



**The Move to Managed Care for Intellectual
and Developmental Disability Services:**
Guidance for State Medicaid and DD Directors, and Payers

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EXECUTIVE SUMMARY



Medicaid managed care is a rapidly growing service delivery model in the United States. The aim of Medicaid managed care is to reduce program costs and provide better utilization of health services through the contracting of managed care organizations (MCOs). Despite adults with intellectual and developmental disabilities (IDD) being more likely to incur higher annual health care costs than people without IDD, and the fact that Medicaid managed care has existed for decades, it has not commonly been utilized for the long-term services and supports (LTSS) of people with IDD. As utilization of managed care for people with IDD is low, there is little research about what standards should be used for traditional as well as alternative payment models such as value-based reimbursement models. For these reasons, and because there is beginning to be an expansion of Medicaid managed care into the IDD LTSS system, evidenced-based quality standards and guidelines about managed care provision for people with IDD are more critical than ever.

In October 2018, CQL | The Council on Quality and Leadership, The Institute on Public Policy for People with Disabilities, and Mosaic organized a symposium with approximately 25 thought leaders in the healthcare and LTSS industry – the stakeholders represented disability rights leaders, service providers, industry associations, managed care organizations, and other key leaders. The ultimate aim of this think tank is to create a roadmap for the key measures which would support people with IDD to receive high quality services and supports.

To continue this work regarding quality services for people with IDD, in March 2019, CQL, The Institute on Public Policy for People with Disabilities, and Mosaic organized the second think tank with approximately 30 thought leaders in the healthcare and LTSS industry. The purpose of this report is to provide guidance regarding quality services and supports for people with IDD. While we recognize the Centers of Medicare and Medicaid Services (CMS) has issued regulations to advance quality, the aim of this report is to provide a framework to ensure that as managed care moves into the IDD LTSS field, the right outcomes are utilized – services and supports that maximize quality.

To do so, this report describes themes from a nominal group technique (NGT) session with thought leaders regarding what quality services and supports for people with IDD entail. Amongst the themes were an emphasis on individualized person-centered services, informed choice, dignity and respect, resources aligned with quality measures, and availability and continuity of well-trained support staff. The report then offers a number of practical steps regarding how to get to the ideal service system for people with IDD, including a discussion of quality standards, workforce issues, best practices, and buy-in. Finally, we provide recommendations and resources which may help assist with the sweeping changes which are required to promote quality services and supports. While our think tank is committed to continuing this work to help create a roadmap to quality services and supports for people with IDD, as the field moves to managed care, regardless of how we get there, it is critical that services maximize people with IDD's quality of life.

INTRODUCTION

In October 2018, CQL | The Council on Quality and Leadership, The Institute on Public Policy for People with Disabilities, and Mosaic organized a symposium with approximately 25 thought leaders in the healthcare and LTSS industry – the stakeholders represented disability rights leaders, service providers, industry associations, managed care organizations, and other key leaders. The ultimate aim of this think tank is to create a roadmap for the key measures which would support people with IDD to receive high quality services and supports. As part of the first think tank symposium, we began one of the first steps by creating an initial report exploring key measures which could support people with IDD to receive high quality services and supports. The first report, *Building the Framework for IDD Quality Measures*, included not only a quantitative analysis of focus groups with the think tank attendees, but also a pilot study examining social determinants of health and value metrics conducted with 28 Mosaic service agencies who supported approximately 3,000 people with IDD. As indicated in the findings, respect, meaningful days, staff training, and many more social determinants have an impact on hospitalizations, injuries, medication errors, and behavioral issues. By focusing on quality, it may be possible to impact programmatic costs.

In March 2019, CQL, The Institute on Public Policy for People with Disabilities, and Mosaic organized the second think tank with approximately 30 thought leaders in the healthcare and LTSS industry. The symposium was designed to develop a common understanding of value-based quality measures for people with IDD to ensure that as the industry moves toward managed care, the quality metrics utilized are meaningful for people with IDD. This report is a result of this symposium; what follows is a summary of those findings. While we recognize more work is necessary before the field may be fully transitioned to managed care, we believe this report should serve as one of the first steps towards doing so in a thoughtful and meaningful way.



BACKGROUND

Medicaid managed care is a rapidly growing service delivery model in the United States (Williamson et al., 2017). The Centers for Medicare and Medicaid Services (CMS) explain, Medicaid “managed care is a health care delivery system organized to manage cost, utilization, and quality. Medicaid managed care provides for the delivery of Medicaid health benefits and additional services through contracted arrangements between state Medicaid agencies and managed care organizations (MCOs) that accept a set per member per month (capitation) payment for these services” (Centers for Medicare and Medicaid, n.d.). As of July 2014, 55 million people in the United States were enrolled in Managed Care (Centers for Medicare and Medicaid, n.d.).

