



Building The Framework For IDD Quality Measures

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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). While Medicaid managed care has existed for almost two decades, it has yet to be frequently used for long-term services and supports (LTSS) for people with intellectual and developmental disabilities (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 (CQL), 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 service providers, industry associations, managed care organizations, and other key leaders. 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 to 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 – a roadmap for the key measures which would support people with IDD to receive high quality services and supports. While we recognize much more work is necessary for evidenced-based standards and guidelines about managed care provision for people with IDD, this report serves as one of many first steps towards quality value-based service provision for people with IDD.

Findings from our data analysis of 28 service agencies who support approximately 3,000 people with IDD revealed that while traditional measures of health are important, many other factors play a role in quality services and supports, and quality of life. 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.

Findings from our focus groups with thought leaders also indicated that although health and safety are foundational building blocks, they are not enough – it is important to ensure people with IDD have meaningful lives. Informed choice, person-centered practices, goals, community living, meaningful days, relationships, dignity and respect, continuity and security, and access to technology were all described as key components of quality. Building quality frameworks demands the creation of quality standards based on evidenced-based best practices. There also needs to be a recognition that quality is an investment. Finally, quality frameworks require a cultural change to person-centered services, not only in systems but in practice.

INTRODUCTION

For many providers and funders in human services, the lack of measurement and evaluative methods is top of mind. Also, as the transition to more managed care long-term services occurs, experts are identifying this gap as a top priority. This is a complex issue and as such, insight from a diverse set of stakeholders from a range of perspectives is critical.

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BACKGROUND



People with IDD have significantly poorer health and shorter life expectancies than the general population (O’Leary, Cooper, & Hughes-McCormack, 2017; Ouellette-Kuntz, 2005). This includes increased prevalence of cardiovascular disease, obesity, hypertension, osteoporosis, and poor oral health compared to nondisabled people (Haveman et al., 2010). People with IDD also tend to experience age related health conditions earlier and more rapidly than nondisabled people (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012; Glasson, Dye, & Bittles, 2014; Nochajski, 2000; World Health Organization, 2001). Their higher rates of chronic health conditions are due to genetics, social circumstances, environmental conditions, and access to health care services (Bittles et al., 2002; Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz, 2005; Taggart & Cousins, 2014). Moreover, people with IDD’s health disparities are often exacerbated by other key social determinants of health, such as poverty and social exclusion (Ouellette-Kuntz, 2005).

Research details, however, that commitment from stakeholders, especially service organizations and their staff, can serve as a significant facilitator (or barrier) to the success of health initiatives for people with IDD. In fact, research has found organizational supports can play a key role in promoting the health of people with IDD (Friedman, Rizzolo, & Spassiani, 2017a). People with IDD are approximately 13 times more likely to have best possible health outcomes present when organizational supports are in place (Friedman et al., 2017a). Moreover, when organizational supports are in place, people with IDD are not only more likely to have an active role in their health, but their health interventions are also more likely to be effective (Friedman et al., 2017a).

The quality of supports people with IDD receive, and by extension their health and quality of life, is also largely influenced by the government services they receive. Long-term services and supports (LTSS) are community or facility based services for people who need support to care for themselves because of disability, age, or functional limitations. The majority of government spending (federal, state, and local) for people with IDD is through Medicaid (e.g., \$49.4 billion in fiscal year (FY) 2015) (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). During the Great Recession (2007-2009) more people were relying on Medicaid because of unemployment, resulting in a drop in the proportion of total federal Medicaid spending going towards people with IDD (Braddock et al., 2015). In wake of

recovery from the Great Recession, states' allocation toward community supports and institutional care increased (Braddock et al., 2015; Friedman, 2017). However, there continues to be large waiting lists for services, as well as an unstable direct support professional (DSP) workforce (Bogenschutz, Hewitt, Nord, & Hepperlen, 2014; Hasan, 2013; Hewitt & Larson, 2007; Hewitt et al., 2008; Larson et al., 2016; Micke, 2015; Taylor, 2008). In 2013, approximately 233,000 people with IDD across the nation were waiting for Medicaid LTSS (Larson et al., 2016).



As states are grappling with a reduced fiscal landscape, Medicaid managed care is a rapidly growing service delivery model has become 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.). The aim of Medicaid managed care is to reduce program costs and provide better utilization of health services through the contracting of MCOs.

As of July 2014, 55 million people in the United States were enrolled in managed care (Centers for Medicare and Medicaid, n.d.). Yet, there is conflicting research about the benefits of managed care for people with disabilities in the United States, particularly regarding 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).

Moreover, while Medicaid managed care has existed for almost two decades, it has also yet to be frequently used for LTSS for people with IDD (Burns, 2009a). As utilization of managed care for people with IDD is low, there is little research about what quality standards should be used for value-based payments for the LTSS of people with IDD. The fact that such Medicaid managed care for people with IDD is understudied and, as a result, may be implemented without an appropriate evidence-base, is particularly concerning given “the health and quality of life of persons with disabilities is particularly sensitive to the accessibility of their health care” (Burns, 2009a, p. 1521).

For example, one study found people who receive support from MCOs are less likely to have opportunities to self-manage their health, which in turn results in less effective health interventions (Friedman, Rizzolo, & Spassiani, 2017b).

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. For example, Medicaid LTSS for people with IDD frequently includes unique services such as residential habilitation, personal care, supported employment, and transportation (Braddock et al., 2015; Friedman, 2017; Friedman & Rizzolo, 2016, 2017; Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). As such, “scholars caution against generalizing from such research to a population with a substantially different health profile” (Burns, 2009a, p. 1521; Currie & Fahr, 2005; Rowland, Rosenbaum, Simon, & Chait, 1995; Sisk et al., 1996). For these reasons, and because there is beginning to be an expansion of Medicaid managed care into the IDD LTSS system, evidenced-based standards and guidelines about managed care provision for people with IDD are more critical than ever.

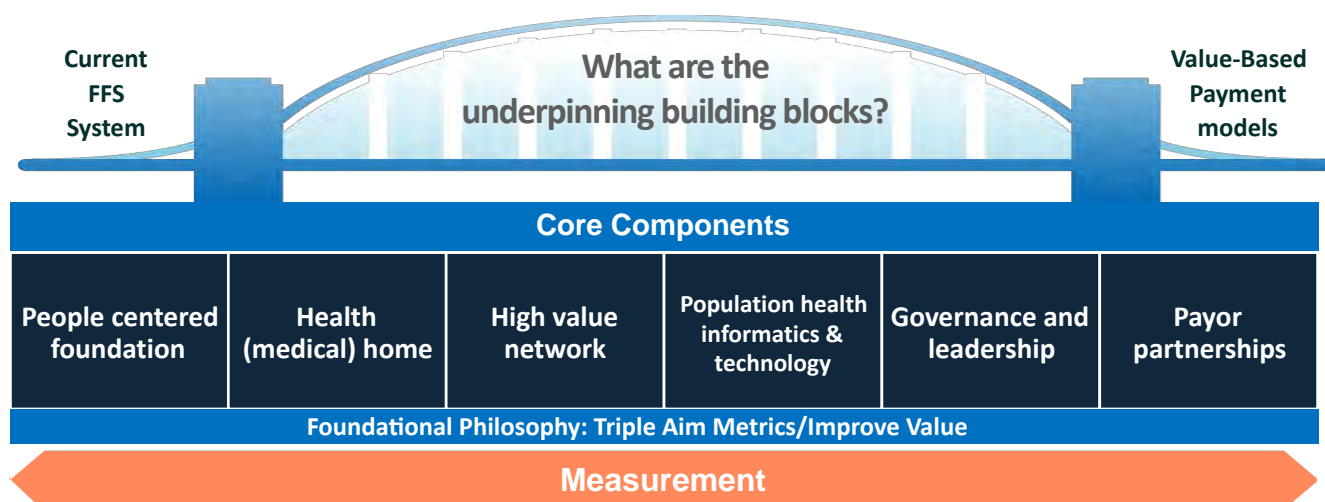


THE BROAD PUSH FOR VALUE-BASED THINKING

Summary of a presentation by Andy Edeburn, Premier

Value-based services are an effort to shift away from traditional fee-for-service services, which are based on the *number* of services provided, to services that promote quality. Value-based thinking recognizes that emphasis on quality ultimately results in reduced health care costs.

The aim of healthcare today includes not only smarter spending (i.e., lower healthcare costs), but also better care – improved quality and satisfaction – and healthier people – improved health outcomes of populations (Institute for Healthcare Improvement, n.d.). As such, value-based thinking represents a cultural shift towards person-centered thinking.



Source: Premier.

