Application of the International Classification of Functioning, Disability, and Health–Children and Youth Version (ICF-CY) to Cleft Lip and Palate

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Objective: **In recent health policy discussions, the World Health Organization has urged member states to implement the *International Classification of Functioning, Disability, and Health: Children and Youth Version* in their clinical practice and research. The purpose of this study was to identify codes from the *International Classification of Functioning, Disability, and Health: Children and Youth Version* relevant for use among children with cleft lip and/or palate, thereby highlighting the potential value of these codes for interprofessional cleft palate-craniofacial teams.**

Design: **The scope of recent published research in the area of cleft lip and/or palate was reviewed and compared with meaningful terms identified from the *International Classification of Functioning, Disability, and Health: Children and Youth Version*. In a five-step procedure, a consensus-based list of terms was developed that was linked separately to *International Classification of Functioning, Disability, and Health: Children and Youth Version* categories and codes. This provided a first draft of a core set for use in the cleft lip and/or palate field.**

Conclusions: **Adopting *International Classification of Functioning, Disability, and Health: Children and Youth Version* domains in cleft lip and/or palate may aid experts in identifying appropriate starting points for assessment, counseling, and therapy. When used as a clinical tool, it encourages health care professionals to go beyond treatment and outcome perspectives that are focused solely on the child and to include the children's environment and their familial/societal context. In order to establish improved, evidence-based interdisciplinary treatments for children with cleft lip and/or palate, more studies are needed that seek to identify all the influencing conditions of activities, children's participation, and barriers/facilitators in their environments.**

KEY WORDS: *activities, body functions, body structures, cleft lip and palate, core set, environmental factors, ICF, ICF-CY, participation*

Children with a history of cleft lip and/or palate (CL/P) are at an increased risk of a range of difficulties and impairments related to their cleft condition (Bzoch, 2004; Peterson-Falzone et al., 2010; Howard and Lohmander, 2011). Some of these difficulties are directly related to the presence of ongoing anatomical or structural problems, such as palatal fistulae, malocclusion, or velopharyngeal insufficiency (Shprintzen and Bardach, 1995; Peterson-Falzone et al., 2010). Other difficulties are related more generally to the effect of having had a cleft condition and include issues related to interpersonal problems such as teasing by peers (Lockhart, 2003; Hunt et al., 2005; DeSousa et al., 2009). The range of difficulties that can present in children with CL/P justifies the need for CL/P teams to focus their intervention efforts, and outcome measurements on more than just the anatomical or structural problems usually encountered in cleft care.

The collection of outcome measures in any health care setting can better enable the respective health care team to identify outcomes, but it also enables the team to quantify the effect that a specific treatment has had on other aspects of their patients' lives. Although there are many discipline-specific (Merrit, 2005; Sell et al., 2009; Neumann, 2010, 2011b) and even condition-specific (Pertschuk and Whitaker, 1982; Harter, 1988; Golding-Kushner, 1990; Smith et al., 2007) classification and outcome measurement tools that could be used in cleft care, these do not easily allow for data to be compared between disciplines or indeed allow

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Submitted July 2010; Accepted January 2012.

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DOI: 10.1597/10-145

for cleft-related data to be compared for other conditions. This is important for purposes such as resource allocation and service planning.

In 2001, the World Health Organization (WHO) published the *International Classification of Functioning, Disability, and Health* (ICF) as a means of providing a scientific basis for understanding health-related states, outcomes, and determinants and to establish a common language for describing these in order to improve communication among users around the world. In this way, the ICF may be used as a statistical, clinical, or research tool.

The adapted *International Classification of Functioning, Disability, and Health: Children and Youth Version* (ICF-CY) for use with children and adolescents aged 0 to 18 was first published in November 2007. Both classification systems stem from the *International Classification of Impairments, Disabilities, and Handicaps*, or ICIDH (WHO, 1980, 2000), and represent a historic shift in global understanding of *disability* (DeKleijn-DeVrankrijker, 2003). The original ICIDH limited its view of impairment and disability to the individual. By contrast, the ICF/ICF-CY includes variables external to the individual, identifying and incorporating aspects such as a person's daily activities, social participation, and contextual factors. It also reflects a shift away from linear-causal assumptions about the patterns and conditions that give rise to disabilities. Therefore, disabilities are seen as arising from an interactive relationship between internal/personal and external/environmental variables.

In general, the ICF-CY is applied by professionals classifying the health status of an individual. Ueda and Okawa (2003) criticized this procedure as reflecting a measurable status of health, not the individual perception of it. The authors highlighted the importance of reflecting the subjective dimension of a disability (Fig. 1). They proposed asking the clients about their subjective impressions of possible restrictions and/or limitations. Threats (2010) supported this by postulating the opportunity for clients to participate in the classification process.

The IFC-CY is a framework and classification tool that implements a "biopsychosocial" view (WHO, 2007). The ICF-CY offers a universal language/terminology for health conditions to facilitate standardized assessment but is not itself an assessment tool. In Resolution WHA54.21 of May 22, 2001, the WHO urged member states to use the ICF-CY in research, observation, and reporting (WHO, 2007).

Due to its complexity—it includes more than 1400 codes for states of health and functioning, spanning 322 pages—the ICF-CY can be challenging to apply in clinical practice. Even when applied to CL/P, it might be difficult to use because not all codes presented are relevant to children with the condition. To reduce this complexity, researchers and clinicians have emphasized the importance of preselecting ICF-CY domains and codes relevant to clients with a restricted health condition (Stucki et al., 2002; McDougall and Miller, 2003; Stucki et al., 2008; see also http://www.icf-research-branch.org/icf-core-sets-projects.html).

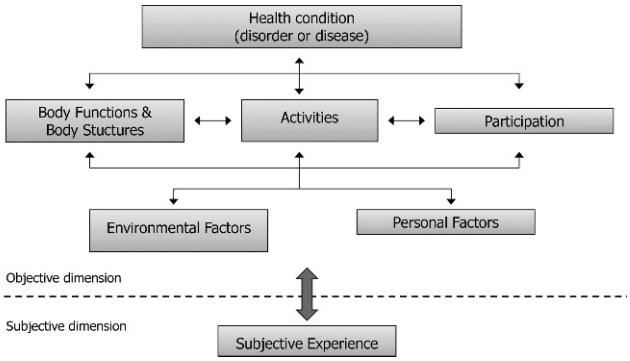

FIGURE 1 Interactive linkage of ICF/ICF-CY components, including a subjective dimension that encompasses the subjective experience of the health problem as postulated by Ueda and Okawa (2003).

According to international guidelines, ICF or ICF-CY core sets are evidence-based, preselected lists of ICF domains and codes relevant for specific disorders (Ewert et al., 2005). For the sake of comprehensiveness, a core set should emphasize the key fields of investigation associated with a given disorder as well as important neglected areas, as captured by specific ICF and ICF-CY codes and domains.

To date, no core set has been published for use in the cleft lip and palate field. Thus far, little research on CL/P has been explicitly designed in accordance with the components of the ICF. In 2008, Neumann and Romonath tried to apply the ICF-CY to a child with CL/P. Also in 2008, McCormack and Worral chose some codes relevant for children with CL/P concerning Body Structures and Body Functions. Regarding Activities and Participation, Neumann (2011a) gave a first insight of individual perception of speech-language impairment in 10 children with CL/P.

The ICF-CY

The ICF/ICF-CY provides a holistic framework for understanding health, functioning, and disability—a framework that integrates biological, psychological, and social aspects (Romonath, 2007). The therapeutic perspective that emerges from this framework places greater emphasis on enabling affected persons—for instance, children with CL/P—to participate in important areas of life regardless of any impairment.

The first two decades of human life are characterized by rapid progression and significant changes in physical, psychological, and social development (WHO, 2007). As such, the new ICF-CY classification system places particular emphasis on the growing competencies, societal participation, and rapidly increasing independence of children and adolescents within their interactive environments.

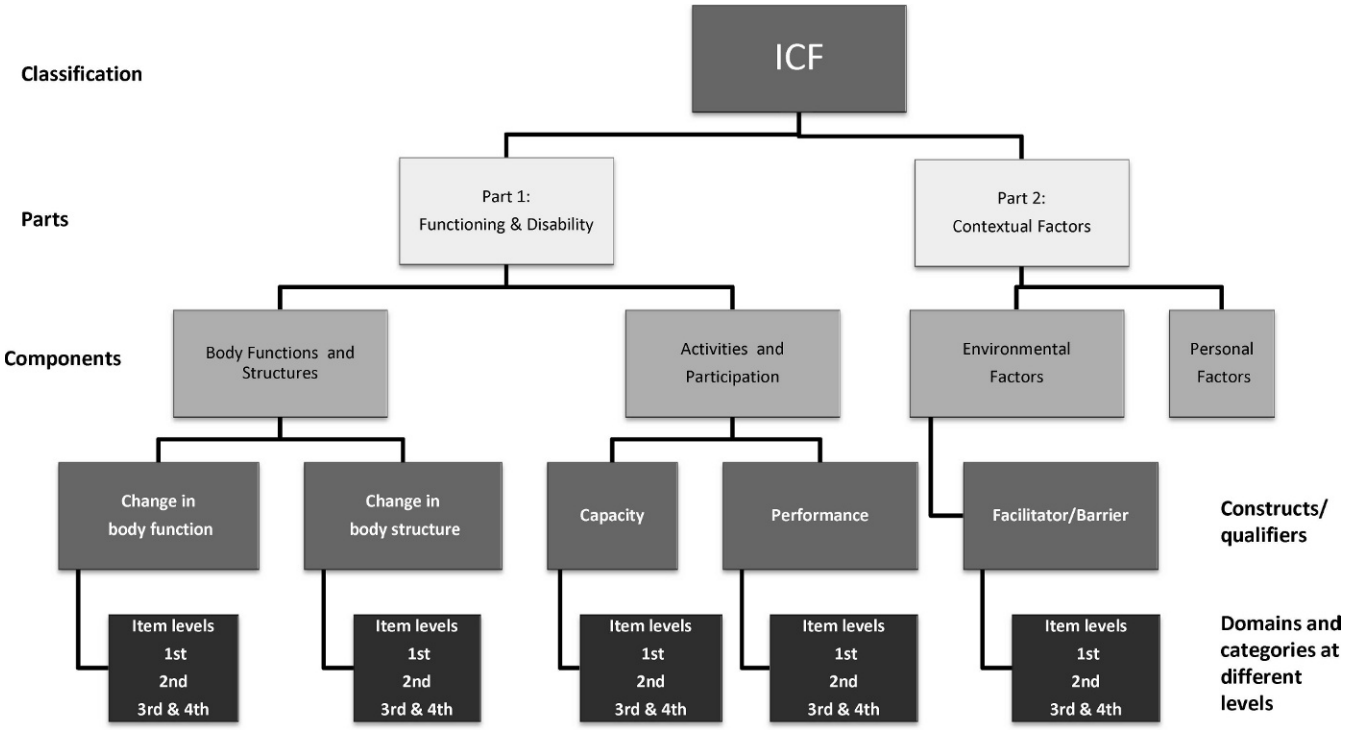

FIGURE 2 Structure of the ICF/ICF-CY (WHO, 2007, p. 231).

The ICF-CY aims to improve the health, education, and rights of children and adolescents worldwide (WHO Work Group, 2006). It incorporates the Convention on the Rights of the Child (United Nations [UN], 1989) and the Convention on the Rights of Persons With Disabilities (UN, 2006). Due to its standardized terminology, the WHO classification supports international intradisciplinary and interdisciplinary communication.

Structure and New Components of the ICF-CY

Like the ICF, the ICF-CY is divided into two parts, which encompass four components. The two parts are given the headings Part 1: Functioning and Disability, with the components (1) Body Functions and Structures; (2) Activities and Participation, and Part 2: Contextual Factors, including the components (3) Environmental Factors; and (4) Personal Factors. These components are denoted with prefixes: s = Body Structures, b = Body Functions, d = Activities and Participation, and e = Environmental Factors. Personal factors are not coded due to their heterogeneity (WHO, 2001). The ICF-CY is divided into chapters, or domains, which subsume a limited number of related codes within a given component (e.g., "d3" or "Chapter 3: Communication") (Fig. 2).

Categories in each domain comprise specific codes and subcodes used to classify specific aspects of health or functioning (e.g., d350 *Conversation* → d3500 *to begin a conversation*). In addition, each code contains at least one qualifier used to denote the magnitude of health or impairment. These qualifiers capture a person's state of health at any given moment, much like a snapshot, without specifying impairments that might have occurred in earlier phases of life.

