



1029 S. Fourth Street • Springfield, IL 62703 • 217-527-3607 • 217-528-0452 fax

[Via e-mail only]
August 26, 2016

Division of Developmental Disabilities
Illinois Department of Human Services
600 E. Ash St. - Bldg 400
Springfield, IL 62703

Re: Draft Notice of Proposed Information Bulletin (8/9/16)
Community-Based health Care and Other Services for Personal Enrolled
in Home and Community-Based Services Waiver

To Whom It May Concern:

The Center is an association that represents more than 200 community-based residential programs including: Community Integrated Living Arrangements (CILA's); Intermediate Care Facilities for persons with Developmental Disabilities (ICF/DD's); and, Medically Complex for the Developmental Disabled Facilities (MC/DD – formerly known as Long-Term Care for Under Age 22 Facilities [SNF/Ped's]), providing services to individuals with developmental disabilities throughout Illinois.

We want to thank you for the opportunity to comment regarding the Division of Developmental Disabilities, Illinois Department of Human Services Draft Notice of Proposed Informational Bulletin regarding Community-Based health Care and Other Services for Personal Enrolled in Home and Community-Based Services Waiver.

We appreciate DHS/DDD's willingness to obtain input regarding this Informational Bulletin.

We support the concept of supporting persons to be able to access services, such as health care, in community-based locations that persons without disabilities use. Community access and 'normalization' are core values for both the individuals, and the providers who serve them.

Of course, there are always limitations based upon individual circumstances, even for those without disabilities.

The DRAFT Informational bulletin fails to recognize major issues and realities which limit individuals and providers from achieving the desired expectations.

- Individuals are receiving CILA Waiver services because they are not like ‘other persons without disabilities’.
- The Illinois health care system is so fragile, it often doesn’t support individual clinical visits:
 - Clinicians (ie: Physicians, Psychologists, Dentists, Podiatrists, etc) are under reimbursed and not reimbursed timely.
 - Due to poor reimbursement, many clinicians want to arrange to see individuals in a block of time, rather than individual scattered appointment.
 - Many needed clinicians do not accept Medicaid reimbursement.
- Provider reimbursement is grossly inadequate to consistently achieve this desired expectation:
 - The rate formula’s underfund DSP’s, Supervisors, QIDP’s, and Nurses compensation, causing providers to become creative in their efficiency of services.
 - The rate formula does not provide for sufficient staff to make frequent individualized trips to clinicians, barbers, beauticians, etc.
 - The rate formula does not provide sufficient reimbursement for the number of vehicles that would be required to make frequent individualized trips to clinicians, barbers, beauticians, etc.

Below are some other general comments received from our waiver services members:

Comment: We believe the title was meant to be “... for Persons Enrolled In ...” rather than “... for Personal Enrolled In ...”

- *The Division of Developmental Disabilities has recently learned that some waiver providers have arrangements with health care and other (non-medical) providers that result in needed services being given in a segregated, non-integrated, setting rather than support persons to access those same services in community-based locations that persons without disabilities use. This bulletin will clarify expectations for the provision of such services for participants in Home and Community-Based Services waivers.*

Comment: The stated purpose paints all “personal” services, and arrangements for those services, with the same brush. Is there any consideration given to the functioning level of some of the individuals and the fact that providing some services in their residence actually promotes treating them with respect and dignity?

I think the argument of segregation and integration is inappropriately generalized here to all personal services. It applies some intent that doesn't exist. It also erroneously suggests that the mere location of a service satisfies the intent of community integration, which is ridiculous.

Comment: Homecare is an option to obtain some health services for community members who do not receive waiver funding. Homecare services such as lab draws is readily available to most community members and should be considered an option for persons in the community based waiver system as well.

Comment: Many provider's offices are not equipped to handle needed medical evaluations for persons who require mechanical lifts or utilize specialty wheelchairs for mobility. As a result, those provisions are more readily obtained timely and effectively by a home visit. Safety and space when transporting the individual and the equipment must be considered, and the individuals dignity.

Comment: Some waiver providers have made available a handicap user efficient private place for such exams to be performed at their own cost. Inability to continue utilizing this would result in deficient medical care, health issues not addressed timely, and this could result in regulatory deficiencies or findings of neglect.

- *Essential components of Home and Community-Based Services (HCBS) are community integration and community access for persons receiving waiver-funded services. The expectation is that persons with Medicaid waiver funding receive all needed and desired services from an array of options and in the same manner as community members who do not receive waiver funding.*

Comment: “All needed and desired services in the same manner.” This expectation has no “face validity”. Individuals currently do not receive the same services in the same manner for a variety of reasons, some of which are directly linked to the lack of funding and availability of providers (ie: psychiatry and dentistry).

Comment: Needed and desired are not the same. Where do we draw the line financially when meeting “desired” services? Transportation is the first issue that comes to mind.