While the majority of the current service system still functions under a fee-for-service model, there is bipartisan support to move away from fee-for-service, towards value. With these changes to Medicare and Medicaid, providers, not payers, will be increasingly held accountable for cost and outcomes. Moreover, commercial payers and managed care organizations are incentivized to follow Medicare's payment and quality models. As a result of these changes, there is an increased alignment between health systems, community resources, and "non-traditional" partners.

Value-based thinking incentivizes quality; leads opportunities to define what "quality" is and what it should mean. Yet, in the current system the majority of "health outcomes" are from traditional metrics, such as hospitalization rates or obesity rates. Successful quality metrics necessitate a shift toward inclusion of social determinants as well. As a result, data insights, analytics, exchange and innovation, are keys to future success and relevance.

LOOKING ACROSS THE INDUSTRY: WHAT STATES ARE THINKING

Summary of a presentation by Stacy DiStefano, *OPEN MINDS*

Approximately 1.5% of the United States population has IDD and public spending on people with IDD has increased (15% between 2006 and 2017 (Braddock et al., 2017)). More people with IDD than ever before are living in the community compared to institutional settings (Braddock et al., 2017), however, there is a shortage of home and community-based options due to long waiting lists, budgetary issues, a lack of housing, workforce issues, and caregiver stress.

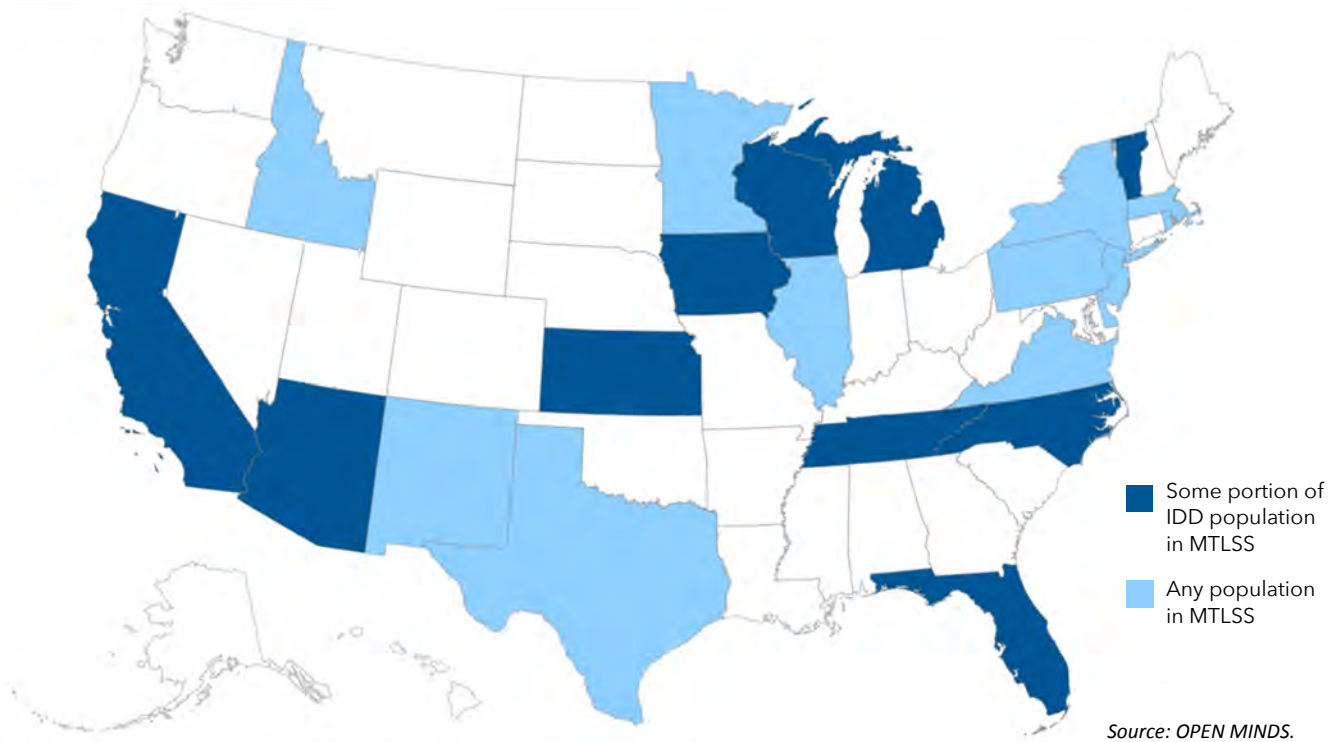
The market for IDD services is also currently being shaped by a number of factors:

- “Pending ‘block grant’ and ‘state discretion’ models for use of federal funding;
- Increase in community-based care and changing CMS rules for home and community-based waivers;
- More long-term care services moving to managed care and competitive purchasing models—including IDD services;
- States struggling to address high service costs against budget constraints – leading to waiver waiting lists;
- New assistive technologies and remote monitoring for supporting people in the community; and,
- New organizations entering the market – both private equity-backed start-ups and extensions of multi-state non-profits.”

As a result of all of these factors, reimbursement models are changing, with many provider organizations currently receiving value-based revenue.



Figure 1. States that include IDD in Medicaid Managed Long Term Services and Supports* (2017)



Currently, 10 states include at least some portion of the IDD population in their Medicaid managed long term services and supports (MLTSS) (see Figure 1).

OPEN MINDS believes value-based reimbursement is here to stay because “of political and competitive pressure on payers, federal government, and employers, downward price pressure on health plans, the success of ‘some’ Accountable Care Organizations (ACOs), the early findings of the Medicare bundled rate initiative, and pressure on health plan medical loss ratios.”

Managed care is likely to result in a number of changes, including “managing the Home and Community-Based Services (HCBS) program, ‘service plans’ created in conjunction with the managing entity, care coordination and service planning ‘integration’ (e.g., LTSS, medical, pharmacy, behavioral, social services), and value-based reimbursement models, which favor ‘integration’ across specialties and levels of care.”

Moving from fee-for-service to managed value-based reimbursement, can result in a greater focus on outcomes, a greater data-driven culture, and a more effective implementation of technology.

Future sustainability of value-based reimbursement requires “understanding what consumers want, what payers (and their health plans) will pay for,” what ‘value’ is, “how system restructuring will change competitive advantage, and how technology will change the ‘value proposition’”

*States vary in MLTSS models and services included under managed care.

SOCIAL DETERMINANTS OF HEALTH

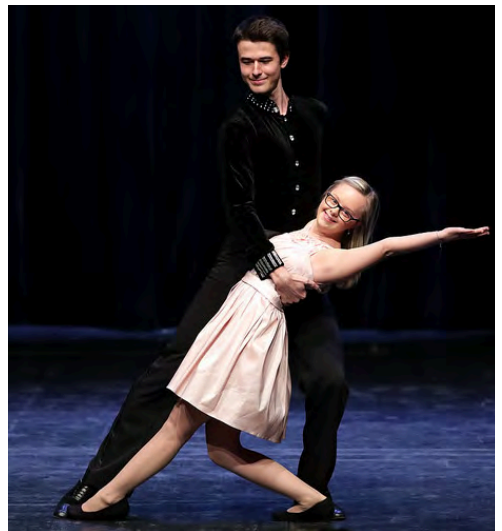
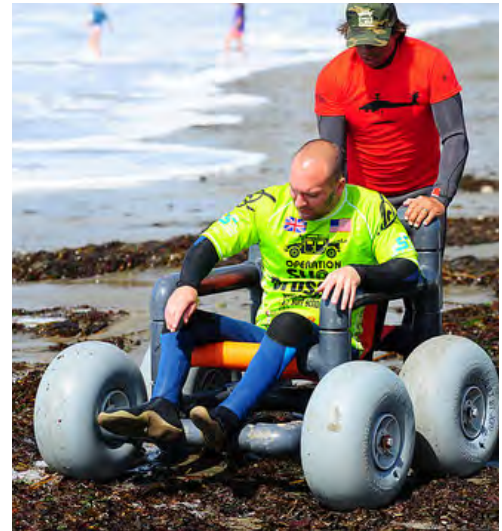
Social determinants of health are conditions, environments, and settings that impact not only health but also overall quality of life. "By working to establish policies that positively influence social and economic conditions and those that support changes in individual behavior, we can improve health for large numbers of people in ways that can be sustained over time. Improving the conditions in which we live, learn, work, and play and the quality of our relationships will create a healthier population, society, and workforce" (United States Office of Disease Prevention and Health Promotion, n.d.). Social determinants of health are critical for health equity.

Social Determinants of Health Index

At CQL, we recently developed a new way of measuring social determinants of health. In order to create the measurement tool we cross-walked the *Healthy People 2020* Social Determinants of Health framework (United States Office of Disease Prevention and Health Promotion, n.d.) with the Personal Outcome Measures®.