The WHO deemed development of the ICF-CY (WHO, 2007) to be necessary in order to capture the unique conditions of maturation, growth, learning, and life that are specific to children and adolescents from birth to age 18. For this, the ICF-CY contains additional codes supplementing the ICF, explanations of existing codes, and further instructions for their application and interpretation with children (Threats and Worrall, 2004; McLeod, 2006; WHO, 2007). As such, the ICF-CY is a derived version of the ICF. In total, it contains 237 new codes concerning the development of children and adolescents. Of the new codes, 168 relate to Activities and Participation (Lollar and Simeonsson, 2006), such as those contained in categories like *Learning and applying knowledge* (chapter 1: d120 to d172) or *Major life areas: education* (chapter 8: d815 to d835). New categories such as *Acquiring language* (d133), *Learning to read* (d140), or *Learning to write* (d145) appear to be especially relevant to the social interaction of children. Individual categories were added to various domains or specified as subcategories. Noteworthy new codes that may prove valuable to professionals working with children include, for example, *Dispositions and intrapersonal functions* (b125), *Basic cognitive functions* (b163), *Growth maintenance functions* (b560 and b569), *Acquiring language* (d133), *Learning through actions with objects* (d131), *Pretalking/Singing* (d331 and 332), *Toileting*

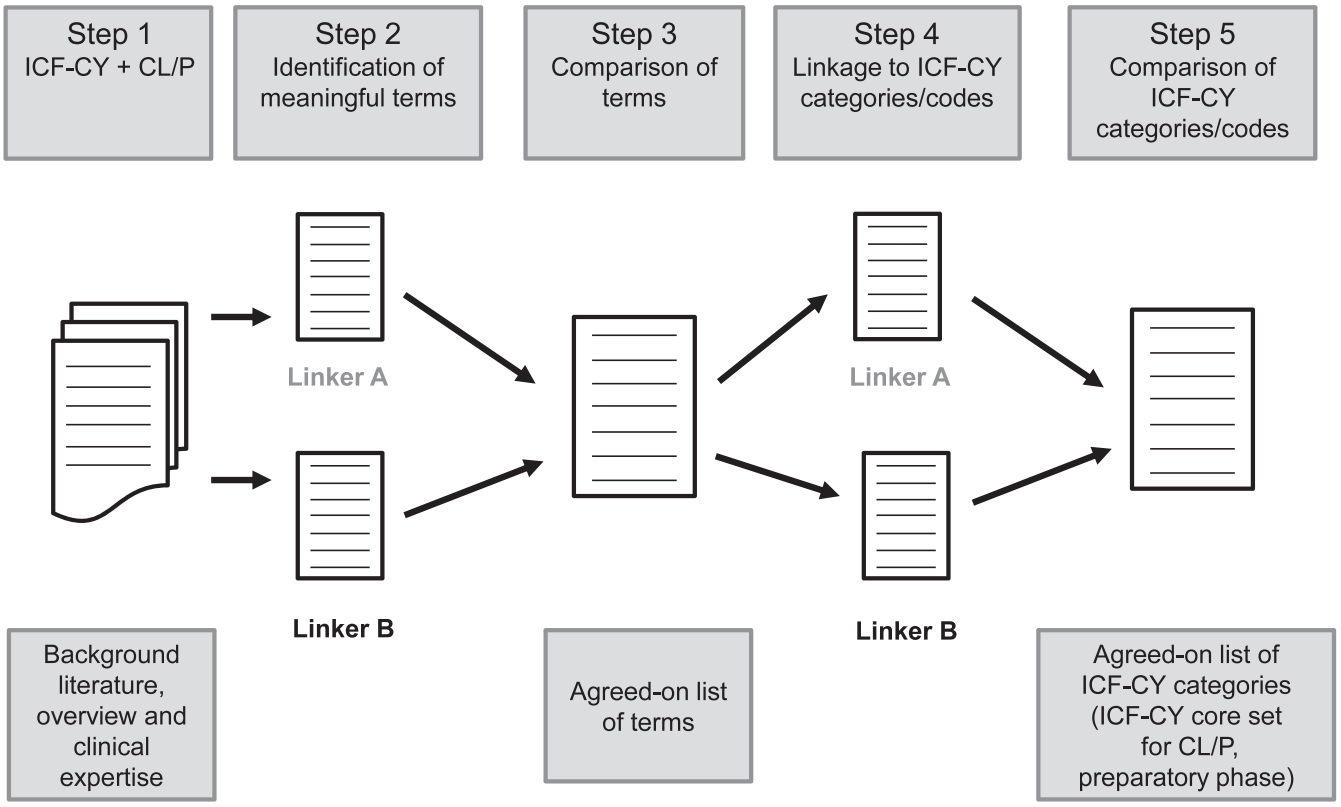

FIGURE 3 Data analysis: multiple coding.

(d530), *Looking after one's safety* (d571), *Preschool education* (d815 and d816), *School life and related activities* (d835), and *Special education and training service, systems, and policies* (e586).

In the ICF-CY, the qualifier *delay* was added to denote a lag in development that can eventually be compensated for (WHO, 2007, p. xx). Delays are further broken down using a 5-point scale indicating the degree of delay: 0 indicates *no delay*; 4 indicates *complete delay*. Unfortunately, the ICF-CY does not provide examples of coding for delay that explicitly differentiate its use from that of other qualifiers. In general, basic data for coding is to be collected by means of direct assessment, observation, qualitative interview, and/or professional estimation.

In order to apply the ICF-CY among children and adolescents with CL/P, it is essential to adopt a procedure that adheres to the standards of evidence-based practice (Reilly et al., 2004; Gillam and Gillam, 2006). Although the process of developing a new data set also requires validation from the clients themselves (Coenen, 2008), the aim of the present project was to identify and to simply describe appropriate ICF-CY codes, supported by the best research evidence available on children with CL/P, in order to aid clinical decision-making (American Speech-Language-Hearing Association, 2005). This may open up a new perspective on children and adolescents with CL/P as well as stimulate future research geared toward development of high-quality, evidence-based speech therapies. As such, the authors opted for an evidence-based approach (Sackett et al., 1996; Porzsolt et al., 2003) in their efforts to identify ICF-CY codes relevant for children with CL/P.

The present article describes a subset of codes for potential use in children and adolescents with nonsyndromic CL/P relevant for interprofessional cleft palate-craniofacial teams. It offers a first draft of a comprehensive core set in a prearrangement phase (Ewert et al., 2005) and gives an additional example of a 3-year-old girl with CL/P. The establishment of ICF-CY core sets in a second step will enable this classification system to be used more efficiently in clinical practice and research.

Methods

To develop a first draft of a core set of ICF-CY for children with CL/P, the authors conducted a five-step consensus procedure proposed by Ewert and colleagues (2005) (Fig. 3). In step 1, the two authors/linkers made a detailed study of the ICF and ICF-CY, their background information, and applications to several health problems in children. To ensure that their selections reflected the most current developments in CL/P-relevant theory and practice, the linkers also conducted a broad overview of current international literature on CL/P, in particular of specialized handbooks and textbooks including Shprintzen and Bardach (1995), Bzoch (2004), and Peterson-Falzone et al. (2010).

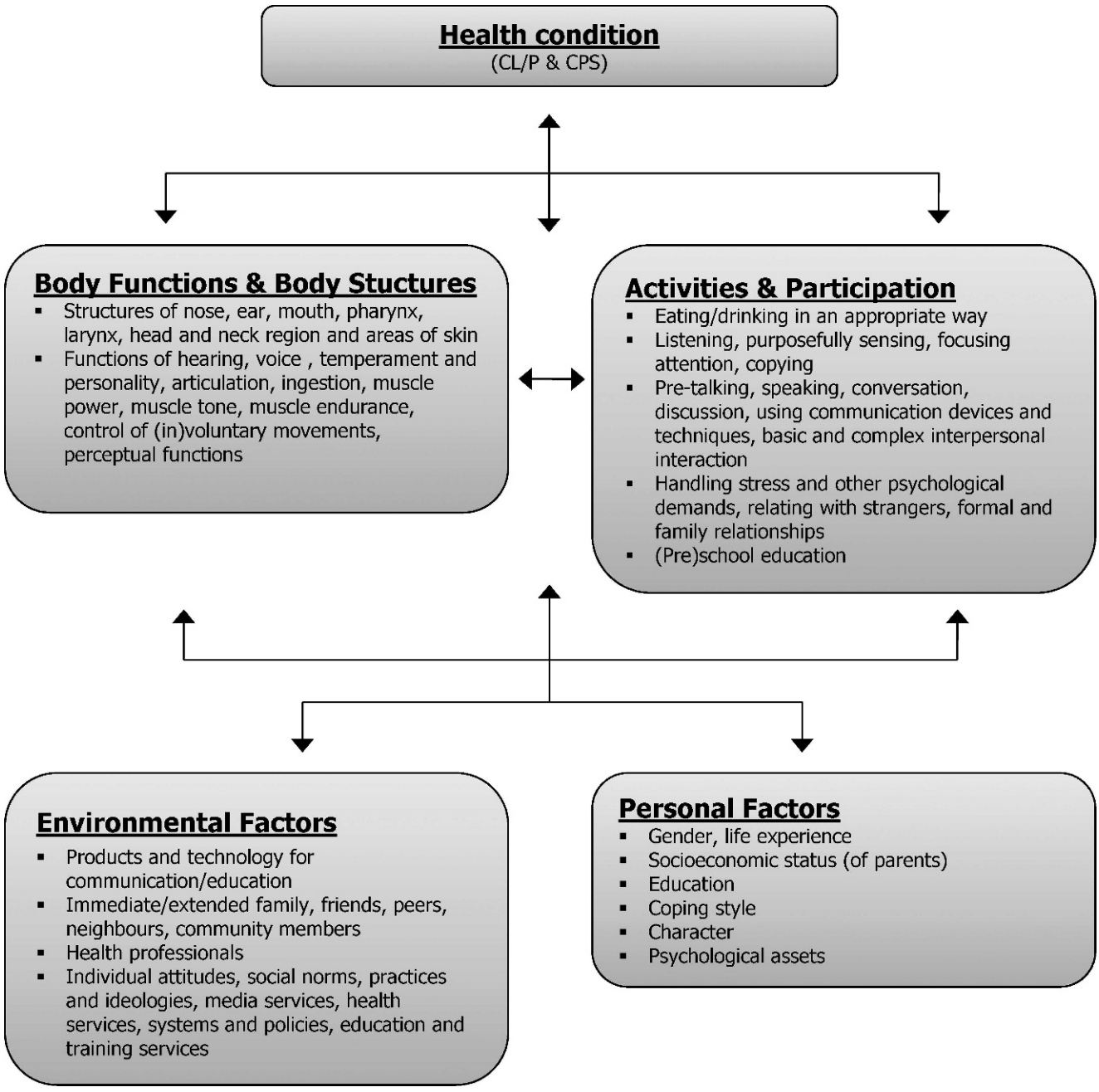

FIGURE 4 Identified CL/P-relevant terms relating to ICF-CY domains.

Drawing on their individual research and practical expertise in CL/P over 10 years, in step 2, the linkers separately identified meaningful terms relating to children with CL/P. The CL/P-relevant terms independently identified by the two linkers were then compared in step 3 and a consensus-based list was generated, which linked in a broad manner to domains of the four components of the ICF-CY. Figure 4 summarizes the most important terms identified.

In step 4, the authors separately linked the terms to ICF categories and codes. They compiled lists of specific selections from among the various codes, up to the fourth level (see Fig. 2).

In the final stage, step 5, the two linkers compared their lists of linkage and developed a consensus-based list of ICF-CY categories/codes, which is characterized by a first ICF-CY core set for children with CL/P in a prearrangement phase (Ewert, 2005).

In addition, a literature overview was carried out for each selected code, with the aim of finding and documenting evidence to support the code's inclusion in the list. However, the reviews of relevant literature from the last two decades failed to provide sufficient evidence in every case. Although at least one reference was found for 16 codes, the review failed to find evidence for 34 codes. This

was often due to low-level study designs, case studies that were too small, or the absence of clinical trials. In such cases, the authors sought to supplement the information base by relying on professional experience or academic opinion (e.g., information from handbooks or founding research).

Results

First Draft of a CL/P Core Set

The results generated a first draft of a core set for children and adolescents with CL/P from 0 to 17 years according to its relevance for those experts providing health services to children with CL/P. In the following section, the identified areas of the ICF-CY, coupled with examples of relevant references, will be summarized to highlight the scope of literature available for various parts of cleft/craniofacial care. Specific ICF-CY codes will appear in brackets. Table 1 contains the same information organized in numerical coding order for each of the ICF-CY's major domains.

Two things should, however, be noted: (1) In Activities and Participation, some codes may serve as facilitators and not necessarily as barriers (see Table 1); and (2) the codes relevant for one child with CL/P will not necessarily bear the same relevance for other CL/P-affected children—each individual child and context is unique (see Table 2). In Figure 4, which follows, the consensus-based list of terms from step 3 is presented.

Body Structures (s)

This component introduced in part 1 of the ICF-CY, Body Structures (s) is defined as anatomical parts of the body (WHO, 2007). During childhood and adolescence, impairments may take the form of developmental delays of body structures, such as growth or maturation problems.

Children with CL/P primarily experience structural issues in the *Head and neck region* (s710) (Weinberg et al., 2006), particularly bone-related issues such as malformation of maxilla or hypoplastic vomer. The incidence of oronasal palatal fistula following palate repair has been reported to range between 5% and 60% (Cohen et al., 1991; Muzaffar et al., 2001; Phua and DeChalain, 2008). Furthermore, *Muscles of the head and neck region* (s7104) (e.g., the musculus orbicularis oris superior, velopharyngeal muscle sling) are often congenitally affected (Ettema et al., 2002; Kuehn et al., 2004; Perry, 2011). *Fibers, structure of gums* (s3201), (upper) *Lip* (s3204), and *Facial skin* (s810) are also likely to be affected in their morphological structure (Nakamura et al., 2005; Peterson-Falzone et al., 2010). Other studies provide evidence of congenitally missing, hypoplastic, or dysmorphic primary and/or *Permanent teeth* (s3200) (Margraf-Stiksrud and Fleischer-Peters, 1996; Semb and Schwartz, 1997; Long et al., 2000; Lockhart, 2003).

