Characterizing Functional Limitations in Children Using the *International Classification of Functioning, Disability and Health-Children and Youth Version* (ICF-CY)

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ABSTRACT

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(Under the direction of Elizabeth Crais)

This project was designed to create and pilot test a checklist for use with populations of children that present challenges for evaluators. The World Health Organization's *International Classification of Functioning, Disability, and Health-Children and Youth* (ICF-CY) system was used to create a checklist to better characterize functional limitations in children. The checklist evaluates Body Structures and Functions, limitations in Activities and Participation resulting from speech-language difficulties, and relevant Environmental factors. Seven children with rare disorders and ten native Spanish-speaking children in Guatemala were evaluated using formal (standardized and non-standardized) tools and the pilot version of the ICF-CY based checklist. The results of testing and case studies demonstrate the clinical utility of the checklist. The main benefit of the ICF-CY checklist was identifying how children's speech-language impairments impacted their participation in daily activities. As a result, the checklist was also used to make functional treatment recommendations.

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CHAPTER 1

INTRODUCTION

Assessing speech and language skills in children with severe disabilities is a challenge. However, successfully describing the child's present skill levels is a critical first step in appropriate treatment planning. This thesis describes the development and pilot testing of a checklist that was designed for use with populations that typically are difficult to assess. The main population studied was children with rare metabolic disorders, but additional pilot data were also collected with a population of children with speech and language impairments whose first language is not English.

One assessment facility that evaluates children with metabolic disorders is the Neurodevelopmental Function in Rare Disorders (NFRD) team affiliated with the University of North Carolina School of Medicine and Duke University Medical Center (DUMC). The NFRD team is focused on helping children with rare, lysosomal storage and neurological disorders improve their quality of life. Lysosomal storage disorders refer to disorders in which an essential enzyme is absent from the body, which results in the progressive accumulation of cell products (Wilcox, 2004). The accumulation of cell products will eventually "interfere with cellular function" (Wilcox, 2004). The NFRD team sees pediatric patients and their families from all over the United States (and sometimes from other countries) to document disease course through assessment and diagnosis, education, and treatment recommendations for children with rare disorders such as Krabbe, Sanfilippo, Metachromatic Leukodsystrophy (MLD), and Adrenoleukodystrophy (ALD). Incidence

estimates indicate metabolic disorders affect approximately one per 7000 to 8000 live births (Wilcox, 2004; Heese, 2008), although the incidence for each disorder is much lower. These disorders generally cause catastrophic neurological symptoms and often progress rapidly, leading to death in infancy or childhood. Early symptoms of these disorders may include (a) loss of developmental skills, (b) progressive dementia, (c) increasing behavioral abnormalities, or (d) signs of muscular or neurological degeneration (Wilcox, 2004).

Presently, there are several experimental treatments available including Enzyme-Replacement Therapy (ERT) and Hematopoietic stem cell transplantation (HCT), but there is no cure for these diseases (Wilcox, 2004; Heese, 2008). HCT involves engrafting healthy donor stem cells into the patient who is lacking an essential enzyme (Wilcox, 2004; Heese, 2008). Research has shown that this is a particularly effective treatment for Hurler syndrome when patients are diagnosed and implanted early (Wilcox, 2004). Enzyme replacement therapy involves periodically introducing the missing enzyme intravenously, but evidence of positive results using this technique is limited (Wilcox, 2004; Heese, 2008). Since HCT and ERT are possible treatments that are still in the experimental stages, appropriate documentation of the benefits and costs of these procedures and their contribution to overall functioning is necessary. In order for the treatments to be proven efficacious, all aspects of functioning for children receiving HCT, ERT or no treatment must be considered. However, current assessment tools, especially in the field of speech and language development, may not be adequate to fully assess functioning in this unique population. One reason that current speech-language assessments are inadequate for use with this population is that the degenerative course of these diseases goes against the expected developmental curve, making it difficult to use standardized measures based on a normative sample of typically developing

children. Thus, there is a need for more appropriate assessments, especially in the areas of speech, language, and swallowing for this population of children.

Patients with rare metabolic disorders often receive comprehensive interdisciplinary evaluations at time intervals of 3 months, 6 months, or 12 months depending on their health conditions. During each appointment, children may receive evaluation of hearing, motor, cognitive and communication abilities and overall health status. When children are seen by speech-language pathologists, they typically are assessed using standardized language measures such as the Clinical Evaluation of Language Fundamentals, Fourth Edition (CELF-4) (Semel, Wiig, & Secord, 2003); the Clinical Evaluation of Language Fundamentals—Preschool, Second Edition (CELF Preschool-2) (Wiig, Secord & Semel, 2004); or the Preschool Language Scale—Fourth Edition (PLS-4) (Zimmerman, Steiner & Pond, 2002). The evaluation also includes informal parent interviews and an oral motor screening.

The assessment protocols initially were selected based on their positive psychometric properties of reliability and validity at the time of selection. Since that time, a need for a more comprehensive evaluation of these children in their life situations has been deemed necessary because the current assessments are limited in their informative capacity. For example, the current norm-based assessment procedures can only capture skill levels that approximate the chronological age range. This is problematic when, for example, a child is chronologically 12 years, 2 months but has a receptive and expressive language age equivalent (based on the PLS-4 concepts) of 10 months. When verbal responses are required for a language measure, like the CELF-4 (Semel et al., 2003), and the child being assessed is nonverbal, it may be difficult to determine the skills the child has maintained, the approximate level of communication impairment or to even document changes in skills. In

addition, the present language measures are limited in the scope of skills assessed and do not consider the child's activities and participation in life situations or contextual factors such as environmental or personal factors. Assessing the child's ability to participate in daily life and use of assistive technology or environmental supports is likely to present a more comprehensive picture of the child's functioning than is possible with the current assessments. This more comprehensive look at a child's abilities may help to develop functional support for communication and other domains.

In order to assess a child's participation in daily life activities and use of supports, an alternative to standardized assessment is needed. One framework that may hold some promise is the *International Classification of Functioning, Disability and Health-Children and Youth* (ICF-CY) developed by the World Health Organization (WHO, 2007). Using a neutral and non-normative classification system such as the ICF-CY framework may allow for better evaluation and classification of functions in this unique population than standardized communication evaluations alone currently provide. The ICF-CY is a classification system that allows for a comprehensive evaluation of the child, including aspects of health and disability and participation in daily activities. Although the entire ICF-CY coding system could be considered, in its published form it contains many codes related to all aspects of health and wellbeing, rather than just communication. The current project proposes to create an ICF-CY checklist and parent interview in an effort to better characterize the children's communicative functioning, activities & participation, and contextual factors. This classification system may provide an additional measure of progress over time as well as a framework that will facilitate writing goals to increase activities, participation and beneficial environmental factors in addition to improving functioning.

The use of a framework such as the ICF-CY (WHO, 2007) in clinical practice is not a new idea. For example, Brown & Hasselkus (2008) suggest that the broader *International Classification of Functioning, Disability, and Health* (ICF, WHO, 2001) may be readily incorporated into speech-language pathology clinical practice owing to the presence of the ICF terminology and framework written into the *ASHA Preferred Practice Patterns* (ASHA, 2004). For instance, ASHA guidelines for conducting assessments indicate that

> ‘‘Consistent with the World Health Organization (WHO) framework, assessment is conducted to identify and describe—
> . underlying strengths and weaknesses related to (type of disorder) that affects communication and swallowing performance;
> . effects of (type of disorder) impairments on the individual’s activities (capacity and performance in contexts) and participation;
> . contextual factors that serve as barriers to or facilitators of successful communication and swallowing and participation for individuals with (type of disorder)impairments.’’ (ASHA, 2004, p. 26).

This project will detail the development and pilot data collection process of a tool developed from the ICF (WHO, 2001) focused on children and youth (CY). Using an ICF-CY based tool may allow clinicians to more effectively and fully assess children with rare, lysosomal storage and neurological disorders. Additional pilot data from a population of Spanish-speaking children with speech and language impairments will also be presented. The purpose of this thesis is to test the utility of an ICF-CY based checklist in clinical practice with a focus on answering the following ICF-CY related question:

1. How feasible is using an ICF-CY based checklist in clinical practice?

CHAPTER 2

LITERATURE REVIEW: THE CASE FOR USING ICF-CY IN CLINICAL PRACTICE

Many previous attempts at standardized classification systems focus on the etiology and diagnosis of diseases for classification purposes. The ICF and ICF-CY have embraced what is termed a "biopsychosocial model" in which the focus is promoting health and wellbeing "with disability framed within the person-environment interaction" (Simeonsson, 2003) (WHO, 2007, p. 19). This unique approach investigates the individual's relationship to the universe and consequently views individuals in a holistic way, within their "universe of well-being" (WHO, 2007, p. 228).

The basis for this project will be the *International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).* The Children and Youth classification system is based on the *International Classification of Functioning, Disability and Health* (ICF) (WHO, 2001) and is designed to more accurately represent characteristics of the developing child and the interactions the child has with his or her environment.

The use of an ICF-CY-based assessment tool may help overcome some of the shortfalls of standardized assessment tools that are currently being used to assess speech and language in children with low-incidence, high severity disorders. Some of the main problems with standardized assessments for the target population were highlighted previously and are discussed in more detail below. First, the development of skills and

subsequent loss of skills in children with rare metabolic disorders does not occur along a normal developmental trajectory. Many of these children achieve at best a standard score of 50 (if a standard score can be determined at all) on standardized evaluations; thus, their progress over time is difficult to track. They also may have maintained some skills that are not assessed using standardized assessments. Next, formal assessments are limited in the number of skills assessed. Assessing an 8-year-old child who has preverbal language skills using the CELF-4 (Semel et al., 2003) is nearly impossible, because of the verbal demands of the assessment. Using the concepts on the PLS-4 (Zimmerman et al., 2002) to obtain a qualitative estimate of language skills also limits the comprehensiveness of assessment because only early developing concepts are tested. Last, current speech and language measures often used by clinicians do not formally assess daily living activities, participation in these activities, and/or environmental factors that may affect participation, all of which are critical areas for maintaining and/or improving quality of life. For the reasons listed above, using a more comprehensive framework, like the ICF-CY, that assesses all aspects of a child's life may dramatically improve assessment and intervention for these pediatric populations.

History and Description of the ICF

The first World Health Organization classification system was published in 1980 bearing the name *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) (WHO, 1980). This version was developed as a supplement to the International Classification of Diseases-Ninth Edition (ICD-9) (WHO, 1977) and consisted of three linear levels of disablement including impairment (the Body level),

disability (the Individual level), and handicap (the Societal level). Three main weaknesses of this version of the classification system were (a) the linear and causal structure of the framework, which could not capture the complex interactions between the components, (b) the view that environmental factors were always negative, never facilitating, and (c) an absence of personal factors such as gender, age, education level, or lifestyle (Ma, Threats & Worrall, 2008).

Based on the criticisms of the first version, several field trials and drafts were conducted to revise the classification system. In May 2001, the *International Classification of Functioning, Disability and Health* (WHO, 2001) was endorsed by the World Health Organization (WHO). The main benefits of the revised ICF (WHO, 2001) version are the inclusion of operational definitions for all categories; a comprehensive coding system; neutral, as opposed to negative, terminology; and an interactional, socially-based model (Ma et al., 2008; WHO, 2007).

Soon after implementation of the ICF, weaknesses in its ability to adequately characterize children were identified. Since that time, a version of the ICF for Children and Youth (ICF-CY, WHO, 2007) has been created. In addition to the many similarities between the revised ICF and the ICF-CY versions discussed below, several changes were made to the revised ICF version in order for it to be used with children. First, the word *delay* was added to the classification system's definition of impairment. Other changes included (a) "modifying or expanding descriptions"; (b) "assigning new content to unused codes"; (c) "modifying inclusion and exclusion criteria"; and (d) "expanding qualifiers to include developmental aspects" (WHO, 2007, p. ix). For examples of each of these changes, readers are referred to Simeonsson, Leonardi & Lollar (2004).

As mentioned above, there are many similarities between the revised ICF and the ICF-CY version. For example, both frameworks make use of the same four components: Body Structures and Functions; Activities and Participation; Environmental Factors and Personal Factors. Body Structures refer to "anatomical parts of the body such as organs, limbs and their components" (WHO, 2007, p.9). For a child with an unrepaired cleft palate, this impairment in structure could be coded using the Body Structure code s3202 (*Structure of the Palate*) and possibly the codes for *hard palate* (s32020) or *soft palate* (s32021). Body Functions are defined as "physiological functions of body systems (including psychological functions") (WHO, 2007, p. 9). For example, a child with an impairment in speech function would be assigned a Body Function code for *articulation functions* (b320). Activities & Participation denote "execution of a task or action by an individual" and "involvement in a life situation," respectively (WHO, 2007, p. 9). An Activities/Participation code relevant to speech and language is *acquiring language* (d133). Environmental Factors "make up the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2007, p.9). An appropriate Environmental Factor code for a child who uses adapted toys for play such as a switch-operated toy would be e11521 (*Adapted products and technology for play*). While there are no specific codes for Personal Factors in the ICF-CY**,** coders are encouraged to note any relevant personal factors for the individual that could include, but are not limited to: "gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, and past and current experience" (WHO, 2007, p.15). Table 1 provides a summary of the current ICF-CY coding system components.

Table 1: ICF Coding System Component Overview (WHO, 2007, p.10)

	Part I: Functioning and Disability		Part II: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity executing tasks in a standard environment Performance executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers/hindrances	not applicable
	Disability			

ICF codes can be used "by clinicians, educators, policy-makers, family members, consumers, and researchers to document characteristics of health and functioning in children and youth" (WHO, 2007, p. xii). Once a code is selected from one of the four components mentioned above, qualifiers must be assigned to each selected code in order for the codes to have meaning. Qualifiers "denote a magnitude of the level of health (e.g., severity of the problem)" and until the qualifier is assigned, the code has "no inherent meaning" (WHO, 2007, p.20). Qualifiers follow codes and are separated from them by a decimal point (or in the case of an environmental facilitator, a plus sign). Further details on coding procedures are discussed below.

