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What Should Be Included in a Measure of Communicative Participation? Perspectives of Speech-language Pathologists

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**WHAT SHOULD BE INCLUDED IN A MEASURE OF COMMUNICATIVE PARTICIPATION?
PERSPECTIVES OF SPEECH-LANGUAGE PATHOLOGISTS**

by

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Partial Fulfillment of the
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ABSTRACT

WHAT SHOULD BE INCLUDED IN A MEASURE OF COMMUNICATIVE PARTICIPATION? PERSPECTIVES OF SPEECH-LANGUAGE PATHOLOGISTS

by Natalie Graceffa

The University of Wisconsin-Milwaukee, 2017
Under the Supervision of Professor Dr. Shelley Lund

As the field has developed, speech-language pathologists (SLP) need to prove, beyond clinical judgment, that their therapy is necessary and ethical. SLPs must prove they are achieving positive, client-appropriate outcomes with their treatment. To bring this validity to the treatment of health, the International Classification for Functioning, Disability, and Health (ICF) was created. The classification system described health as three different pieces: Body Function and Structure, Activities, and Participation. All three are vital to maintaining health. Participation can be seen as the end outcome, as it describes involvement in a situation or context. The ultimate goal of speech-language therapy is that an individual can participate appropriately in their environments. There are currently outcomes measures for Activity and Participation, but SLPs in the field have reported varying degrees of dissatisfaction with these measures.

To find out more about their dissatisfaction, the research team conducted online focus groups with 14 practicing speech-language pathologists in varying work settings. The transcripts were analyzed and coded with NVIVO software and themes were drawn out from the text. Overall, participants had primarily negative attitudes regarding outcomes measures. Participants also discussed the characteristics of their ideal functional communication outcomes measure and their needs in their current approach to assessment in their setting. Participants also discussed needs in the profession as a whole.

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LIST OF ABBREVIATIONS

AAC	Augmentative and Alternative Communication
ADL	Activities of Daily Living
ASHA	American Speech Language and Hearing Association
FIM	Functional Independence Measure
ICF	International Classification of Functioning and Disability
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
NOMS	National Outcomes Measurement System
SLP	Speech-Language Pathologist
TOPS	Test of Problem Solving
WAB	Western Aphasia Battery
WHO	World Health Organization

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CHAPTER 1

Introduction

The field of speech-language pathology has, over the past few decades, undergone a major shift in how it evaluates its work. We have begun asking questions in order to ensure that our work is valid and results-driven, including: what is the goal of speech, language, and swallowing interventions? To reduce the degree of impairment? To improve functioning? How do Speech Language Pathologists (SLPs) determine if treatment has been successful with their clients? What is the desired outcome of therapy? These questions reflect the development of, and focus around achievement of “outcomes.” Historically, the fields of healthcare and speech-language pathology have focused on measuring the reduction of underlying impairment, rather than evaluating patients’ communication skills in a broader context of functional health (Ma, Threats, & Worrall, 2008). In recent years, SLPs have shifted their attention to improving the communication skills of a person to navigate their everyday life, so this must also be a core aim of intervention (Schlosser, 2003).

History of Outcomes Research

When the field of speech-language pathology was in its infancy, it was frequently assumed that SLPs’ clinical experience was sufficient to justify decisions made in clinical intervention (Frattali, 1998). As the field has developed, providing evidence on which to base these decisions has become increasingly necessary to advance the field and add value to inform the professional judgment of SLPs. In an effort to document the value of SLPs’ services, the field directed its attention to efficacy research.

Efficacy research. Efficacy research is designed to prove that a treatment will produce a result that SLPs intended or predicted under optimal conditions (Frattali, 1998). This is an essential measure for testing specific experimental interventions. Researchers can control variables in the treatment of their participants in order to ensure valid testing of a result independent of all other conditions; therefore, determining causation rather than a correlation in treatment results. This type of research is informative but difficult to accomplish, especially in the populations that SLPs regularly treat. For example, to study a specific intervention with a school-age child, researchers must isolate the factor of development for a child that may work outside of a treatment to improve a child's results and may null the possibility that a treatment is responsible for a result. For this reason, we must maximize the usefulness of other types of research, explained below, when it's not possible to parse out the factors accountable for change.

Effectiveness research. In contrast, effectiveness research intends to determine which services and interventions are successful in affecting a defined variable to produce a predicted result, under typical conditions (Frattali, 1998). This research is intended to model naturalistic expectations for treatments that are not controlled in a lab, but instead in practice. The results of these types of studies are more generalizable to practicing SLPs, who can gain the most relevant information for their own clinical decisions from understanding how a treatment will affect a typical population, specifically a defined variable that they are attempting to change (Schlosser, 2003). The results of effectiveness research have the potential to give practicing professionals a clearer understanding of the extent to which a treatment will allow clients to reach desired goals and acquire skills. This type of research is especially helpful in comparing the effect of one intervention to another, which is necessary for clinical decision-making. However, there are limits to these findings. Effectiveness research is often comparative, and measures success based

on the change made to one defined variable. While this is needed in some scenarios, it does not mirror practical cases where a change affects multiple aspects of a subject's life.

Outcomes Research. Outcomes research is most closely related to effectiveness research in that it is performed under naturalistic conditions, as opposed to in a lab. This research is focused on assessing outcomes in multiple aspects of the patient's life, rather than one variable (Granlund & Blackstone, 1999). For example, rather than simply researching the accuracy of a child's productions of /r/ sounds, the research would evaluate how a child is communicating in relationships with same-age peers and teachers, involving multiple processes of communication in many situations. The goal of this research is not to prove direct causation between an intervention and an outcome by eliminating confounding variables. Instead, outcomes research is intended to simulate clinical practice where it is beneficial to know what interventions would most likely result in the best results for the individual receiving treatment. Outcomes, according to Carol Frattali (1998), are positive or negative changes in the health of groups of people or individuals for which credit can be given to prior or current health care. While the definition is not complex, the difficulty lies in the criteria by which to define "health," the intended outcome of the definition. As mentioned above, SLPs are looking for improvements in the communication skills (or swallowing proficiency) of a client. It is not an issue of when the next idea for intervention will surface, but instead how we parse out the most successful of those ideas to achieve the best outcomes. To do that, we must define our success criteria appropriately and learn more about our outcomes (Frattali, 1998). In order to follow through on that goal, we need to be sure that the questions we ask allow us to evaluate the most relevant outcomes.

In current practice of outcomes measurement, Frattali (1998) created a useful framework of three questions that can be used to understand the evidence needed to consider an intervention

as successful with the resulting outcomes. Researchers need an operational definition so they can answer the first question, *what do you mean?* Answering this question is essential as it is impossible to call a result successful without a definition of a successful result. The second question is, *how do you know?* This question necessitates that researchers garner sufficient evidence to support a claim to be true. Finally, the claim of success must be understood and studied within a pragmatic context. The question asked here is, *what difference does it make?* Many researchers have proposed using the International Classification of Functioning and Disability (ICF) developed by the World Health Organization (WHO, 2001) as a model for evaluating outcomes (Blackstone and Granlund, 1999; Lund, & Light 2007; Schlosser, 2003), so we look to it for guidance in answering these questions.

History of the ICF

The field of speech-language pathology has, over the last decade, attempted to embrace the growing importance of health classification as it has been increasingly adopted in related health care professions and for health funding (Ma et al., 2008). The preceding factor in this trend was a development of a framework addressing the need for consensus regarding definitions of health outcomes. These definitions are necessary across fields of medical study and work. As consensus has been widely reached regarding these health outcomes, the field of speech-language pathology has increasingly adopted the framework as a guide for its practice.

The first model. The World Health Organization developed the first framework as an attempt to classify health and health outcomes in 1980 titled, *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). It described health in three levels: impairment, disability, and handicap (WHO, 1980). Impairment refers to a loss or abnormality of

functioning at bodily or structural level. For example, an individual who has had their leg amputated would have qualified as having an impairment. A disability refers to a restriction or limitation to an individual's ability to perform an Activity (likely resulting from an impairment). In an example for disability, an individual with a leg amputation would not be able to run. Finally, a handicap refers to an inability to fulfill the duties of a social role that an individual would typically fulfill. Referring to the aforementioned example, this individual would have a handicap if they were not able to complete their occupational duties due to their impairment. These levels related to each other in a linear fashion as designated by the ICIDH, therefore the handicap was the most debilitating of the three levels, which would have been preceded by impairment, then disability (Ma et al., 2008). While this framework was essentially the first of its kind to classify levels of health in this manner, there were limitations to its structure and unforeseen implications. The limitations of this classification included that the hierarchical classification of disablement did not adequately satisfy the experience of health and lack thereof. An individual is not always impaired in function if they have a disorder of some type, nor does it necessarily affect their social functioning. One example discusses the issue this causes when a person with a moderate fluency disorder has a minimal handicap that interferes with their social functioning, and vice versa (Ma et al., 2008). Though the ICIDH would classify their dysfluencies as a disability, the handicap is almost entirely dependent on the individual's perception of the effect it has on their ability to functionally communicate. In reality, these categories are not linear and have far more overlap than the model allowed. Secondly, according to Ma et al. (2008), the environment was not seen in the contextual nature that we see today, but rather only existing as a potential barrier to recovery. In reference to the aforementioned example, the environment may resolve a handicap if the individual who stutters is surrounded by

supportive listeners who allow the individual to have dysfluencies without judgment. Finally, personal factors, characteristics of the individual distinct to their health status, were not included as influences on health. Again in reference to the person who stutters, personal factors will affect how a person experiences a disability. This individual may have an effective coping style that minimizes the restrictions they experience from this disability.

The second revision. With the limitations of the initial version of the ICIDH, and rising pressure from within the medical community for the World Health Organization (WHO) to implement growing “knowledge and management of disabilities,” (Ma et al., 2008), the WHO began to develop the *International Classification of Impairments, Activities, and Participation* (ICF). Between 1997 and 2001, the WHO made revisions systematically to the ICIDH. These revisions were released as beta drafts in June 1997 and July 1999, one titled, *The International Classification of Impairments, Activities, and Participation*, (WHO, 1997) and, *The International Classification of Functioning and Disability* (WHO, 1999), respectively. The new model included, among other revisions, contextual classification of environmental factors that influence health and disability (Tsai, 2014). With further revisions made after discussions within the WHO, the *International Classification of Functioning, Disability, and Health* (ICF) was created as an official WHO classification system in 2001 (Tsai, 2014). It contained general solutions to the issues found in the previous editions, including definitions of Personal and Environmental Factors as well as an updated model more accurately outlining how the framework’s defined terms interact with each other in the context of health. These revisions have allowed speech-language pathologists to be more comfortable using it as a conceptual framework for “defining domains and selecting evaluation measures,” (Lund & Light, 2006, p. 285).

