Report for JLARC, State of Washington

Review and Analysis of Employment and Community Inclusion Measurement

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EXECUTIVE SUMMARY

The recent HCBS Settings Rule (2014) emphasized the need for states to assure that services for people using HCBS facilitate personal autonomy, choice, and community inclusion. This mandate emphasizes the need for services that increase the opportunities of people with a disability to participate in competitive, integrated employment, and access the community at the same levels as their peers without disabilities. In 2017, the Joint Legislative Audit and Review Committee (JLARC) was charged with conducting a performance audit of employment and community inclusion services provided for adults with developmental disabilities in the State of Washington. The Rehabilitation and Research and Training Center on Home and Community Based Services (HCBS) Outcome Measurement (RTC/OM) developed this report to provide the context and guidelines for measuring the quality of employment and community inclusion services for individuals with intellectual and developmental disabilities (IDD). The report is designed to answer the following key questions:

1. *What are the existing approaches to measuring the outcomes/benefits of community-based employment services and community inclusion services?* and
2. *What are the types of benefits/outcomes (tangible and intangible) of community-based employment services and community inclusion services for people with IDD?*

The following report is a synthesis of the activities conducted by the RTC/OM to answer these questions; it includes the following major sections:

I. The importance of measuring outcomes of services of people with disabilities
II. Measurement approaches
III. Data-driven decision making
IV. Current state of measurement in employment and community inclusion
V. Recommendations for Washington State

A brief summary of the report content follows:

Employment and Community Inclusion Measurement Approaches

Measuring the quality of life of people with or without disabilities is a complex task that requires accounting for a number of contextual factors. Despite the challenge, quality of life measurement is essential to understanding the relationship between the services provided and the outcomes experienced by the person with a disability and the community as a whole. The National Quality Forum developed a conceptual framework for measuring Home and Community-Based Services. This framework outlines key domains and subdomains related to community inclusion and employment and is useful reference for conceptualizing and designing a measurement approach.

Data-Driven Decision Making (DDDM)

Data by themselves do not automatically lead to any meaningful change unless it is used purposefully and systematically. DDDM is the iterative process of systematic collection, analysis and interpretation of data to inform practice. A cyclical model for transforming data into a data into knowledge and decision making (Mandinach et al., 2008) was illustrated as a means of driving the DDDM process.

Potential Indicators Measuring the Outcomes of Employment and Community Inclusion

The approaches to measuring outcomes are discussed and numerous potential indicators and approaches to measuring the benefits of employment and community inclusion services are reviewed. Examples of both systems and person-centered indicators are discussed including reciprocity, continuity, and reduction in caregiver burden. In the context of the greater focus on what is important to the individual, we argue for the importance of including a person-centered measurement approach.

Employment and Community Inclusion Services and Measurement in Washington State

The State of Washington emphasizes an Employment First approach to providing services. Working-age adults (ages 21-61 years) are required to first participate in employment services (i.e. individual and group supported employment) for nine months before they can switch to community inclusion services. Currently, the State of Washington primarily measures employment and community inclusion through data collected using the CARE database and the National Core Indicators (NCI). These two approaches limit the evaluation of the benefits/outcomes for people with IDD to descriptive information at a state level that lacks utility for systematic improvement of services and individual outcomes for people with IDD.

Current National Measurement of Employment and Community Inclusion

National measurement programs (i.e., NCI, CQL POMs, CAHPS HCBS) are described and reviewed. Measures currently under development by the RTC/OM are also discussed. In addition, the RTC/OM database of HCBS instruments was used to provide examples and descriptions of other instruments that provide person-centered measurement of employment and community inclusion. Lastly, the community inclusion and employment measurement approaches and services in the State of Washington are compared with other selected states.

Recommendations for Washington State

Based on the information provided in the report, recommendations focused in six areas of outcome measurement are outlined: (1) use of guiding questions of interest; (2) use of multiple assessment tools, including person-centered measures; (3) use of measures only for their intended purposes; (4) attention to interviewer training and measure administration fidelity; (5) development of an appropriate sampling frame; and (6) purpose of data collection (summative or formative) with an emphasis on data-driven decision making.

Review and Analysis of Employment and Community Inclusion Measurement

I. Importance of Measuring Outcomes of People with Disabilities (Activities 1a; 1b; 1g)

Introduction

Measuring the quality of life of people with or without disabilities is a complex task. Unlike measuring objects and events, evaluating different aspects of human life must include numerous contextual factors, including health and employment status, type and place of residence, social connectedness, and participation in leisure activities. Information that is centered in the context of real lives that takes into consideration differences in what individuals want and need is more difficult to obtain and interpret in a way that informs policy. We often assume that the services provided for people with disabilities are effective. This assumption is, however, often supported only by anecdotal evidence or sometimes by no evidence at all. In order to assure that the resources invested into Home and Community Based Services (HCBS) at federal, state, and local levels are well utilized, it is essential that an evidence-based, person-centered outcome monitoring system that is psychometrically sound (i.e., provides reliable and valid information) is in place to evaluate the effectiveness of services for individuals with disabilities.

This report is intended to provide the context and guidelines for measuring outcomes associated with employment and community inclusion services for individuals with intellectual and developmental disabilities (IDD). The report is designed to answer the following questions:

I. *What are the existing approaches to measuring the outcomes/benefits of employment services and community access services;* and

II. What are the benefits/outcomes (tangible and intangible) of employment services and community inclusion services for people with IDD?

Context for Measuring Outcomes

Under the recent *HCBS settings rule* (Centers for Medicare & Medicaid Services - CMS, HHS, 2014), there is a heightened need to assure that the services persons with disabilities receive allow them to exercise personal autonomy, community inclusion, and choice. In particular, CMS emphasizes that states move towards promoting the full inclusion of individuals receiving HCBS in the greater community, including providing opportunities for: (a) employment in competitive, inclusive settings; (b) full engagement in community life; (c) control over personal resources; and (d) the delivery of services in the community. The rule also emphasizes that levels of inclusion are to be equivalent to those of individuals who do not experience disability. States are required to work with CMS to develop plans to bring programs into compliance with this guidance and effectively implement these plans in the near-future. Compliance with the rule inherently requires high quality measurement to track the extent to which HCBS services lead to desired outcomes and to pinpoint where improvements are warranted by the state and providers.

Although sheltered or facility-based employment has been an option for adults with ID for decades, over 15 years ago the Rehabilitation Services Administration eliminated sheltered employment as a preferred outcome for individuals with ID who receive vocational supports (Wehman, Revel, & Brooke, 2003). It has been noted that although there are generally fewer individuals with ID working in sheltered settings today there has not been a corresponding increase in the percentage working competitively (Butterworth, et al., 2012). Although individuals with ID employed in sheltered settings are more likely to be immune from job loss due to factors such as a recession, they lag behind their peers with ID employed competitively in terms of wages and other benefits (Migliore, Mank, Grossi, & Rogan, 2007; Siperstein, Parker,

& Drasche 2013). Another concern for those in the field is that most adults with ID employed in sheltered settings are unlikely to ever transition into a more inclusive competitive employment (Blanck, Schartz, & Schratz, 2003), despite the claim that these types of settings serve to prepare individuals with disabilities for competitive employment (Cimera, 2011).

The State of Washington responded assiduously to the requirements of the CMS settings rule by soliciting public comment, conducting a systematic evaluation of setting types, and developing a statewide transition plan. The transition plan includes the results of the state's systematic evaluation of Washington's HCBS settings, the plan for ongoing evaluation, and a work plan and timeline for achieving the major milestones needed for compliance with the final rule. The *Washington State Revised Transition Plan for New HCBS Rules* received final approval by CMS in 2017. In the description of settings, the transition plan lists Community Inclusion, Individual Supported Employment, and Group Supported Employment as services falling within the HCBS setting. According to the transition plan, all major milestones related to community inclusion and employment services (i.e. individual supported and group supported) were completed as of 2017. The major exception was pre-vocational services. These services were not considered capable of compliance with the final rule and are therefore being phased out by 2019. Efforts to transition participants receiving pre-vocational services into alternative services (including employment and community inclusion services) began in 2015 and are scheduled to be completed by January of 2019.

In 2006, the U.S. Department of Health and Human Services (HHS) through CMS contracted with the National Quality Forum (NQF) to reach consensus on key domains to measure the quality of Home and Community-Based Services (HCBS). The committee settled on the following definitions of HCBS quality:

> *Home and community-based services (HCBS) refers to an array of services and supports delivered in the home or other integrated community setting that promote the independence, health and well-being, self-determination, and community inclusion of a person of any age who has significant, long-term physical, cognitive, sensory, and/or behavioral health needs.*

The conceptual framework for measurement developed by the NQF committee ultimately included 11 domains and 40 subdomains (see Figure 1 & Appendix A).

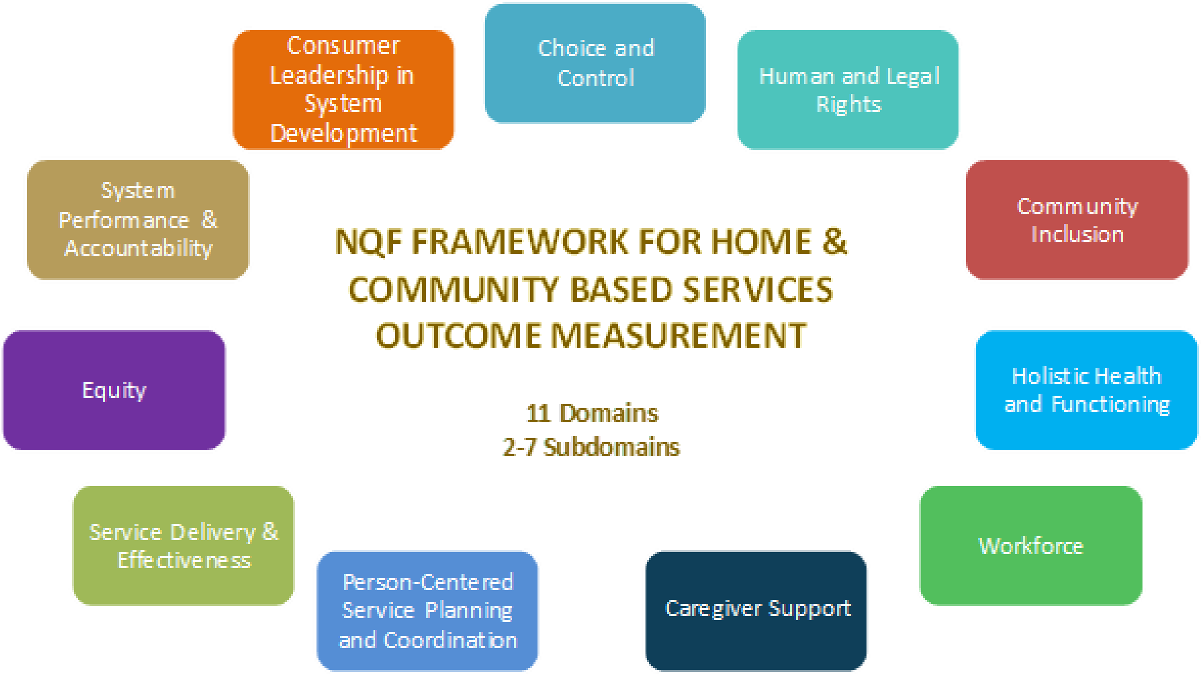

Figure 1. National Quality Forum HCBS Outcome Measurement Framework: Domains

One of the main domains in the NQF framework is *Community Inclusion*, defined as the level to which people who use HCBS are integrated into their communities and socially connected, in accordance with personal preferences. Subdomains include: (1) Social connectedness and relationships or the level to which individuals who use HCBS develop and maintain relationships with others; (2) Meaningful activity referring to the level to which individuals who use HCBS engage in desired activities (e.g., employment, education, volunteering, recreation & leisure, etc.), and (3) Resources and settings to facilitate inclusion: or the level to which resources and involvement in inclusive community settings are available to individuals who use HCBS (NQF, 2016).

The committee also listed barriers and challenges to measuring such domains and quality, including a lack of standardized measures across the country; limited access to timely data on HCBS programs; variability across the numerous federal, state, local, and privately funded programs with respect to reporting requirements; and the administrative burden of data collection, management, reporting, and incorporation into quality improvement activities.

One strength of this report is the broad view it takes on HCBS quality, including its comportment with Centers for Medicare and Medicaid Services (CMS) interest in promoting the quality of waivered services. Another strength is that the committee has provided a framework for measures to be developed and/or adapted to improve data collection and ultimately the quality of life of HCBS consumers.

The weakness of the NQF approach is that committee did not systematically seek consumer and other stakeholder input, relying mostly on expertise of committee members. This lead to some key issues for people with disabilities and other stakeholders being omitted or hidden within existing domains and subdomains. The Research and Training Center on HCBS Outcomes Measurement (RTC/OM) at the University of Minnesota conducted a study to obtain such feedback across nationally representative stakeholder groups, including: (a) Persons with disabilities (intellectual & developmental disability, physical disability, traumatic brain injury, mental health, and age-related disability), (b) Family members, (c) Providers, and (d) Program administrators. The study included a total of 320 participants in 58 participatory planning and decision-making groups (PPDMs) nationally to find out to what extent different stakeholder groups agreed with the proposed NQF domains and subdomains as being the most important to measure, if they viewed any key topics as missing, and why they conceptualized specific domains and subdomains as more or less important to measure.

Stakeholder weightings and qualitative discussions revealed that many people affected by HCBS viewed *Transportation and Employment* as domains or subdomains of their own. Consistently across stakeholder groups, participants expressed that employment should not be subsumed under the domain of Community Inclusion and under the sub-domain of meaningful activity. Further, many participants felt that Transportation should not be subsumed under Community Inclusion and under the sub-domain of resources and settings. Participants from all groups expressed the opinion that both of these outcomes were of such critical importance that they deserved to be considered as domain in and of themselves.

Overall, this study validated and refined the NQF framework. The process recognized a need to better define several of constructs to be measured (e.g. current measures of Community Inclusion focus far too much on only the physical aspects of inclusion). Further, it revealed that greater attention needed to be devoted to determining whether measures being used are sensitive to changes in policy, service provision, etc., in order to inform policy and have the potential to have an impact on the outcomes experienced by people with disabilities.

The National Quality Forum (NQF) has established a committee and process for endorsing measures within the field of HCBS. In considering a measure for endorsement for use in public and private payment systems, the committee follows four main criteria: (1) The strategic importance of the measure; (2) Cross-cutting issues about measure properties (e.g. psychometric properties); (3) Consensus across different stakeholders about measure feasibility and usability; and (4) Consensus with respect to the development process for the measure, considering other measures in the field.

Although CMS requirements and the NQF framework are necessary components, the values of each state, in this case, the State of Washington, should be central in determining the specific outcomes and components that should be measured when evaluating the quality of HCBS outcomes experience by recipients. In 2016, Washington's Department of Social and Health Services Developmental Disability Administration (DDA) published the *Developmental Disability Administration Guiding Values.* The document is based on the work of a committee that included self-advocates and advocates, families, residential service providers, county staff, employment providers, DDA staff, and other stakeholders. The stakeholder committee reviewed two core documents used to guide the services and supports for people with disabilities in the state: *The Residential Services Guidelines* (1988; rev 2013*)* and *County Guidelines* (1992). Subsequently, the following were articulated as core values to guide disability policy in the State: (1) *Inclusion* (being present in and part of the community); (2) *Status and Contribution* (being valued and respected by others); (3) *Relationships (*connections to others); (4) *Power and Choice*- (having choice and control); (5) *Health and Safety* (being healthy and safe); and (6) *Competence*-(being able to do what one needs and wants to do). Any effort to measure outcomes for people with disabilities in Washington should align with these guiding values.

To accomplish the goals outlined by CMS, NQF, and expressed in the values and guidelines relevant to employment and community inclusion for people with disabilities in the state of Washington, the next step is to identify key indicators of successful outcomes of employment and community inclusion for people with IDD to measure.