According to the ICF-CY (2007, p. xix-xx), there is a ten-step process for assigning codes related to problems in children and youth. The coding process is reviewed below with an example for a child who has difficulty with feeding and swallowing.

(1) "Define information available for coding and identify whether it relates to the domain Body Functions, Body Structures, Activities/Participation or Environmental Factors" (WHO, 2007, p. xix).

For Step 1, the information to be coded is that the child "has difficulty with bolus manipulation during feeding leading to frequent oral spillage." This information initially relates to the domain of Body Functions, because it can be considered a "physiological function of body systems" (WHO, 2007, p.9).

(2) "Locate the chapter (4-character code) within the appropriate domain that most closely corresponds to the information to be coded" (WHO, 2007, p. xix).

For Step 2, the chapter code b510 (*ingestion functions*) most closely corresponds to the available information.

(3) "Read the description of the 4-character code and attend to any notes related to the description" (WHO, 2007, p. xix).

For Step 3, the description for b510 *ingestion functions* reads "functions related to taking in and manipulating solids or liquids through the mouth into the body" (WHO, 2010).

(4) "Review any inclusion or exclusion notes that apply to the code and proceed accordingly" (WHO, 2007, p. xix).

For Step 4, inclusions are: "functions of sucking, chewing and biting, manipulating food in the mouth, salivation, swallowing, burping, regurgitation, spitting and vomiting; impairments such as dysphagia, aspiration of food, aerophagia, excessive salivation, drooling and insufficient salivation" (WHO, 2010). Exclusions are: "sensations associated with digestive system (b535)" (WHO, 2010). The code b510 continues to appear appropriate for this case, given the inclusions and exclusions.

(5) "Determine if the information to be coded is consistent with the 4-character level or if a more detailed description at the 5- or 6-character code should be examined"(WHO, 2007, p. xix).

For Step 5, the 5-character code b5103 (*Manipulation of food in the mouth*) may be more descriptive.

(6) "Proceed to the level of the code that most closely corresponds to the information to be coded. Review the description and any inclusion or exclusion notes that apply to the code" (WHO, 2007, p. xix).

For Step 6, the code b5103 (*Manipulation of food in the mouth*) is described as

"Functions of moving food around the mouth with the teeth and tongue" (WHO, 2010). There are no inclusions or exclusions listed.

(7) "Select the code and review the available information in order to assign a value for the universal qualifier that defines the extent of impairment in body function and structure, activity limitation, participation restriction (0=no impairment/difficulty to 4=complete impairment/difficulty) or environmental barrier (0=no barrier to 4=complete barrier) or facilitator (0=no facilitator to +4=complete facilitator)" (WHO, 2007, p. xix-xx).

For Step 7, the code b5103 is selected and the universal qualifier 2 is selected to indicate a moderate impairment that affects functioning up to "half of the time" (WHO, 2007, p.21).

(8) "Assign the code with the qualifier at the 2nd, 3rd or 4th item level. For example, d115.2 (moderate difficulty in listening)" (WHO, 2007, p. xx).

For Step 8, the code assigned to this case is b5103.2 (moderate difficulty in *manipulation of food in the mouth*).

(9) "Repeat steps 1 to 8 for each manifestation of function or disability of interest for coding where information is available" (WHO, 2007, p. xx).

For Step 9, based on additional information, Activities & Participation codes such as d550 (*eating*) and d560 (*drinking*) or Environmental Factor codes such as e1100 (*Food*), e115 (*Products and technology for personal use in daily living*), e310 (*Immediate Family*), and e340 (*Personal care providers and personal assistants*) could be coded.

(10) "Parents and consumers may participate in the process by completing age-appropriate inventories that allow specific areas of functional concern to

be highlighted, but they should do so before full evaluations and codes are provided by professionals or a team of professionals" (WHO, 2007, p. xx).

The previous example provides an overview of how the ICF-CY coding system can be used to characterize a child's current level of functioning in a specific area (e.g., swallowing). For the present study, codes related to speech, language, and swallowing functioning will be selected for use with individuals with rare lysosomal storage and neurological disorders. For further details of the complete ICF-CY classification system and coding conventions, the reader is referred to WHO (2007).

The ICF and ICF-CY Today

The ICF is currently being used extensively around the world in countries including Africa, Argentina, Australia, Brazil, Canada, Chile, Colombia, Croatia, Denmark, Finland, Germany, Greece, Hong Kong, India, Ireland, Italy, Japan, Korea, Mexico, New Zealand, Nicaragua, Portugal, Saudi Arabia, Slovenia, Sweden (southern portion), and the United Kingdom (Ma et al., 2008). For example, in Japan, the ICF is being used in National Health Insurance and National Long-Term Care Insurance Organizations (Ma, Worrall & Threats, 2007a). Nevertheless, at present, there is only emerging clinical use of this framework in the United States.

The lack of use of the ICF framework in the United States may be attributed in part to the need to develop more ICF-based assessment tools that specifically interface with relevant ICF codes (Simeonsson, 2009). Additionally, more empirical research on the use, reliability, and validity of such instruments is needed for the field to advance its use of the ICF in clinical practice. The more widespread incorporation of the ICF and

ICF-CY into clinical practice in speech-language pathology could serve to facilitate communication between speech-language pathologists and other professionals, especially in international settings (Ma et al, 2008). As suggested, the ICF has wide-ranging positive implications for improved practice and benefits including (a) "to provide a scientific basis for understanding and studying health, health-related states, outcomes, and determinants;" (b) "to establish a common language for describing health and health-related states in order to improve communication between different users, such as health-care workers, researchers, policy-makers and the public, including people with disabilities;" (c) "to permit comparison of data across countries, health-care disciplines, services and time"; and (d) "to provide a systematic coding scheme for health information systems" (WHO, 2007, p. 5). Currently, however, there is only one published, accepted, and verified ICF-CY checklist tool available for clinical use and it is for children who have speech impairments (McLeod, 2004), so in general clinicians must fit the coding system and framework to suit their specific needs. Two possible methods for applying the ICF concepts to practice are by using Core Sets and Linking Rules, and are described below.

Core Sets

Core sets are groups of codes selected from the ICF (or ICF-CY) for their relevance for use with patients with particular conditions or circumstances. To increase the efficiency of coding, these subsets of codes aim to target only the information that is necessary for patients with specific conditions to increase the efficiency of coding. Lollar & Simeonsson (2005) indicate that selecting codes for core sets should balance

"comprehensiveness with practicality" (p. 327). In other words, the core set is designed to facilitate efficiency in clinical practice without sacrificing a thorough evaluation. The concept of only using well-selected codes for the core sets is verified by the statement that "20% of the codes will explain 80% of the variance observed in practice" (Ustun, Chatterji & Kostanjsek, 2004, p. 7). In fact, the World Health Organization (WHO) has suggested that using between 3 and 18 of the 1424 available ICF codes may be "adequate to describe a case" (WHO, 2007, p. 235). Core sets have already been developed for 12 chronic conditions in adults including rheumatoid arthritis, low back pain, stroke and depression as part of a collaboration between the WHO, the Department of Physical Medicine and Rehabilitation and the ICF Research Branch of the WHO Family of International Classifications (FIC) Collaborating Center (CC) at the Ludwig Maximilian University Munich (Cieza, Ewert, Ustun, Chatterji, Kostanjsek & Stucki, 2004). These core sets are still undergoing empirical validation (Cieza et al., 2004).

Illustrations of Use of Core Sets

A core set may include codes from all four components—Body Functions and Structures, Activities & Participation, Environmental factors and Personal Factors (Ma, Yiu, & Abbott, 2007b). Table 2 provides an example of a core set with codes from all component areas that can be used to characterize functioning in individuals with various voice disorders.

Table 2 Example of a Core Set for Voice Disorders

Body Structures
s110 Structure of brain
s1106 Structure of cranial nerves
s340 Structure of larynx

s3400 Vocal folds
Body Functions
b126 Temperament and personality functions
b152 Emotional functions
b310 Voice functions
b3100 Production of voice
b3101 Quality of voice
Activities & Participation
d330 Speaking
d350 Conversation
d360 Using communication devices and techniques
d3600 Using telecommunication devices
d845 Acquiring, keeping, and terminating a job
d850 Remunerative employment
d920 Recreation and leisure
d9204 Hobbies
d9205 Socializing
Environmental factors
e125 Products and technology for communication
e225 Climate
e2250 Temperature
e2251 Humidity
e250 Sound
e2500 Sound intensity
e2501 Sound quality
e260 Air quality
e310-e399 Support and relationships
e410-e499 Attitudes
e515 Architecture and construction services, systems, and policies
e580 Health services, systems, and policies

(Ma et al., 2007b)

Children with rare disorders such as Hurler Syndrome occasionally have voice impairments that may be an indicator of an underlying structural impairment and may sometimes be severe enough to limit activities or restrict participation. For example, consider a child who has a neurological voice disorder (impairment of s1106 *structure of cranial nerves*) and who has aperiodic dysphonia (impairment in b3101 *quality of voice*). When the child loses his voice, he may not be able to participate fully in *recreation and*

leisure (d920) activities such as *socializing* (d9205). Thus, using the ICF-CY classification system allows the clinician to represent the functional limitations created for this child by his voice disorder. By being able to identify the functional limitations caused by the voice disorder during the evaluation, hopefully the limitations will be targeted in intervention.

Core sets of indicators for Autism and Asperger's syndrome have also been suggested (Simeonsson et al., 2004). The authors compiled two lists of 13 to 16 ICF Body function and Activities & Participation codes with qualifiers to help characterize functioning in children with these disorders. Note that in Table 3, qualifiers have been added to each of the codes to indicate severity of impairment for a specific adolescent with Asperger's syndrome.

Table 3. Core Indicators of an Adolescent with Asperger's Syndrome

Body Function Codes	Activities & Participation Codes
Mental Functions: -b140.2 attention functions (moderate impairment) -b164.1 higher-level cognitive functions (mild impairment)	**Learning & Applying Knowledge:** -d160.2 focused attention (moderate impairment) -d165.2 solving problems (moderate impairment) -d177.1 making decisions (mild impairment)
	General Tasks & Demands: -d240.2 handling stress & other psychological demands (moderate impairment)
	Communication: -d315.1 communicating with-receiving nonverbal messages (mild impairment) -d350.2 conversations (moderate impairment)
Sensory Functions & Pain: -b265.2 touch functions (moderate impairment)	**Interpersonal Interactions & Relationships:** -d720.3 complex interpersonal interactions (severe impairment)

	-d750.3 informal social relationships (severe impairment)
	Major Life Areas: -d820.1 school education (mild impairment)
	Community, Social, & Civic Life: -d910.1 community life (mild impairment)

(Simeonsson et al., 2004)

Research Support for Use of Core Sets with Children

In general, the ICF framework has been applied far more extensively in the adult population than in the pediatric population. However, research on the utility of core sets for use with pediatric populations is emerging. For example, Bonanni et al. (2009) evaluated a group of children with Angelman syndrome, a condition characterized by global impairments in areas such as cognition, motor skills, and language skills. In this study, ICF-CY codes were selected to attempt to develop a core set for this population. Selected codes allowed the researchers to characterize and capture changes in symptoms across development and over time, demonstrating the utility of the tool for "orienting interventions and recording effectiveness" in this population of children (Meucci et al., 2009, p. S127).

Another recent study by Montirosso, Ceppi, D'Aloisio, Zucca & Borgatti (2009) represented an initial step towards identifying relevant codes for a core set for children with Alternating Hemiplegia of Childhood (AHC). This study is interesting in that, like lysosomal storage diseases, AHC is a rare condition. Establishing a core set of relevant codes to document functioning, disability, and contextual factors for the population of children with rare lysosomal storage and neurological disorders could facilitate

professional discussion and improvement in service provision on a national or even international level.

Linking Rules

To improve efficiency of coding procedures, another concept that has been implemented in ICF coding is using linking rules to match health-status measures with ICF codes. Linking rules, as summarized by Cieza, Geyh, Chatterji, Kostanjsek, Ustun & Stucki (2005), allow clinicians to systematically assign ICF codes to health-status, technical and clinical measures and interventions. For example, McLeod & Threats (2008) demonstrated the use of linking procedures in a case study that matched ICF codes to written text (e.g., case history information and patient records). The authors reported that, "Sam has an interdental lisp (b320), mild expressive (b16710) and receptive (b16700) language impairment, and a mild stutter (b330)" (McLeod & Threats, 2008 p. 99). The system of linking rules referenced in Cieza et al. (2005) obviates the need to develop clinic-specific checklists and core sets, but requires rigorous operational definitions to identify "meaningful concepts" and "aim(s) with which (each) corresponding technical or clinical measure is used" (Cieza et al., 2005). Cruice (2008) notes that linking rules or "linkage procedures" involves scrutinizing each item and trying to map the content to a particular ICF code (p. 41).

Intuitive linking rules, such as those completed by McLeod & Threats (2008) and described above, may be used in the present study to link appropriate ICF codes to information from the parent interview. For example, parents may report that their 6-year-old child is able to follow one-step directions like *"Get your shoes."*, but cannot follow a

series of two directions such as "*Put your book in the book-bag* and *get your shoes.*" For this child, the Activities & Participation code d220 (*undertaking multiple tasks*) may be identified as an area of need. Next, the child may be assigned the qualifier 4 (indicating complete impairment) for the area *undertaking multiple tasks* (d220) because he is completely unable to perform this task, which would be considered appropriate for his developmental level. Thus, one code that would help characterize functioning in this child is d220.4, indicating complete impairment in the area of *undertaking multiple tasks* (d220). Since there is no impairment (corresponding to the qualifier 0), in the Activities and Participation area d210 (*undertaking a single task*), the child could also be assigned the code d210.0.