Current structure of the ICF. Currently, the ICF is structured in two parts, covering four components of health. Part one, titled “Functioning and Disability,” includes Body Functions and Structures, and Activities and Participation. Part two is titled “Contextual Factors,” and includes Environmental Factors and Personal Factors (WHO, 2001). This restructuring addresses the issue of a hierarchical relationship between “levels” of health. The new model is shown in Figure 1.

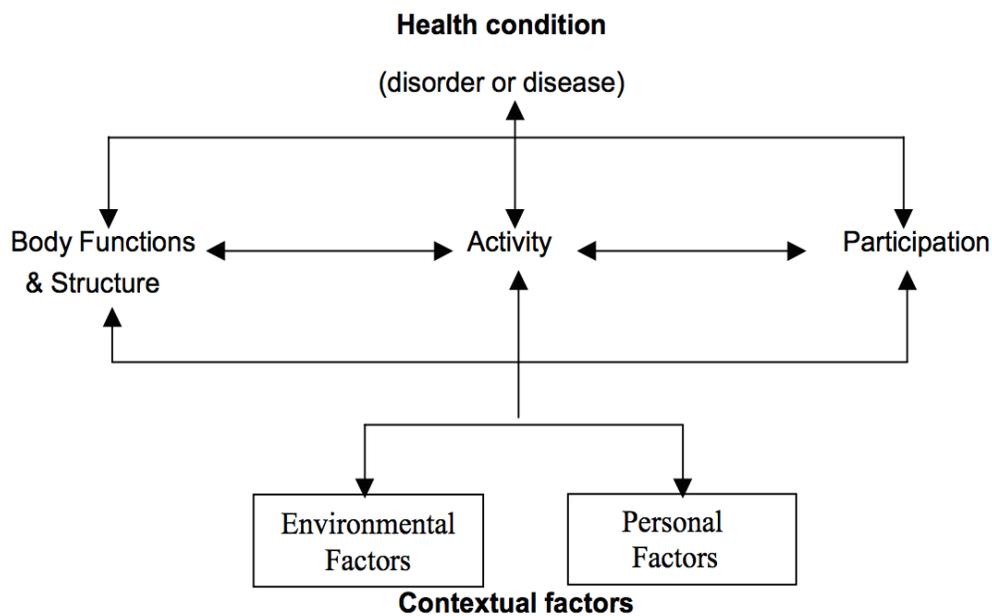


Figure 1. The ICF restructured hierarchy of health to reflect more complex interactions between terms (WHO, 2001).

With this structure, “disablements are the outcomes of complex and multi-dimensional interactions between an individual’s health conditions and the contextual factors around him/her,” (Ma et al., 2008). These also include operational definitions of all categories, more clearly allowing professionals to define their outcomes. Defined terms include Body Functions, Body Structures, Impairments, Activity, Participation, Activity Limitations, Participation Restrictions, and Environmental Factors. Body Functions and Structures refer to the

physiological and psychological functions of the body and the anatomical components of the body, respectively. An abnormality in either of these areas could result in an Impairment. Similar to the ICIDH definition previously mentioned, an Impairment results from a loss or deviation of function or structure. For examples of outcomes SLPs would measure, Body Functions may include voice production, while Body Structures would include intact structure of the vocal folds. A resulting impairment in that area would include vocal fold paralysis. The ICF definitions differ from the ICIDH when discussing Activity and Participation. Activity is the execution of a task by the individual, while Participation is involvement in a life situation, adding life context to differentiate it from Activity. Researchers Lund and Light measured these outcomes in a 2006 study. In measuring Activity, researchers evaluated participants with complex communication needs requiring Augmentative and Alternative Communication (AAC) services and their receptive language skills using a standardized assessment. As standardized assessment does not measure these skills in a functional life context, these tasks are labeled Activity. In evaluating participants' communicative interaction, researchers could collect data on participants' Participation in life situations. By collecting and analyzing conversations with the participant and three different partners, researchers were able to analyze the participant's skills in the context of communication with another person. While distinct definitions can be applied to these categories, items belonging in these categories often contain overlap or similarity that can blur the lines of outcomes measured by these definitions (Threats & Worrall, 2004).

The ICF is also now able to classify overall health of all people and is not limited to individuals with "disabilities." The retooled ICF is adept at relating a health condition more closely to the individual and examining how they could function in their everyday life. The further benefit of this new classification was an opportunity for more relevant applications of

these concepts to the field of speech-language pathology. Adoption of the terms within the framework then allowed SLPs the opportunity to utilize a common language that could translate the scope of the field for other professionals encountered in various settings. However, some significant discrepancies persist. While the ICF is more detailed than previous versions, there are still areas lacking within the framework over which practicing SLPs and researchers alike raise concerns (Ma et al., 2008).

Challenges of the Current Model

Researchers list multiple challenges they face with the current ICF. One challenge, according to Ma et al. (2008), is that the full potential of the ICF has not been fully understood. Per this research team, the ICF can be used as a “research tool to measure outcomes, a clinical tool to set and evaluate goals, a social policy tool to design and implement policy, and an educational tool to raise awareness,” (Ma et al., 2008, p. 7). These possibilities are not being fully realized for a variety of reasons, namely that professionals cannot currently trust that this tool will adequately help them meet those goals. One reason for this mistrust and confusion is that the profession and the ICF do not move quickly enough in unison to promote change in how these concepts are applied to practice (Ma, et al., 2008). This is due to a number of concepts remaining too vaguely defined for SLPs to utilize to their full potential. It is difficult for SLPs to quickly adapt these concepts to their practice when they are not fully understood and are often disputed in the profession, while the ICF does not take a firm stance. This issue has been heavily disputed in discussion of the terms, “environmental factors” and “participation,” which will be discussed in greater detail in subsequent sections. With no central body to garner consensus on these terms, it is difficult for the field to utilize their potential in general practice and ultimately

to client benefit. Currently, the ICF is not sufficiently meeting the field's need for an answer to the question, "what do you mean?" when measuring outcomes. Without an answer to this question, outcomes researchers cannot hope to answer the subsequent questions that help take outcomes research further into clinical applicability, and ultimately begin to solve critical issues faced by the ICF and the profession. This project proposes to identify how SLPs answer the question, "what do you mean?" when they are measuring outcomes.

The challenges of defining participation. As was stated earlier, the ICF separates itself into two parts, one of which is "Functioning and Disability." This is the area where researchers collect the information they can use to define outcomes, as these areas are where changes from intervention will be observed. This section is further split into Body Functions and Structures, and Activities and Participation. Because the former division is largely based on the individual and functioning within their body, it is much easier to measure outcomes at these levels than in the latter. Historically, outcomes have been studied in the field of speech-language pathology at the Body Function and Structure level (Eadie et al., 2006), likely because they are the most easily observable and the results are primarily objective. For example, a child with a phonological disorder (a Body Functions Impairment) can have easily observed improvements when articulation of individual phonemes is corrected.

In the Activities and Participation section, it is much more difficult to be objective and definitive with our current status of consensus, or lack thereof. This is evidenced by the ICF itself, in a statement (WHO, 2002), demonstrating various ways Activity and Participation can be interpreted within the healthcare field. The two terms currently can be understood in four different ways. Activity and Participation can be defined as separate concepts where there is no overlap between the terms. This would require a more specific definition for both terms from the

ICF, as evidenced by the lack of a consensus among health care professionals. A second option is that there could be partial overlap between terms giving the option of some codes fitting in both categories. Third, professionals utilizing the ICF for outcomes could count broad categories as Participation while the specific items within the category are considered Activity. For example, professionals should consider a broad category listed in the ICF under communication (e.g. Communication-Receiving) as Participation, while specific items listed within the category (e.g. comprehending literal and implied meanings of spoken messages) would be considered Activity. Finally, professionals could count each item as both Activity and Participation (WHO, 2002). According to Threats and Worrall (2004), the growing trend in the field is to follow the fourth option and see both Activity and Participation as synonymous terms. However, a number of researchers have called for the ICF to more clearly define and differentiate the two terms (Whiteneck & Dijkers 2009). Participation has proven difficult to define due to a lack of consensus across the field of healthcare. However, there is some consensus about the necessary features of Participation not included in the ICF definition.

While some in the field call for the terms to be synonymous, others want to delve deeper into each definition (Threats & Worrall, 2004). The definitions of these terms in the ICF were first created as an effort to find an alternative to the negative terminology (e.g., handicap) that had attempted to classify the consequences of disorder, rather than characterize abilities (Whiteneck & Dijkers, 2009). As presented earlier, Activity is defined as “the execution of a task or action by an individual,” while Participation is defined as “involvement in life situation,” (Threats & Worrall, 2004). Threats and Worrall currently report that there are a number of ways that SLPs understand these vague distinctions, and while the current trend is to view them as synonymous, this is not yet agreed upon in the field. However, multiple conceptual distinctions

have been made that should be considered that would not allow these terms to remain synonymous (Whiteneck & Dijkers, 2009). One is that Activity takes place within an individual, while Participation involves performance within society. Another is that Activities are related to Body Functions and Structures in that they are easily limited by deficits and impairments, while Participation is more often limited by environmental factors in society. Finally, Activity is action preoccupied with results, while Participation is the end itself, rather than the means, so it is engaged in for its own benefit (Whiteneck & Dijkers 2009).

The operational definition of Participation proposed by Chang and Coster (2014) has sought to eliminate ambiguous terms, as well as to create a model that can be used to perform the ICF's intended function of measurement development. The definition derived from these efforts to clearly define Participation is as follows, "active involvement in activities that are intrinsically social and occur in a societally-defined context," (Chang & Coster, 2014, p. 1792). As a result of the discrepancies in its definition, and a lack of consensus within the field of speech-language pathology regarding the use of Participation as an outcome separate from Activity, researchers Chang, Coster & Helfrich (2013), found that there are currently no self-proclaimed Participation measures covering all Participation domains. Very few of those analyzed, all of which are motor measures, measure only Participation. Instead they measure a mix of content areas, including Activity and Body Function.

