



May 20, 2011

Shari Repinski,
Assistant Director
Program Services
CDHS-Division for Developmental Disabilities
4055 S Lowell Blvd
Denver, CO 80236

Dear Ms. Repinski,

Thank you for providing an opportunity to review, comment upon and recommend improvements to proposed amendments to Colorado's HCBS Medicaid waivers for people with intellectual/developmental disabilities (I/DD).

Colorado chapters of The Arc appreciate the need for expenditure adjustments in order to meet the expectations of the FY 2012 appropriation. We understand that imposing additional limits on units of services for some benefits and/or implementing "hard caps" on services is one way to control costs but we are concerned about unintended consequences that could result in cost increases in other areas of publicly funded services and the negative impact on people.

The arbitrariness of across-the-board service limits and caps on benefits contradicts years of efforts by leaders in the Colorado developmental disability community—families, advocacy organizations, Community Centered Boards, service providers and state agencies—to build a service system based on meeting individual needs and desires. We respectfully suggest that the underlying premise, *i.e.* standardization, of the proposed waiver amendments, anticipated reductions in case management services, and the presumption that SIS scores for 15% of individuals will be reduced are steps in the wrong direction. A standardized, one-size-fits-all approach is contrary to everything we know about effective human service system design and is particularly discouraging given the current federal administration's commitment to Community Living—intended to ensure the "fullest inclusion of all people in the life of our nation."

In general, we are concerned that for many people, the proposed waiver amendments could lead to:

- increased isolation,
- exclusion from community life,
- greater health and safety risks, and
- ineffective service plans designed to "fix" system problems rather than meeting individual needs.

Additionally, we believe that CDHS/DDD has an obligation to consider the fiscal impact on other taxpayer funded systems related to these proposed changes. Cost containment should not result in cost shifting.

Our final general comment is related to the process for seeking public input on these proposed waiver amendments. We received the draft changes on April 27, 2011 from CDHS. However, the information was shared and discussed with other stakeholders at least three weeks earlier. On May 19, 2011 CDHS/DDD distributed additional changes regarding behavioral specialist qualifications and announced public hearings just to review

those proposals. No public meetings were scheduled regarding other waiver amendments. While it may not have been intentional, the resulting perception of this somewhat disorganized and haphazard approach is that the department is not serious about public input.

We offer the following comments on specific waiver amendment proposals:

Day Habilitation Service Limits:

- The proposed limit of 24 hours per week—across the board—for both the HCBS-DD and Supported Living Services waivers—disregards requirements for Individual Plans to be based on individual needs. If the Interdisciplinary Team determines that 40 hours per week of services is required and the plan is approved, there is no rational basis for the state to automatically reduce services by 30%.
- The HCBS-DD waiver is designed to be comprehensive. Individual plans are built to address physical, mental, social, and occupational needs of each person enrolled. A “hard” cap on day habilitation services is contrary to the comprehensive purpose of the waiver. At a minimum, DDD should provide—through the Prior Authorization Request (PAR) process—for exceptions to this cap.
- The reduction in hours can result in additional staffing requirements for group homes
- There will be increased expenses for CCBs and state staff for managing Medicaid appeals
- A reduction of day activities will lead to increased behavioral problems leading to greater demands on first responders, increased emergency room usage etc. etc.
- Indirect costs will be incurred by community organizations resulting from increased demand for advocacy and legal representation
- The reduction of day habilitation hours for 178 individuals in the SLS waiver is a “double whammy.” The Spending Authorization Limits (SPAL) for these individuals has already resulted in hardship. Additionally, it is difficult to see how any savings will actually occur. The SPALs remain the same. CDHS/DDD must assume that the SPALs will be reached—regardless of the array of services included.
- Again, as with the HCBS-DD waiver, there must be a provision for exceptions to the “hard” cap.

Behavioral Support Services

Chapters of The Arcs in Colorado and the Autism Society of Colorado have collaborated to develop this response to proposed changes to Behavioral Services in the adult DD waivers.

Our organizations also advocated strongly for inclusion of behavioral services in previous waiver renewals for DD services. We are grateful that DDD has recognized the importance of behavioral services for people with I/DD by adopting policies and implementing services that allow people to live safely in the community.

Prior to these important policy changes for citizens with I/DD with co-occurring behavioral issues, adults with ID/DD had very little access to these important services. Without consistent access to behavioral services, it was evident that many people lived in a hopeless cycle of behavioral melt-downs, followed by involvement of law enforcement, followed by EMS stabilization and transportation, followed by Emergency Department services, a return to the community setting where the underlying cause of the behavior could not be addressed, followed by another behavioral melt-down...

We know that many referrals to our state’s Regional Centers resulted from inadequate community resources to address behavioral needs. The cost to Colorado taxpayers for these services was (and continues to be) significant.

After the implementation of behavioral services in the waivers, there was a corresponding reduction in emergency room use related to dangerous behaviors.

After being made aware of proposed reductions to behavioral services, The Autism Society of Colorado reached out to service providers for information about appropriate levels of service needed to address and correct underlying causes of unsafe behavior. Responses to this informal survey informed us that 80 units of service are not enough to remediate unsafe behavior for people with high levels of need. (Respondents reported that an average of 102 hours of services was need.)

Even for people with ID/DD who have reliable communication systems, 80 units may be insufficient time for analyzing behavior, creating plans to teach and maintain different behaviors, and making plan adjustments when needed. However, for people with ID/DD who do not have reliable communication systems, the proposed 80 unit limit is likely to be seriously inadequate. The proposed annual cap is also unlikely to meet the needs of people with complex behavioral profiles. Attached to this letter are two case examples that clearly illustrate the potential problem.

As with the proposed amendments to restrict day habilitation services, we believe that the spectrum of need in the I/DD community—as well as the wide range of individual needs—must be respected and accounted for in the waiver. A “soft cap” of 80 units might be reasonable for people with reliable communication systems. But higher levels are required for people with unreliable communication systems. Through the PAR process, it should be possible for case managers to adjust these service caps based on need.

Additionally, there should be a waiver mechanism to ensure that people who need more than one behavioral assessment per year will have access to what they need. The PAR process for people who need more than one assessment could help control costs. If one provider is unable to determine the cause of the behavior and provide a plan for amelioration, individuals should be able to access services from another provider. Behavioral specialists are not “mind readers”—what works best with an individual who does not communicate may be achieved through discovery over time.

Although we understand the pressure to contain costs, our job is to advocate for the health and welfare of the whole person with I/DD. Damaging and expensive cycles of interaction with police, paramedics, and Emergency Departments is not in the best interest of people with I/DD. Adequate, effective, and humane behavioral interventions that teach safe behaviors are critical to the individual’s well-being and the health and welfare of caregivers. By providing appropriate behavioral services, costs to other Medicaid programs and law enforcement systems can be reduced.

In conclusion, we respectfully submit that people with I/DD should not have to suffer when the system fails. People with I/DD did not create the “design” flaws in the service delivery/re-imburement system. Unfortunately, the proposed changes will make them pay for mistakes to which they did not contribute.

It is disheartening to contemplate the regressive, exclusionary impacts on Colorado citizens with I/DD that will occur with these proposed wavier changes.

Thank you for your attention.

Sincerely,

Marijo Rymer
Executive Director
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On behalf of Colorado Chapters of The Arc and the Autism Society of Colorado.