In the interest of identifying the most salient impairments and restrictions in Body Functions and Structures and Activities and Participation, items that are not impaired are generally not coded. However, in the Environmental Factors component, both negative and positive factors can be coded as necessary. For example, if a child is able to communicate using *assistive technology* (e1251) this may be coded as a complete facilitator (+4), indicated by the code e1251+4. If for the same child, the classroom teacher does not allow him to use the assistive device at school, then this would be a complete barrier (.4) to communication due to the *attitude of a professional* and coded as e455.4. In contrast, sometimes the school purchases a device that can only be used at school, and not at home, which would be a substantial barrier to communication because of an *education policy* (e585.3).

As the goal of this project is to create a formal ICF-CY-based tool, linking rules will be used to create the tool by linking content in the form of interview questions to

specific ICF-CY codes. For example, several questions from the structured interview developed by Kronk et al. (2005), "How does your child learn a new skill?" or "Does he/she imitate you performing a chore?" link directly to *copying* (d130) in the component Activities/Participation. If parents indicate a need in this area when asked the questions, clinicians may assign a qualifier to that area to indicate that the child's participation in *copying* (d130) is restricted.

Current Research of the Use of the ICF with Diverse Disorders

Recently, entire issues of three different peer-reviewed journals were dedicated to the ICF and ICF-CY, reviewed current research in this area and argued for "applying a holistic approach in dealing with functioning and disability" (Ma et al., 2007 p. 243). The journal issues were *Seminars in Speech and Language* (Vol. 28, No. 4, 2007), the *International Journal of Speech-Language Pathology* (Vol. 10, No. 1-2, 2008), and *Disability and Rehabilitation* (Vol. 31, No. S1, 2009). Three studies that focused on assessment and intervention in communication and swallowing disorders are reviewed below.

In examining the utility of use of the ICF for children with language impairments, Westby (2007) suggested that planning intervention based solely on scores from standardized tests is not sufficient. Instead, an assessment should "determine how the person's quality of life can be enhanced by optimizing communication" (Westby, 2007, p. 266). This is a critically important consideration. For example, if the focus for intervention is truly improved function in context, then the context must be evaluated. For instance, through the assessment of *interpersonal interactions and relationships* (d7-

Activities and Participation), clinicians can evaluate the quality of the child's relationships with family members, strangers, and peers. Through the assessment of *products and technology* (e1-Environmental factors) and *attitudes* (e4-Environmental Factors), the availability and use of assistive technology related to communication and the attitudes of people who routinely interact with the child can be evaluated. In regard to Body Structures, Westby (2007) asserted that although many language impairments may be caused by structural impairments in the brain, the specific location is often unknown so it is not necessary to code. In the present study, clinicians will be encouraged to code only the most informative data. As a result of the disease process, many of the children with rare metabolic disorders or other neurologically-based speech and language impairments may have structural damage to the brain, but lesion localization is not always identifiable.

Additionally, Westby (2007) states that using Standard Deviations on standardized language measures to inform qualifiers may be acceptable as long as skills presented on the assessment are deemed to be comparable to skills in authentic communication. For example, consider that a clinician is trying to determine the qualifier for the Body Functions code b16700 (*reception of spoken language*) and knows that the child scored 3 standard deviations below the mean on a standardized assessment of receptive language. Using standard deviations to determine the appropriate severity qualifier, this child would be assigned the qualifier 3 indicating a severe impairment in the area of *reception of spoken language* (b16700.3) (Lollar & Simeonsson, 2006). However, if the child cannot indicate his/her knowledge of receptive language on a formal assessment, but demonstrates more skills in spontaneous interactions or based on

teacher or parent report, then these perspectives must be considered when assigning the qualifier. Children with severe attention deficits may have more skills than they can demonstrate on a standardized assessment and actual participation in life situations can be considered when coding severity using the ICF-CY. The use of standard deviations will be discussed further in the Methodology section.

Finally, Westby (2007) states that goals for intervention should be both: (a) impairment-based, focusing on skills the child needs to improve the capacity to use language, and (b) social-based, that are focused on how to improve the child's performance in his/her life situations (e.g., at school, in the community). Thus, impairment-based goals and social-based goals target both capacity and performance, respectively. Using the ICF framework should help to orient coders to needs in areas beyond function (e.g., goals targeting Body Function code b320 *articulation functions* exclusively) and could include goals that target the Activities & Participation code d880 *engagement in play* or the Environmental Factor code e1401 *assistive products and technology for culture, recreation and sport*. The possibility that use of the ICF-CY framework will facilitate the creation of more goals related to Activities & Participation and Environmental Factors will be explored in the present study.

Additional studies from the three journal issues noted above include a focus on Alternative and Augmentative Communication (AAC). With regard to AAC intervention, Granlund, Bjorck-Akesson, Wilder & Ylvén (2008) used the ICF-CY framework to create goals. The authors found that goals related to Participation were more functional and more directly related to the child's ability to communicate with family members than goals related to Body Function or even Activities. Specifically, the

authors reported that in order to participate in everyday settings, "it is not sufficient for him or her to simply have assistive technology that substitutes for an impaired body function (e.g., a voice output communication aid [VOCA])...rather, the child must also learn to spontaneously perform the task (i.e., communicate) in family interaction in the home" and arguably, beyond (Granlund et al., 2008). Current standardized testing often results in treatment recommendations based solely on impairments in Body functions, so use of the ICF-CY may result in goals that target Activities & Participation. This concept is important for all clinicians to remember to implement in their recommendations and interventions and use of the ICF (and ICF-CY) should provide an adequate framework for developing and targeting functional goals.

As noted in the journal special issues, dysphagia is another disorder that requires comprehensive assessment. Dysphagia is a relevant domain to examine with the population of children with rare metabolic disorders, because feeding and swallowing skills are often affected by the disease process. Threats (2007) suggested multiple codes that identify some of the psychosocial effects of living with dysphagia. Identifying the child's routine Activities and Participation is key, because failing to consider these aspects for assessment and intervention is one of the main reasons that patients (and caregivers) may not follow through on professional recommendations (Threats, 2007). Especially in the population of children with rare metabolic disorders who have significant cognitive and motor limitations, mealtimes may be some of the most enjoyable times during the day. Parents will likely be resistant to implementing recommendations at home if they feel that the recommendation is not integrated into their established routine and will change the quality of interaction around mealtime. More

information about the importance of evaluating Activities & Participation and considering the parent's perspective is found below in the section on ICF Coding Challenges.

Inter-rater Reliability & Feasibility Studies of the ICF

Several studies have evaluated the functionality, reliability, and feasibility of the ICF in clinical practice. Ogonowski, Kronk, Rice & Feldman (2004) completed a study in which two raters independently assigned ICF Activities & Participation codes to children with disabilities including ADHD, Cerebral Palsy and Developmental delay based on individual test items as well as standard scores from one (of three) assessment measures. All three test measures used had strong psychometric properties of validity and reliability. The study was designed to see if high inter-rater agreement could be achieved. The authors found that high rates of agreement were possible, but more likely when developmental norms were provided and when ICF codes corresponded to only one test item. Ogonowski et al. (2004) consequently suggested that the ICF as a coding system could lead to better and more balanced views of children (than standardized testing alone), especially those who have a spectrum diagnosis (which is similar to the presentation of rare disorders in children). For children with spectrum diagnoses, the ICF could provide "essential information about the severity of the underlying condition in terms of its impact on functioning," which is something that current standardized measures are unable to do (Ogonowski, et al., 2004, p.354).

In a follow-up study to Ogonowski et al. (2004), Kronk, Ogonowski, Rice & Feldman (2005) also looked at inter-rater reliability in assigning ICF Activities &

Participation codes based on a structured parent interview with built-in developmental norms to reference during coding. The authors achieved good to excellent reliability in identifying and rating severity of areas of need for the children in the study (Kronk et al., 2005). This study supports the use of a parent interview to evaluate selected Activities & Participation in children with special health care needs. A structured parent interview, like the one created by Kronk et al. (2005), will be used in the present study to assess Activities & Participation and Environmental Factors in children with rare disorders. Using parent report to obtain information about the child's activity limitations and participation restrictions will be necessary in many cases, because the children will either be too young or unable to report for themselves. The main benefit of the structured interview is that the questions can be directly mapped to one ICF code, so that based on parent response it should be fairly straightforward to determine whether that code represents an area of need for the child. For example, if the parent is asked "How well does your child concentrate?" and responds "He's six and he can't even concentrate long enough to listen to a story," then the examiners would indicate that *focusing attention* (d160) is an area of need for this child. To determine how severe the impairment is and which qualifier to assign to the child, the developmental norms provide guidance about what is appropriate for each age range (see Table 4 based on Kronk et al., 2005). Mapping codes to only one item on the checklist and including developmental norms for reference purposes should help strengthen inter-rater reliability for an ICF-CY-based checklist as demonstrated by Kronk et al. (2005).

Table 4. Sample Developmental Norms for Structured Parent Interview

	Need?	Qualifier	9m -2y	2-5y	5-12y	12-21y
Focusing Attention (d160) (concentration, freedom from distraction) How well does your child concentrate?			responds to name, listens to stories	listens to stories	school work	

(Kronk et al., 2005)

In a separate study by Ibragimova, Bjorck-Akesson, Granlund, Lillvist, & Eriksson (2005), in field trials using published ICF checklists in Sweden, the authors found that even with a standardized measure, subjectivity of ratings emerged. For example, as mentioned above, because clinicians tend to focus on functionality, they were far less likely to select environmental barriers such as negative *attitudes of professionals* (e4) as contributing factors to Participation restriction in areas such as *school education* (d820) or *school life and related activities* (d835). This perspective is important to keep in mind so that all aspects of functioning are considered as possible contributing factors; however, the extent to which this is done by individual clinicians is bound to have an effect on reliability, so guidelines for coding must be made explicit.

The feasibility of using an ICF-CY-based checklist in clinical practice was evaluated in a study by Ibragimova, Granlund, & Bjorck-Akesson (2009). Clinicians were asked to evaluate the functioning of children using the checklist and were asked to give their subjective opinion about the tool's feasibility. Clinicians reported overall that the tool was feasible for use in clinical practice, but did report difficulty assessing information related to other professions. For the present study, this should not be a problem because only codes related to speech, language, and swallowing will be selected

for use. Additionally, the majority of respondents in the Ibragimova et al. (2009) study reported that using an ICF-CY-based checklist was helpful for obtaining a comprehensive view of the children assessed. The Ibragimova et al. (2009) study shows promise for the utility and feasibility of an ICF-CY-based tool for use in clinical practice. However, two limitations of the study are that the feasibility findings were all based on subjective measures (i.e., open-ended questions posed to clinicians) and that the population of children assessed was not described. Both of these limitations may make it difficult to compare the results obtained by Ibragimova et al. (2009) to findings from the present study.

Possible Limitation of the ICF Coding System

Part of the feasibility portion of the current study will assess informally the ability of the ICF-CY to capture the range of severity of impairments in functioning for children with rare disorders. Strong test-retest reliability has been established by others for coding Activities & Participation over time (Battaglia et al., 2004). Additionally, in the same study, ICF coding was shown to be sensitive enough to document subtle changes in health status (Battaglia et al., 2004) indicating that the ICF coding framework could be useful for capturing such subtle changes in functioning in children in the present study. However, a limitation to documenting changes in health status was noted in a study by Bonanni et al., (2009). In that study, ICF-CY codes were used with children with Angelman syndrome. Results from assessments with this population indicated that it is possible to find ceiling effects with the ICF-CY. For example, for one child in the study, seizures were already coded as a severe impairment, so when seizure activity worsened

there was no way to document this change in severity using the ICF-CY. This is a potential problem for the current population of children seen by the NFRD who often experience neural degeneration leading to severe impairments in functioning. Consequently, the usefulness of the ICF-CY for the population of children with rare disorders will be evaluated in the present study.

ICF Coding Challenges

Despite its potential limitations, the overwhelming impression from clinicians who are using the ICF in the field is that it is applicable and clinically useful for a range of populations (Kronk et al., 2005; Simeonsson, 2009; Threats, 2007; Westby, 2007). However, there are still several concerns that need to be addressed by anyone considering its use. In addition to some of the issues related to coding raised previously, there are additional challenges including the need for broader-based assessments, ways to differentiate capacity from performance, additional considerations for coding Environmental factors and Personal factors, and the importance of parent perspectives in ICF coding. Each of these issues will be discussed below.

Moving beyond assessing body functions. First of all, many clinicians have a very narrow lens for evaluating their patients. McLeod & McCormack (2007) reviewed the content of available speech assessments and found that the majority of these assessments assessed only Body Functions (e.g., b3 *Voice and Speech Functions* and b320 *Articulation Functions*). McLeod & McCormack (2007) refer to Lollar & Simeonsson (2005) who indicate that although body function is important, a focus on functional improvement, observable in daily activities, is also necessary considering that

improved functioning is often viewed as a measure of progress. Consequently, using the ICF-CY framework for assessment may be beneficial to help clinicians consider and incorporate Activities & Participation and Contextual factors into assessment and treatment (McLeod & McCormack, 2007; Simeonsson, 2009).

The importance of evaluating contextual factors was demonstrated in a pilot study examining the functional profiles of children with Tourette's syndrome using an ICF-CY questionnaire. In the study, Meucci, Leonardi, Zibordi, & Nardocci (2009) found that Environmental factors often accounted for the difference between performance and capacity in the children who were assessed. In other words, many children in the study were able to perform better in life situations with environmental facilitators than they were able to without environmental facilitators. This finding underscores the need to assess Environmental factors and target them as part of the treatment plan, because enhancing facilitators in the environment may have a direct and positive impact on a child's performance and participation.