The Personal Outcome Measures® was developed to comprehensively measure quality of life of people with disabilities while also paying attention to the key role organizational support can play in improving individual outcomes. Unlike other quality of life measures that are based on organizational standards, the Personal Outcome Measures® focuses on a person-centered definition of quality of life, including choice, self-advocacy, self-determination, and community inclusion. The Personal Outcome Measures® has been continually refined through initial pilot testing, 25 years of administration, research and content experts, a Delphi survey, and feedback from advisory groups. The current version of the Personal Outcome Measures® includes 21 indicators divided into five factors: my human security; my community; my relationships; my choice; and, my goals.

For the Social Determinants of Health Index, we selected



Personal Outcome Measures® indicators that conceptually fit into the following five *Healthy People 2020* Social Determinants of Health categories:

- Economic stability;
- Education;
- Social and community context;
- Health and health care; and,
- Neighborhood and built environment (United States Office of Disease Prevention and Health Promotion, n.d.)

We then ran an exploratory factor analysis (EFA) with promax rotation of Personal Outcome Measures® interviews with approximately 1,078 people with disabilities (conducted by certified reliable interviewers) from 2017 (Friedman, 2018). The findings of the EFA revealed the CQL Social Determinants of Health Index is comprised of three factors (see below).

THE CQL SOCIAL DETERMINANTS OF HEALTH INDEX FACTORS

<ul style="list-style-type: none"> • People interact with other members of the community • People participate in the life of the community • People perform different social roles • People choose where to work • People choose where and with whom to live 	<ul style="list-style-type: none"> • People exercise rights • People are treated fairly • People are respected • People experience continuity and security 	<ul style="list-style-type: none"> • People have the best possible health • People are safe
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Table 1 presents the means for each of the three factors. The average person had 50% of the social determinants present in their life. As indicated by the index, people with IDD frequently score higher on health and safety, compared to choice and engagement, or person-centeredness.

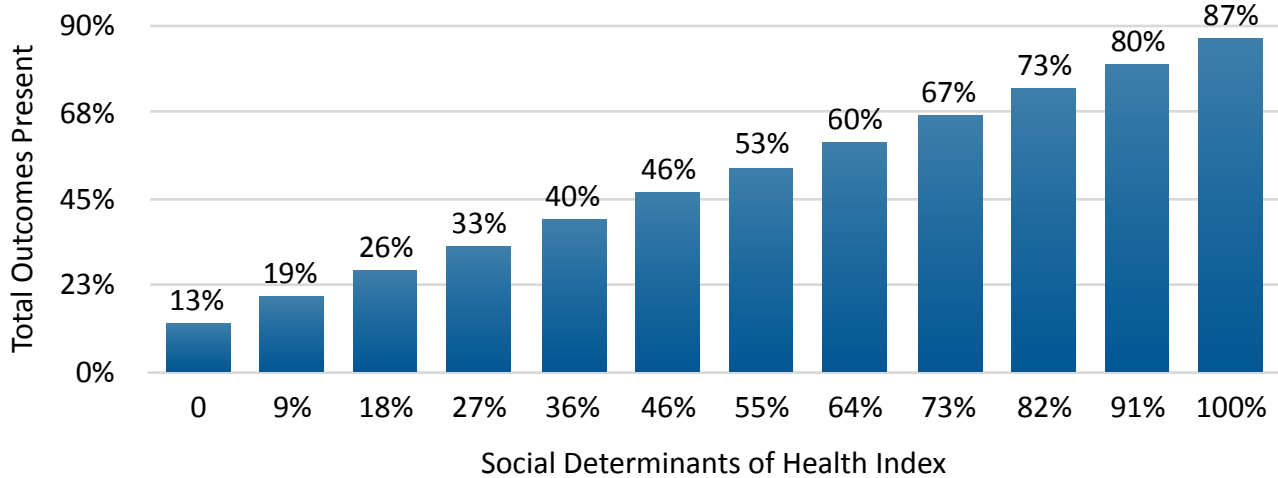
Table 1. Social Determinants of Health Index Factor Means (*n* = 1,078)

	M	SD
Factor 1: Choice and engagement	0.40	0.33
Factor 2: Person-centeredness	0.50	0.38
Factor 3: Health and safety	0.69	0.35
<i>TOTAL</i>	<i>0.50</i>	<i>0.28</i>

The Impact of Social Determinants of Health on Overall Quality of Life

We ran a linear regression model to explore the relationship between the social determinants of health and overall total personal quality of life outcomes and there was a significant relationship ($F(1,1042) = 1781.43, p < .001, R^2 = .79$), indicating the higher people scored on the social determinants of health index, the more quality of life outcomes they had present.

Figure 2. Relationship between Social Determinants of Health & Personal Outcomes

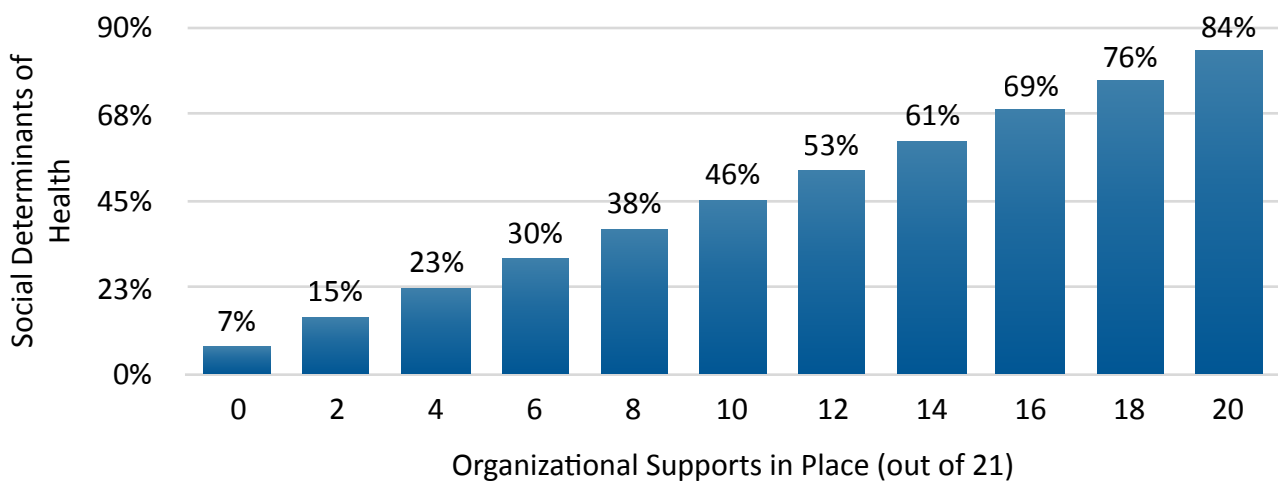


For example, a person that scores 50% on the Social Determinants of Health Index is expected to have half, or 50%, of their quality of life outcomes present. Whereas a person who scores 100% on the Social Determinants of Health Index is expected to have almost 90% of outcomes present – a significantly higher quality of life.

The Impact of Organizational Supports on Social Determinants of Health

As we found that social determinants of health are important to quality of life, we next explored how social determinants can be facilitated. To do so, we looked at the relationship between organizational supports and social determinants of health using a linear regression model. These include supports to facilitate personal outcomes around health, safety, choices, and many more. Findings revealed the more organizational supports people receive, the significantly higher their social determinants of health ($F(1, 1029) = 2344.29, p < .001, R^2 = 0.83$).

Figure 3. Impact of Organizational Support on Social Determinants of Health



For example, a person who has 8 out of the 21 organizational supports in place is expected to score 38% on the Social Determinants of Health Index, whereas a person who receives 16 out of the 21 organizational supports is expected to score 69% on the Social Determinants of Health Index.

Value Metrics

While the Social Determinants of Health Index examines social determinants at the individual level, as organizations play a key role in facilitating social determinants and quality of life, it is important to also examine metrics at the organizational level. To do so, we analyzed data from 28 organizations using the Basic Assurances® tool and their impact on other health metrics.

The Basic Assurances® tool is an organizational assessment that ensures accountabilities for health, safety, and human security within service provider organizations. The application of the Basic Assurances® involves two broad evaluation strategies – evaluation of both the system and the organizational practice. Policies and other systems are important for sustainability and consistency over time, but the actual practice of the policy at the organization level is critical to quality services. The *Basic Assurances*® contains 10 Factors, 46 Indicators, and over 300 quality probes (or sub-indicators).

This analysis is the result of a partnership with Mosaic, a faith-based organization with agencies across the United States. Mosaic provided CQL with de-identified data about the Basic Assurances®, health metrics, and incident reports from FY 2016 to 2018, and CQL independently conducted all analyses. This pilot is comprised of data from 28 service agencies who supported a total of 2,955 people with IDD.

