

# Collaborative Work Group for Adults with Developmental Disabilities

February 11, 2015

- ACCESS Idaho
- Idaho Association of Developmental Disability Agencies
- Case Management Association of Idaho
- Center on Disabilities and Human Development
- Division of Medicaid
- Disability Rights Idaho
- Idaho Council on Developmental Disabilities
- Vocational Rehabilitation
- The Idaho Self-Advocate Leadership Network
- Residential Supported Living Association
- Division of Family and Community Services
- Vocational Services of Idaho
- Idaho Health Association/ICFs-ID
- LINC/Centers for Independent Living
- Office of the Governor
- Legislators

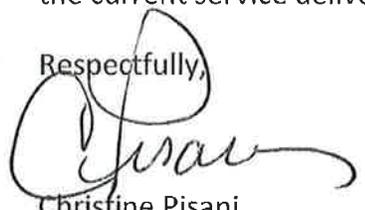
Senator Lee Heider, Chairman  
 Senate Health and Welfare Committee  
 Statehouse  
 Boise, ID 83720

Dear Chairman Heider and Committee Members:

Thank you for the opportunity to present the work of the Collaborative Workgroup on the Redesign of the Adult Developmental Disability service system. The report presented today represents a tremendous amount of work completed by many people over the past three years. The Collaborative Workgroup convened in 2011 and collectively we recognized the need to provide informed policy recommendations as a response to the directives from House Bill 260. Stakeholders also recognized we had an opportunity to create an improved service system. Each stakeholder holds this value and it has driven our commitment to the work.

I strongly encourage your review of our report. There is a significant amount of work included to help inform you of the current service delivery system, best practice in the field of developmental disabilities, research conducted, and the 2015 initiatives underway. All of the Collaborative Workgroup members are available to answer any questions or to be a resource to you to help understand the current service delivery system.

Respectfully,



Christine Pisani  
 Executive Director  
 Idaho Council on Developmental Disabilities



# Executive Summary

## 2014 Report of the Collaborative Work Group on Services for Adults with Developmental Disabilities: Findings and Initiatives January 27, 2015

---

### Vision

The Collaborative Work Group (CWG) on Adult Developmental Disability (DD) Services represents a range of people with developmental disabilities, service providers, advocates, agencies and policymakers. This group has convened to constructively influence the development of Idaho's adult DD service system consistent with the following vision:

*By 2020, adults with developmental disabilities living in Idaho enjoy the same opportunities, freedoms and rights as their neighbors. They have access to sustainable service systems that provide quality, individualized supports to meet their lifelong and changing needs, interests and choices.*

### Core Question

Given the unique and diverse needs of adults with developmental disabilities, the paid and unpaid, public and private nature of the system, and the finite resources available through Medicaid, the CWG seeks to design the system so it provides optimum supports and opportunity for productive living.

### Findings

1. Idaho's self-direction option provides for a wide array of services, contingencies and choices
2. Employment is an important and desirable outcome for most people with DD
3. An opportunity exists to improve Idaho's assessment and resource allocation process
4. A managed care organization model is designed for medical care; it would be difficult to develop a managed care organization to appropriately serve the DD population

### 2015 Initiatives

1. Collaborate on Home and Community Based Services Rules Implementation
2. Revise the current assessment and resource allocation system to ensure that resources are matched to actual individual needs and aligned with the person centered planning process
3. Enroll Idaho as a participant in the National Core Indicators Project (<http://www.nationalcoreindicators.org>)
4. Generate a solid infrastructure, in coordination with University of Idaho's Center on Disabilities and Human Development, that provides the adult DD population an active, consistent and effective voice in systems change



# 2014 Report of the Collaborative Work Group on Services for Adults with Developmental Disabilities: Findings and Initiatives

JANUARY 27, 2015





**2014 Report of the  
Collaborative Work Group on Services for  
Adults with Developmental Disabilities”  
Findings and Initiatives**

<b><i>EXECUTIVE SUMMARY</i></b>	<b>4</b>
<b><i>INTRODUCTION</i></b>	<b>5</b>
<b><i>THE CURRENT SERVICE SYSTEM</i></b>	<b>7</b>
<b><i>RESEARCH</i></b>	<b>11</b>
<b><i>FINDINGS</i></b>	<b>13</b>
<b><i>2015 INITIATIVES</i></b>	<b>17</b>

**TABLE 1: CWG MEMBERSHIP**  
**TABLE 2: NATIONAL CORE INDICATORS**

**APPENDIX A: CHECKLIST**  
**APPENDIX B: STATE MATRIX**  
**APPENDIX C: ARIZONA STUDY SUMMARY**

# Executive Summary

## 2014 Report of the Collaborative Work Group on Services for Adults with Developmental Disabilities: Findings and Initiatives January 27, 2015

---

### Vision

The Collaborative Work Group (CWG) on Adult Developmental Disability (DD) Services represents a range of people with developmental disabilities, service providers, advocates, agencies and policymakers. This group has convened to constructively influence the development of Idaho's adult DD service system consistent with the following vision:

*By 2020, adults with developmental disabilities living in Idaho enjoy the same opportunities, freedoms and rights as their neighbors. They have access to sustainable service systems that provide quality, individualized supports to meet their lifelong and changing needs, interests and choices.*

### Core Question

Given the unique and diverse needs of adults with developmental disabilities, the paid and unpaid, public and private nature of the system, and the finite resources available through Medicaid, the CWG seeks to design the system so it provides optimum supports and opportunity for productive living.

### Findings

1. Idaho's self-direction option provides for a wide array of services, contingencies and choices
2. Employment is an important and desirable outcome for most people with DD
3. An opportunity exists to improve Idaho's assessment and resource allocation process
4. A managed care organization model is designed for medical care; it would be difficult to develop a managed care organization to appropriately serve the DD population

### 2015 Initiatives

1. Collaborate on Home and Community Based Services Rules Implementation
2. Revise the current assessment and resource allocation system to ensure that resources are matched to actual individual needs and aligned with the person centered planning process
3. Enroll Idaho as a participant in the National Core Indicators Project (<http://www.nationalcoreindicators.org>)
4. Generate a solid infrastructure, in coordination with University of Idaho's Center on Disabilities and Human Development, that provides the adult DD population an active, consistent and effective voice in systems change

## Introduction

# Respect

The Collaborative Work Group (CWG) on Adult Developmental Disability (DD) Services is a group of individuals who have come together to constructively influence the development of Idaho's adult DD service system. Convened by the Idaho Council on Developmental Disabilities (ICDD) in November 2011, the group aspires to achieve the following vision:

*By 2020, adults with developmental disabilities living in Idaho enjoy the same opportunities, freedoms and rights as their neighbors. They have access to sustainable service systems that provide quality, individualized supports to meet their lifelong and changing needs, interests and choices.*

The CWG represents a range of people with developmental disabilities, service providers, advocates, state agencies and policymakers. It features an eight-member steering committee that meets monthly to do the detailed work. The steering committee presents its work to the full membership of the CWG for feedback and approval at least three times a year.