Considering the presence and interdependence of contextual factors (including Environmental and Personal factors) can help clinicians more fully determine the impact of disability and functioning on the patient's quality of life (Cruice, 2008). Assessment procedures that consider the patient's quality of life may result in improved service provision for individuals with disabilities (Cruice, 2008; Meucci et al., 2009).

Differentiating capacity from performance. Another coding issue is differentiating performance from capacity. For each Activities & Participation component code, clinicians are directed to rate both performance or "what individuals do in their current environment" (WHO, 2007, p. 230) and capacity without any assistance,

defined as “the highest probable level of functioning that a person may reach...in a uniform or standard environment” (WHO, 2007, p. 230). Determining capacity in speech-language domains with standardized testing is somewhat difficult, because communication in a standardized environment would likely be very artificial (O’Halloran & Larkins, 2008). To remedy this difficulty, O’Halloran and Larkins suggest administering the Communication Activities of Daily Living (CADL-2; Holland, Frattali, & Fromm, 1998); however, that measure is not appropriate for the age range in this study. Substituting available, authentic measures of communication, some of which are suggested by Westby (2007), could suffice to measure capacity.

Coding Environmental factors. In the future, operationalizing the process of coding Environmental factors will be necessary. In a study by Battaglia et al. (2004), determining the presence of Environmental factors was shown to be relatively easy, but the authors found it difficult to assign a severity qualifier and determine if the factor was a facilitator or a barrier. For the domain of Environmental factors, clinicians need to consider that for any individual, Environmental factors may be negative or positive in nature and may be assigned any severity qualifier. For example, in a study that evaluated the clinical usefulness of the ICF-CY for characterizing the Activities & Participation and Contextual Factors (i.e., Environmental and Personal factors) for children with brain tumors, the authors suggested that for children with a life-threatening diagnosis, all Environmental factors may be seen as facilitators (Ajovalasit et al., 2009). The authors cited *relationships* (formal and informal) (E3), *attitudes* (E4), *technologies* (E1) and *service facilities* (E5) as important facilitators. The results may be due to some inherent bias in the study by Ajovalasit et al. (2009), but the finding is important to consider for its

relevance to the present study in which many of the children also have life-threatening diagnoses.

In addition to simply having barriers (negative Environmental factors) or facilitators (positive Environmental factors), a given Environmental factor can sometimes be a barrier and a facilitator for the same child depending on the context (Battaglia et al., 2004). For example, a child whose parents (e310 *Immediate family*) believe that they should talk for him so he does not get fatigued may be helping him, but at the same time they (e310 *Immediate family*) may be restricting his participation in life situations and conversations with others. Depending on the context, the child's family (e310 *Immediate family*) may be considered a facilitator or a barrier.

In order to clarify Environmental factor ratings, Howe (2008) provides detailed examples of what kinds of Environmental factors can be evaluated by speech-language pathologists. For example, in the Environmental factor chapter 2 (*Natural Environment and Human-made changes to Environment*), "background sound" is discussed as both a facilitator and a barrier (WHO, 2007). For example, it could be a facilitator to a man with Parkinson's disease who will increase his volume level in the presence of background noise. However, it may be characterized as a barrier for an individual with a hearing impairment, because it will further impair their ability to participate in communicative interactions. Thus, Environmental factors need to be examined in relation to the individual with the health condition, the individual's functioning, and the context.

Personal factors. Another issue that has been raised in the ICF literature is how important it is to differentiate Personal Factors from functional status when assessing

using the ICF (McCormack & Worrall, 2008). For example, if the given characteristic such as hyperactivity existed before the onset of the health condition, then it would be considered a Personal Factor. However, if it did not exist before the onset of the health condition then it may be considered part of the disease and consequently a functional condition. This is relevant to the population being studied and young children in general, because the early onset of the disease may make it difficult to differentiate between these two concepts. Since there are no specific codes for Personal Factors, noting any salient Personal Factors in the patient's records is critical. Once Personal Factors are identified, their interactions with Environmental factors are important considerations for treatment planning (Howe, 2008). For example, "a personality trait, an example of a personal factor, can influence a person's self-perception of the benefit of having a hearing aid, an Environmental factor" (Howe, 2008, p. 35). Assessing and documenting Personal Factors should help clinicians create appropriate and individualized treatment recommendations.

The importance of parent perspectives. Including parents in evaluation procedures is critical when assessing young children (Crais, 2010), but it is important to recognize that all evaluators have certain biases. Work by Thomas-Stonell, Oddson, Robertson & Rosenbaum (2009) indicated that parent ratings of child needs and improvement after speech-language therapy (outcome measures) generally reflected the domain of Participation more than any other. For example, parents tended to notice changes in functioning related to areas such as *communication* (d3), *learning and applying knowledge* (d1), and *interpersonal interactions and relationships* (d7). The clinicians in the same study tended to focus more on Function-related goals targeting

areas such as *voice and speech functions* (b3) and *mental functions of language* (b167). Thus, parent input in assessing Activities and Participation needs and the child's progress may be necessary for clinicians to consider and monitor functioning in domains other than Body functions. As suggested by Thomas-Stonell et al. (2009), the use of an ICF-CY-based outcome measure and parent report would help orient clinicians to those more-forgotten domains when planning treatment and tracking efficiency of services. Each of the previous sections has reviewed the coding challenges that must be overcome by each clinician who develops an ICF-CY-based tool until a formal coding guide is created.

In response to the need for a formal coding guide, the WHO and the American Psychological Association (APA) are scheduled soon to jointly publish the *Procedural Manual and Guide for the Standardized Use of the ICF: A Manual for Health Professionals*. This manual should clarify the ICF for clinical use (Ma et al., 2008). For example, in the upcoming manual, coders are directed to consider intelligibility a Body Function rather than an Activity (McCormack & Worrall, 2008). Coders were previously unsure how to approach intelligibility. Considering that it is measured based on interactions with people, it could possibly be coded as an Activity limitation rather than a Body function impairment. Unfortunately, the APA resource is not yet available to the general public. However, several important points, reviewed by Threats (2008), will help direct the development of the survey tools used for the current project including (a) how to interpret Activities & Participation codes, (b) how to interpret capacity and performance codes for Activities & Participation, and (c) how to document severity using the qualifiers. Coders are also given the following advice (a) "if a given code does not make sense, do not use it"; (b) "if two codes always end up having the same meaning use

only one of them"; and (c) "If a code is too vague, the clinician may work with their facility to develop 'within facility use only' subcodes for an item" (Threats, 2008). Formal coding guidelines would be very helpful, but in the absence of a coding manual, developing operational definitions and coding consistently will be critical.

In sum, there has been limited use of and information about the ICF-CY for assessing speech and language skills in children due to the absence of formal ICF-CY-based tools, a formal coding system manual, and the perceived functionality of current standardized assessments. The purpose of the current study is to test the utility of an ICF-CY based checklist for use in clinical practice. This tool proposes to overcome some of the limitations of current standardized assessments by more accurately measuring and coding progress or regression in patients undergoing treatment for these disorders. In the future, the coding system could be extended for use with other disciplines and used internationally to help collect data especially on rare disorders. More data on children's functioning at different disease stages may help clarify diagnostic markers, specify disease subtypes, document facilitators and barriers to treatment and result in more appropriate treatment recommendations. This project will specifically describe the reliability, feasibility, and comprehensiveness of an ICF-CY-based tool for clinical use in assessing and providing speech, language and swallowing treatment recommendations for children for whom standardized testing is difficult. The focus of this study is on answering one research question:

1. How feasible is using an ICF-CY based checklist in clinical practice?

CHAPTER 3

METHODOLOGY

The proposed research question was investigated in part through interactions with patients of the Neurodevelopmental Functions in Rare Disorders team (NFRD). Jenna Mory, M.A. and her clinical supervisor, Lisa Domby, M.S., completed the data collection process and were added to the IRB application for the research team as individuals who had access to the data for the longitudinal project operating out of the UNC School of Medicine. In addition, pilot data were collected by both clinicians using the checklist in one preschool and two schools for children with disabilities in Guatemala during a service-learning trip organized by Lisa Domby through the Division of Speech and Hearing Sciences at the University of North Carolina at Chapel Hill.

Participants

The sample size for the study was 7 children from the NFRD team and 10 children from Guatemala. Once the research proposal was approved, the researcher planned to assess any children with pre-scheduled appointments with the NFRD team between January and March 2010. Children were seen on January 25, February 8, February 15, March 1 and March 15, 2010. During that time period, all children who were scheduled to be seen by the speech-language pathologist were included in the study. Each of the children seen after February 15, 2010 (including all the children seen in Guatemala) was assessed individually using the updated version of the checklist (see

Appendix B). Most of the North Carolina participants in the study were patients returning for follow-up with the NFRD team, but a few were new patients. However, of the returning patients the majority had not had a formal speech-language evaluation at their previous visit. Participants in Guatemala were selected by teachers and the speech-language pathologist based on concerns in the areas of speech, language or both. All evaluations in Guatemala took place between March 8, 2010 and March 12, 2010.

Checklist Development and Coding

The checklist was developed and modified several times during data collection. Initially, codes from the ICF-CY manual were selected from the components of Body Structures, Body Functions, Activities & Participation, and Environmental factors for use based on their perceived relevance to speech, language, or swallowing behaviors in the population of children with rare disorders. In the first version of the checklist, every code that could have relevance to any speech, language, or swallowing areas was included in the checklist. This was done with the idea that after the checklist was used, the number of codes could be reduced to form a "core set" that included only the most commonly used codes (McLeod & McCormack, 2007; Westby, 2007; Threats, 2007; Ma et al., 2007). In terms of formatting, the 41 Body Structures codes and the 89 Body Functions codes were grouped by category (e.g., Voice and Speech Functions) and listed with the idea that the qualifier (i.e., 0,1,2,3,4) could be selected for each necessary code based on the child's needs. For the 94 Activities and Participation codes, the structured parent interview developed by Kronk et al. (2005) was used as a model. For example, the question "How well does your child understand language compared to other children

his/her age?" was developed to assess areas of need for 7 different Activities & Participation codes including d310 Communicating with—receiving spoken messages, d3100 Responding to the human voice, and d3101 Comprehending simple spoken messages. In addition to the developmental norms given on the Kronk et al. (2005) parent interview, more detailed communication developmental norms were added to the checklist based on skills listed on the Vineland Adaptive Behavior Scales (Sparrow, Balla & Cicchetti, 1984).

For the 41 Environmental factor codes, five questions were developed to identify potential Environmental factors. Each question referenced a particular section of Environmental factor codes from which one or several codes could be selected based on the child's individual needs. To assess the Environmental factors chapter 1 Products and Technology, parents were asked "Is your child currently using assistive technology of any kind? Do you (and your child) find that helpful?" In addition, space for observations and noting any Personal Factors was also included at the end of the checklist. After the first version of the checklist was created, pilot data collection began. Changes made during the data collection process are described further in the Results section.

During the coding for each child for the components of Body Structures and Functions, relevant codes were selected from the subset of codes on the checklist based on their specific relevance to the particular patient during the evaluation. Use of the case history, observation, direct assessment, and parent report were the forms of information for selecting the codes for each child. According to the ICF-CY (WHO, 2007, p. xxi), "with young children and those with limited verbal skills, the primary caregiver can serve as a proxy respondent." As mentioned above, some Body Function impairments may be

linked to specific structural impairments, but many will not (Westby, 2007). If there was an obvious body structure impairment that corresponded to the body function impairment, it was coded. For example, if a child had unilateral tongue weakness (s3203 *tongue*) that interfered with *articulation functions* (b320), the tongue weakness was coded as an impairment in Body Structures. In the absence of a clear structural component or in the case of a structural impairment so broad as to not be informative (e.g., brain), only the functional impairment was coded. When there was no clinically obvious impairment for a structure or function, those codes were not selected for coding.

Body Structure impairments can be coded with up to 3 qualifiers. The severity of the impairment was coded (1st qualifier), but the 2nd and 3rd qualifiers for type and location of impairment, respectively, were only coded if it was deemed appropriate by the evaluator. In the previous example, where the child had an impairment in the Body structure s3203 *tongue*, using three qualifiers may be helpful. Using three qualifiers can indicate that the *tongue* (s3203) is moderately impaired (2), due to aberrant dimensions (4), on both sides (3). The child would be assigned the code s3203.243 to characterize the tongue impairment. Impairments in Body Functions were coded using the severity qualifier, where 0 indicates no impairment and 4 indicates complete impairment. Operational definitions based on the Procedural Manual for each of these qualifiers were determined, but were also approximately aligned with the Standard Deviation equivalents proposed by Simeonsson & Lollar (2006), whenever possible. These standards are included below as a guideline.

