

AN ALLIANCE BRIEFING PAPER

Waiting Lists for Intellectual and Developmental Disabilities Services in Colorado

Introductory Analysis and National Trends

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Introduction

Alliance and its members were heartened by the growing interest of the Colorado legislature and administrative branch in resolving the decades-long Colorado waiting list crisis. This briefing paper seeks to support this effort by providing background analysis of the current state of Colorado waiting lists for persons with intellectual and developmental disabilities (I/DD), as well as national waiting list trends. Alliance is committed to this effort, and will work to provide research and policy analysis to assist Colorado's elected officials in this important initiative.

Background

Services and supports to individuals with I/DD in Colorado are provided through Medicaid Home and Community Based Services (HCBS) and programs supported by state general funds. Medicaid HCBS are offered primarily through three programs: the mandatory state plan home health services benefit, the optional state plan personal care services benefit (which Colorado currently does not have), and Section 1915(c) HCBS Waivers. Colorado currently has 12 HCBS waivers, two of which are specifically for adults with I/DD: the Supported Living Services (HCBS-SLS) waiver and the Waiver for Persons with Developmental Disabilities (HCBS-DD), often called the comprehensive services waiver. Several other waivers serve children with disabilities: the Children with Autism, Children's Extensive Support (HCBS-CES), Children's HCBS and Children's Habilitation Residential Program waivers. Waiting lists exist for the autism and HCBS waivers. In 2013, Governor Hickenlooper proposed funding to eliminate the current waiting list for Children's Extensive Support. The funding was approved by the legislature, and the process to enroll all those on the waiting list should be complete by fiscal year 2013-2014.

State general funds support the Family Support Services Program (FSSP) and state-funded Supported Living Services. Waiting lists exist for both programs. Early Intervention Services are provided to children with both general funds and federal dollars through the Individuals with Disabilities Education Act Part C Early Intervention program. There is no waiting list for EI services because Part C prohibits waiting lists.

Waiver services are not an entitlement in Medicaid, yet demand for HCBS has grown steadily throughout the decades. Federal-state HCBS Waiver spending grew from \$2.2 million in 1982 to \$27.9 billion in 2011.¹ Most states cannot meet the current demand for these services. Sec. 1915(c) allows states to use a broad range of strategies to meet both the federal cost neutrality requirements (total per-person spending must be lower than providing equivalent services in an institutional setting) and state budgetary restrictions.² Cost containment strategies include the following:

- Financial eligibility: Colorado and most states set financial eligibility at 300% of the federal Supplemental Security Income program federal benefit rate, which was \$2,022/mo in 2011. (This is the same rate most states use for nursing facility eligibility in Medicaid.)

¹ Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., Lulinski, A., Wu, J. (2013). *The State of the States in Developmental Disabilities: 2013*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

² Kaiser Commission on Medicaid and the Uninsured, *Medicaid Home and Community-Based Service Programs: 2009 Data Update (Dec. 2012)*, available at: <http://kff.org/medicaid/report/medicaid-home-and-community-based-service-programs/>

- Functional eligibility criteria: Some states are stricter for HCBS than institutional services. The person must exhibit deficiencies in a certain number of Activities of Daily Living, such as bathing or eating. Colorado does not have stricter requirements for HCBS.
- Cost controls: More than 80% of waiver states used cost control over and above the federal mandated cost neutrality formula. Examples include expenditure caps, service provision and hourly caps, and geographic limits. Colorado reported using “Cost Limits” only.³
- Consumer Direction: Some states include initiatives such as consumer choice in the allocation of funds from individual service budgets or the hiring and firing of service providers. States can choose to make this optional or mandatory. Colorado allows consumer direction in two waivers (Elderly, Blind and Disabled and Mental Illness) through the Consumer Directed Attendant Support Services (CDASS) program. This is not currently available for Colorado’s I/DD waivers.
- Waiting lists: States are allowed to maintain waiting lists for services when demand exceeds resources.

Waiting Lists for I/DD Services

Waiver guidance from the Centers for Medicare and Medicaid Services (CMS) discusses waiting lists as a record of persons whose entrance to the waiver must be deferred until capacity becomes available through turnover or the appropriation of additional funding by the legislature.⁴ Colorado law governing DD services defines waiting list as “a list of persons with intellectual or developmental disabilities who are waiting for enrollment into a program provided pursuant to this article.”⁵ These definitions capture the common understanding of waiting lists for services: a list of individuals who meet the eligibility requirements for a program, but who must wait for services due to limited program resources.