HCBS Outcome Indicators

The University of Minnesota's RTC/OM database of HCBS instruments and items (https://rtcom.umn.edu/node/181#HCBS-Instrument-Database) was first reviewed. Items from

10 instruments that were coded as being person-centered and measuring the NQF domains for community inclusion (meaningful activity 136 items; social connectedness 86 items) and employment (23 person-centered items) were the initial focus of this work. When multiple items or scales identified similar indicators of an outcome, we attempted to combine them into one summary indicator that would sufficiently cover the concept.

Important indicators of these domains from the RTC/OM development process for employment and community inclusion measures were also included in this process. While developing measures of employment and community inclusion (i.e. social connectedness, meaningful activity), the RTC/OM conducted thorough literature reviews. The literature reviews identified themes that emerged from peer-reviewed literature that included both qualitative and quantitative analysis of these domains (i.e. employment, community inclusion). Literature reviews were searched looking to identify broad themes (e.g. frameworks for aspects of community inclusion, such as reciprocity) to generate additional indicators related to employment, social connectedness, and meaningful activity.

In addition, a broad literature review as conducted searching for additional outcomes and indicators associated with employment and community inclusion services. The literature review included the use of the following search engines: PubMed; PsycINFO, Scopus, MedLine, Google Scholar; and others. Several combined variations of search terms were used to identify potential indicators associated with community inclusion and employment, including: community access, employment, inclusion, relationships, social connectedness, skills, benefits, outcomes, developmental disabilities, etc.

Finally, as a group with experience in outcome measurement of services and outcomes for people with IDD, other potential indicators that did not emerge from our more formal processes described above were generated. This process relied on our knowledge of different interrelated aspects of such programs (e.g., reduction in respite care investments) as potential indicators of program successes. Indicator concepts identified during the group discussions were then incorporated into the literature search to determine if research supported the relationship between the potential indicator and either community inclusion or employment services.

Figures 2 and 3 below outline two sets of potential indicators for the two programs of services separated by stakeholder group (individuals with disability, family members, and the state) and program (employment vs. community inclusion). We also divide the provided indicators by whether they are system-based or person-centered.

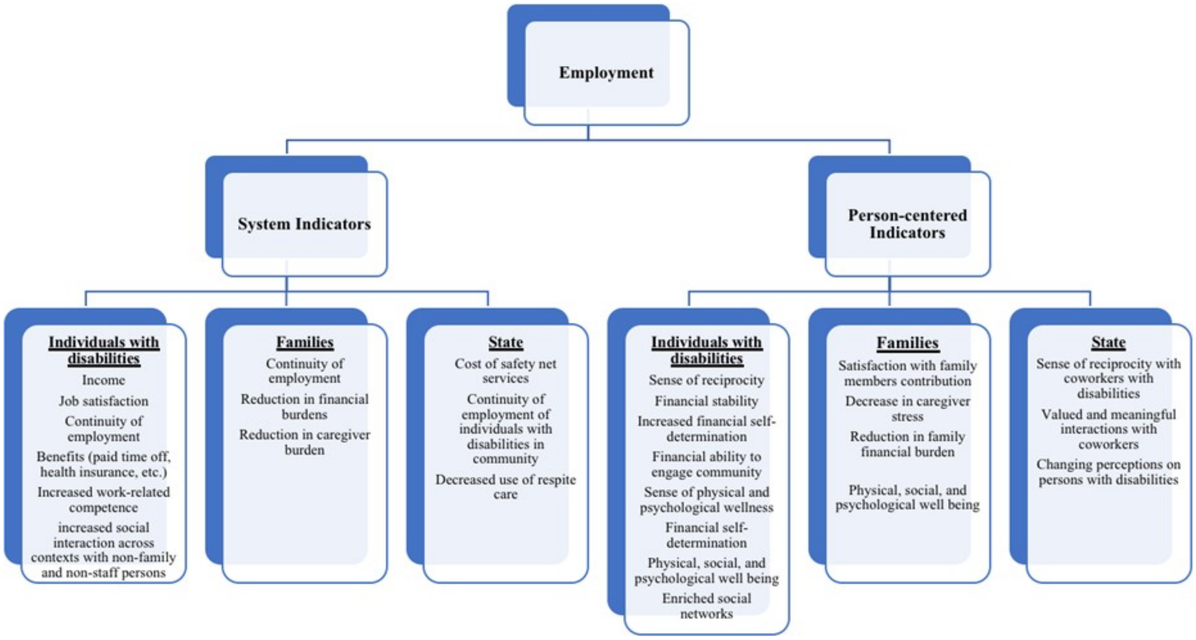

Figure 2. *Examples of employment quality indicators by stakeholder group and program type*

Based on our review, several indicators have been identified as important across all three groups of stakeholders (individuals with disabilities, families, and state) and both programs of services (employment and community inclusion), including the indicators of reciprocity and

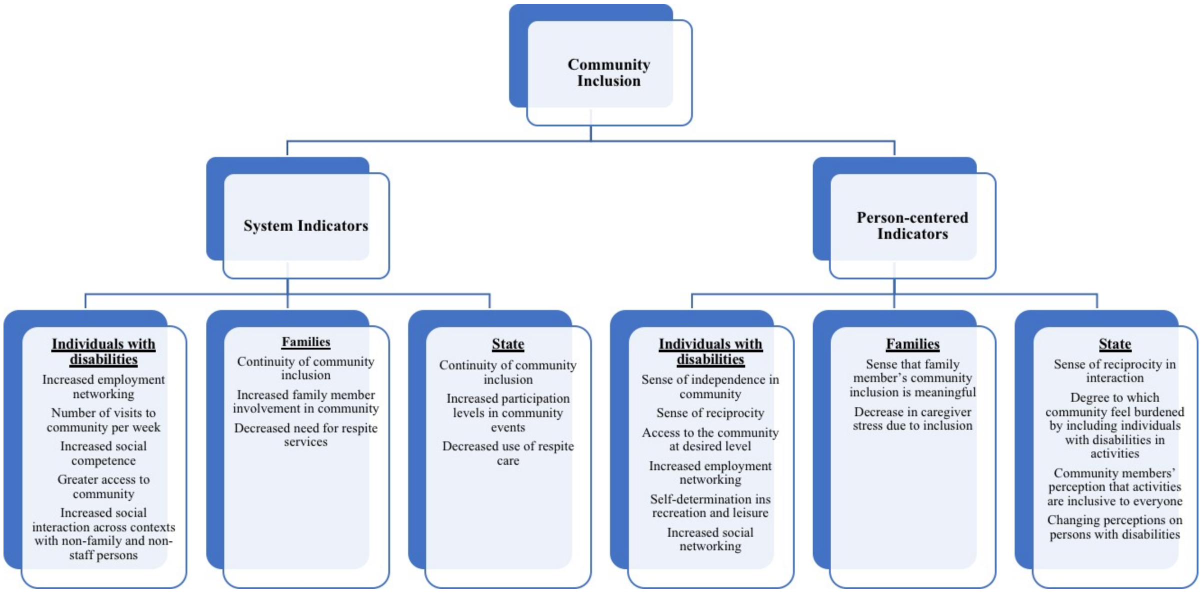

Figure 3. *Examples of community inclusion quality indicators by stakeholder group and program type*

continuity. In addition, it became apparent that the actual domains of employment and community inclusion are related and should not be considered as separate entities in measurement, which can include being associated with similar factors.

Since the move from deinstitutionalization to community inclusion began, many researchers in the field have noticed a gap between people with disabilities living *in* the community, but not truly being *of* those communities. The concern is that while people might physically live in a community and participate in community activities, they do not experience full membership, including developing and maintaining meaningful relationships with others (Amado, Stancliffe, McCarron, & McCallion, 2013; O'Brien, 2003). Reciprocity was therefore identified as a potentially important indicator of success when it comes to employment and community inclusion as it indicates individuals with disabilities being fully incorporated into a work or community environment. It is not uncommon for individuals with disability to have physical access to work and community settings, but to still experience isolation within the larger group. Measures that address reciprocity from the perspective of multiple stakeholders in a community can provide policymakers and providers a much more personal sense of how effectively services are supporting program aims.

Similarly, we highlight the idea of the *continuity* of employment and social inclusion experienced by persons with disability. This concept is important to consider with respect to measuring outcomes. Often, individuals with disabilities have short-lived employment experiences and interactions with other individuals in the community. This can be due to the instability of support services, cultural differences, stereotypes held by substantial members of the general public that lead to individuals with disabilities being treated differently (often with a lack of respect), and communication barriers. Individuals with intellectual and developmental disabilities who are employed, for example, for a variety of reasons experience less job security compared to those who do not have disability (Kaye, 2009; Schur, 2009). Among the factors associated with this instability are the greater likelihood of their having entry level, temporary jobs, experiencing transportation difficulties, and/or needing to restrict their employment earning and hours because they can potentially lead to reductions in services and supports. Furthermore, we know that individuals with disabilities work fewer hours than persons without disabilities (Bruyère, Erickson, & VanLooy, 2000), and are much more likely to be in entry-level and part-time jobs (Kaye, 2009; Schur, 2009). Research focused on the community inclusion of people with IDD indicates that, overall, they tend to experience lower levels of involvement with community groups. Leisure activities tend to be solitary and passive in nature, with training/support staff as opposed to friends being most likely to accompany them (Verdonschot et al., 2009). Therefore, an indicator of employment at any given time point or a count within a certain time period of community inclusion that does not consider continuity may not accurately reflect the manner in which services are having an impact on long-term outcome in these areas.

Benefits for Families, Providers, Employers, and Society

Benefits to families. The employment and community inclusion outcomes of persons with intellectual disabilities are closely related. In addition, outcomes in these areas have an impact not only upon the individual him or herself, but on family members, providers, employers, the immediate community, and society at large. Employment- and community inclusion-related services, for example, can be conceptualized as providing respite for caregivers. Access to such supports will decrease the need for informal caregiving by family members. There is evidence that the benefits of reduced caregiver burden extends beyond the immediate, temporary relief provided to family members but actually improves overall health. Family caregivers of people with disabilities have reported higher incidence of chronic health conditions (e.g. obesity, high blood pressure) and mental health concerns (Yamaki, Hsieh, & Heller, 2009; Seltzer, Floyd, Song, Greenberg, & Hong, 2011) associated with long-term caregiver burden. Moveover, caregiver burden is associated with a lower quality of life (e.g. Ünalan et al., 2001; Koehler, Fagnano, Montes, & Halterman, 2014) and overall sense of well-being (Eisenhower & Blacher, 2006; Fianco et al., 2015).

Research directly linking community inclusion or employment services to a decrease in caregiver burden is limited. There is evidence, however, that services designed for increased community participation may lead to a reduction in caregiver burden for some populations. For example, participation in community reintegration programs on the part of persons with TBI has been demonstrated to be associated with reduced caregiver burden (Gerber & Gargaro, 2015; Geurtsen, van Heugten, Meijer, Martina, & Geurts, 2011). Notably, in Cadman et al. (2012) the unmet need for social contact and appropriate daily activities among transition age young adults with autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD) were among the factors contributing to greater burden levels for caregivers. Indicators of the distal benefits of persons with IDD taking part in employment and/or community inclusion programs could explore the impact that receiving such services has on caregiver stress and burden.

Benefits to providers, employers, and society. Over the past decade a number of studies (e.g., Burge, Ouellette-Kuntza, & Lysaghtb, 2007) have found that the majority of general public believes that community-based employment is the best employment option for people with ID. They also express the opinion that such employment positively contributes to the workplace with respect to improved public image, cost effectiveness, stability, and contributions related to work performance. Graffam, Smith, Shinkfield, & Polzin (2002) found that with appropriate supports, the performance of employees with disabilities as a group was comparable to that of “average” (non-disabled) employees, especially with respect to reliability and maintenance factors. In addition, workplace modifications and changes to staff training and supervision resulted in benefits to productivity, improved staff skills and practices, and workplace and customer relations. Financial effects were mostly reported as cost neutral, with more financial benefits than costs incurred. Lysaght, Ouellette-Kuntz, & and Lin (2012) noted that integrated employment in the community also contributes to the social connectedness of all workers.

The Institute for Corporate Productivity (2014) recently identified four key findings at the organizational level of the effect of employing people with IDD: (1) Companies that hire people with IDD experience the addition of highly motivated employees, demonstrating an inclusive and diverse culture that is attractive to critical new employees, and improving customer satisfaction; (2) The profile of a worker with IDD demonstrates qualities that reflect those of any other staff member including dependability, engagement, motivation, consistent attendance, attention to work quality, and high productivity; (3) Most participating employees noted that hiring workers with IDD had been a positive experience, with many of them indicating that their experience exceeded their expectations; and (4) Challenges to the employment of persons with ID fewer than expected and resources to support their success greater than anticipated.

Community and social inclusion remains an important element of well-being for people with ID (Buntinx & Schalock, 2010) and a key component of the United Nations Convention on the Rights of Persons with Disabilities (Quinn & Doyle, 2012). In spite of the focus on community inclusion that accompanied deinstitutionalization over 40-years ago, people with IDD continue to experience high rates of social isolation (Bigby, et al, 2008, Forrester-Jones et al., 2006, Milner & Kelly, 2009) with their social networks are comprised mainly of family members and professionals (Lippold & Burns, 2009).

When most professionals discuss the concept of community inclusion their focus is on persons with ID as the beneficiaries. However, people without disability and members of the society also derive both direct and indirect benefit from efforts devoted to this outcome. Research, for example, indicates that social inclusion promotes happiness, mental health (Forrester-Jones et al., 2006), well-being (Johnson, Douglas, Bigby, & Iacono, 2012), and decision-making capacities (Johnson, Douglas, Bigby, & Iacono, 2009). At the other end of the spectrum actual and perceived social isolation are both associated with increased risk for early mortality (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Segrin & Domschke, 2011; Valtorta, Kanaan, Gilbody, Ronzi, & Hanratty, 2016). When this occurs not only does the person with the disability benefit, but the society as a whole as such individuals demonstrate greater independence and autonomy requiring fewer and/or less extensive supports. (Mahar et al., 2013, Mansell et al., 2002). The socially included individual who enjoys greater mental health is also less likely to need psychiatric or physical health care. Other researchers have suggested that promoting community and social inclusion has the potential to support the employment of persons with ID (Power, 2013), and protect against abuse (Quinn and Doyle, 2012).

The distal benefits of community inclusion, hinge upon broader changes in the community and society of attitudes and behaviors. Research suggests, however, that community inclusion can decrease negative attitudes, stereotypes, stigma, and discrimination against people with ID (Johnson et al., 2009, Mahar et al., 2013, Power, 2013). Contact with people with disabilities has been shown in a number of studies to be a good predictor of more positive attitudes toward groups as a whole as well as individuals. Increased levels of community inclusion therefore have the potential to decrease negative attitudes (Sharma, Forlin, Loreman, & Earle, 2006). Enhanced community inclusion also fulfills the aims of national and international public policies and mandates (e.g., Convention on the Rights of Persons with Disabilities and national policies, 2006) (Cobigo et al., 2012, Duggan and Linehan, 2013, Mahar et al., 2013, Martin and Cobigo, 2011, Overmars-Marx et al., 2014, Power, 2013) as well as the recent HCBS settings rule.

Outcome indicators associated with employment and community inclusion services, including reciprocity, continuity, and impact on caregivers need to be considered in relation to a number of factors including their importance, usability, and the feasibility of obtaining the data, an issue we will return to later in this report. Some indicators including average income or percentage of people employed are easily obtained. Others such as reciprocity in relationships and continuity take more effort and resources to collect but support one to better understand the experiences of service recipients. Expending the resources to collect high quality objective (e.g.

how long have you worked here?) and/or subjective (e.g. do you feel your relationships with co-workers are going to continue in the future?) indicators of constructs similar to those reviewed above have the potential to significantly improve our understanding of the impact of existing programs as well as shed light on changes that could improve future outcomes. Although such outcome measurement may require additional financial resources, it has the potential to lead to more accurate, nuanced, and person-centered information about the impact of various services and supports on the lives of persons with intellectual and developmental disabilities in ways that, in the long run may improve outcomes or reduce the need for resources.