CWG seeks to influence the entire system, the core of which are Medicaid-paid services, as well as other important community and natural supports, paid and unpaid, such as employment, housing and transportation—supports essential to helping adults with developmental disabilities live meaningfully inclusive and productive lives.

CWG acknowledges and cautions that any changes to any part of the system recognize the impact of that change among other services, supports, systems and lives.

In its nearly 3 years of functioning, the CWG has undertaken the following scope of work, producing deliverables in most cases discussed in more detail later in this report. The CWG has

- Surveyed providers and people with disabilities to determine what is working and not working in the current system, generating a Checklist (See Attachment A) of qualities to feature in any proposed changes to the system
- Researched other states and compared respective assessment, service array and budgeting processes, detailed in a summary document (see Attachment B)
- Worked on and helped pass legislation for supported employment
- Visited and generated a corresponding report about the State of Arizona's system, where some CWG members met with state personnel, providers and adults with developmental disabilities to understand the nuances of that system in order to inform ideas about MCO functionality (see Attachment C)
- Generated a list of findings and features under development for the future system as presented in this document—the CWG's 2014 Report: Findings and Initiatives (Report)

- Initiated a more thorough examination and use of the existing Self Direction program to promote the opportunity and flexibility the existing program offers
- Initiated a study of needs assessment processes to ensure the best assignment of services and most appropriate allocation of financial resources

The findings and initiatives presented in this Report focus primarily on Idaho’s Division of Medicaid (Medicaid) and support efforts undertaken by the Employment First Consortium. In addition to completing the more robust implementation of the Self Direction program and investigating effective and efficient improvements to the existing needs assessment process, in 2015 the CWG will look at the status, needs and opportunities related to the non-Medicaid aspects of the system—the community and natural supports so integral for living healthy and productive lives.

Always, the CWG work and recommendations are grounded in the following values:

- Respect
- Safety
- Choice
- Quality
- Community Inclusion

More information about the CWG, including an introductory video and group products, can be found on the ICDD website, at: <http://www.icdd.idaho.gov/projects/Adult%20Services/ASR.html>

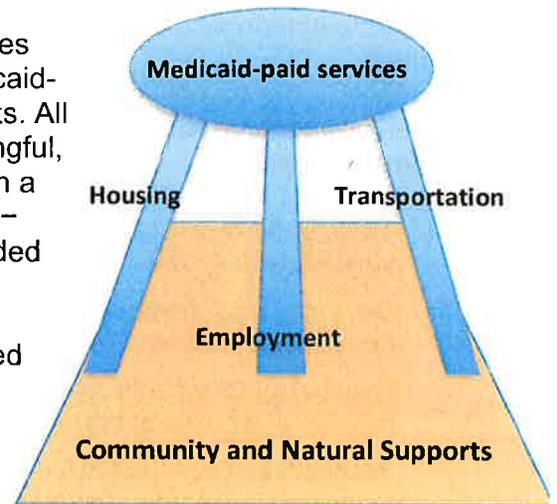
**Table 1: CWG Membership**

<b>CWG Members</b>	<b>Delegate</b>	<b>Alternate</b>
ACCESS Idaho	Trinity Nicholson**	Lisa Cahill
Idaho Assoc. of Developmental Disability Agencies	Maureen Stokes**	Corey Makizuru
Case Management Assoc. of Idaho	Joanne Anderson	None
Care Providers Network of Idaho (CFHs)	Eva Blecha	Becky Solders
Center on Disabilities and Human Development, UI	Julie Fodor, PhD	Richelle Tierney**
Division of Medicaid	Art Evans**	Jean Christensen*
Disability Rights Idaho	Jim Baugh**	Dina Brewer
Council on Developmental Disabilities	Christine Pisani **	Tracy Warren
Vocational Rehabilitation	Jane Donnellan	None
Self Advocate Leadership Network	Noll Garcia*	Kristyn Herbert*
Residential Supported Living Assoc.	Bill Benkula **	None
Division of Family & Community Services (crisis)	Oscar Morgan	None
Vocational Services of Idaho	Kelly Keele**	Cassie Mills
Idaho Health Assoc./ICFs-ID	Tom Moss	Kris Ellis
LINC/Centers for Independent Living	Roger Howard	None
Office of the Governor	Tammy Perkins	None
Legislature	Rep. Sue Chew*	None
Legislature	Sen. Lee Heider	None

# The Current Service System

safety

The service system for adults with disabilities features an important combination of Medicaid-paid services and other community supports. All are required to enable adults to live meaningful, productive lives. Like a stool with its legs on a foundation—a range of community supports—Medicaid pays for many core services needed for eligible adults; however other non-Medicaid supports, such as housing, employment and transportation, are required to enable living as independently as possible. Without one key community support, other supports become more intensive and quality of life diminishes.



## Developmental Disabilities – Idaho’s Definition

The Section 66-402(5) Idaho Code defines a developmental disability as:

A chronic disability of a person that appears before 22 years of age and is

- Attributable to impairment such as mental retardation, cerebral palsy, epilepsy, autism or other condition found to be closely related to or similar to one of these impairments that requires similar treatment or services, or is attributable to dyslexia resulting from such impairments.

The condition:

- Results in substantial functional limitations in three or more of the following areas of life activity: self-care, receptive and expressive language, learning, mobility self-direction, capacity for independent living, or economic self-sufficiency;
- Reflects the needs for a combination and sequence of special interdisciplinary or generic care, treatment or other services, which are of life-long or extended duration and individually planned and coordinated.

## Services for Adults with Developmental Disabilities – An Overview

### *Medicaid Services*

Medicaid is a federal program with a roughly 70/30 federal to state match providing funding for medical and health related services for people with low income in the United States. The Bureau of Developmental Disabilities Services (BDDS) within the Idaho Department of Health and Welfare Division of Medicaid manages the Medicaid-paid services for adults with developmental disabilities.

In Idaho, adults with developmental disabilities may be eligible for Medicaid benefits. Adults can apply for those benefits through an Idaho Department of Health and Welfare Independent Assessment Providers in a process that takes only a couple of hours. Eligibility is determined within a couple months.

The following services and supports are available for adults with developmental disabilities through Idaho Medicaid:

- Targeted Service Coordination—a service for individuals who cannot access, coordinate or maintain services on their own
- Developmental Therapy—skill development services provided through individual or group therapy in the home, community or a center
- Community Crisis Supports—interventions for individuals who are at risk of losing housing, employment or income, or who are at risk of incarceration, physical harm, family altercations or other emergencies
- Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/ID) Services—an ICF/ID is a home for up to 8 individuals. The home has shared dining, living and cooking areas. Each individual can have a private bedroom or share a bedroom with another individual. Services provided by the ICF/ID are designed to meet the needs of individuals requiring in-home care, and provide services 24 hours a day

Through a Medicaid Waiver program (Medicaid Home and Community-Based Services §1915(c) of the Social Security Act), Medicaid provides each state the opportunity to provide an array of services that assist Medicaid beneficiaries to live in the community and avoid institutionalization. States have broad discretion in designing the waiver program to best complement traditional Medicaid services, meet the needs of the state's population in a manner that is cost-effective, and employ a variety of service delivery approaches, including participant direction of services.<sup>1</sup> Medicaid Home and Community-Based Services Rules have been revised in 2014, providing even more flexibility, assurances and choice for the participant.

