



2012 Community Forum

BELIEVING IN THE POTENTIAL OF ALL

Imagine!

Innovative Resources For Cognitive and Physical Challenges



Create and offer innovative supports for people with cognitive, developmental, physical, and health related needs.

We are live online!

Low cost initiative to include interested stakeholders who might not be able to be here in person.



Brief Reflection

- Board of Directors
- Imagine! Staff
- Network of Providers
- 2009 – 2012
- What is next?





FOCUS ON THE FUTURE

- Long term care is changing
- State is considering changes necessary for a sustainable system
- Opportunity for stakeholder input



Alliance is a non-profit statewide association of Community Centered Boards and Service Provider Organizations committed to the advocacy of member organizations and the individuals and families they serve.

FOCUS ON THE FUTURE

PROJECT EXPERTS

PROJECT CONSULTANT

Wanda Seiler, The Rushmore Group

- 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.

SUBJECT MATTER EXPERTS

- Robin Cooper: Waivers
 - Director of Technical Assistance at NASDDDS. Robin's 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.
- Patti Scott: Self Direction
 - In 1995, Patti 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.
- Ric Zaharia: Managed Care
 - 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.

PHASE I: FOCUS GROUPS



FIVE FOCUS GROUPS

- Western Slope, Grand Junction, July 11th;
- Southeast, Pueblo, July 12th;
- Northeast, Windsor, July 13th;
- North Denver Metro, Longmont, July 14th;
 - Debbie Spencer, Chestor House
 - Ailsa Wonnacott, ACL
- Denver Metro, Lakewood, July 14th



PARTICIPANT DEMOGRAPHICS

- 84 Total Participants – 63 female; 25 male
- 68% self-advocates (11) or family member (57)
- 32% Other Stakeholders
- Age Range 27 – 73
- Median age 50.74



COMMON THEMES AND ISSUES

1. Service System Access
2. Systems
3. Provider Capacity and Quality
4. Health and Wellness
5. Advocacy



1. SERVICE SYSTEM ACCESS

The way people enter and navigate the DD service system

Waiting List

- Wait length is long and unpredictable
- Stories of family hardship
- Families feel forced to “feign” emergencies
- Parents are counseled to relinquish custody
- Referral agencies “no longer bother”



SERVICE SYSTEM ACCESS, cont.

Information and Referral

- System is complex and difficult to navigate
- People don't know where to go
- Limited access to people who know the system best
- State provides inaccurate and inconsistent information
- Inaccurate eligibility determinations (co-occurring disorders)
- Families rely most on other families



2. SYSTEMS

Infrastructure that undergirds the service system

Role of State Agencies

- Unsolicited criticism
- DDD hinders the provision of services
- HCPF doesn't understand disability needs
- DDD, HCPF and CDPHE have inconsistent standards



SYSTEMS, cont.

Change...

- is not well planned
- starts, stops and restarts (roller coaster effect)
- is accompanied by unintended, negative consequences
- is resulting in system regression!

3. Provider Capacity and Quality

Provider capacity and competency to meet service needs

- Comments were comparatively positive
- People are grateful for the services they are receiving
- Staff are committed and caring
- There is a wide continuum of housing options from which people may choose
- There is good collaboration and cooperation between CCBs, SPO and other local agencies

PROVIDER CAPACITY AND QUALITY, cont.

*Provider capacity and competency to
meet service needs*

Lack of...

- person centered planning and services
- self direction opportunities
- employment options
- understanding the importance of social roles

4. HEALTH AND WELLNESS

Supports so people can have the best possible health

Limited access to medical providers

- Rural areas
- Mental Health Services
- Dentistry under general anesthesia

Importance of communication

- Medical History
- Role of staff accompanying participants' doctor visit
- Role of staff in supporting health lifestyle choices



5. Advocacy

- Comments were very positive
- Many people expressed appreciation for the support and assistance of local Arc Chapters
- The advocacy of CCBs and SPOs has a positive influence
- Family Advocacy is essential

PHASE II: WORKGROUP MEETINGS



WORKGROUP MEETING 1

MEMBERS

- Jennifer Shook, The Legal Center, Grand Junction
- Larry McDermitt, Arc of Weld County
- Carol Meredith, Parent, Arc of Arapahoe/Douglas
- Marijo Rymer, Arc of Colorado
- Diana Holland, Parent
- Rob DeHerrera, Developmental Disabilities Resource Center
- Ann Reneau, CO Office of State Planning and Budgeting
- John Berry, CO Health Care Policy and Finance
- Barb Ramsey, CO Division for Developmental Disabilities
- Joscelyn Gay, CO Department of Human Services
- Project Steering Committee
- Subject Matter Experts (Robin Cooper, Ric Zaharia, Patti Scott)

STATE THE PROBLEM(S)

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



1. SYSTEM IS TOO COMPLEX

Complexity...