Regardless the type of indicators used, both high quality measurement practices (NQF, 2017; CMS, 2017) and discretion when interpreting results are critical for decision-making related to HCBS. Collecting and properly summarizing information on the impact of services designed to enhance quality of life (e.g., employment and community inclusion services), is critical because even well intended programs do not always have their intended impact on the persons for whom they were developed. Additionally, even programs that do show evidence of substantial positive impact may have unintended consequences and/or room for improvement. High quality measurement illuminates both the extent to which and manner in which programs are effective and where there are areas of needed improvement helping policymakers to make more informed decisions.

The following sections explore important approaches to measurement, including considerations of quality of data, etc. and existing measures and methods other states employ, and concludes with recommendations as to best practices in using data to make decisions. All of these sections are based on important principles to measurement overall and specifically to quality of life outcomes (employment and community inclusion) for individuals with intellectual and developmental disabilities.

II. Analysis of Measurement: Key Factors for Consideration (Activities 1a & 1b)

We begin by briefly discussing the purpose of measurement activities (i.e. the intended use of data and analysis) which supports the overall measurement process through requiring the organization to clearly articulate the questions that it desires to answer with the data it collects. Next, we consider the sources (i.e., types) of data that are collected. A third consideration covered entails the importance of collecting data related to the outcomes experienced by service recipients that is person-centered. Finally, the psychometric quality of the data (i.e., its reliability and validity) are discussed with a focus on the need to ensure that interpretation of the data provides as accurate an understanding of reality as is possible with results that can be trusted to inform future research or policy.

The Purpose(s) of Measurement

An important consideration when selecting measures is consideration of the purpose of the process. There are many ways in which measures can be used and a clear understanding of the intended purpose and use of a measure is critical to selection of the appropriate assessment tool(s). Here we focus on three levels that exert a significant impact of measure selection, and subsequently, interpretation of results.

Individual outcome measurement. Individual outcome measurement refers to efforts that focus on making inferences about the outcomes that individual recipients of services experience. Measurement at this level must be fine-grained, capable of assessing the degree to which each individual is progressing toward or has reached his or her unique goals and outcomes. Measurement at this level is powerful tool for evaluating a person’s quality of life and the degree to which a provider organization has effectively individualized supports to promote the individual making progress toward or achieving goals and outcomes that are important *to* him/her rather than viewed by others as important *for* the person. At this level of measurement, assessment items/questions, and scales *must be person-centered* reflecting the uniqueness of each individual and what they desire out of life. When data of this nature is successfully collected and interpreted on a longitudinal basis, service providers can use it to truly individualize supports and make data-based decisions to facilitate the achievement of individual outcomes. This can only be accomplished if measurement includes a process for determining how the person defines his or her outcomes.

System quality assurance. System quality assurance measurement refers to initiatives that focus on arriving at a determination of the quality of services a person receives or whether they meet national, state, or other standards. This includes the delivery of services, the ease and length of time it takes to arrange for them, and how they are delivered to individuals. Initiatives focused on quality assurance can take place at state, county, provider, or other organizational levels (e.g., an advocacy or self-advocacy group). At its most basic, this level of measurement focuses on compliance. When used appropriately and in a longitudinal fashion, however, system quality measurement allows users to determine if services and supports are being provided in an equitable fashion across persons living in different areas of the state, or of different ages, racial ethnic group membership and gender. Is a state, for example, providing services to HCBS recipients in a timely manner, and of a form that leads to persons experiencing a true sense of inclusion in the community (i.e., a feeling of *being of the community* rather than merely *living within the community*), regardless of their geographic location in the state. The goal is to understand the impact of policies, programs/service practices, and longitudinal trends in outcomes for larger groups of individuals or organizations (e.g., adults with disabilities across multiple regions, providers of services for people with IDD in a state).

Effective system quality assurance measurement is especially important when organizations at federal, state, county, or provider levels are experiencing changes in the types or forms of services they provide (e.g., when standards of care change). In these cases, such efforts can provide evidence that the organization is question has sufficiently changed its approach to the provision of services to meet new requirements (e.g., the recent HCBS settings rule (Centers for Medicare & Medicaid Services - CMS, HHS, 2014).

A subset of system quality assurance entails *performance measures*. Performance measures refer to data that focus on a group outcome (or standard) as the unit of analysis and look for positive change or performance in relation to a set goal (e.g. percentage of persons with IDD receiving employment supports currently working within inclusive, competitive employment settings). These analyses tend to be more descriptive and/or comparative and often include a benchmark. The goal of performance measurement is to link service delivery with changes (or differences between systems) in the proportion of individuals experiencing some (positive) outcome. A benefit to this approach is that it allows for progress to be marked or quality to be maintained in relation to a goal. This approach, however, does not allow for individual differences to be considered and is rarely able to account for person-centered approaches.

System-level policy analysis. Federal, state, and county policy all have the potential to exert an impact on the conceptualization and delivery of services and supports to persons with disabilities. State policies and practices in service planning shifting from a program to person-centered approach, for example, are likely to have an impact on numerous aspects of quality of life for persons with intellectual disabilities including the probability of competitive or supported employment (Hall, Butterworth, Winsor, Gilmore, Metzlev, 2007), satisfaction with employment, and both access to inclusive activities and the experience of inclusion within the community A person-centered process of understanding an individual's dreams and vision for the future, mapping existing and needed the resources to the supports and services needed to achieve personally identified life goals, has been demonstrated to result in service planning that is much more likely than traditional approaches to have a positive impact on quality of life. State policies, for example, that clearly articulate that integrated person-centered employment is a goal of service planning have the potential to translate into higher employment rates and satisfaction with employment. In fact, the more clearly a state identifies the goal of integrated employment, or community inclusion the more positive the outcomes in these areas experienced by adults with ID (Hall et al., 2007).

It is important to note that those factors assessed in relation to employment and community inclusion may be related to individual characteristics, programmatic innovations, or broad system-level policy. In each of these cases, however, the goal of measurement is to assess the extent to which past, current, or newly implemented policy and practices demonstrate a sufficient effect size to justify the expenditures associated with the supports being provided to persons with IDD and/or the need for new or additional services. Data collection and analysis therefore needs to be undertaken in a manner that allows for one to identify those factors (i.e., programs, policies, etc.) associated with clearly delineated, specific outcomes (e.g., employment within inclusive community-based settings) for specific groups of individuals (e.g., adults with ID in need of supports with a specific level of intensity) and make decisions about whether current approaches are effective, and if needed, how to improve the services and outcomes for the individuals.

Units of Measurement

Based on the purpose of measurement, it is important to decide what is going to be the *unit of measurement* and subsequently of data analysis. Data collected from different stakeholders (individuals with disabilities, groups of individuals, family members, providers, state, etc.) using various types of assessment tools lend themselves, for better or worse, to answering different types of questions about quality of services and quality of life. It is therefore critical to understand what types of decisions one desires to make based on the information collected. Answers to this question will determine at what level data needs to be collected and from whom such that one can obtain the most useful and valuable information. Accuracy and efficiency of the data collection need to be considered as well to assure that the conclusions made based on the data reflect reality and have not placed an undue burden on participants.

Data Sources

Along with a determination of the purpose(s) and unit of measurement, it is important to consider from what source(s) data will be collected. There are many ways to classify data sources (e.g., national databases vs. local samples, online vs. in person) when one is focused on research per se. Within a research context, *primary* sources are typically conceptualized as limited to those from whom one directly collects information. Using this definition, any individual who is directly asked questions by the researcher is considered a primary data source. This could be the person with a disability him- or herself, a family member, direct support staff or a case manager. Secondary sources on the other hand include all information not collected directly by the researcher and may include information extracted from administrative data sets, other research that has been undertaken, or a variety of other sources.

Within the context of HCBS outcome evaluation this delineation can be both artificial and misleading. Rather, we argue that in when evaluating personal outcomes, one is better off considering the specific questions being asked and the capacity of the individual with a disability to adequately understand and provide an informed response to the item when making decisions as to from whom we are likely to get the most reliable and valid information.

Many of the questions asked in HCBS outcome evaluations require immediate, first-hand accounts from the person who has had a direct connection with the experience in question or require the individual to indicate a personal preference. In these cases, the individual with a disability him- or herself is justly considered as the *only* primary source of information. Family members, staff, or case managers who did not directly observe behavior relevant to the question and who do not have direct access to the preferences of the person with a disability should in these cases, be considered as secondary (typically far less accurate) sources and in the same manner as information contained within an administrative data set.

Primary data sources - Persons of disabilities. There are a multitude of surveys currently used in the HCBS outcome measurement field ranging from surveys created and used by providers to those utilized at state or federal levels. Many of the survey instruments are administered through an interview with the person with a disability and other people involved in their services. Generally, the self-report instruments are administered through an in-person interview to avoid low response rates and missing or incomplete data, and to provide needed assistance with comprehension for persons with IDD. This approach to data collection provides a more comprehensive and thorough understanding of the outcomes in comparison to the piecemeal information typically available in clinical and administrative databases and allows measurement to be more *person-centered (see below)*, especially when the ability exists for other persons familiar with the individuals to provide verification or assist with interpreting questions and answers.

Persons with disabilities, although most often the best source to provide information about items related to preferences (e.g., "Do you have the amount of control you desire over _______") are not always the best source to answer all questions about services and outcomes due to reliability and validity issues as a result of cognitive limitations and/or other issues related to the feasibility and burden of data collection, time constraints, etc. Due to the issues noted above, a common type of data collection used when the target person is an individual with IDD who has extensive support needs is the utilization of proxy respondents. Proxies are used when the person with a disability is unable, in a reliable and valid manner, to respond to a question or series of questions. This could be due to the construct being evaluated, the time frame a person is asked to utilize when responding, or poor, overly complex wording of questions.

When proxy respondents are used, they are most often a family member or caregiver who knows the person well. The accuracy and usefulness of data from proxy respondents has been debated in both the general measurement field and particularly with respect to assessment of the outcomes experienced by persons with intellectual disabilities (e.g., Claes et al., 2012; Kozlowski et al., 2015). Some have concluded that specific questions related to observable aspects of the person's life (e.g., Did the persons case manager attend their service planning meeting?" or "How long did it take for the person to change their residence following a request being made to the case manager to do so?") are acceptable when answered by a proxy, *if* the proxy is familiar with the person, and has directly observed that area of the person's experience.

It is clear, however, a person with a disability should answer all questions about their own attitudes, preferences or personal states (Claes et al., 2012). Some of the most widely used HCBS outcome tools are designed in such a manner that some questions can, if necessary, be answered by a proxy, but other items must be answered by the person with a disability him- or herself or left unanswered.

Secondary sources - Administrative databases. A typical source of data for measuring the outcomes and quality of services provided to people with disabilities are administrative databases at the federal, state, and provider levels. For example, in the state of Washington, the Comprehensive Assessment Reporting Evaluation Tool (CARE) collects information on individual outcomes related to employment (e.g. hours of employment related services, etc.) at the provider and state levels. At the national level, the Rehabilitation Services Administration 911 (RSA-911) database is a public access database that captures individual characteristics, services provided, and employment outcomes at the point of closure (after services have ended) from VR services.

Administrative databases have the advantages of being more easily accessible and a less expensive way to access data than face-to-face data collection. Further, databases can be more objective by including answers to concrete and factual questions, including demographic information, number of visits to the doctor, and whether a person is employed or not. They can also be more consistent due to repeated procedures for data collection and entry.

However, if administrative databases are the only source of data, they may provide an incomplete picture of quality of life outcomes for people with disabilities (Iezzoni, 2002) and they may also be inaccurate and/or outdated. Most administrative databases were originally designed for financial and accountability reporting and not with outcome questions in mind

(Gandhi, Salmon, Kong, & Zhao, 1999). Outcome-related data most often entered into databases tend to be limited in scope (e.g. frequency counts or number of service hours and frequently) and are not intended to answer more complex, in-depth outcome questions especially those related to *how* a person is delivered services and supports or their personal outcomes (Motheral & Fairman, 1997; Harpe, 2009). Moreover, the data from these databases tend to be piecemeal and incomplete, and not well-designed for providing complete measurement of the personal outcomes individuals experience or the manner in which outcomes and services are interrelated. Administrative databases are most often not designed to include individual contextual information related to outcomes, such as intensity of support needs or information about the specific services a person received or their quality (Lin et al., 2015; Gandhi, Salmon, Kong, & Zhao, 1999). An additional limitation of information included in administration databases is that it is infrequently based upon person-centered questions. Therefore, although large amounts of data are often available and easily accessible, they provide an incomplete picture of an individual’s or program’s outcomes.

Person-Centered Approaches to Measurement

Person-centered approaches are ways of planning, providing, and organizing services rooted in listening to what people want and helping them live in their communities based on their choices (NASDDDS, 2018). Inherent in person-centered approaches to service delivery are an emphasis on developing supports and opportunities for persons that fit their desires and needs rather than on 'fixing' or changing them as well as supporting the individual’s self-determination and autonomy. Person-centered approaches are rooted in ensuring the individual with a disability is at the center of all decisions which relate to their life. Person-centered thinking entails an ongoing process of listening to persons and understanding their dreams and visions for life, sharing ideas, and seeking feedback from them on a regular basis to ensure that all individuals are supported in working towards their personal goals, even as they evolve and change. The provision of services and supports in a person-centered manner is a key aspect of the HCBS settings rule (Centers for Medicare & Medicaid Services - CMS, HHS, 2014)

In the measurement context, application of a person-centered approach requires: (a) collecting information from individuals with disabilities themselves rather than from administrative data sets or proxy respondents (e.g., staff or family members); and (b) asking questions in such a manner that support the person's preferences being taken into consideration both with respect to the specific life outcomes measured and their perspectives regarding the degree to which these are achieved. In the past and to this day much HCBS outcome measurement is not undertaken in a person-centered manner. For example, most tools for measuring the personal control individuals' exercise over various aspects of their services and lives, focus on the absolute level of control they experience in a pre-specified range of areas. Measurement of self-determination, a construct research suggests is much more closely associated with quality of life, however, requires understanding of the degree of control individuals have over their lives, their desired levels of control, and the extent to which these aspects of life are important to them.

In a similar manner, most current measures of community inclusion are based upon the frequency with which individuals engage in a pre-specified set of activities within the community (e.g., shopping, going out to eat, etc.,). The greater the frequency of these activities the more included in the community a person is assumed to be. The experience of inclusion within a community, however, is much more nuanced than this approach allows. Different people have different preferences with respect to: how often they engage in community activities; in what activities they engage, and with whom. Measuring community inclusion in a person-centered manner, at a minimum, requires one to understand the community activities in which individuals actually *desire* to take part, the extent to which they are able to engage in these activities when, where, and with whom they wish, and if they feel welcome and their involvement appreciated.

Psychometric Properties of Measures

The psychometric requirements for HCBS outcome measures that allow them to be used with confidence are based on the NQF (National Quality Forum) Scientific Acceptability of Measure Properties (NQF, 2013), scientific soundness of measures as defined by the Thomson Reuters (Galantowitcz, 2007) as well as standard psychometric principles. Psychometric properties of measures include evidence of reliability (consistency across people and time) and validity (measuring what is claimed to be measured), both of which are issues related to data *accuracy*.