The *Structure of nose* (s310) is often impaired, in particular the nasal septum and external nose (Hermann et al., 2002). So too is the *Mouth* (s320), especially the structure of the hard and soft palates (Berry et al., 1999; Perry, 2011). Maxillary skeletal retrusion (s7101: *Bones of face*) may also be observed, depending on the timing and types of surgery a patient has undergone (Schweininger, 1991; Kuijpers-Jagtman and Long, 2000; Nakamura et al., 2005). Furthermore, the *Structure of pharynx* (s330) may be impaired, particularly the oral and nasal pharynx, due to compensatory hypertrophic tonsils and/or adenoids (Oosterkamp et al., 2007). Mutation of the *Larynx* (s340) may be present, such as vocal nodules on the vocal folds (e3400) following sustained hyperfunctional dysphonia (D'Antonio et al., 1988), often caused by velopharyngeal insufficiency. The *Middle ear* (s250) may exhibit cicatrizations in the *Tympanic membrane* (s2500) caused by chronic otitis media (Tunçbilek et al., 2003). Some studies indicate the possibility of genetically augmented elasticity in the *Eustachian tube* (s2509), in which case the tube may collapse and inhibit ventilation of the middle ear (Arnold et al., 2005). Another potential middle ear ventilation disorder may stem from covering of the eustachian tube by parts of the nonoperated cleft velum, as observed by Godbersen (1990). Finally, concerning the *Structure of the inner ear* (s260), there is some discussion of a small percentage (5%) of children who experience sensorineural hearing loss (Bardach et al., 1992). Actual studies also show deviations in *Structures of the brain* (s110), especially in the *Structure of cortical lobes* (s1100) and *Structure of cerebellum* (s1104) in children, especially in boys, with isolated CL/P (Nopoulos et al., 2007) and in boys with CL/P and worse articulation proficiency (Conrad et al., 2010). Also children with nonsyndromic CL/P may show significantly smaller volumes of the left thalamus and left auditory cortex (s1100, *Structure of diencephalon* s1102; Yang et al., in press).

Body Functions (b)

Body Functions (b) encompasses physiological functions (including psychological functions) of the human body (WHO, 2007). The ICF-CY gives particular attention to delays in the emergence of body functions during childhood and adolescent development.

Children with CL/P may experience difficulty with a number of different functions individually described in the ICF-CY. Following surgery, impairments of children's *Repair functions of the skin* (b820) can result in scarring that constrains their *Sensation related to the skin* (b840) or *Other touch functions* (b265) in the orofacial area (Essick et al., 2005). As a result of middle ear problems (Zheng et al., 2009), affected children may also experience loss of functional integrity in their *Perceptual functions* (b156), such as *Auditory (self-)perception* (b1560) (Brunner et al.,

TABLE 1 First Draft of an ICF-CY Core Set for Children With CL/P*

Code	*Description*	*Relevant for CL/P*	*Evidences*
s110	Structure of the brain	s1100 Structure of cortical lobes s1102 Structure of diencephalon s1104 Structure of cerebellum	Nopoulos et al., 2007; Conrad et al., 2010; Yang et al., in press
s250	Structure of middle ear	s2500 Tympanic membrane s2501 Eustachian canal s2502 Ossicles s2509 Structure of middle ear, unspecified	Tuncbilek et al., 2003; Zheng et al., 2009; Arnold et al., 2005; Godbersen 1990
s260	Structure of inner ear	s2600 Cochlea	Bardach et al., 1992
s310	Structure of nose	s3100 External nose s3101 Nasal septum s3102 Nasal fossae	Hermann et al., 2002
s320	Structure of mouth	s3200 Teeth: s32000 Primary dentition s32001 Permanent dentition s3201 Gums s3202 Structure of palate: s32020 Hard palate s32021 Soft palate s3204 Structure of lips: s32040 Upper lip s3205 Philtrum	Semb & Schwartz, 1997; Long et al., 2000; Berry et al., 1999; Peterson-Falzone et al., 2010; Ettema et al., 2002; Kuehn et al., 2004; Shprintzen & Bardach, 1995; Nakamura et al., 2005 Kummer, 2001; Trotman et al., 2007
s330	Structure of pharynx	s3300 Nasal pharynx s3301 Oral pharynx	Oosterkamp et al., 2007
s340	Structure of larynx	s3400 Vocal folds	D'Antonio et al., 1988
s710	Structure of head and neck region	s7100 Bones of cranium s71008 Bones of cranium, other specified s7101 Bones of face s7104 Muscles of head and neck region s7105 Ligaments and fasciae of head and neck region	Kuijpers-Jagtmann & Long, 2000; Nakamura et al., 2005; Cohen et al., 1991; Muzzafar et al., 2001; Phua & DeChalain, 2008
s810	Structure of areas of skin	s8100 Skin of head and neck region	
	Body Functions		**Body Functions**
b126	Temperament and personality functions	b1260 Extraversion b1264 Openness to experience b1265 Optimism b1266 Confidence	Edwards et al., 2002; Edwards et al., 2005
b156	Perceptual functions	b1560 Auditory perception b1562 Olfactory perception b1563 Gustatory perception	Brunner et al., 2005
b230	Hearing functions	b2300 Sound detection b2301 Sound discrimination b2302 Localization of sound source b2303 Lateralization of sound	Godbersen, 1997; Hermann & Bitter, 1991; Visnawathan et al., 2008
b265	Other touch functions		Essick et al., 2005
b270	Sensory functions related to temperature and other stimuli	b2702 Sensitivity to pressure	
b310	Voice functions	b3101 Quality of voice	Wermke et al., 2002; Wermke et al., 2010; Kummer et al., 1992; Warren et al., 1994; Grunwell et al., 2000; Guildersleeve-Neumann et al., 2001; Imatomi et al., 2005; Wyatt et al., 1996; Gunther et al., 1998
b320	Articulation functions		Chapman & Hardin, 1992; Wyatt et al., 1996; Golding-Kushner, 2001; Willadsen & Albrechtsen, 2006; Baylis et al., 2008; Lohmander & Persson, 2008; Yamashita & Michi, 1991; Gibbon & Crampin, 2002; Chapman et al., 2003; Salas-Provance et al., 2003; D'Antonio et al., 2001; Peterson & Graham, 1990; Kummer et al., 1992; Zajak et al., 1996; Whitehill, 2002, 2004; Hodge & Gotzke, 2007; Suzuki et al., 2006
b440	Respiration functions	b4402 Depth of respiration	Wetmore, 1992
b450	Additional respiratory functions		Hairfield et al., 1984; Wyatt et al., 1996; Yamashita & Trindade, 2008
b510	Ingestion functions	b5100 Sucking b5101 Biting b5102 Chewing b5103 Manipulation of food in the mouth b5104 Salivation b5105 Swallowing	Wohlleben, 2004; Reid et al., 2007; Arvedson & Brodsky, 2002 Kummer, 2008; Ohkiba & Hanada, 1989
b730	Muscle power functions	b7300 Power of isolated muscles/muscle groups	Maserei et al., 2007; Carvajal et al., 1992; Ravera et al., 2000
b735	Muscle tone functions	b7350 Tone of isolated muscles/muscle groups	
b740	Muscle endurance functions	b7401 Endurance of muscle groups	Nohara et al., 2006; Kuehn et al., 2007
b760	Control of voluntary movement functions	b7600 Control of simple voluntary movements b7601 Control of complex voluntary movements b7602 Coordination of voluntary movements	Kemp-Finchan et al., 1990; Yamashita & Michi, 1991; Gibbon & Crampin, 2002; Trotman et al., 2007; Wyatt et al., 1996; Trotman et al., 2005

TABLE 1 Continued

Code	*Description*	*Relevant for CL/P*	*Evidences*
b765	Involuntary movement functions	b7659 Involuntary movement functions, unspecified	Kuehn & Moller, 2000; Phua & Chalain, 2008; Bearn et al., 2001; Webb et al., 2001; Inman et al., 2005
b820	Repair functions of the skin		
b840	Sensation related to the skin		Essick et al., 2005
d115	Listening		
d120	Other purposeful sensing	d1200 Mouthing d1202 Smelling d1203 Tasting	Schaedler, 2002
d130	Copying	e.g., Copying tones	
d133	Acquiring language	d1330 Acquiring single words or meaningful symbols	Jocelyn et al., 1996; Broen et al., 1998; Willadsen & Chapman, 2011
d160	Focusing attention	d1600 Focusing attention on the human touch, face and voice	Kummer, 2001
d176	Mental functions of sequencing complex movements		Kummer et al., 2007
d240	Handling stress and other psychological demands	d2401 Handling stress d2402 Handling crisis	Speltz et al., 2000
d250	Managing one's own behavior	d2502 Approaching persons or situations	
d330	Speaking		Howard & Lohmander, 2011; Peterson-Falzone et al., 2010;
d331	Pre-talking		Willadsen, 2006; Chapman et al., 2008; Hardin-Jones & Chapman, 2008
d335	Producing nonverbal messages	d3350 Producing body language	Adachi et al., 2003
d350	Conversation	d3500 Starting a conversation d3503 Conversing with one person d3504 Conversing with many people	Kuehn & Moller, 2000; Poe & Snyder, 2005; Brand et al., 2009; Chapman et al., 1998; Frederickson et al., 2006
d355	Discussion	d3550 Discussion with one person d3551 Discussion with many people	
d360	Using communication devices and techniques	d3600 Using telecommunication devices	
d550	Eating	d5501 Carrying out eating appropriately	Glass & Wolf, 1999
d560	Drinking	d5601 Carrying out breast-feeding d5602 Carrying out feeding from bottle d5608 Drinking, other specified (s. d550)	Mizuno et al., 2002; Reid, 2004; Reid et al., 2006; Bessell, 2011
d660	Assisting others	d6602 Assisting others in communication	
d710	Basic interpersonal interactions	d71040 Initiating social interactions d7105 Physical contact in relationships	Slifer et al., 2004
d720	Complex interpersonal interactions	d7200 Forming relationships	Schultz, 2008; Leonard et al., 1991; Richman & Eliason, 1993; Ramstad et al., 1995; Broder et al., 1994
d730	Relating with strangers		
d740	Formal relationships		
d760	Family relationships	d7600 Parent-child relationships d7601 Child-parent relationships	Carlisle, 1998; Johansson & Ringsberg, 2004
d810	Informal education		Coy et al., 2002; Ludwigson, 1998
d815	Preschool education		
d820	School education		Persson et al., 2010; Danino et al., 2005
d830	Higher education		
d880	Engagement in play	d8800 Solitary play d8803 Shared cooperative play	
d910	Community life	d9100 Informal associations d9102 Ceremonies d9103 Informal community life	
d920	Recreation and leisure	d9200 Play d9201 Sports d9202 Arts and culture d9205 Socializing	
e115	Products and technology for personal use in daily living	e1152 Products and technology used for play	
e125	Products and technology for communication	e1251 Assistive products and technology for communication	
e130	Products and technology for education		
e310	Immediate family		
e315	Extended family		
e320	Friends		
e325	Acquaintances, peers, colleagues, neighbors and community members		
e345	Strangers		
e355	Health professionals		Canady et al., 1995; Strauss, 1999; Knapke et al., 2010
e360	Other professionals		

TABLE 1 Continued

Code	*Description*	*Relevant for CL/P*	*Evidences*
e410	Individual attitudes of immediate family members		Johansson & Ringsberg, 2004; Tobiasen & Hiebert, 1984; Kasuya et al., 2000
e415	Individual attitudes of extended family members		Johansson & Ringsberg, 2004
e420	Individual attitudes of friends		Schultz, 2008
e425	Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members		Schröder, 1997; Hunt et al., 2005; Hunt et al., 2006
e445	Individual attitudes of strangers		
e450	Individual attitudes of health professionals		
e455	Individual attitudes of other professionals		
e460	Societal attitudes		
e465	Social norms, practices, and ideologies		
e555	Associations and organizational services, systems, and policies		
e560	Media services	Information found on World Wide Web	Antonarakis & Kiliaridis, 2009
e570	Social security services, systems, and policies		
e575	General social support services, systems, and policies	e5750 General social support services e57500 Informal care of child or adult by family and friends	
e580	Health services, systems, and policies		
e585	Education and training services, systems, and policies	e5850 Education and training services e5851 …systems e5852 …policies e5853 Special education and training services e5854 …systems e5855 …policies	
	Age, gender, social background, life experiences, fitness, lifestyle, habits, education, coping styles, profession, character, overall behavior pattern, psychological assets		Topolski et al., 2005; Rubin & Wilkinson, 1995; Patrick et al., 2007; Persson, 2011
	Body Structures		Broder et al., 1992, 1994
	Body Functions		Broder et al., 1992, 1994
	Activities & Participation		Neumann, 2011a
	Environmental Factors		

* ICF-CY = *International Classification of Functioning, Disability, and Health–Children and Youth Version*; CL/P = cleft lip and/or palate.