- makes the system difficult to understand and navigate
- stifles creativity
- conceals service gaps
- inhibits flexibility
- consumes time and resources
- results in unintended consequences
- causes confusion, uncertainty and frustration
- makes management and administration difficult

2. SYSTEM FOCUS IS NOT THE PERSON

We lose focus when...

- scarce and diminishing resources create fear and uncertainty
- planning requirements fail to promote person centered planning
- we get conflicting direction from state agencies
- we try to fit people's needs to funding streams
- we are forced to meet new people's needs without time for planning



SYSTEM FOCUS IS NOT THE PERSON, cont.

We must...

- Treat people holistically
- Provide strong leadership
- Affect fiscal stability and predictability
- Ensure case managers are advocates for the people they support
- Support people, not allow regulations, to drive services
- Restore trust that the system will “do right” by people

3. NO MECHANISMS TO SUPPORT SELF-DIRECTION

Without infrastructure to support self direction...

- we spend money on services people don't want
- people must request permission to self direct
- providers who support self direction risk regulatory consequences



NO MECHANISMS TO SUPPORT SELF DIRECTION, cont.

We must...

- ask people what they want
- support people to have relationships – boy/girlfriends, spouses
- appreciate the importance of employment in a meaningful life
- afford people the dignity of risk
- give people the information they need to take control
- implement mechanisms to support self direction such as fiscal intermediaries, employers of record, and personal agents.

4. RESOURCE ALLOCATION DOESN'T MEET PEOPLES NEEDS

- Long waiting lists with unclear selection process
- People enter comp services when offered, not when needed
- Disparity of service access between rural and urban areas
- 11 waivers – people are denied access to the waiver that fits but not to the waiver that doesn't

RESOURCE ALLOCATION DOESN'T MEET PEOPLES NEEDS, cont.

We must...

- Ensure the most efficient use of administrative resources
- Be transparent and accountable in the allocation of individual and system resources
- Ensure services are delivered in the least restrictive most appropriate settings
- Never force families to relinquish custody to get their children services
- Carefully plan community re-integration
- Build a sustainable service system



5. INSUFFICIENT DATA TO ACCESS/EVALUATE SYSTEM

We lack...

- IT resources
- reliable data essential to decision making
- the means to reliably project budget utilization and future needs
- systemic outcome data to measure the quality of services



INSUFFICIENT DATA TO ACCESS/EVALUATE SYSTEM, cont.

We must...

- be able to measure the impact of system changes
- promote efficiency and consistency in data collection
- fix a dysfunctional backed-up system for eligibility re-determinations
- restore confidence and trust



System Redesign Considerations

- Combine DD Waivers – reduce complexity and confusion
- Managed Care – integrate acute care
- 1115 Demonstration Waiver – explore potential for efficiency
- Must address Waiting List
- Support Self Direction



Recommendations in the works

- Create online tools that support system access
- Identify, gather and analyze data
- Streamline compliance – one licensing agency
- Train Stakeholders
- Leverage employment resources
- Develop behavioral supports
- Make person centered planning happen
- Collaborate with education

WHAT CAN YOU DO?

- Read/request a copy of the Focus Group Report
- Provide input/feedback to a Steering Committee Member
- Read/request a copy of the Focus on the Future Final Report (available Fall 2011)
- Be informed, participate!

<http://www.alliancecolorado.org/>





Boulder County Initiative

BCI Program Design

- Reach out to identify all adults in Boulder County who are eligible for developmental disabilities services.
- Assess their personal situation by using a combination of the Supports Intensity Scale and a Family Analysis Survey Instrument.
- Plan to address the most important issues that adults have who are waiting for State and Federal funded services.
- Arrange and deliver support on a “strengths-based approach”, which is quite different from the deficit-based approach currently used in Medicaid Waiver programs.