Reliability. One example related to reliability that must be considered when selecting measures is whether the measure in question is based upon a few or even a single item or is derived on the basis of multiple items. In most cases, it is preferable to have multiple indicators of a specific construct (e.g., community inclusion) that are used to form a scale. Scales significantly improve the quality of measurement of a construct beyond an individual or group of items for a number of reasons. Responses to any single item include some error due to accidental mistakes in recording the response, misunderstandings, and sometimes as a result the subjective nature of the question (e.g. asking the same person about job satisfaction on Tuesday can produce a different response than it might on Friday). In addition, groups of items allow one to more adequately “saturate” the construct being measured capturing more critical information about it. Summing or averaging across those items enhances the probability that one will get a clearer and more stable indication of that person's experience. An excellent example of the pitfalls that can occur when using single or only a few items to measure a construct can be seen in the manner in which a number of currently existing HCBS outcome measurement tools assess the community inclusion experienced by service recipients. Asking an individual 3-4 questions about how many times he/she has gone out into the community in the last month to eat, shop, and recreate provides an extremely limited understanding of the extent to which that individual experiences being include in the community. Statistical tests, including internal reliability (e.g., Cronbach's alpha), and inter-rater reliability (between scorers or observers) and test-retest reliability (between two or more survey administrations conducted within a short period of time), provide evidence that the scales and the items of which they are composed measure a concept consistently and accurately. Without such evidence, it is unclear the measure has the potential to achieve its claimed purpose, a potential failure of validity.

Validity. In order to ensure that a measure reflects its intent different types of validity are typically assessed. *Face or social validity* indicate the extent to which people responding to a measure understand that it is designed to evaluate the intended content area. *Criterion validity* refers to evidence that the measure is closely related to other measures that have been determined on the basis of research to assess the same or a very similar outcome. There are two types of criterion validity – concurrent and predictive. In a study of *concurrent validity,* a test or survey is administered at the same time as the criterion is collected. For example, an employment test could be administered to current employees, then a rating of those employees' job performance could be obtained from their direct supervisors independently. In a study of *predictive* validity, the test scores are collected first; then at some later time the criterion measure is collected. For the previous example, a test or survey would first be administered to job applicants. After those individuals hired have worked in the job for a year, their test scores could be correlated with their first-year job performance ratings. Predictive validity provides somewhat more useful data about survey or test validity because it has greater fidelity to real-life situations related to how the survey or test will be used. *Content validity* indicates the extent to which a measure covers the measured area with sufficient breadth and depth. *Ecological validity* provides evidence that the results obtained apply to real-life situations. In order to determine *construct validity*, the information gathered for the more specific types of validity is summarized and an overall match between the measure and the intended construct is evaluated.

Recently, Kane has made a case for use of an *argument-based approach to validation* (Kane, 2006; 2013; 2016) Kane (2016; 2013) contends that test scores/survey results can have multiple interpretations and uses, and that *it is the proposed interpretation/use of an assessment that is validated, not the survey itself or survey scores/results.* He argues that validity depends on how well the evidence supports the proposed interpretation and use of survey or test results. The primary use of HCBS data is to: (a) determine the outcomes experienced by persons who receive services; (b) understand the quality of supports with which they are provided; (c) when needed, enhance the quality of the supports received in a manner that enhances the outcomes persons experience. Users need to understand how to accurately interpret the data, make appropriate decisions based upon it, select supports that best fit an individual’s needs, and when appropriate change services. Validation of the IUA of HCBS Outcome Measures must therefore not take place in isolation, but rather, include an evaluation of the interpretation and use of data created through the assessment process, carefully considering the extent to which the assessment serves its primary purpose when used in a high-fidelity manner. This ties validation to the concept of data literacy and data-based decision-making/instruction.

Other important considerations when developing and selecting measures are their feasibility, usability, and importance. *Feasibility* refers to the extent to which information for the measure may be captured without undue burden to the individual, family (in terms of time), or state (in terms of the cost of measurement). *Usability* corresponds to the likelihood that information provided by the measure will be understandable and useful to its intended audience, and lead to quality improvement. This relates to closely to the *argument-based approach to validation* proposed by Kane, 2013; 2016). *Importance* refers to the relevance of the measure to the lives of the target population.

III. Data-Driven Decision Making (DDDM; Activity 1b)

A primary reason to collect data in relation to HCBS outcomes is to use it in decision-making. Decisions about whether an innovative program is having its intended impact or needs to be changed, if a State needs to commit additional resources in order for specific outcomes for persons with disabilities to come in line with the recent HCBS settings rule (2014), or to determine which of two program options that the most significant impact on the lives of the people it is intended to support program can all be better made if reliable and valid data are able to be accurately interpreted and transformed into knowledge.

This section is intended to provide guidelines on how data collected with HCBS outcome measures can be effectively used to inform decision making at state, regional, and program levels. The iterative model outlined in Figure 4 provides guiding steps to follow when making decisions about the outcomes of services, interventions or policies for persons with ID.

DDDM refers to the systematic collection, analysis, and interpretation of data to inform practice and is considered an iterative process, with outcomes at both individual and systems levels. It focuses on making data actionable (Williams & Hummelbrunner, 2011) translating data

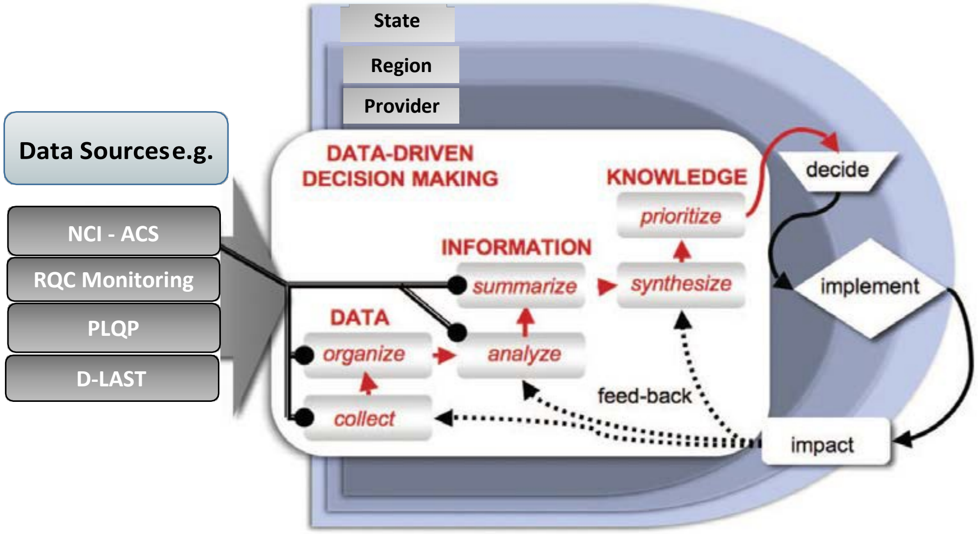

FIGURE 4. Conceptual framework for data-driven decision making adapted from *A Conceptual Framework for Data-Driven Decision Making* by E. B. Mandinach, M. Honey, D. Light, and C. Brunner. Copyright 2008 by Teachers College Press.

into actions that inform programming - a skill referred to as data literacy (Mandinach, 2009a).

The key steps for transforming data for decision-making are based upon a cyclical process through which data is transformed into information and knowledge (Carlson et al. 2011; Easton, 2009; Mandinach et al., 2008; Williams & Hummelbrunner, 2011).

The very first set of steps in the DDDM process is to identify the area(s) of need, target population of the evaluation and specific outcomes for which one needs to collect data. It is also important to outline a long-term evaluation plan, including goals, objectives, and a timeline.

The next step illustrated by Mandinach and colleagues (Mandinach et al., 2008) entails data collection. In order for data collection to address the identified need(s) and goal(s) of the evaluation, informed decisions need to be made about measures/instruments to be used to collect data based on the information presented in the first part of the report. These decisions are in part guided by the data that are already being collected and information already available within the state. In addition, awareness has to be built about all of the aspects of the selected measure(s)/

instrument(s), including administration format (interview, electronic survey, type of response options, etc.), directions (are proxy responses allowed, what is the selection process for participants, etc.), and what data are generated through this assessment (only quantitative, quantitative and qualitative, scale, binary, etc.).

The data collected then must be prepared for data analyses. This phase includes data entry and upload into a data-analytic tool or software. At the next phase, data needs to be contextualized. Context is used to ground the data and transform them into information. At the information level, information is analyzed and summarized. Users analyze the data according to the specific questions they are asking and the information they need in order make decisions at a particular level (e.g., provider organization or individual). Analysis can be quantitative, qualitative or both. Summaries are then developed pertaining to the potential and/or actual impact of programs or policies on HCBS recipients, as well as systems performance. These summaries assist users in identifying and focusing on critical performance patterns that may require intervention and change.

Through analysis and summarization, raw data is transformed into information about aspects of the service system that are performing well and where there are difficulties. Information then becomes transformed into knowledge. At the knowledge level, users synthesize and prioritize what they have learned. Information is synthesized in a way that helps users begin to build a quality enhancement knowledge-base about system performance and HCBS recipient outcomes from which programmatic decisions can be made. Finally, users at multiple levels collaborate to prioritize the knowledge gained and determine specific courses of action which are then used to make implementation decisions and evaluate impact. Once the information is generated by the DDDM, appropriate dissemination approaches and mechanisms need to be put in place for findings to be communicated effectively to targeted stakeholders.

The data of data-driven decision-making. Data in the present context includes information collected and organized to represent some aspect of the State of Washington's Community Inclusion and Employment Programs for persons with IDD. This includes information ranging from the personal outcomes of program participants with respect to their employment and inclusion, the quality of services received, whether supports are person-centered, and the costs associated with this programming. Information collected through the Washington state monitoring system will hopefully already provide data that can be transformed into a comprehensive picture of how the system is operating and its costs. Data collected through a longitudinally-focused HCBS outcome monitoring system would have the capacity to provide information with respect to the personal outcomes experienced by persons with ID and the benefits the programs bring to the people they serves, their families, and the community/society as a whole. The objective needs to reflect the end-goal of equipping stakeholders at the state, regional, and county levels with the tools needed to engage in high fidelity DDDM to improve outcomes based on the analysis and interpretation of high quality data (Weiss 1998; Rossi et al., 1999).

IV. Current Measurement: Employment & Community Inclusion (Activities 1d; 1e; 1f)

In this section, we review two of the major national efforts to measure HCBS quality outcomes for people with IDD that include employment and community inclusion as well as other methods currently used by states. The current state of measurement in the state of Washington is then summarized. Finally, information is presented with respect to instruments included in the RTC/OM database that include person-centered items related to employment and community inclusion as well as measures the RTC/OM team is developing in this area.

National Core Indicators (NCI) Program **(Human Services Research Institute)**

The National Core Indicators Adult Consumer Survey (NCI-ACS) was developed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) (Bradley & Moseley, 2007) for the purpose of measuring quality assurance at the *state* level. The NCI-ACS is used to collect data on service users with IDD and has three sections. The *Background Information Section* includes questions related to personal demographics, disability diagnoses, health, mobility, communication, residence type and size, employment, and behavioral supports. These items are typically completed by agency staff or case managers/service coordinators based on agency records, but may also be completed by the individual or family members. *Section I* includes questions on employment/daily activity, home, friends and family, safety, and satisfaction with supports/services. *Section I* items can only be answered by the individual receiving services through a face-to-face interview; proxy responses are not accepted. *Section II* includes items related to community inclusion, choices, rights, and access to needed services. These items can be answered by the individual or a proxy with the source of information (e.g., self or proxy) is recorded individually for each item.

NCI-ACS is administered annually or biannually in 46 states, which allows for state-level analyses as well as comparisons across states. The instrument covers eight out of the 11 NQF domains, including items on community inclusion and employment. Although some of the items on the NCI-ACS meet the criteria for being person-centered many do not. The instrument has demonstrated good psychometric properties in some areas including inter-rater reliability and internal consistency for groups of items representing the choice and control construct. Of specific interest in the present case, exploratory factor analysis indicates that the community inclusion items load on a single factor although internal consistency reliability is low. In the employment area, the NCI-ACS includes twenty items approximately 1/3rd of these demonstrate good internal consistency.

Overall, the weakness of the NCI-ACS includes the fact many items that purport to measure the same concept do not have good internal consistency reliability suggesting that they are not collectively measuring a specific, singular concept (e.g. community inclusion). NCI also possesses limitations with respect to the extent that its individual items and groups of items are person-centered. Questions, for example, do not allow for respondents to indicate whether they possess the degree of control they desire over various aspects of life or are able to engage in the activities they desire to the extent that they desire, when they desire, and with whom they desire. Instead questions and response options merely capture the absolute levels of control people have, the frequency with which they engage in pre-selected activities, and the supports they receive in these areas. This approach limits the ability of NCI analyses to capture where services may need improvement in terms of what consumers (and their families) personally value.

Table 1 includes a listing of areas assessed by the NCI-ACS related to employment and community inclusion. Several additional factors should be noted about the development and use of the NCI-ACS. Since Section I of the NCI-ACS can only be completed by persons with disabilities themselves, results tend to primarily reflect the experiences of persons with mild to moderate ID. Section II of the instrument, although able to be completed by persons with disabilities or proxies, can potentially result in a proxy with little understanding of the day-to-day experiences of the target individuals responding to questions. In addition, although the NCI-ACS

Table 1: Sections of NCI-ACS focused on Employment & Community Inclusion

Background information *(Completed from agency records)*	• Employment status (paid vs. workshop employment) • Duration of employment • Benefits • Type of Employment
Section I. *(Completed by person w/ disability)*	• Employment status • Desire for employment • Satisfaction with current employment • Enrollment in programs or workshops • Satisfaction with program or workshop • Enrollment in training related to employment
Section II. *(Completed by person w/ disability or proxy)*	• Frequency of visits in the community (e.g. shopping, errands, eating out, etc.) • Who, if anyone, accompanied target individual

is currently used by most states in order to survey the recipients of HCBS, it was not designed to be used longitudinally or to make comparisons between states. As a result, at the current time it is not known whether the instrument possesses sufficient sensitivity to change to be used longitudinally in an effort to determine the impact of policy and programmatic changes that take place within a state. Due to differences in how states sample persons with disabilities and collect information using the NCI-ACS, one must also be extremely cautious about making comparisons between states based on their NCI-ACS data.

The Council on Quality and Leadership, Personal Outcome Measures (CQL-POMS)

The Council on Quality and Leadership Personal Outcome Measures (CQL-POMS) is used both nationally and internationally for assessing HCBS quality of life (QOL) outcomes. The POMs database was established in 1993 and has been used to revise and update the instrument and items. As opposed to the NCI-ACS which was specifically designed for use by states, the CQL-POMS was developed so that it could also be used at the provider level.

In 2017, an analysis of internal consistency and a principle components analysis was performed using data collected from 2015 and 2016 (Friedman, 2017). As a result of this analysis, the 21 indicators measured by the instrument were reorganized into the following five components: *My Human Security*, *My Community*, *My Relationships*, *My Choices*, *My Goals* (The Council on Quality and Leadership, 2017). Table 2 lists the components and individual indicators/outcomes included for each.

Data for the CQL POMS is collected in three stages by trained, certified interviewers. The three stages involve:

Table 2. Outcomes Measured by Factors of the CQL POMS

Factor	Outcomes/Indicators
My Human Security	• Are Safe; • Free from Abuse and Neglect; • Best Possible Health; • Treated Fairly; • Are Respected; • Continuity and Security; • Exercise Rights
My Community	• Interactions with others in community; • Integrated Environments; • Participation in Community Life; • Use of Environments
My Relationships	• Intimate Relationships; • Have Friends; • Possess Natural Supports; • Decide When to Share Personal Information; • Perform Social Roles
My Choices	• Choose Where and With Whom to Live; • Choose Services; • Choose Where to Work
My Goals	• Realize Personal Goals; • Choose Personal Goals

1) Having an in-depth conversation with the person with a series of open-ended questions related to each of the 21 indicators;
2) Interviewing providers, service coordinators, case managers, etc. to follow up about the indicators and organizational supports provided; and
3) Observing the person or reviewing records to fill in information gaps.

After the interviewer completes the three stages of administration/data collection, he/she determines if an outcome has been reached (whether the outcome and support needed is present; Friedman, 2017; The Council on Quality and Leadership, 2017).