The following variables were used as dependent variables (DVs) for the analyses:

- *Hospitalizations data*: every visit to the hospital, regardless of whether people were admitted or not.
- *Appointments*: any type of medical appointment, ranging from family medicine to specialists; this included psychiatric appointments as well.
- *Medication errors*: documentation of every time there was a medication error, regardless of the reason.
- *Injuries documented*: any type of injury event (e.g., redness, bruising, bleeding, lesions, unknown origin, etc.).
- *Behavioral issues*: all behavioral events or issues.

For all analyses, we controlled for agency size (the number of people the agency supported); because of collinearity, agency size was built into the DVs, resulting in the DVs all becoming ‘rates’ – the number of events per every one person the agency supported. For example, the hospitalization rate was the number of hospital visits for every one person the agency supported.

To examine differences in the DVs depending on each individual Basic Assurances® indicator, Mann-Whitney U was utilized. One-sided *p* values (exact) were utilized. Each model had a built-in control for organization size to minimize issues of collinearity. Below we present a snapshot of the significant findings. Statistics are presented in the Appendix.

Hospitalization Rates

Findings revealed, organizations that had systems in place around respecting people’s concerns and responding accordingly, had significantly lower hospitalization rates (see Figure 4). When they did so, they had a hospitalization rate of 1.03 for every one person they served (over a three year period) versus 2.57 for when they did not have organizational systems in place promoting respect of people’s concerns. For example, in an organization that supports 500 people, hospitalizations would be expected to drop from 1,285 (for a three year period) to 515 when organizations respect people’s concerns.

Figure 4. The Organization Respects People’s Concerns and Responds Accordingly (Systems)

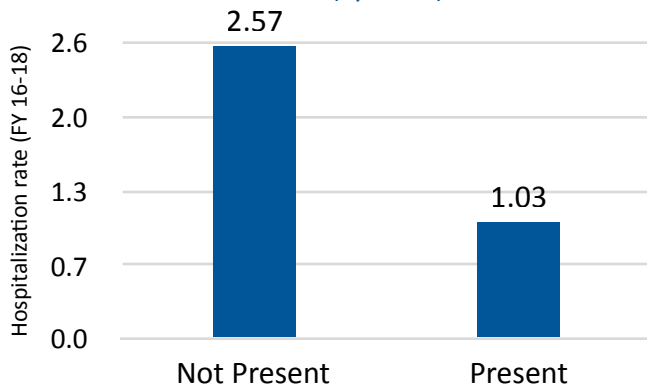
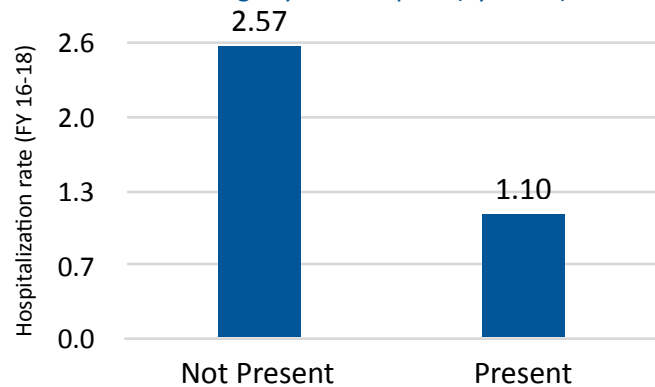


Figure 5. Supports and Services Enhance Dignity and Respect (Systems)



Respect was actually a common theme across these analyses. Figure 5 presents another example. When systems were in place to enhance services and supports that promote dignity and respect, agencies also had significantly lower hospitalization rates. When organizations put systems in place to ensure people had meaningful work and activity choices – they had a "meaningful day" – hospitalization rates were significantly lower, at 0.65 per person supported over a three year period versus 1.74 per person supported (Figure 6).

Natural supports also resulted in lower hospitalization rates (Figure 7). When organizations facilitated each person’s desires for natural supports, there were lower hospitalization rates. When organizations had systems in place addressing individualized emergency plans, the hospitalization rate was 1.03 over a three year period, compared to 2.35 for when they did not have a system of individualized emergency plan in place (Figure 8).

Figure 6. People Have Meaningful Work And Activity Choices (Systems)

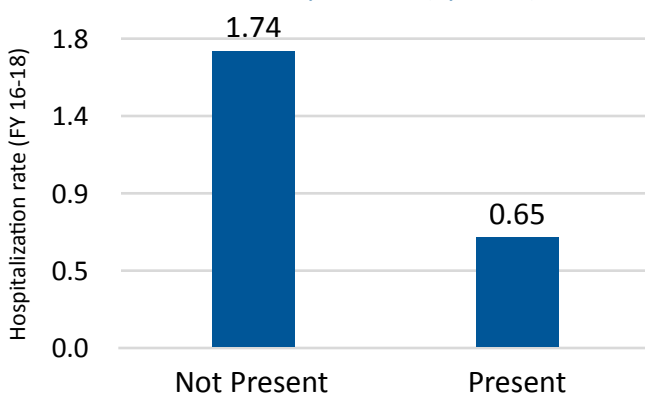
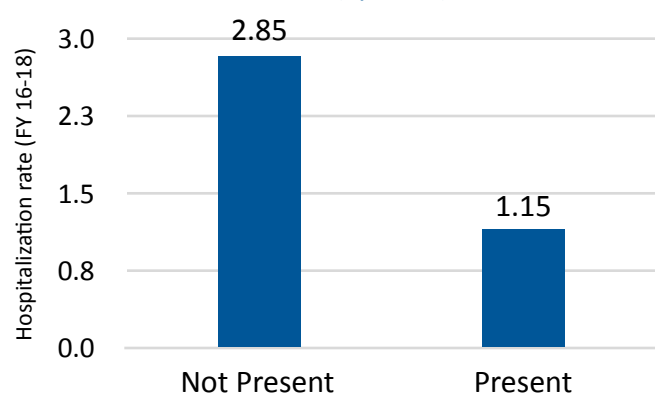


Figure 7. The Organization Facilitates Each Person’s Desire For Natural Supports (Systems)



When organizations treated people with psychoactive medications for mental health needs *consistent with* national standards of care, hospitalization rates were lower (Figure 9).

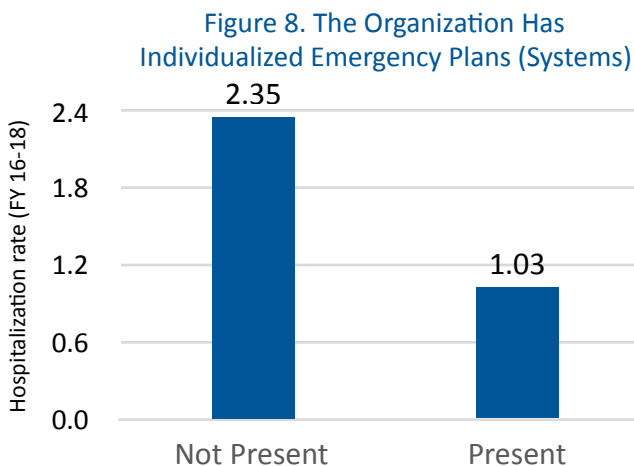
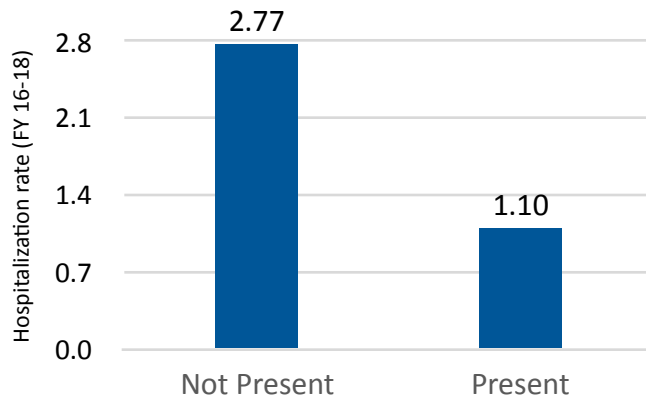


Figure 9. The Organization Treats People With Psychoactive Medications For Mental Health Needs Consistent With National Standards Of Care. (Practice)



Appointment Rates

We also examined differences in appointment rates. When organizations had systems in place to ensure people were free from abuse, neglect, mistreatment, and exploitation, the medical appointments rate was cut in half (Figure 10). But perhaps a bit less immediately obvious, when organizations had systems in place to implement ongoing staff development, there were also significantly fewer appointments (Figure 11).