Idaho's Division of Medicaid has worked with intentionality to develop a quality waiver program, which features the following DD Waiver services:<sup>2</sup>

- Residential Habilitation—Certified Family Home and/or Supporting Living
  - Certified Family Home: an individual can live in the home of his/her parents, the home of another family member, or the home of someone in the community who is not related. Some supports and services will be provided in the home and some supports and services will be provided in the community.
  - Supporting Living Services: an individual can live in his/her own home, apartment, or an apartment with up to two other individuals. Supports and services can be provided in the home or apartment and in the community to help the individual live as independently as possible.
- Chore Services—might include washing windows, moving heavy furniture, or shoveling snow.

<sup>1</sup> <http://www.healthandwelfare.idaho.gov/Portals/0/Medical/DD%20Waiver.pdf>

<sup>2</sup> <http://www.healthandwelfare.idaho.gov/Portals/0/Medical/DevelopmentalDisabilities/Medicaid%20Services%20and%20Supports.pdf>

- Respite Services—services provided on a short-term basis due to the absence of the normal caregiver, and limited to the individual who lives with non-paid caregivers
- Supported Employment—provides support in a competitive work setting with job coaches who help the individual learn the job.
- Non-medical transportation—transportation to community services.
- Environmental Accessibly Adaptations—provides for certain interior and exterior changes to the home, which enable individuals who would otherwise be institutionalized to function with greater independence in the home.
- Specialized Medical Equipment and Supplies—additional supports when the state plan limits are used up, or the equipment or supply is not available under the regular state plan. Items must be necessary for the direct medical or remedial benefit of the individual.
- Personal Emergency Response Systems (PERS) A PERS unit is a portable or stationary device that is used to call for help in an emergency. This item is sometimes referred to as a “lifeline.”
- Home Delivered Meals—a service that delivers one or two nutritious meals each day for individuals who are alone for significant parts of the day, who have no regular caregiver for extended periods of time, and who are unable to prepare a meals without assistance.
- Skilled Nursing—Provides professional nursing services to individuals who need them. Nursing services must be recommended by a physician and must be listed on the participant’s plan.
- Behavioral Management and Crisis Management—This service is delivered to individuals who are having a psychological, behavioral or emotional crisis. Behavioral and crisis management is an emergency back up and provides direct support for the individual in crisis.
- Adult Day Health—a supervised and structured day program for individuals to receive a variety of social, recreational and health activities.
- Self-Directed Community supports—this is a Medicaid option for adults who are eligible for the DD waiver. This option provides participants the opportunity to make their own choices about supports, giving them freedom to manage their own lives. Participants do not have to choose supports alone. They have as much or as little help as they need from a support broker, a circle of support, and a fiscal employer agent (FEA).
  - Participants will have an individualized budget, create a support and spending plan, hire workers, and buy goods and services. Participants must agree to follow four guiding principles:
    - Freedom to plan their own lives
    - Control over their Medicaid dollars to buy supports and services
    - Support to become involved in their communities
    - Responsibility for their choices and decisions
  - If self-direction does not work, individuals can go back to receiving traditional Medicaid DD services.

Currently, approximately 3500 adults receive Medicaid waiver services in Idaho, served by approximately 100 Medicaid Providers. The services provided in Idaho are found to be more extensive than those provided in other states the CWG researched.

## *Community and Natural Supports*

Any individual has a range of needs specific to their condition and community that must be met in order to live as independently and meaningfully as possible in their own community. CWG has identified the following list of essential needs:

- a. Food and Housing
- b. Health Care
- c. Safety
- d. Employment
- e. Development of Independent Living Skills
- f. Mental and Behavioral Health
- g. Integration in Community Activities
- h. Transportation
- i. Protection of Rights and Self Determination

Clearly, some of these needs can be met through Medicaid services but many of them cannot. Putting all these pieces together for a single individual in a specific location requires attentive planning and meaningful individual, family, agency, and community engagement.

The CWG defines community supports as those resources in the community needed by the individual to help them live their lives as fully as possible – those needs beyond what Medicaid can provide, but which may be paid or non-paid, provided by agencies and entities other than Health and Welfare (Housing, Vocational Education, Transportation, communities, families), and which complete the individual's system of care.

Work undertaken and anticipated by the CWG around community supports, specifically employment and housing, are discussed in more detail in future chapters of this report.

### **Core Question**

Given finite resources available through Medicaid, and the unique and diverse needs of the adult DD population, the underlying question the CWG needs to address is how to design the system so it provides optimum supports and opportunity for productive living.

## Research

# Choice

To inform its understanding of DD system options and possibilities, the CWG studied the following 11 states:

- Arizona
- Colorado
- Florida
- Michigan
- New Mexico
- New York
- North Carolina
- Ohio
- Oregon
- Rhode Island
- Wyoming

Research involved reviewing the individual states' websites, and interviewing Directors, state Developmental Disabilities Councils, and state agency personnel.

Summarily, CWG learned many states authorize their services regionally instead of statewide, sometimes resulting in different rates and services in different regions of the state. Other states have long waiting lists. One common element was identified in many of the states CWG explored is using the Supports Intensity Scale (SIS) as the tool to establish budgets for adults with Intellectual and Developmental Disabilities. The National Office of United Cerebral Palsy has rated Arizona number one in the nation for service delivery for people who experience intellectual disabilities and developmental disabilities.

Arizona's system featured some components that warranted additional research, including functioning as a state-managed care organization (MCO), no wait lists, a responsive reimbursement methodology, and a heralded partnership between the state agencies, advocacy and provider groups.

In Arizona, state employees function as service coordinators and participate in individual Person-Centered-Planning<sup>3</sup> meetings and plan development. The Arizona Department of Economic Security (equivalent to Idaho's Department of Health & Welfare) contracts with Raising Special Kids, the Arizona Parent Training Center, to conduct and oversee coordinator training. Extensive training is provided on a range of topics including education about how to develop unpaid supports, and how to help adults and families develop those supports where they may be limited or not currently in place.

One downfall in Arizona is that Arizona does not have a 1915(c) waiver – they operate an 1115 demonstration waiver. People who qualify for the 1115 must function on an individual cost neutrality. Individual cost neutrality means if they cannot pay for the supports they need for 24-hour care in their own home with

<sup>3</sup> Person Centered Planning is an ongoing problem-solving process used to help people with disabilities plan for their future. In person centered planning, groups of people focus on an individual and that person's vision of what they would like to do in the future.

the funds they are provided, they must either have natural supports willing to sign a risk agreement with the state or they must live in a 6-8 bed group home. However, family members of children living in these group homes express satisfaction with the supports and services their loved ones receive.