There are several outcomes related to community inclusion included in areas targeted by the CQL. The *My Community* factor includes the following outcomes related to community inclusion: *Interact with others in Community*; *Integrated Environments*; and, *Participate in Community Life*. In addition, the *My Relationships* factor includes other outcomes related to community inclusion such as: *Have Friends* and *Perform Social Roles.* Some of the items used to collect information about the outcomes are person-centered, but many are not.

The *Choose Where to Work* indicator within the *My Choices* factor provides information specifically related to choices and support related to employment. Although some aspects of employment are measured within the instrument, the entire instrument would need to be administered to obtain the employment related outcomes. This may not be feasible for states or organizations that are already collecting other outcome measures and wish to only collect supplemental measures of employment.

The CQL-POMS has the advantage of providing a comprehensive and person-centered measurement of the outcomes of the person with a disability. The instrument has been used for several years by a variety of organizations and states, and the developers have attempted to use the available data to routinely revise and enhance the instrument. The CQL-POMS is intended to provide a comprehensive, holistic, approach to measuring individual outcomes. It is, however, designed to be administered as one comprehensive instrument, not as a measure of individual constructs (i.e. employment or community inclusion). Moreover, items designed to measure employment and community inclusion outcomes are intertwined with other components and indicators. This creates a further challenge in separating the specific outcome areas of interest to the State of Washington from the other outcomes measured by the CQL-POMS. An additional challenge posed by this approach is the extensive, intensive training needed by interviewers/data collectors in order to ensure that information is collected with high fidelity.

CAHPS HCBS Experience of Care Survey (HCBS-EOC)

The Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services Experience of Care Survey (HCBS-EOC) survey is a third instrument used to measure the outcomes associated with HCBS. Recently developed, the instrument's development was funded by CMS with the intention of creating a standardized tool for collecting HCBS performance data (CMS, 2017) in a manner similar that which has been used for years within the context of managed care organizations. There are some potential advantages to using the CAHPS HCBS-EOC. To date, it is the only HCBS related survey to receive NQF endorsement (The reader should take note of the fact that the NQF was established under the auspices of CMS). The 2016 NQF endorsement included 19 measures. CMS sponsorship and NQF endorsement provide additional advantages in that many states may adopt use of the tool and making standardized, comparative data between states and providers more obtainable in the future. However, it must be acknowledged that HCBS-EOC 12 of these measures are "single-item measures" (only one item is used to measure the concept), and in spite of being endorsed by the NQF, the tool has a number of serious shortcomings. Internal consistency reliability estimates associated with measures composed of more than a single item reported by the developers are extremely poor with the majority ranging from α = .20 - .55 (Chronbach's alpha). This is well below the standard acceptable level used by most in the measurement field (α = .70). Despite the potential for widespread adoption, the CAHPS HCBS does not adequately measure employment or community inclusion. Furthermore, the instrument does not use a person-centered approach to measurement with few of its items taking into account the preferences of the person with a disability. In addition, it is the opinion of RTC/OM staff that evidence for the criterion validity of the CAPHS HCBS-EOC is sorely lacking. At this stage in its development the tool is best used for the purposes of monitoring general program quality.

HCBS Outcome Measures Currently Under Development

The University of Minnesota's Research and Training Center on HCBS Outcome Measurement (RTC/OM) is a five-year collaborative center housed within the University's Institute on Community Integration (ICI). It operates as a consortium in collaboration with University of California–San Francisco, Temple University, The Ohio State University, and The National Council on Aging and is funded by the National Institute on Disability, Independent Living and Rehabilitation Research NIDILRR/ACL. The center's main charges are to validate the NQF framework, develop a database of existing instruments and measures of HCBS outcomes organized according to the coverage of the National Quality Forum (NQF) domains and subdomains (https://rtcom.umn.edu/node/181), conduct a gap analysis between the existing instruments/measures and the NQF framework, and develop and validate measures that fill the identified gaps. The target populations for measurement include persons 16-years of age and older with IDD, traumatic brain injury, physical disabilities, mental health challenges, and age-related disabilities.

To date, there are few instruments designed to measure HCBS outcomes that have undergone rigorous psychometric evaluation. Developers of most tools have failed to conduct cognitive testing of items during the development phase to ensure that questions are interpreted as intended, respondents are able to limit their responses to the time frames specified in questions, and persons being interviewed have available response options that accurately reflect their perspectives. Some widely used instrumentation has yet to be adequately evaluated for test-retest or inter-rater reliability, sensitivity to change, or criterion-related validity. In addition, those evaluations in the area that have been conducted have, for the most part, been undertaken at the level of entire instruments or subscales, rather than the measure level (Smith & Ashbaugh, 2001; Lakin et al., 2008). In spite of the paucity of evidence supporting the technical adequacy of existing measures, states and policy-makers are using them to make critical decisions that have a significant impact on the lives of people with disabilities.

Given the scope of the RTC/OM, it is not possible to develop and validate measures in all domains of the NQF. Measures on which the Center is focusing have therefore been prioritized based on stakeholder feedback as well as on the following feasibility factors related to the extent that measures are:

1) Commonly used across instruments;
2) Relevant across populations;
3) Possess greatest possibility of obtaining data from individual, proxy or administrative data sets;
4) Have highest likelihood of being psychometrically sound;
5) Demonstrate the highest utility across stakeholder groups; and
6) Are person-centered.

A special focus is on those domains where there is a dearth of measures, but that are rated as of high priority.

A total of eight prioritized measure concepts have been developed and forwarded for testing. These include three measure concepts under the NQF domain of Choice and Control (Personal Choices & Goals, Choice of Services & Supports, and Self-Direction), three under the domain of Community Inclusion (Transportation, Meaningful Activity, and Social Connectedness), an Employment measure concept established as its own domain based on the results of the NQF HCBS Outcome Measurement Framework national validation study, and a measure concept under the domain of Human/Legal Rights (Freedom from Abuse/Neglect).

The selected measures are undergoing extensive cognitive testing, followed by piloting and will later be tested at a national level with participants from all five disability groups. At the end of the funding cycle, the measures will be evaluated based on their usability, feasibility and psychometric properties and based on NQF standards submitted for NQF endorsement. Those measures recommended will be: (1) usable and feasible to stakeholders; (2) have satisfactory established thresholds for reliability and validity; (3) able to discriminate between people; and (4) sensitive to change (for those measures for which this characteristic is applicable).

Measures focused on the Experiences of Caregivers

One reported area of measurement interest for the State of Washington is information that will permit a better understanding the impact of its programs on family members. In the U.S. today, 58% of persons with IDD who are Long Term Support and Service (LTSS) recipients live in the home of a family member (RISP, 2016). Family members engage in significant amounts of caregiving and often pay the price for providing these supports in the form of a higher incidence of chronic health conditions and mental health concerns (Yamaki, Hsieh, & Heller, 2009; Seltzer, Floyd, Song, Greenberg, & Hong, 2011), a lower quality of life (e.g. Ünalan et al., 2001; Koehler, Fagnano, Montes, & Halterman, 2014), and overall sense of well-being (Eisenhower & Blacher, 2006; Fianco et al., 2015).

In developing its HCBS Outcome Measurement Framework (2016), the National Quality Forum included a *Caregiver Support* domain. The NQF operationally define this construct as follows, “Caregiver Support domain is defined as the level of support (e.g., financial, emotional, technical) available to and received by family caregivers or natural supports of individuals who use HCBS” (NQF, 2016 pp. 19). Caregiver support is composed of four subdomains: (1) *Family caregiver well-being* or the level to which the family caregiver is assisted in terms of his/her physical, emotional, mental, social, and financial well-being; (2) *Family caregiver training and skill-building* which refers to the extent to which appropriate training and skill-building activities are available to caregivers who desire such activities; (3) *Family caregiver/natural support involvement* or the degree to which family caregivers are included in developing plans for an implementing the person-centered support plan for the HCBS recipient; and (4) *Family caregiver access to resources* or the level to which the family caregiver is aware of and able to effectively access resources (NQF, 2015; 2016).

It is easy to hypothesize that Washington State’s employment and community inclusion programs have a potentially positive, direct impact on family members who serve as caregivers and an indirect effect on others in the family group. To verify that hypothesis, however, technically adequate measurement tools are needed that are reliable, valid, sensitive to change, and measure the potential types of positive impact that access to such programs might have on families. Unfortunately, at this time, in spite of the NQFs inclusion of a family caregiver domain in its HCBS outcome measurement framework, there are few measures that adequately cover potentially positive outcomes associated with the involvement of persons with IDD in employment and community inclusion programs (RTC/OM, 2018). Many of the currently available measures designed for caregivers solely function to assess the burden of care and stress experienced by family members who provide supports or were designed for use with caregiving associated with age-related disability and chronic illness. A review of those measures currently include din the UMN RTC/OM HCBS Outcome Measurement Data-base yielded the following results.

Survey for Caregivers Supporting a Person with a Disability Outside of the Disability Support Service System

The *Survey for Caregivers Supporting a Person with a Disability Outside of the Disability Support Service System* (SCSPWD) was designed as a measure of concepts related to informal caregiving. Informal caregiving is not supported by the formal disability system. The instrument measures six domains (not NQF domains) of informal caregiving: (1) caregiving responsibilities; (2) needs of care recipients and caregivers; (3) experiences with the formal system; (4) compensation strategies; (5) expectations and planning towards the future; and (6) demographics (ASPE, 2015). This instrument has a wider focus that includes caregivers of people with disabilities rather than including only caregivers of people with dementia as most instruments targeting caregivers. Despite several (15) items addressing caregiver well-being, very few of the items are directly related to caregiver burden. Within the *compensation strategies* domain there is a section that addresses whether caregiving responsibilities have led to employment related changes for the caregiver (e.g. reduction in number of hours, taken paid or unpaid leave, changed job). These items may address the caregiver financial burden. However, overall, the instrument has limited usefulness for directly measuring caregiver burden. In addition, there are no published studies validating or reporting the psychometric properties of the instrument.

Caregiving in the U.S. Survey

The *Caregiving in the U.S. Survey* (CGUS) was developed as part of a national study of caregiving in the United States (NAC & AARP Public Policy Institute, 2015). This instrument also has a caregiving focus that goes beyond caregivers of people with dementia. The instrument includes the following six categories: *short-term physical condition, long-term physical condition, emotional or mental health problem, developmental or intellectual disorder or mental retardation, behavioral issues, memory problems*. A large portion of the instrument measures specific caregiving activities and supports, but some items measure the level of caregiver burden and associated outcomes. Among outcomes related to caregiver burden measured are: the impact of caregiving on the caregiver's health, and the physical, emotional, and financial stress and "strain" the caregiver experiences. Some items also address the employment outcomes the caregiver experience as a result of their responsibilities (e.g. leave of absence, early retirement, turning down a promotion). The instrument was designed for either telephone or online administration. Although some of the 125 total items measure level of and outcomes associated with caregiver burden, the majority assess other aspects of caregiving.

Additional Caregiver Measures Reviewed

An additional eight caregiver measures identified through an extensive review of the literature were reviewed and are listed below along with the limitations associated with each.

1) **National Study of Caregiving - NSOC:** Primarily measures caregiving duties performed and responsibilities.
2) **Performance Outcome Measurement Project Caregiver Services Survey Instrument - POMP-Caregiver:** Items are primarily related to quality of support for caregiving or the caregiver's need for additional resources/information/assistance
3) **National Core Indicators Family/Guardian Survey - NCI FGS**: Focus is on quality of supports and services etc.

4) **National Core Indicators Adult Family Survey - NCI AFS:** Items are primarily related to quality of caregiving services
5) **Burden Scale for Family Caregivers – BSFC:** Designed for and validated on caregivers of people with dementia.
6) **Caregiver Strain Index - CSI:** Short 11-item measure which is quite dated (1983). Wording of items and validation indicate it is designed for use with persons who are caregivers for individuals with age-related chronic illness and disability.
7) **Caregiver Appraisal Scale - CAS:** Lots of burden items, but all items written for "ELDER" care.
8) **Zarit Burden Interview - ZBI:** Specially designed to reflect the stresses experienced by caregivers of dementia patients. Validation studies are dated, items worded very broadly.
9) **Tailored Caregiver Assessment, Personal Family Caregiver Survey - T-CARE:** Designed for unpaid family caregivers of persons with age-related disabilities including dementia. Several items capture burden.

V. Services and Assessment Initiatives in the State of Washington

Employment and Community Inclusion Services in Washington State (Activity 1C)

The State of Washington, through the Developmental Disabilities Administration (DDA), provides Employment and Community Inclusion[1] services for adults with disabilities of working age (ages 21 years or older) participating in waivers or served through skilled nursing facilities. Services emphasize an employment first approach and are designed to encourage participants of working age to prioritize the use of funding and services for employment support rather than community inclusion activities (DDA Policy 4.11, 2013).

Service Eligibility. In Washington State, Community Inclusion and Employment services are mutually exclusive in that participants cannot simultaneously receive both services of both

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[1] *Note: Prior to 2017,* Community Inclusion services were called Community *Access* services in Washington.

types. In terms of eligibility, however, the two services are not independent. If an individual is under the age of 62, they must first participate in nine months of employment services before becoming eligible for Community Inclusion supports. Individuals receiving Community Inclusion services can return to Employment services at any time. Exemptions from the eligibility requirements can also be requested if:

1) The participant's medical or behavioral health records document a condition that prevents them from completing nine months of Supported Employment services;
2) The service was requested but not delivered within 90 days of the referral (WAC 388-845-0603).

Participants aged 62 years and older are not required to participate in Employment services to be eligible for Community Inclusion support. Eligibility for and determination of services provided are based on an individualized, person-centered assessment termed the Comprehensive Assessment Reporting Evaluation (CARE) tool (WA DSHS DDA Policy 4.11, 2013; See also Chapter 388-845 of Washington Administrative Codes: WAC 388-845-0603; WAC 388-845-0610; WAC 388-845-0610; WAC 388-845-2100).

The overarching goal of the State's employment services is to encourage adults with disabilities of working age to obtain *gainful employment* that includes or works toward a living wage (DDA Policy 4.11, 2013). Currently there are three primary types of employment services in the State: Individual Supported Employment, Group Supported Employment, and Pre-Vocational services. Individual Supported Employment services are provided to the individual to assist in obtaining and maintaining employment that earns the minimum wage or higher.

Group Supported Employment are services accessing supervised employment in integrated settings of eight persons or less. Pre-Vocational services are provided in non-integrated settings and are designed to train individuals for employment in integrated settings, but include little to no public interaction. These services are being phased out in Washington after 2019.

Phases of employment services. Once approved, employment services are categorized into four distinct phases for billing purposes. The following are categories and examples of services that might be provided for each phase:

- *Phase 1* services are categorized as *intake*, *discovery*, *assessment*, or *job prep*. Examples of services and activities in Phase 1 include: completing initial assessments and paperwork; identifying job interests, skills and goals; and, learning about hygiene and professional appearance, interview skills, and resume development.
- *Phase 2* services are categorized as *marketing/job development.* Examples of Phase 2 services include networking, educating employer, and activities that work with the employer to develop accommodations and supports.
- *Phase 3* services and supports are categorized as *Job Coaching/Job Support* or *Retention/Follow Along.* Examples of services include transportation coordination; orientation; on-site instruction to individual, coworkers and supervisors; development of natural employment supports; periodic on-site visits.
- *Phase 4* services are categorized as *record keeping*. This phase includes services such as notes, progress reports, records management, and reporting.

Community Inclusion Services

Community Inclusion services in Washington state were originally only for individuals of retirement age (62 or older), but the service eligibility requirements were modified following two legislative work groups conducted in 2011 on Employment and Community Inclusion services (Dean & Associates, 2011; Washington State Department of Social and Health Services, 2011; State of Washington, 2012). The amount of support (service hours) is determined by an individualized assessment through the DDA using a support intensity scale (SIS; WAC 388-828-9310, 2018). Services provided are based on an individualized person-centered planning process and according to the State of Washington Administrative Code:

1) Are provided in typical, integrated community settings:
2) Are individualized services that promote skill development, independent living, and community integration for individual learning how to actively and independently engage in their community; and
3) Provide opportunities for individual to develop relationships and increase independence.