2005). The *Hearing problems* (b230) that such children experience could be described as *Impairments of sound detection* (b2300), *Discrimination* (b2301), *Localization* (b2302), *Lateralization* (b2303), or *Speech discrimination* (b2304), as proposed by Godbersen (1997) and Hermann and Bitter (1991). Indeed, Visnawathan et al. (2008) have found a very high incidence of hearing loss among newborns with CL/P (82%).

Due to the lack of separation between their oral and nasal cavities, affected infants and children may exhibit problems with *Ingestion functions* (b510) (Arvedson and Brodsky, 2002). Problems in this area may primarily concern *Sucking* (b5100) (Wohlleben, 2004; Reid et al., 2007) and *Swallowing* (b5105) as a result of velopharyngeal insufficiency (Ravera et al., 2000; Kummer, 2001; Nagaoka and Tanne, 2007) and/or *Muscle power dysfunction* (b730), which is present in 25% to 30% of newborns (Masarei et al., 2007). During childhood, swallowing patterns may deviate from what is considered normal (Ohkiba and Hanada, 1989).

Muscle power (b730), *Muscle Tone* (b735), and *Endurance* (b740) functions related to individual orofacial muscles, or groups of muscles, may display elevated levels of activity—the superior orbicularis oris muscle (Carvajal et al. 1992; Ravera et al., 2000), for example. There is also evidence of possible fatigue to the velopharyngeal muscles (Nohara et al., 2006; Moon et al., 2007). *Control of voluntary movement functions* (b760) may be hindered by oral motor dysfunctions (Kemp-Finchan et al., 1990, Ravera et al., 2000), impaired coordination of the tongue (Yamashita and Michi, 1991; Gibbon and Crampin, 2002), lip (Trotman et al., 2007a; Trotman et al., 2007b), and facial grimace (Wyatt et al., 1996; Trotman et al., 2005). With regard to *Mental functions of sequencing complex movements* (d176), a study by Kummer et al. (2007) using the Apraxia Profile (Hickman, 1997) found some evidence of apraxia characteristics among children with solitary cleft palate. Furthermore, children's *Involuntary movement functions* (b765) are often affected, especially in velopharyngeal movement and its valving, as reported by Kuehn and Moller (2000) and Phua and Chalain (2008).

Children with CL/P are likely to develop *Voice disorders* (b310) concerning the *Quality of voice* (b3101), even in early

TABLE 2 First Draft of an ICF-CY Core Set for Children With CL/P, Illustrated Using the Example of "Maria" (3 Years 7 Months)*

Code	*Description*	*Relevant for CL/P*	*Maria (3 y 7 mo) With Unilateral CL/P*
	Body Structures		**Body Structures**
s110	Structure of brain	s1100 Structure of cortical lobes s1102 Structure of diencephalon s1104 Structure of cerebellum	?
s250	Structure of middle ear	s2500 Tympanic membrane s2501 Eustachian canal s2502 Ossicles s2509 Structure of middle ear, unspecified	Scars in tympanic membrane due to multiple paracenteses
	Structure of inner ear	s2600 Cochlea	–
s310	Structure of nose	s3100 External nose s3101 Nasal septum s3102 Nasal fossae	Deviation of nasal septum, undersized nostrils
s320	Structure of mouth	s3200 Teeth: s32000 Primary dentition s32001 Permanent dentition s3201 Gums s3202 Structure of palate: s32020 Hard palate s32021 Soft palate s3204 Structure of lips: s32040 Upper lip s3205 Philtrum	Lack of lateral incisors in primary dentition, anterior open bite, chapped lips, history of primary surgery; oronasal alveolar fistulae, shortened and scarred soft palate, shortened upper lip, lack of lip vermilion
s330	Structure of pharynx	s3300 Nasal pharynx s3301 Oral pharynx	Hypertrophic tonsils and adenoids
s340	Structure of larynx	s3400 Vocal folds	-
s710	Structure of head and neck region	s7100 Bones of cranium s71008 Bones of cranium, other specified s7101 Bones of face s7104 Muscles of head and neck region s7105 Ligaments and fasciae of ead and neck region	Dysplasia of vomer, history of primary surgery concerning velopharyngeal muscles and musculus orbicularis oris superior
s810	Structure of areas of skin	s8100 Skin of head and neck region	Severely scarred hard palate and skin of upper lip
b126	Temperament and personality functions	b1260 Extraversion b1264 Openness to experience b1265 Optimism b1266 Confidence	Introverted, shy, takes time to get confidence
b156	Perceptual functions	b1560 Auditory perception b1562 Olfactory perception b1563 Gustatory perception	Minimized olfactory perception caused by habitual mouth breathing
b230	Hearing functions	b2300 Sound detection b2301 Sound discrimination b2302 Localization of sound source b2303 Lateralization of sound	Some problems with sound detection and discrimination of /f/ and /v/
b270	Sensory functions related to temperature and other stimuli	b2702 Sensitivity to pressure	Restricted sensibility of touch at the upper lip
b310	Voice functions	b3101 Quality of voice	Moderate hypernasality
b320	Articulation functions		Substitution of voiceless plosives by glottal stops, passive articulations
b440	Respiration functions	b4402 Depth of respiration	Normal costo-abdominal respiration
b450	Additional respiratory functions		Habitual mouth breathing (day and night)
b510	Ingestion functions	b5100 Sucking b5101 Biting b5102 Chewing b5103 Manipulation of food in the mouth b5104 Salivation b5105 Swallowing	Hypersalivation, biting with left canine and first premolar, chewing inadequately and fast, infantile swallowing style
b730	Muscle power functions	b7300 Power of isolated muscles/muscle groups	
b735	Muscle tone functions	b7350 Tone of isolated muscles/muscle groups	Hypotonia of tongue muscles and musculus orbicularis oris superior
b740	Muscle endurance functions	b7401 Endurance of muscle groups	–
b760	Control of voluntary movement functions	b7600 Control of simple voluntary movements b7601 Control of complex voluntary movements b7602 Coordination of voluntary movements	Orofacial dysfunctions, especially coordination of lip and tongue voluntary movements, grimace
b765	Involuntary movement functions	b7659 Involuntary movement functions, unspecified	–
b820	Repair functions of the skin		
b840	Sensation related to the skin		
	Activities & Participation		**Activities & Participation**
d115	Listening		

TABLE 2 Continued

Code	*Description*	*Relevant for CL/P*	*Maria (3 y 7 mo) With Unilateral CL/P*
d120	Other purposeful sensing	d1200 Mouthing d1202 Smelling d1203 Tasting e.g., Copying tones	–
d130	Copying		–
d133	Acquiring language	d1330 Acquiring single words or meaningful symbols	–
d160	Focusing attention	d1600 Focusing attention on the human touch, face and voice	–
d240	Handling stress and other psychological demands	d2401 Handling stress d2402 Handling crisis	Quickly becomes stressed
d250	Managing one's own behavior	d2502 Approaching persons or situations	–
d330	Speaking		Able to produce words, phrases, and sentences with literal and applied meaning in an age-appropriate way
d331	Pretalking		–
d335	Producing nonverbal messages	d3350 Producing body language	Minimal use of body language
d350	Conversation	d3500 Starting a conversation d3503 Conversing with one person d3504 Conversing with many people	Difficulty initiating conversation due to shyness (especially with strangers), difficulty conversing with siblings or other children without impairments
d355	Discussion	d3550 Discussion with one person d3551 Discussion with many people	–
d360	Using communication devices and techniques	d3600 Using telecommunication devices	Speaks on telephone with parents and grandparents
d550	Eating	d5501 Carrying out eating appropriately	Difficulty eating and drinking appropriately due to escape of nutrition through fistula and out of her nose
d560	Drinking	d5601 Carrying out breast feeding d5602 Carrying out feeding from bottle d5608 Drinking, other specified (s. d550)	See d550
d660	Assisting others	d6602 Assisting others in communication	–
d710	Basic interpersonal interactions	d71040 Initiating social interactions d7105 Physical contact in relationships	Little initiation of social interactions
d720	Complex interpersonal interactions	d7200 Forming relationships	–
d730	Relating with strangers		–
d740	Formal relationships		–
d760	Family relationships	d7600 Parent-child relationships d7601 Child-parent relationships	Very good emotional relationship and support
d810	Informal education		–
d815	Preschool education		Maria has been in kindergarten since she was 2 y 6 mo old
d820	School education		–
d830	Higher education		–
d880	Engagement in play	d8800 Solitary play d8803 Shared cooperative play	Able to play with objects or toys by herself or with others
d910	Community life	d9100 Informal associations d9102 Ceremonies d9103 Informal community life	Has contacts for play, is integrated, receives invitations to birthday parties
d920	Recreation and leisure	d9200 Play d9201 Sports d9202 Arts and culture d9205 Socializing	Parents are engaged, take her to playgrounds or theater
	Environmental Factors		**Environmental Factors**
e115	Products and technology for personal use in daily living	e1152 Products and technology used for play	Has toys
e125	Products and technology for communication	e1251 Assistive products and technology for communication	Maria wears glasses
e130	Products and technology for education		Has books and educational toys
e310	Immediate family		Optimal support of parents
e315	Extended family		
e320	Friends		Has a female playmate of same age in kindergarten
e325	Acquaintances, peers, colleagues, neighbours and community members		Contact with children in neighborhood
e345	Strangers		–
e355	Health professionals		Cleft palate team, speech-language therapist
e360	Other professionals		Nursery nurse
e410	Individual attitudes of immediate family members		Optimal
e415	Individual attitudes of extended family members		Accepted by whole family
e420	Individual attitudes of friends		Optimal
e425	Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members		
e445	Individual attitudes of strangers		Receives looks due to scars
e450	Individual attitudes of health professionals		Supportive
e455	Individual attitudes of other professionals		Supportive

TABLE 2 Continued

Code	*Description*	*Relevant for CL/P*	*Maria (3 y 7 mo) With Unilateral CL/P*
e460	Societal attitudes		Stigmatization (being different from others)
e465	Social norms, practices, and ideologies		Face important part of self-identification; demanding norms of communication
e555	Associations and organizational services, systems and policies		Support of cleft palate self-help organization (Wolfgang-Rosenthal-Gesellschaft)
e560	Media services	Information found on World Wide Web	http://www.cleftnet.de; http://www.lkgs-net.de
e570	Social security services, systems and policies		Tax privilege; financial support due to disability rating
e575	General social support services, systems and policies	e5750 General social support services e57500 Informal care of child or adult by family and friends	
e580	Health services, systems and policies		–
e585	Education and training services, systems, and policies	e5850 Education and training services e5851…systems e5852 …policies e5853 Special education and training services e5854 …systems e5855 …policies	Able to attend a kindergarten near home
	Age, gender, social background, life experiences, fitness, lifestyle, habits, education, coping styles, profession, character, overall behavior pattern, psychological assets		Middle class, healthy lifestyle, cooperative education, diminished self-esteem, partial experience of not being understood (SPAAC-D)
	Subjective Experience	Referring to all domains	**Subjective Experience**
	Body Structures		Dislikes having chapped lips
	Body Functions		Awareness of reduced intelligibility, wants to speak like other children
	Activities & Participation		Dislikes speaking with strangers, conscious of her reduced intelligibility
	Environmental Factors		Feels well integrated in kindergarten and in family

* ICF-CY = *International Classification of Functioning, Disability, and Health–Children and Youth Version*; CL/P = cleft lip and/or palate.

infancy (Wermke et al., 2002; Wermke et al., 2011). These voice disorders include hypernasality or hyponasality or cul-de-sac resonance (Kummer et al., 1992; Warren et al., 1994; Grunwell et al., 2000; Guildersleeve-Neumann and Dalston, 2001; Imatomi et al., 2005) and symptoms of hyperfunctional voice disorders such as hoarseness (D'Antonio et al., 1988; Wyatt et al., 1996; Gunther et al., 1998; Guyette et al., 2000). It is not surprising that these voice disorders exist, given that persistent velopharyngeal insufficiency can be found in more than 30% of patients following primary cleft palate repair (Bearn et al., 2001; Webb et al., 2001; Inman et al., 2005). With regard to *Articulation functions* (b320), affected children may display disorders in articulation and phonology (Folkins, 1985; Chapman and Hardin, 1992; Wyatt et al., 1996; Golding-Kushner, 2001; Willadsen and Albrechtsen, 2006; Baylis et al., 2008; Lohmander and Persson, 2008) such as dentalization, middorsum palatal misarticulation (Yamashita and Michi, 1991; Kuehn and Moller, 2000), double articulation (Wyatt et al., 1996; Gibbon and Crampin, 2002), or backing to velar or uvular, pharyngeal, or glottal articulation (D'Antonio et al., 2001; Chapman et al., 2003; Salas-Provance et al., 2003; Peterson-Falzone et al., 2006). Nasal emission and nasal turbulence (including phoneme specific) also may be observed (Trost, 1981; Peterson-Falzone and Graham, 1990; Kummer et al., 1992; Zajak et al., 1996; Howard and Lohmander, 2011). According to Peterson-Falzone (1995) in a study of 110 children, these sorts of misarticulations persist, continuing to affect 66% of adolescents. Because the function of enunciation is already captured by b320, the function of reduced speech intelligibility among children with CPS (Whitehill, 2002; Whitehill and Chau, 2004; Hodge and Gotzke, 2007, Konst et al., 2000) may also be subsumed under this code.

