Community Living Advisory Group

Waiver Simplification Subcommittee

Co-chairs: Tim Cortez and Marijo Rymer

Recommendation from the Waiver Simplification Subcommittee

A. Change Rationale/Problem Definition:

Background:

Currently Colorado has two Home and Community Based (HCBS) Medicaid Waivers for adults with Intellectual/Developmental Disabilities. The HCBS Developmental Disabilities (DD) waiver provides comprehensive residential habilitative services and the HCBS Supported Living Services (SLS) Waiver provides a range of services that do not include residential support or 24 hour supervision. The intensity, level and degree of supervision for services under both waivers are determined by the needs and preferences of the individual based on the Supports Intensity Scale (SIS) Assessment.

Colorado has established annual allocation limits under the SLS waiver (referred to as Service Plan Authorization Limits--SPALs.) In the DD Comprehensive waiver, there is no limit on access to 24-7 residential supervision although there are some limits on specific services available to persons who receive DD Waiver benefits.

The SIS was originally intended as a guide to help adults with IDD, their families and case managers design service/support plans that meet individual needs and preferences; In Colorado, the SIS has been used primarily to determine the level of funding available for persons utilizing the waivers.

Community-Centered Boards (CCBs) are currently the single point of entry for the DD and SLS waivers. CCBs determine eligibility for services; administer the SIS; work with clients and their families to develop an annual service plan and provide ongoing case management. Many agencies, including most CCBs, also provide services and supports for the two adult waivers.

Neither waiver for adults with IDD offers self-direction opportunities. The Consumer Directed Attendant Services and Supports (CDASS) option for Health Maintenance, Personal Care Services, and Homemaker Services has not been extended to these waivers.

In Colorado, like most states, the HCBS DD (residential) waiver was first used to ensure that persons transitioning from state operated institutional settings could move into community based living environments. Most people in Colorado who receive benefits under the DD Waiver live in small group homes, apartments or host homes. Some live with onsite staff.
support in homes or apartments with three or fewer residents with IDD. A few are able to
live in their own homes with full time supervision and support while some live in family
homes and use the Family Caregiver service delivery option to access supports and services.

The SLS wavier was designed to provide less intense levels of support for individuals who
preferred or required non-residential services. People receiving SLS benefits often live in
the family home or in their own homes. There are many instances where the lack of DD
waiver resources has limited the choices available to people resulting in situations wherein
DD waiver eligible persons can only access the SLS waiver which, in turn, places an
extraordinary and often impossible burden on natural support systems.

States establish caps on the number of people that can be served in any HCBS Medicaid
waiver. In CO, as in most states, the demand for these resources exceeds the cap and long
waiting lists are the result. Families can place the names of their children on a wait list for
either/both the DD and SLS waiver when the child turns 14 in hopes that a resource will be
available when the child reaches adulthood and is no longer eligible for services through
Special Education, Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) or one of the
HCBS Children’s waivers. Additionally, people who receive SLS waiver services can remain
on the DD waiver wait list.

Problem:

- Because of the long waiting lists in CO, when either a DD or SLS resource becomes
  available, most individuals accept the resource that is offered—regardless of whether
  the services available in that waiver address their individual needs and preferences.
  Consequently, there are some individuals who may have preferred to live quasi-
  independently who accepted the DD residential waiver because other support options
  were not available and there are many people receiving services through the SLS
  wavier who require much more intense services than the wavier was designed to
  provide.

- Additionally, over the past few decades, individuals with IDD and their families have
  made it clear that they wish to have greater control and flexibility over the types of
  services and supports that they obtain. The early community based system created
care-taking environments in the community that offered far greater choice and
freedom than that provided in institutions but the underlying principle of “care-
taking” still characterized most HCBS Medicaid waivers for persons with IDD.

- Today, most people with IDD prefer to live as independently as possible and the
  service delivery system is evolving from “taking care of” people to providing the
  supports they need to maximize their skills and meet their preferences. Technology
  will continue to make independent living a possibility for many more people with IDD.

- Another factor that should be considered in re-design of waivers for persons with IDD
  is that the average lifespan of individuals with IDD has increased dramatically. In the
1960s, for example, the average longevity of people with Down syndrome was around 31 years; in 1993 the mean was 56 and for all people with IDD, the mean was 66; for the general population the mean was 70. Today, people with IDD, in most cases, can expect to live a typical life span of 75+ years. (Braddock—2013)

When the HCBS waivers were first introduced for people with IDD, life spans were considerably shorter and, consequently, the service delivery system did not have to react to the natural changes that occur as adolescents move toward adulthood and into middle and old age. The needs and desires of people with IDD change over time as do the needs and desires of everyone else. Likewise the needs and abilities of other people who support individuals with IDD (e.g. families and friends) also change over time—as do the lives of those who provide support for the general population.