The DSHS DDA's *Community Inclusion Frequently Asked Questions* (2018) document indicates that Community Inclusion services do not include "specialized and/or segregated activities with only individuals with disabilities, isolating activities with no opportunities to develop relationships with community members who are not paid staff, or activities that don't occur in your local community."

Billable activities categories for Community Inclusion services include: *Intake; Discovery; Community Participation and Coordination;* and, *Other Support Hours*. Examples of *Intake* activities include meeting with the individual, family, support persons and completing initial history and paperwork. Activities included in the *Discovery* category include "identifying people and places within the local community where an individual's interest, culture, talent, and gifts can be contributed and shared with others with similar interests," developing goals and timelines, and sampling various activities. Billable activities listed for *Community Participation, Skill Development* include the development of "supports to promote independence, personal growth and/or engagement" in socialization, education, recreation, and personal development. Billable activities included as *Other Support Hours* include record keeping activities such as taking and keeping notes, progress reports, and file maintenance.

Data collected in Washington related to Employment and Community Inclusion Outcomes

The State of Washington currently collects data related to Employment and Community Inclusion through the CARE assessment tool and administrative billing data. A substantial amount of data is collected through use of the CARE tool. During the assessment process, the

CARE tool is used to collect information about the client including: demographics, diagnoses, strengths, and needs. The information gathered using the CARE tool is then used to develop an individualized care plan, determine services, and track client progress. Data collected through the billing system for Community Inclusion services include indicators such as: number of service units, provider staff hours, number of hours consumer spent on volunteer activity, and other activities. Employment data collected through the provider billing system include the number of client hours paid, number of client hours volunteering in non-segregated community activities designed to build skills and broaden awareness of job opportunities, and gross wages.

The State of Washington also collects the NCI-ACS on a biannual basis. As part of the program, the state conducts the NCI-ACS interviews with a sample of at least 400 individuals with disabilities. Multiple subdomains of the NQF framework are measured during this process including some items related to the employment subdomain and subdomains related to Community Inclusion services (i.e. Meaningful Activity and Social Connectedness). However, it may be difficult to specifically associate data from the NCI-ACS to Employment and Community Inclusion services because the NCI-ACS is designed to be used as a comprehensive instrument rather than as a tool for measuring Employment and Community Inclusion services separately. In addition, because the sampling only includes 400 individuals on a biannual basis, and the items are not specifically designed for Washington's programs; it may not provide sufficient data to understand the outcomes of the Employment and Community Inclusion services.

VI. Comparison of the State of Washington to Other States (Activity 1D)

As part of this project, ICI staff conducted a series comparisons between the approaches the State of Washington and a number of other states have taken in their efforts move toward compliance with the HCBS settings rule (Centers for Medicare & Medicaid Services - CMS, HHS, 2014) with a specific focus on employment, community inclusion, and the measurement of outcomes associated with programs in these areas. Based on the recommendations of Mary Lou Bourne, Director of National Core Indicators and Quality Assurance at NASDDDS, discussions with JLARC staff, and the availability of state level information with respect to programming, expenditures, and measurement in these areas, the States of Oregon, Maryland, Maine, Indiana, and Oklahoma were initially selected for comparison. When it became apparent that some types of data were not available for several of these states, California and Virginia were added to the comparison group.

Table 4 (see below) provides information with respect to the primary outcome measures used for state level analyses in each state, the employment and community inclusion programs available, expenditures, person-centered benefits, and recent (within the past 5-years) initiative that states have taken in the two primary areas of interest. More specific comparisons between states including information related to percentages of persons with IDD within each state who take part in community-based work and non-work programs can be found in the section below.

Employment Comparisons

Information with respect to the employment of persons with disabilities (see Table 5) is drawn from the *State Data Bluebook* (2016), a comprehensive summary of state level data on employment and employment services in the United States (Winsor, et al., 2017). Data related to the: *Percentage of day and employment funding that support integrated employment services* and *percentage of persons receiving day and/or employment services served in integrated settings* were drawn from the American Community Survey (ACS) a project of the U.S. Census Bureau which include adults with disabilities in and out of service systems aged 18-64. The source for

Table 4: State Grid: Comparison of Washington State to Other States (Activity 1D)

State	Outcome Measures	Services (CI, E)	$ Spent/Person/State Resident and Per Service User*	Person-Centered Benefits	Recent Initiatives (within last 5 years)
Washington	• *NCI-ACS* • Provider Billing & Adm. indicators collected through CARE tool	**A. Employment** 1) *Individual Supported &* 2) *Group Supported Employment* **B. Community Inclusion** 1) *Community Inclusion* -Provided in integrated settings in the community -Can only access one service at a time (community inclusion or employment)	$51 per resident $35,048 per user	-CARE tool incorporates a person-centered service and support planning process -Some parts of NCI measurement process are person-centered	- Pre-Vocational services (services delivered in non-integrated settings) being phased out - Executive Order and Task force to increase the number of people with disabilities in the state workforce
Oregon	• *NCI-ACS* • *Oregon Individual Experience Survey*	**A. Employment:** 1) *Individual Supported Employment* - Job development & coaching to achieve integrated, competitive employment **B. Community Inclusion** - Focus on employment but can also access supports for community inclusion - Support services through community brokerage to access community	$17 per resident $5,676 per user	- PC Services and Supports Planning - Some parts of NCI measurement are person-centered	- Recent drive to reduce/eliminate sheltered workshops and increase competitive integrated employment

State	Outcome Measures	Services (CI, E)	Spent/Person/State Resident and Per Service User*	Person-Centered Benefits	Recent Initiatives (within last 5 years)
Maryland	• *NCI-ACS* • *CAHPS HCBS EOC* • *Community Settings Ques. (CSQ)* - Minimal measurement of Empl. & Comm. Inclusion - Not person centered	**A. Employment** 1) *Employment Discovery & Customization* -Assist in finding competitive, integrated employment - Time limited to 6 months 2) *Supported Employment & Group Employment* **B. Community Inclusion** 1) *Community Learning Serv.* -Must be in community - Groups of 4 or less w/ DD -Designed to help develop employment skills 2) *Community Pathways Waiver-* PC plan can include a mix of supports including Supported Employment and Community Learning	$145 per resident $51,546 per user	- PC Services and Supports Planning - Some parts of NCI measurement are person-centered	- Legislation phasing out subminimum wage employment
Indiana	• *NCI*; • *Individual Exper. Survey* 2015 • Annual report completed by Indiana Institute on Disability and Community	**A. Employment** *1) Individual Integrated Employment Serv.* *2) Pre-Vocational* *3) Group Employment* **B. Community Inclusion:** 1) *Community Habilitation* - Individual & group activities 2) *Community Inclusion/access supports*	$80 per resident $31,282 per user	- PC Services and Supports Planning - Some parts of NCI measurement are person-centered	- *2017-2018 Person Centered Approach: LifeCourse* plan. tool. - 2017 Task Force to assess. Services & supports avail. to people w/IDD - 2016-2017 Model emphasizing increased supported employment opportunities

State	Outcome Measures	Services (CI, E)	Spent/Person/State Resident and Per Service User*	Person-Centered Benefits	Recent Initiatives (within last 5 years)
Maine	• *NCI*	**A. Employment** 1) *Supported Employment* *Group Work Supports* -Sub-minimum wage -Community Inclusion listed as employment service as volunteering **B. Community Inclusion** *1) Day Services* - Structured 2) *Community Supports* -(center-based)- assist in developing natural supports	$253 per resident $70,171 per user	- PC Services and Supports Planning - Some parts of NCI measurement are person-centered	
Oklahoma	*NCI;* *Oklahoma Advocates Involved in Monitoring (OK- AIM)* - Quality monitoring by vol. & advocates -Limited measurement of community inclusion and employment -2015 annual report	**A. Employment** *1) Supported Employment* -Integrated employment setting includes: job development; assessment; job coaching; & supportive assistance *2) Prevocational Services* - Center- & Community Based Services **B. Community Inclusion** -No formal community inclusion service found -supports available for community inclusion/access	$79 per resident $59,508 per user	-PC Services and Supports Planning -Some parts of NCI measurement are person-centered	

*Based on expenditure per state resident for all HCBS funded services only. From Larson, Eschenbacher, Anderson, Taylor, Pettingell, Hewitt, Sowers, & Bourne (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Minneapolis: University of Minnesota, RTC on Community Living, Institute on Community Integration.

the last five columns in Table 5 is the *IDD Agency National Survey of Day and Employment Services*. This survey is completed by state agency directors and/or staff. Staff from the State Data Bluebook follow-up with agencies when there are unexpected increases or decreases in any of the information reported. Data from this source only includes those persons receiving day and employment services from a state developmental disability agency. Though exact ages are not provided, it can be assumed in most states these services begin at approximately age 18, with others beginning services later, and continue into later adulthood.

The following information for Washington and each of the comparison states are displayed in Table 5:

- *Percentage of day and employment* ***funding that support integrated employment*** *services*- The percent of total funding for day and employment programs a state spends that support integrated employment (placement, on-the-job service, job coaching, etc.).
- *Percentage of persons receiving day and/or employment services* ***served in integrated settings***-The percent of individuals receiving services who work in integrated, community settings.

Table 5. State comparisons of employment/day settings and employment funding

	Employed without disability	Employed with cognitive disability*	Funding for integrated employment services**	Integrated work setting***	Facility-based non-work***	Community-based non-work***	Facility-based work***
California	71%	22%	9%	12%	0%	75%	12%
Indiana	75%	25%	4%	12%	48%	74%	34%
Maryland	77%	31%	33%	37%	61%	0%	0%
Maine	79%	17%	7%	32%	0%	NA	0%
Oklahoma	73%	22%	51%	60%	0%	28%	56%
Oregon	74%	29%	20%	32%	36%	33%	29%
Virginia	76%	26%	17%	27%	63%	6%	5%
Washington	80%	31%	88%	85%	<1%	14%	4%
U.S. Total	68%	25%	11%	19%	37%	31%	17%

Note. Percentages for each state's categories of employment/day settings can exceed 100% as state can place individuals in multiple categories. Some data was filled in from previous year when unavailable for 2015. *Includes individuals with and without disability related employment services. **Out of all day and employment funding, NOT all DD services. ***Percentages based on those receiving day/employment services only.

- *Percentage of persons receiving day and/or employment services* ***served in facility based non-work***- Facility-based non-work includes all services that are administered in a setting where the majority of participants have a disability and does not involve paid employment of the participant.
- *Percentage of persons receiving day and/or employment services* ***served in community-based non-work***- Community-based non-work includes all services focused on allowing individuals with disabilities access to the community setting where most people do not have disabilities and does not involve paid employment of the participant.
- *Percentage of person receiving day and/or employment services* ***served in facility-based work***-Facility-based work includes all services that are administered in a setting where the majority of the participants have a disability and involves paid work (e.g. sheltered workshops, work activity center, or extended employment programs.)

Since this data does not consider number of hours served, it is important to take caution in comparing the numbers. For example, some states may have more people work less than 8 hours a week than others, an important consideration when considering true integrated, community employment. However, there is a trend between the degree to which a state funds integrated employment over other day programs and the percentage of people on such funding actually employed in integrated settings. Based on American Community Survey data on the entire population, this trend may extend to the general population (those not in the state DD service system) via higher expectations and cultural shifts in attitude towards those with disabilities.

Service Mix Comparisons

A second set of between state comparisons focused on the percentage of people within each state who receive *both* employment and day services, or *both* employment and relationship/social services. This information is drawn from state reporting on the National Core Indicators-Adult Consumer Survey (NCI-ACS), from 2014-15 (CA & MD), 2015-16 (WA) and 2016-17 (IN, ME, OK, OR, VA, & US average) data sets in order to include all of the states selected for comparison. A section of the NCI background survey, often completed by case managers, asks “Which services and supports funding by the state (or county) agency does this person receive?” with a list of options.

The percentages below are based on affirmative (yes) responses to the following three type of services (as described to those completing the survey by the NCI):

- Assistance finding, maintaining, or changing jobs;
- Day services other than employment (e.g. day program or workshop); and
- Help with relationship issues, meeting people (helping finding friends or organizations to be a part of)

The degree to which persons with IDD who received employment services also received either of the other two types of services was compared. As can be seen in Table 6, there are large differences between the degree to which states fund employment and alternative services. Note the "relationship/social" service category may vary from state-to-state in implementation and interpretation by those completing the NCI survey. Based on the U.S. total, there appears to be some flexibility nationwide with respect to receiving services that cut across these categories, with some states exceeding that average and some well below.

Table 6. Mixture between employment and other day services

State	Receive both employment and day (not employment-related) services	Receive both employment and relationship/social inclusion services
California	NA	9%
Indiana	8%	8%
Maryland	NA	NA
Maine	28%	27%
Oklahoma	2%	47%
Oregon	NA	NA
Virginia	11%	13%
Washington	1%	3%
U.S. Total	21%	22%

Note. NA= not available

Relationship between Services and Employment and Community Inclusion Nationwide

To develop a stronger sense of how funding categories relate to both employment and community inclusion, NCI data was analyzed in a more systematic manner. The following analysis is designed to answer the question:

- What is the relationship between different categories of service and employment and community inclusion?

In order to answer this question, two regression models were tested, one for employment and the other for community inclusion. Data came from 36 states, including Washington, from the 2015-16 NCI-ACS survey on 11,894 individuals. Variables were entered in two steps with important control variables, such as mobility, entered first and service categories entered last. This process allowed us to *control for* important differences between states in their service populations and better understand the impact of service categories.

Integrated, community-based employment was the outcome of interest assessed in the first model. Results of this analysis are shown in Table 7. Severity of the intellectual disability, mental health diagnosis, behavioral needs of participants were all associated with less employment, a consistent finding in the literature. Regarding services, employment services had the strongest association with integrated employment: those receiving employment services were estimated to be 6 times more likely to have integrated employment than those who do not. Day, education/training, and transportation services were all associated with less integrated employment.

Table 7. Logistic Regression Model Predicting Integrated Employment

	B	S.E.	Wald	df	Sig.	Odds Ratio
ID Level	**- .810**	**.057**	**202.30**	**1**	**.000**	**.445**
Mobility	**1.29**	**.135**	**91.26**	**1**	**.000**	**3.63**
Vision or Hearing Impairment	-.024	.096	.063	1	.802	.976
Mental Health Diagnosis	**-.393**	**.068**	**33.05**	**1**	**.000**	**.675**
Behavior Needs	**-.433**	**.080**	**29.33**	**1**	**.000**	**.649**
Autism Diagnosis	.125	.094	1.76	1	.184	1.13
Verbal Expression	**.942**	**.159**	**35.16**	**1**	**.000**	**2.56**
Gender (F)	**-.211**	**.065**	**10.73**	**1**	**.001**	**.809**
Employment Services Received	**1.86**	**.071**	**697.03**	**1**	**.000**	**6.45**
Day Services Received	**-.389**	**.065**	**35.47**	**1**	**.000**	**.678**
Education/Training Services Received	**-.663**	**.070**	**90.38**	**1**	**.000**	**.515**
Transportation Services Received	**-.491**	**.070**	**48.90**	**1**	**.000**	**.612**
Constant	-2.36	.227	108.99	1	.000	.094

Note. Bolded variable significant. Estimated impact of all variables included on community inclusion (*R-squared)* was 17-32% with services categories estimated as explaining 6-12% of employment differences.

Community Inclusion

In our analysis focused on community inclusion, codes were created that assigned each participant either a 0 or a 1 depending on whether they engaged in shopping, errands, entertainment, and eating “0” or “1 or more times” during the past month. This process yielded a reliability across those four types of community inclusion, of .632 based on Cronbach’s alpha, a questionable result, but with potential to gain insight into relationships. The four community choice items were averaged to create a scale ranging from 0 (on average 0 community inclusion trips per month across categories) to 1 (on average 1 or more community inclusion trips per month across categories). For example, a person could have a score of .5 on this scale, indicating that they engaged in half of the activities assessed at least once a month. This variable was used as the outcome for community inclusion, utilizing the same approach employed to assess employment. The only difference between the two analyses is that the focus was Social/Relationship rather than Education/Training services Results of this analysis are shown in Table 8.