The aim of Medicaid managed care is to reduce program costs and provide better utilization of health services through the contracting of MCOs. Yet, there is conflicting research about the benefits of managed care for people with disabilities in the United States, particularly the cost effectiveness and quality (Bindman, Chattopadhyay, Osmond, Huen, & Bacchetti, 2004; Burns, 2009a, 2009b; Caswell & Long, 2015; Coughlin, Long, & Graves, 2008; Duggan & Hayford, 2013; Premo, Kailes, Schwier, & Richards, 2003; Wegman et al., 2015; Williamson, Fitzgerald, Acosta, & Massey, 2013; Williamson, 2015; Williamson et al., 2017). For example, one of the few studies to examine managed care for people with intellectual and developmental disabilities (IDD) found that managed care did not reduce acute health expenditures – it was cost-neutral (Yamaki, Wing, Mitchell, Owen, & Heller, 2018).



Despite adults with IDD being more likely to incur higher annual health care costs than people without IDD, and the fact that Medicaid managed care has existed for decades, it has not commonly been utilized for the long-term services and supports (LTSS) of people with IDD (Burns, 2009a; Lunskey, De Oliveira, Wilton, & Wodchis, 2019). One of the reason for this is because people with IDD are a unique population that, in many instances, require a different set of services and supports than nondisabled people or even people with other types of disabilities. As of 2015, 70% of Medicaid funding for people with IDD was allocated specifically for Medicaid Home and Community Based Services (HCBS) waivers (Braddock et al., 2017). HCBS waivers allow states to create community-based LTSS programs particularly tailored to populations that would typically require institutional care, such as people with IDD. Friedman’s (2017) in-depth study of 111 1915(c) HCBS waivers from 46 states and the District of Columbia found that, of the billions of dollars projected, health and professional services – traditional acute care services – comprised less than 5% of total HCBS IDD spending projections (Friedman, 2017). Instead, the majority of spending in FY 2015 was projected for wrap-around type services, such as residential habilitation (42%), supports for people to live in their own or family home (companion, homemaker, chore, personal assistance, supported living; 20%), and day habilitation (16%; Friedman, 2017).

Managed care represents an opportunity to not only possibly increase the quality of services but also reduce costs (Williamson et al., 2017). However, as utilization of managed care for people with IDD is low, there is little research about quality standards for the managed LTSS of people with IDD. Moreover, the majority of existing research about managed care for people with disabilities more broadly is about health care services and controlling costs, not about quality (Williamson et al., 2017). Yet, according to people with IDD themselves, both access and quality are important aspects of Medicaid managed care (Gibbons, Owen, & Heller, 2016). Not only is quality managed care provision for people with IDD understudied, it may also be implemented without an appropriate evidence-base as a result. For these reasons, the purpose of this report is to provide guidance regarding quality service and supports for people with IDD. While we recognize CMS has issued regulations to advance quality, the aim of this report is to provide a framework to ensure that as managed care moves to the IDD LTSS field, the right outcomes are utilized – services and supports maximize quality.

REQUIREMENTS FOR QUALITY SERVICES FOR PEOPLE WITH IDD

Approximately 30 stakeholders who represent state governments, disability rights leaders, LTSS systems, quality bodies, MCOs, policy experts, and academics participated in the nominal group technique – a structured brainstorming research process. The stakeholders, who had a combined 720 years of experience in the field, were tasked with defining quality services for people with IDD.

Establishing Foundational Components of Quality

The stakeholders recognized that quality is intentional and ongoing – it is neither accidental nor a single event. Moreover, while regulations have their role, they are not necessarily a sufficient mark of quality but instead involve minimum standards. However, it was recognized that there are a number of foundational components which are necessary for quality outcomes.

Health was recognized as a foundational component of quality. This is particularly pertinent as people with IDD have significantly poorer health and shorter life expectancies compared to the general population (Ouellette-Kuntz, 2005; Taggart & Cousins, 2014). However, it was recognized that health in and of itself does not encompass quality. As a result, stakeholders noted the importance of integrating LTSS with medical care, and ensuring quality metrics examine and include both health and social measures as health disparities are exacerbated by social factors. In fact, research indicates that although medical care is important for health, it is only responsible for 10-15% of preventable mortality in the United States; instead, people’s health is largely impacted by the conditions in which people live, work, and play (Braveman & Gottlieb, 2014; Currie et al., 2009; Sederer, 2015). The World Health Organization (2010) notes “the roots of most health inequalities and of the bulk of human suffering are social: the social determinants of health” (p. 39). As such, attention to both health and social determinants of health are necessary.

Stakeholders agreed before there can be quality, people with IDD must be free from abuse, neglect, and exploitation. Estimates



Credit: Fiona Yarosh-Field

suggest 25-67% of people with IDD have experienced some form of abuse or mistreatment (Baladerian, 2013; Horner-Johnson & Drum, 2006). Moreover, according to the United States Justice Department, people with IDD are seven times more likely to be victims of sexual assaults than nondisabled people (Shapiro, 2018). Even amongst people with IDD there are disparities; people with IDD with the highest support needs are 8.1 times more likely to experience abuse and neglect than people with IDD with lower support needs (Friedman, 2018a). In fact, via their audits of Connecticut, Massachusetts, and Maine, the U.S. Department of Health and Human Services (HHS), Office of Inspector General, Administration on Community Living, and Office for Civil Rights (2018) concluded incidences of abuse and neglect “are not isolated incidents but a systemic problem” (p. 3). To remedy these problematic disparities, in addition to recommending stronger incident management, investigation processes, and compliance protocols, the HHS et al. (2018) also suggested “quality assurance mechanisms that ensure the delivery and fiscal integrity of appropriate community-based services” (p. 3).