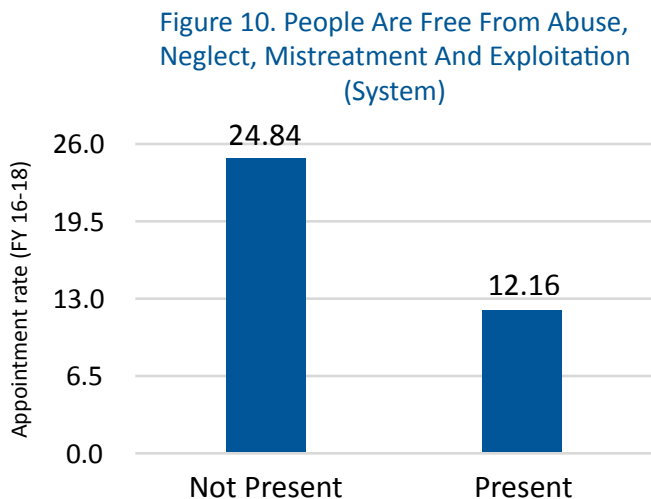
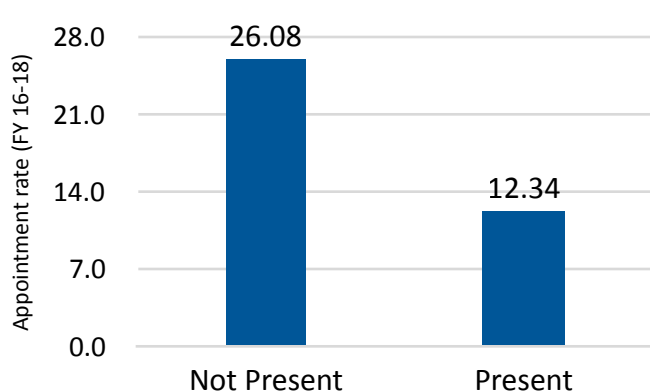


Figure 11. The Organization Implements An Ongoing Staff Development Program (System)



Medication Errors Rates

Medication errors are a significant concern for service organizations. When organizations treated people with psychoactive medications for mental health needs consistent with national standards of practice there were fewer medication errors (see Figure 12). When agencies treated people consistent with national standards of care, there were 3.13 medication errors for every one person they supported over the three year period, versus when they did not there were 14.92 for every one

person they supported. Also when people were free from unnecessary intrusive interventions, there were significantly fewer medication errors (Figure 13).

Figure 12. The Organization Treats People With Psychoactive Medications For Mental Health Needs Consistent With National Standards Of Care (Practice)

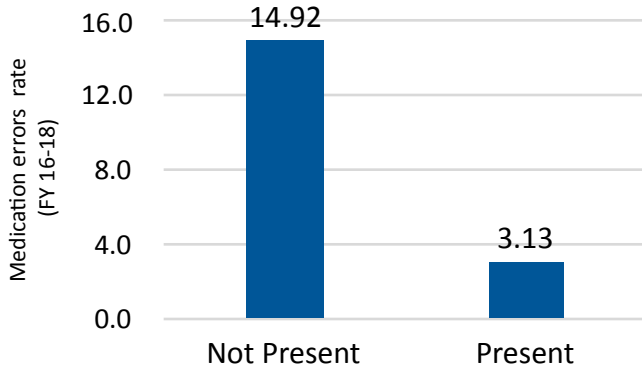
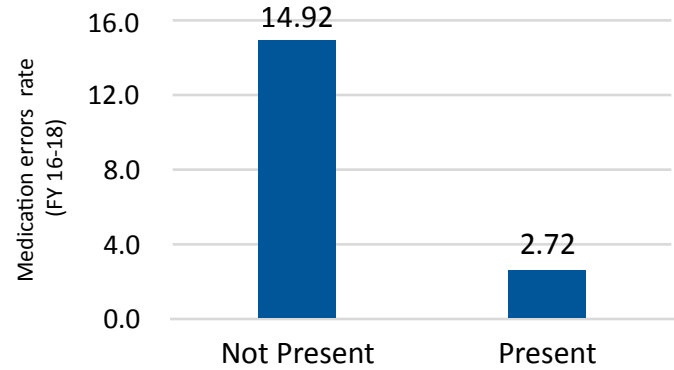


Figure 13. People Are Free From Unnecessary, Intrusive Interventions (Practice)



Injury Rates

Another variable we looked at was injuries. Analyses revealed dignity and respect was yet again a critical component. When organizations had practices in place to respect people’s concerns and respond to them accordingly, the injuries rate of the people they supported was significantly lower (Figure 14). When agencies did not respect people’s concerns, there was a rate of 12.61 injuries for every one person they supported over the 3 year period, whereas when they did respect people’s concerns it dropped significantly to 5.85 injuries per person they supported. Similarly, when supports and services enhanced dignity and respect, the injury rate dropped from 12.77 to 5.98 (Figure 15).

Figure 14. The Organization Respects People’s Concerns and Responds Accordingly (Practice)

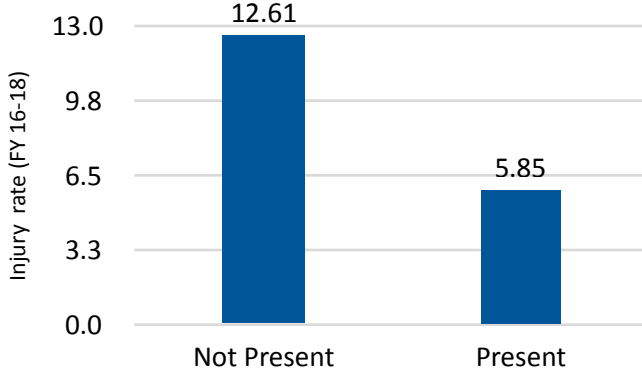
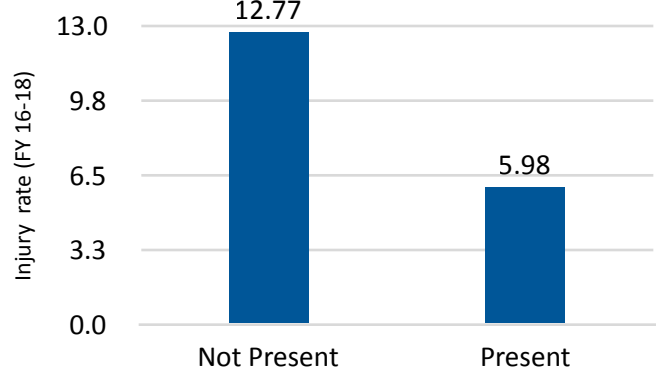


Figure 15. Supports and Services Enhance Dignity and Respect (Practice)



When systems were in place to ensure people have meaningful work and activity choices, the injury rate dropped from 9.38 for every one person over the three year period served to 3.02 (Figure 16).

When organizations had systems in place to facilitate each person’s desire for natural supports, the injury rate was significantly lower (Figure 17). For example, for an organization that serves 500

people, the number of injuries is expected to go down from 9,600 to 3,100 over a three year period when the organization facilitates each person's desires for natural supports.

Figure 16. People Have Meaningful Work And Activity Choices (System)

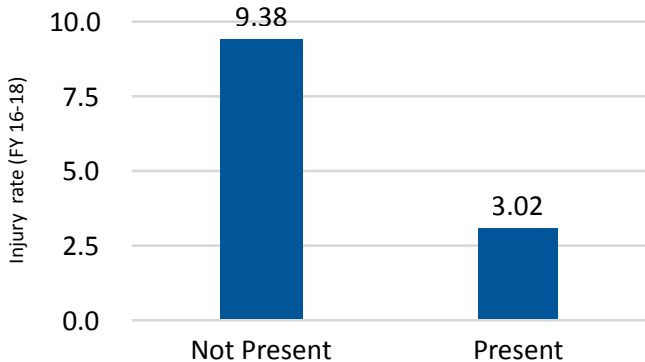
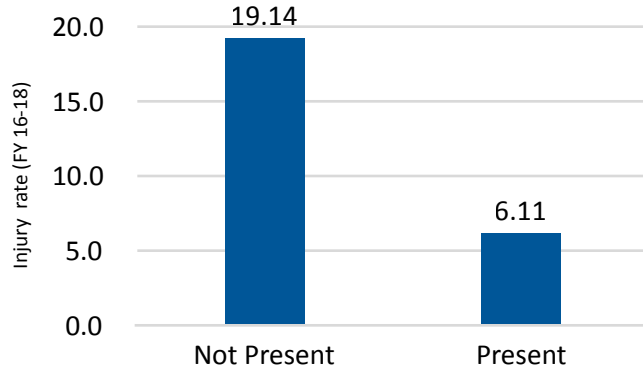


Figure 17. The Organization Facilitates Each Person's Desire For Natural Supports (Systems)



Behavioral Issues Rates

In terms of behavioral issues, when organizations respected people's concerns and responded accordingly, the behavioral issues rate dropped from 11.07 to 2.70 per person served for a three year period (Figure 18). Similar results were found when people had meaningful work and activity choices – when organizations ensured people had meaningful days – there were significantly fewer behavioral issues (Figure 19).