Table 8. Linear regression model predicting community inclusion

	Standardized Coefficients	t	Sig.
(Constant)		26.712	.000
ID Level	**-.063**	**-5.717**	**.000**
Mobility	**.126**	**12.903**	**.000**
Vision or Hearing Impairment	**.026**	**2.818**	**.005**
Mental Health Diagnosis	**.023**	**2.277**	**.023**
Behavior Needs	-.012	-1.157	.247
Autism Diagnosis	**.047**	**4.899**	**.000**
Verbal Expression	**.035**	**3.181**	**.001**
Gender (F)	**.022**	**2.361**	**.018**
Employment Services Received	.010	1.077	.281
Day Services Received	**-.032**	**-3.341**	**.001**
Social/Relationship Services Received	**.062**	**6.270**	**.000**
Transportation Services Received	-.016	-1.605	.109

Note. Bolded variable significant. Estimated impact of all variables included on community inclusion (*R-squared)* was 4% with services categories estimated at less than 1% of community inclusion differences. This model cannot calculate odds ratios like the previous model since the outcome is a scale.

As one might expect, higher levels of intellectual disability/intensity of support needs were significantly associated with *less* community inclusion, while mobility, vision/hearing impairments, mental health diagnoses, autism diagnoses, verbal expression, and gender (females) were all associated with higher level of community inclusion. Social/relationship services demonstrated the strongest association with community inclusion, suggesting those with such services were more likely to be included in the community. Day services on the other hand were associated with less community inclusion.

Readers are cautioned against over-interpretation of the community inclusion model due to some issues with reliably using these four items to measure community inclusion. Further, the NCI-ACS does not ask if the person is satisfied with their level of community inclusion and may be missing other indicators of inclusion important to persons with IDD.

Overall, the employment related services persons with IDD receive explain more positive outcomes related to employment than social/relationship services account for positive outcomes related to community inclusion. The most interesting finding across both analysis is that receiving day services appears to be related to less employment and less community inclusion, at least as measured by the NCI.

VII. Measure Recommendations for the State of Washington (Activity 2a)

Person-Centered Measures of Employment & Community Inclusion Services & Outcomes (Activity 1e)

On the basis of ongoing conversations with representatives from the State of Washington’s JLARC over the course of this project, RTC/OM staff developed a set of specifications or requirements, based upon the information available, for measures that would meet the current needs of the State. Measures will need to:

(1) Provide information with respect to the personal *employment* and *community inclusion* outcomes experienced by individuals with disabilities currently served by State of Washington Employment and Community Inclusion programs;
(2) Allow users to measure *additional outcomes* (e.g., self-determination/choice & control; social connectedness and reciprocity; freedom from abuse & neglect) that are likely to be associated with the quality and stability of as well as satisfaction with employment and community inclusion;
(3) Support evaluation of the impact of program participation beyond the HCBS recipient to understand its effects on family members, employers, support providers, and the state/society/community as a whole;
(4) Track the extent to which personal outcomes are associated with expenditures in each of the two target programs;
(5) Be person-centered or based upon the preferences, likes and dislikes of persons with intellectual disabilities who participate in the targeted programs;
(6) Extend beyond the evaluation of personal outcomes to include assessment of the quality and equity with which supports and services in the targeted areas are provided across the state;
(7) Possess sufficient sensitivity to change to allow for evaluation of the impact of state and federal policy and programmatic changes on personal outcomes;
(8) Allow for the collection, analysis, and interpretation of data using both a cross-sectional and longitudinal format through which a select group of program users can be followed over a significant length of time;
(9) Be based on the principles of Universal Design for Assessment (UDA) such that measures can be used with persons with emerging communication skills and cognitive challenges;
(10) Possess the flexibility to be used in either a formative/progress monitoring or summative fashion;
(11) Have utility and the ability to be used in data-driven decision making (DDDM) at state, regional, provider, and individual levels to make policy and programmatic decisions;
(12) Be feasible to implement, minimizing costs and burden to informants; and
(13) Possess the capability to be utilized to measure those outcomes and services that are prioritized and associated with the articulated values of the State of Washington.

In developing the recommendations provided in this section of the report, the project team conducted an extensive search for assessments of employment and community inclusion outcome measures for people with IDD using the UMN *RTC/OM HCBS Measurement Outcome Relational Data-base* (https://rtcom.umn.edu/node/181#HCBS-Instrument-Database). The data-base includes 197 outcome measurement tools with each item for each instrument coded for a number of critical characteristics, including person-centeredness, respondent (e.g. person with a disability, family member, etc.), response options, data collection mode and administration, and NQF domain and subdomain (e.g. community inclusion-meaningful activity). In addition, the psychometric properties (e.g., reliability & validity, etc.) of measures and instruments were coded (when available) as well as the contexts and populations with which the measures are used.

Measure Selection Criteria

Instruments with person-centered items measuring employment and community inclusion outcomes were selected from the RTC/OM database for this report. The concept of community inclusion is broad and includes a variety of potential concepts; after a review of the Community Inclusion services for the State of Washington, we determined that *meaningful activity* and *social connectedness* subdomains of the NQF framework most closely matched the community inclusion services provided by the State. The operational definition of meaningful activity used for the NQF HCBS Outcome Measurement Framework is as follows: “The level to which individuals who use HCBS engage in desired activities (e.g., employment, education, volunteering) (NQF 2016, p. 21).” The NQF definition of *social connectedness* is: “The level to which individuals who use HCBS develop and maintain relationships with others” (NQF, 2016, p. 21). Using the RTC/OM database, an initial list of 16 HCBS instruments with person-centered items related to employment, meaningful activity, or social connectedness was extracted. Next, the characteristics of the selected instruments were evaluated for whether they were relevant and appropriate for the State of Washington. Instruments were excluded when they were designed to measure outcomes within the home or residential setting instead of community (i.e. PELI-NH-nursing home setting), and instruments with a very narrow scope (i.e., UCLA LS-loneliness). A list of the remaining instruments and the number of person-centered items in each of the three chosen subdomains (Employment, Meaningful

Activity, and Social Connectedness) can be found in Table 9. The selected instruments have been developed for use with several different populations, including people with IDD.

Table 9. Instruments Selected from the RTC/OM Database by Person-Centeredness and Subdomain

			Person-Centered (PC) Items in Subdomain				
Instrument	**Total Items**	**Total Items in Subdomains**	**Total PC in Subdomains**	**% PC in Subdomain**	**Employment PC**	**Meaningful Activity PC**	**Social Connectedness PC**
CAN	81	14	14	17%	1	6	8
CPI	39	23	22	56%	2	10	12
CQL POM	723	131	25	3%	2	7	17
NCI-ACS	190	59	10	5%	5	3	5
PEONIES	149	37	19	13%	4	7	9
PES-HCBS	117	17	11	9%	8	2	2
PROMIS-SPDSA	12	12	12	100%	0	6	6
PROMIS-SSRA	44	37	37	84%	4	33	13
QOLS	16	10	10	63%	0	6	4
TUCPM	78	78	52	67%	2	52	0

Note: Some items were coded into more than one subdomain; therefore, the total number of person-centered items is sometimes different than the total of all three individual subdomains.

The following are brief descriptions of the remaining instruments including the target population and general measurement approach:

- *Camberwell Assessment of Need revised (CAN)* - The CAN was designed to assess the needs of people with mental health conditions. Of the 81 total items, six items measure meaningful activity, eight items measure social connectedness, and one item measures employment. The general purpose of the instrument is to determine if there are unmet needs and, if so, whether the person wants more support (Slade et al., 1999).

- *Community Participation Indicators (CPI)* - The CPI was designed to measure the level of participation in the community for people with mental health needs. The respondent is asked how frequently they engage in a variety of activities, whether each activity is important to them, and if they participate in the activity "enough" (Heinemann, 2010).

- *The Council on Quality and Leadership Personal Outcome Measures (CQL POM)* - The CQL POM is a large and comprehensive instrument (723 total items) designed for people with age-related, mental health, and intellectual or developmental disabilities. Although some of the items are relevant to community inclusion and employment, the instrument is designed to be administered as a whole instrument including all scales. Thus, this instrument would not be feasible for measuring community inclusion and employment outcomes in the State of Washington (CQL, 2017).

- *National Core Indicators Adult Community Survey (NCI-ACS)* – The NCI-ACS was developed for the purpose of measuring quality assurance at the *state* level (Bradley & Moseley, 2007) and used to collect data on service users with IDD and has three sections. The *Background Information Section* includes questions related to personal demographics, disability diagnoses, health, mobility, communication, residence type and size, employment, and behavioral supports. *Section I* includes questions on employment/daily activity, home, friends and family, safety, and satisfaction with supports/services. *Section II* includes items related to community inclusion, choices, rights, and access to needed services. These items can be answered by the individual or a proxy with the source of information (e.g., self or proxy) is recorded individually for each item.

- *Personal Experience Outcomes Integrated Interview and Evaluation System (PEONIES)-* The PEONIES was designed for adults with physical, developmental or age-related disabilities. The items address the personal outcomes experienced and whether services and supports related to these areas are sufficient (Karon & Schlaak, 2012).

- *Participant Experience Survey Home and Community-Based Services (PES-HCBS)* - The PES-HCBS was designed for individuals receiving HCBS. The person-centered items included in the survey primarily measure how much choice and control the individual has over employment, meaningful activity, and social connectedness (CMCSC, 2012).

- *PROMIS Satisfaction with Participation in Discretionary Social Activities (SPDSA)* and *Satisfaction with Social Roles and Activities (SSRA)* - Both PROMIS surveys were designed for the general population and people with chronic conditions. The items are designed to measure global, physical and mental health and specifically ask the respondent to rate the level of satisfaction they have with their ability to do a variety of activities (PROMIS, 2018).

- *Quality of Life Questionnaire (QOL)* - The QOL was designed for individuals with intellectual disability. The questionnaire includes items measuring the general quality of life the respondent reports and their satisfaction and general satisfaction with some activities including employment (Schalock & Keith 1993).

- *Temple University Community Participation Measure (TUCPM)* - The TUCPM was primarily designed to be used with people with mental health conditions. The measure lists several activities and assesses whether the activity is important to the respondent and if they participated in the activity enough over the previous 30 days (Salzer, & Burns-Lynch, 2016).

Additional Measures for Consideration

The University of Minnesota's RTC/OM on HCBS Outcome Measurement has developed and is currently in the process of evaluating the psychometric properties of a number of measures that, once validated, would appear to be a good fit for the needs of the State of Washington. These measures focus on *Employment*; and two critical aspects of Community Inclusion – participation in *Meaningful Activities* and *Social Connectedness*. Each of these measures are person-centered and designed to be administered as part of a conversational interview with persons with IDD. Interviewers initiate the conversation through asking a series of standardized probe questions designed to provide the respondent with an opportunity to initiate a conversation about that area of his/her life. Based upon the information elicited interviewers complete measure protocol indicating the individual's perspectives and experiences on each of the items. Following a response to each item/area included in the measure, interviewers socially validate the person answer to confirm their response.

Community Inclusion – Social Connectedness: Social connectedness is one of three subdomains (social connectedness, meaningful activity, and resources/settings to facilitate inclusion) of the NQF domain of *Community Inclusion*. It is operationally defined as: the degree to which individuals who are HCBS recipients experience a sense of belonging in their community and have the supports needed to develop and maintain friendships and other forms of social relationships with others. As conceptualized in the literature, social connectedness has six components all of which are assessed with this measure: belongingness; reciprocity, social-emotional support; instrumental support; informational support, and companionship Social connectedness is important to measure in relation to HCBS outcomes as social isolation and loneliness are common results of poorly managed support and care systems for individuals with disabilities. Further, having a socially connected life, with community-based experiences is one of the goals of the move towards deinstitutionalization for persons with IDD.

The RTC/OM *Social Connectedness* measure was developed to assist users in better understanding the extent to which persons with disabilities experience a sense of social-emotional connectedness in their community and have the supports needed to develop and maintain these connections. The measure is composed of 15-items that persons respond to a series of statements on the basis of a 4-point Likert type scale ranging from strongly disagree to strongly agree. Items focus on a number of aspects of social connectedness. One set of items centers on the extent to which individuals' feel a part of their community and a welcomed by others. A second series of questions focus on the degree to which individuals have the opportunities they desire to spend time with friends, family and other members of their social network. A third aspect centers on the extent to which individuals feel they have valued social roles in the community and both receive and are able to provide to others a variety of types of social support (social-emotional; instrumental; informational; & companionship).

Community Inclusion – Meaningful Activity. This measure is designed to assess the extent to which persons with disabilities who receive Home and Community Based Services (HCBS) engage in desired meaningful activities. Meaningful activities include those events, behaviors and actions that are important, enjoyable, and/or perceived valuable to the individual. The activities themselves can be instrumental or functional (e.g., shopping), social and/or cultural (e.g., attending a club or group meeting), and recreational/leisure focused with activities in this area differentiated on the basis of their level of physical demand.

The purpose of the measure is to solicit information from HCBS recipients with respect to the following aspects of the activities in which they engage:

- How important/valued is each type of activity
- To what degree do people get to engage in each type of activity
- How enjoyable/satisfied are they in participating in each type of activity
- To what extent do they receive support to engage in preferred activities and explore new ones
- To what extent the level of support provided by HCBS encourages the participants to be as independent as they can be

The measure is structured according to these guiding questions. It currently consists of 25 items, five per each aspect of meaningful activity.

Employment: the *RTC/OM Employment measure* under development is designed to capture the degree to which HCBS recipients have access to employment opportunities in line with their needs, choices, and goals, and the supports necessary to maintain the desired level of employment. There are two primary measures that focus on Job Experiences and Barriers to Employment.

The *Job Experiences* measure is composed of a series of 15- items designed to capture information about the quality of employment services, employment experiences, and job satisfaction. An example of an item related to HCBS quality is “The employment services you are receiving right now help you stay employed.” An item related to job satisfaction is “You work the number of hours you want to work.” Most of the questions in this measure are scored on a 4-point, strongly disagree to strongly agree scale with both a not applicable and don’t know option. The *Barriers to Employment* measure is initiated through gaining information as to whether an individual desires paid employment, has looked for work in the past, and/or gave up looking. These questions have simple yes/no response options. The remainder of this section asks about the quality of current employment supports (if applicable) and barriers to employment. An example of a question related to barriers is “You have the training you need to find a paid job.” All of these response options for these items are scored on a 4-point strongly disagree to strongly agree scale with both a not applicable and don’t know option.

The above instrument descriptions demonstrate the wide-range of possible ways to measure employment or community inclusion. It also underscores the challenge of choosing from existing instruments and measures a tool that perfectly matches the needs of the State of Washington.

Desired Life Outcomes Assessment Tool (DLAST). The Desired Life Outcomes Assessment Tool (DLAST) is designed to provide a measure/assessment of the extent to which the most important personal goals of an individual with a disability covered by the NQF HCBS Outcome Measurement Framework: (1) Are currently being pursued by the person; (2) the progress that is being made toward the achievement of these goals (or if they have been achieved); (3) the adequacy of current services in supporting the individual to achieve or make progress toward these goals; and (4) when needed, the additional supports the individual believes they could use to support additional progress.

What is unique about the DLAST is that the individual who receives supports determines those areas most important to him or her and it is these areas of life as well as the degree to which outcomes in these areas have been realized that is assessed. The DLAST is designed to be used to measure progress towards any of the domains and subdomains included in the NQF framework though it could easy be restricted to those goals focused on employment and community inclusion.

The DLAST is designed for use at the provider and individual level in order to provide a more in-depth person-centered perspective picture of whether individuals who are the recipients of HCBS are:

1. Making progress toward or currently experiencing the life outcomes they desire; and
2. Being provided with services and supports within each identified area that has or is helping them achieve or move closer to their desired outcomes.