The challenges of defining environmental factors. The ICF includes environmental factors, a departure from the ICIDH that placed sole accountability for health on the individual, in order to attempt to describe the complex interaction between our environment and health. As Participation is widely defined within the context of the social environment and community, environmental factors are an important classification to consider when assessing the dimensions

of health. This interaction is understandably complex, and decades of research has not unlocked the ideal explanation of this relationship. As Whiteneck and Dijkers (2009) explain, the ICF appropriately left the specifics of its framework to future research to identify. The ICF did explain how environmental factors should affect the classification system in saying, “an individual’s functioning in a specific domain is an interaction or complex relationship between the health condition and contextual factors,” (WHO, 2007, p. 17). This is a definition that is intertwined with the idea that will be explored in the next section that Participation is inherently social, therefore needs to be measured and evaluated from within a community or environment outside the individual. The ICF divides environmental factors into two levels; factors that are present in the individual’s immediate environment (e.g., whether a child’s parents are Deaf or hearing), and those that are characteristics of the wider societal environment (e.g., community-wide distrust of hospitals and health care). However, according to Whiteneck and Dijkers (2009), no separation is made in the accompanying ICF taxonomy. Therefore, there currently is no field-approved classification of the potential interactions of the environment on health, leaving a gap in an area where goals and intervention can be targeted. This is not something that will be further explored in this study but is something we look forward to researchers continuing to develop that will gain solutions to currently unanswered questions.

Outcomes Measurement

Ultimately, outcome measures assure invested parties in intervention that these practices have “value to the individuals served and to society,” (Lund & Light, 2006, p. 284). These parties include clients, their families, organization administrators, insurance companies and other funding agencies. Those invested members of the process need accountability for justifying

costs, ensuring accountability, and ensuring that these practices are the best available for the individuals being served, as is the ethical obligation of the profession (Lund & Light, 2006). In their 2007 article, Kagan and Simmons-Mackie posed the question, “would the choice of assessment method and intervention change if speech-language pathologists knew that their jobs depended on achieving outcomes...?” (p. 309). This question was referring to treatment for life Participation for individuals with aphasia, but the principle applies to treatment of all populations seen for therapy by an SLP. By definition, therapeutic interventions are designed to achieve outcomes, so it logically follows that assessments should be chosen to most efficiently assess current outcomes and goal achievement. In order to perform outcomes measurement effectively, the outcome must be clearly defined, especially when following Frattali’s (1998) framework and answering our second question, “*how do you know?*” Outcomes can be measured at all levels of the ICF (WHO, 2001); however, to determine the impact of an intervention on a person’s life, we must evaluate outcomes at the Participation level.

Outcomes at the level of participation. When measuring outcomes and following the aforementioned definitions, it is clear that distinctive information can be derived from outcomes of Activity and Participation. As explained by Whiteneck and Dijkers (2009), people with a disability may avoid activities they cannot complete due to their disorder but may not have Participation restrictions if adequate supports are provided (i.e. assistive devices, personal assistance, policies, social support, etc.). In theory, full Participation should be possible for any individual within our society, regardless of disability, but Activity may remain limited.

In a more specific example, an individual may be unable to speak. This would be considered by the ICF as an Activity limitation. However, with an assistive device and educated conversational partners, they may be able to interact with others in their communities to

accomplish their goals with little trouble, ultimately participating in conversation and connecting with others for the purpose of communication and bypassing the need for speech production. Conversely, an individual may have no problem articulating sounds and being understood phonetically in a conversation, but may be unable to connect with friends and family through conversation. Though he or she can speak, they cannot communicate in conversation to participate in relationships important to them. These distinctions are essential to outcomes measurement in order to determine the impact these abilities and subsequent interventions have in the individual's life.

Participation is the end goal, and communication (and interventions to improve it) are tools that can be used to reach the end goal (Mirenda, 1993). By emphasizing Participation as a prioritized outcome, we ensure that all intervention will be intended to advance patient progress towards the end goal and will make impactful change to the patient's life. Without long term expectations in sight, "short term goals become mere exercises," (Lund & Light, 2007, p. 332).

Communicative participation. To determine the effect of communication on an individual's Participation, Eadie et al. (2006) identified the concept of communicative participation. They defined the term as, "taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication. Communicative participation may occur in multiple life situations or domains and includes, but is not limited to, personal care, household management, leisure, learning, employment, and community life. Because communicative participation is measured in a social context, by definition it involves more than one person and must involve a communicative exchange (i.e., a message and the opportunity for a response from a communicative partner)." (Eadie, et al., 2006, p. 309). This definition provides much needed

clarity for distinguishing Activity from Participation within the context of communication and gives further direction to how measurement of communicative participation can be utilized in our field.

It is essential for SLPs to obtain information on the construct of communicative participation from the populations they serve. Describing why it remains essential is central to answering and exploring our final question from Frattali's (1998) framework of outcome measurement, "*What difference does it make?*" Eadie et al. (2006) explain that there are four reasons to measure this construct. The first reason is that Participation is the one area of the ICF categories that can be affected by any aspect of disablement and contextual factors. It is necessary to take stock of these possible alterations to Participation in order to understand the full effect of disablement and contextual factors in any form. Second, communicative participation should be a central focus for those individuals whose disorder is communication-based or not. To illustrate this, we can imagine that while an individual with paralyzed vocal folds will have rather obvious barriers to Participation in spoken conversation, a person with generalized anxiety disorder may be similarly limited with communicative participation if their anxiety prohibits them from seeking conversation in social contexts. Third, it is important to understand the impact of our therapeutic intervention as SLPs with measures that appropriately reflect the client's wants and needs and prioritizes them effectively when choosing interventions. Finally, the more the field can study and measure communicative participation, the more we can understand how this construct interacts with other variables (e.g. quality of life) (Eadie et al. 2006).

As mentioned above, while the field has operated sufficiently thus far with its clinicians seeing Activity and Participation as nearly synonymous terms, the potential for more impactful

interventions cannot be reached with this option. This impact could be the difference between someone interacting appropriately in social situations with peers in school (Participation), and simply knowing how to respond to a greeting (Activity). Researchers have called for efforts to more clearly differentiate these ideas for the benefit of the profession, but have run into some barriers in those efforts, two of which are discussed below.

Methods of Measuring Outcomes

Assessment has many purposes, including developing a diagnosis, establishing therapy goals, justifying funding, and monitoring progress, all based on the results gained from the assessment and the information it communicates about the individual's functioning and health (Lund & Light, 2006). An outcomes-based assessment can accomplish these things, and evaluate outcomes in the process. In theory, it appears that SLPs should always look to an outcome-based measure to guide their practice. However, there are two central issues that face practicing SLPs that prevent them from reaching this ideal. One is that outcomes measures that assess communicative participation are not widely available, and tools that do measure communicative participation also include measurements of other constructs such as Body Functions and Structures or Activities (Eadie et al., 2006). Second, SLPs often do not understand what constitutes a functional communication outcomes assessment at the level of participation and therefore cannot know the potential that such an instrument can have on their practice and success with their clients (American Speech-Language and Hearing Association [ASHA], 2013). When these two issues are addressed, it is likely that outcome measures will be more widely used by practicing SLPs, to the benefit of the clients served.

SLP perceptions of functional communication outcomes assessments. According to the American Speech-Language and Hearing Association (ASHA) in a survey conducted in 2013, fewer than half of the SLPs in health-care settings surveyed used functional communication outcome measures in their documentation (ASHA, 2013). The survey intended to assess the amount of functional outcome measures at the level of activities and participation used in health care settings by SLPs. Functional outcome measures were defined in the survey as measures “that describe a patient’s functioning, Activities, and/or Participation in activities of daily living (ADLs), by clinician or self-report,” (ASHA, 2013). These include tools like ASHA’s National Outcomes Measurement System (NOMS), Functional Independence Measures (FIM), and self-report tools like the Voice Handicap Index (VHI).

However, when responding to the survey, SLPs around the United States responded that they had used functional outcome measures, but when asked which ones, they responded they had used what the survey defined as clinically-derived outcome measures. In contrast to functional outcome measures, clinically-derived measures are “standardized tools that have been normed and validated for the target population,” (ASHA, 2013). These include tests like the Western Aphasia Battery (WAB), and the Test of Problem Solving (TOPS). These measures are normed on typically-developing children, but the results given would provide data on outcomes at the Body Functions and Activity, rather than at the level of Participation, (Eadie et. al, 2006). With outcomes assessment, SLPs have the opportunity to more closely define their goals and measure progress in functional areas of the individual’s life. In the survey, even including unintended instruments, outcome measures were only used by 40% of the SLPs surveyed (ASHA, 2013). The highest group of SLPs utilizing outcome measures in their documentation

was in rehabilitative hospitals with 84%. The potential exists that if SLPs were more aware of the potential of these instruments, they would use them more often.

More recently a survey was conducted that greatly contrasted ASHA's findings. An unpublished survey by Heuer, Lund, and Heilmann (2017) found that 79% of surveyed SLP's currently utilized outcome measures of functional communication. A disparity of use existed between SLPs that served adult populations and child populations, with 92% of the former utilizing outcome measures of functional communication and 59% of the latter. In addition to inquiring about use, researchers also asked participants to rate their satisfaction with available measures and their effectiveness. Roughly half of participants reported being "somewhat satisfied" with available measures, and 85% rated them as somewhat effective or effective. With the disparity in results of these surveys and little explanation for the rather low satisfaction ratings, further research and analysis is needed of SLP perspectives on these measures.

We know from general knowledge of assessments and from studies about the assessments available in the field of speech-language pathology that the outcomes most likely to be included in assessment fall under the ICF category of Body Functions and Structures, likely due to the ease of quantifying and observing these outcomes (Eadie, 2001; Threats, 2000). Targets that assess outcomes at the level of Body Functions and Structures include measures of articulation accuracy, physiology of swallowing function, number of disfluencies, and many others. These measures are not useless; they are extremely important to assessing health and helping diagnose disorders within the populations we serve. However, there is a discrepancy in the amount and frequency with which other outcomes are studied and this is not an accident. It is more challenging to study and assess outcomes outside of these that are a direct function of the body.

It is much easier to study how well someone can produce an articulation target than how well they can relate to their community through communication.