Figure 18. The Organization Respects People's Concerns and Responds Accordingly (Practice)

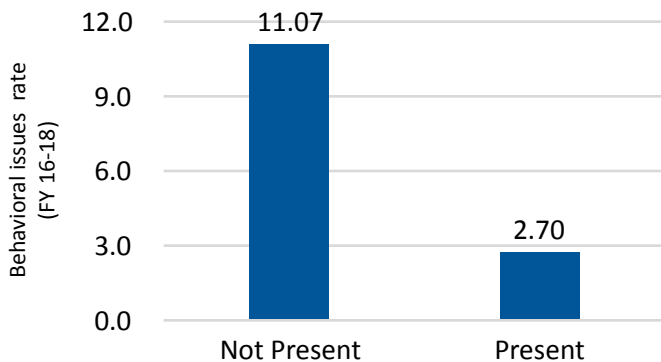


Figure 19. People Have Meaningful Work and Activity Choices (Practice)

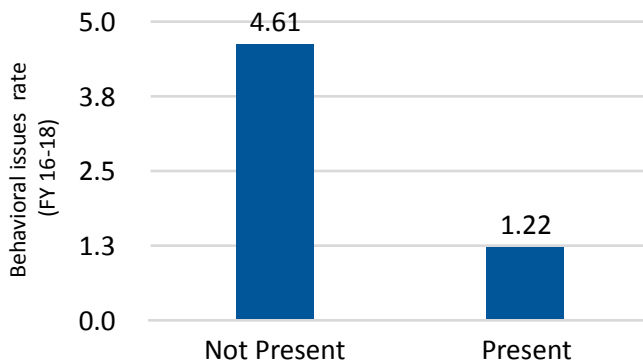
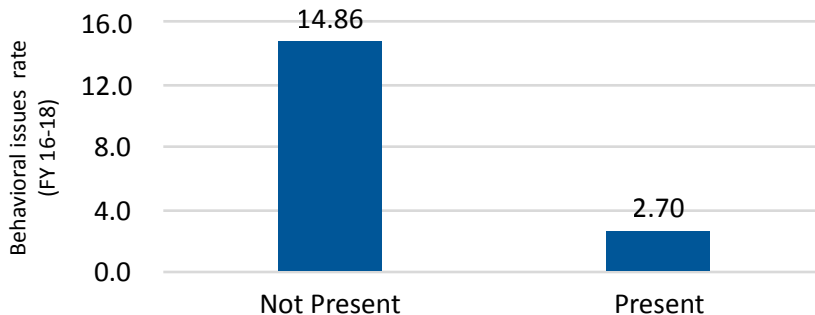


Figure 20. The Organization Ensures Thorough, Appropriate, & Prompt Responses To Substantiated Cases of Abuse, Neglect, Mistreatment and Exploitation (Practice)



When organizations ensured thorough, appropriate, and prompt responses to substantiated cases of abuse, neglect, mistreatment and exploitation, and to other associated issues identified in the investigation, the behavioral issues rate dropped from 14.86 for every 1 person served (over a three year period), to 2.70 for every 1 person served (Figure 20).

Most of the findings have examined how different ways organizations support people with IDD can impact health, but there were additional findings related to the ways agencies treated their staff. When organizations implemented ongoing staff development programs, the behavioral issues rate amongst the people they supported dropped significantly from 14.86 to 1.97 over the three year period (Figure 21). Similarly, when organizations treated their employees with dignity, respect, and fairness, the behavioral issues rate dropped from 11.58 to 1.97 over the three year period (Figure 22). For example, an organization that serves 500 people which does not treat their employees with dignity and respect is expected to have 5,800 behavioral issues over a three year period, whereas if they do treat their employees with dignity and respect the number is projected to drop to less than 1,000 behavioral issues, indicating the way staff are trained and treated trickles down to the behaviors of the people supported.

Figure 21. The Organization Implements An Ongoing Staff Development Program (Practice)

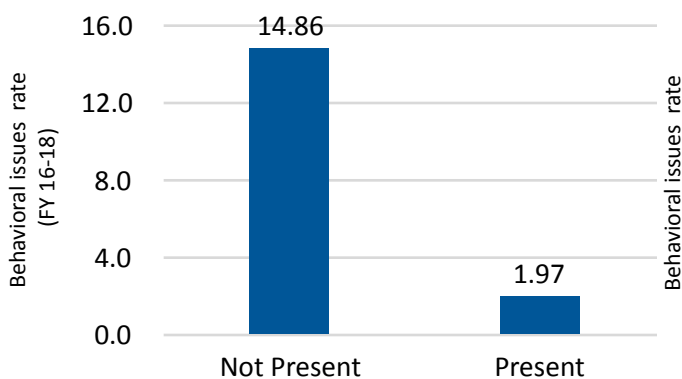
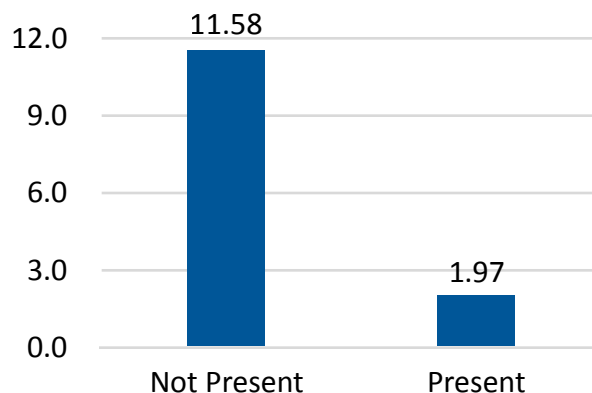


Figure 22. The Organization Treats Its Employees With Dignity, Respect And Fairness (Practice)



When organizations provided continuous and consistent services and supports for each person, the behavioral issues rate dropped from 18.61 to 2.46 per person served over the three year period (Figure 23).

Figure 23. The Organization Provides Continuous and Consistent Services and Supports For Each Person. (Practice)

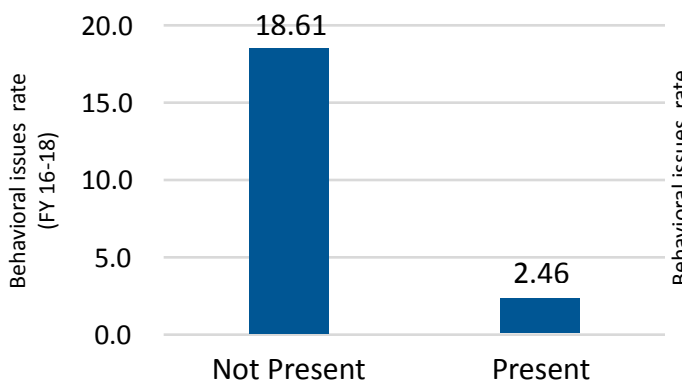
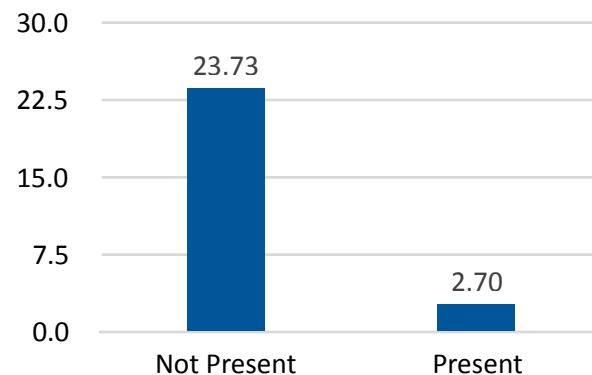


Figure 24. People Are Free From Unnecessary, Intrusive Interventions (System)



When organizations had systems in place and they were put into practice, to ensure people were free from unnecessary intrusive interventions, the behavioral issues rate dropped from 23.73 for every one person supported over the three year period to 2.70 (Figure 24). For example, for an organization that serves 500 people, the number of behavioral issues would be projected to go down from 12,000 to 1,400 for incidents over a three year period when people are free from unnecessary intrusive interventions.

Limitations and Directions For Future Study

When interpreting these findings, a few limitations should be noted. First, this study was a pilot with a relatively small sample size (28 agencies who supported 3,000 people with IDD). Moreover, it was a sample of convenience and the agencies in the sample represented one umbrella organization. It should also be noted we conducted a secondary analysis; as such, we do not know if hospitalizations were appropriate or used in lieu of primary care. We do not know if injuries were inflicted by others, or preventable. We also need more information about training - is there a particular training that leads to better results for people receiving supports? Future research should replicate this study with a larger and more diverse sample, adding additional variables and questions.