States often use waiting lists when their waiver programs are at capacity or when state legislatures do not fully fund the maximum number of enrollment slots approved by CMS.⁶ Some states maintain detailed waiting lists of service needs for persons with I/DD.⁷ Others do not formally collect waiting list data, but state officials acknowledge that significant demand for services exists.⁸

In 2011, 38 states reported waiting lists, and ten reported no waiting list (see attached Table 11).⁹ Nationally, waivers for people with I/DD had the greatest number of individuals on waiting lists (316,673).¹⁰ This number makes up 62 percent of the total persons on all waiver waiting lists.¹¹ Individuals on I/DD waiting lists also experience the longest wait times nationally, an average of 40 months.¹² However, this does not necessarily mean that individuals waiting get no services. States report

³ Id. Table 9.

⁴ Application for a 1915 (c) Home and Community-Based Waiver [version 3.5] Instructions, Technical Guide and Review Criteria 2008. Centers for Medicare and Medicaid Services.

⁵ C.R.S. Section 27-10.5

⁶ Kaiser Commission on Medicaid and the Uninsured, 2012.

⁷ Braddock, et al. 2013.

⁸ Id.

⁹ Kaiser Commission on Medicaid and the Uninsured, 2012.

¹⁰ Id.

¹¹ Id.

¹² Id.

that most individuals on waiting lists are successfully screened for Medicaid eligibility and receive other Medicaid (non-HCBS waiver) services while they are waiting, such as state plan benefits.¹³

In 2011, Colorado reported that 7,936 individuals were enrolled in its state I/DD waivers.¹⁴ As of June 2013, 2,151 individuals were waiting for HCBS-DD and HCBS-SLS; 440 children were waiting for HCBS-CES; 148 individuals were waiting for state-funded SLS; and 5,941 individuals were waiting for Family Support Services.¹⁵ The Colorado Human Services Board recently approved a rule change in the definition of “Developmental Disability” for Colorado. The revised regulation is expanded to allow individuals to become eligible for services on the basis of impairment of adaptive behavior resulting from a neurological condition. This expansion is likely to increase demand for I/DD services. Because the state has not allocated new dollars to fund entrance to services for the expanded population, this change may also add to the waiting lists for I/DD services.

Managing a Waiting List

States encounter a number of questions when determining how to manage their waiting lists.¹⁶

Do we assess individuals’ need for services or simply maintain a list of individuals who express interest in waiver services? In Colorado, we currently determine eligibility before placing an individual on the waiting list. However, for the Family Support Services Program (FSSP), State-funded Supported Living Services and the HCBS waivers, a service plan is not developed until enrollment.

If we do an assessment, do we assess both need for services and financial eligibility for Medicaid? Currently, Colorado does both. Counties determine financial eligibility for Medicaid and the Community Centered Boards (CCBs) determine that a person has a developmental disability and do functional eligibility determination for waivers. CCBs provide information and referral for any person found not eligible for I/DD waivers based on the assessments.

If we do an assessment, how often do we reassess needs? In Colorado, case managers make contact with each person on the waiting list each year to provide information and referral and to see if they are still interested in receiving services or whether their status has changed. Additional eligibility determination and assessment of need is not completed again unless there is sufficient reason to believe the person’s needs have changed. As needs change and upon request, individuals can be removed from waiting lists. Intensive case management support is provided to individuals with crisis and emergent needs to stabilize their current setting or assist with securing alternatives.

Do we maintain a centralized waiting list or delegate responsibility to local administrative entities? Colorado maintains a centralized waiting list, but CCBs maintain local waiting list information for

¹³ Id.

¹⁴ Braddock 2013, Table 14.