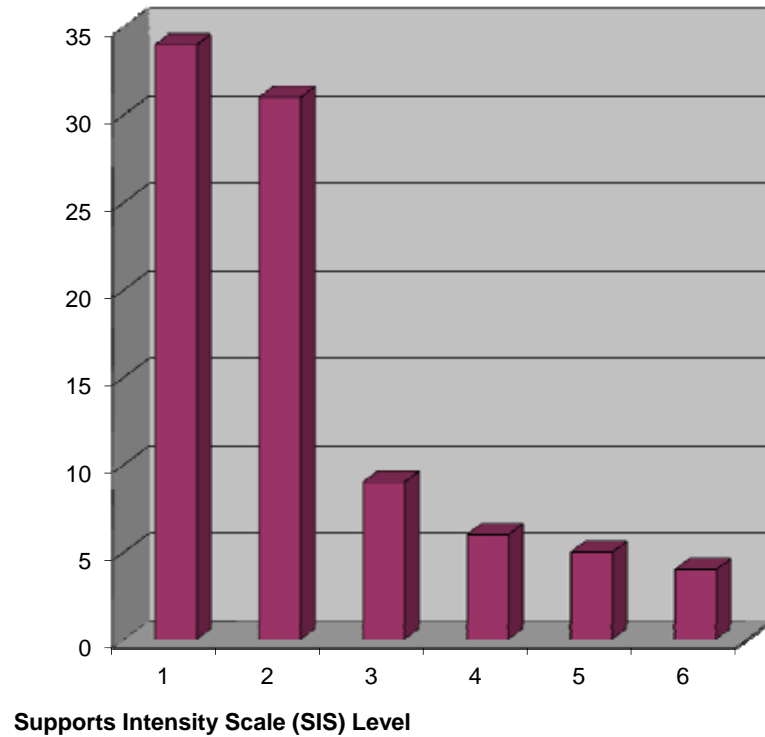


Boulder County Adults Eligible and not receiving State Funded Services

- Identified – 184
- Participating – 80
- In Process – 29
- Researching – 14
- Uninterested or otherwise unavailable – 61 (33%)
- Anticipated growth this year – 20