Appendix B provides a summary of the states reviewed and description of how those systems work. Appendix C describes in more detail the findings of CWG study of Arizona's MCO-operated program, which had direct bearing on future considerations for Idaho's program presented in the next section.

## Findings

Supports and services for people with developmental disabilities are most effective when they are flexible, adaptive and conform to the natural flow of the participant's needs, life and choices.

To provide appropriate supports for the DD community, a system of care must be broad and flexible, addressing an individual's needs for:

1. Food and Housing
2. Health Care
3. Safety
4. Employment
5. Development of Independent Living Skills
6. Mental and Behavioral Health
7. Integration in Community Activities
8. Transportation
9. Protection of Rights and Self Determination

Medicaid plays a leading role in providing health care, independent living skills and mental and behavioral health. Medicaid also has a role in providing for safety, employment, community integration, and transportation along with other state agencies and community supports. Food and housing are not part of the Medicaid program, except for people in long-term care facilities. People with developmental disabilities need help with obtaining and coordinating assistance from Medicaid and non-Medicaid service providers.

A good system of care will support as precisely as possible the approved services to meet an individual's unique needs, with reimbursement rates to match the actual cost of providing the service.

### Findings

#### ***Federal Medicaid regulations can create challenges to flexibility and adaptability of services***

Most Medicaid Services are specifically defined. Services are provided by people with specific qualifications employed by certified provider organizations. Services come in units, usually specific blocks of time. Each service has a specific reimbursement rate and billing code. These are features of a medical model of reimbursement for procedures and office visits. The CWG recognizes service definitions and rate setting create strong incentives and disincentives, and CWG seeks to be aware of the incentives it creates.

Life does not take place in defined time blocks. Life happens all of the time everywhere you go and whomever you are with. Life requires a kind of free flowing, constantly adapting, creative responsiveness. This is often incompatible with the discreet units of precisely defined billing codes, or "services".

Acknowledging this reality and addressing it to the extent possible in the design of the system is key to the CWG Vision for adults with developmental disabilities.

***Idaho's self-direction option provides for a wide array of services, contingencies and choices***

Idaho's "My Voice My Choice" (MVMC) self-directed (waiver) option makes possible a high level of participant choice, control and flexibility within the Medicaid system. It can be creatively adapted to a participant's needs and choices. It is possible to use the MVMC option to access services from traditional providers in a way that preserves choice and flexibility. This option currently serves 574 adults and has experienced steady growth.

In order to leverage those opportunities, CWG has, in partnership with the Division of Medicaid, embarked on an effort to generate a greater understanding of the opportunities the self-directed option affords by engaging participants and providers in the process of testing those opportunities, then measuring and reporting on outcomes in response. The CWG has undertaken a number of surveys to learn about levels of satisfaction with the self-directed option. Preliminary results indicate an opportunity to provide some education to dispel some of the myths and misinformation about who can access and how to access self-direction, as well as who may provide services within the option.

***Employment is an important and desirable outcome for most people with DD***

The Collaborative Work group endorses the efforts of Employment First Consortium, another group convened by the ICDD for the purpose of improving how employment services and systems work in Idaho so people with DD are able to reach their career goals. The Consortium provided specific employment service definitions and system improvement recommendations to inform the work of the CWG.

The CWG reviewed and supported legislation proposed by a collaborative workgroup including both CWG and Consortium members. The law was passed by the 2014 State Legislature and allows individuals to request additional service plan dollars for community supported employment services. One result of this statute change is that more people who are eligible for the DD waiver are able to include long-term employment support services under Medicaid in their service plan. This enables them to access vocational rehabilitation services rather than be added to the waitlist for the extended employment services program.

Employment provides individuals with developmental disabilities the opportunity to be an active participant in their community and to: build relationships, increase their social capital, improve their overall health, and become economically self-sufficient. Having a job has a positive effect on overall quality of life.

***An opportunity exists to improve Idaho's assessment and resource allocation process***

CWG purports assessments should:

- Provide information to establish eligibility for DD services and for waivers

- Determine the needs of participants and the amount and types of services that can meet those needs utilizing a person centered planning process
- Allocate resources consistent with the participant's needed support level

Idaho currently uses the Scales of Independent Behavior – Revised (SIB-R), which has not been updated or re-normed for a long time. There is some indication the SIB-R may be re-normed in the future, but there is no indication of when or whether it will be updated for use on current software systems.

There is also some dissatisfaction with how the SIB-R is implemented and the consistency and thoroughness of its use. Furthermore, adults with developmental disabilities and families have expressed frustration with the SIB-R's deficit based approach as opposed to using a strength-based approach consistent with current principles around best practice.

CWG is investigating the use of other methods of assessing the need for services and matching needs to resources including the InterRAI, Arizona's assessment /planning process, the Supports Intensity Scale (SIS) and others. While the SIS is better than the SIB-R in that it actually asks about services and supports the participant needs, instead of merely about their skills. However, it still assigns numbers to responses and yields a final overall supports score. Any evaluation that reduces the information about service needs to a single number (or 2 or 3 numbers) retains some of the objectionable features of the SIB-R.

InterRAI, however, continues to be a tool of high interest to the CWG. Work is underway to further understand its features. CWG envisions an opportunity to conduct an assessment resulting in an individual's need for resources based on an objective individual determination, rather than a score or a correlation. This will allow participants' broad flexibility and opportunity to make the best use of the resources to meet participant needs. While the CWG continues to study InterRAI, the DHW Division of Medicaid has committed staff resources to research and test assessment and resource allocation models, working actively with CWG to find the best statewide solution.

In addressing needs, "Natural Supports," or unpaid sources of assistance, may provide needed support and community integration for people with DD while reducing dependence on government financed services. Because "natural supports" are voluntary, they often are not predictable or reliable. CWG finds natural supports an underdeveloped resource in Idaho. However, the state does pay for support provided by family members, which may actually undermine the concept of natural supports. The issue and the resource warrant study and development.

***A managed care organization model is designed for medical care; it would be difficult to develop a capitated managed care organization to appropriately serve the DD population.***

A managed care organization (MCO) combines the functions of health insurance, delivery of care, and administration in a single organization. Typically, MCOs (such as health insurance companies) have considerable experience with medical care management. Medical managed care strategies rely on preventive treatment and care management to realize savings by reducing more expensive surgical and in-patient treatments.

DD services are very different from medical treatments and procedures. There is no reason to expect that the disability will be “cured” or that the participant will be rehabilitated to the level of complete independent functioning. DD services provide long-term supports for activities throughout the participant’s day and life span. Unlike medical procedures and therapies, DD services are not generally delivered in clinical settings and are most effective when they are integrated into home and community activities. DD services emphasize skill-building, adaptation, and supportive assistance rather than surgery, medication, and symptom control. Furthermore, federal requirements (and best practices) for individualized “person centered planning” and the ongoing supportive nature of DD services challenge the suitability of medical managed care models.

