor. Their duties changed, requiring more time at a computer than spent with a person. Whether an artifact of CMS oversight, planning processes became standardized, formalized and increasingly counterintuitive to person centered planning.

Changes in funding methodology to a fee for service reimbursement also contributed to a cultural drift away from a person centered planning focus. Systems could not predict expenditures and thus manage funding. In response to a structural deficit, funding was cut, capped and categorized. Diminishing resources and fiscal uncertainty created challenges for providers. Case management conflict heightened as agencies re-configured services to address budgetary constraints. Providers struggled to absorb funding cuts while concurrently assuming additional responsibilities. Reimbursement methodologies derived to control expenditures fell short in promoting agency missions, values and positive service outcomes. In its haste to find and maintain funding streams, agencies have neglected to talk to people to find out what is important to and for them. Incrementally these changes have contributed to the decline of person centered thinking.

Regardless the cause of the drift from a person-centered focus, the system must re-mission to person-centeredness. It must be held accountable for person centered planning and the outcomes that people seek – jobs, homes, relationships and meaningful days and lives.

Recommendation 3a: Make Person Centered Planning Happen

- Convene a stakeholder's task force to explore and select strategies to improve person centered planning.
- Work with state officials to identify and disassemble regulatory requirements that discourage person centered planning.
- Create an initiative that engages self-advocates, families, providers, advocates and collaborating agencies in the training and implementation of person centered thinking.
- Develop measures of person centeredness that enable providers to benchmark and measure improvement.

Recommendation 3b: Collaborate with Education

- Initiate a dialogue between and among local and state entities to develop a common understanding about the needs of students served by multiple systems and transitioning between school and I/DD services.
- Identify service gaps and overlaps that exist between school and I/DD services.
- Realign supports and funding to address gaps and eliminate redundancies.
- Develop outcome measures by which to evaluate the performance of implemented changes.

Problem 4: There are no formal systemic mechanisms to self direct I/DD services

Colorado's experience with self directed services has been in the areas of aging and physical disabilities. State officials report a different experience than other states where self direction has been a tool to promote self-determination and efficiency. Without consistent monitoring of service units and unit rates, costs in Colorado programs that allow self-direction skyrocketed. While legislation mandates access to self directed services, the state has approached expansion into the I/DD arena with reluctance and caution.

While self directed I/DD services can be found in "pockets" across Colorado, there is no infrastructure to support these activities. Providers willing to be creative have found ways to support fiscal intermediary activities.   They have used Agency with Choice employment arrangements to support people to co-employ staff that come into their homes. Sensitive to a highly regulated environment, providers have become wary of this "ask for forgiveness rather than permission" approach to doing business and seek formal mechanisms to support self direction.

Recommendation 4a (System Redesign)

Make self directed services an option that anyone can choose for any service. Self direction could and should provide a mechanism by which people get the services they want and need as opposed to those that are available.   While certainly this should be a virtue of all system services, self direction provides an intuitive method of giving people control of their lives in a way that we all expect. People must be allowed to hire, direct and fire the people that provide their services. This must include providers who come into a person's home to assist with the most intimate activities of daily living. This level of control must be available without geographic limitations.   Inherent in control is providing people the training, information and authority they need to be in charge of their services. With the proper mechanisms and safeguards, self direction can be financially efficient AND promote self determined lives.

- Revisit and expand upon work already done: Ad Hoc Committee on Self-determination, (2003) Recommendations for a Self-determination Process in Colorado for Persons with Developmental Disabilities.

- Learn from the past. Self directed services can be structured in a way that costs less / not more and is sustainable.

- Create infrastructure to facilitate self direction – fiscal intermediary services, employers of record, information systems, personal agents and other mechanisms that are necessary to ensure anyone who chooses to, can self-direct.

- People who choose self direction must have the training and information they need to make good decisions – anything less withholds "true" control. People must be empowered to make decisions that meet their needs and preferences within a wide array of available supports.

- Self-direction must empower people to have the flexibility to make things work by taking advantage of natural supports and local community resources.

- Create a reliable means to assess and assure the quality of self directed services that is respectful of people's homes and informed choices.

**Problem 5: There is no data infrastructure to assess our system**

"Without reliable data, we can't make good decisions."