Because the DLAST incorporates the use of Goal Attainment Scaling (GAS) quality reviewers can use the tool to determine the relative success of provider organizations in helping individuals receiving supports achieve their desired outcomes. People supporting the individual can potentially use the tool to help them identify what is most important to the person and work with providers to ensure that support plans are person-centered and focus on helping each person achieve their desired life outcomes.

Quality reviewers can use the DLAST to assess several things. First, when results are compared to person-centered or individualized service plans the tool provides important information about whether case managers have identified the Desired Life Outcomes most important to the target HCBS recipient. Once a Desired Life Outcome is identified, it is possible to explore whether services and supports are in place to achieve the outcome and if these supports are adequate and acceptable to the individual who receives supports. If a personal outcome is identified through the DLAST with the recipient of services and it is determined that the necessary supports are not in place to achieve the goal, a quality reviewer can explore the reasons for this situation. The degree to which goals in specific outcome areas have been achieved by persons served by case managers in a particular organization as well as the areas where there are common or persistent difficulties in achieving goals will help both the quality reviewers and the care management organizations to identify barriers that need to be addressed. It may be that a particular type of service is not available or that the care managers lack information or skill in an area. The DLAST tool will be useful in making this determination.

The DLAST is administered as a conversational interview with quality reviewers initially focusing on identifying the desired life outcomes of the HCBS recipient, their goals, wishes, and dreams. A *Summary Worksheet* provides a convenient way to note the person's desired life outcomes in the personal outcome areas of focus. Reviewers query the respondent about life outcomes (including changes in life) that they are either currently attempting to achieve or desire to work on in the immediate future listening for any progress or successes that have been achieved and barriers persons have encountered. After confirming that the individual's desired life outcomes have been identified, the next step is to determine the extent to which these outcomes are currently being achieved. Once HCBS recipients provide information that allows for a determination of the extent to which they believe their personal goals have been achieved or progress toward them made, the reviewer confirms that they accurately understand the recipient's appraisal and rates each outcome using a 5-point goal attainment scale (-2; -1, 0; +1; +2). After determination of the extent to which desired personal outcomes have been achieved or are goals toward which an individual is currently working, the focus of the interview shifts to a discussion of the types of supports and services the recipient of HCBS receives and those he/she believes would be helpful to support experiencing desired outcomes. Once an understanding of the adequacy of supports and services has been attained, the reviewer completes a set of goal attainment ratings, similar to those described above, for each set of supports within each outcome area under analysis using the 5-point scale.

Factors to Consider in Undertaking Measurement

Each of the instruments and measures reviewed in this section has strengths and characteristics that in specific situations would recommend its use. Some (e.g., *NCI-ACS*) are widely used including in the State of Washington and could potentially be utilized, with due caution, in comparisons of services and outcomes in Washington and other states. Others (e.g., the *CQL-POM, RTC/OM HCBS Outcome Measures,* and DLAST) provide more detailed information about the domains of interest (Employment & Community Inclusion) and can be used at the regional and provider level. The latter two measures are also suitable for use as part of a data-driven decision-making processes.

All instruments reviewed in this report, however, have significant limitations with respect to possessing unknown psychometric properties (reliability, validity, sensitivity to change), low feasibility if the intent is to use them on a large-scale basis, or difficulty administering them effectively with segments of the IDD population. At the current time, decisions made solely on the basis of *one* of these instruments would be ill-advised. The NCI-ACS, for example, though widely used, lacks published studies with respect to the reliability and validity of its "scales" or groupings of items, and includes many questions that are not person-centered. In addition, it was not developed to be used longitudinally or at levels below the state. Administration of the CQL-POM can only be undertaken by highly trained interviewers who must complete a very rigorous and expensive training and mentoring process. In addition, administration of the interview, review of records and observational aspects of the tool make it extremely time consuming to complete at anything above a provider level. It should also be noted that many of the best instruments identified may have been developed for purposes and populations other than those which are of primary interest to the State of Washington.

Given the current state of measurement in the HCBS field, as well as the complex constructs targeted for assessment (i.e., community inclusion and employment satisfaction) are much more difficult to measure than the number of times a person has fallen or been taken in to the community for shopping, it is essential for states, counties, and providers to have extremely well thought out measurement plans that include: (1) clearly outlined guiding questions of interest (i.e., what do we want to know and at what level – state, region/county, provider, individual); (2) use of multiple measures to assess the construct sufficiently (i.e., the use of different measures, including those that are person-centered, to ensure adequate understanding of outcomes associated with the same construct); (3) use of measures only for their intended purposes; (4) strict attention to interviewer training and measure administration fidelity; (5) development of a sampling frame that will allow one to answer the primary questions of interest; and (6) whether the data to be collected will be used in a summative fashion or as part of a data-driven decision-making process. In the section that follows, each of these “measurement process” issues is addressed.

VIII. Recommendations with Respect to a HCBS Measurement Process

The importance of guiding questions. The foundation of any analysis of HCBS service or outcome data is the specific question or set of questions one desires to answer. In the absence of a set of hypotheses to dispel confirm or questions one wants to answer, it is difficult to discern exactly what data/information, at what level, from what set of informants one needs to collect and analyze. Decisions in this area need to consider both the questions that are being asked and the sampling frame required to answer those questions. If the question at hand revolves around how the State of Washington compares to other states with respect to employment outcomes, a different sample is needed than a situation in which one desires to determine the equity with which employment supports and services are available to individuals with disabilities residing in urban, suburban and rural areas in the state. Understanding the question(s) one wants to answer also provides information with respect to who the best informants or persons to survey/interview might be. In the case of HCBS, understanding the personal outcomes support recipients experience requires persons with disabilities to be interviewed. If one, however, is interested in acquiring knowledge with respect to the impact of employment and community inclusion services on family members, parents and siblings would be a better choice. Knowing the question(s) one wants to answer is the first step to establishing an effective measurement system. The use of guiding questions will also assist in selecting the most appropriate indicators at a systems or personal levels with the right stakeholders in mind (persons with disabilities, family members, providers, etc.).

Use of multiple measures to assess the construct sufficiently. If one desires to understand the association that exists between specific employment support expenditures and employment outcomes at the state level, it is clear that information will need to be drawn from different data sources. In the State of Washington, this might mean accessing information from CARE and the most recent results of the NCI-ACS. If the goal, however, is to better understand the degree to which expenditures and employment supports in different regions of the state lead to HCBS recipients with intellectual disabilities not only acquiring positions within competitive employment settings, but also feeling satisfied with their current employment, being valued and respected by their fellow workers, and achieving this personal employment goals, additional information will need to be accessed. In this case, the information available through NCI-ACS will not adequately saturate those aspects of the employment construct one is attempting to better understand and additional information from measures including the CQL-POM, RTC/OM measures, and/or DLAST will be needed.

The critical point here is that, with the current state of HCBS measurement, no single measure is likely to provide all of the information necessary to fully understand the constructs and outcomes that are of interest. Depending on the specific questions being asked, multiple measures are going to be necessary. At least one of the data sources needs to provide person-centered information, (i.e. be sourced from people with disabilities or from the target population such as caregivers). This approach provides interested parties with both a more complete picture of the area of interest (i.e., community inclusion involves much more than the frequency with which one accesses the community over a 30-day period as it conceptualized by a number of widely used HCBS measurement tools), and reduces the risks of using instruments whose psychometric qualities have yet to adequately assessed with the population(s) of interest.

A difficulty many organizations desiring to measure HCBS outcomes encounter is that they wish to conduct analyses and desire to answer questions with data that has been collected with tools/instruments that have be developed with different purposes and functions in mind. One illustrative example is the attempted use of NCI-ACS data to: make comparisons between states; answer questions related to changes that occur over time (i.e., longitudinally) as a result of policy or programmatic changes; or compare the HCBS outcomes and experiences of an individual to a state "average." Staff from the Human Services Research Institute (HSRI) who developed and administer the NCI will be the first to inform users that the NCI-ACS was not developed, nor has it been validated to serve any of these purposes. Rather, it is meant to serve as a cross-sectional "snapshot" of the services and outcomes received and experienced by groups of representative HCBS recipients within a specific state at one point. Differences in the sampling frames, administrative methods (i.e., how interviews are conducted), and the training interviewers receive in different states are typically unknown introducing potentially serious confounding factors into analyses. Additionally, because its intended use is cross-sectional, HSRI staff have not conducted the necessary research to determine the extent to which their measures of HCBS outcomes and the quality of services are sensitive to change. A state attempting to use the NCI-ACS to measure changes in the lives of specific HCBS recipients as a result of the introduction of new programs runs the risks of concluding the program was ineffective when, in actuality, change did occur but the measure was not sufficiently sensitive to detect it.

Interviewer training and measure administration fidelity. A basic assumption within the HCBS measurement field is that if one is interested in better understanding the outcomes and experiences of persons with IDD, it is the individual with a disability him or herself who needs to provide the information. This presents challenges as the intensity of support needs of persons with IDD varies greatly. Some individuals with IDD possess only emerging expressive communication skills. Others may have a difficult time attending to the main focus of questions they are being asked and/or misunderstand the construct under consideration. Still others may provide answers to questions that are colored by an acquiescence response set or select only the most recent response options with which they are provided. If we are to include the perspectives of individuals with more than minimal intellectual disabilities in our HCBS evaluations, those persons who serve as interviewers/surveyors need to be highly trained and possess sufficient skills to engage in extended conversations with persons with a variety of support needs.

Training needs to include a wide variety of strategies based on Universal Design for Assessment (UDA) that provide interviewers with the skills to build rapport with and effectively engage respondents, ask questions in a person-centered but neutral manner, accurately reframe questions when needed in a way interviewees can understand, and probe for additional information (when necessary) in a sensitive, respectful manner. The fidelity of interview administration must be monitored on an ongoing basis such that all interviewers are using a similar process to collect the information that will serve as data to be analyzed.

All too often, interviewer training is limited to the initial instruction a data collector receives and little fidelity monitoring occurs. This is especially prevalent when interviews are conducted by large, national data collection organizations, the interviewers of which may not possess more than a limited knowledge of persons with IDD. Ongoing attention to “how” information is being collected by interviewers and frequent “training refreshers” ensures that information is collected in a reliable manner consistent with measure protocols as well as increases the likelihood that persons being interviewer will have a positive experience. This increases the likelihood that the respondent will consent to taking part in future data collection efforts.

Development of a sampling frame. It is often mistakenly thought that the more data that one collects, the better. However, the assumption that a large sample of individuals with disabilities (e.g., 1,000) is more representative than one of smaller size (e.g., 250) is a fallacy. At times, a much smaller sample, based upon a well-developed sampling frame can yield more accurate information than a large one. The size and composition of a sample needs to be sufficient to answer the question(s) of interest and is based upon a number of factors including: (1) the type of design and analyses one will be conducting; (2) the number of analyses; (3) how broadly and to what target populations one desires to generalize results; (4) the confidence one needs to have in the results generated (i.e., what is the likelihood the results obtained are due to actual effects/differences or due to chance/error).

For illustrative purposes one can think about the samples one would need to answer the following questions. The first case concerns a general question about the percentage of HCBS recipients with intellectual disabilities living in Washington receiving employment services who worked in integrated, community-based settings during 2017-2018. Based upon the question of interest, in this case one would want to develop a sample representative of all areas of the state of persons with IDD who had received a pre-determined minimal number of hours of employment supports of any type. If, however, one’s question focused on the extent to which a recent employment initiative in the state had, over the past 3-years, enhanced regional/county equity in the delivery of employment supports to eligible persons with IDD and improved a variety of employment outcomes for those who had varying levels of support needs, one’s sample would look quite different. As part of the process of developing samples to answer specific questions one must also consider that, in most states, recipients of supports are not required to take part in program evaluation, but do so on a voluntary basis or are compensated through payment of a minimal participation fee.

Data-driven decision-making. All too often state's collect large amounts of data from persons with disabilities, family members, case managers, and providers with respect to their HCBS experiences. In most cases, however, little is done with this data after it is collected other than to use it to support arguments for compliance with CMS regulations. We believe that this greatly diminishes the potential utility of the data and results in a system which, while striving for improvement, all to infrequently uses the data it has available to determine: (1) what resources are needed, (2) where they are needed, and (3) by whom they are needed in order to improve the quality of supports provided to persons with IDD and the personal outcomes they experience.

Recently, the CMS and ACL have emphasized the need for a shift from the use of data for compliance to its utilization to stimulate continuous improvement. There are good reasons for this shift as evidence exists that data-driven decision-making (DDDM) results in improvements in outcomes in education, healthcare, and business (Carlson, et al. 2011). As reviewed early in this report (see Figure 4 & pp. 27-31) DDDM refers to the systematic collection, analysis, and interpretation of data to inform practice. The key steps for transforming data for decision-making are outlined in Figure 4 and based upon a cyclical process through which data is transformed into information and knowledge (Mandinach et al., 2008; Williams & Hummelbrunner, 2011).

Data that can be utilized for a DDDM process in the State of Washington includes all technically adequate information that represents aspects of the State's Community Inclusion and Employment Programs for persons with IDD. This includes information from administrative data sets including the Comprehensive Assessment Reporting Evaluation Tool (CARE), Budget Auditing

Report System (BARS) as well as additional outcome information collected through NCI-ACS and other tools that the State decides to select in order to provide a more nuanced perspective on outcomes associated with HCBS recipient involvement in the programs of interest. Data collected through a longitudinally-focused HCBS outcome monitoring system and used formatively through a DDDM process would have the capacity to provide information not only with respect to the personal outcomes experienced by persons with ID and the benefits of programs, but be translated in to knowledge that can improve the functioning and outcomes of the system.

The end-goal of this recommendation is equipping stakeholders at the state, regional, and county levels with the tools needed to engage in high fidelity DDDM to improve outcomes based on the analysis and interpretation of high quality data (Weiss 1998; Rossi et al., 1999). It will require some investment both to ensure that all persons involved in such an effort acquire the *data-literacy* skills need to transforms data into actionable knowledge and decisions and to develop a *data system* that brings data from a variety of data sets together and allows for its presentation and analysis in a manner that it can be effectively used for DDDM purposes. A measurement system with the capacity to bring together high quality, person-centered data from various sources and that taps into a variety of levels of the system will allow for informed decisions to be made about policy, resource allocation, and programs that reflect both the State of Washington’s values and are in compliance with the recent HCBS Setting Rule (2014).

IX. Conclusion

There are many layers to determining the benefits/outcomes of community-based employment and community inclusion for people with disabilities. Given the need to respect the human and legal rights of individuals with disability and well as their dignity, it is critical that people with disabilities themselves are provided with targeted and systematic opportunities to express their views and experiences of their employment and community support needs and outcomes. Only after we understand what the people who are the recipients of supports are telling us about what is most important to them, can we start to examine benefits/outcomes for the other stakeholders and support systems, (e.g., caregivers, providers, etc.). The funding associated with the provision of services represents only the tip of the iceberg when evaluating the benefits and overall outcomes of community-based employment and community inclusion for people with ID. Apart from individual benefits for the person receiving HCBS (e.g., feeling socially included, purposeful and valued), benefits for others in employment and other community settings (e.g., feelings of reciprocity, enhanced opportunities for social relationships, increased opportunity to work and live in inclusive and accepting environments) need to be evaluated.

Quality of life for those with and without disability is not static, but rather, has the potential to change significantly over time. It is multifaceted and significantly more complex than frequency counts of the how often people with ID have been supported to access the community or the number of hours they work. We can no longer be satisfied with measurement systems that provide only a partial snapshot of how people with disabilities and other stakeholders experience employment and community inclusion at a single point. Additionally, given the resources used to obtain this information and the burden it creates for persons with disabilities and their families, we can no longer justify using it primarily to demonstrate compliance. The collection, analysis, interpretation, and reporting of data needs to be carefully planned and executed with the goal of continuous systems improvement and enhancement of the quality of life of people with disabilities.

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