Nationally, more than 25% of persons who provide primary support for a person with IDD are over the age of 60. (2013—Braddock)

- Clearly one of the most important issues that must be addressed in waiver re-design is the need to ensure that persons with IDD have as much control and direction as possible over the types and intensity of supports as well as the methods of delivery. Some families and individuals with IDD prefer and have the resources and skills to design and direct very complex service plans and to hire and monitor support staff. Others would prefer to delegate some or all of those responsibilities to outside agencies. People with IDD and their families prefer to decide with whom they live and by whom support is provided even if they choose to obtain those services through an agency of their choice.

As a result of all these factors and Colorado’s restrictions on service delivery options such as self-determination and self-direction for people with IDD, the demand for a wide array of services that promote independence with optimal choice for adults will continue to grow at the same time that the demand for full support options including a choice of residential services will increase.

In short—the current system is both inflexible and outdated; the service delivery models and reimbursement structures are overly restrictive; the CO Waivers do not provide options for self-direction, and individual choice is limited.

**B. Recommendation and anticipated outcomes**

The Waiver Simplification (WS) Subcommittee recommends that the CO Department of Human Services, Division for Developmental Disabilities with the CO Department of Healthcare Policy and Financing convene a work group to begin the process of exploring the advantages, disadvantages and fiscal implications of a re-designed HCBS Medicaid waiver to support eligible adults with IDD.
• The work group should be convened no later than Oct. 1, 2013 and should be small enough to be effective but large enough to represent persons currently served in the adult system as well as the families of younger persons with IDD who will enter the system in the next decade.

• Additionally, the WS Subcommittee recommends that the Departments in conjunction with the Work Group be charged with ensuring that the needs and preferences of persons currently receiving services in the DD or SLS waiver are thoroughly explored and addressed.

• The WS Subcommittee recommends that the work group explore a re-designed waiver for adults with IDD that will include flexible service definitions and easy access to enable participants to access services and supports when and where needed based on individual needs and preferences. The new waiver should ensure that participants can readily adjust and make changes in services as needs and preferences change.

• The WS Subcommittee proposes that a re-designed waiver for adults with IDD incorporates these principles:
  
  o Freedom of choice over living arrangements, social, community, and recreational opportunities
  o Individual authority over supports and services
  o Support for individuals to organize resources in ways that are meaningful to them
  o Health and safety assurances
  o Opportunities for community contributions
  o Responsible use of public dollars

C. How does the Recommendation address the goals of Triple Aim?

a. Improved Consumer Experience: People with IDD and their families have long noted that the current CO HCBS Waiver services for people with IDD are too complex, rigid, and not responsive to individual needs and circumstances. A single adult waiver for persons with IDD must be designed to allow individuals to access the services they need and prefer throughout their lives as their situations change. With options for self-directed services in most all areas of waiver provisions, persons with IDD will have greater control and influence over the services and supports they receive.

b. Improved Health and Social Integration: With greater flexibility and enhanced responsiveness, individual service plans can be readily modified to accommodate changes in health, family, and social conditions. Greater individual control over the types of services provided as well as the direction of service providers will allow for enhanced social integration.
c. **Fiscal Responsibility:** A flexible HCBS Medicaid waiver for adults with IDD will allow individuals to move among less and more intensive levels of support based on individual needs and conditions. The goal of a potential new waiver is to ensure that public funds support the services that people need when they need them with ready access as individual situations merit.

D. **Type of action required (e.g., administrative, regulatory, statutory)**

The implementation of a new HCBS Medicaid waiver will require statutory change as well as changes to Colorado rules. Initial administrative action to convene the work group is required.

E. **Likely fiscal impact**

The fiscal impact is not known at this time. The WS Subcommittee acknowledges that the current levels of funding for HCBS Waivers for persons with IDD are clearly insufficient to meet the needs of those who are eligible for services.

F. **HCPF/DHS-DDD comment**

The DHS-DDD agrees with the WS Subcommittee’s Recommendation to begin the formal process to explore the advantages, disadvantages and fiscal implications of a new re-designed HCBS Medicaid waiver to support eligible adults with IDD. This formal process should start through the convening of a waiver re-design work group.

The DHS-DDD supports this recommendation because it addresses the Department’s Triple Aim goals. Additionally it aligns with the principles of self-determination, self-direction, person-centered service planning and delivery with a re-designed waiver that is flexible, easy to navigate and provides choice and control to people receiving the supports. Because the fiscal impact is not yet known, much work will need to be done in the re-design process to analyze projected fiscal impact to ensure fiscal responsibility and a financially sustainable service delivery system.

Submitted to the CO Community Living Advisory Group  
On behalf of the CO Waiver Simplification Subcommittee  
August 19, 2013  

**Marijo Rymer**  
Executive Director  
The Arc of Colorado  

**Tim Cortez**  
LTSS Division  
Supervisor, Program Development Unit  
Department of Health Care Policy and Financing