- *The provision of medical examinations and treatments, professional hair care services (cuts, color, etc.), counseling sessions, breast exams, x-rays, laboratory testing, and similar professional services within a CILA, developmental training, or other waiver-funded location is not supported by the Division of Developmental Disabilities.*

Comment: Does this same criteria apply to flu shots? Some DT programs make arrangements for public health or Walgreens to come to the home to administer shots? Would this no longer be acceptable? Instead of being able to coordinate care in a timely, cost-effective manner, that is less disruptive to individuals, we must make arrangements to take them outside of the home because that is not a segregated environment?

- *HCBS waiver providers that also operate intermediate care facilities (ICF) may not use those ICF locations for the provision of related services to persons receiving waiver funded services.*

Comment: So, if a waiver provider has coordinated a particular vendor to come to a community-based ICF/DD we cannot have CILA individuals come to that facility to receive the same service in the same community?

- *On rare occasions, some HCBS participants may have conditions that prevent them from leaving their CILA home to obtain such services. In such cases, an individualized plan for ensuring the delivery of those services within the person's home could be supported if the plan is based on the specific needs of the individual and not the convenience of the providers involved.*

Comment: Who determines this or evaluates this provision and when? Could it be possible that the “convenience” referenced is not for the provider, but for the individual? Could “convenience” also promote more effective, personally focused service that is less disruptive and thereby be in the better interest of the individual served?

Comment: Who will determine this or evaluate this provision and when? Could it be possible that the “convenience” referenced is not for the provider, but for the individual? Could “convenience” also promote more

effective, personally focused service that is less disruptive and thereby be in the better interest of the individual served?

Comment: Person Centered Planning, and the Implementation Strategies, should include the individual's choice to receive services in the least restrictive environment as possible and appropriate. This would ensure that the current needs of the individual to secure these services in the most appropriate manner is continually addressed through the review process.

- *The Division recognizes the struggles providers sometimes have in meeting the needs of the individuals they serve during these difficult financial times. Providers are commended for their efforts to ensure individuals' healthcare and personal needs are addressed. In spite of financial difficulties, it is critical that service provision is individualized and community-based.*

Comment: What a patronizing statement(s)! How are they commending us and do they really understand the financial impact on obtaining healthcare and personal needs for the individuals we serve? Maybe if they had to arrange a psychiatry or dental appointment for one of our individuals and experience the difficulty of making a 2 hour round trip with 2 staff for an appointment they would have better sense of the impact and challenge. How does driving that distance represent integration?

Comment: Some medical services can certainly be individualized but community-based, as implied here, will result in lapses of appropriate medical care for the above mentioned reasons. Home care guidelines address homebound status as not able to independently access the community and when doing so requires assistance of specialty transportation, use of medical devices such as full mechanical lifts, specialized seating, and with the assistance of a trained personnel. Many individuals living in the CILA settings qualify under this description of homebound. The hardship of them being transported for a lab test could further worsen their condition or be omitted as the risk vs benefit is outweighed. Home care is a normalized option to access to health care for all community members, including those residing in CILA home settings.

Comment: Persons with significant behavioral and developmental disabilities may be best served in the homelike environment that they are currently residing in. Anticipating health care appointments can require

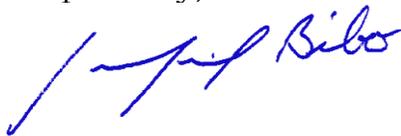
use of dangerous medications be given prior to the appointments posing risk of side effects not to mention an altered clinical picture of the individual when seen by physicians. Having a health eval in their own environment (CILA home) is usually much less of a stressor and not require pre-sedation.

DHS should not have jurisdiction over how an individual living in a CILA setting seeks and obtains medical care of any kind. It is up to the licensed medical provider to operate within their scope of practice and health/safety guidelines preventing any barbaric or risky health care interventions being performed in an inappropriate setting.

Comment: IN SUMMARY: The waiver service providers work hard to negotiate services for individuals that are within their financial means. Though we concur that our desire is to have individuals participate in their daily lives in the same fashion as those without disabilities, there MUST be recognized the realities, limitations, and barriers. This bulletin has the potential to restrict the ability of providers to secure quality services for individuals at a reasonable cost. If this is the expectation, can we expect DHS to negotiate rates with various service providers throughout the state and send waiver providers a list? Concern that needed services are secured and provided should take precedence over concern that services are provided in a specific environment.

We want to thank the Division for their consideration of our comments and objections. If you have any questions, please contact me at: 309-368-1672.

Respectfully,



J. Michael Bibo
President
Center for Developmental Disabilities
Advocacy and Community Supports

ec: Greg Fenton, Director, Division of Developmental Disabilities, Illinois
Department of Human Services

Marie Rucker, Executive Director, "The Center"