Another foundational aspect of quality for people with IDD is improved financial circumstances. The overwhelming majority of people with disabilities live in poverty, which is problematic as economic factors are crucial social determinants of health and quality of life (Abbott & Elliott, 2017; Bamba et al., 2009; Braveman & Gottlieb, 2014; Fremstad, 2009; United States Office of Disease Prevention and Health Promotion, n.d.; World Health Organization, 2006). Not only is socioeconomic status in and of itself a social determinant of health, it is also associated with other conditions that can impact people with IDD’s quality of life. For example, financial resources impact the neighborhoods and communities people reside in and inhabit. Meanwhile, neighborhood conditions can either facilitate or hinder ones’ community resources, health, risk behaviors, exposure to violence, and ones’ opportunities and choices (Currie et al., 2009; Fisher & Baum, 2010).

“Quality requires equity.”

The Impact of System Transformation

In addition to having these foundational components, quality services for people with IDD necessitate a comprehensive service system, including an adequate community infrastructure. Stakeholders noted quality demands a transparent system, and ease of access. Currently, in addition to being difficult to navigate, there is a tremendously long waiting list for services in many states. As of 2016, 423,735 people with IDD were waiting for Medicaid HCBS services alone (The Henry J. Kaiser Family Foundation, n.d.). A quality service system must be nimble and responsive to the needs of people with IDD – a service system that is rigid and inflexible to people’s needs will not produce quality outcomes for people with IDD.

An ideal service system for people with IDD would more significantly leverage natural resources as supports to promote quality. If communities are designed the right way – by investing in a community infrastructure that is more accessible

“If you go into [many] group homes, you can go back to 1985 and you can’t tell a difference from now. We’re stuck in a time warp. Is progress going to pass us?”



and inclusive, such as with more accessible transportation, more housing opportunities and natural support networks – transforming the role of specialized and formal supports.

One cannot tackle the current issues with the system and quality without addressing direct support professional (DSP) workforce issues. DSPs provide a wide and complex range of services to people with disabilities and older adults, such as support with personal care, household tasks, self-determination, etc. Currently in the United States there is an astronomically high annual turnover rate for DSPs, between 30% and 70% per agency (American Network of Community Options and Resources, 2017; Bogenschutz, Hewitt, Nord, & Hepperlen, 2014; Keesler, 2016). This turnover, often referred to as a ‘crisis’ because of how it impacts service providers and people with IDD, is a product of the combination of a taxing workload, low pay and few benefits, and a lack of career path. IDD providers compete with other industries, such as nursing home and home health care fields, and the service industry, for DSPs. The workforce crisis not only puts a tremendous financial burden on service organizations, costing an estimated \$784 million annually in the United States alone, it also impacts the quality of life of people with IDD (Britton Laws, Kolomer, & Gallagher, 2014; Friedman, 2018b; Hasan, 2013; Hewitt & Larson, 2007; Keesler, 2016; Venema, Otten, & Vlaskamp, 2015; National Council on Disability, 2017). As such, quality requires a stable and well-trained workforce; quality service provision is not possible unless DSPs also have lives of quality. One such mechanism to move towards this is the professionalization of DSPs, which will not only result in better supports for

“A quality service system requires that both people providing supports *and* people receiving them have quality of life.”

people with IDD as a result of competency-based training, but also an expanded tenure of DSPs as a result of a career ladder and wage stabilization (Smith, Macbeth, & Bailey, 2019).

When attending to quality, it is also important to ensure people with IDD with more significant or complex impairments, such as people with dual diagnosis (IDD and psychiatric disabilities) or with more significant support needs are not left behind. Stakeholders recognized that people with more complex needs often cost more to support and require providers have more expertise, which can be challenging in the current system, especially to provide person-centered services and supports while operating with limited resources. This is reflected in research which indicates that people with IDD with more severe impairments experience quality of life disparities compared to people with IDD with less severe impairments, “likely largely attributed to the fact that they also received fewer individualized organizational supports than people with less severe impairments” (Friedman, in press, p. 12). In addition, a lack of adequate community-based services and supports for people with dual diagnosis is one of the most common causes for re-institutionalization (Causby & York, 1991; Friedman, 2019b; Intagliata & Willer, 1982; Lulinski-Norris, Rizzolo, & Heller, 2012; Lulinski, 2014). Quality demands adequate services for everyone — people with more complex or significant disabilities cannot be left behind in the shift to managed care simply because of fiscal concerns.