As for *Respiration functions* (b440), children and adolescents with CL/P may experience problems with the rate, rhythm, and depth (clavicular breathing) of their respiration (Warren et al., 1990; Trindade et al., 1992) due to involuntary nasal air emission (Dieckmann, 1996). These children may have *Additional respiratory functions* (b450) that are compromised by (habitual) mouth breathing (Wyatt et al., 1996; Kummer, 2001) due to a short and/or scarred upper lip (Trotman et al., 2007b; Howard and Lohmander, 2011), incompetent closure of the mouth (Trotman et al., 2007a), or pharyngeal flap surgery (Yamashita and Trindade, 2008). Furthermore, in many cases, the nose is unable to perform its major inspiratory, expiratory, and cleaning functions without primary and/or secondary surgery (Wetmore, 1992).

Conceived as a biopsychosocial framework, the ICF-CY also encompasses mental functions such as consciousness, personality, emotion, and language. Here too, the ICF-CY contains codes relevant for children and adolescents with CL/P. These include *Temperament and personality functions* (b126) that correlate with *Dispositions and intrapersonal functions* (b125), such as approachability (b1255), or problems regarding *Extraversion* (b1260), *Conscientiousness* (b1262), or *Psychic stability* (b1263). Several studies have demonstrated problems in these areas of psychosocial functioning among adolescents affected by CL/P (Richman

and Eliason, 1993; Ramstad et al., 1995; Cochrane and Slade, 1999; Edwards et al., 2002; Edwards et al., 2005; Persson, 2011), though some studies do manage to negotiate these areas (Bressmann et al., 1999).

Activities and Participation (d)

The third component of the ICF-CY contains two constructs: Activities and Participation. As previously mentioned, the codes for both constructs are indicated with the prefix *d*. The WHO defines *Activity (d)* as "execution of a task or an action by an individual"; whereas, the term *Activity Limitation* (AL) is used to describe "difficulties an individual may have in executing activities" (WHO, 2007). *Participation (d)* refers to "involvement in a life situation"; *Participation Restrictions* (PR) thus constitute "problems an individual may experience in involvement in life situations" (WHO, 2007). In addition, two unique qualifiers are used to classify and further distinguish the domains of this component: *capacity* and *performance*. The *capacity* qualifier "describes an individual's ability to execute a task or an action" in a standard environment; it is used to identify "the highest probable level of functioning that a person may reach in a given domain in a given moment" (WHO, 2007). The *performance* qualifier, on the other hand, is used to describe what a person does in her/his individual environment or societal context, in other words, a person's "involvement in a life situation" (WHO, 2007); as such, this qualifier depends on the component Environmental Factors (e).

Children and adolescents with CL/P may exhibit problems in any number of domains contained in the ICF-CY component Activities and Participation. As a result of multiple surgeries (lip, hard palate, soft palate) occurring during infants' developmental phase of oral organization, affected babies may have fewer opportunities for *Purposeful sensory experiences* (d110 to d129), in particular *Mouthing* (d1200), limiting them at this early stage of development (Schaedler, 2002). Furthermore, infants with otitis media and hearing problems are likely to experience difficulty *Listening* (d115) to auditory stimuli (Schönweiler et al., 1999; Schaedler, 2002) and *Focusing attention* (d160) *to human voice* (d1600) (Kummer, 2001).

In the domain of *Basic learning* (d130–d159), infants with CL/P may be restricted in their cognitive and psychomotor development (Speltz et al., 2000), in *Copying* (d130) facial expressions or sounds before undergoing primary surgery. General impairment to facial expressions may occur as a result of a dysplastic musculus orbicularis oris. *Acquiring language* (d133) can also prove problematic during childhood (Willadsen and Enemark, 2000; Hardin-Jones and Chapman, 2008; Willadsen, in press), with evidence suggesting that children with CL/P often score lower than their peers on verbal performance tests (Richman and Eliason, 1993; Jocelyn et al., 1996; Broen et al., 1998; Richman et al., 2005).

These types of impairments can, in turn, contribute to difficulties producing communication (d330 to d349 *Communicating–Producing*). Children's *Pretalking* (d331) may be restricted by phonetic motivated speech disorder or delay in speech development as a result of interruptive surgeries (Willadsen and Albrechtsen, 2006; Chapman et al., 2008). A limited number of studies have documented restrictions in *Producing nonverbal messages* (d335), in particular *Intentional body movements* (d3350): Researchers report on restrictions to facial gestures (hindered by grimace), for instance, or to hand and arm gestures among adolescents (Adachi et al., 2003). Younger children, therefore, might also exhibit difficulties initiating gestures.

In the domain of *Conversation* (d350), older children or adolescents with heightened awareness of their speech disorder may have inhibitions that impact their ability to *Start a conversation* (d3500) or to participate in *Conversing with one person* (d3503) or *Conversing with many people* (d3504). According to Kuehn and Moller (2000), there is general agreement that children and adolescents with a cleft palate "perform less well in the conversational arena and use language less effectively for communication" (Kuehn and Moller, 2000). Indeed, preschool and school-aged children with CL/P have been observed to exhibit communicative retirement (Pope and Snyder, 2005; Brand et al., 2009), with 35% reportedly displaying low assertiveness and rather low responsiveness. Researchers note a significant correlation between affected children's speech production skills and their conversational assertiveness (Chapman et al., 1998; Frederickson et al., 2006). Naturally, these difficulties could also impact their *Discussion* (d355) skills. Under *Using communication devices and techniques* (d360), such as calling a friend on the telephone (d3600), children or adolescents with CL/P may exhibit reservations due to decreased intelligibility.

Overall, there has been little research into the sociocommunicative competence of children with CL/P (Kuehn and Moller, 2000)—this still holds true today, nearly 10 years after Kuehn and Moller first highlighted the lack of studies in this area. Actually, only outlying publications reflect communicative participation in clients with CL/P (Havstam and Lohmander, 2011; Neumann, 2011c; Havstam et al., in press).

Chapter 5 of the ICF-CY deals with *Self-Care* (d5). Two important domains found in this chapter may pose difficulties for children with CL/P, regardless of their age or stage of development: *Eating* (d550) and *Drinking* (d560). Infants, especially those with bilateral cleft lip and palate, often have difficulty *Carrying out breast-feeding* (d5601) or *Feeding from bottle* (d5602) (Mizuno et al., 2002; Reid, 2004; Reid et al., 2006; Reid et al., 2007; Masarei et al., 2007; Bessell et al., 2011). Older children may have difficulty *Drinking or eating in public* (d5608) due to nasal leakage of food caused by velopharyngeal insufficiency and/or palatal fistula (Glass and Wolf, 1999). This can prove to be a strong social restriction, hindering

their ability to eat and drink in a way that is culturally accepted.

Children or adolescents with CL/P may exhibit restrictions in the domain of *Basic interpersonal interactions* (d710), particularly in *initiating social interactions* (d71040) (Broder et al., 1992; Slifer et al., 2004). During adolescence, affected persons may have difficulty with *Complex interpersonal interactions* (d720) (Lockhart, 2003; Hunt et al., 2005; DeSousa et al., 2009; Hutchison et al., 2011; Stock, 2011). *Forming relationships* (d7200) may prove challenging, especially initiating relationships that could become permanent, romantic, or intimate (Leonard et al., 1991; Patrick et al., 2007; Schultz, 2008). Shyness may evolve out of communicative retreat, causing difficulty in *Interpersonal relationships with strangers* (d730)—for instance, asking a stranger for information—or in *Other formal relationships* (d740), such as interactions with teachers or speech-language therapists (Cochrane and Slade, 1999). *Family relationships* (d760) are the most important relationships in the lives of developing children. The ICF-CY makes a distinction between the *Parent-child relationship* (d7600), the *Child-parent* (d7601) relationship, the *Sibling relationship* (d7602), and the relationship to the *Extended family* (d7603). The parent-child relationship may be characterized by parental traumata in the first weeks after birth, individual coping strategies, stress, and/or excessive demand (Carlisle, 1998; Johansson and Ringsberg, 2004). When their infant is a bit older, some parents of children with CL/P exhibit overprotectiveness in their educational style on *Informal education at home* (d810) (Tobiasen and Hiebert, 1984; Coy et al., 2002), which may adversely affect the infant's development (Kasuya et al., 2000; Lockhart, 2003; Hunt et al., 2005; DeSousa et al., 2009; Hutchison et al., 2011). Ludwigson (1998), for example, found that increased maternal directiveness was significantly related to poorer language performance in children with cleft palate speech. This, in turn, may adversely affect the child-parent relationship (Ludwigson, 1998).

The ICF-CY's Activities and Participation component also contains a section on *Major life areas* (d8), including *Education* (d810 to d839), *Work and employment* (d840 to d859), and *Economic life* (d860 to d879). Affected adolescents, for example, may have difficulty *Maintaining a job* (d8451) due to conspicuous facial characteristics and speech problems (Broder et al., 1994; Topolski et al., 2005). Also, adolescents with CL/P experience significant deficits in their educational level (Danino et al., 2005; Persson et al., in press).

In terms of *Community Life* (d910), children with CL/P may be poorly integrated in *Informal associations* (d9100), *Ceremonies* (d9102), or *Informal community life* (d9103) as a result of their facial impairment or decreased speech intelligibility (Broder et al., 1994; Schultz, 2008). Concerning *Recreation and leisure* (d920), affected children may have difficulty in areas like *Arts and culture* (d9202) when, for example, their CL/P hinders their ability to learn a wind instrument, sing in a group, or act in a play.

Environmental Factors (e)

Part 2 of the ICF-CY covers Contextual Factors, beginning with the component of Environmental Factors, which are described as making up the physical, social, and attitudinal environment in which people live and conduct their lives; they are further classified as facilitators or barriers (WHO, 2001). Environmental Factors should be coded from the perspective of the person whose situation is being described. Items in this component can act as facilitators or barriers, and certain factors may represent barriers when absent, as in the case of a needed service that is lacking. In general, the vast majority of the environmental factors described are relevant to those with CL/P. However, certain factors are particularly important for the development of children and adolescents with CL/P. For example, in order for an affected infant to develop with as few restrictions as possible, the support of *Immediate* (e310) and *Extended family* (e315)—parents, siblings and grandparents—is required. The *Individual attitudes of family members* (e410 and e415) may present barriers to affected infants' emotional development, in particular expressions of sadness, uncertainty, frustration, or disapproval toward the newborn child (Johansson and Ringsberg, 2004). As a counter example, having a (best) *Friend or friends* (e320) later in life can help affected children and adolescents deal with difficult social situations, like teasing, when *Their individual attitudes* (e420) are characterized by support (Schultz, 2008). Indeed, whether expressed by fellow kindergarteners or any number of other social groups, the individual attitudes (e.g., acceptance or taboo) conveyed by *Acquaintances, peers, and neighbors* (e325 and e425) can either reinforce or harm children's ability to handle CL/P impairments (Hunt et al., 2005; Hunt et al., 2006; Schröder, 1997).

Health professionals (e355)—such as surgeons or speech-language therapists—and *Teachers* (e360) can act as facilitators by displaying a positive attitude and providing individual support to children and their parents (Canady et al., 1997; Strauss, 1999; Knapke et al., 2010).

The *Individual attitudes of strangers* (e445) or *Social attitudes* (e460) conveyed by strangers may present barriers to affected children and adolescents, particularly when these attitudes include expressions of prejudice or reservation. Regarding *Social norms, practices, and ideologies* (e465), certain communication norms may apply that affected children are unable to fulfill. In terms of sources of support, affected adolescents or parents of affected children may enlist the aid of others via contact addresses, group meetings, or seminars of *Associations and organizational services, systems, and policies* (e555). These may include patient organizations and self-help groups, such as the (European) Cleft Palate Foundation. They may also use *Media services* (e5600) to gather information about clefts and their treatment, in particular the Internet, by visiting sites like http://www.acpa-cpf.org, http://www.cleftline.org,

or http://www.cleftnet.de (Antonarakis and Kiliaridis, 2009). In addition, *Social security services, systems, and policies* (e570) may act as facilitators when they provide a disability rating and/or enable compensatory payments or taxation concessions on behalf of affected families with small children. Furthermore, *Health services, systems, and policies* (e580) typically represent facilitators, providing services such as medical treatment, rehabilitation, speech-language therapy, specialized surgeries, or orthodontics. Finally, in the area of *Education and training services* (e585), *Special education* (e5853 to e5855) programs may enable children with CL/P and associated syndromes to receive the individual support they need in order to succeed in settings ranging from preschool to postsecondary institutions.

Personal Factors

The second, and final, component introduced in part 2 of the ICF-CY is Personal Factors. These are described as constituting the special background of an individual's life, such as a person's age, gender, life experience, ethnic affiliation, character, level of fitness, level of education, or social status. However, the ICF-CY purposefully avoids classifying these factors, due to their clear sociocultural heterogeneity.

Independent observers, such as clinicians of the cleft palate-craniofacial team, are typically charged with assessing the personal factors of children with CL/P. It should be noted that their assessments cannot be expected to capture the subjective experience of affected children or the distress they may feel regarding any given disability. When a professional seeks to analyze the personal factors of children with CL/P and/or those of their parents, it is important to assess these factors according to the way in which they influence their possibilities to interact with others, their capacity to execute activities and their performance of social participation. This will make it possible to develop an optimal, individualized therapy that emphasizes these ICF-CY categories. Important factors for assessment might include how the aesthetic aspects of the child's facial appearance are handled; his or her level of self-confidence; and the influence of parents' education or coping style on very young children (Lockhardt, 2003; Neumann and Romonath, 2008; Persson, 2011).