This is particularly apparent when measuring outcomes at the level of Participation. Participation as an outcome has been increasingly used to improve rehabilitation outcomes, so, in accordance, more Participation outcome measures have become available. In 2003, Perenboom and Chorus found that most instruments dedicated to Participation did have some consistency in measuring that construct, but also included a significant number of items that measured other levels of the ICF, specifically Activity and Body Functions and Structures. In 2006, researchers also found that, of six instruments evaluated thoroughly that were intended to address communicative participation, only 26% of the items were consistent with that definition (Eadie et al, 2006). In studying these instruments, Eadie et al. identified currently occurring trends that prepared the field of speech-language pathology for the development of valid outcome measures for communicative participation. These trends included a growing consensus about this terminology as research is disseminated, a growing emphasis on client-centered decision making, and advancements in instrument development allowing these outcomes to be quantified (Eadie et al., 2006). With these trends, and a clear framework to define what we mean by communicative participation, how we measure communicative participation, and documenting the difference this outcome makes, we are able to pursue further development of these measures. In examining the research disseminated regarding SLP utilization of functional communication outcome measures, it has become clear that SLP's intend to use these measures but cannot do so due to the inadequacy of currently available measures.

This project seeks to gain a deeper understanding of the needs and wants of SLPs who work in various settings and with various populations, regarding outcome measures. In the

aforementioned survey of SLPs and their use of functional outcome measures, researchers found that 79% of SLPs use functional outcome measures in their practice (Heuer, Lund, & Heilmann, 2017). SLPs reported moderate satisfaction with these measures, due to patient fatigue and a lack of outcome measures appropriate for the specific patient population needed. SLPs also reported use of global functional outcome measures (e.g. FIM, NOMS, G-codes) that contain general outcomes not appropriate for individualizing evaluation of patient progress and goal setting. These results suggest a need for more meaningful outcome measures that allow professionals to document and prioritize well-being and life Participation. This is a direction preferred by health-care policy makers in contrast to the current practice of SLPs to define outcomes by impairment rather than function (Kagan & Simmons-Mackie, 2005). In pursuit of this direction and the most effective evaluation of the practice of speech-language pathology, it is important to understand the current experience and future desires for SLPs with outcome measures and communicative participation. With this in mind, this study will pursue a deeper examination of SLP perception of functional communication outcome measures, communicative participation, and how to move forward into outcomes measurement in the most relevant way to SLPs and their clients.

Specifically, this study will answer the following questions:

What are speech-language pathologists' experiences with outcomes measurement?

What do speech-language pathologists who want to be included in a functional outcome measure of communicative participation?

CHAPTER 2

Methods

Research Design

The research question stated above was answered with qualitative methods of research. Qualitative research is particularly fitting to begin to solve a question with the goal of deciphering the “meaning individuals or groups ascribe to a social or human problem,” (Creswell, 2013, p.44). Based on previous research, the target SLP population does not have a satisfactory, valid, and reliable tool with which to evaluate their clients at the level of communicative participation. This need must be met by further analyzing what SLPs need for a satisfactory tool. Specifically, this study used a phenomenological approach. Phenomenological research, as defined by Creswell (2013), gives a central meaning to a group of individuals’ common experiences of a problem or phenomenon. The goal of this project is to uncover the needs of a group of professionals; therefore, it is necessary to use a systematic process to assign meaning to the testimonies of multiple individuals. The emphasis in this process sits on drawing out meaning without presuppositions. Applying a systematic framework to qualitative study allows for researcher presuppositions to be greatly diminished. That systematic framework includes assuring that participants belong to a group that has common and united experiences of a phenomenon, so these criteria must be carefully outlined.

Participant recruitment. Participants were recruited through internet postings to the ASHA special interest groups in Language Learning and Education (SIG 1), Neurogenic Communication Disorders (SIG 2), School-Based Issues (SIG 16), Gerontology (SIG 15) and Augmentative and Alternative Communication (SIG 12) and the general message boards: ASHA members, SLP Health Care, SLP Private Practice, and SLP Schools. Posts recruiting participants

were also made to the following Facebook groups for SLPs: School-Based Speech and Language Therapy, and UWM AAC Lab. After providing informed consent, participants were asked to fill out a short demographic survey inquiring about their educational background, continuing education, work setting, specialization, and current caseload to ensure compliance with the study's selection criteria and separation into the appropriate focus group if that criteria is met (refer to Appendix A). There were 103 responses to the demographic survey, from which 14 individuals participated in the study. Six individuals did not meet the selection criteria, which included five individuals with less than three years of experience in the field, one individual that lived outside of the United States of America, and one individual that was not a speech-language pathologist.

Selection Criteria. As defined by Binger et al., (2012), participants fell within the categories of general practice clinicians, intervention specialists, or experts. General practice clinicians provide a range of clinical services as part of their daily practice. They do not specialize in intervention services for one target population, but the agencies they serve work with that population. An intervention specialist spends at least 50% of their clinical workload providing direct services (e.g. assessment, instruction, funding assistance, and follow-up) to one disorder/intervention population. Experts focus on developing and maintaining the knowledge, technical, policy, and service bases of one disorder/intervention field. They include university faculty, consultants, researchers, technology developers, policy-makers, and administrators of special service groups. All categories of participants have certifications as an SLP and are currently employed as an SLP. For the purposes of this study, all of the participants had a workload with 75% or more of their time spent providing services to one of the target populations, as well as possessing specific skills in intervention and assessment as evidenced by

continuing education (Binger et. al, 2012). Participants were excluded from participation in the study if they did not have at least 75% of their caseload represented by one or more of the target populations meeting our definition of general practice SLPs (e.g. 60% pediatrics and 40% adults, or 70% pediatrics and 30% AAC). Participants were also excluded if they did not have at least three years of clinical experience.

Focus groups with participants were conducted over an online conference call and therefore there were no restrictions on the place of residence for the participants. To participate, subjects needed access to the internet and a computer enabled with a webcam so that they could be recorded and the focus group conversations could be transcribed accurately. Participants were fluent in English in order to participate in the focus group that was conducted in English.

Participants

14 ASHA Certified SLPs participated in the project. Participants were interviewed in 6 separate focus groups. Participants fell in one of three categories: SLPs who specialized in pediatric services, SLPs who specialized in adult services, and SLPs who specialized in augmentative and alternative communication. Though focus groups are most successful with 6-8 interviewees (Patton, 1990), the focus groups were conducted with 1-5 people per group due to difficulties in scheduling SLPs from around the country. The total number of participants fell in the range recommended for phenomenological study (i.e., 5-25 people) (Creswell, 2013). Participating SLPs worked in a variety of settings, including but not limited to schools, hospitals, outpatient rehabilitation centers, day programs, and universities. Of the 14, five worked in schools, two in universities, three in outpatient rehabilitation, three in hospitals, and one in private practice. Three participants worked with pediatric populations, four with AAC

populations, five with adult populations, and two with mixed populations. Participant years of experience ranged from 7-47 years and the average was 22 years. Further participant demographics, identified by their assigned pseudonym, are listed in Table 1.

Table 1

Individual Participant Characteristics

Pseudonym	Group	Date	Years Practicing	State	Setting
Patricia	Peds	6-5-17	30+	New Mexico	School
Anne	Peds	6-5-17	20-30	Illinois	School
Sharon	AAC	6-8-17	20-30	Nebraska	University
Angie	AAC	6-8-17	10-20	Florida	School
Brianna	AAC	6-8-17	5-10	Indiana	University
Karen	Adults	6-19-17	30+	California	Private Practice
Tracy	Peds	6-26-17	10-20	Connecticut	School
Katie	Adults/Peds	6-26-17	20-30	Wisconsin	Outpatient/Day Program
Tammy	Adults	6-26-17	5-10	Wisconsin	Hospital
Vicky	Adults	6-26-17	20-30	Arkansas	Outpatient
Jillian	Adults	6-26-17	10-20	Wisconsin	Hospital
Helen	Peds/AAC	6-28-17	10-20	Ohio	School
Jane	AAC	6-28-17	20-3	Colorado	Other/Private Practice
Casey	Adults	6-28-17	10-20	New Hampshire	Hospital

Note: Table includes relevant characteristics of 14 participants. Pseudonym denotes the name given to the participant to protect anonymity. Group denotes the primary population the participants work with (AAC: Augmentative Alternative Communication, *Peds*: children aged 0-18).

Procedure

For this research, the individuals participating in the study were contacted by email and combined into groups based on their availability. The focus groups had a size of 1-5 participants per group.

Focus groups. The focus groups were performed over an online video conference call using the Skype for Business platform. Skype for Business is a secure system that allows the call to be audio and video recorded. The focus group interviews lasted 20-100 minutes depending on the size of the group and progression of the discussion. The average group length was 48 minutes. The focus groups were conducted by the focus group moderator, Natalie Graceffa, and assistant moderator and research advisor, Dr. Shelley Lund. The discussion focused on the experiences of the participants with outcomes measurement and their needs for future development of outcomes measures. It should be noted that emphasis did not include discussion or necessity of consensus on responses (Patton, 1990). Participants were asked to respond to questions one at a time, but heard the responses of other focus group members and were able to respond with comments as they wished.

In an initial contact email, the researcher provided materials for participants to review which are presented in Appendices B and C. The materials included definitions of the following terms: *clinically-derived assessment*, *proprietary outcomes measures*, *functional outcomes measurement*, *communicative participation*, *Participation*, *functional communication*, *Activity*, *Body Structure and Function* and a case study to illustrate the definitions (Appendices B and C, respectively). The focus groups began with review of these materials and terms to be used during the interview to provide context and uniformity to the interview. A focus group script and questions were followed to guide the discussion. Questions were open-ended and emphasize professional experience of outcomes measurement and not consensus on any discussed aspect of outcomes measurement. The script is provided in Appendix D.

Data collection. Researchers recorded the focus group video and audio to assist in data analysis. The focus group interviews were orthographically transcribed, using pseudonyms to identify the involved participants.

Data analysis. The transcripts were subject to open and axial coding by first assigning concept codes to individual statements (Corbin & Strauss, 2015). Statements were assigned codes to capture their basic content. Due to the nature of qualitative analysis, categories arose from the data and were not assigned or defined before analysis. This was done to prevent researcher bias in deriving codes from the data gathered, and allow themes to arise from various stages of grouping, which was done through a process of axial and selective coding. This process determined common themes across participants.

NVivo qualitative analysis software was used to assist with analysis of the data. NVivo provides methods to organize and re-organize coded ideas to give structure to qualitative data. The software can also run queries to compare the responses of the different groups of participants. Researchers ran queries to determine if different themes arose from the groups of participants.

CHAPTER 3

Results

Four main themes were identified during analysis: Satisfaction with Available Assessments, Ideal Measure Characteristics, Approach to Assessment, and Needs in the Profession. Table 2 gives a summary of these themes, their sub-themes, and relevant and specific examples of listed in the focus groups.