A Cultural Shift is Needed

Quality demands a cultural shift in the service system as well as amongst providers. The current LTSS system is based on and shaped by “the legacy of institutionalization and congregate care... meaning that ‘services today have become standardized, inflexible and unaccountable to those they serve’” (Spagnuolo, 2016, n.p.). Medicaid has traditionally had an institutional bias (Crossley, 2017; Kaye & Williamson, 2014; Lakin, Prouty, & Coucouvanis, 2006; Mitchell & Dowe, 2019; Ryan & Edwards, 2015; Woodcock, Stockwell, Tripp, & Milligan, 2011). Though much progress has been made since initiation of the HCBS Waiver program in the early 1980s to rebalance the system, much remains to be done. While the institutionalization of people with IDD is at an all-time low and community living at an all-time high, people with IDD largely still fail to be meaningfully included in, and engaged with, the community. Many people with IDD have merely become physically relocated into the community instead of true community integration (Cullen et al., 1995; Forrester-Jones et al., 2002; Friedman, 2019c). The Medicaid HCBS Settings Rule is a further step toward realizing the goal of community access that advocates and scholars have

“Our system is not part of the community. We’ve created a very insular parallel universe.”

“If this is all you’ve ever had, you might think it’s good enough.”

been promoting for decades. The rule recognizes “innovative strategies” must be “develop[ed] and implement[ed] to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living” (Centers for Medicare and Medicaid Services, 2014b, n.p.).

“We must have high expectations of people receiving supports, just like we do everyone else.”

Another cultural shift that must occur for quality is high expectations. People with IDD and their families should have high expectations regarding the quality of their services – they should not feel they simply have to ‘accept’ what little they are given. In addition, as a service system, we must have high expectations of and for people with IDD. Services cannot be designed around low expectations about the abilities of people with IDD. It is common to focus on what people with disabilities cannot do (Adler, Wright,

& Ulicny, 1991; Carey, 2003; Goodley, 1997; Keller & Galgay, 2010; Spagnuolo, 2016; Wright, 1985). Not only that, but people often exaggerate people with disabilities’ disadvantages and portray them as incompetent and dependent, resulting in the limiting of their opportunities and an emphasis on exclusion and ‘protections’ rather than civil rights (Carey, 2003, 2009; Keller & Galgay, 2010).

Moreover, there must be a cultural shift that emphasizes dignity and respect. Respectful practice includes: recognizing a person’s personhood; supporting the person to control their life; recognizing complexity regarding choice, judgements, wellbeing, and dignity; and, sensitivity as reflected through interactions and language (Bigby, Frawley, & Phillips, 2014). Research indicates that in addition to being a human right, dignity and respect can help facilitate people with disabilities’ quality of life and possibly reduce expenditures (Friedman, 2018c; Friedman, 2019a).

As such, organizational culture needs to shift to reflect high expectations for people with IDD. Currently, providers operate in a regulatory and legal environment that emphasizes compliance, and leads to decisions prioritizing keeping people safe to the detriment of encouraging risk. Quality demands organizational culture move beyond compliance and custodial models of care and instead attend to dignity of risk. Avoidance of risk is often built into the physical and social environments of people with IDD (Perske, 1972). As a result, people with IDD have long been denied the opportunity to take the risk like nondisabled people, or even people with other disabilities (Hudson, 2003; Perske, 1972; Susman, 1994). Instead, providers must balance duty of care and dignity of risk – they should not over-support people or take away people’s choices but rather support the person to understand the risks and benefits to reduce this risk.

Person-Centered Approaches are Central

Participants agreed, person-centered planning needs to be at the core of any systems change. Quality is not transferable between people - it differs from person to person and demands individualized person-centered practices. Quality necessitates person-centered services; any cultural shift or system transformation must be person-centered. In fact, the rise of consumer empowerment and patients’ rights movements, and the emphasis on person-centered planning and self-determination, came directly out of understandings that quality of life was dependent on these concepts (Schalock, 2004).

“We need to go back to not starting with services. The only way to do it is to start with person-centered plans and build a resource map and see what’s already out there and then fill in the gaps using formal services.”



As self-determination is a necessary component of person-centered practices, the stakeholders also believed it was an essential component of quality. Self-determination “seeks to maximize autonomy and choice and ensures that persons with disabilities are empowered to live as independently as possible” (Kietzman & Benjamin, 2016, p. 118). Self-determination includes not only people with IDD speaking out about what is important to them and what they want, but also being in charge of daily decisions (Nonnemacher & Bambara, 2011). According to self-advocates with IDD, “making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us?” (Inclusion International, 2014, n.p.).

“The person receiving services must be in the driver’s seat throughout the process.”

The stakeholders recognized that there are instances where many providers might have the best intentions and believe they are being person-centered, but lack an informed understanding of true person-centered practices and quality. Unfortunately, many person-centered practices are currently abstract philosophies rather than actual practices. In fact, in both recognition of both the importance of person-centered services, and the current gap between person-centered theory and practice, the HCBS Settings Rule prioritizes person-centered planning and requires services be driven by peoples’ preferences and goals (Centers for Medicare and Medicaid Services, 2014b). CMS notes HCBS must “optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them” (Centers for Medicare and Medicaid Services, 2014a, p. 1).