Sample Application of the Draft CL/P Core Set

In order to aid the understanding of the individual codes that have been identified, examples drawn from the case of an actual child with CL/P and cleft palate speech (Maria [name changed], 3 years 7 months) are provided to illustrate the application of these codes. When looking at the child or adolescent, the ICF-CY offers five questions to consider:

1. "Is the child or adolescent manifesting problems in body functions?
2. Does the child or adolescent have problems of organ, limb, or other body structures?
3. Does the child or adolescent have problems executing tasks or actions?
4. Does the child or adolescent have problems engaging in age-appropriate life situations?
5. Are there environmental factors that restrict or facilitate the child's or adolescent's functioning?" (WHO, 2007, p. xxi)

Case Vignette of Maria (3 years 7 months) With CL/P

Maria is a 3-year-old girl who was born with a unilateral cleft lip and palate. She lives with her parents in a rural environment, attends a kindergarten, and has contact with children in the neighborhood. After primary surgery, she had a severely scarred hard palate and upper lip, deviation of nasal septum, and scars in the tympanic membrane due to multiple paracenteses. Her tonsils and adenoids are hypertrophic, and as a result she exhibits habitual mouth breathing, hypersalivation, and an infantile swallowing style. She has some problems with sound detection and she produces glottal stops for voiceless plosives, although a moderate degree of hypernasality is present. Her language acquisition is age appropriate. Sometimes Maria is somewhat unintelligible when she is speaking, a fact that she is aware of. She is a little shy and she shows some restrictions in initiating conversations and in basic social interactions. Due to the escape of food and drink through a palatal fistula, she has some problems eating and drinking in a socially appropriate way. Maria has a very good relationship with her family and has their support. The parents offer her books and educational toys, and they go with her to playgrounds and the theater. The family has the support of a cleft palate-craniofacial team, as well as a cleft palate self-help organization, and financial support due to a disability rating. The attitudes of health professionals involved in her care are very supportive.

With reference to the five questions defined above, the problems manifested by this child suggest codes in chapters 2, 3, 7, and 8 of the Body Structure component. For the Body Functions component, most of the applicable codes would be found in chapters 1, 2, 3, 4, 5, 7, and 8. For the Activities and Participation component, chapters 2, 3, 5, 6, 7, 8, and 9 contain codes applicable to documenting Maria's performance and/or restrictions. Codes defining the nature of barriers as well as facilitators in the child's situation would include some found in chapters 1, 3, 4, and 5 of the Environmental Factors component.

Table 2 summarizes the codes preselected by the authors as relevant to children with CL/P, casting them in the framework of a core set of codes. This first draft of a core set illustrates how ICF-CY codes can be narrowed to a clinically practicable number for a given disorder.

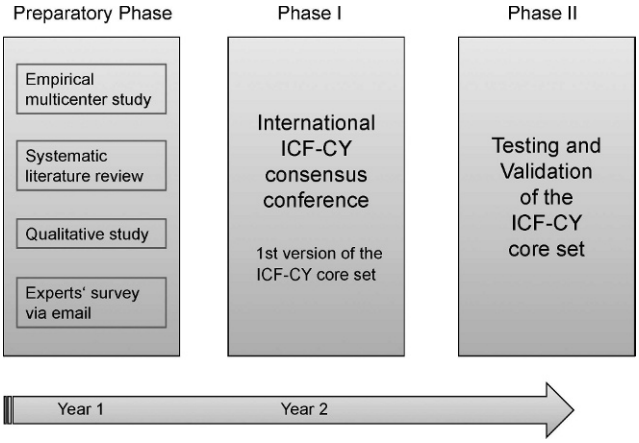

FIGURE 5 The ICF/ICF-CY core sets development process.

Discussion

The draft of a core set described in Table 1 represents a preselected list of codes identified by the authors as relevant for children with CL/P, which the authors hope will serve to encourage further discussion and research. Despite a dearth of evidence and the lack of randomized controlled studies or cohort studies to support them, some codes were chosen based on professional experience or academic opinion. Referring to the "ICF Core Sets Development Process" (http://www.icf-research-branch.org/icf-core-sets-projects.html; Fig. 5), this paper reflects on one part of a first step in a preparatory phase.

The first draft presented here can serve as a starting point for conducting a systematic literature review of all identified codes in order to gather high-quality data or to ask for surveys from interdisciplinary experts via e-mail to confirm or discuss the chosen codes. Furthermore, an empirical multicenter study or a qualitative patient-interview study may help to verify the codes or possibly detect additional codes or indeed identify the need for new codes. It may be a benefit to then hold an interdisciplinary international ICF-CY consensus conference (phase I) to publish an initial version of an ICF-CY CL/P core set, which then should be tested and validated in clinical practice (phase II) (Rentsch and Bucher, 2006; Coenen, 2008; Tate and Perdices, 2008). There will still be a long way to go before developing an internationally accepted core set for children and adolescents with CL/P. The draft of a core set presented here is, therefore, by no means exhaustive because all of the codes were selected by just two authors who are both speech language pathologists.

The studies cited reflect the continuing professional emphasis on Body Structures, Body Functions, and Activities when it comes to research on children with CL/P. Researchers typically focus on the symptoms of CL/P disorders while overlooking other aspects, as indicated by the clear lack of evidence-based studies concerning Participation, Environmental Factors, and Personal Factors. This symptom-focused research trend holds true internationally (Kuehn and Moller, 2000). Indeed, the role of Activities and Participation for children and adolescents with CL/P remains underinvestigated, both at the fundamental research level and in the field of assessment and therapy concepts.

"A loss of health is a loss not only to the person but also to the person's family and society as a whole." (Brundlandt, 2002, as cited in Threats, 2010). Yet achieving a better understanding of contextual factors appears to be crucial to the field of CL/P. Development of children is a dynamic process: Interactions, for example with family members, are crucial to a child's cognitive and communicative functioning and growth. Just as important in these developmental stages are the impacts of children's physical and social environment to detect barriers and/or facilitators for individual development. It is important that additional representative studies be conducted in this area.

More studies are also needed to identify the personal factors of the child that enable unrestricted speech-language acquisition and healthy psychosocial development. Qualitative methods should be established for this purpose as part of the standard toolbox used in craniofacial research, as recommended by Nelson (2009). Equally important are future studies (Kuehn and Moller, 2000; Yazdy et al., 2007) that seek to identify all the conditions that obstruct speech and language development and/or hearing maturation in children with CL/P.

Overall, clinical experts working with children with CL/P should increase their understanding of, and attention given to, the relationship between impairments/restrictions occurring in ICF-CY components of Body Functions, Body Structures, Activities and Participation, Environmental Factors, and Personal Factors. This should improve their ability to accurately appraise the cognitive, communicative and participative limitations of children with CL/P and to develop more specific individualized treatment plans.

In its original version, the ICF-CY still holds limitations for use in clinical settings. For instance there is some overlap between the codes for Body Functions, Body Structures, and Activities and Participation (e.g., attention versus focusing attention); Personal Factors may also be difficult to distinguish. The upcoming publication of the *Procedural Manual and Guide for the Standardized Use of the ICF: A Manual for Health Professionals* (in evaluation) should lead clinicians to engage in the consistent, reliable, and valid use of the ICF across various fields (Reed et al., 2005). Use of the ICF-CY in children and adolescents with CL/P would also be vastly improved by using developmental core sets for children of different age groups, as introduced by Simeonsson and Lollar (2006) and developed by Ellingssen and Simeonsson (2011) for children from birth up to 17 years of age. This should make it possible to better distinguish the development, capabilities, and contextual factors of young children with CL/P from those of adolescents.

The primary aim should be to identify treatments that expand the social and communicative participation of children with CL/P (WHO, 2001). To that end, the ICF-CY provides a useful framework for classifying the individual challenges of cognitive development, speech-language acquisition, social activity/participation, and environmental attitudes experienced by a given child with CL/P. Aided by this framework, cleft palate-craniofacial teams will be able to develop precise therapeutic aims and customized treatment plans. Furthermore, when developing such plans, health care professionals should critically reflect on the role of *Societal norms, practices, and ideologies* (e465) in the lives of children with CL/P, for these can represent significant barriers to, or facilitators of, communication and social participation. As early as 2000, Kuehn and Moller stated, for example, ''The future of language issues in persons with cleft lip and palate needs to focus on those early conditions and environmental milieu that might optimize language learning…. It is important that we focus on those skills that result in effective overall communication as well.'' Keeping this in mind, an important task of the cleft palate-craniofacial team will be the counseling of immediate family members, educators, teachers, and friends/peers, as well as general social support services, systems, and policies about possible barriers for development of children with CL/P in order to change disadvantageous conditions.

In clinical practice, members of the cleft palate-craniofacial team have traditionally tended to focus on body functions when assessing and treating children. Yet as far back as 2000, Threats suggested that clinicians must attend to the relationship between all the components of the ICF/ICF-CY in order to identify appropriate treatments for individuals with communication impairments. This seems particularly true in the case of children and adolescents with CL/P. For this reason, there is a need to develop ICF/ICF-CY-compatible Activity and Participation assessments and treatment concepts in the future. The use of the Speech Activities and Participation of Children (McLeod, 2003) in children with CL/P might be a first step to enable clinicians to gain precise insight into the activities and participation of children by asking them (*subjective dimension*) and their parents, siblings, friends, and teachers about the impact of their communication problems (Neumann, 2011a). Tools such as this may help clinicians plan individualized therapies orientated toward ICF-CY domains while simultaneously embedding family, friends, teachers, and/or strangers into the therapeutic process, for instance, in ''in vivo'' training.

Conclusion

The authors believe that the ICF-CY offers a new and important perspective on children with CL/P, one that aids our understanding of the social impact of impairments in body structure and body function, activity limitation, participation restrictions, and barriers in the environment. The ICF-CY provides a useful framework for documenting and planning therapies for children and adolescents with CL/P, in cooperation with them and their families. For this, it might help health professionals to listen to children with CL/P reflecting on their individual problems with their cleft conditions. When used as a clinical tool, it encourages moving beyond interventions that are focused solely on the client. Widespread implementation of the ICF-CY in clinical practice will certainly facilitate more meaningful sharing of diagnostic and treatment data between clinicians as well as collaborative, cross-linguistic, intercenter speech research. Moreover, the ICF-CY contributes to greater awareness of communicative and social participation as a health concern. It also underscores the need to support the ability of children to communicate, hear, and act without restrictions, enabling them to fully participate in society. Furthermore, applying the ICF-CY to children and adolescents with CL/P highlights the need for more high-quality, evidence-based research into activities and participation, environmental factors, and personal factors. Research in these areas will aid development of new and broader therapeutic concepts and methods based on the ICF-CY's biopsychosocial framework. In its 2007 to 2008 work plan, the WHO urged all ICF-CY users—including health and social services professionals or support persons, and (especially) those with disabilities themselves—to identify and submit proposals for updates to the ICF-CY. Researchers should seize the opportunity to create future projects aimed at identifying and allocating new codes concerning CL/P.

In order to successfully implement the ICF-CY as a new, comprehensive approach in clinical settings, a definite core set must be developed that ensures procedural efficiency. ''Thus the ICF can be a practical tool to achieve the highest vision of full integration of persons with functional health limitations in society, but only if that is what the people decide they want'' (Threats, 2010).

References

Adachi T, Kochi S, Yamaguchi T. Characteristics of nonverbal behavior in patients with cleft lip and palate during interpersonal communication. *Cleft Palate Craniofac J*. 2003;40:310–316.

American Speech-Language-Hearing Association. Evidence-based practice in communication disorders [position statement], 2005. Available at http://www.asha.org/policy. Accessed October 25, 2011.

Antonarakis GS, Kiliaridis S. Internet-derived information on cleft lip and palate for families with affected children. *Cleft Palate Craniofac J*. 2009;46:75–80.

Arnold WH, Nohadani N, Koch KHH. Morphology of the auditory tube and palatal muscles in a case of bilateral cleft palate. *Cleft Palate Craniofac J*. 2005;42:197–201.

Arvedson J, Brodsky L. Feeding with craniofacial anomalies. In: Arvedson JC, Brodsky L, eds. *Pediatric Swallowing and Feeding. Assessment and Management*. New York: Delmar; 2002:527–561.

Bardach J, Morris HL, Olin WH, Gray SD, Jones DL, Kelly KM. Results of multidisciplinary management of bilateral cleft lip and palate at the Iowa Cleft Palate Center. *Plast Reconstr Surg*. 1992;89:419–432.

Baylis AL, Munson B, Moller KT. Factors affecting articulation skills in children with velocardiofacial syndrome and children with cleft palate or velopharyngeal dysfunction: a preliminary report. *Cleft Palate Craniofac J*. 2008;45:193–207.

Bearn D, Mildinhall S, Murphy T, Murray JJ, Sell D, Shaw WC, Williams AC, Sandy JR. Cleft lip and palate care in the United Kingdom—the Clinical Standards Advisory Group (CSAG) study. Part 4: outcome comparisons, training, and conclusions. *Cleft Palate Craniofac J*. 2001;38:38–43.