Table 2 Themes, Sub-Themes, and Results Identified Through Selective Coding of Focus Group

Transcripts

Themes	Sub-Themes	Examples of participant responses
Satisfaction with Available Assessments	Negative Attitudes	<ul style="list-style-type: none"> - Assessments restricted by availability. - Available tools not functional. - Patient needs do not match assessment measure (structure, results, etc.) - Assessment results do not meet requirements of work setting.
	Positive Attitudes	<ul style="list-style-type: none"> - Many assessments available in some settings - The structure is appropriate for my work place - My work setting/population allows me to be flexible with assessment practices. - SLPs have created their own measures for their settings.
Ideal Measure Characteristics	Ideal Structure	<ul style="list-style-type: none"> - Customizable measure that can fit varying levels of functioning - Portable, tangible measure - Incorporate self/proxy report
	Ideal Results	<ul style="list-style-type: none"> - Include normed data to compare to appropriate peers. - Generates ideas for goals and objectives - A measure to justify clinical judgment - Assessment to measure progress and show functional growth
	Ideal Characteristics	<ul style="list-style-type: none"> - Can administer in 30-60 minutes. - Easy to use, not requiring preparation work. - Targets functional outcomes. - Specific measure with a broad range.
Approach to Assessment	Purpose of Assessment	<ul style="list-style-type: none"> - Establish baseline level of functioning - Qualify a student/patient for further care - Show growth and progress - Support authentic communication

	Assessment Selection	<ul style="list-style-type: none"> - Clinicians prefer informal measures to gather information - Setting requires standardized assessment for reimbursement. - Clinicians create measures of their own of gathered subtests from other assessments.
	Goal Setting	<ul style="list-style-type: none"> - Determined by self/proxy report - Patient-centered goals - Set and modify goals with multidisciplinary team - Set manageable goals
	Outcomes/Targets	<ul style="list-style-type: none"> - Functional activities based on setting/history/patient priorities - Assessments targeting complex, higher level skills - Assessments for various output/access methods - Assessments targeting participation outcomes like social communication in various settings
	Team Members	<ul style="list-style-type: none"> - Includes: medical staff, academic staff, ancillary staff, fellow SLPs - Emphasize multidisciplinary assessment
Needs in the Profession	Define Terminology	<ul style="list-style-type: none"> - Define terms including: functional, outcomes, cueing strategies, modeling. - Define with video examples. - Field does not have consistent terminology, some is made up.
	SLP Variability	<ul style="list-style-type: none"> - Clinical experience determines choice of assessment - Colleagues share some opinions on outcomes measures - Younger SLPs have more flexibility in choosing assessment measures
	Connecting Research and Practice	<ul style="list-style-type: none"> - SLPs have an ethical responsibility to be up to date on evidence-based practice - Field needs to merge research with clinical practice - Further research needed for outcomes measures
	Work Setting Restrictions	<ul style="list-style-type: none"> - Inconsistency across school districts creates confusing among SLPs - It is difficult to qualify students for therapy in the school setting - There are time restraints across settings on assessment time. - Need normed data to qualify some populations

Note: Abbreviation of SLP stands for speech-language pathologist

Satisfaction with Available Assessments

The researcher identified two sub-themes for the theme satisfaction with available assessments: Negative Attitudes and Positive Attitudes.

Negative Attitudes. Negative attitudes were referenced by all 14 participants, and were mentioned a total of 81 times. Participants from each group expressed some dissatisfaction with current available assessments. These negative attitudes stemmed from lack of availability of assessments, dissatisfaction with the results provided, and inappropriate portions of tests for their population. Participants reported that some settings had a very limited supply of assessments. Casey commented on the lack of availability of measures in her setting: “The hospital inpatient rehab hospital that we work at, we only have the BDAE (Boston Diagnostic Aphasia Examination), so when we’re doing testing we’re only going to be using that...” Some other SLPs commented that the assessments available do not provide the results they need in their setting or for their population. It can be difficult to maintain objectivity in many assessments, according to participants. The results are often not as functional as they claim to be, according to Sharon: “So I guess my experience is that I’ve used outcome measures but they rarely measure the change that I’ve tried to get at and I’m not sure that they are extremely sensitive to actual change in people’s lives.” Still other participants lament the portions of the test that are not needed for their populations, like Karen: “I’m not satisfied because I think we ask patients to go through too much stuff that they really don’t need to get the information we need for treatment.” For this reason, Karen has used the same clinically-derived assessment that, to her admission, is expired, because it was the only assessment that was customizable to her needs and the needs of her patients. The number of comments in this theme were further analyzed to determine if there were any differences between the groups of participants. Pediatric SLPs reported negative and positive factors 15 and two times, respectively. Adult-focused SLPs reported negative and positive factors 49 and nine times, respectively. AAC SLPs reported negative factors 14 times

and did not report any positive factors, while mixed SLP's reported negative factors 10 times and positive factors three times. 100% of participants reported negative factors of assessment.

Positive Attitudes. This sub-theme was mentioned by five participants for a total of 14 references. Some SLPs had positive attitudes regarding assessments and outcomes measures, and ways they have adjusted their assessment practices. In contrast to the pervasive negative attitudes towards assessment, only 36% of participants included positive comments regarding the assessment process when asked an open-ended question regarding their experiences in assessment. Some SLPs reported having many assessments available to them in their work setting, like Jillian: "we're very fortunate to have many, many standardized tests, we have shelves and shelves of them..." Some participants discussed their own assessment practices and their ability to be flexible with them in their workplace. Many discussed their attempts at creating their own informal measure made of subtests from other tests, like Tammy: "As far as the clinically-derived measures, in my professional life, I don't think more than once have I ever administered an entire test and sat down and done the entire Western or the entire Boston, I think it's partly just familiarity with your population."

Ideal Measure Characteristics

The researcher identified three sub-themes in this category from the participants' transcripts: Ideal Structure, Ideal Results, and Ideal Characteristics.

Ideal Structure. This theme was mentioned by 11 participants and mentioned a total of 49 times. Participants were asked about what they would like in an outcome measure, and many had thoughts on the ideal structure they could use in their setting. The most common theme

among participants was the desire for a customizable measure that could be started at their patient's estimated level of function and with the patient's/caregiver's concerns. Sharon had the following idea: "If you could come up with something ... that just helped people work through the problem space to come up with an individualized answer...just to make it a little quicker and to be sure some of the details and you know the nuances don't get too lost." Sharon also identified the following priority: "I would say that my priority when I think about these ideas is personalization, so that whatever we're doing, whatever our plan is to go somewhere, it has to be what I would call...an authentic communication need." It was also discussed that the measure should incorporate self-report or proxy report from a caregiver or family member. When participants were asked about the value of self-report, though some said it can be unreliable, all participants discussed its value to practice. Anne discussed how it can be a valuable tool for getting families on board: "we have run into a few families that are a little bit more hesitant than we would like them to be, so I think that (family/self-report) definitely plays a role in outcomes measures." While some opinions were unanimous, there was some disagreement around the ideal system for scoring an outcomes measure. Sharon wrestled with this idea: "While life is not a rating scale, it's also not exactly a binary...I would like to see it move maybe more towards that, more objective kinds of things, less percentages, and maybe thinking about some...things being a binary." Sharon explained that there are some skills that can be graded along a scale, and some skills that exist in a binary; either they exist or do not.

Ideal Results. This sub-theme was mentioned by all 14 participants and referenced 34 times. Clinicians also discussed the ideal results they would like to see from the assessments they give. Many clinicians, especially those working in the school settings, need normed data to qualify their students for therapy. In a clarifying summary that participants of one focus group

agreed with unanimously, the assistant moderator asked this question: “One of the things I heard was that the things that are out there that measure the thing you want are either informal or there’s no norm-type data and that’s what you need in a school setting, am I correct in that summary?” Clinicians also expressed interest in a measure that would generate ideas for goals, which Tracy had not encountered thus far: “Yeah, I think that sometimes it can be difficult to find something that accurately looks at the communication...and that generates good ideas for objectives and goals.” Patricia also advocated for a rating scale-type system that would help support clinician judgment: “I think maybe a 1-5 scale, or some, another way that tells us something we need to know, justifies our position, standard scores are really hokey.” Finally, clinicians wanted to have an assessment that accurately measured patient progress and growth outside of their clinical judgment, which can be skewed. Anne hoped for a measure like this: “hopefully there’s someone out there that can think of...some kind of assessment or tool that we can use to measure progress and accuracy.” This was further explained by Sharon, who sees an opportunity for more objectivity: “folks talked about the idea that to be objective about how intelligible a person is you really need a person who doesn’t know them to do the rating, because you get this clinician drift...this placebo effect.”

Ideal Characteristics. This sub-theme was mentioned by all 14 participants and was referenced 49 times. Ideal characteristics of the measure were discussed in the group and clinicians valued speed of use, ease of use, functionality, and specificity over a broad range of skills. Sharon discussed an idea about having the assessment on an app: “That would be quick and easy, maybe it could be an app where you ask people to download the app and make a quick judgment.” Some also discussed frustration with prepping formal tests and wasting time. Sharon discussed the difficulty between making it easy to use, and assuring it maintains true

functionality, another ideal characteristic. “You’ve got this balancing act between making it easy to use and you don’t have to do a lot of hours and hours of you know prep work to use it, but yet that is truly getting at what the individual wants to change.” The other difficulty present is maintaining the ability to hone in on a target skill, but also being able to get a full picture of the communicator, as Anne sums up: “I just think it needs to be specific, yet broad at the same time.”

Approach to Assessment

There were five sub-themes identified under this greater theme: Purpose of Assessment, Assessment Selection, Goal Setting, Outcomes/Targets, and Team Members.

Purpose of Assessment. This sub-theme was mentioned by all 14 participants a total of 106 times. Many purposes of assessment were discussed in the focus groups to support or express dissatisfaction with measures available. One of the fundamental purposes of assessment is to gain general information about patient functioning. Katie discussed how she needed this information about receptive language first: “You have to see where they are at baseline (with receptive language) before you can even dive into memory, problem-solving, orientation.” As was discussed earlier, assessment, particularly formal and standardized assessment, is needed to qualify patients or students for services. Patricia discussed that she primarily uses the CELF-5, the Listening Test, and the Goldman-Fristoe to do this: “because I have to have 1.5-2 standard deviations from the norm to qualify a student, and I’m very much bothered by that.” Jillian primarily uses functional communication measures like the Functional Independence Measure System (FIMS) for this purpose. “We are using FIMS, from the time they’re admitted to the hospital, and then those are being tracked, and then all of our rehab patients, inpatient rehab

patients are also getting FIMS on admission and discharge.” When staff were setting goals and making those adjustments, it was imperative to the focus group participants that they were supporting authentic communication, as Sharon identified earlier when discussing “authentic communication needs.”