Conclusion

While traditional measures of health are important, many other factors play a role in quality services and supports, and quality of life. As indicated in the findings above, respect, meaningful days, staff training, and many more social determinants have an impact on hospitalizations, injuries, medication errors, and behavioral issues. We need to work to ensure measures of ‘value’ are holistic and ensure quality metrics are not only *value-based* but *valuable* to people with IDD.



BUILDING THE FRAMEWORK FOR VALUE BASED MEASURES



What Is Quality?

‘Quality’ is relative – what it means to different people and in different context can be open to interpretation. The aim of the symposium was to help determine what quality services and supports for people with IDD involves; key themes from discussions with the approximately 25 thought leaders are presented below. Although there were a variety of different themes that emerged over the course of the day, one consistent theme emerged – all attendees believed quality services go well beyond just health and safety metrics. Moreover, services and supports should not be driven by regulation alone, but rather by personal needs and preferences.

“What is value?
Is it in the eye of
the beholder?”

Although health and safety in and of themselves do not wholly encompass quality, they were seen as the foundational building blocks upon which everything else is built. In fact, supporting people to be healthy and safe is an important aspect of supporting them to achieve valued life outcomes. People must feel safe in their environments and be free from abuse, neglect, mistreatment, and exploitation. It is also important that conceptualizations of health not focus solely on the person’s impairments, but rather the health of the whole person. People with IDD must also have access to health and wellness supports, such as physical activity and nutrition.

Once these foundational building blocks are in place, it is important to ensure people have a meaningful life. People with IDD must be supported to reach their potential to live a life of quality. Quality necessitates a holistic approach, which includes a wrap-around robust service delivery model throughout the lifespan, especially during times of transition. In fact, attendees recognized the important role of family in determining quality as it is often not only the person with IDD being supported but the family as well; as a result, there are outcomes that are also relevant to family members.

For quality services and supports, attention should be paid towards social measures. Often called social determinants of health (SDOH), these social measures include those factors that contribute to health and quality of life (e.g., social support, access to opportunities, etc.), but are beyond traditional health metrics.

Informed Choice

One of the most commonly described aspects of quality was true informed choice. It was recognized that people with IDD must not only have choices, but these choices must be based on information regarding numerous options and opportunities. Examples of choice-making opportunities include people with IDD choosing their goals, what they do during the day (e.g., where they work and play), where and with whom they spend their time, and where they live and with whom they live. Furthermore, efforts must be made to provide opportunities to people who may not primarily use verbal communication to make choices; people who do not primarily use verbal communication need to have alternative mechanisms to express their wants and needs.

Person-Centered Practices and Meaningful Goals

Ultimately, informed choice is about control over ones' life – about services and supports truly being person-centered. People with IDD must be supported to find their voice and become empowered. People with IDD must also be centered in their own lives – and have a say in what is happening. As such, a vast array of services must be designed around the person to meet their interests and choices, rather than services and supports being limited by a set menu of services.

Although person-centeredness is a cornerstone of quality, it was recognized that person-centeredness is unfortunately often still a philosophy and not a practice. Person-centered plans

“Regardless of mechanism, it should be **person-centered.**”

must not only be developed in such a way that is relevant to the person's goals and desires, but monitored and adjusted regularly based on feedback and timeliness. Furthermore, the goals in these plans must be meaningful and chosen by the person with IDD. As all people grow and change, goals should be evolve and change over time, not become stagnant.

Community Living

Community integration was also considered a critical aspect of quality. Community is not merely a place people with IDD go or have a presence, rather it is “a place people have a stake in, a place people feel they belong” (Hingsburger, 2017). Community integration is about engagement and being embedded into the community – it is a place where people have connections and meaningful

social roles. Are people spending time in their community, doing things they like and want to do, and experiencing new things? Are they spending time with non-paid people? Community integration means people with IDD not only develop social ties and relationships that result in natural supports, but also are integral community members themselves.

Meaningful Days

Another common theme regarding the meaning of quality was ensuring people with IDD have meaningful days, including community-based employment opportunities. People must be able to choose what they do during the day, and those activities must be meaningful. Community employment outcomes must always be prioritized. Moreover, although people should have community-based employment, having a job in the community is not enough; people must have a job that is based on their personal choice, work the amount they want to be working, and be satisfied with their job.

“People need to have a meaningful day.”

Relationships

Relationships were also frequently mentioned as a marker of quality services and supports, especially because people with IDD often face isolation and loneliness. Quality services and supports involve ensuring people with IDD have the relationships that are most important to them. Quality services and supports also help people with IDD build relationships beyond paid staff, including by extending into their communities. Services and supports should also facilitate creation of a network of natural supports and lifelong connections.

Dignity and Respect

Dignity and respect was recognized as a vital aspect of quality. People should not only feel respected and valued, but as part of dignity and respect, people should have control over their lives and have





real and meaningful choices. Services and supports should enhance dignity and respect in both systems and in practices. One central component of dignity and respect is the dignity of risk. Avoidance of risk is often foundational in built and social environments of people with IDD (Perske, 1972). However, “it is difficult to learn how to make decisions and handle risk if the chance to undertake either of these activities is denied... [providers are] keen to encourage decision-making in theory but unwilling to allow choices that result in very minimal risky behavior” (Hudson, 2003, p. 261). If people with disabilities are truly to have equal opportunities, this includes the opportunity to take risks. In alignment with dignity of risk, support should only be provided to the degree necessary. The best support involves balancing duty of care and dignity of risk.

Continuity and Security

Continuity and security was also described as an aspect of quality services and supports for people with IDD. Lack of continuity and security includes the disruptions in people with IDD’s lives due to factors such as a lack of personal decision making, economic insecurity, and most frequently, the services and supports they receive from organizations. The provision of services and supports from human service organizations often links people with IDD’s lives to organizational processes and change. As such, the stability, tenure, and retention of DSPs is a critical component to the continuity of services. While in the current service system, some DSP turnover is likely unavoidable, quality services and supports work to ensure a lack of continuity does not result in unmet needs. More attention is drawn to workforce issues later in the summary report.

Embracing Technology

Finally, attendees also believed quality involves creative uses of technology. Technology should not only be embraced for the sake of improving services and supports, but also utilized to reduce unmet needs.

Building Quality Frameworks

In addition to unearthing trends in what quality services and supports for people with IDD involve, the findings of this meeting also revealed potential ways to build quality frameworks.

Creating Quality Standards

One of the first steps in doing so is to create quality standards. There was a recognition that across the country states are doing different things and everyone was working from a different perspective. Often these experiences and perspectives were siloed and not shared outside of the state or network. As such, it was recommended that best practices in Medicaid managed care not only be established, but shared across networks and systems. There must be collaboration across groups and quality bodies.

It was also recommended that quality standards should be based on data and measures. Outcome measures often focus on the avoidance of negative outcomes – negative things that did not happen such as reduced incidents, hospitalizations, etc. – rather than measuring positive outcomes in

“Start with outcomes and then determine the methods to get to those outcomes.”

people’s lives. As one discussion group noted, “the key is how you measure it and consistency in how you measure.” Most everyone agreed, regardless of the tool or tools that are used to measure quality outcomes, they should be person-centered, especially as there currently is a tension between person-centered services and funding wherein the expectations for person-centered services are high but the funding to support those services is low. Some participants felt it was necessary to

have a data collection methodology that collects data at the individual level to be applicable to providers and MCOs for value-based payments. The tool/s should also be multidimensional and examine many perspectives (e.g., the person, their family).

Symposium discussion also emphasized the need for common baseline understandings and definitions of key concepts, particularly as values often differ depending on perspectives (e.g, payer, government, people with IDD, family, provider, etc.). It would be useful to have common definitions of value-based systems among all parties – a common language. For example, a common understanding of the purpose of the HCBS system would be fruitful since not all systems or players understand the uniqueness and nuances of the IDD HCBS LTSS system. Baseline understandings and standards would also make it easier to consistently execute value-based standards across the country because everyone would be speaking the same language.

One such way that was suggested to help set baseline standards was accreditation. Accreditation ensures consistency in quality standards across service and support providers. It was noted that “the absence of accreditation in this field is a real weakness.” As it is based on consistent standards, accreditation is a useful foundation for value-based payments. Accreditation models must look at not only systems, but also practices from varying perspectives – as both are necessary to

“Our values should be that people are treated with dignity and respect, and able to reach their potential. If these values aren’t embedded in the system, it’s just going to be about the cost. The dignity of people is key.”

ensure the highest quality person-centered services and supports for people with IDD.

