



January 20, 2012

Memo To: Kevin Casey, Director, Division of Developmental Disabilities

From: Tony Paulauski, Executive Director

Subject: New Adult Waiver Comments for Improvement

Introduction

Thank you for the opportunity to provide comments on the Home & Community Based Adult Waiver.

The recommendations included in this memo are focused on increasing and improving the ability of people receiving waiver services to live, work and recreate in their local communities. Illinois is on the precipice of a significant shift in how it provides services to people with intellectual and other developmental disabilities, moving from an institutionally biased system to one that supports and promotes community based service options. The *Ligas* settlement agreement will make services available to 3,000 people with developmental disabilities and, along with closures of State Operated Developmental Centers (SODCs), will ensure the transition of many others to community services. The success of this important shift will depend in large part on the

ability of people on the waiver to access the services they need to fully participate in their communities.

Recommendations specific to expanding access to self-directed services and goods are not included in this memo because we understand the Division is currently working with Robin Cooper and the Council on Developmental Disabilities on this effort. The Division is also currently working to develop specialized services and community settings for individuals with significant medical and/or behavioral challenges. These modifications to service standards and the overall system itself will have a positive impact on the ability of people with developmental disabilities to access and engage in their local communities. Since these changes are already underway, they are not discussed in this memo.

Recommendations are grouped into two categories, short term and long term, based on the relative 'ease' of adopting the changes to the waiver and the overall service system. All changes will require amending the current waiver and developing new policies and procedures to ensure implementation meets all state and federal requirements. The positive impact, balanced with the level of effort required to implement the recommendations, dictates whether a recommendation is categorized as short term or long term.

SHORT TERM RECOMMENDATIONS

Assistive Technology: Although the current waiver includes Assistive Technology services, the description of the service itself includes no reference to IT or other new technologies. Specific reference to various technologies in the service definition itself would strengthen the waiver and increase the ability of people to access such items as computers, iPads, smart phones, touch pads, etc. Division policies for approval of Assistive Technology should not include significant barriers to access. If they do, those policies should be reviewed and rewritten as needed. New applications specifically designed to assist people with intellectual and other developmental disabilities are developed and introduced daily. For example, Michael Smull recently partnered with an IT professional to develop an iPad application that easily supports creation of an individual plan by people with developmental disabilities themselves.

Family Advocacy Resources: Advocacy models like the Illinois Life Span Program should be a part of the waiver under the administration section of the waiver. This would allow the Division to bill for a percentage of the Life Span Program that works with individuals eligible for Medicaid services.

Family Support Services: Adding a family support service to the waiver will formalize and facilitate the ability of families to connect with one another to create local networks of support. These networks will be a powerful tool in efforts to increase community

capacity and the use of natural supports. Funding for this type of service could pay for time of a Family Mentor to coordinate local meetings, host one to one meetings and group activities. Family leadership and advocacy training could also be provided by the Family Mentor, in our case, the Family Support Network. This type of service will help develop and expand community access by empowering families themselves.

Peer to Peer Support Services: Another important way to ensure people with developmental disabilities are supported and valued in their local communities is to provide a formal, funded mechanism for them to support each other. The mental health field has established the concept of peer to peer support as vital to the success of treatment. As this service concept begins to take hold in this field, it is necessary to fund these activities to ensure their long-term success. People with developmental disabilities can achieve positive results from being able to formally work with one another to share experiences and learn about opportunities in their local communities. As with the Family Support Service, funding for this service would go to people with developmental disabilities who meet criteria to serve as Peer Mentors individually, or to groups of individuals. Adding this service to the waiver will memorialize the idea of self-advocates learning from one another and help build strong networks of peer to peer support throughout the state.

Person Centered Planning: The lack of funding for Person-Centered Planning (PCP) through the waiver is a significant deficit. The Individual Support Plan (ISP) is referred to as a “participant centered support plan” throughout the waiver document, but there is no specific service available to support the facilitation and development of a Person-Centered Plan. A good person-centered planning process and the resulting PCP will establish long-term goals for each individual and can serve as the basis for development of the annual Medicaid required ISP (or “participant centered support plan”).