Berry DA, Moon JB, Kuehn DP. A finite element model of the soft palate. *Cleft Palate Craniofac J*. 1999;36:217–223.

Bessell A, Hooper L, Shaw WC, Reilly S, Reid J, Glenny A-M. Feeding interventions for growth and development in infants with cleft lip, cleft palate or cleft lip and palate. *Cochrane Database System Rev*. 2011, (2):CD003315. doi:10.1002/14651858.CD003315.pub3.

Brand S, Blechschmidt A, Müller A, Sader R, Schwenzer-Zimmerer K, Zeilhofer H-F, Holsboer-Trachsler E. Psychosocial functioning and sleep patterns in children and adolescents with cleft lip and palate (CLP) compared with healthy controls. *Cleft Palate Craniofac J*. 2009;46:124–135.

Bressmann T, Sader R, Ravens-Sieberer U, Busch R, Zeilhofer HF, Horch HH. Lebensqualitätsforschung bei Patienten mit Lippen-Kiefer-Gaumenspalte: Erste Ergebnisse [Quality of life research in patients with cleft lip and palate: first results]. *Dtsch Zeitschr MKG*. 1999;3: 134–139.

Broder HL, Smith FB, Strauss RP. Effects of visible and invisible orofacial defects on self perception and adjustment across development eras and gender. *Cleft Palate Craniofac J*. 1994;31:429–436.

Broder HL, Smith FB, Strauss RP. Habilitation of patients with clefts: parent and child ratings of satisfaction with appearance and speech. *Cleft Palate Craniofac J*. 1992;29:262–267.

Broen PA, Devers MC, Doyle SS, Prouty JM, Moller KT. Acquisition of linguistic and cognitive skills by children with cleft palate. *J Speech Lang Hear Res*. 1998;41:676–687.

Brunner M, Stellzig-Eisenhauer A, Pröschel U, Verres R, Komposch G. The effect of nasopharyngoscopic biofeedback in patients with cleft palate and velopharyngeal dysfunction. *Cleft Palate Craniofac J*. 2005;42:649–657.

Bzoch KR. *Communicative Disorders Related to Cleft Lip and Palate*. Austin: Pro-Ed; 2004.

Canady JW, Means ME, Wayne I, Thompson SA, Richman LC. Continuity of care: University of Iowa cleft lip/palate interdisciplinary team. *Cleft Palate Craniofac J*. 1997;34:443–446.

Carlisle D. Feeding babies with cleft lip and palate. *Nurs Times*. 1998;94:59–60.

Carvajal R, Miralles R, Cauvi D, Berger B, Carvajal A, Bull R. Superior orbicularis oris muscle activity in children with and without cleft lip and palate. *Cleft Palate Craniofac J*. 1992;29:32–37.

Chapman KL, Graham KT, Gooch J, Visconti C. Conversational skills of preschool and school-age children with cleft lip and palate. *Cleft Palate Craniofac J*. 1998;35:503–516.

Chapman KL, Hardin MA. Phonetic and phonologic skills of two-year-olds with cleft palate. *Cleft Palate Craniofac J*. 1992;29:435–443.

Chapman KL, Hardin-Jones M, Halter KA. Relationship between early speech and later speech and language performance for children with cleft lip and palate. *Clin Ling Phon*. 2003;17:173–197.

Chapman KL, Hardin-Jones MA, Goldstein JA, Halter KA, Havlik RJ, Schulte J. Timing of palatal surgery and speech outcome. *Cleft Palate Craniofac J*. 2008;45:297–308.

Cochrane VM, Slade P. Appraisal and coping in adults with cleft lip: associations with well-being and social anxiety. *Br J Med Psychol*. 1999;72:485–503.

Coenen M. *Developing a Method to Validate the WHO ICF Core Sets From the Patient Perspective: Rheumatoid Arthritis as a Case in Point*. Munich: University of Munich; 2008. Dissertation. http://edoc.ub.uni-muenchen.de/8038/1/Coenen_Michaela.pdf. Accessed October 23, 2011.

Cohen SR, Kalinowski J, LaRossa D, Randall P. Cleft palate fistulas: a multivariate statistical analysis of prevalence, etiology, and surgical management. *Plast Reconstr Surg*. 1991;87:1041–1047.

Conrad AL, Dailey S, Richman L, Canady J, Karnell MP, Axelson E, Nopoulos P. Cerebellum structure differences and relationship to speech in boys and girls with nonsyndromic cleft of the lip and/or palate. *Cleft Palate Craniofac J*. 2010;47:469–475.

Coy K, Speltz ML, Jones K. Facial appearance and attachment in infants with orofacial clefts: a replication. *Cleft Palate Craniofac J*. 2002;39:66–72.

Danino A, Gradell J, Malka G, Moutel G, Herve C, Rosilio C. Social adjustment in French adults who had undergone standardized treatment of complete unilateral cleft lip and palate [in French]. *Ann Chir Plast Esthet*. 2005;50:202–205.

D'Antonio LL, Muntz H, Province M, Marsh J. Laryngeal/voice findings in patients with velopharyngeal dysfunction. *Laryngoscope*. 1988; 98:432–438.

D'Antonio LL, Scherer NJ, Miller LL, Kalbfleisch JH, Bartley JA. Analysis of speech characteristics in children with velocardiofacial syndrome (VCFS) and children with phenotypic overlap without VCFS. *Cleft Palate Craniofac J*. 2001;38:455–467.

DeKleijn-DeVrankrijker MW. The long way from the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) to the *International Classification of Functioning, Disability, and Health* (ICF). *Disabil Rehabil*. 2003;25:561–564.

De Sousa A, Devare S, Ghanshani J. Psychological issues in cleft lip and cleft palate. *J Indian Assoc Pediatr Surg*. 2009;14:55–58.

Dieckmann O. Sprachentwicklung bei Lippen-, Kiefer-, Gaumenspalten aus sprachheilpädagogischer Sicht. In: Andrä A, Neumann HJ, eds. *Lippen-, Kiefer-, Gaumenspalten. Entstehung-Klinik-Behandlungskonzepte*. Reinbek: Einhorn; 1996:253–279.

Edwards TC, Huebner CE, Connell FA, Patrick DL. Adolescent quality of life, part I: conceptual and measurement model. *J Adolesc*. 2002;25:275–286.

Edwards TC, Patrick DL, Topolski TD, Aspinall CL, Mouradian WE, Speltz ML. Approaches to craniofacial-specific quality of life. Assessment in adolescents. *Cleft Palate Craniofac J*. 2005;42:19–24.

Ellingssen KM, Simeonsson RJ. WHO ICF-CY developmental code sets. Available at http://www.icf-cydevelopmentalcodesets.com/Home_Page.html. Accessed October 27, 2011.

Essick GK, Dorion C, Rumley S, Rogers L, Young M, Trotman CA. Report of altered sensation in patients with cleft lip. *Cleft Palate Craniofac J*. 2005;42:178–184.

Ettema S, Kuehn D, Perlman A, Alperin N. Magnetic resonance imaging of the levator veli palatini muscle during speech. *Cleft Palate Craniofac J*. 2002;39:130–144.

Ewert T, Geyh S, Grill E, Cieza A, Zaisserer S, Stucki G. Die Anwendung der ICF der Neurorehabilitation anhand des ICF-Modellblattes und der ICF Core Sets. *Neurol Rehabil*. 2005;11:179–188.

Folkins JW. Issues in speech motor control and their relation to the speech of individuals with cleft palate. *Cleft Palate J*. 1985;22:106–122.

Frederickson MS, Chapman KL, Hardin-Jones M. Conversational skills of children with cleft lip and palate: a replication and extension. *Cleft Palate Craniofac J*. 2006;43:179–188.

Gibbon FE, Crampin L. Labial-lingual double articulations in speakers with cleft palate. *Cleft Palate Craniofac J*. 2002;39:40–49.

Gillam S, Gillam R. Making evidence-based decisions about child language intervention in schools. *Lang Speech Hear Serv Schools*. 2006;37:304–315.

Glass RP, Wolf LS. Feeding management of infants with cleft lip and palate and micrognathia. *Infants Young Child*. 1999;12:70–81.

Godbersen G. Das Kind mit Lippen-Kiefer-Gaumenspalte. *Laryngorhinootologie*. 1997;76:562–567.

Godbersen G. Die mechanische Verlegung der Tubenostien. Zur Pathogenese von Ohrenerkrankungen bei Gaumenspalten. *Folia Phoniatr Logop*. 1990;42:105–110.

Golding-Kushner KJ. Standardization for the reporting of nasopharyngoscopy and multiview videofluoroscopy: a report from an international working group. *Cleft Palate J*. 1990;27:337–347.

Golding-Kushner KJ. *Therapy Techniques for Cleft Palate Speech and Related Disorders*. San Diego: CA Singular; 2001.

Grunwell P, Bronsted K, Henningsson G, Jansonius K, Karling J, Meijer M, Ording U, Wyatt R, Vermeij-Zieverink C, Sell D. A six-centre international study of the outcome of treatment in patients with clefts of the lip and palate: the results of a cross-linguistic investigation of cleft palate speech. *Scand J Plast Reconstr Hand Surg*. 2000;34: 219–229.

Guildersleeve-Neumann C, Dalston RM. Nasalance scores in noncleft individuals: why not zero? *Cleft Palate Craniofac J*. 2001;38:106–111.

Gunther E, Wisser JR, Cohen MA, Brown AS. Palatoplasty: Furlow's double-reversing Z-plasty versus intravelar veloplasty. *Cleft Palate Craniofac J*. 1998;35:546–549.

Guyette TW, Sanchez AJ, Smith BE. Laryngeal airway resistance in cleft palate children with complete and incomplete velopharyngeal closure. *Cleft Palate Craniofac J*. 2000;37:61–64.

Hardin-Jones M, Chapman KL. The impact of early intervention on speech and lexical development for toddlers with cleft palate: a retrospective look at outcome. *Lang Speech Hear Serv Sch*. 2008;39: 89–96.

Harter S. *Manual for the Self-Perception Profile for Adolescents*. Denver: University of Denver; 1988.

Havstam C, Laakso K, Lohmander A, Ringsberg K. Taking charge of communication: adults' descriptions of growing up with a cleft-related speech impairment. *Cleft Palate Craniofac J*. In press. doi:10.1597/10-033.

Havstam C, Lohmander A. Communicative participation. In: Howard S, Lohmander A, eds. *Cleft Palate Speech. Assessment and Intervention*. West Sussex: Wiley-Blackwell; 2011:305–316.

Hermann NV, Kreiborg S, Darvann TA, Jensen BL, Dahl E, Bolund S. Early craniofacial morphology and growth in children with unoperated isolated cleft palate. *Cleft Palate Craniofac J*. 2002;39:604–622.

Herrmann W, Bitter K. Der Spracherwerb des Kindes mit Lippen-Kiefer-Gaumenspalte. III. Ergebnisse. *Dtsch Z Mund Kiefer Gesichtschir*. 1991;15:382–392.

Hickman LA. *The Apraxia Profile*. San Antonio: Communication Skill Builders; 1997.

Hodge M, Gotzke CL. Preliminary results of an intelligibility measure for English-speaking children with cleft palate. *Cleft Palate Craniofac J*. 2007;44:163–174.

Howard S, Lohmander A, eds. *Cleft Palate Speech. Assessment and Intervention*. West Sussex: Wiley-Blackwell; 2011.

Hutchison K, Wellman MA, Noe DA, Kahn A. The psychosocial effects of cleft lip and palate in non-Anglo populations: a cross-cultural meta-analysis. *Cleft Palate Craniofac J*. 2011;48:497–508.

Hunt O, Burden D, Hepper P, Johnston C. The psychosocial effects of cleft lip and palate: a systematic review. *Eur J Orthod*. 2005;27: 274–285.

Hunt O, Burden D, Orth D, Orth M, Hepper P, Stevenson M, Johnston C, Orth M. Self-reports of psychosocial functioning among children and young adults with cleft lip and palate. *Cleft Palate Craniofac J*. 2006;43:598–605.

Imatomi S. Effects of breathy voice source on ratings of hypernasality. *Cleft Palate Craniofac J*. 2005;42:641–648.

Inman DS, Thomas P, Hodgkinson PD, Reid CA. Oro-nasal fistula development and velopharyngeal insufficiency following primary cleft palate surgery—an audit of 148 children born between 1985 and 1997. *Br J Plast Surg*. 2005;58:1051–1054.

Jocelyn LJ, Penko MA, Rode HL. Cognition, communication, and hearing in young children with cleft lip and palate and control children: a longitudinal study. *Pediatrics*. 1996;97:529–534.

Johansson B, Ringsberg KC. Parents' experiences of having a child with cleft lip and palate. *J Adv Nurs*. 2004;47:165–173.

Kasuya M, Sawaki Y, Ohno Y, Ueda M. Psychological study of cleft palate children with or without cleft lip by kinetic family drawing. *J Craniomaxillofacial Surg*. 2000;28:373–379.

Kemp-Fincham SI, Kuehn DP, Trost-Cardamone JE. Speech development and timing of primary veloplasty. In: Bardach J, Morris HL, eds. *Multidisciplinary Management of Cleft Lip and Palate*. Philadelphia: WB Saunders; 1990:736–745.