Assessment Selection. This sub-theme was mentioned 231 times by all 14 participants. Many clinicians talked about their process of gathering data about their clients and their assessment routine. Specifically, clinicians that characterized their patient population as low-functioning tended to utilize informal measures as formal measures are not appropriate for their clients. The following quote from Helen illustrates this point: “what I do with more complex students is, I start with like a play-based type thing so I can see their social skills any of their functional communication that we get in just requesting objects or completing things within the school setting...I try to get a language sample if there is any verbal output.” This is complicated when their work setting requires formal measures, and even restricts informal measures. Patricia explains: “because I’m in a school setting that’s been very restrictive about what we can and cannot do in terms of students. We’re not supposed to touch a student without permission to test. We’re not supposed to do anything informal. But we do it.” As another flexible area of assessment selection, it became clear throughout the focus groups that many clinicians, especially in hospitals and rehab facilities, have created their own measures from subtests of other clinically-derived assessments. Tammy explained this process: “This is good, I don’t feel so bad because Katie said she uses a bunch of subtests and that’s exactly what I do too...I will use portions of the Boston, the Western Aphasia battery, and then we also have a couple...informal assessments.” With the exception of the SLPs that worked with adults, each population group mentioned informal assessments significantly more often than formal

assessments. With adults, informal measures were mentioned 43 times and formal measures were mentioned 42 times, the only difference that was not greater than 9 mentions. There also existed a gap in how often clinicians mentioned clinically-derived assessments and functional communication outcomes measures. Clinically-derived assessments were mentioned much more frequently across populations and work settings, with the exception of clinicians that worked with individuals who had AAC needs and SLPs employed in universities, who mentioned functional communication assessments more often than clinically-derived assessments.

Goal Setting. This sub-theme was mentioned by 12 of the 14 participants a total of 47 times. During assessment, a priority of the process for many clinicians is to identify areas for potential goals from the results of the assessment. This can be done first by centering the patient and family in the process. Jillian explains: “So I think that social support and the family feedback and stuff is huge. We definitely look at it to incorporate it into their functional outcomes measures and things...maybe if they added something in that additional measure for family support.” Casey agreed and sees patient-centered outcomes as a priority in the process: “They’re the most important part of this. Because they’re only gonna be motivated and driven by what they want to work on.” In addition to centering family and patient outcomes, Jane and others discussed collaborating with the multidisciplinary team to set goals: “we collaborate and consult a lot, so we’ll try and you know, also prioritize what the intervention teams want.” Jillian, along with her multidisciplinary team, also makes sure the goals are manageable throughout the patient stay with FIMS goals: “when we go into for example, a rehab staffing, we have initial FIMS, current FIMS, and then goal FIMS that we report on...and we might modify the goal FIMS.”

Outcomes/Targets. This sub-theme was referenced by all 14 participants, and was mentioned 109 times. The most important part of assessment is the information garnered from

the assessment that informs a clinician's practice. The participants listed at length many outcomes they prioritized in their own assessment practice, and those they would like to see assessed more accurately in future tools. Some of those assessment targets would be characterized as functional activities. These activities appear to be deemed functional due to the patient's needs, history, and priorities. Anne illustrated this in the priority outcome she chose: "I focus a lot on literacy, um, because so much of language is developed through the literacy and my kids are so low, um we really do a lot of literacy and trying to encourage them to be able to sit and listen to a book." Priority targets also included outcomes of participation, though they were not as commonly cited as activities. These are often difficult to target outside of a patient's natural context, but Anne also described how she assessed these outcomes in the classroom: "So as far as communicative participation, we at our school have a really interesting kind of environment where all of our kids have autism or related disability or something like that so we're constantly, staff-wise, always looking at where the kids can increase their communicative participation and be able to participate throughout their day." Many participants discussed difficulty with finding assessments that targeted skills suitable for their more high-functioning clients. Jillian said: "So those are things that I feel like everyone in our department struggles with a little bit is just liking to see measurements of that higher level cognition, especially for people that want like study skills or you know, returning." Finally, clinicians expressed interest in outcomes that measured a person's communicative functioning that was not done verbally. Casey explained: "I like the idea of having something with functional communication that's not just more of an expressive, either a verbally or written expression, so seeing if there's, because people communicate in other ways besides that, like an output method, so possibly natural gestures, pantomime, something like that."

Team Members. This sub-theme was mentioned a total of 39 times by 12 participants. In discussing assessment, each participant mentioned a member of the team that was not the clinician or patient. In some settings these teams are larger and more formal, and vice versa in others. Jillian discussed the team at her work setting: “So rehab docs, social work, OT, PT, Speech, dietician, psychology, pretty much everybody’s there, and they kind of talk about any new admits and any urgent issues or discharge planning issues but that’s a nice place to gather information about their functioning you know in the PT gym or socially up on the unit.” Some participants emphasized multidisciplinary assessment with those populations with multiple disabilities. Helen discussed the teamwork with AAC evaluations: “with the more complex, we tend to do, in Ohio, or I’m sure this is national, but we do an initial assessment and then we do an evaluation every three years, so I do a multidisciplinary, like I do an evaluation with an OT, PT, and speech and we’ll set up switches try different modes of access, a lot of times we’ll try different positioning.” Mentions were made in reference to team members when discussing assessment in general and using self or proxy-report as assessment. This was most often referenced with SLPs who worked with adults, who referenced these a combination of 52 times. However, those SLPs who worked with AAC populations were the least likely to reference other team members, referencing the idea only 14 times in total. This number is unexpected given that clients with AAC needs often employ a multi-disciplinary team approach to acquiring a communication system.

Needs in the Profession

The final theme identified in the coding process was Needs in the Profession. This theme included areas of growth concerning assessment identified by participants. The sub-themes

identified were: Define Terminology, SLP Variability, Research and Practice, and Work Setting Restrictions.

Define Terminology. This sub-theme was mentioned 52 times by all 14 participants. A problem identified by multiple participants throughout the groups was poorly defined terms within the field. Some of the terms identified were *functional*, *outcomes*, *cueing strategies*, and *modeling*. Jane identified these issues and their impact on the field: “Again I think in terms of prioritizing outcomes, you know a lot has to go around education and really trying to get consensus or meet in the middle or go full speed ahead with really defining what functional participation means you know, in addition to communicating basic wants and needs.” In fact, some participants asserted that there is made-up terminology permeating the field that is not universally understood, as explained by Sharon: “The field does not have consistent terminology, some is made up, we have and continue to do a terrible job, like people make up terminology.” Sharon used the examples of “modeling” and “visual cues” as terms that have various meanings depending on who is using the terminology. Sharon proposed, and the general idea was shared with some other participants, that narrated video be used more often to illustrate concepts and terminology when possible. “I think we not only have to define it, I think we have to provide, when we can, video samples because I don’t think we can assume, even the three of us talking amongst ourselves that we know exactly what we’re talking about.”

SLP Variability. This sub-theme was mentioned by 13 participants a total of 49 times. While many of the participants in this study shared beliefs and ideas, the greater population of SLPs contains a lot of variability. Clinical experience can determine decisions made on a daily basis. Jillian said, “There’s a lot of uniformity (in our department) and kind of training to kind of create that so that we all do things very similarly, which I think is good, for the most part but

then sometimes you know I think there's a little bit of variability in terms of what assessments people like and dislike." Tracy identified further perceived differences: "So I think sometimes there may be SLPs who look more just at the standardized test without looking at how that, their language is actually affecting their performance if that makes sense." There can also be much consistency between SLPs and their opinions about and approaches to outcomes measures. This can be dependent on the setting, target population, or can be common across the field. Karen explained her colleagues' thoughts: "I think some do (share opinions on outcomes measures), and I don't know of anyone, I don't think anybody is completely satisfied with any formal test."

Research and Practice. This theme was mentioned by four participants a total of 13 times. Maintaining knowledge of current research in your target population, setting, and beyond is a duty of SLPs and all medical and academic professionals. Helen said, "Well I was gonna say ethically that is our responsibility to research and be on top of the treatments too." Some participants discussed that this is not currently occurring in the field. For that reason, they suggested the field move forward to incorporate research to practice. Jane said: "I think, again as a field we've done a terrible job with it and we have to be finding a way to merge research with clinical practice." If the field is to improve their use of research, future research must be done to further knowledge. Sharon discussed her feelings about the focus group: "I just wanted to say that I think this is a good starting point, I'm glad that you put this together to kind of get information from others within the field that are actually practicing and working with individuals that are using AAC because I definitely think it's something that needs to be explored."

Work Setting Restrictions. This sub-theme was mentioned by 10 participants a total of 41 times. An SLP's work environment can impact many of their decisions concerning assessment, regardless of patient population. For an example, for those SLPs that worked with children and

adolescents in schools, inconsistency across school districts creates confusion among SLPs, like Helen: “I feel like there needs to be some generalization across what districts are teaching people from different programs...looking at research, looking at the treatment approaches, I think it would help develop the profession.” Further difficulties reported by the SLPs who worked in schools is that it is often difficult to qualify a student for therapy, and usually requires normed data. This has been quoted in previous passages, and remains a theme throughout those participants in schools. Finally, there are often time restraints specific to each setting. Vicky talked about her colleagues’ experiences in acute care: “So in acute care they look at it a little bit differently than I do. I look at more higher level subtle skills cognitively than they do. They don’t always see that in their setting because they’re so in and out.”

CHAPTER 4

Discussion

The purpose of this study was to learn more about speech-language pathologists' experiences with functional communication outcomes measures, and what they want in an ideal assessment. There were four themes identified in the coding process, with sub-themes under each theme that more appropriately capture the specifics of each theme. In the following paragraphs, these sub-themes and connections to the current body of literature are applied to the research questions posed in the introduction. Limitations of the study, directions for future research, and implications for clinical practice are also discussed.