Responsibility for convening the team and coordinating the development of the plan itself should rest with the Individual Services and Support Advocacy (ISSA) staff. This will position the ISSA to firmly know and understand the wishes of the person served so they can more effectively advocate for them during development of the ISP (until such time as they also become responsible for that process; see Long Term Recommendations). This will also be vital for those preparing transition plans for those that will transition from institutions to community settings.

The Division can look to other states that make this service available through the waiver for a service definition and recommendations on how to best implement. For example, with the plethora of good person-centered planning models and trainings available, the state may opt to establish criteria for the tools that are to be used, rather than dictating the use of one or more specific models.

Positive Behavioral Supports: Shift the focus of the current Behavior Intervention and Treatment (BIT) service toward Positive Behavioral Supports. The current service definition for BIT in the adult waiver specifically includes reference to Applied Behavioral Analysis (ABA), Relationship Development Intervention (RDI) and Floor Time. These techniques are primarily identified as behavioral interventions for children with autism spectrum disorders. A positive behavioral approach to behavioral support services would greatly benefit adults with intellectual and other developmental disabilities in Illinois.

Positive Behavioral Support is widely considered best practice and “encompasses behavioral strategies to deal with a broad range of situations from teaching routine tasks and social skills to responding to acts of aggression and self-injury.”¹ When used to assist people with developmental disabilities who may or may not have co-occurring diagnosis, the focus is on use of a person-centered approach that treats people with dignity and respect.

The current Behavioral Intervention and Treatment service definition is written broadly enough that it does encompass the concepts behind Positive Behavioral Supports. However, it does not specifically identify PBS in the definition and continues to allow the use of restraint, even with the protections provided in the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-108). This change would demonstrate that an increased focus on this behavioral support model would greatly benefit adults with developmental disabilities.

Respite Care: Respite care supports should be a separate billable support within the waiver.

Transition Supports: Add Transition Supports to the Medicaid waiver to ensure people transitioning from institutional settings to community settings are able to pay basic start-up costs and purchase furniture or other household items. The Division currently offers a version of this type funding to some who transition to a CILA, but it is not available through the waiver. Whether or not it is authorized is based more on the needs of the CILA provider than the needs of the person. A new service definition and policies that stress the funding is to be used for start-up costs and to purchase household items that will remain the property of the individual, not the organization, will need to be developed. Medicaid requires that the service only be available to those transitioning from institutions (public or private) to community settings. It cannot be used for people coming into waiver services from the waiting list or for people moving from one community service provider to another. Other states that have transition funding available as a waiver service allow one-time use of the funding when a person initially

¹ AAIDD (http://www.aamr.org/content_281.cfm?navID=98)

transitions to the community and generally cap the total funding amount at between \$1,500 and \$2,000 dollars.

Transportation: Transportation should be a separate billable service to access integrated individualized waiver supports/services in the community, especially for employment related supports.

Virtual Support Technology: Many states now offer 'virtual' or real-time, camera-based supports through the Medicaid waiver for people who need assistance in their homes or apartments. Small interactive cameras are placed in the common areas of homes to assist people with developmental disabilities. The cameras are monitored at an off-site location and the agency is required to have float-staff available to go to any home within a set amount of time (usually 10 minutes or less). Use of this type of technology must be guided by a clear vision that establishes the rights of the person served, the circumstances under which this type of support is appropriate, and protections to ensure the information collected through the camera is secure.

In Illinois, where the fiscal environment is challenging, it is important that use of technology not become a sub-standard replacement for direct support staff in large CILA homes. A service definition and related policies should be developed that stress that virtual technology supports are to allow people with developmental disabilities to live independently in smaller settings. For example, a person that needs general supervision may be able to live in an apartment or small home with another person through the use of virtual support services, instead of in a large CILA that is staffed 24/7. This will decrease cost for the state and increase the independence of people who are able to choose this option. The decision on whether or not to use technology-based support services should rest with the individual and his or support team, not with the provider agency.