Table 5. Qualifiers Related to Standard Deviations and Population Frequency

Standard Deviation	**Population Frequency**
0=no problem <1 s.d.	0=no problem 68%
1=mild problem -1 to -1.5 s.d.	1=mild problem 26%
2=moderate problem -1.5 to -2.5 s.d.	2=moderate problem 2%
3=severe problem -2.5 to -3.0 s.d.	3=severe problem 1%
4=complete problem >-3 s.d.	4=complete problem <1%

(Simeonsson & Lollar, 2006)

In order to evaluate Activities & Participation and Contextual factors (i.e., Environmental and Personal Factors), the parent questionnaire discussed above was utilized. This parent questionnaire was modeled after the questionnaire used by Kronk et al. (2005), shown in Table 4. The questionnaire linked questions directly to ICF codes to determine areas of need (in the domains of Activities & Participation and Contextual factors) for the child. All areas of need were then assigned a severity qualifier using developmental norms as a guideline (Kronk et al., 2005). Although several ICF-CY studies (e.g., Meucci et al., 2009; Thomas-Stonell et al., 2009; Ajovalasit et al., 2009) have questioned the reliability of parent informants, many children who were participants in the study were unable to self-report. Additionally, Kronk et al. (2005) asserted that "Standard assessments supplemented by parent interview can be used for reliable coding." Considering these factors, every effort was made to verify the reported behaviors through observation or direct assessment during the course of the evaluation. As with the Body Structures and Function codes, Activities and Participation codes and Environmental factor codes related to speech, language, and swallowing functions for this population were selected. For each of the Activities and Participation codes, parents were asked an open-ended question written to correspond directly to the selected code. For example, for the code d235 (*managing one's behavior*) the question was "How is your child able to manage his/her own behavior?" Based on the parent response, the

evaluator determined if that code represented an area of need for the child or not. If there was a need, then the appropriate qualifier(s) was applied. Needs in the Activities and Participation domain were in part determined, as in Kronk et al. (2005), based on developmental expectations. The behavioral expectations were determined in part by using the Vineland Adaptive Behavior Scales (Sparrow, Balla & Cicchetti, 1984). Items from this measure were shown to be most easily mapped to ICF codes in a study by Ogonowski et al. (2004). In addition, the structured questionnaire designed by Kronk et al. (2005) was used as the model for the present questionnaire.

Relevant Personal Factors such as temperament, education, and upbringing were noted at the bottom of the questionnaire based on observation or parent report. Though the NFRD testing protocol may seem extensive, due to requirements within the clinic all protocols must be used. However, the comprehensive testing may be a strength according to Watter, Rodger, Marinac, Woodyatt, Ziviani, & Ozanne (2008, p. 347) who found that "multiple assessments—across disciplines and across ICF domains—provide optimal description of performance in children." The less extensive testing battery used in Guatemala with less parent report allowed us to make an interesting comparison with regard to ease of coding. This issue will be discussed in the results section.

There is some controversy as to how to interpret the Activities & Participation and Environmental factor codes. For the purpose of this study, Activities & Participation were maintained in one list although they were interpreted broadly as a combination of individual and societal interactions. For example, recognizing that a domain like *communication* (d3) represents individual activities as well as participation in society could function to prevent evaluators from losing these two, distinct perspectives (i.e.,

individual and societal), a concern expressed by O'Halloran & Larkins (2008). Environmental factors were coded alone, not linked to other components, which is one option suggested by the ICF Manual (WHO, 2007, p. 239).

The combination of formal standardized, informal and ICF-CY-based testing protocols were used to test the proposed research question. In order to increase reliability, the process of developing operational definitions and specific coding procedures will need to be described further for clinicians who will use the ICF-CY-based tools. The two clinicians (Lisa Domby and Jenna Mory) who assessed the children attempted, but were unable to calibrate the coding system with each other because of clinic-specific constraints. Since inter-rater reliability using the ICF-CY checklist was not established, the process of collecting data and assigning codes and qualifiers to characterize functioning and identify areas of need for each child evaluated by the NFRD team and in Guatemala will be presented in a descriptive manner.

Procedures

The standardized speech-language evaluations were administered with each NFRD patient, when possible, in accordance with the established test protocols. Those assessments included (a) a brief, informal parent interview, (b) an oral-motor examination, based on the Kaufman Speech Praxis Test for Children, Part 1—Oral Movement Level (Kaufman, 1995), and (c) one of the following speech-language assessments: the Clinical Evaluation of Language Fundamentals, Fourth Edition (CELF-4, Semel et al., 2003), the Clinical Evaluation of Language Fundamentals—Preschool, Second Edition (CELF Preschool-2, Wiig et al., 2004), or the Preschool Language Scale—Fourth Edition (PLS-4, Zimmerman et al., 2002). Occasionally additional

measures such as the Goldman-Fristoe Test of Articulation, Second Edition (Goldman & Fristoe, 2000) were employed, as needed. In addition to these assessments, the ICF-CY based checklist and interview were used to evaluate and code the present level of functioning for each patient. Further details about the development of the ICF-CY checklist are included below.

In Guatemala, the Bilingual Early Language Assessment (BELA, Heise-Baigorria, 2006-2007), a non-standardized evaluation tool was used to assess the children's receptive and expressive language in the context of basic concepts that are cross-culturally relevant. The BELA was created by early childhood educators to monitor the development of basic and early language concepts for bilingual children in both of the child's languages. This measure was selected for use in Guatemala, because it is a free tool that was designed to be culturally appropriate for any child at the preschool developmental level. While the tool is not standardized, it does give the administrator a general idea of the child's skill level and is particularly beneficial in identifying blocks of skills that are undeveloped. In addition to administering the BELA to the children in Guatemala, the children's areas of strength and need were rated using the ICF-CY checklist. These ratings were completed based on skills demonstrated during the evaluation, observations from the evaluation and occasionally teacher or parent report.

CHAPTER 4

RESULTS & DISCUSSION

This project was initiated to begin development of a tool that incorporates the ICF-CY framework and that could be useful for assessing, monitoring progress, and helping create functional goals for intervention for children with rare metabolic disorders. As a secondary benefit, the checklist was utilized with ten children with speech and language impairments in a language other than English. The results section of this paper summarizes and comments on the process of creating and modifying the instrument, as well as presents pilot data and several case studies that demonstrate the instrument's potential usefulness and limitations in clinical practice. In this section, use of the tool with the NFRD team and in Guatemala is summarized with a presentation of preliminary pilot data. The benefits and limitations of the tool and the ICF-CY framework for use in clinical practice are also discussed.

Checklist Modification

The first version of the checklist was a good start; however, after only a few attempts at using the extended version of the checklist, it became obvious that there were simply too many codes for the tool to be used in this clinical setting. After that realization, the unpublished ICF-CY Speech, Language and Communication core set created by Eva Bjork-Akesson and Ylva Segnestam was used (with permission) to reduce

the number of codes in the domains of Body Functions and Environmental factors. All 17 Body Functions codes from the core set were included, in addition to 8 other codes relating specifically to feeding and swallowing. This resulted in a change from 43 to 25 codes, making that section much more manageable. Additionally, the Body Functions portion of the checklist originally had quite a bit of overlap with the Activities and Participation content, so reducing the number of Body Functions effectively reduced redundancy in the checklist. The list of Environmental codes to choose from contained 41 codes. Using the list of communication Environmental factors from the Bjork-Akesson and Segnestam core set reduced the number of codes to 17. The core set was not used to help reduce the number of Body Structure codes because it did not contain any. Instead, the number of Body structures codes from the original version of the checklist was reduced from 41 to 25 by excluding several more obscure brain regions and several codes related to bone and muscles. No codes were deleted from the Activities and Participation section of the checklist because even after using the checklist with the first few patients on the NFRD team, it was obvious that the Activities and Participation areas were yielding some of the most useful information about the children. In addition, these items had the least overlap with the standardized tools utilized. Children seen by the NFRD team after February 15, 2010 and all of the children seen in Guatemala were assessed using the final version of the checklist. See Appendix A for a comparison of the Body Structures and Functions codes that were included in the original and revised versions of the checklist. The complete final version of the checklist can be found in Appendix B.

During the data collection phase of the project, it was determined that formal statistical analyses would not be performed due to several limitations including time constraints and a reduced number of children scheduled to be seen by the NFRD team during the course of the study. However, in the absence of formal statistics, a descriptive presentation of the findings is offered.

Using the ICF-CY Checklist in Chapel Hill with the NFRD

The timeframe set aside for the study was during the months of January, February, and March 2010. Seven children were seen by the NFRD team in these months. These children ranged in age from 1 year 11 months to 14 years 11 months, with a mean age of 7.4 years and a standard deviation of 4.5 years. Their diagnoses included Tay Sachs Disease, X-linked Adrenoleukdystrophy, Late Metachromatic Leukodystrophy, Acute Lymphoblastic Leukemia (ALL), Pelizaeus Merzbacher Disease (PMD), Sanfilipo Syndrome, and Specific Language Impairment. Table 6 provides demographic information for study participants. The initials of each child have been changed to protect the identities of the patients. Following that are general findings and two case studies that demonstrate the clinical usefulness of the ICF-CY based checklist for evaluating children with rare disorders.

Table 6 NFRD Patient Characteristics

Patient (Return or New)	Age at Evaluation (Gender)	Diagnosis	Treatment course
1. KM (R)	9;1 M	Tay Sachs	Transplant
2. KS (R)	8;8 M	ALL	Transplant 09/06
3. TS (N)	8;1 M	Behavior/Lg processing/SLI	n/a
4. TX (R)	14;11 M	X-linked ALD	n/a
5. KI (R)	4;9 M	Pelizaeus Merzbacher Disease	Transplant 2/06

		(PMD)	
6. BM (R)	1;11M	Sanfilippo Syndrome, Type A	Transplant 07/09
7. BE (R)	4;1 F	Late MLD	n/a

General Findings

In Chapel Hill, using the checklist to work with children who have degenerative diseases, who can have any combination of symptoms, allows the unique pattern of deficits along with their impact on activities and participation for that individual child to be recorded and hopefully easily monitored over time. Additionally, the detailed Activities & Participation interview section allowed us to detail the impact of each child's functional limitations on their participation in daily activities and to make an appropriate diagnosis for one child. Without having such detailed questions readily available, it may have been difficult to identify specific, functional areas to target in intervention for this population of children. After the checklist was revised, it was relatively easy to use in clinical practice as a supplement to standardized testing. It also allowed for a more comprehensive evaluation of each child's speech-language abilities and limitations in their natural contexts. Table 7 summarizes the codes assigned to each child and adds any comments related to benefits and/or problems discovered during each evaluation.

Table 7. Summary of NFRD Results

Child	Codes Assigned	Possible Benefits	Problems Noted
1. KM	b110.2 Consciousness b1561.3 Visual perception b1565.3 Visuospatial perception b163.3 Basic cognitive function b164.4 Higher-level cognitive function b1670.3 Reception of language	-Incorporating Activities and Participation information could help create participation-based goals	-What can be considered severe in one case may not be as severe as another case -Is absence of skill coded as n/a or 4-

	b1671.3 Expression of language		complete impairment?
2. KS	d230.1 Carrying out daily routine d240.1 Handling stress and demands d7.1 Interpersonal interactions and Relationships d71040.1 Initiating social interactions d750.1 Informal social relationships	-Good language skills, but poor pragmatics skills discovered through parent interview	-Absence of codes for Resonance in ICF-CY
3. TS	b1448.2 Working memory b1642.2 Time management b1670.1 Reception of language b1671.2 Expression of language d175.1 Solving problems d177.1 Making decisions d210.1 Undertaking a single task d220.2 Undertaking multiple tasks d230.1 Carrying out daily routine d71021.1 Maintaining social interactions d720.1 Complex interpersonal interactions d750.2 Informal social relationships d820.1 School education	-Comprehensive evaluation helped confirm a diagnosis of SLI and identify the impact of the child's language impairment on daily functioning	-No ICF-CY codes for texture avoidance
4. TX	d110.3 Watching d140.3 Learning to read d145.3 Learning to write d163.2 Thinking d220.3 Undertaking multiple tasks d550.2 Eating d720.2 Complex interpersonal interactions d730.2 Relating with strangers b1670.2 Reception of language b3300.1 Fluency of speech b3302.2 Speech of speech b5102.2 Chewing b5103.2 Manipulation of food in the mouth	-Description of abilities in context	-Limited information about vision status so difficult to know if apparent areas of need due to low vision, low language skills or both
5. KI	d133.3 Acquiring language d155.1 Acquiring skills d210.3 Undertaking a single task d310.1 Communicating with-receiving spoken messages d330.3 Speaking d815.2 Preschool education e125.3 Barrier in Technology (AAC)	-Clear example of how a goal targeting Environmental Factors could directly impact communication (providing access	-Motor limitations may prevent child from being able to demonstrate knowledge

	b5105.2 Swallowing	to AAC)	
6. BM	d120.1 Other purposeful sensing d130.3 Copying d131.2 Learning through actions with objects d133.2 Acquiring language d137.2 Acquiring concepts d1550.2 Acquiring basic skills d163.2 Thinking d210.1 Undertaking a single task d230.1 Carrying out routine d310.1 Communicating with-receiving spoken messages d330.1 Speaking d550.3 Eating d560.2 Drinking d71040.1 Initiating social interactions d880.1 Engagement in play b147.2 Psychomotor functions	-Personal factors (temperament-shy, slow to warm up to people) may hinder child's ability to benefit from therapy, limit communicative opportunities	-Motor limitations may prevent child from being able to fully demonstrate knowledge
7. BE	d110.3 Watching d133.4 Acquiring language d137.3 Acquiring basic concepts d155.4 Acquiring skills d163.4 Thinking d175.4 Solving problems d177.4 Making decisions d310.3 Communicating with-receiving spoken messages d330.4 Speaking d550.4 Eating d815.3 Preschool Education e115+3 Products and Technology (AAC) e320+3 Friends	-Facilitative benefits of environmental factors -Possibility to make recommendations to increase activities & participation in preschool	-Children dependent on tube feedings may be more or less included at mealtime, but coding system does not include much detail for coding participation in this area

Case Studies

Case 1 (K.S.)

K.S. was diagnosed with Acute Lymphoblastic Leukemia (ALL) in April 2006 at the age of 4;9. He underwent cord blood transplant as part of his treatment in September 2006 at the age of 5;3. He has been followed by the NFRD team for evaluation of

neurodevelopmental function since transplant. His most recent evaluation (and his participation in this study) was in January 2010 at the age of 8 years 8 months. The speech-language evaluation consisted of a brief oral motor examination, the Clinical Evaluation of Language Fundamentals, fourth edition (CELF-4, Semel, Wiig, & Secord, 2003), and the researcher-created ICF-CY parent interview and checklist.