A couple states are experimenting with an MCO model in which a state agency (such as the Division of Developmental Disabilities) acts as an MCO. However, they must overcome the reality of the financial incentives built into MCO models, where a “per member per month” (PMPM) payment system may encourage the reduction of services without any incentives for improved outcomes. Idaho Medicaid services for people with DD already employ managed care strategies including prior authorizations, comprehensive services plans, care coordination, independent assessments, and individual service budgets. Some services, such as supported living and certified family homes, are already structured as capitated daily rates for comprehensive supports. The MCO feature Idaho has not adopted is a single capitated rate for the entire population. This is specifically because of the wide variations within the DD population. Some capitation features, including the limits on the total funding available in individual budgets, are featured in Idaho’s system. A high level of quality assurance is important for any DD service system, but it is even more important for managed care models.

In order to ensure Idaho’s funding is most appropriately budgeted for each individual, CWG finds that deploying a more effective assessment and resource allocation process will secure better outcomes than a capitated MCO contract structure.

## 2015 Initiatives

# Community Inclusion

### ***Collaborate on Home and Community Based Services Rules Implementation***

In January 2014, the Center for Medicare and Medicaid Services (CMS) passed new final rules for the use of home and community-based Medicaid funding. The rule enhances quality, adds protections for individuals receiving services, ensures individuals have full access to the benefits of community living, are able to receive services in the most integrated setting, defines person-centered planning requirements, and provides for additional compliance options for waiver programs.<sup>4</sup>

Idaho's Division of Medicaid has already conducted a Gap Analysis and issued a Transition Plan for residential services to work toward the requirement of the new rules. The National Association of Councils on Developmental Disabilities has acknowledged Idaho for having produced one of, if not the most, responsive draft transition plans among the states.

Idaho also recently released the draft Transitional Plan for Non-residential settings.

Idaho is also fortunate in that it has an already established group—the CWG—to collaborate with the Division to implement the rules over the next five years. The CWG's vision for adults with DD is generally consistent with the new rules. The HCBS rules provide a framework for important parts of the DD system with which Idaho must comply. The CWG must ensure that the enhancements it proposes to the system are in compliance with these federal rules.

As the CMS HCBS rules are implemented, the Division of Medicaid is providing monthly updates to the CWG Steering committee on the status of transition planning and outreach to stakeholders. To ensure adults with developmental disabilities have a real voice in the implementation of the rules and reflect the actual impact, CWG members from the Council on Developmental Disabilities (ICDD), the Center on Disabilities and Human Development (CDHD), and Medicaid are working collaboratively to create a survey and conduct statewide focus groups with adults with developmental disabilities and families.

In addition to the statewide focus groups, ICDD and the CDHD are creating a statewide study of adults with significant disabilities to learn of their experiences with the implementation of the HCBS rules. The results of this study, along with information collected through the focus groups, will provide a wealth of information from people served by the developmental disabilities waiver. This baseline of information will then be provided to the Division of Medicaid for its

<sup>4</sup> <http://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-01-10-2.html>

use in evaluating service provider compliance within the first year of HCBS rules implementation and in future years.

**Revise the current assessment/resource allocation system to ensure that resources are effectively matched to actual individual needs and are aligned with the person centered planning process.**

Much of CWG’s current effort is in the study of needs assessment options and of interRAI specifically. CWG will continue to pursue this opportunity through 2015.

**Enroll Idaho as a participant in the National Core Indicators Project™<sup>5</sup>**

The National Core Indicators™ (NCI) is a voluntary effort by public developmental disabilities agencies to measure and track their own performance. Core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice and health and safety. Forty-two states have joined and are able to compare outcomes against each other’s data. States participants report the acquisition of data that allows them to project future needs, trends, and where a state system may have a shortfall of available services to meet a growing demand.

The following table identifies the core indicators and what each addresses:

Core Indicator	Address
<b>Individual Outcomes</b>	How well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports.
<b>Health, Welfare and Rights</b>	(a) Safety and personal security (b) Health and wellness (c) Protection of and respect for individual rights
<b>System Performance</b>	(a) Service coordination (b) Family and individual participation in provider-level decisions (c) The utilization of and outlays for various types of services and supports (d) Cultural competency (e) Access to services.
<b>Staff Stability</b>	Provider staff stability and competence of direct contact staff.
<b>Family Indicators</b>	How well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.

**Table 2: National Core Indicators**

<sup>5</sup> <http://www.nationalcoreindicators.org/>

Idaho is one of thirteen states that have not joined NCI. With an acknowledged participation fee and need for Idaho staff resources, the CWG still finds participation in the NCI would prove advantageous to the state.

***Generate a solid infrastructure, in coordination with University of Idaho's Center on Disabilities and Human Development (CDHD), providing the adult DD population an active, and effective voice in systems change***

One of CWG's initiatives was to pursue a meaningful and consistent way to engage the adult DD population throughout the state and at all levels of functionality in systems change. CWG considers it essential for people with developmental disabilities are at the core of shaping their new service delivery system. While people with developmental disabilities have been involved throughout the work of the CWG, it was strongly felt that there was a need to be doing more to get a broader and deeper range of feedback from adults with developmental disabilities across the state.

Thanks to the leadership and expertise offered through CDHD, an important link through the policy, advocate and service levels of the DD population is being established.

CDHD houses the Coordinator for its own CDHD Community Advocacy Committee (CAC). The CAC's mission is to guide CDHD leaders by "providing insight into the opportunities and challenges facing people with disabilities and their families on national, state and local levels." The same person who holds the position as Coordinator for the CAC is also the state coordinator for the Idaho Self-Advocate Leadership Network (SALN). SALN is Idaho's statewide self-advocacy organization led by and for adults with developmental disabilities. SALN receives funds through a contract with the DD Council. SALN consists of a network of local chapters in Moscow, Nampa, Boise, Pocatello and Idaho Falls. Self-advocates participate in statewide and national self-advocacy education and participate on task forces developing state and national public policy. Members provide valuable insight into the lives of adults with developmental disabilities.

To help fulfill the objective for participant voices in CWG efforts, the CAC/SALN Coordinator now participates on the CWG Steering Committee. In that role, the Coordinator will use existing structures and processes to consistently engage adults with developmental disabilities in discussions about issues and ideas from the CWG. The process will capture opinions of adults with varying disabilities and from diverse geographical areas of the state.

***The following lists additional initiatives CWG will pursue in 2015:***

1. Create incentives for desired outcomes as opposed to units of service, and develop objective criteria and participant satisfaction measures to drive a robust quality assurance program.
2. Avoid administrative burdens created by compartmentalizing daily activities into multiple discreet billing codes and service definitions, to the extent allowed by federal Medicaid regulations.
3. Expand the use of current Medicaid models which allow for flexible and responsive supports such as the "My Voice, My Choice" (MVMC) option and Supported Living services.