Speech-Language Pathologists' Experience of Assessment

Negative attitudes. When asked questions regarding the assessment process, participants gave information about their frustrations with assessment in general, not just with functional communication outcome measures. The attitudes were overwhelmingly negative when discussing the experience of assessment in the field, across populations and work settings. This is consistent with latest research that has surveyed clinician opinions about outcomes measures and assessment in general. In a survey regarding functional communication outcomes measures by Heuer, Lund, & Heilmann (2017), 49% of participants in the survey responded that they were "somewhat satisfied" with functional communication outcome measures. In a survey by Simmons-Mackie, Threats & Kagan (2005), limitations to assessment were reported by 56% of participants. In the present study, 100% of the participants reported negative aspects of outcomes assessment. This led to a greater frequency of clinicians choosing informal measures to assess their clients. The negative attitudes included allusions to similar limitations that have been

referenced in the aforementioned studies. These limitations included time constraints, “organization logistics, patient logistics,” (Simmons-Mackie, Kagan & Threats, 2005, p. 7), and lack of availability. The most frequently-referenced limitations to outcomes measurement in the present study and in the Heuer, Lund, and Heilmann study, were assessments not measuring what they are supposed to measure (functional outcomes), and assessments not being appropriate for target populations due to a variety of factors (length, level of functioning, output method). The frequency of negative attitude references and trends in limitations that have existed for at least the last 17 years, indicate a need for development of more appropriate outcome measures that meet the needs of SLPs. Further, the issues discussed in the current study existed across populations and settings, indicating a widespread problem.

Positive attitudes. Participants discussed satisfaction with their ability to alter and adjust measures to their needs, if their work setting allowed. A few of the participants discussed using only subtests of formal tests, or relying heavily on other informal measures to collect evaluation data. While the practice of using clinically-derived assessments informally or formally (administering only chosen subtests of an assessment vs. administering the full standardized assessment) was not researched in previous studies, the use of clinically-derived assessments was documented in the ASHA 2013 Health Care Survey which indicated that fewer than half of the SLPs surveyed utilized outcomes measures in their practice (40%). Participants in the present study also reported satisfaction with their informal assessments, indicating that there is a need for further development of assessments to give reliability and validity to the measures used in the field.

Team members. The participants made consistent references to others involved in outcomes measurement. This included fellow SLPs, other medical professionals, and family

members of their patients. The multidisciplinary approach is one that is effective but often has many limitations in settings where it cannot be billed equally for each professional (“11 Part B Billing Scenarios”). Mentions were made about team members when discussing outcomes measurement and using self or proxy-report as assessment. This was most often suggested with SLPs who worked with adults, who alluded to each a combination of 52 times. However, those that worked with AAC populations were the least likely to reference other team members, mentioning the idea only 14 times in total. Clinicians that work with clients with AAC needs often work with multidisciplinary teams to provide AAC services (Binger et. al 2012); however the results of the current study indicate that this may not extend to outcomes assessment.

Characteristics of an Ideal Measure

The second research question looked at what SLPs value and want in the outcome measures they need for their populations and work settings.

Assessment approach. Participants in the present study describing ideal results from an assessment often described *accurately* assessing outcomes, and showing growth. Participants and researchers in a 2005 survey regarding outcomes assessment in aphasia dealt with the same questions (Simmons-Mackie, Threats & Kagan, 2005). Researchers asked, “what constitutes improvement. For example, is improvement a higher score on a standardized aphasia test such as the *Western Aphasia Battery*? Is it improved ability to express wants and needs?” (p. 12). Participants emphasized “functional” outcomes showing growth in the patient’s natural context, emphasizing that this was not always achieved with the functional communication outcomes measures or clinically-derived measures currently available.

In previous research done by Heuer, Lund, and Heilmann (2017), respondents to a survey indicated the purposes for which they used both functional communication outcomes measures and clinically-derived measures. On the whole, clinically-derived measures were used more frequently for baseline data and goal setting, while functional communication outcomes measures were used more for acquiring funding or reimbursement, and for quality of life or “satisfaction” measures. This is consistent with the codes drawn out from the focus groups in the present study, which identified the purposes of assessment as showing growth, establishing a baseline, supporting authentic communication, and acquiring funding or qualifying a patient for therapy.

Ideal characteristics. In the present study, participants identified the ability to get the assessment completed in 30-60 minutes as a top priority. Time constraints were identified as a leading limitation to current outcomes measurement practices, so an efficient measurement tool is a vital tool. Another top priority was that the measure was customizable to fit the client. The criteria for “fitting the client” included being able to incorporate clinical judgment to administer the test to fit the client’s anticipated level of functioning, and being able to adjust it to client needs while maintaining the ability to obtain normed results. It should be mentioned that although efforts were made to clarify differences between clinically-derived measures and outcomes measures, there may have been some confusion of the measures within the groups. Characteristics that are typically present in both types of measures were mentioned. In a 2005 survey for outcomes measurement in aphasia, time constraint was named as the top barrier to outcome assessment by the most participants (Simmons-Mackie, Threats & Kagan, 2005). Other top priorities included ease of use and validity of functional outcomes measurement. Priority outcomes cited throughout the focus group transcripts in the current study were largely

characterized as communication outcomes at the Activity level of the ICF. Activities, as defined by the ICF and discussed in the introduction, are functional tasks performed by an individual. These tasks do not include the context in which they are performed. Participation outcomes, as defined by the ICF, are characterized as involvement in a life situation. As discussed in the introduction, both categories of outcomes are vitally important to patient functioning and quality of life, but it is important that clinicians know the difference and value outcome progress in both areas.

Limitations of the Study

This study employed qualitative methods to pursue knowledge about SLP's experiences of outcome measures and assessment in their settings. This was an appropriate method for answering this question, but it has its limitations. The researcher completed all aspects of transcribing, coding and analyzing the data without assistance. The information garnered from coding could reflect researcher bias as she devised the focus group questions, conducted the focus groups, and analyzed the data. There was also no participant check in place due to time constraints of the study. The number of individuals who participated in the study, 14, also serves as a limitation and cannot claim to represent the opinions of all speech-language pathologists. Further, there was a larger concentration of speech-language pathologists from the Midwest as some participants were contacted through local networks. Six of the 14 participants were located in the Midwest, with three of those participants living in Wisconsin. Finally, the focus groups themselves were a limitation. Due to difficulties scheduling participants, two of the groups were structured as interviews with a single participant. Further, technical difficulties throughout the groups with downloading Skype for Business and using home computers made some

participation in the groups difficult, so those who participated did so on the condition that they could operate the program and troubleshoot any difficulties. Due to the focus of the study, there is also a self-selection bias. Those who volunteered to participate may have had particularly strong opinions about outcomes measurement which may not be reflective of the general population of SLPs.

Clinical Implications and Directions for Future Research

This study identified several themes regarding the shared experiences among speech-language pathologists with outcomes measures and assessment in the profession. Having concrete examples of these themes can resonate with other speech-language pathologists. It can also assist in describing the current limitations of assessment and exploring ways to work through them. The recommendations for clinical practice in the following paragraphs are based on the information garnered from the focus group discussions.

Clinicians often create informal measures of their own to use to assess their clients so they can set appropriate goals and measure progress. Participants often felt that they made up their own tool or modified validated tests to gather information they thought was needed. While this provides the clinician with flexibility in assessing, it can lead to clinical bias such that the clinician uses assessments as justifications, rather than tools to discover and describe function. This practice can also lead to threats to validity because tests are not being administered according to standardized procedures. Clinicians should continue to seek out valid instruments that meet the appropriate targets and work with multiple types of assessments to assure their therapies are making measurable change in their clients' everyday functioning.

Participants identified difficulties in using a common language for outcomes measurement. Clinicians can facilitate discussions within and outside of their department in their work setting to agree on definitions for terminology used to assure that all are working towards the same goals. These poorly-defined terms include: functional, participation, outcomes, and progress. To do this, the field should adopt consistent terminology and define these common terms so that there is a resource to point to for all professionals. Participants identified difficulties in using a common language for outcomes measurement. To combat this, the field should work to adopt consistent terminology.

Clinicians did not refer to outcomes of Participation with the same frequency as Activity outcomes in the present study. Clinicians should familiarize themselves and colleagues in the field with the Participation model and increase emphasis on outcomes falling under this category to promote further outcome improvement that makes a difference in a client's individual community functioning.

Future research should pursue more information about the issues brought up in the present study. Similar studies should be completed to validate the present results with a larger participant population. Further research should also include pursuit of consensus on relevant terms for assessment discussed earlier, and use of these definitions consistently in future research. Further, work should be done towards development of a functional communication outcomes measure that more appropriately measures the outcomes prioritized by clinicians. Those outcomes include quality of life, functional Activity, communicative participation, and caregiver report of function. This should include suggestions from clinicians working with varied populations and in settings as it has been shown that priorities are similar across those groups.

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APPENDIX A

Demographic Information Survey

Participant # _____

1. Are you currently practicing as a Speech-Language Pathologist?

2. If no, do you currently hold your Clinical Competency Certificate (CCC) as a Speech-Language Pathologist?

3. Please indicate your highest level of education.

4. How long have you held your CCC's?

5. How many years have you been a practicing SLP?

6. Please indicate your state of residence.

7. What is your current work environment? (select all that apply)

_____ Schools

_____ University

_____ Acute Hospital

_____ Inpatient Rehabilitation

_____ Subacute Rehabilitation

_____ Outpatient Rehabilitation

_____ Pediatric Hospital

_____ Skilled Nursing Facility

_____ Subacute Rehabilitation

OTHER _____

8. Indicate what percentage of your client hours are spent with the following populations?

- _____ Adults (18+)
- _____ Children (0-17)
- _____ AAC (all ages)
- _____ Other _____

9. Approximately how many evaluations for each of the following have you conducted in the last year?

- _____ Adults
- _____ Children
- _____ AAC
- _____ Other

10. Approximately what percentage of your time throughout the year is spent providing continuing education, training, or consulting for other professionals regarding your population?

- _____ Continuing Education
- _____ Consulting
- _____ Other Relevant Activities (list): _____

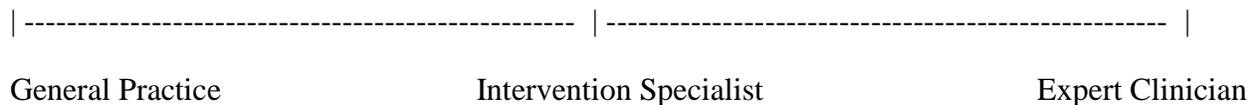
For the following items, please select all that apply.

Do you provide continuing education training?

If yes, to whom?

Researchers
 Educators
 Medical Professionals

Based on the definitions below (Beukelman, Ball, & Fager, 2008), how would you rate yourself? (place an x on the continuum)



General Practice Clinicians provide a range of clinical services as part of their daily practice. Although they do not specialize in intervention services for one target population (children,

adults, or AAC), the agencies where they work serve those populations.