In many regards, the Colorado I/DD system is at a pivotal point in its evolution. Entrenched in a service delivery system that may be unsustainable, change is inevitable. Reliable data is essential to making decisions and critical in monitoring the impact of those decisions.   How many people are waiting for services? Will I/DD expenditures exceed budgeted appropriations? Confidence in the data available to answer these and other critical questions is limited. Self-advocates and families must have access to data to make informed choices. Providers have limited access to data gathered systemically. Information systems that support core functions are inadequate.

Outcome measures are essential to assessing system performance. ==Personal and systemic outcomes need to be measured across I/DD services.== Other states have outcome data. They are able to draw intra and interstate comparisons, employ modeling processes to inform decision-making and benchmark to improve system performance. As a system, we must identify the outcomes we value and find an efficient and reliable means to measure system performance and the impact of change.

While the limitations of the current data infrastructure may be seemingly imperceptible to people receiving services, the impact of decisions made because of inadequate data, is not. Neither is the unstable and unpredictable environment created when a system cannot accurately assess its position and work toward shared goals.

Recommendation 5a: Identify, Gather and Analyze Data

- Working with stakeholders, determine data essential to the efficient and effective management of the I/DD service system.
- Collaborate with state departments – Health Care Policy and Financing and Human Services.
- Develop consistent standards.
- Create a plan to gather and analyze essential data.
- Implement and refine data collection and analysis.

Recommendation 5b: Identify and Measure Meaningful Outcomes

- Work with stakeholders to identify outcomes that best reflect service quality.
- Convene a workgroup to explore tools and processes which assess and measure selected outcomes.
- Implement a system that assesses meaningful outcomes.
- Evaluate and refine outcome measures.

References

Braddock, D., Hemp, R., Rizzolo, M.C., Haffer, L., Shea Tanis, E., & Wu, J. (2011), *The state of the states in developmental disabilities, 2011.* Boulder, CO and Washington, DC: University of Colorado School of Medicine, Department of Psychiatry and American Association on Intellectual and Developmental Disabilities.

Appendix A: Acronyms

CCB – Community Center Boards

CMS – Center for Medicare and Medicaid Services

DDRC – Developmental Disability Resource Center

DHS - Department of Human Services

DPHE – Department of Public Health and Environment

HCBS – Home and Community Based Services

HCPF – Health Care Policy and Finance

I/DD – Intellectual and Developmental Disabilities

JBC – Joint Budget Committee

SADLIE – State the problem, Analyze the Problem, Develop a solution, Legitimize a Solution, Implement, Evaluate (Problem solving model)

SELN – Supported Employment Leadership Network

SPO – Service Provider Organizations

Appendix B: Focus on the Future Steering Committee and Workgroup Members

Name	Organization	Mtg 1		Mtg 2		Mtg 3
		Day 1	*Day 2*	*Day 1*	*Day 2*	*Day 1*
Larry McDermott	The Arc of Weld County	X	X		X	X
Carol Meredith	The Arc of Arapahoe and Douglass County	X	X	X	X	X
Mike Atlas-Acuña*	Colorado Bluesky		X	X	X	X
John Barry	Health Care Policy and Financing			X		X
Steven Block	Denver Options					X
Chris Collins*	Alliance	X	X	X	X	X
Mark Emery*	Imagine!	X	X	X	X	X
Rob DeHerrera	Developmental Disabilities Resource Center	X	X	X	X	X
Joscelyn Gay	CO Department of Human Services			X	X	
Diana Holland	Developmental Disabilities Resource Center	X	X		X	X
Roger Jensen*	Starpoint	X	X	X	X	X
Ron Marquez*	Developmental Disabilities Resource Center	X	X	X	X	X
Sally Montgomery*	Mosaic	X	X	X	X	X
Jeff Nichols*	Mesa Developmental Services	X	X	X	X	X
Barbara Ramsey	CO Department of Human Services			X	X	X
Ann Renaud	Office of State Planning and Budget			X	X	
Marijo Rymer	The Arc of Colorado			X	X	X
Melodie Beck	Office of State Planning and Budget					X
Jeremy Schupbach	Alliance	X	X	X	X	X
Jennifer Shook	The Legal Center	X	X	X	X	
Debbie Spencer*	Chestor House			X	X	X
Tom Turner*	Community Options			X	X	X