4. Remove barriers and disincentives to using MVMC to access services from traditional service providers, and encourage systems that allow providers to offer service packages to participants.
5. Adopt an “Employment First” approach to services, encouraging employment to be considered in each person’s planning process and incentivizing employment outcomes for people with DD.
6. Explore the opportunity for Medicaid to contract with Independent Living Centers to provide training to participants on navigating the service system, managing their own services, avoiding abuse and exploitation, and selecting providers.
7. Explore the opportunity for Medicaid to contract with Idaho Parents Unlimited (IPUL) to train parents and family members on selecting and managing services and supports.
8. Explore the opportunity for Medicaid to conduct frequent (annual if possible) review of provider rates and costs.
9. Explore how Medicaid may be able to increase the available training for providers.

CWG efforts will continue to seek increased flexibility and responsiveness in a manner integrated into the natural flow of participants’ lives.

## APPENDIX A: CHECKLIST

This page intentionally left blank.

**Collaborative Adult Work Group System Changes  
Reference Checklist – 2013/2014  
December 3, 2013**

**HOW TO USE THIS CHECKLIST**

*The following list of questions are to be used as a reference to help ensure proposed and implemented changes to the Adult Developmental Disabilities system respond to the needs, priorities and suggestions identified by the Collaborative Work Group. In posing these questions, the Collaborative Work Group recognizes regulatory requirements and fiscal constraints may affect the extent to which any of these can be implemented. However, Collaborative Work Group recommends any systems change consider how it does, to the extent feasible, best respond to the following questions. The goal is to intentionally improve the system to achieve the vision, and to specifically not harm what currently exists.*

*Subsequent pages provide a list of parameters respective to Medicaid rules and key definitions. Another checklist specific to participant needs, priorities and suggestions is pending.*

In the development of our recommendations for and implementation of a Developmental Disabilities system for adults, have we ensured, to the extent possible . . .

- . . . a) the two eligibility processes include steps to effectively cross-reference other eligibility processes (Aged & Disabled Wavier, Developmental Disabilities Waiver, Intermediate Care Facilities for Individuals with Intellectual Disabilities, Intermediate Care Facilities for Individuals with Developmental Disabilities) with which an individual may also be involved?

- ... b) services (or service packages) are flexible and easy to adapt to an individual's changing needs?
- ... c) the individual budget process addresses all needs identified in the "person center planning" meeting, including those that fall outside of
  - a. "Medically necessary"? – *(See definitions below)*
  - b. "Health and safety"? - *(No definitions provided)*
- ... d) the individual budget process and person centered planning process work together to best meet individual needs?
- ... e) DHW clinical review processes collaborate more effectively with the person centered planning process? – *(See definitions below)*
- ... f) long-term employment supports are available to all individuals?
- ... g) specified services are governed by the same rules and regulations regardless of who is providing the service?
- ... h) reimbursement rates cover all costs incurred with providing services?
- ... i) billing procedures are structured in a user-friendly way that minimizes billing errors?
- ... j) regulations ...
  - ... 1) around data collection avoid duplication and enhance training?
  - ... 2) involving oversight of para-professional staff avoiding duplication and enhance training?
  - ... 3) allow services to include recreation and exercise?
  - ... 4) accommodations and additional dollars are in place to support services provided in rural areas?
- ... k) our provider network system offers career opportunities for both professionals and para-professionals featuring benefits, living wages and training?
- ... l) an effective communication system provides consistent information between different services?
- ... m) our system actively pursues a communication, outreach and information center that effectively brings best practices and progressive thought to all service providers and facilitates a shared understanding of the service delivery system?

## Definitions

1. Person Centered Planning
2. Medically Necessary
3. Health and Safety
4. Quality Services
5. Quality Personnel

*Definitions from Centers for Medicare & Medicaid Services Idaho Administrative Procedures Act:*

### **Person Centered Planning**

Centers for Medicare & Medicaid Services Technical Guide - An assessment and service planning process is directed and led by the individual, with assistance as needed or desired from a representative or other persons of the individual's choosing. The process is designed to identify the strengths, capacities, preferences, needs, and desired outcomes of the individual. The process may include other persons, freely chosen by the individual, who are able to serve as important contributors to the process. The PCP process enables and assists the individual to identify and access a personalized mix of paid and nonpaid services and supports that assist him/her to achieve personally defined outcomes in the community.

Idaho Administrative Procedures Act - A meeting facilitated by the plan developer, comprised of family and individuals significant to the participant who collaborate with the participant to develop the plan of service.

### **Medically Necessary**

Centers for Medicare & Medicaid Services Technical Guide - Services or supplies that are proper and needed for the diagnosis or treatment of a medical condition, are provided for the diagnosis, direct care, and treatment of the condition, and meet the standards of good medical practice

Idaho Administrative Procedures Act - A service is medically necessary if:

- a. It is reasonably calculated to prevent, diagnose, or treat conditions in the participant that endanger life, cause pain, or cause functionally significant deformity or malfunction; and

b. There is no other equally effective course of treatment available or suitable for the participant requesting the service that is more conservative or substantially less costly.

c. Medical services must be of a quality that meets professionally recognized standards of health care and must be substantiated by records including evidence of such medical necessity and quality. Those records must be made available to the Department upon request.

**Health and Safety, Quality Services and Quality Personnel – no specified definitions from Centers for Medicare & Medicaid Services or the Idaho Administrative Procedures Act**

## **Medicaid Parameters**

Medicaid is required to use CPT and HCBS procedure codes for billing. These codes are nationally recognized and are required by CMS. Each code comes with a description of the service. Instructions included as part of the description often identifies the minimum qualification of the provider and the billable unit.

Self-Direction services are not defined the same way and are therefore not subject to the same requirement.

Reimbursement rates are tied to the qualifications of the provider, and are established by the State of Idaho through a stated process.

Services purely diversional and recreational in nature fall outside the scope of HCBS wavier services. However, social and recreational programming is allowable. It is the intent of the service (socialization vs. diversion) that makes the difference.

Currently, medical necessity and health and safety requirements are a part of the exception review process. This criterion is applied to service requests that exceed the assigned budget. Exception review is attached to the current system – if redesigned, this may become moot.

**This page intentionally left blank.**

## APPENDIX B: STATE MATRIX

**This page intentionally left blank.**

## Supports and Services State Comparisons – pg 1

Current Services	Idaho 1915i	Michigan 1915 b/c <small>School age 26</small>	Arizona 1115, 1915K PCS-self dir.	Rhode Island 1115 Has wait list	New Mexico 1915i & 1915c	New York 1915 b/c?	Colorado 1915c	Wyoming 1915c Has Wait list 2-3 yrs	Oregon	North Carolina 1915 b/c
Adult Day Care	X	X Waiver b/c			X C waiver?		X SLS waiver	Looks like no	See dev. therapy	X
Behavioral & Crisis Mgt.	X	X State plan	X		X C waiver	X Clinics article 16	X SLS waiver		X	X
Chore Services	X	X Waiver b/c					X			
Developmental Therapy	X	X Waiver b/c includes pre-voc	X Day treatment	X Includes pre-voc	X C waiver – customized community	X Comm. & center Day services	X - SLS waiver Include pre-voc Spec. Habilit. & Comm. Connection	X waiver	X pre-voc, comm. Acc. & day services	X Day supports, community networking
Emergency Response	X	X Waiver b/c		X w/in res support	X C waiver		X SLS waiver	X waiver		X
Environmental Modifications	X	X Waiver b/c	X	X waiver	X C waiver	X	X SLS waiver includes vehicles	X waiver		X
Home Choice (MFP)	X				X		X	X	X	X Community Transition
Home Delivered Meals	X	X Waiver b/c					X MFP - 2013			
ICF/ID	X	X State plan	X Group home	X Waiver 24 hr res hab		X	X Group home 4-8	X waiver	X Group Home	X Group Home
Medication Mgt.	X	X State plan	X		X State plan	X	X MFP - 2013	X Waiver Tele-med	X	
Nursing Services	X	X Waiver b/c	X		X C waiver	X	X MFP - 2013	X waiver	X	
Therapies – OT, PT, Speech etc.	X	X State plan	X		X State plan		X State plan	X waiver	X	X