Not only should services and supports be driven by the goals and desires of the person, an ideal service system should aim to be completely self-directed, where people can get what they want and need and receive the services to make that happen, rather than making people fit into a mold and have services based on a set menu. Self-direction transforms people with IDD from passive recipients of services to active consumers who direct services (Heller, Arnold, McBride, & Factor, 2012; Kraiem, 2011; Swaine, Parish, Igdalsky, & Powell, 2016) because of its basis on “three critical assumptions: (1) people with disabilities are experts on their service needs; (2) choice and control can be introduced into all service delivery environments; and (3) consumer direction should be available to anyone with a disability, regardless of who is paying for their services... Rather than an

agency telling a person with a disability the services that might benefit him or her, the dynamic switches to the agency listening to what the person with a disability wants and needs for services” (Swaine et al., 2016, pp. 464-465). As such, the expansion of self-direction is encouraged by CMS who has “urge[d] all states” allow people the opportunity to direct services (Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015, p. 191) “without regard to their support needs” (Centers for Medicare and Medicaid Services, 2014b, n.p.). Self-direction and person-centered planning not only often lead to fewer services because services are based only on what people want, but can also save money as rarely the entire authorized budget is used. It was recognized that not everyone may be able to self-direct but there should be a system of supports to help promote self-direction for all people, including those with extensive support needs. Right now the self-direction system is complex and often requires the assistance of a family member or surrogate. It was believed that technology could be leveraged, such as through the use of avatars, and artificial intelligence, to help introduce and promote self-direction.

People Must Have Opportunities and Their Choices Must Be Informed

In alignment with the Settings Rule, the stakeholders agreed choice is a central aspect of quality. The stakeholders specifically emphasized informed choice. People with IDD being presented with only two options and being told to choose between them is not truly choice. Instead, people must have education, experience, and exposure. As they have often been conditioned to acquiesce or accept what they have, people with IDD need support and training to make informed choices. People with IDD must not only have the opportunity to try new things, but must also have a wide variety of options to choose from.

“We need to support people to live a good life through experience, decision-making, and balanced risk.”

Creating Room for Families

In addition to being based on informed choice, person-centered services should reflect the cultural considerations, routines, and traditions of the person and their family. Family involvement is an important aspect of quality. Moreover, as the United States LTSS system is largely built upon unpaid informal family labor – the majority of people with IDD live with family members, however only a fraction of funding goes towards family caregivers – supports for family members are also needed (Braddock et al., 2015; Caldwell, 2006; Gallanis & Gittler, 2012; Rizzolo, Hemp, Braddock, & Schindler, 2009). In addition to formal supports, it may also be helpful to have peer to peer support for people with IDD and their families. Finally, while stakeholders agreed families play an important role in quality, there was also a recognition that sometimes people with IDD and their family members and/or legal guardians may want different things. As such, it was suggested these points of contention necessitate conflict resolution strategies.

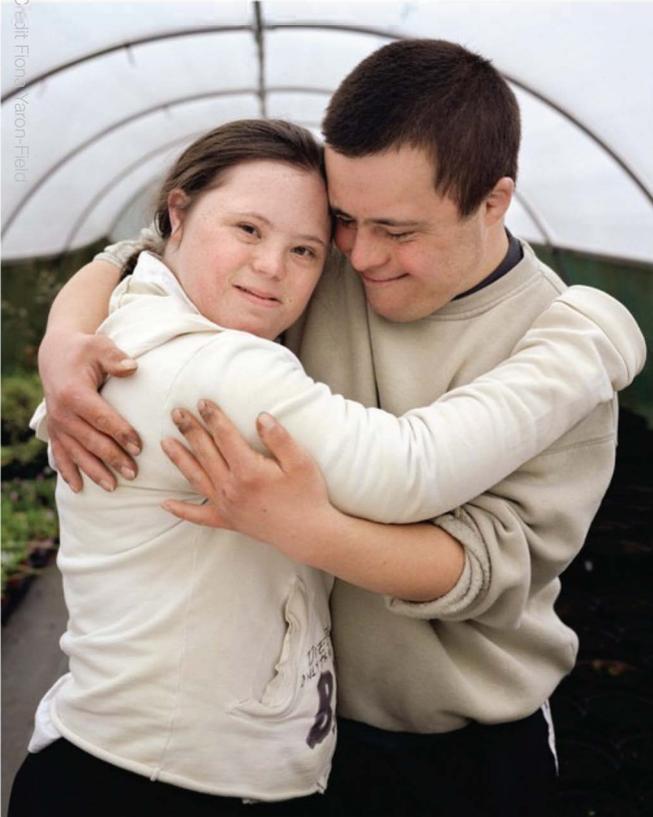
Building Responsive Services

Quality demands services are person-centered – services must be responsive to the person. The stakeholders were adamant that quality is not possible through group goals, activities, or warehousing. Instead, services should be designed around personally defined outcomes; personally defined outcomes “are important because they put listening to and learning from the person at the center of organizational life... The personal outcome approach also results in a different perspective on organizational process. When organizations realize that supports are methods, not ends in themselves, they become more thoughtful in connecting services with priority outcomes. They start to question whether they should continue services and supports that may have a strong constituency but are unconnected to personal outcomes. Using personal outcomes, organizations often find new methods to increase flexibility in making management decisions” (The Council on Quality and Leadership, 2017, pp. 9-10).