* Denotes Alliance Steering Committee members

Appendix C: Focus on the Future Contributors

Alliance Members

Anschutz Family Foundation

The Colorado Health Foundation

Consortium of Innovative Practices, Montgomery, Alabama

Other contributions pending

Appendix D: Facilitator and Subject Matter Expert Biographies

Wanda Seiler, Project Consultant

Wanda Seiler is a Senior Consultant with the Rushmore Group. She has worked in the disabilities field for over 15 years and has over 20 years of state government experience. Prior to her work with the Rushmore Group Wanda served eight years as the Director of Developmental Disabilities in South Dakota and successfully led system change initiatives in the area of reimbursement methodology, self-directed services, and person centered planning. During her tenure, South Dakota was able to correct a significant structural budget deficit and eliminate all waiting lists for developmental disabilities services. As a consultant with the Rushmore Group, Wanda provides technical assistance to county and state governments in the areas of quality improvement and systems change.

Robin Cooper, Subject Matter Expert, HCBS Waivers

Robin Cooper works with state, county, and local governments as well as advocacy and provider organizations on issues in long term community services for people with disabilities. She is the Director of Technical Assistance at NASDDDS. Her main focus is assisting states to redesign support coordination systems and providing technical assistance to states to modify their Medicaid-financed home and community-based waiver and state plan programs to include more person-centered and participant-directed options. Prior to her joining the association in 1994, Ms. Cooper managed Wisconsin's Medicaid home and community based services waiver for persons with developmental disabilities. She has also been a direct services worker and case manager. She has had the privilege of learning from and assisting individuals with disabilities for 39 years. She holds bachelor's and master's degrees from the University of Wisconsin Madison.

Patti Scott, Subject Matter Expert, Self-Directed Services

Patti has a deep commitment to a world in which all people are included and have equal opportunity. In 1995, she co-founded Neighbours, Inc., an innovative agency that affords people with disabilities the opportunity to take control of their own lives; to be self-directing. In the past sixteen years Neighbours has supported people in New Jersey to move into their own homes, control their own supports and resources, and live full, rich lives in their local communities. Neighbours has also been involved in service brokerage through New Jersey's self-determination project (brokering for over 60 people) and has worked with various counties in Pennsylvania to develop Brokerage, Self-Determination initiatives, Fiscal Agent services, Agency With Choice services, and community connections. In 2005, Neighbours began partnering with the state of New Jersey on Real Life Choices, NJ's self-directed systems change effort. Neighbours is currently providing Supports Coordination for people who are utilizing consumer direction through this initiative.

In 2009 Patti founded Neighbours, International, an organization focused on training, technical assistance, facilitation and systems transformation in a variety of states and countries.

Ric Zaharia, Ph.D., Subject Matter Expert, Managed Care

From 1990 to 1995 Ric served as Director of the Utah Division of Services to People with Disabilities, and from 2000 to 2006 he served as the Director of the Arizona Division of Developmental Disabilities.

From 1986 to 1990 Ric served as Director of Behavioral Services for the Colorado Division for Developmental Disabilities, where his major assignment was assisting in the facility downsizing efforts for the Pueblo and Wheat Ridge Regional Centers.

His published research on mortality in the 1990's identified the value of community placement for people living in California developmental centers, as well as cautions for future outplacement from public facilities to community based services.

Ric recently retired from the Arizona Division of Developmental Disabilities and is currently serving as a Vice President for the Consortium on Innovative Practices. In addition, he is a fellow in the American Association on Intellectual and Developmental Disabilities (AAIDD), a Board member for Tu Nidito, a support organization for children dealing with death and serious medical illnesses, and a victim advocate for the Pima County Attorney's Office.

Ric's doctoral work was completed at George Peabody College at Vanderbilt University in 1978. He lives in Tucson with his wife, Caryle.

Appendix E: Recommendation Champions

Recommendation 1c: Create Online Tools to Improve System Access - Champions: Mark Emery and Jeff Nichols

Recommendation 2b: Develop Increased Capacity for Behavioral Supports - Champions Debbie Spencer and Carol Meredith

Recommendation 2c: Leverage Employment Resources - Champions Mike Atlas-Acuña, Diana Holland and Larry McDermott

Recommendation 3a: Make Person Centered Planning Happen - Champions Tom Turner, Roger Jensen and Marijo Rymer

Recommendation 3b: Collaborate with Education - Champions: Ron Marquez, Mark Emery

Recommendation 5a: Identify, Gather and Analyze Data - Champion Rob DeHerrera

Recommendation 5b: Identify and Measure Meaningful Outcomes - Sally Montgomery; Jeff Nichols