

BRINGING LONG-TERM SUPPORTS & SERVICES INTO THE 21ST CENTURY

BACKGROUND

We live in an environment of changing resources and demand for long-term supports and services requiring a comprehensive adjustment in how we assess, deliver, regulate, fund, and assure accountability of services to people with disabilities. The tools to succeed in meeting the challenges and achieving the goals of true community integration and person-centered supports exist, but maximizing their potential requires review and modification of every aspect of the current service system. In support of “*The Rights of People with Cognitive Disabilities to Technology and Information Access*,¹” ANCOR believes greater access to technology has potential to support people with disabilities and those who work for them in attaining full integration and person-centered goals for each person.

Ever improving health care is succeeding in assisting people of all abilities to live longer. The aging bulge of Baby Boomers and the shrinking availability of paid and unpaid support persons challenge the realization and expectation of full and complete achievement of the *Olmstead Decision* and *CMS’ Final HCBS Rule*. Simultaneously, innovation and technology have brought us ready access to hardware and software to provide greater autonomy and independence for people with disabilities. We need to find a way to maximize and incentivize the use of new tools and methods to meet existing challenges and achieve better outcomes now and in the future.

To this end, whether in needs assessment, service planning, resource allocation, rate-setting, or policy-making, the use of technology must be viewed and treated as a form of oversight and support. The methods, standards, funding, and accountability of today’s service system for people with disabilities and seniors were established when the only tool available to supervise and support individuals was the physical presence of a caregiver, whether it be family or direct support professionals. As such, the terms “staff” and “supervision” are frequently used interchangeably in regulatory, funding and assessment tools. A person’s need for support is often measured by the amount of on-site staff assistance he requires to successfully complete a task, which may then be used to establish the person’s resource allocation. As no “service” could be provided without the presence of “staff,” many rate-setting and funding methodologies tie payment solely to “staff on-site.” These outdated tools and way of thinking deter innovation, self-determination, quality outcomes and the most effective use of resources.

Assuring individuals with disabilities are empowered to lead independent lives is the driving force behind enhancing technological development and implementation. Employing technology to support individuals and their families can not only be resource-efficient, but, it can offer a powerful tool to enable community integration and person-centered supports by extending the reach of support persons. The inextricably linked “supervision” and “staff on-site” not only has driven funding and regulatory development, it has been the basis for historical service models. As a result, group living has dominated our service models historically. As the Centers for Medicare and Medicaid Services (CMS) identifies, true community integration is better achieved in non-segregated living, working, social, and recreational environments. While technology assists a person to safely spend more time outside the physical presence of a support person, the use of technology must not be mistaken as the lack of need for or responsibility of the support person for supervision and support. Similarly, the departure from traditional paper records and tracking and the extension of administrative technology can

¹ 2013 Coleman Institute for Cognitive Disabilities

assist in assuring the safety and quality service provision of an individual, while also improving efficiencies for a provider agency.

In light of these findings, ANCOR has developed the following positions and recommendations on technology and the provision of quality disability services:

ANCOR believes greater incorporation of technology in the delivery of services is consistent with and supportive of achieving outcomes set out in the *CMS HCBS Rule*, where outcome oriented services are defined by the nature and quality of the individual's experiences.

- This includes person-centered supports and services selected by the individual from among options including non-segregated living and work environments. States struggle in trying to achieve new, forward thinking expectations using old tools and measures where quality and 'service' are defined in the number of hours of direct support time on-site, instead of the 'nature and quality of the individual's experiences.'
- Like initiation of the HCBS waiver itself, new ways of supporting people are frequently met by fear and resistance, which can result in severely limiting the potential of the new options available. National leadership and identification of leading practices are needed to facilitate necessary changes and allow individuals access to outcome oriented supports across all states.

ANCOR believes that providers should have access to and be provided with training on the same technologies that are available in arenas of CMS and health care systems.

- This includes electronic health records, online administrative records, and ways to measure the benefits of this administrative technology.
- Funding is a crucial component in access to technology. Providers of IDD services should be able to access federal funding just as other health care systems do.

ANCOR believes that to meet the expectations of the *Olmstead Decision* and the *CMS HCBS Rule* that CMS must identify and remove barriers limiting a person's access to all available technological resources which may have a positive effect on independence, privacy and integration.

- This requires acknowledgement that on-site direct support professional time is no longer the only standard or measure of services delivered or determination of a person's need for support and supervision.
- Policymakers should consider how to apply methodologies that have been successful in other areas to expand support for people with disabilities (*e.g.* telehealth).
- This further would recognize a workforce shortage and support needs that will not be filled without the assistance of technology.

ANCOR believes if supports are to be truly person-centered that individuals should, with the assistance of their selected circle of support, make decisions on critical quality of life matters and how to best achieve them including through the use of technology.

- Individuals should choose which if any technologies help them live more independent, quality lives. To ensure person-centered, outcome driven services it is important to entrust the authority and rights of individuals and their circle of support to decide the type of supervision, the level of risk and the best means to maximize dignity and privacy, remains with the individual. A person-centered informed consent and planning process without undue pressure from outside entities, rules, or oversight groups is necessary to enable this.

ANCOR believes we must further assure regulatory and payment methodologies enable rather than deter service providers and families access to the most innovative emerging technologies to promote integration and efficiency.

- This requires sufficient flexibility for support teams to adjust methodologies as a person's needs and skills change. Support teams must have the flexibility to transition from on-site staff to technology-enabled remote supervision without jeopardizing loss of services or access to adequate resources. Incentives to encourage people with disabilities, their families, circles of support, and teams to try new approaches while retaining the ability to return to previous supports, if needed, must be encouraged to facilitate change and person-centered outcomes.