“Quality necessitates changes in supports and services that reflect their age and place in the life course.”

Quality services also entail supporting people to have a meaningful life, and doing so in a creative, accessible, and trauma-informed manner. As aforementioned, it is important to make sure people are not over-supported and that there is dignity of risk. Services must also wrap-around and address the whole person and all domains of their life throughout the lifespan. Moreover, those services should be seamless and include stability and continuity in support.

Employment services were particularly discussed as a critical aspect of quality supports. More specifically, integrated employment was described as especially valuable. Unfortunately, people with disabilities are employed at significantly lower rates than nondisabled people; in fact, employment is one of the largest gaps between people with disabilities and nondisabled people (Office of Disability Employment Policy, 2013; Rogan & Rinne, 2011; Russell, 2000). Moreover, the majority of people with IDD are funneled into segregated, often non-work, settings, such as day habilitation or prevocational sheltered workshops. People with IDD are not only interested in working in integrated settings, research indicates with the right supports people with IDD, despite their support needs, are able to succeed in integrated settings (Centers for Medicare and Medicaid Services, 2011;



Migliore, Mank, Grossi, & Rogan, 2007; Rogan & Rinne, 2011). According to the Centers for Medicare and Medicaid Services (2011), “because it is so essential to people’s economic self sufficiency, as well as self esteem and well being, people with disabilities and older adults with chronic conditions who want to work should be provided the opportunity and support to work competitively within the general workforce in their pursuit of health, wealth and happiness. All individuals, regardless of disability and age, can work – and work optimally with opportunity, training, and support that build on each person’s strengths and interests. Individually tailored and preference based job development, training, and support should recognize each person’s employability and potential contributions to the labor market” (p. 3). Supported employment also provides higher quality of life than sheltered and segregated employment

(Jahoda, Kemp, Riddell, & Banks, 2008; Kilsby & Beyer, 1996; Migliore et al., 2007; Rogan & Rinne, 2011; Verdugo, Schalock, Keith, & Stancliffe, 2005).

Stakeholders also believed that relationships were an important part of quality and supports should help facilitate relationships. This is especially pertinent as people with IDD are more lonely and isolated than nondisabled people; moreover, relationships can help facilitate well being and quality of life (Fulford & Cobigo, 2018; Lafferty, McConkey, & Taggart, 2013; Petrina, Carter, & Stephenson, 2014; Petrina, Carter, Stephenson, & Sweller, 2017; Ward, Atkinson, Smith, & Windsor, 2013). Relationships can also create a system of natural supports and help people become an integral part of the community. Moreover, a pilot study found that natural supports are associated with reduced hospitalizations and injuries of people with IDD (Friedman, 2018c).

Achieving Outcomes Through Technology

The pursuit of quality also necessitates creative uses of technology, especially as it often helps propel innovation. In fact, research indicates people’s access to technologies, such as mass media, information technologies, social media, and other technologies, can all impact health and quality of life – access to technology is a social determinant of health (United States Office of Disease Prevention and Health Promotion, n.d.; US Department of Health & Human Services, 2015). Yet, many people with IDD do not have access to technology. Moreover, many IDD service providers are not funded in order to have up to date technology. Providers need modern technology, such as technology that facilitates business

“Technology usage for people with IDD is stagnant and exemplifies how they have been left behind.”

processes, billing, and record keeping. Moreover, technology is one possible mechanism to help promote independence amongst people with IDD; it may also help save costs. While technology creates opportunities for creative and innovative services, and should be encouraged, stakeholders cautioned it should not be used to substitute for all personal aspects of services.

“It doesn’t matter if a robot makes my diet coke but person-to-person services *matter!*”

Business Acumen in Human Services

Finally, providers cannot offer quality services and supports to people with IDD if their own business practices are floundering. As such, quality services require business acumen. As it is one of the leading reasons of provider collapse, financial stability of providers is paramount (Oss, 2018a, 2018b). Stakeholders also recognized that mergers and acquisitions are currently being used as a defensive survival mechanism, while they should instead be an attempt to increase agencies’ ability

“Supports must be tethered to the community. We’re gonna lose that connection to community when providers pull out and everyone scrambles.”

to provide quality services and supports. While it is true that not all providers should be in business, stakeholders were concerned that the move to managed care may result in too few providers, especially causing difficulty for small niche organizations that are often able to provide dynamic services. Quality services require a system that is the right size and does not have too many or too few providers.



PRACTICAL STEPS: HOW TO GET TO THE IDEAL SERVICE SYSTEM

There needs to be a recognition that payer-system reform is here – there will be change – as such, the culture of not only providers but also state agencies is going to have to change in order to move toward quality services and supports; this shift will impact everything and everyone. Historically, the field has been risk averse, however, the shift to managed care, if done with thoughtful planning, meaningful stakeholder engagement, and sufficient funding, represents an opportunity to not only improve the bottom line but also improve the lives of people with IDD. States can utilize MTLSS as a tool to achieve the outcomes they want.