## Supports and Services State Comparisons – pg 2

Current Services	Idaho 1915i	Michigan 1915 b/c <small>School age 26</small>	Arizona 1115, 1915K PCS-self dir.	Rhode Island 1115 Has wait list	New Mexico 1915i & 1915c Has wait list	New York 1915 b/c?	Colorado 1915c	Wyoming Has Wait list 2-3 yrs	Oregon	North Carolina 1915 b/c
Personal Care Services	X	X State plan		X waiver			X SLS waiver	X waiver		X
Psycho-Therapy	X	X State plan	X			X	X		X 1915(f)	
Psychosocial Rehab (PSR)	X	X State plan	X				X MFP – 2013		Not sure	
Residential Hab. Certified Family/ Supported Living	X	X Comm. living b/c Home-based state plan	X Habitatation Adult dev. home	X Waiver Shared living & 24 hr res hab	X C waiver Special medical home	X Certified family & Supported living	X Certified family & Supported living	X Waiver Group & Indv.	X Waiver	X In home skill building, intense support and res. support
Respite	X	X Waiver b/c	X	X Short term	X State plan	X Self-directed	X SLS waiver	X State plan	X	X
Self-Directed Services	X	X Waiver b/c Choice Voucher	X		X C waiver	X Includes respite	X Attendant in-home support	X Waiver Agency w/Choice	X	X 2 models: Agency w/choice and Employ of Record
Service Coordination	X	X State plan	X waiver	X waiver	X State plan	X	X State plan?	X waiver	X	X Community Guide Services
Specialized Medical Equip.	X	X Waiver b/c	X waiver	X w/in res support	X C waiver	X	X SLS waiver & State plan	X waiver	X	X
Supported Employment	X	X (long term thru Med.)	X	X	X (also has self-employment)	X	X	X	X	X
Transportation	X	X State plan	X		X C waiver	X	X	Looks like no	X	X

Other services offered not specific to DD - Adult foster Care - Idaho

Residential assisted living (A&D waiver) – Idaho and Arizona

Home Health Aid – Arizona

Hospice – Arizona

### Supports and Services **Not** Offered in Idaho – pg 3

Current Services	Idaho 1915i	Michigan 1915 b/c <small>School age 26</small>	Arizona 1115, 1915K <small>PCS-self dir.</small>	Rhode Island 1115 <small>Has wait list</small>	New Mexico 1915i & 1915c <small>Has wait list</small>	New York 1915 b/c?	Colorado 1915c	Wyoming <small>Has Wait list 2-3 yrs</small>	Oregon	North Carolina 1915 b/c
Adult Ed. Supports						X				
Attendant Care			X							
Day Treatment for MI		X <small>State plan</small>								
Elderly DD targeted services						X				
Family Training		X <small>State plan</small>					X		X	
Homemaker			X	X			X <small>SLS waiver</small>	X <small>waiver</small>	X	
IBI for Autistics						X				
IRA Homes (up to 14)						X				
Mentorship							X			
Nutrition					X			X		
Counseling										
Residential for Non-waiver		<small>Not sure which</small>								
Risk Screening for Inapp. Behaviors					X				X	
Socialization					X				X	
Sexuality										
Therapeutic recreation							X			

Note – other states allow individuals using the Self-Directed Waiver to purchase services from providers Idaho restricts this

**North Carolina** also offers: Assistive Technology Equipment and Supplies, Natural Supports Education, Vehicle Modifications and Specialized Consultation Services (i.e. Tele Consultation)

**This page intentionally left blank.**

## **APPENDIX C: ARIZONA STUDY SUMMARY**

**This page intentionally left blank.**

**Arizona Fact-Finding Trip Report**  
**to**  
**Idaho's Collaborative Workgroup (CWG) on Services for Adults with**  
**Developmental Disabilities**  
**July 24, 2014**

## **CWG Arizona Fact-Finding Trip Report**

In May 2014, a group of stakeholders from Idaho's Collaborative Workgroup (CWG) on Services for Adults with Developmental Disabilities visited Arizona to investigate their DD service delivery system. The stakeholders who visited Arizona included Christine Pisani, Bill Benkula, Art Evans, and Matthew Wappett. This trip included visits with state employees, policymakers, self-advocates, and families. This report outlines some of the key findings from this investigatory trip and provides backup documentation as an additional resource for consideration by the entire CWG.

### **Background**

Arizona was one of the first states to create a comprehensive system for people with developmental disabilities committed to serving everyone eligible through an 1115 Medicaid Waiver (NASDDDS, 2010). Arizona has created a highly cost effective service system by moving away from large congregate settings and supporting individuals living with their families or in small community residences. As a result, Arizona is one of the most cost effective programs in the country, with only one state in the nation spending less per capita (NASDDDS, 2010). *The Case for Inclusion 2014* report put out by United Cerebral Palsy (UCP) ranked Arizona's Medicaid system for serving individuals with intellectual and developmental disabilities as #1 in the nation (UCP, 2014).

The Arizona Long Term Care System (ALTCS) serves over 34,970 people with developmental disabilities (AHCCCS, 2014). There has been steady growth in the program: from FY 2005 through FY 2013, enrollment in the DD program increased from 15,937 to 34,970 or 119.4%; of this amount approximately 26,000 receive long term care services, the other 8,900 individuals, who do not meet ALTCS eligibility, are served through a developmental disability "state only" funded program. This "state only" program provides for support coordination services and focuses on helping individuals find resources and natural supports in their communities. The annual budget for the ALTCS and "state only" program is approximately \$900 million.

### **Trip Agenda & Data Sources**

Data that inform this report were derived from multiple conversations with stakeholders in Arizona. The data was primarily qualitative and taken from transcripts (see attached), notes, and personal recall by the participants on the fact-finding trip.