Vacancy Factor: Discontinue the practice of paying for non-Medicaid reimbursed bed-hold when a person leaves a CILA setting on a short-term basis for hospitalization, short-term rehabilitation, crisis stabilization, etc. Instead, calculate a reasonable vacancy factor into the CILA rate, based on historical use of bed-hold funding. Incorporating a vacancy factor into the rate is allowed by Medicaid and will allow the state to capture Federal Financial Participation (FFP) of this funding. As changes to the CILA rate methodology are made, the Division will need to strengthen regulations and policies to ensure that the individual is protected from discharge or movement to another provider home when the absence is truly short-term. The financial benefit of this change will increase as the number of people in CILA settings increases.

LONG TERM RECOMMENDATIONS

Restructure Day Programs to Focus on Employment Outcomes: In order to fully support adults with developmental disabilities in their efforts to become active and contributing members of their communities, it is imperative that the state restructure the service definitions and funding structures to support employment, self-employment micro-enterprises, etc. This must include adopting strong “employment first” focused service models. The Division should follow recent guidance from CMS to create service definitions that focus on accessing competitive employment. CMS recently clarified expectations and standards for employment supports in a letter to State Medicaid Directors and in a presentation given at an HCBS waiver conference.

The current waiver adopts a “one size fits all” model, funding nearly everyone at \$11,500 per year, regardless of level of need or service type. As identified by the Rate Review Committee, this creates a reverse-downsizing incentive because this annual amount is less than ICF/MR providers receive for similar Day Training programs. The low funding level and lack of a true rate methodology pushes people into large, segregated Day Training programs and congregate work settings.

The recent Department of Justice settlement agreement with the state of Georgia places significant emphasis on the ability of people transitioning from state facilities to access jobs in their local communities. This echoes the experiences of other states that have rebalanced their service systems. In addition to increasing community capacity for residential services, states must also recognize the importance of ensuring access to employment-related services and other meaningful day time activities.

A new realistic rate methodology will need to be developed to foster “employment first” practices.

Increase Expectations and Improve the Quality of ISSA Services: The Bogard Consent Decree established independent, free standing service coordination throughout Illinois. This system alleviated potential conflict of interest. Therefore, any recommended changes in ISSA are that those services will be offered as independent, free standing services. As described in the waiver document, Individual Service and Support Advocacy (ISSA) is the foundation of a strong quality management system in Illinois and is vital to ensuring adults with developmental disabilities are able to access services on the waiver and achieve their personal goals and outcomes. Ensuring that these providers have the knowledge, are free standing of other direct services, and have the experience and authority to act on behalf of those they serve is critical to the success of the waiver program. The following recommendations would require significant systemic changes, but they would strengthen the role and the impact of ISSA:

- Individuals should have the ability to choose their Individual Service Coordinator and/or Individual Service Coordination organization at anytime, but the choice of the ISC may be subject to travel and geographic considerations.
- In addition to development of the Person Centered Plan (see Short Term Recommendations), shift responsibility for coordination, development and overseeing of the Individual Service Plan, or participant centered support plan, from CILA and DT employed QSPs to ISSA staff. Currently the ISSA must 'approve' the ISP, but responsibility for development of the ISP rests with the QSP for the provider organization. Shifting responsibility for convening the Individual Support Team meeting and overseeing the development of the ISP to the ISSA would strengthen their role as an independent advocate for the person served. This shift would allow the QSP to devote more time on the implementation of the ISP, but the QSP would still play a role in the development of the ISP. With this shift in additional responsibilities, the ISSA rate needs to be reworked and reasonable caseload ratios need to be established as well. We would recommend a ratio of 40:1, monthly visits of 65 hours per year and driving time, especially in rural areas.
- Merge the responsibilities of Service Facilitators and ISSA for those that self-direct their services. The current self-direction model that requires both a Service Facilitator and ISSA can be confusing to families and to adults on the waiver. Streamlining oversight and responsibility for the various service planning and quality assurance functions for people that chose to self-direct will improve this service option as long as these services are free standing. These services could easily be merged into one function. Merging the responsibilities will provide greater efficiencies and provide clarity of these supports and services for family members. You could also add ISSA as another choice for individuals that require service facilitation.