Producing Cultural Change

In order to create quality standards and build better frameworks, there must be cultural change. The current service system is very much entrenched in the culture and legacy of fee-for-service medical models. Fee-for-service models pay based on the number of services provided, rather than the quality of those supports. Older models are often frequently risk-averse. In contrast, quality value-based services should aim to build services around the person, and not the other way around. As such, there must be a vast array of services offered and available.

For this change to occur, there must be provider buy-in. Providers must not only be informed of the aims and philosophies of these changes, they must also be invested in making them happen. This organizational transformation is necessary at every level of the organization, from the people providing direct supports to organizational leadership.

While recently a shift has begun towards person-centered services and supports in regulations and policies, this shift is still more of an abstract philosophy rather than a practice. While the philosophical change regarding focusing on a person's whole life, such as the HCBS final settings rule, is commendable, funding is not there to support real change – funding does not align with these priorities, making this transformation unattainable for many people who receive Medicaid

funded services. For example, work opportunities are often constrained by very low day service rates, which are based on congregate settings and not individual supports aligned with real work.



Investing in Quality

There can be no conversation about quality improvement without discussing cost and financing – the two are often intertwined. Participants recognized there needs to be a recognition that quality person-centered services and supports for people with IDD are an investment. Quality is often in conflict with funding, however. Truly committing to creating personalized services requires a robust and adequately funded service delivery system.

As such, there needs to be a focus on rates and rate structures. Rates need to reflect the desire to focus on a person's

whole life and be person-centered as is emphasized in regulations and policies. For example, funding is necessary to assuage the long waiting lists of people who are trying to get services, particularly as caregivers age and more people need services. Funding continues to lag significantly behind the commitment to create personalized services, and the quality of services and supports people receive, and their quality of life as a result, can be significantly hindered.

There is perhaps no better example of a need to invest in quality than DSP workforce issues. Staff turnover and the lack of a stable and reliable workforce is a chronic issue, and has a significant impact on quality. Providers need to have the ability to pay for talent, yet the ability to do so is often out of their control because of funding limitations and rates set by the state. In addition to an investment in staff funding, there should also be an investment in staff development and training. Staff credentialing could be a useful mechanism to expand staff development. Quality services and supports also require a cultural shift that treats DSPs themselves with dignity and respect, particularly as the impacts of doing so trickles down to people with IDD.

“If we could solve workforce issues, quality wouldn't be such a large issue - we'd have services with **unlimited potential.**”

Quality frameworks demand we also look at the relationships between services and outcomes, and outcomes and healthcare. By doing so, there will be more evidence that by emphasizing quality, and the metrics described above, there will be more opportunities for returns on investments and cost savings. For example, reductions in hospitalizations, falls, incidents, emergency room use, and staff turnover can all result in cost savings for the system. These savings can then be shared and/or redistributed in order to increase the quality of services or supports provided. For example, cost savings could be utilized to increase DSP rates or increase staff development.

One such mechanism to encourage cultural change and facilitate quality is for States and MCOs to provide incentive payments. For example, as DSPs play a critical role in quality services, there could be incentive payments for adopting DSP hiring best practices, and/or development and training. There could also be incentive payments for customer satisfaction. Another way to create incentive payments would be to create a partial deemed status for accreditation. Providers could also be rewarded for innovation; doing so not only encourages dynamic services and supports, but also gives providers the flexibility to innovate.

“Is it ethical to assign a monetary value to quality of life?”

There also needs to be an alignment between what MCOs are incentivizing and what providers are doing, in order to ensure both groups are working towards and measuring the same thing. Moreover, if payments are incentivized, careful attention needs to be paid to the ethics of attaching money to quality and value. Is it ethical to place a specific monetary value on quality of life and outcomes? For example, how does one put a price tag on the cost of trusted relationships, which we know are an important part of creating quality and value? Careful attention to these ethical quandaries requires decisions based upon evidence-based best practices.

To build quality frameworks, payment systems also need to be structured so that MCOs can ensure the small boutique providers are able to survive and are not left behind in a changing landscape full of mergers and acquisitions. In fact, often these boutique providers are uniquely able to provide dynamic and personalized services and supports because of their size.

Moreover, attention also needs to be drawn to the business processes and skills of providers. In the managed care market, providers need to be able to develop business cases on the value of their services. Knowing how much services and support really cost is more important than ever in the shift away from traditional fee-for-service models.

Conclusion

Findings from our focus groups with thought leaders from across the country indicated that although health and safety are foundational building blocks of quality, they are not enough — it is important to ensure people with IDD have informed choice, community living, meaningful days, relationships, dignity and respect, and much more. Quality frameworks demand not only evidenced-based best practices but also a recognition that quality is an investment, both financially and philosophically.



MOVING FORWARD

This report represents a culmination of findings from a symposium attended by approximately 25 thought leaders in the healthcare and LTSS industry as well as data analysis from 28 agencies that support approximately 3,000 people with IDD. The symposium was designed to begin developing a common understanding of value-based quality measures for people with IDD as the industry moves to managed care. While the ultimate aim is to have a roadmap for the key measures which would support people with IDD to receive high quality services and supports, this report serves as but one of many first steps.

While the sample size of the pilot quantitative analysis was small, the findings point us in directions for future research. In terms of next steps, we will expand the sample size to see if the same findings hold true with larger numbers. We also plan to continue the conversation with these thought leaders and others about how we can define quality to make it meaningful for those we support. This is a new partnership and we can all learn from each other's experiences, positionalities, and knowledges.

Taken together, our findings imply that it may be possible to impact programmatic costs by shifting to focus on factors that impact quality, such as dignity and respect, and meaningful days. This report is the first step in bridging the existing social determinants of health and value-based payments literature with LTSS quality of life work. While it is preliminary, it is unique and promising, and should be pursued with vigor.



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APPENDIX

	Median		U	p (exact)	r
	Not Present	Present			
HOSPITALIZATION RATE					
The Organization Respects People’s Concerns and Responds Accordingly. (System)	2.57	1.03	16	0.005	0.47
Supports and Services Enhance Dignity and Respect. (System)	2.57	1.10	6	0.007	0.44
People Have Meaningful Work and Activity Choices. (System)	1.74	0.65	36	0.003	0.51
The Organization Facilitates Each Person’s Desire for Natural Supports. (System)	2.86	1.15	3	0.02	0.34
The Organization Has Individualized Emergency Plans. (System)	2.35	1.03	22	0.002	0.52
The Organization Treats People with Psychoactive Medications for Mental Health Needs Consistent with National Standards of Care. (Practice)	2.77	1.10	14	0.045	0.33
APPOINTMENT RATE					
People Are Free from Abuse, Neglect, Mistreatment and Exploitation. (System)	24.84	12.16	35	0.04	0.33
The Organization Implements an Ongoing Staff Development Program. (System)	26.08	12.34	27	0.04	0.35
MEDICATION ERROR RATE					
The Organization Treats People with Psychoactive Medications for Mental Health Needs Consistent with National Standards of Care. (Practice)	14.92	3.13	4	0.004	0.47
People Are Free from Unnecessary, Intrusive Interventions. (Practice)	14.92	2.72	13	0.003	0.50
INJURY RATE					
The Organization Respects People’s Concerns and Responds Accordingly. (Practice)	12.61	5.84	29	0.009	0.45
Supports and Services Enhance Dignity and Respect. (Practice)	12.77	5.98	20	0.035	0.35
People Have Meaningful Work and Activity Choices. (System)	9.38	3.02	38	0.004	0.49
The Organization Facilitates Each Person’s Desire for Natural Supports. (System)	19.14	6.11	5	0.032	0.35
BEHAVIORAL ISSUES RATE					
The Organization Respects People’s Concerns and Responds Accordingly. (Practice)	11.07	2.70	35	0.02	0.39
People Have Meaningful Work and Activity Choices. (Practice)	4.61	1.22	14	0.045	0.33
The Organization Ensures Thorough, Appropriate and Prompt Responses to Substantiated Cases of Abuse, Neglect, Mistreatment and Exploitation, and to Other Associated Issues Identified In The Investigation. (Practice)	14.86	2.70	18	0.03	0.37
The Organization Implements an Ongoing Staff Development Program. (Practice)	14.86	1.97	34	0.003	0.51
The Organization Treats Its Employees with Dignity, Respect and Fairness. (Practice)	11.58	1.97	35	0.011	0.43
The Organization Provides Continuous and Consistent Services and Supports for Each Person. (Practice)	18.61	2.46	34	0.009	0.44
People Are Free from Unnecessary, Intrusive Interventions. (Practice)	23.73	2.70	11	0.002	0.53

Note. All rates control for agency size. Rates are per every 1 person with IDD supported.



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