Results indicated no abnormalities on the oral motor exam. On the CELF-4, K.S. received standard scores of 111, 110, and 116 (where 85-115 is the average range) in the areas of Core Language, Receptive Language and Expressive Language, respectively. While K.S.'s scores on the standardized measure place him in the high average range for language skills, through the course of the ICF-CY interview his father identified three areas of need that were not obvious to the clinicians in the context of a standardized evaluation. His father indicated mild difficulties with *carrying out the daily routine* (d230.1), *handling stress and other psychological demands* (d240.1), and *difficulty with interpersonal interactions and relationships* (d7.1). More specifically, *initiating social interactions* (d71040.1) and *informal social (peer) relationships* (d750.1) were more difficult for K.S. While all of K.S.'s areas of need were mild and his language was in the average range according to standardized testing, his father reported there are some breakdowns in his ability to participate in several daily activities and in his ability to use his language skills effectively to actively participate in his school setting. If intervention were provided, it could be focused on helping K.S. improve his peer relationships by learning how to initiate with peers as well as learning strategies to self-regulate, self-prompt, and self-direct daily routines using visual supports or self-talk. No other areas of need in any other domain were noted through the interview.

Using the ICF-CY based checklist in this case allowed the clinicians to probe beyond the level of Body Functions (*receptive* (b1670) and *expressive* (b1671) *language functions*) to find out how K.S. was using his language skills in his daily life and in natural environments. Through the course of the interview, pragmatic use of language and language memory emerged as potential areas to target in intervention, areas not typically covered on standardized measures. In K.S.'s case, the mild limitations of his pragmatic functions of language could in part have resulted from being ill for several years of his young life and simply not being able to interact or learn how to interact with peers due to his immunosuppressive status.

Case 2 (B.E.)

B.E. was diagnosed with Late Metachromatic Leukodystrophy (MLD) in April 2008 at the age of 2;2. She did not undergo cord blood transplant, but has been followed by the NFRD team to evaluate her neurodevelopmental function since diagnosis. She was most recently seen in March 2010 by the NFRD team (and participated in the study) at the age of 4;1. Due to B.E.'s restricted use of vision, motor control, and speech output, the speech-language evaluation consisted primarily of parent interview. Caregiver report throughout the interview enabled the team to complete a Preschool Language Scale, fourth edition (PLS-4, Zimmerman, Steiner & Pond, 2002) protocol to detail B.E.'s current abilities. Some of B.E.'s highest receptive language skills, reported by her mother included being able to anticipate what is happening and using eye contact or gaze and/or searching for sound sources with her eyes to see what is happening around her. In terms of expressive language abilities, B.E. uses differential vocalizations, smiling,

laughing, and snorting sounds to express pleasure and displeasure when interacting with her family or when sounds, objects, or actions are presented. B.E.'s age equivalent scores on the PLS-4 were 2 months for Auditory Comprehension, less than 1 month for Expressive Communication, and 1 month for the Total Language score.

Functionally, many skills on the ICF-CY checklist were rated as severe impairments or limitations; however, using the ICF-CY checklist allowed the clinicians to identify areas where B.E. could potentially participate more actively and also areas where she is being included as a result of others' efforts. Currently, B.E. is being followed by an Alternative and Augmentative Communication (AAC) team and consequently has regular access to *switch-operated toys*, which allow her to participate in play (e115+3). B.E. also has a best *friend* at her preschool that does not like to leave her alone and is constantly interacting and sharing enjoyment with her (e320+3). However, one area that could be targeted in intervention is more active participation in her *preschool education* (d815.3), which is currently limited both by her communication impairments as well as her motor limitations. Based on that finding, a recommendation was made to start using Voice Output switches with repeated story-lines or song lines so that A.D could activate the switch as part of a circle time activity.

In B.E.'s case, the ICF-CY was useful in identifying factors in her environment that were already facilitating her participation. In addition, other areas to target in intervention to increase participation were identified and recommendations were made to target those areas.

Using the ICF-CY Checklist in Guatemala in Preschools and Schools for Children with Disabilities

Ten children were seen in Guatemala by graduate students, Jenna Mory and Audrey Lewis, and Speech-Language Pathologists, Lisa Domby and Jessica Witt in the month of May 2010. The children evaluated ranged in age from 3 years to 19 years, with a mean age of 6.2 years and a standard deviation of 4.7 years. Each of the children was evaluated using the Bilingual Early Language Assessment (BELA, 2006-2007). Each child was selected by their teacher or the speech-language pathologist in order to provide baseline data to help with classroom and speech-language recommendations. All of the children were tested individually in a vacant classroom in each of their schools. Their diagnoses included Down Syndrome, Cerebral Palsy, Speech Impairment, Language Impairment, Learning Disabilities, and possible Traumatic Brain Injury (TBI). Below are general findings and two case studies that demonstrate the clinical usefulness of this tool for evaluating children in Guatemala. Table 8 provides demographic information for Guatemala study participants.

Table 8 Guatemala Patient Characteristics

Patient	Age	Gender	Diagnosis
1. K	7	M	Speech/Language Impairment
2. D	5	F	Cerebral Palsy
3. G	5	F	Down Syndrome
4. T	5	M	Hearing Impairment
5. L	5	F	Cerebral Palsy
6. M	19	M	Speech/Language Impairment

			(Possible Traumatic Brain Injury)
7. C	7	F	Speech/Language Impairment
8. S	3	M	Speech/Language Impairment
9. A	3	M	Speech Impairment
10. B	3	M	Speech/Language Impairment

General Findings

In Guatemala, the checklist was particularly helpful in identifying limitations in Participation and obtaining baseline measures of functional and activity limitations. These baseline measures were reported to the Speech-Language Pathologists in the area to provide targeted intervention to the children based on their functional limitations. Providing a general inventory of areas of skills and needs will allow the Speech-Language Pathologist to easily identify areas to target for each child as well as a way to monitor progress as intervention continues. Table 9 summarizes the codes assigned to each child and adds any comments related to benefits and/or problems discovered during each evaluation.

Table 9. Summary of Guatemala Results

Child	Codes Assigned	Possible Benefits	Problems Noted
1. K	d350.2 Conversation e585+2 Education system b1670.2 Reception of language b320.1 Articulation functions	-Deficits not demonstrated on BELA assessment, other areas of more advanced skills evaluated with checklist highlighted areas of need	-Lack of information and absence of parent, SLP, or teacher report limited number of codes that could be assigned
2. D	d3102.1 Comprehending complex spoken messages d330.2 Speaking	-Speech problem may be limiting child's ability to	-Lack of information, limited detail

	d350.3 Conversation e310+3 Family b1670.1 Reception of language b1671.3 Expression of language b320.2 Articulation functions b7.2 Neuromuscular Movement-related functions	practice and learn language (spoke only in 1-2 syllables at a time due to poor respiratory support)	
3. G	d130.2 Copying d137.2 Acquiring basic concepts d210.2 Undertaking a single task d310.3 Communication with-receiving spoken messages d330.3 Speaking d350.4 Conversation d7.3 Interpersonal interactions and relationships d750.3 Informal social relationships d815.3 Preschool education d880.3 Engagement in play b1670.3 Reception of language b1671.3 Expression of language b320.3 Articulation functions	-Interaction with peers observed in classroom which demonstrated impact of language impairment on peer interactions	-Lack of information, limited detail -Split in receptive and expressive language abilities, but both severe so no way to differentiate this in assigning codes
4. T	d1332.3 Acquiring syntax d220.3 Undertaking multiple tasks d310.1 Communicating with-receiving spoken messages d330.3 Speaking b230.2 Hearing functions s250.2 Structure of middle ear	-Degree of hearing loss can link directly to Body function area and qualifiers	-Hearing loss may lead to inconsistent abilities depending on context (noise level), but only able to rate in 1 context
5. L	d133.3 Acquiring language d310.3 Communicating with-receiving spoken messages d330.3 Speaking d710.3 Basic interpersonal interactions d815.3 Preschool education e125.3 Lack of technology for communication (AAC) e410.3 Attitudes of family b156.1 Perceptual functions b167.3 Mental functions of language	-Importance of environmental factors to prognosis	-Lack of information from parents, teacher, or SLP so limited detail

	b3.3 Voice and speech functions b320.3 Articulation functions b7.3 Neuromuscular movement-related functions		
6. M	d133.3 Acquiring language d137.3 Acquiring basic concepts d140.3 Learning to read d145.3 Learning to write d163.3 Thinking d210.3 Undertaking a single task d310.3 Communicating with-receiving spoken messages d330.3 Speaking d350.3 Conversation d7.3 Interpersonal interactions and relationships d820.3 School education d835.3 School life and related activities e535.2 Lack of speech-language services e585.2 Lack of targeted instruction (necessary modifications) b167.3 Mental functions of language b320.3 Articulation functions	-Personal factors indicated desire to interact and high level of stimulability for articulation	-Lack of information about development and history of possible TBI
7. C	d133.3 Acquiring language d137.3 Acquiring basic concepts d210.2 Undertaking a single task d310.3 Communicating with-receiving spoken messages d330.3 Speaking d350.3 Conversation d7.3 Interpersonal interactions and relationships d820.3 School education d835.3 School life and activities e585+2 Facilitative school setting b140.2 Attention functions b167.3 Mental functions of language b320.3 Articulation functions b7.2 Neuromuscular movement-related functions	-Personal factors of distractibility and persistence observed	-Lack of information about early development of speech/language, no parent report -Split in receptive and expressive language abilities, but both severe so no way to differentiate this in assigning codes

8. S	d130.2 Copying d133.3 Acquiring language d210.1 Undertaking a single task d240.2 Handling stress d310.2 Communicating with-receiving spoken messages d330.3 Speaking d350.4 Conversation d750.2 Informal social relationships d815.3 Preschool education d880.3 Engagement in play e585+3 Facilitative school placement e310.1 Family attitudes	-Personal factors (avoidance behaviors) and motivators noted during evaluation -Communication impairment created a lot of frustration and made handling stress difficult -Environmental factors can be facilitators/barriers at the same time	-Temperament of child made it difficult to fully assess his abilities
9. A	d1331.2 Combining words d1332.2 Acquiring syntax d310.2 Communicating with-receiving spoken messages d330.2 Speaking d350.3 Conversation d7.2 Interpersonal interactions and relationships d815.2 Preschool education d880.2 Engagement in play e310+3 Facilitative family b167.2 Mental functions of language b320.2 Articulation functions	-Articulation skills are inhibiting child's ability to learn and practice more advanced language as well as participate actively in his preschool and play with peers	-Unable to observe child interacting directly with peers
10. B	d1331.2 Combining words d1332.2 Acquiring syntax d137.3 Acquiring basic concepts d210.2 Undertaking a single task d310.3 Communicating with-receiving spoken messages d330.3 Speaking d720.3 Complex interpersonal interactions d815.2 Preschool education d880.2 Engagement in play e310+2 Facilitative family b1670.2 Reception of language b1671.3 Expression of language	-Child repeated everything so has great imitation skills (Personal/prognostic factor) -Child's mother works with him (facilitative Environmental factor)	-Child has ability to repeat complicated structures, but is not using those structures productively or functionally (only way to code that is through personal factors) -Picky eater, but no way to specifically code this through ICF-CY -Further observation of child with peers needed to fully assess quality of interaction

Case Studies

Case 1 (J.)

J. was a 5 year old little girl with a diagnosis of Cerebral Palsy. She was in her first year of attending a school for children with disabilities in the village of Santa María de Jesús. She participated in the Bilingual Early Language Assessment (BELA), which yielded a measure of receptive and expressive language skills. Since neither parent nor teacher report was available, many of the skill areas that could be assessed were either impossible to assess secondary to lack of information (e.g. *eating* and *drinking*) or due to J's limited motor skills (e.g. *carrying out a daily routine*). The examiners did their best to use observation during the evaluation to appropriately rate J's abilities and areas of need.

On the ICF-CY overall, J was given severe ratings in the areas of *mental functions of language* (b167.3), *reception of language* (b1670.3) and *expression of language* (b1671.3). It is suspected based on the results of the BELA and clinician judgment that J has greater overall receptive language skills than expressive language skills. However, since both skill areas are severely impaired, it is not possible to make this distinction by using the checklist alone. Additionally, another factor that may have limited J's ability to show us her knowledge in certain areas was the severe impairment in *articulation functions* (b320.3) resulting from dysarthria associated with Cerebral Palsy. J's articulation was extremely labored and consisted at most of two syllables per breath unit. Of the Activities and Participation areas, specific areas of need were noted for *preschool education* (d815.3-severe restriction), *engagement in play* (d880.3-severe restriction), and *interpersonal interactions and relationships (with strangers)* (d730.3-severe restriction).

It is assumed that these restrictions in participation could be due to both motor and communication considerations. Additionally, two Environmental factor codes were used based on information obtained from the SLP working at the school. First, *attitudes of individual immediate family* members was noted as a severe barrier (e410.3) due to reports that in J's first years of life she was understimulated, because of the perception that because of her motor limitations she also had cognitive limitations. Additionally, the lack of available *alternative and augmentative communication methods* (e125.3) is currently restricting J's ability to fully participate through communication and play in her school and home environments.

In J's case, the ICF-CY was helpful to identify environmental modifications that could be put into place to maximize her participation. In addition, it allowed us to establish a pre-treatment baseline of current skills, which would have been less comprehensive using only the BELA. Several limitations of the system were identified with this case study as well. Some limitations include the difficulty of rating items when the child has concurrent motor involvement that restricts participation, regardless of the child's communication abilities. Another limitation was the impossibility within the framework to show differential grades of severity, which in the case of speech-language pathology, may be necessary information for the interventionist. This suggests that supplementing the checklist with some non-standardized or standardized test could help the SLP to know more information about those skill areas (i.e. receptive and expressive language). Additionally in this case, parent report, teacher report, and classroom observation were not possible so it was helpful to know that the checklist can still be used, but should be done so with caution. Those extra sources of information

undoubtedly could provide a wealth of information and richness to the description of any child, so whenever possible those sources should be used in conjunction with the checklist.