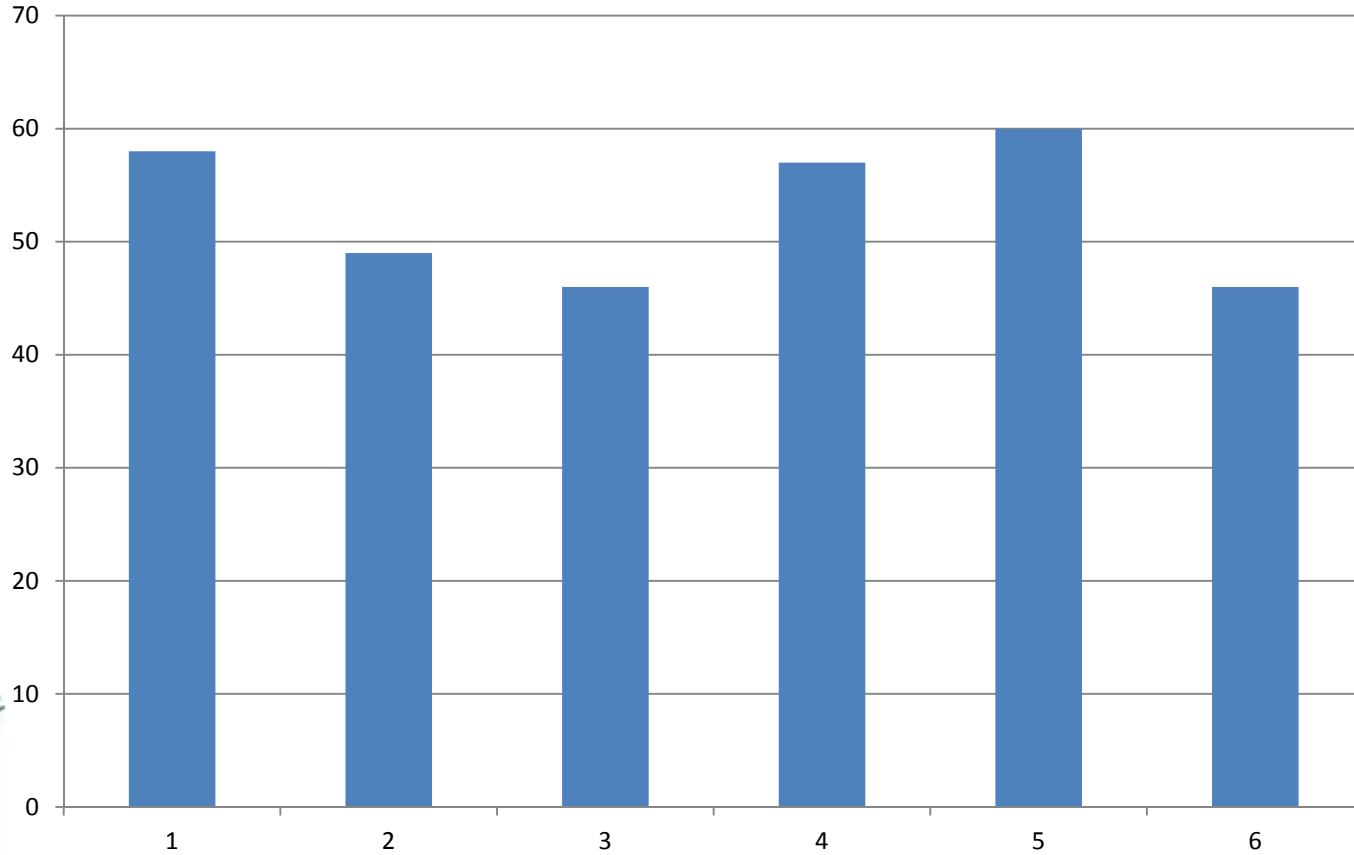
Demand Management

Supports Intensity Scale (SIS) Levels for 89 BCI Assessments



Supports Intensity Scale Enrolled in State Funded Service

Imagine! Total 344

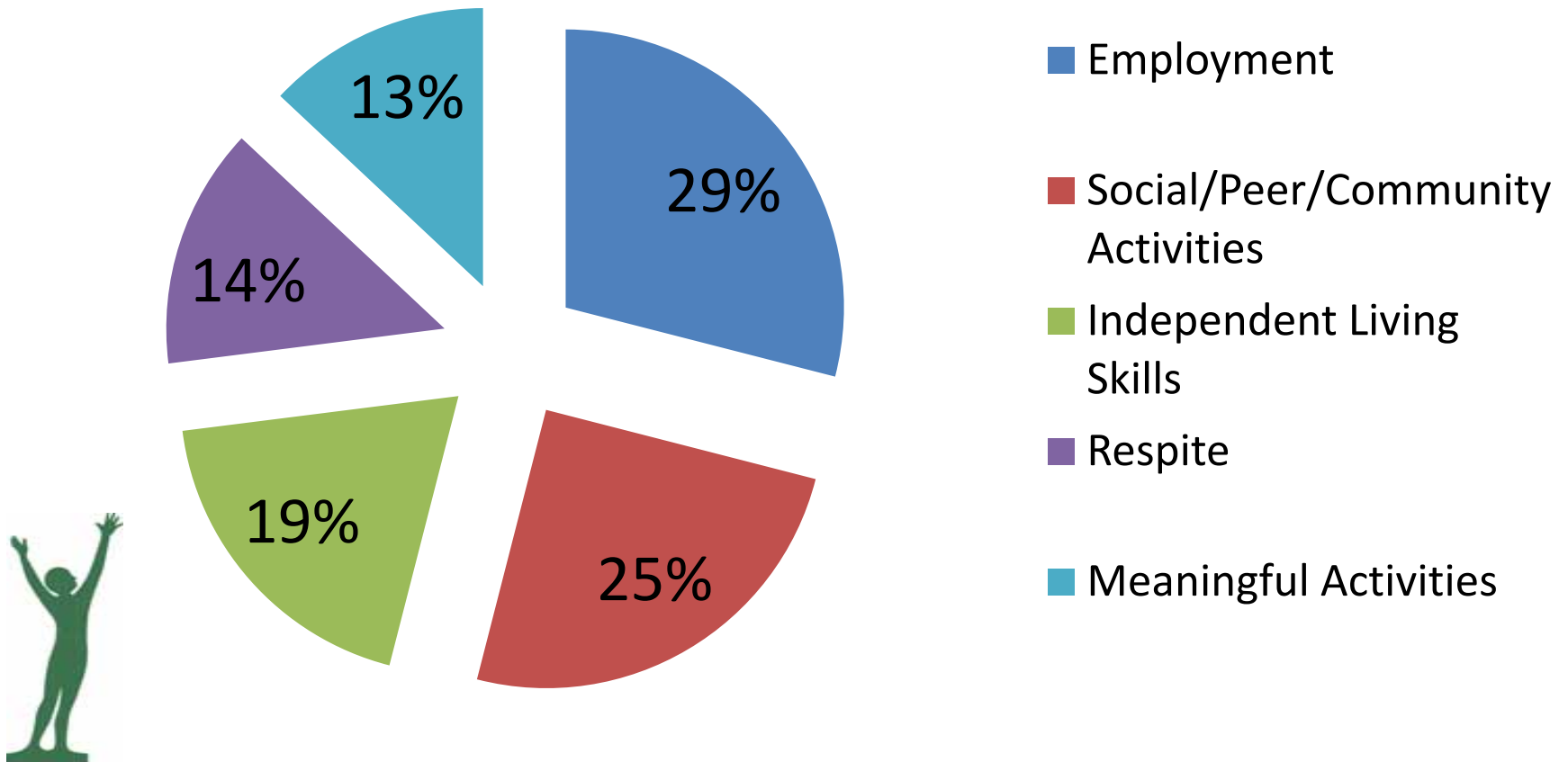


BCI Navigator

- Consult adults and their families to navigate and plan.
- Identify natural supports that may already exist but may not be utilized.
- Develop a Plan that addresses self-identified priorities.
- Identify and access resources to fulfill Plan