The agenda for the visits conducted on the Arizona trip was as follows:

#### **Thursday, May 1, 2014**

**10:30 am** Meeting with staff from Arizona Health Care Cost

Containment System and the Division of Developmental Disabilities  
**12:15 pm** Lunch with Arizona DD Council Staff and Council Members  
**2:30 pm** Raising Special Kids - Parent meeting to discuss the AZ managed care model

**Friday, May 2, 2014**

**10:00 am** Jon Meyers, Executive Director, The ARC of Arizona  
**11:00 am** Health & Wellness Fair - Disability Empowerment Center  
**1:00 pm** Meeting with participants of the service system  
**3:30 pm** Gompers Habilitation Center

**General Findings and Observations**

The AZ system has achieved much of their success through an 1115 R&D waiver (as opposed to a 1915(c) waiver, like Idaho). This allows them much more flexibility and leeway in how they manage their systems, define their cost methodology, and conduct quality assurance. The 1115 R&D waiver requires more reporting and oversight from CMS, but in the long run it has allowed Arizona to serve more people with disabilities in a more efficient manner. Much of what Arizona has accomplished would be difficult, and in some cases impossible, under a 1915(c) waiver.

AZ has a one-time assessment and qualification process. When an individual qualifies for the ALTCS program they do not have to go through annual reassessments or qualification processes. Arizona currently uses a person-centered planning model facilitated by care coordinators to identify individuals needs and to determine necessary services. Nevertheless, they are currently conducting a proof of concept pilot with the SIS this summer and are in contract talks with Arizona's two UCEDDs to take on the task of conducting annual assessments for ALTCS clients using the SIS. They are currently unsure of how the SIS assessment process would affect the budgeting process for clients.

Because they operate under an 1115 waiver AZ uses an individual cost neutrality model as opposed to an aggregate cost neutrality model like Idaho. Each client's needs and ISP is reviewed by AHCCS (the fiscal side of ALTCS) through a Cost Effectiveness Study (CES) to ensure that the costs for each person receiving services in the community does not exceed an institutional threshold for costs. The department reported that most adults with disabilities who qualify for the ALTCS program are living with their parents/families, which helps to keep costs contained. Arizona's narrow definition used for ALTCS eligibility also helps keep costs contained.

Another mechanism that Arizona uses for cost containment is the use of "shared risk agreements" with individuals with disabilities and their families. Arizona will rarely provide 24-hour monitoring or support services for individuals with significant medical conditions, even if a medical professional or the family feels that those services are necessary. ALTCS, through the care coordinator, will

negotiate an arrangement with the family where they will compromise on a “reasonable” amount of support and will then ask the family to assume the risk of monitoring the other times. For example, the state may provide for 12 hours a day of monitoring/support for an individual on a ventilator who requires constant adjustment and suction to keep the ventilator clear, and then Medicaid will ask the family to provide that support for the other 12 hours. The families sign a “shared risk agreement” that releases the state from liability for the time that the family is providing the support. Arizona Medicaid also uses these shared risk agreements for individuals who want to self-direct their own services or who want to live independently in the community. In the event there is no way to assure safety under the shared risk agreements model, and the individual requires 24 hour supports, Arizona does have several 6 to 8 bed group homes that are available but they are not licensed as ICF/IDs.

ALTCS clients have the ability to self-direct their services within a set of programmatic constraints. Clients can hire and fire staff through the use of a fiscal intermediary, but they are unable to pay them as they wish because all service rates are set by the state and cannot exceed institutional rates to ensure individual cost neutrality. As mentioned earlier, ALTCS will also use shared risk agreements to provide additional flexibility for clients who want to pursue activities and/or living arrangements that are not wholly supported through Medicaid. Medicaid contracts with an independent living center to provide extensive training called “This is My Life” to individuals with developmental disabilities. The training addresses the importance of speaking up, how to speak up, the service system, and many other topics related to controlling one’s services and quality of life (see: <http://www.abil.org/this-is-my-life/>).

High quality care coordination/support brokerage is a linchpin to the success of the ALTCS system. State staff, advocacy organization personnel, parents, and self-advocates all commented on the importance of high quality care coordination in the ALTCS system. Care coordination is delivered directly by the State (i.e. care coordinators are State employees) and there is a strong focus on identifying and leveraging natural supports before bringing in paid supports. Care coordinators receive extensive and ongoing training from the Arizona Division on Developmental Disabilities (ADDD), and are constantly being monitored and evaluated by the ADDD (see attached ADDD Training Planning and Tracking Form for Support Coordinators). Care coordinators typically have caseloads of 50-60 clients.

Consumer satisfaction appears to be high for individuals who are in the system; although we did learn that it can be difficult for some individuals to get into the ALTCS system. This was evidenced by the fact that there are many legal firms that specialize in helping clients qualify for ALTCS. Self-advocates whom we spoke with informed us that it is NOT necessary to have attorneys assist when applying for services, but that many people are denied services because Arizona uses such a narrow definition for eligibility. Legal firms typically become

involved after people have been denied access; legal firms help individuals appeal their case, and provide assistance in arguing that the individuals does, in fact, meet the eligibility criteria and should be allowed access to the services available. For example Teresa Moore, a national self-advocate whom we met with, had no trouble applying for and accessing the ALTCS program, but her friend that also met with us, was denied access because he sustained his spinal cord injury in a car accident at age 16.

It became clear from our conversations that ALTCS and the State of Arizona were deeply committed to creating functional partnerships between the state agencies, advocacy organization, and provider groups. In addition to contracting with independent living centers to provide self-advocacy training, Arizona Medicaid also contracts with the Arizona Parent Training Center to provide parent training to learn about the service system, how to navigate the service system, and provides the ability to have parents involved in systems change and public policy discussions directly related to the service system. This center is also directly involved in the development of the training curriculum and the actual training of the care coordinators. Rates for providers are kept current by a very specific methodology of reviewing rates annually and doing a mandatory re-basing of rates every 5 years. Arizona uses the same method of setting rates as Idaho has in statute but in Idaho that method has never fully been implemented.

Guardianship appears to be encouraged within Arizona and there are self-service centers available to download all of the forms necessary to file for guardianship. This was a clear theme through our discussions with the state and with parents.

AZ places a high priority of data and specifically in their participation in the National Core Indicators project. The National Core indicators data provides robust data that helps them gauge their effectiveness and it assists the State in being proactive in planning for future needs. Although participating in the NCI did place an additional administrative burden on the State, the benefits far outweigh the costs of participation according to ALTCS personnel.

All of the people we met with mentioned that Arizona's service system was very urban-centric and that people residing in rural and remote areas (anywhere outside of the Phoenix/Scottsdale or Tucson areas) have limited access to quality services. Several people mentioned having to move closer to urban areas to receive the services and supports they needed.

Arizona has the largest American Indian population of any other state. Most of the tribal groups are located in the "Four Corners" area in the north of the state, although there are several large tribal groups located in the Phoenix area. All of the parties we spoke with mentioned the challenges inherent in delivering services to this rural population. We did learn that the "Four Corners" region has its' own protection and advocacy organization to assist tribal members in accessing services.

Idaho Council on Developmental Disabilities  
208-334-2178

[info@icdd.idaho.gov](mailto:info@icdd.idaho.gov)

<http://www.icdd.idaho.gov/projects/Adult%20Services/ASR.html>