¹⁵ Medicaid Funding Requested Waiting List Report, March 31, 2013, Division for Developmental Disabilities, Office of Long Term Care, Colorado Department of Human Services. Available at: <http://www.colorado.gov/cs/Satellite/CDHS-VetDis/CBON/1251617259764>

¹⁶ Auerbach, R., Reinhard, S.C. (Aug. 2006). *Challenges Posed by Waiver Waiting Lists*. Community Living Exchange. Available at: <http://www.hcbs.org/moreInfo.php/doc/1786>

persons in their catchment areas and are responsible for conducting information and referral and eligibility determinations. CCBs authorize enrollments for FSSP, State funded-SLS, and HCBS-SLS. The State authorizes enrollments for HCBS-CES and HCBS-DD.

When funding becomes available for additional waiver enrollments, how do we allocate those new resources? Are the resources allocated centrally? Are they allocated to local administrative entities? Some resources are allocated by the Colorado legislature, e.g., during the last session, the legislature allocated resources to those “most in need”, which it defined as those age 50 and above. Otherwise, the state goes through the central waiting list and identifies the next individual. Order of selection is based on the date of the determination of developmental disability. Exceptions are made when a person is in an emergency situation and needs immediate enrollment. HCBS waivers allow for some enrollments to be reserved for target populations (e.g., persons moving from institutions, high risk, foster care, etc.). The enrollment is assigned to the local CCB for a person and the CCB follows through with the enrollment activities. CCBs continue to have ability to fill vacated Supported Living Services resources (both state-funded and waiver) and can authorize enrollment into the HCBS-SLS waiver based on available resources assigned through contract with each CCB. All authorizations for enrollment into additional HCBS-DD or newly added SLS waiver resources are assigned by the Department.

CCBs have more authority with regard to the Family Support Services Program. While statute and rules outline general requirements, they do not provide specifics on service delivery. For many years, the Division for Developmental Disabilities enforced the "most in need criteria". But after massive cuts to the FSSP budget, the requirements were relaxed to allow CCBs to manage the program with the greatest degree of flexibility. Many CCBs continue to use the "most in need" decision-making model in some form to ensure transparency and uniformity in the enrollment process.

Statute requires each CCB to have a FSSP Council, which serves as an advisory body to the CCB specific to the local administration of the program. CCBs have different procedures for administering the program and making decisions about prioritization, services, numbers served, etc. These procedures are developed according to the council's recommendations.

Are there certain criteria to be used to give service priority for individuals in certain categories, such as those transitioning from institutions or at risk of institutionalization? In Colorado, criteria vary by program. Persons waiting for FSSP are prioritized based on CCB-defined criteria e.g., most in need criteria. Children receiving HCBS-CES receive priority to enroll into SLS when age 18. Children with DD/ID who are in foster care receive priority to enroll into HCBS-DD. The HCBS waivers allow for the state to reserve enrollments for persons who are transitioning from institutions, in emergency situations, or meeting the high risk criteria.

What does it mean to Eliminate Waiting Lists?

Although some states report having eliminated waiting lists for I/DD programs, the absence of waiting lists does not necessarily mean that everyone is getting all of the services they need. An overview of state services and supports for people with I/DD, including states that have eliminated waiting lists, suggests that eliminating a waiting list for a particular program means that everyone who meets the eligibility criteria for the program is receiving *some* service(s) through the program. Ideally, the I/DD service

system would provide the right services at the right time, when and where recipients want to receive them. However, this is not always the case even in states that do not have waiting lists for services. For example, although HCBS services are considered an entitlement in California, recent budgetary restrictions and stringent eligibility criteria have degraded services and disenfranchised recipients.

Strategies to Reduce HCBS Waiting Lists

Waiting list initiatives in the states have generally involved expanding family support to prevent or delay the need for placement or obtaining new or reallocated resources from the following: closure of state-operated institutions; converting Intermediate Care Facilities for Persons with Intellectual Disability (ICFs/ID) to HCBS waiver programs, capping reimbursement for existing programs or seeking additional Medicaid funding.¹⁷ While not a comprehensive list, the following are some examples of state initiatives to reduce waiting lists.

- Hawaii eliminated its waiting list in 2000 as part of the settlement agreement in *Makin et al. v. State of Hawaii*.¹⁸
- Idaho eliminated its waiting list in 1999 when the legislature removed the “cap” on the projected number of waiver participants.¹⁹
- California does not have a waiting list because HCBS are considered an entitlement under the state’s Lanterman Act, however, budgetary restrictions have degraded services in recent years.
- New Jersey allocated an additional \$11.7 million in the 2004 Division of Developmental Disabilities budget to open 84 additional group homes to serve over 400 individuals.²⁰
- Kentucky’s Governor identified funding to serve an additional 500 persons on the waiting list in 2003 legislation.²¹
- New York created the New York State – Creating Alternatives in Residential Environments and Services program to address the needs of individuals on the waiting list for residential placement.²² Originally established for five years, the NYS-CARES program is now a permanent part of the state budget.