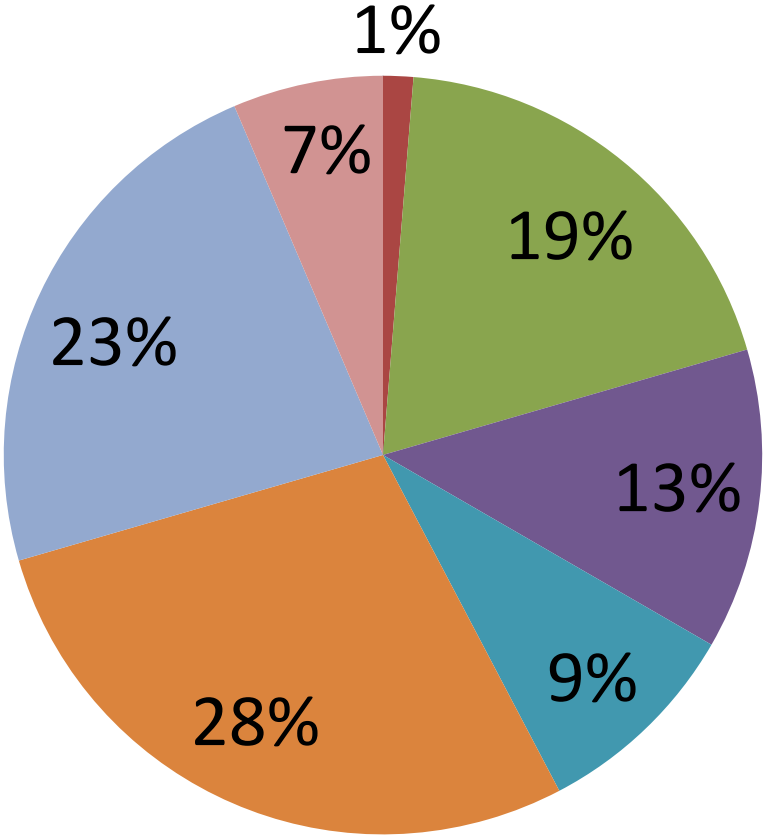


Top Five Priorities of Those Assessed



Sustainable Circumstances

- 1 -- 6 months
- 7 -- 12 months
- 1 -- 3 years
- 4 -- 6 years
- 7 -- 10 years
- Indefinitely
- No response
- Other



Boulder County Initiative

Outcome:

Recognize the growing unmet need of adults and utilize our limited resources in a way that will positively affect the most people.





Colorado State of Affairs

Long Term Care System Redesign

- Move the Division of DD from Dept Human Services to Dept Health Care Policy and Financing.
- Move Children's Habilitation and Residential Program from Dept Human Services to Dept Health Care Policy and Financing.
- Move the State Unit on Aging from Dept Human Services to Dept Health Care Policy and Financing.
- Move Early Intervention from Division of DD to new Office of Early Childhood Development.



State Government

- Governor's 2012-13 Budget Proposal adds 173 more resources for developmental disabilities services.
 - 46 (HCBS-DD) Medicaid waiver enrollments for youth transitioning out of the foster care system;
 - 50 Supported Living Services (HCBS-SLS) Medicaid waiver enrollments for youth aging out of the Children's Extensive Support (HCBS CES) Medicaid waiver;
 - 47 HCBS-DD Medicaid waiver emergency enrollments for people who need immediate residential services; and
 - 30 HCBS-SLS Medicaid waiver enrollments to address the needs of individuals in high-risk emergency situations on the Supported Living Services (SLS) waiting list.



State Government

- Current 2011- 12 Budget Shortfall, \$8.7 million
- Cost containment at the discretion of DHS
 - Delay filling vacancies; currently about 350,
 - Caps on Targeted Case Management,
 - Caps on Day Habilitation Services,
 - Narrow definition of behavior services,
 - Conduct Audits of Supports Intensity Scale.

What would you like to talk about??



Imagine!

Questions

Re: protecting Identity

How can families/caregivers/guardians know that social security numbers and Medicaid numbers are not being used fraudulently? Is there a way to check this information?

Re: SLS

How will people receiving long term care be effected by the change in organizational authority and, in particular, how will SLS beneficiaries be effected?