Compliance and attention to regulations, while foundational, are not indicators of quality. While regulations are important, they do not produce outcomes. There needs to be a recognition that regulatory transformation is necessary to make Medicaid managed care work. Providers will not have the time and energy to focus on quality if they are spending the majority of their time dealing with

“Compliance and quality are not the same. Compliance is the foundation, and then quality is what you build on. Compliance doesn’t get you outcomes or get you paid.”



regulations and documenting them. Quality transformation needs to move beyond regulatory transformation.

We need a system that starts by defining quality and then determines the measures to get there. The most successful path forward is one that starts with quality at the center of its goals, rather than focusing on cost savings. Doing so demands moving beyond clinical and/or process measures to looking at outcomes. Satisfaction data of the people being support is also just as important as outcomes data – if people are not satisfied, the outcomes do not matter.

It was recognized that this move towards quality needs to be evidence-based and data-driven. Often providers do not know the real costs involved in providing services because of a trend over the last few years away from requiring cost reporting, and lack of



uniformity where the practice is still supported or required, artificial limits, and disallowed costs. Data is critical, particularly as evidenced-based practices are scarce. System transformation should be based on best practices and evidenced-based research. Moreover, attention needs to be drawn to social determinants of health as it helps connect outcomes and quality. As a result of wrap around services, many IDD providers have been focusing on social determinants of health for decades but it has not necessarily been recognized as such. Data that shows that emphasizing social determinants of health not only improves quality but can help reduce costs is necessary.

Quality standards are also needed. There are a lot of quality measures out there, and a number of people working on quality measurement, but there are a lot of discrepancies and no uniform quality standards. The stakeholders believed CMS needs to take a stronger role in providing guidance regarding quality managed care for people with IDD. Moreover, it was believed there needs to be a funded outcome workgroup for which Medicaid would agree to adopt the findings.

“Quality is not measuring things because they are easy to measure. Measure what we value, not value what we measure.”

There not only needs to be quality standards but quality standards also need to be enforceable. Some stakeholders suggested healthcare parity to enforce quality from a policy perspective. Moreover, there also needs to be more guidance and information sharing to help providers in the pursuit of quality services. As a result of inconsistencies in how providers measure and view quality, providers need training about agreed upon, well defined quality measures,

including what quality truly is, how to measure it, and how to do it – most states are currently compliance-oriented. Others recognized it is hard, if not impossible, to implement quality standards without associating dollars to make it happen. Indeed, the shift to quality is an investment. If provider organizations are unstable because of an underfunded system that will not be a good starting point for advancing change. An unstable provider system does not align with innovation.

There was a recognition that an ideal service system requires attention to workforce issues. DSPs need better training and to be adequately compensated. As such, providers need more money for the training and certification of DSPs, in addition to more money for wages. Possible mechanisms to improve workforce issues also include incentivizing



organizations for DSP retention, recruitment, and training. There should be quality/outcome measures around the workforce because of the ripple effect it has on people with disabilities. It may also be beneficial to have value-based payments to DSPs who help support people with disabilities to reach their goals/outcomes because they are helping the person's plan achieve outcomes.

In addition, due to the increasing complexity of the field, coupled with decades of trying to manage a workforce crisis that continues to deepen, there needs to be a long term commitment to increasing the business acumen of providers to equip them to not only survive, but excel in a managed care environment. For example, providers not only need to know what their services cost, they also need to be able to provide plans with requested data, negotiate contracts, and have the expertise to switch business models.

The service systems also needs to be streamlined – there is a current lack of consistency in how provider organizations measure and view quality. The system should also be transparent where regulators, people with IDD and their families, and the public are able to tell how plans and providers are doing in terms of quality. There was also a recognition that the transition to managed care and quality needs to be strategic and deliberate. There needs to be capacity building to create a stable system that is able to successfully attend to quality.

“Quality is a negotiation between the state and payer.”

When these changes are made, a wide variety of people need to be at the table and on the same page. Stakeholders, including community-based organizations (CBOs), need to be involved in contract design. Moreover, it is important for self-advocates with IDD and family members to drive conversations about quality. MCOs can also act as partners to help achieve valuable outcomes.

As one participant noted, “at the end of the day, quality starts and ends with what’s the goal of the state and how they align it with that goal. The goal of the state has to be the goal of the stakeholders.” During this shift to quality and managed care, state agencies also need to change too – they cannot continue concentrating so much on process if they are expecting to achieve outcomes. Aims and conversations need to not only move from a medical model to a more person-centered one, but also shift from focusing on savings to sustainability. Moreover, there needs to be mutual agendas at the state level between different agencies, such as the Medicaid agency and the developmental disabilities (DD) agency. State agencies also need to provide MCOs with more flexibility so they can focus on quality. There cannot be competing priorities wherein a state has certain requirements that limit MCOs’ abilities to provide dynamic and creative services; health plans only have as much flexibility as the state gives them.

“MCOs are in the midst of a sandwich - states dictate what they want and people with IDD and families [are] on the other side.”

In addition, for a successful shift, there needs to be buy-in from providers. Moreover, there needs to be buy-in from workforce unions to ensure they have a role in the future and do not resist change due to fear of losing their jobs such as they did with deinstitutionalization efforts.