Case 2 (S.)

S. was a 3 year old little boy who attended a preschool affiliated with the organization "Pequeños, pero listos" (Let's Be Ready) in the town of Alotenango, Guatemala. He participated in the BELA assessment of receptive and expressive language skills at his preschool and was accompanied during the evaluation by his mother. Before the evaluation the Speech-Language Pathologist for the school, Jessica Witt, reported that the child was able to say a few words mostly consisting of reduplicated syllables, had some imitation abilities, but that he primarily used pointing with vocalizations of "ah" to request. He also reportedly is starting to get frustrated when people do not understand him and a diagnosis of Apraxia of Speech is being considered.

During the evaluation, some of the most valuable information obtained included the behaviors that S. demonstrated when tasks were hard for him. At the beginning of the assessment with easier receptive language tasks, he was able to attend and fully participate. With more language based and later-developing receptive concepts and almost all of the expressive concepts, S. tried to leave the room, started crying, and got other toys out to play with instead of focusing on the presented task. The behaviors S. demonstrated when his production abilities were tested could be noted under personal factors. In addition, S. would consistently attend during book sharing activities so this substantial motivator, related to books, could be noted under personal factors as well.

These behavioral observations would be important for a clinician to consider when structuring intervention for S.

Additionally, throughout the evaluation the following Activities and Participation areas were rated: *copying* (d130.2-moderate limitation), *acquiring language* (d133.3-severe limitation), *acquiring concepts* (d137.2-moderate limitation could be related somewhat to inability to express knowledge), *acquiring basic skills* (d1550.2-moderate limitation), *acquiring complex skills* (d1551.3-severe limitation), *undertaking a single task* (d210.1-mild limitation with familiar routine directions with cues), *undertaking multiple tasks* (d220.3-severe limitation), *handling stress and other psychological demands* (d240.2-moderate limitation related to inability to express himself), *comprehending simple spoken messages* (d3101.1-mild limitation), *comprehending complex spoken messages* (d3102.2 or .3-moderate to severe limitation), *speaking* (d330.3-severe limitation), *family relationships* (d760.2-moderate restriction), *preschool education* (d815.3-severe restriction) and *engagement in play* (d880.3-severe restriction). In terms of Environmental factors, a substantial facilitator was noted for the *communication services* (e585+3) that S. will receive and a mild barrier was noted with the *immediate family* (e310.1) because the mother tends to anticipate S.'s needs rather than encouraging him to request desired items.

Overall, using the ICF-CY checklist with this family and in the preschool setting where we could observe peer interactions allowed us to gain more information about how S. is limited by his communication impairment. It is likely that with successful Speech-Language Services focused on production abilities, some of S.'s avoidance behaviors will

decrease and his participation in daily activities will increase, because he will be better able to communicate.

Limitations

In Chapel Hill, the ICF-CY checklist was a useful addition to the speech-language assessment protocol. However, there were some limitations that were noted as the pilot data were collected. First, there were some areas that examiners wanted to code but could not, because those areas do not exist within the ICF-CY framework. Some of those areas included children who had resonance problems (e.g. hypernasality, hyponasality), a history of otitis media, and/or presence of texture sensitivity during feeding. These are all areas that if coded may be targeted in intervention and may be considered in treatment or may affect the way treatment is conducted; therefore having them available to code in the future may be important.

Additionally, since the ICF-CY checklist was designed to be based on parent report, when parents were unavailable or could not provide information about the child's activities and participation, completing the checklist accurately was challenging. This happened many times in Guatemala, but because information could be collected by observation and teacher report, completing the checklist was possible. However, in Guatemala it was also more difficult to collect personal information including birth dates, case history, and/or parent report, which limited the number of areas that the examiners felt they could complete confidently, especially related to Environmental factors, feeding and swallowing, and family relationships. In the absence of parent report, it was also difficult to know for several of the areas where motor abilities are required to

demonstrate understanding (e.g. *carrying out a daily routine*), whether the child understood the task, but was unable to complete it independently. In addition, knowing if the child is able to complete tasks with moderate assistance or if the child is unable to perform the task at all, is useful information. In these cases, where parent report was limited, direct observation of the child in play activities and with peers was found to be the best indicator of areas of need, with or without referring to the developmental norms embedded in the interview form. Completing the checklist without parents is not viewed as optimal practice, however, and it would be beneficial whenever possible to gain parent input.

Another limitation of the checklist was the time it takes to complete. Although the second version of the checklist was much easier to use, if direct observation was necessary due to lack of parent report or if there were many children to see in one day, adding the checklist to the list of things to do could be overwhelming. However, the time that was spent completing each checklist yielded valuable information for each child seen and consequently demonstrated the benefits of using the tool. Hopefully, in further research and practice in clinical use and with planful modifications, the time it takes to complete the checklist will decrease.

Although the checklist was developed and tested by the same two clinicians, many coding challenges were discovered as the checklist was put into clinical use. Overall, the absence of a formal coding system made coding difficult, but with additional time and attention, coding rules could be developed for individual checklists and with practice used quickly to evaluate children. Below some difficulties that were observed are discussed with possible solutions.

One of the first coding challenges was figuring out what information to use to select the appropriate qualifier. Some of the qualifiers were very easy to select based on standardized or objective measures. For example, for one of the children who had hearing thresholds at 50dB, indicating a moderate hearing loss, he consequently received a moderate qualifier in *hearing functions*. When examining expressive and receptive language, standard scores can be used to select qualifiers, which would make selecting mild, moderate, or severe impairment relatively straightforward. For the domain of Activities and Participation, developmental norms were included in the parent interview form to serve as a guideline for determining the appropriate qualifier. Those norms were shown to be useful in achieving inter-rater reliability in the studies by Kronk et al. (2005) and Ogonowski et al. (2004), but seemed to be much less helpful for use with the children with rare metabolic disorders. This could be because the majority of the children by the NFRD team are far off the normal developmental trajectory and most of their skills represent severe limitations on Activities and Participation. For these children, using developmental norms, parent report and direct observation of the child in the natural environment (possible in Guatemala) seemed to provide good information about the child's abilities. In addition, operationalizing the observation process for determining qualifiers may occur naturally in clinical practice where one clinician is evaluating all of the children over time.

Thinking about how many of the children with rare disorders had severe limitations or restrictions in activities and participation, it is important to realize that some areas may be impossible to assess. For instance, due to task-related variations in abilities, clinicians sometimes wanted to assign a rating between two categories (e.g.,

moderate-severe). In addition, it was often difficult to know whether to code certain items as "not applicable" or as complete impairment (qualifier of 4) that could not be formally assessed (either in a clinical setting or due to motor limitations) or were very advanced. In general, if the child could not be evaluated for the skill in the clinic room and the parents could not report on the child's participation or if the skill was very advanced for the child (e.g., Reading for a 1 year old), then no code was assigned and "n/a" was written out to the side of the code or group of codes.

Another consideration related to coding was that formal evaluation tools occasionally limited the information that was available for coding. For example, with one child in Guatemala, the receptive and expressive language measure, the BELA, did not show that the child had any deficits. Had the child been observed in the classroom or doing grade level work, because of the clinicians' impressions interacting with him, it is likely that some areas of need would have emerged when asked to perform tasks closer to his chronological age level. Thus, it is important to consider the value of observing the child in all natural environments or at least eliciting parent report about those areas to obtain a more well-developed representation of the child's abilities and needs.

The last challenge discussed here is the problem of using the ICF-CY checklist to compare across children. This was more of a concern with the NFRD, because most of the children seen there have severe limitations in many areas, but one child's severe limitation may not represent the same degree of severity in another child. In terms of evaluating the children with rare metabolic disorders, it may be better to measure only *within* child variation as opposed to *between* child variation since the degrees of severity may vary widely in this population due to individual disease course. That being said,

groups of within children ratings may be the best way to present data at the international level until more strict coding guidelines or specifications are developed.

Treatment Recommendations

In the initial planning of the project, comparing the types of treatment recommendations made from evaluations performed in the Fall without the ICF-CY with the ones from the Spring using the ICF-CY was going to be part of the scope of this project. The purpose of that would have been to see if using the ICF-CY checklist during evaluations helped to create more functional recommendations and/or more recommendations more heavily focused on increasing access to activities and participation. This analysis did not take place, however, because the patients seen over the designated periods of time did not have enough similar characteristics to be able to compare them nor were two visits for the same patient scheduled in each of the target time slots.

In the absence of a formal comparison, it was noted that once the examiners started talking about the Activities and Participation areas from the ICF-CY, often they decided that more could be done to facilitate active participation. For example, with the child described in Case 2 from the NFRD, the examiners recommended a voice-output switch in order for B.E. to have more active participation in her school setting. This switch was to be used by programming repetitive lines from stories or songs for her to activate during group activities. While B.E. luckily already had access to switch-activated toys in her preschool, voice-output switches could increase the level of interaction that she could have with others since having a switch with voice-output could

lead to more responses from others. Overall, recommendations using the ICF-CY checklist tended to focus first on ways to increase the child's participation in specific daily activities, which often provided a context for targeting needed body functions as well. Without the ICF-CY, the focus on how the child's abilities enable or restrict their participation may easily be lost; instead focusing only on the speech and language functions the child has out of context. Targeting goals within an authentic routine or activity is likely to help the child participate more actively in those routines in the future.

Clinical Applications

There were several important clinical applications that emerged from this research. Chiefly, the ICF-CY framework was found to be incredibly useful for creating functional goals to target areas of activities and participation. With the framework in mind, clinicians can think about the ways that what they target in intervention can have a direct impact on the child's quality of life and ability to participate actively in daily activities.

Additionally, on the NFRD research team, there is a need for a system that can help document disease progression in the children who have rare disorders. Using the ICF-CY checklist to document affected areas and progression of deficits in those areas, could serve as a way to compare children on the international level where standardized measures simply do not exist. In the USA, many standardized speech-language evaluations exist, but in other countries if tools exist they would not be the same ones used here in the United States. Thus, the ICF-CY checklist could facilitate comparison of

disease course as it is tracked and updated over time for each child, consolidating data from different children for each rare disorder with researchers around the world.

In Guatemala, something that emerged from the evaluations was that none of the children seemed to have a 1 to1 correspondence while they were counting. Although this was noted on the ICF-CY checklist as a problem with learning basic concepts, a larger issue emerged suggesting that the way the concept of counting was being taught was rote learning as opposed to learning in a way that would generalize. Based on the tracking of these concepts across children, a problem with the curriculum was identified and the speech-language pathologist there has decided to help teachers incorporate a new way of teaching counting into teacher education. Without noting the skills of these ten children across different villages and with a variety diagnoses, this general trend may not have emerged.

Future Research

From this preliminary study, several future areas of need have emerged related to use of an ICF-CY based checklist in clinical practice. First, more longitudinal research is needed to determine the usefulness of using within-client ratings to track and monitor progress or decline depending on the patient population. At the NFRD, the pattern of skill decline would be extremely helpful to document natural disease progression and speed of progression as well as any changes or reversals in the progression resulting from successful treatment. In Guatemala and in other areas that do not have as many language evaluation tools, the ICF-CY checklist could be used to identify baseline behaviors and

document progress as a result of intervention and to continue to monitor all areas of speech, language and swallowing to determine future areas of need.

Other studies could focus on comparing treatment recommendations and goals before the use of the ICF-CY checklist in clinical practice compared with after using the checklist. One could assume that goals developed prior to using the ICF-CY checklist may have related more to areas of Body Function, whereas after using the checklist goals may be more functional or related to specific areas of Activities and Participation.

Lastly, in the absence of a formal coding manual, which is still in development, specific coding rules may be developed for use with the speech-language ICF-CY checklist from this study. If a formal rule set is developed, the checklist could then be tested for inter-rater reliability. It may also be helpful to test intra-rater reliability to see if the checklist would be reliable for use in assessment and progress-monitoring activities completed by individual clinicians.

Feasibility and Justification for Use in Clinical Practice

The feasibility of the ICF-CY checklist for clinical use has been evaluated within this study, acknowledging its limitations and suggesting some recommendations for improving the ICF-CY checklist for clinical settings. Feasibility was assessed by evaluating difficulties learning the coding system, the possibility of achieving reliability between clinicians, and the additional time required to complete the checklist with each client. Based on the study findings, using an ICF-CY checklist to classify functional limitations in children with rare disorders or any speech, language, swallowing disorder is strongly encouraged.