Intervention Specialists spend at least 50% of their clinical workload providing direct services (e.g., assessment, instruction, funding assistance, and follow-up) to one disorder/intervention population (AAC, Aphasia or Child Language).

Experts focus on developing and maintaining the knowledge, technical, policy, and service bases of one disorder/intervention field (children, adults, or AAC) They include university faculty, consultants, researchers, technology developers, policy-makers, and administrators of specialized service programs.

APPENDIX B

Relevant Focus Group Terms

Focus Group Terms:

1. Outcomes: Positive or negative changes in the health of groups of people or individuals for which credit can be given to prior or current health care.
2. Participation (as defined in the *International Classification of Functioning, Disability and Health* (ICF) and by Chang & Coster, 2014): Active involvement in activities that are intrinsically social and occur in a socially-defined context.
 - a. *Example of relevant SLP outcomes*: Rating a client’s ability to recount a story to a same-aged peer in the school environment.
3. Activity: The execution of a task by the individual.
 - a. *Example of relevant SLP outcomes*: Measuring “receptive language skills” in a standardized assessment, e.g. understanding one-unit directions. This skill is not performed in a social context.
4. Body Structure and Function: Body Functions and Structures refer to the physiological and psychological functions of the body and the anatomical components of the body, respectively
 - a. *Example of relevant SLP outcomes*: Body Functions may include voice production, while Body Structures would include intact structure of the vocal folds.
5. Communicative Participation (as defined by Eadie, et al. 2006): taking part in life situations where knowledge, information, ideas, or feelings are exchanged. It may take the form of speaking, listening, reading, writing, or nonverbal means of communication.

Communicative participation may occur in multiple life situations or domains and includes,

but is not limited to, personal care, household management, leisure, learning, employment, and community life. Because communicative participation is measured in a social context, by definition it involves more than one person and must involve a communicative exchange (i.e., a message and the opportunity for a response from a communicative partner).

- a. *Example of relevant SLP outcomes:* Rating to what extent an employee can understand and execute their boss' instructions for an assignment delivered via email.
6. Clinically-Derived Assessment: Standardized tools that have been normed and validated for the target population (e.g., the Western Aphasia Battery [WAB], the Test of Problem Solving [TOPS], the Aspiration-Penetration Scale).
7. Proprietary Outcomes Measures: Organization-specific software or customized outcome measurement tools (e.g., The Rehab Outcome Measures [ROMS], Lifeware™).
8. Functional Communication Outcomes Measure: Measures that describe a patient's functioning, activities, and/or participation in ADLs (e.g., Functional Independence Measures [FIM], ASHA's National Outcomes Measurement System [NOMS]). These also include patient-reported outcome measurement tools, such as the Voice Handicap Index (VHI) and overall quality of life (QoL) related tools, such as the Pediatric Quality of Life Inventory (PedsQL).

APPENDIX C

Case Studies

Each focus group will only receive the case study relevant to their clinical population.

Case Study 1: Adults

A 67-year old man presents to you in an outpatient setting that had a cerebrovascular accident (CVA) 11 months ago. After collecting a patient history, you gather that he has become increasingly socially isolated since the CVA and relies on his spouse as his primary form of communication to others. You decide to administer the Western Aphasia Battery (WAB) to gather information on the severity of his aphasia.

What type of assessment would this be categorized as?

Answer: Clinically-Derived Measure

The WAB provides an aphasia quotient of 72, qualifying his deficits as “moderate”, with particular deficits in expressive language as evidenced by his low performance in the naming and spontaneous speech picture description subtests. Patient strengths include receptive naming tasks (“point to the comb.”) and following multi-step directions (“point to the door before you point to the window”).

In your assessment you’re required to report outcomes using the NOMS scales (National Outcomes Measurement System) in his highest deficit area. In reporting on expressive language, you’re given a scale from 1 to 7 (1 = least functional, 7 = most functional) accompanied by descriptions describing an individual’s proficiency in language expression in a social communicative context. You decide to rate him as a level 4: “The individual is successfully able to initiate communication using spoken language in routine daily activities with familiar communication partners. The individual usually requires moderate cueing, but is able to demonstrate use of simple sentences (i.e. semantics, syntax and morphology) and rarely uses complex sentences/messages.”

What type of assessment would this be categorized as?

Answer: A functional communication outcomes measure.

Case Study 2: Children

A child aged 4;6 presents to you with the following language difficulties. He is a late talker according to his mother. Per mother report, “he was not putting words together until about age 3;6.” Since he began talking, he has not developed the vocabulary at the same rate as his peers. The child’s syntactic patterns are also exhibiting age-inappropriate errors. The child has significant difficulty telling stories about recent events. With other peers, he has difficulty making friends as he is often not aware of his difficulties and other students have problems understanding him and having patience to play a game with him or having a conversation with him. You decide to administer the CELF-P (Comprehensive Evaluation of Language Fundamentals-Preschool).

What type of assessment would this be categorized as?

Answer: Clinically-Derived Measure

The child is assessed and scored with his core language score putting him at an age-equivalent of 3;2, a year and a half below his actual age. The child has particular deficits in expressive language as evidenced by performance in the subtests “recalling sentences,” “word structure” and “expressive vocabulary”. In order to comply with your district’s requirements, you’re required to report outcomes using the NOMS scales (National Outcomes Measurement System) for pre-kindergarten in relevant areas, in this case communication. The scale contains a rating system between levels 1 and 7 (1 = least functional, 7 = most functional). An example rating in the area of “Spoken Language Expression” for this child may be:

Level 4: The individual is successfully able to initiate communication using spoken language in simple, structured conversations in routine daily activities with familiar communication partners. The individual usually requires moderate cueing, but is able to demonstrate use of simple sentences (i.e., semantics, syntax, and morphology) and rarely uses complex sentences/messages.

What type of assessment would this be categorized as?

Answer: Functional Communication Outcomes Measure

Case Study 3: AAC

A child aged 4;8 presents to you with spastic cerebral palsy. She was born prematurely with very low birth weight. She is able to voluntarily move upper and lower extremities, though they are also characterized by involuntary movements. Generally, her movement is slow and arduous. She is a non-verbal communicator with a very limited phonological inventory. It has been determined that she is at a developmentally appropriate level for expressive and receptive language as evidenced by her performance on language assessments thus far and use of PECS (Picture Exchange Communication System). She is a social child that enjoys interacting with others. For the purposes of assessment in the process of determining the appropriate high-tech AAC device for this child, the Vineland Adaptive Behavioral Scales was administered.

What type of assessment would this be categorized as?

Answer: Clinically-Derived Measure

The child was given standard scores in the areas of Communication, Daily Living Skills, Socialization, and Motor Skills. She scored the following:

Communication: 62 (borderline adaptive functioning)

Daily Living Skills: 64 (mildly deficient adaptive functioning)

Socialization: 71 (borderline adaptive functioning)

Motor skills: 35 (severely deficient adaptive behavior)

In order to comply with your district's requirements, you're required to report outcomes using the NOMS scales (National Outcomes Measurement System) for pre-kindergarten in relevant areas, in this case communication. The scale contains a rating system between levels 1 and 7 (1 = least functional, 7 = most functional). An example rating in the area of "Spoken Language Comprehension" for this child may be:

Level 6: The individual is able to understand communication in most activities, but some limitations in comprehension are still apparent in vocational, avocational, and social activities. The individual rarely requires minimal cueing to understand complex sentences. The individual usually uses compensatory strategies when encountering difficulty.

What type of assessment would this be categorized as?

Answer: Functional Communication Outcomes Measure

APPENDIX D

Focus Group Script

I. WELCOME

- a. Thanks for agreeing to be part of the focus group. We sincerely appreciate your willingness to participate.

II. INTRODUCTIONS

- a. Moderator
- b. Assistant Moderator
- c. Other focus group members

III. PURPOSE OF FOCUS GROUPS

- a. The reason we are having these focus groups is to find out what speech-language pathologists (who specialize in adults/children/AAC) want to be included in a functional outcome measure of communicative participation? We need your input and want you to share your honest and open thoughts with us.

IV. GROUND RULES

- a. WE WANT YOU TO DO THE TALKING.
 - i. We would like everyone to participate. I may call on you if I haven't heard from you in a while.
- b. THERE ARE NO RIGHT OR WRONG ANSWERS
 - i. Every person's experiences and opinions are important. Speak up whether you agree or disagree. We want to hear a wide range of opinions.
- c. THERE IS NO NEED FOR THE GROUP TO COME TO A CONSENSUS REGARDING ANY QUESTIONS DISCUSSED
 - i. When conducting a focus group, our sole motivation is to understand what professionals in the field need from their outcomes measurements and what future needs they anticipate. Those do not have to be the same in each person. Your honest input is very appreciated!
- d. WHAT IS SAID IN THIS ROOM STAYS HERE
 - i. As was discussed in the consent form you signed prior to entering this group, a pseudonym will be applied to your name in transcriptions of the group discussion and reporting of results. The recordings will be private and not shared with anyone outside of those mentioned on the consent form (IRB, moderator, assistant moderator).
- e. WE WILL BE TAPE/VIDEO RECORDING THE GROUP
 - i. We want to capture everything you have to say. We don't identify anyone by name in our report. You will remain anonymous.

V. PRESENTATION OF APPROVED AND DEFINED TERMS FOR FOCUS GROUP AND CASE STUDIES

- a. Research has shown that the definition of functional communication outcomes measures is not widely known within the field and these measures are often confused for other oft-used measures during the assessment process.
- b. Upon meeting criteria for this focus group, each member was given a list of definitions for relevant terms to be used in the focus group and a case study corresponding to your target population (See APPENDIX B).
- c. We will review this information now by reading over the terms and relevant case study and will clarify any questions about the terminology after review.

VI. DISCUSSION

- a. Describe your experiences with assessing your clients for communicative participation and functional communication.
- b. To what extent do you see your experiences reflected in your professional colleagues' experiences?
- c. Are you satisfied with current measures available for measuring functional communication in (specialization)?
 - i. If not, why?
 - ii. If so, why?
- d. What outcomes do you prioritize when assessing your clients?
- e. If you could create an ideal measure for your measuring participation/functional communication outcomes, what would it include?
- f. What role do you think self-report should have in outcomes measurement?
- g. Is there anything else you'd like to share that we have not touched on?

VII. CONCLUSION

- a. Thank you so much for your time. We will be sending you a summary of the analysis, we would appreciate you letting us know if we have captured the essence of the discussion.