Develop More Flexible Residential Service Models: Illinois should move away from the CILA service definition which ties residential habilitation services to a specific group home model. A more generic individual habilitation service can be developed and used in small group settings by an individual living independently (supported living) or in a home with family. This service should have the option to be self-directed where appropriate. The Personal Support service definition in the current waiver is a good starting point for development of an individual habilitation service that is not tied to a specific residential model. Modifications would need to be done with the understanding that the service would be offered to all people on the waiver, not just those in the Home-Based program. A new rate methodology would also have to be developed for the service to ensure adequate compensation for Direct Support Professionals (DSP),

staffing ratios when one DSP supports more than one individual, and appropriate administrative expense for the provider agencies.

This change could support a number of innovative service models. For example, this service definition could easily be used by micro-boards and cooperatives. It could also be used in shared-living situations where the home or apartment is controlled by the person with a developmental disability, and he or she chooses a housemate who is paid on a part-time basis to provide support. The housemate can have rent and food covered by the Medicaid waiver under a service used in other states that covers modest living expenses for unpaid caregivers.

When the Community Integrated Living Arrangement (CILA) concept was developed in the 1990s it was intended to provide an integrated community living experience for people with intellectual and other developmental disabilities. Over the years, the model has drifted toward an overly structured, institution-like model that, with limited exception, looks nothing like what was originally intended. At this point it would be difficult to unwind the CILA model as originally intended from what it has evolved into over the years. For this and a number of other reasons, developing a new service that breaks from the CILA model, as it now exists, would go far in improving the lives of people with developmental disabilities in Illinois.

Residential service models under the new waiver should be limited to no more than four persons living together and include incentives for smaller community living options of three people or less.

Micro Boards: As we create more innovative models to support individuals with disabilities leading self-directed lives, rules should be developed that encourage the use of Micro Boards and Cooperatives. Micro Boards create circles of natural supports around individuals with disabilities that focus on living, working and building inclusive opportunities within communities. Cooperatives provide inclusive community services for groups of individuals who are each supported by their family and friends. Current practice requires a Micro Board or Cooperative to become a traditional service provider and a lengthy process to get licensed and started up, particularly for those who need or already have CILA funding. We would recommend startup, training, reporting and funding of innovative residential models with a Micro Board or Cooperative be similar to the Home-Based Services model with flexible funding to support sufficient care in a one-person CILA or other innovative residential models.

With sufficient start-up funding, groups of Micro Boards can form Cooperatives to provide resources and support, which could more easily apply for and support licenses for housing and employment, training and quality assurance for areas around the state.

The Illinois Association of Micro Boards and Cooperatives would be responsible for maintaining quality and compliance across the state to assure that Micro Boards and Cooperatives were delivering quality inclusive services based on the hopes and dreams of those served.

CONCLUSION

The recommendations above are provided in an effort to encourage full access to community services for those who are currently on the waiver and those who will benefit from the *Ligas* settlement agreement and closures of State Operated Developmental Centers. These recommendations can be included as amendments to the current 1915(c) waiver for adults with developmental disabilities. Recommendations for Assistive Technology, Transition Supports and Positive Behavioral Supports will require an amendment to the waiver, coupled with changes to current Division policy and practice. The Short and Long Term Recommendations can also be included in the development of other types of waivers, Accountable Care models and even a Care Coordination Innovation Project, as described by the Illinois Department of Healthcare and Family Services.

We appreciate the opportunity to provide comments on the Home & Community Based Adult Waiver and look forward to discussions on these recommendations.