APPENDIX A: Changes to Checklist

Codes Removed from Final Version of Checklist	Codes Retained in Final Version of Checklist
Body Structures s1101 Structure of midbrain s1102 Structure of diencephalon s1105 Structure of brain stem s120 Spinal cord & related structures s220 Structure of eyeball s430 Respiratory System s4303 Muscles of respiration s520 Structure of esophagus s710 Structure of head and neck region s7100 Bones of cranium s7101 Bones of face s7102 Bones of neck s7104 Muscles of head and neck region	Body Structures s110 Brain s1100 Structure of cortical lobes s1103 Basal ganglia & related structures s1104 Structure of cerebellum s1106 Structure of cranial nerves s240 Structure of external ear s250 Structure of middle ear s260 Structure of inner ear s310 Structure of nose s320 Structure of mouth s3200 Teeth s3202 Structure of palate s32020 Hard palate s32021 Soft palate s3203 Tongue s3204 Structure of lips s330 Structure of pharynx s340 Structure of larynx s3400 Vocal folds s430 Structure of respiratory system s5 Structures related to the digestive system s7 Structures related to movement
Body Functions b110 Consciousness b122 Global psychosocial functions b1400 Sustaining attention b1401 Shifting attention b1402 Dividing attention b1403 Sharing attention b1440 Short-term memory b1441 Long-term memory b1448 Working memory b1470 Psychomotor control b152 Emotional Functions b1520 Appropriateness of emotions b1521 Regulation of emotions b1522 Range of emotion b1560 Auditory perceptual functions b1561 Visual perceptual functions b1562 Visuospatial perceptual functions	Body Functions b140 Attention functions b144 Memory functions b147 Psychomotor functions b156 Perceptual functions b167 Mental functions of language b1670 Reception of language b1671 Expression of language b230 Hearing functions b3 Voice and Speech Functions b310 Voice functions b320 Articulation functions b330 Fluency and rhythm of speech functions b510 Ingestion functions b5100 Sucking b5101 Biting b5102 Chewing

b163 Basic cognitive function b164 Higher-level cognitive functions b1640 Abstraction b1641 Organization and planning b1642 Time management b1643 Cognitive flexibility b1644 Insight b1645 Judgment b1646 Problem-solving b16700 Spoken language b16701 Written language b16702 Sign language b16703 Gestural language b1672 Integrative language functions b176 Mental function of sequencing complex movements b210 Seeing functions b2304 Speech Discrimination b235 Vestibular functions b240 Sensations associated with hearing & vestibular function b3100 Production of voice b3101 Quality of voice b3300 Fluency of speech b3301 Rhythm of speech b3302 Speed of speech b3303 Melody of speech b340 Alternative vocalization functions b3401 Making a range of sounds b4 Respiratory system b440 Respiratory functions b4400 Respiration rate b4401 Respiratory rhythm b4402 Depth of respiration b735 Muscle tone functions b7358 Muscle tone functions (oral) b760 Control of voluntary movement functions b7601 Control of complex voluntary movements b7602 Coordination of voluntary movements b761 Spontaneous movements b765 Involuntary movement functions	b5103 Manipulation of food in the mouth b5105 Swallowing b51050 Oral swallowing b51051 Pharyngeal swallowing b51052 Esophageal swallowing b7 Neuromuscular Movement-Related Functions

APPENDIX B: Checklist Final Version

Child's Name: _____ Evaluator: _____

	Year	Month	Day
Date of Evaluation:			
Date of Birth:			
Chronological Age:			

[Activities and Participation] *Look at performance in current environment*:
0 no difficulty 1 mild difficulty 2 moderate difficulty 3 severe difficulty 4 complete difficulty

What does your child like to do?	Code	Need	Qualifier	9m ≤ 2y	2 ≤ 5y	5 ≤ 12 y	12 ≤ 21 y
1. Learning & Applying Knowledge	d1						
Watching (attending to visual stimuli) Do you notice your child watching the world around him/her?	d110	Y/N	0 1 2 3 4	Turns eyes and head towards sound; watches for 5 sec			
Other purposeful sensing (d1200 Mouthing, d1201 Touching) How does your child explore his/her environment?	d120 d1200 d1201	Y/N Y/N Y/N	0 1 2 3 4 0 1 2 3 4 0 1 2 3 4				
Copying How does your child learn a new skill? Does s/he imitate you?	d130	Y/N	0 1 2 3 4	gesture, sound, action	chore; complex phrases	complex chore	
Learning through actions with objects	d131	Y/N	0 1 2 3 4		imitates complex actions (shaving)		
Acquiring language (d1330 Acquiring single words or meaningful symbols, d1331 Combining words into phrases, d1332 Acquiring syntax) How well is your child learning	d133 d1330 d1331 d1332	Y/N Y/N Y/N Y/N	0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4	sounds/ gestures (<1); acquiring single words at least 50 by 2yrs	combining words; asks questions; present – ing; possessive s; reg. past tense	refining syntax	essentially adult-like

language?							
Acquiring concepts (basic) How well is your child learning basic concepts?	d137	Y/N	0 1 2 3 4		colors		
Learning to read/write How would you describe your child's reading and writing skills?	d140 d145	Y/N Y/N	0 1 2 3 4 0 1 2 3 4		recognize letters & common signs	reads simple stories; writes reports	reading for information
Acquiring skills How well does your child learn new skills? (d1550 basic – waving in response or d1551 complex-playing games)	d155 d1550 d1551	Y/N Y/N Y/N	0 1 2 3 4 0 1 2 3 4 0 1 2 3 4		basic games		games requiring decision making; sports
Thinking (playing pretend) How well does your child come up with new ideas on his/her own?	d163	Y/N	0 1 2 3 4				
Solving problems How well does your child solve problems?	d175	Y/N	0 1 2 3 4		stool to climb	academic & social issues	
Making decisions How well does your child make decisions?	d177	Y/N	0 1 2 3 4				Think about what could happen before doing something
2. General Tasks & Demands	d2						
Undertaking a single task What types of chores/tasks does your child do independently? Can s/he complete a single task? (go get shoes)	d210	Y/N	0 1 2 3 4		1 step directions	making bed take out trash	prepare to do homework
Undertaking multiple tasks	d220	Y/N	0 1 2 3 4		2 step directions	set table gather	complete project

Can your child complete multiple tasks without constant prompts? Follow multiple commands?					3 step directions	trash	
Carrying out daily routine How well does your child carry out daily routines? (getting dressed/ready)	d230	Y/N	0 1 2 3 4			get ready for school, self-care	
Handling stress and other psychological demands How well does your child handle stress & frustration?	d240	Y/N	0 1 2 3 4		tolerates changes in routine	controls anger	controls anger if does not get own way
Managing one's own behavior How well is your child able to manage and control own behavior?	d250	Y/N	0 1 2 3 4				
3. Communication	d3	Y/N	0 1 2 3 4				
How well does your child understand language compared to other children his/her age?				no, bye-bye;	words, sentences, questions	stories	
-Communicating with-receiving spoken messages	d310	Y/N	0 1 2 3 4				
-Responding to the human voice	d3100	Y/N	0 1 2 3 4				
-Comprehending simple spoken messages	d3101	Y/N	0 1 2 3 4				
-Comprehending complex spoken messages	d3102	Y/N	0 1 2 3 4				
-Communicating with—receiving nonverbal messages	d315	Y/N	0 1 2 3 4				
-Communicating with—receiving formal sign	d320	Y/N	0 1 2 3 4				

language messages -Communicating with-receiving written messages	d325	Y/N	0 1 2 3 4				
How does your child communicate with you? Does he/she use words, babble, make vocalizations? -Speaking -Pre-talking -Producing nonverbal messages -Producing messages in formal sign language -Writing messages -Conversation -Using communication devices and techniques	 d330 d331 d335 d340 d345 d350 d360	 Y/N Y/N Y/N Y/N Y/N Y/N Y/N	 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4	babble, words	sentences, short conversations, tells basic stories	extended conversations; explains ideas in more than 1 way	
5. **Self-Care**	d5						
Eating Tell me about your child's feeding skills.	d550	Y/N	0 1 2 3 4	eats solid foods, sucks/chews on finger foods, feeds with fork/spoon	utensils, cutting food; chews with mouth closed	preparing sandwich	preparing meal
Drinking	d560	Y/N	0 1 2 3 4	drinks from cup/straw	pouring		
7. Interpersonal Interactions and Relationships	d7	Y/N	0 1 2 3 4				
Family relationships How well does your child interact with family members? (parent-child, sibling, extended family)	d760 d7601 d7602 d7603	Y/N Y/N Y/N Y/N	0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4	parent-child; looks for familiar adults; patty-cake	siblings	extended family relationships	
How well does your child relate to people in general? -Basic	d710	Y/N	0 1 2 3 4		helps others when needed (5yrs);	under-stands indirect cues in conversat	

interpersonal interactions -Social cues in relationships -Initiating social interactions -Maintaining social interactions -Complex interpersonal interactions -Relating with strangers	 d7104 d71040 d71041 d720 d730	 Y/N Y/N Y/N Y/N Y/N	 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4		adjusts behavior depending on audience	ion; starts conversa-tions; acts appropri-ately with strangers	
How well does your child relate to/interact with peers? -Informal social relationships (peers)	d750	Y/N	0 1 2 3 4		parallel/ pretend play; best friend	complex, inter-active play	
8. Major Life Areas	d8						
How well does your child do at school? Is he or she able to fully participate in the classroom and in play? -Preschool education -School education -School life and related activities -Engagement in play -solitary play -onlooker play -parallel play -shared, cooperative play	 d815 d820 d835 d880 d8800 d8801 d8802 d8803	 Y/N Y/N Y/N Y/N Y/N Y/N Y/N Y/N	 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4 0 1 2 3 4				
9. Community, Social and Civic Life	d9						
How does your child participate in the community, recreation activities and/or religion or spirituality?	d910 d920 d930	Y/N Y/N Y/N	0 1 2 3 4 0 1 2 3 4 0 1 2 3 4				

Environmental Factors (.0 no barrier .1 mild barrier, .2 moderate barrier, .3 severe barrier, .4 complete barrier, +0 no facilitator, +1 mild facilitator, +2 moderate facilitator, +3 substantial facilitator, +4 complete facilitator)

1. Is your child currently using assistive technology of any kind? Do you (and child) find that helpful? (see e1)

2. Are there conditions under which your child's hearing, speech, language, swallowing is better or worse?

3. Is your child currently receiving Speech-Language services? If so, are you satisfied with those services? (see e3,e4,e5)

4. Is your child currently in an educational placement that supports his/her Speech-Language or swallowing goals and needs? Are you satisfied with those services? (see e5)

5. Do you have a support system to help you meet your child's needs? If so, please describe. How do the attitudes of these individuals help/hinder your child's progress? (see e3 and e4)

Personal Factors noted:

_____

Body Structures	Code	Need?	Qualifier	**Body Functions**	Code	Need?	Qualifier
1. Structures of the Nervous System	s1			**1. Mental Functions**	b1		
-Brain	s110	Y / N	0 1 2 3 4	-Attention functions	b140	Y / N	0 1 2 3 4
-Structure of cortical lobes	s1100	Y / N	0 1 2 3 4	-Memory functions	b144	Y / N	0 1 2 3 4
				-Psychomotor functions (Specific mental functions of control over motor and psychological events at the body level)	b147	Y / N	0 1 2 3 4

				-Perceptual functions (Auditory, Visual, Visuospatial)	b156	Y / N	0 1 2 3 4
--Basal ganglia & related structures	s1103	Y / N	0 1 2 3 4	-Mental functions of language	b167	Y / N	0 1 2 3 4
-Structure of Cerebellum	s1104	Y / N	0 1 2 3 4	--Reception of language	b1670	Y / N	0 1 2 3 4
-Structure of cranial nerves	s1106	Y / N	0 1 2 3 4	--Expression of language	b1671	Y / N	0 1 2 3 4
2. The Eye, Ear and Related Structures	s2			**2. Sensory Functions and Pain**	b2		
-Structure of external ear	s240	Y / N	0 1 2 3 4	-Hearing functions	b230	Y / N	0 1 2 3 4
-Structure of middle ear	s250	Y / N	0 1 2 3 4				
-Structure of inner ear	s260	Y / N	0 1 2 3 4				
3. Structures in Voice and Speech	s3			**3. Voice and Speech Functions**	b3	Y / N	0 1 2 3 4
-Structure of nose	s310	Y / N	0 1 2 3 4				
-Structure of mouth	s320	Y / N	0 1 2 3 4				
--Teeth	s3200	Y / N	0 1 2 3 4	-Voice Functions	b310	Y / N	0 1 2 3 4
--Structure of palate	s3202	Y / N	0 1 2 3 4				
---Hard Palate	s32020	Y / N	0 1 2 3 4				
---Soft Palate	s32021	Y / N	0 1 2 3 4	-Articulation Functions	b320	Y / N	0 1 2 3 4
--Tongue	s3203	Y / N	0 1 2 3 4				
--Structure of lips	s3204	Y / N	0 1 2 3 4				
-Structure of pharynx	s330	Y / N	0 1 2 3 4	-Fluency and rhythm of speech functions	b330	Y / N	0 1 2 3 4
-Structure of larynx	s340	Y / N	0 1 2 3 4				
--Vocal folds	s3400	Y / N	0 1 2 3 4				
4. Structure of	s430	Y / N	0 1 2 3 4	**5. Functions of the Digestive,**	b5		

Respiratory System				**Metabolic, and endocrine systems**			
				-Ingestion functions	b510	Y / N	0 1 2 3 4
				--Sucking	b5100	Y / N	0 1 2 3 4
				--Biting	b5101	Y / N	0 1 2 3 4
				--Chewing	b5102	Y / N	0 1 2 3 4
5.Structures related to the digestive system	s5	Y / N	0 1 2 3 4	-Manipulation of food in the mouth	b5103	Y / N	0 1 2 3 4
				-Swallowing	b5105	Y / N	0 1 2 3 4
				--Oral Swallowing	b51050	Y / N	0 1 2 3 4
				--Pharyngeal Swallowing	b51051	Y / N	0 1 2 3 4
				--Esophageal Swallowing	b51052	Y / N	0 1 2 3 4
7.Structures related to movement	s7	Y / N	0 1 2 3 4	**7. Neuro-muscular Movement-Related Functions**	b7	Y / N	0 1 2 3 4

Environmental Factors

e1 Products and Technology

- e115 Products and technology for personal use in daily living
- e125 Products and technology for communication

e3 Natural Environment and Human-made changes to environment

- e310 Immediate Family
- e315 Extended Family
- e320 Friends
- e340 Personal care providers and personal assistants
- e355 Health professionals
- e360 Other professionals

e4 Attitudes

- e410 Individual attitudes of immediate family members
- e415 Individual attitudes of extended family members
- e420 Individual attitudes of friends

e5 Services, Systems, and Policies

- e535 Communication services, systems, and policies
- e585 Education and training services, systems, and policies

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