HCBS waiting lists do have implications on state compliance with the *Olmstead* decision, which requires them to provide services outside of institutions if beneficiaries are able to live in the community and do not oppose doing so.²³ A number of waiting list lawsuits have been brought in the states.

Recent Efforts to Reduce I/DD Waiting Lists in Colorado

Mandy R. Lawsuit

A waiting list lawsuit was filed in Colorado in 2000. In *Mandy R. et al. v. Owens et al.*, the plaintiffs

¹⁷ Braddock, et al. 2013.

¹⁸ Id.

¹⁹ Id.

²⁰ Braddock, D., Hemp, R., Rizzolo, M.C., Haffer, L., Tanis, E.S., Wu, J. (2011). *The State of the States in Developmental Disabilities: 2011*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

²¹ Id.

²² http://www.nysegov.com/citguide.cfm?ques_id=336&superCat=119&cat=413&content=relatedfags

²³ Kaiser Commission on Medicaid and the Uninsured, 2012.

alleged that the state was in violation of a number of federal laws, including the Medicaid “reasonable promptness” requirement and the *Olmstead* decision by maintaining waiting lists for I/DD services. The court dismissed the claims, finding that “*Olmstead* does not stand for the proposition that a state must create, expand or maintain programs for the purpose of preventing disabled individuals from becoming institutionalized.”

Multi-Year Funding Effort

In 2006, Alliance published a brief entitled *Waiting...: A Colorado crisis involving 3,746 individuals with Developmental Disabilities*. The brief outlined a set of recommendations for a multi-year plan to address the waiting list, which led to the formation of an interim committee the following year.

In 2007, the Colorado General Assembly convened an interim committee to study the waiting list for long term services. The committee passed several recommendations for legislation which began a multi-year effort to address the I/DD waiting list. House Bill 08-1101 requires an annual review of the waiting list situation by the Colorado General Assembly and provides heightened awareness of the waiting list crisis. It also prevented monies not yet expended from being reassigned from their intended purpose of helping those individuals with developmental disabilities. It created the Developmental Disabilities Services Cash Fund with the goal of eliminating the state's developmental disability services waiting lists by 2013. However, due to the recession, dollars were never allocated to the cash fund until FY 2012-2013.

Ballot Initiative

In 2008, a coalition of families, advocates, community centered boards, service providers and other citizens and organizations pushed for a ballot initiative, Amendment 51, to increase state sales tax to provide funding for long-term services for people with I/DD. If passed, a phased-in tax would have generated \$185.1 million annually to be placed in the Developmental Disabilities Long-Term Service Cash Fund and used to reduce the state’s waiting lists for services.²⁴

CES Waiting List

In the last legislative session, Governor Hickenlooper proposed enough funding to eliminate the current waiting list for the Children’s Extensive Supports waiver. The Colorado Assembly approved the increase and children on the CES waiting list are in the process of being enrolled in services. This process should be completed by fiscal year 2013-2014.

Conclusion

In recent decades, state and federal policymakers have responded to consumer preferences by offering alternatives to institutional care by expanding home and community-based service options. Unfortunately, the demand for these services far exceeds available resources in most states. Colorado and other states have employed a variety of strategies to address waiting lists for I/DD services. To make progress toward eliminating its waiting list, Colorado will likely need to employ a multifaceted and multi-year approach including systems change strategies and a commitment to expand resources. Community capacity to serve individuals on the waiting list must be considered to ensure that providers can continue to offer quality services and supports.

²⁴ Retrieved from [http://ballotpedia.org/wiki/index.php?title=Colorado_Sales_Tax_for_Developmentally_Disabled,_Amendment_51_\(2008\)&oldid=1274063](http://ballotpedia.org/wiki/index.php?title=Colorado_Sales_Tax_for_Developmentally_Disabled,_Amendment_51_(2008)&oldid=1274063)”