CONCLUSIONS



Providers are a natural partner to help achieve valued outcomes, they not only provide comprehensive support for the whole person, they often have trusted relationships with the person with IDD and serve as community navigators. Providers have the expertise when it comes to integrated LTSS for people with IDD and can act as a partner when it comes to achieving valued outcomes. Providers can serve as the eyes on the ground to help check on quality and help recognize early warning signs to assist with prevention. Moreover, not only can providers help fill in gaps, but by supporting the whole person, including health, behavioral, and community access, it can ultimately translate into financial savings which can be reinvested, such as for compensation for DSPs.

“We [providers] want to educate, influence, and be held accountable for quality measures.”

It is important to recognize that IDD services are different from supports for all other populations. For other health conditions or disabilities services and supports are often time limited. However, what may be adequate for other populations, may not be adequate for people with IDD as although service needs may ebb and flow during their lifespan, services and supports are often lifelong. As such, services for people with IDD require an integrated service delivery system that meets the

“Long-term services and lifelong supports are the underpinning of managed LTSS for people with IDD – you can manage and coordinate that but always will be responsible for some level of services and payment. Stability leads to better outcomes and results for everyone.”

needs of the whole person, from physical and behavioral health, to residential and employment services.

As services for people with IDD are lifelong and should be designed for the whole person – these are not acute health care needs that will go away – instead, there will always be costs and expenses involved. Moreover, increasing volume will not necessarily produce cost savings, particularly in areas where the system is woefully underfunded. Instead, cost savings can be created by focusing on quality – there is value and financial incentives in non-medical services. Although medical stability is important and paramount to

providers by itself, it does not reflect quality LTSS for people with IDD. Savings can come from getting people into the right service lines and providing them the right amount of supports. By emphasizing quality of life and social determinants of health, there can be reduced medical costs. Better services will save money that can then allow MCOs to serve more people.

LTSS, behavioral health, and medical health all have to be considered in totality in order to achieve desired goals. Yet, currently there is a mismatch between funding and quality. Payments do not correlate with what is valued. For example, one participant noted although competitive employment is associated with better outcomes than segregated employment, sheltered workshops have better rates and require less staff to operate. It is important that payments are aligned with quality metrics. Moreover, this also requires states recognize the importance of quality measures; currently states predominantly rely on clinical measures in their RFPs.

It is important to measure beyond traditional health metrics not only because it can help produce cost savings (e.g., social determinants of health) and be utilized to formulate value-based payment programs, but also because integrated services are the law as mandated by the HCBS Settings Rule, *Olmstead v. L.C.*, and the Americans with Disabilities Act.

“The interests of a plan (reduced spending) and what a person with IDD wants (choice and personalized services) are more closely aligned than we often think.”

This report has attempted to address a wide number of issues regarding quality. In recognition that sweeping changes are necessary to promote quality services and supports, below we provide a number of resources and tools. This list is in no way comprehensive, but we believe it is a good starting point, providing practical steps and solutions for the issues described above. Our think tank is also committed to continue our work to help create a roadmap to quality services and supports for people with IDD. As the field moves to managed care, it is critical that that services are valuable to people with IDD and maximize their quality of life.

Resources:

- [Advancing Value & Quality in Medicaid Service Delivery for Individuals with Intellectual & Developmental Disabilities \(American Network of Community Options and Resources \(ANCOR\)\)](#)
- [Basic Assurances® \(The Council on Quality and Leadership \(CQL\)\)](#)
- [Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities](#)
- [Building the Framework for IDD Quality Services \(CQL, Institute for Public Policy for People with Disabilities, and Mosaic\)](#)
- [Circle Library \(OPEN MINDS\)](#)
- [Cognitive Technology Database \(Coleman Institute for Cognitive Disabilities\)](#)
- [Defining Community: Implementing the New Medicaid Home and Community-Based Services Rule \(Autistic Self Advocacy Network \(ASAN\)\)](#)
- [DSP Code of Ethics \(National Alliance for Direct Support Professionals \(NADSP\)\)](#)
- [DSP toolkit \(ANCOR\)](#)
- [Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community \(National Council on Disability\)](#)
- [Joint Report: Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight \(US Dept. of HHS\)](#)
- [MLTSS for People with Intellectual and Developmental Disabilities: Strategies for Success \(National Association of States United for Aging and Disabilities \(NASUAD\) & National Association of State Directors of Developmental Disability Services \(NASDDDS\)\)](#)
- [Personal Outcome Measures® \(CQL\)](#)
- [Predictors of Abuse and Neglect \(National Core Indicators\)](#)
- [Resource Library \(ASAN\)](#)
- [The Case for Medicaid Self-Direction: A White Paper on Research Practice, and Policy Opportunities \(National Council on Disability\)](#)
- [The Current State of Health Care for People with Disabilities \(National Council on Disability\)](#)
- [The Rights of People with Cognitive Disabilities to Technology and Information Access \(Coleman Institute for Cognitive Disabilities\)](#)
- [Workforce Infrastructure in Support of People with Disabilities: Matching Human Resources to Service Needs \(National Council on Disability\)](#)

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