Knapke SC, Bender P, Prows C, Schultz JR, Saal HM. Parental perspectives of children born with cleft lip and/or palate: a qualitative assessment of suggestions for healthcare improvements and interventions. *Cleft Palate Craniofac J*. 2010;47:143–150.

Konst E, Weersink-Braks H, Rietveld T, Peters H. An intelligibility assessment of toddlers with cleft lip and palate who received and did not receive presurgical infant orthopedic treatment. *J Commun Disord*. 2000;33:483–501.

Kuehn D, Ettema S, Goldwasser M, Barkmeer J. Magnetic resonance imaging of the levator veli palatini muscle before and after primary veloplasty. *Cleft Palate Craniofac J*. 2004;41:584–592.

Kuehn D, Moller KT. Speech and language issues in the cleft palate population: the state of the art. *Cleft Palate Craniofac J*. 2000;37:348-1–348-35.

Kuijpers-Jagtman AM, Long RE. The influence of surgery and orthopedic treatment on maxillofacial growth and maxillary arch development in patients treated for orofacial clefts. *Cleft Palate Craniofac J*. 2000;37:527–527.

Kummer AW. *Cleft Palate and Craniofacial Anomalies—Effects on Speech and Resonance*. New York: Delmar; 2001.

Kummer AW, Curtis C, Wiggs M, Lee L, Strife JL. comparison of velopharyngeal gap size in patients with hypernasality, hypernasality and nasal emission, or nasal turbulence (rustle) as the primary speech characteristic. *Cleft Palate Craniofac J*. 1992;29:152–156.

Kummer AW, Lee L, Schaadt Stutz L, Maroney A, Weidenbach Brandt J. The prevalence of apraxia characteristics in patients with velocardiofacial syndrome as compared with other cleft populations. *Cleft Palate Craniofac J*. 2007;44:175–181.

Leonard BJ, Brust JD, Abrahams G, Sielaff B. Self-concept of children and adolescents with cleft lip and/or palate. *Cleft Palate Craniofac J*. 1991;28:347–353.

Lockhart E. The mental health needs of children and adolescents with cleft lip and/or palate. *Clin Child Psychol Psychiatry*. 2003;8:7–16.

Lohmander A, Persson C. A longitudinal study of speech production in Swedish children with unilateral cleft lip and palate and two-stage palatal repair. *Cleft Palate Craniofac J*. 2008;45:32–41.

Lollar D, Simeonsson RJ. The ICF for children and youth. Presented at Improving Information on Disability and Functioning; Australian Institute of Health and Welfare; 2006; Sydney, Australia.

Long RE, Semb G, Shaw WC. Orthodontic treatment of the patient with complete clefts of lip, alveolus, and palate: lessons of the past 60 years. *Cleft Palate Craniofac J*. 2000;37:533-1–533-13.

Ludwigson H. *Parental Communication/Interaction With Children With Cleft Palate*. Minneapolis: University of Minnesota; 1998. Dissertation.

Margraf-Stiksrud J, Fleischer-Peters A. Auswirkungen von Normabweichungen auf die Psyche. In: Sergl HG, ed. *Psychologie und Psychsomatik in der Zahnheilkunde*. München: Urban und Schwarzenberg; 1996:133–152.

Masarei AG, Sell D, Habel A, Mars M, Sommerlad BC, Wade A. The nature of feeding in infants with unrepaired cleft lip and/or palate compared with healthy noncleft infants. *Cleft Palate Craniofac J*. 2007;44:321–328.

McCormack J, McLeod S, McAllister L, Harrison LJ. A systematic review of the association between childhood speech impairment and participation across the lifespan. *Int J Speech Lang Path*. 2009;11: 155–170.

McCormack J, Worral LE. The ICF Body Functions and Structures related to speech language pathology. *Int J Speech Lang Pathol*. 2008; 10:9–17.

McLeod S. *Speech Participation and Activity of Children (SPAA-C)*, version 2.0, 2003. Available at http://athene.riv.csu.edu.au/~smcleod/SPAAC2.pdf. Assessed October 20, 2011.

McLeod S. A holistic view of a child with unintelligible speech: insights from the ICF and ICF-CY. *Adv Speech Lang Pathol*. 2006;8:293–315.

McDougall J, Miller LT. Measuring chronic health condition and disability as distinct concepts in national surveys of school-aged children in Canada: a comprehensive review with recommendations based on the ICD-10 and ICF. *Disabil Rehabil*. 2003;25:922–939.

Merrit L. Physical assessment of the infant with cleft lip and/or palate: perform a focused physical assessment. *Adv Neonatal Care*. 2005; 5:125–134.

Mizuno K, Ueda A, Kani K, Kawamura H. Feeding behavior of infants with cleft lip and palate. *Acta Paediatr*. 2002;91:1227–1232.

Moon JB, Kuehn DP, Chan G, Zhao L. Induced velopharyngeal fatigue effects in speakers with repaired palatal clefts. *Cleft Palate Craniofac J*. 2007;44:251–260.

Muzaffar AR, Byrd HS, Rohrich RJ, Johns DF, LeBlanc D, Beran SJ, Anderson C, Papaioannoua AA. Incidence of cleft palate fistula: an institutional experience with two-stage palatal repair. *Plast Reconstr Surg*. 2001;108:1515–1518.

Nagaoka K, Tanne K. Activities of muscles involved in swallowing in patients with cleft lip and palate. *Dysphagia*. 2007;22:140–144.

Nakamura N, Suzuki A, Takahashi H, Honda Y, Sasaguri M, Ohishi M. A longitudinal study on influence of primary facial deformities on maxillofacial growth in patients with cleft lip and palate. *Cleft Palate Craniofac J*. 2005;42:633–640.

Nelson PA. Qualitative approaches in craniofacial research. *Cleft Palate Craniofac J*. 2009;46:245–251.

Neumann S. *Sprachtherapeutische Diagnostik bei Menschen mit Lippen-Kiefer- Gaumen Segel-Fehlbildung* [*Speech Assessment in People With Cleft Lip and/or Palate. Development of a Speech Assessment for German Speaking Countries*]. Hamburg: Dr. Kovac; 2010. Dissertation.

Neumann S. Listening to children with cleft lip and palate in Germany. In: Roulstone S, McLeod S, eds. *Listening to Children and Young People with Speech, Language, and Communication Needs*. London: J & R Press; 2011a:183–189.

Neumann S. *LKGSF komplex. Sprachtherapeutische Diagnostik bei Lippen-Kiefer-Gaumen Segel-Fehlbildung* [*CLP Complex. Speech Assessment in People With Cleft Lip and/or Palate*]. München: Ernst Reinhardt; 2011b.

Neumann S. Speech activity and participation (ICF-CY) in children with cleft palate speech. Keynote lecture presented at the European Craniofacial Congress (ECC2011); Salzburg, Austria; 2011c.

Neumann S, Romonath R. Kinder mit LKGS-Fehlbildung im Spiegel der ICF-CY [Children with cleft lip and palate in the view of the ICF-CY]. *Die Sprachheilarbeit*. 2008;53:264–273.

Nohara K, Tachimura T, Wada T. Levator veli palatini muscle fatigue during phonation in speakers with cleft palate with borderline velopharyngeal incompetence. *Cleft Palate Craniofac J*. 2006;43:103–107.

Nopoulos P, Langbehn DR, Canady J, Magnotta V, Richman L. Abnormal brain structures in children with isolated clefts of the lip or palate. *Arch Pediatr Adolesc Med*. 2007;161:753–758.

Ohkiba T, Hanada K. Adaptive functional changes in the swallowing pattern of the tongue following expansion of the maxillary dental arch in subjects with and without cleft palate. *Cleft Palate Craniofac J*. 1989;26:21–30.

Oosterkamp BCM, Remmelink HJ, Pruim GJ, Hoekema A, Dijkstra PU. Craniofacial, craniocervical, and pharyngeal morphology in bilateral cleft lip and palate and obstructive sleep apnea patients. *Cleft Palate Craniofac J*. 2007;44:1–7.

Patrick DL, Topolski TD, Edwards TC, Aspinall CL, Kapp-Simon KA, Rumsey NJ, Strauss RP, Thomas CR. Measuring the quality of life of youth with facial differences. *Cleft Palate Craniofac J*. 2007;44: 538–547.

Perry JL. Anatomy and physiology of the velopharyngeal mechanism. *Semin Speech Lang*. 2011;32:83–92.

Perry JL, Kuehn D, Sutton D. Morphology of the levator veli palatini muscle using magnetic resonance imaging. *Cleft Palate Craniofac J*. In press. doi:10.1597/11-125.

Persson M. Long-term educational and physical outcomes and their potential impact on psychosocial health. Paper presented at the European Craniofacial Congress (ECC2011); Salzburg, Austria; 2011.

Persson M, Becker M, Svensson H. Academic achievement in individuals with cleft—a population-based register study. *Cleft Palate Craniofac J*. In press. doi:10.1597/09-047.

Pertschuk M J, Whitaker LA. Social and psychological effects of craniofacial deformity and surgical reconstruction. *Clin Plast Surg*. 1982;9:297–306.

Peterson-Falzone SJ. Speech outcomes in adolescents with cleft lip and palate. *Cleft Palate Craniofac J*. 1995;32:125–128.

Peterson-Falzone SJ, Graham MS. Phoneme-specific nasal emission in children with and without physical anomalies of the velopharyngeal mechanism. *J Speech Hear Disord*. 1990;55:132–139.

Peterson-Falzone SJ, Hardin-Jones MA, Karnell MP. *Cleft Palate Speech*. St. Louis: Mosby; 2010.

Peterson-Falzone SJ, Trost-Cardamone J, Karnell M, Hardin-Jones MA. *Treating Cleft Palate Speech*. St. Louis: Mosby-Elsevier; 2006.

Phua YS, de Chalain T. Incidence of oronasal fistulae and velopharyngeal insufficiency after cleft palate repair: an audit of 211 children born between 1990 and 2004. *Cleft Palate Craniofac J*. 2008;45:172–178.

Pope AW, Snyder HT. Psychosocial adjustment in children and adolescents with a craniofacial anomaly: age and sex patterns. *Cleft Palate Craniofac J*. 2005;42:349–354.

Porzsolt F, Ohletz A, Gardner D, Ruatti H, Meier H, Schlotz-Gorton N, Schrott L. Evidence-based decision making: the 6-step approach. *ACP J Club*. 2003;139:1–6.

Ramstad T, Ottem E, Shaw WC. Psychological adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. Self-reported problems and concerns with appearance. *Scand J Plast Reconstr Surg Hand Surg*. 1995;29:329–336.

Ravera MJ, Miralles R, Santander H, Valenzuela S, Villanueva P, Zúñiga C. Comparative study between children with and without cleft lip and cleft palate, part 2: electromyographic analysis. *Cleft Palate Craniofac J*. 2000;37:286–291.

Reed GM, Lux JB, Bufka LF, Peterson DB, Threats TT, Trask C, Stark S, Jacobson JB. Operationalizing the *International Classification of Functioning, Disability and Health* in clinical settings. *Rehabil Psychol*. 2005;50:122–131.

Reid J. A review of feeding interventions for infants with cleft palate. *Cleft Palate Craniofac J*. 2004;41:268–278.

Reid J, Kilpatrick N, Reilly S. A prospective, longitudinal study of feeding skills in a cohort of babies with cleft conditions. *Cleft Palate Craniofac J*. 2006;43:702–709.

Reid J, Reilly S, Kilpatrick N. Sucking performance of babies with cleft conditions. *Cleft Palate Craniofac J*. 2007;44:312–320.

Reilly S, Douglas J, Oates J. *Evidence-Based Practice in Speech Pathology*. London: Whurr Publishers; 2004.

Rentsch HP, Bucher PO. *ICF in der Rehabilitation*. Idstein: Schulz-Kirchner; 2005.

Richman LC, Eliason MJ. Psychological characteristics associated with cleft palate. In: Moller KT, Starr CD, eds. *Cleft Palate. Interdisciplinary Issues and Treatment*. Austin: Pro-Ed; 1993:357–380.

Richman LC, Ryan SM. Do the reading disabilities of children with cleft fit into current models of developmental dyslexia? *Cleft Palate Craniofac J*. 2003;40:154–157.

Richman LC, Wilgenbusch T, Hall T. Spontaneous verbal labeling: visual memory and reading ability in children with cleft. *Cleft Palate Craniofac J*. 2005;42:565–569.

Romonath R. Suggestions for applying the ICF in developmental dyslexia in adolescents. Paper presented at the 27th Congress of the

International Association of Logopedics and Phoniatrics (IALP); 2007; Copenhagen, Denmark.

Sackett D, Rosenberg W, Gray J, Haynes R, Richardson W. Evidence-based medicine: what it is and what it isn't. *Br Med J*. 1996;312:71–72.

Salas-Provance MB, Kuehn D, Marsh J. Phonetic repertoire and syllable structure characteristics of 15-month-old babies with cleft palate. *J Phonet*. 2003;31:23–38.

Schaedler A. Der frühkindliche Sprachentwicklungsverlauf bei Kindern mit Spaltbildungen im Alter von 0 (Geburt) bis 1;6 Jahren. Berlin: Humboldt Universität zu Berlin; 2002. Dissertation. Available at http://edoc.huberlin.de/dissertationen/schaedler-annette200206-26/HTML/index.html. Accessed October 20, 2011.

Schönweiler R, Lisson JA, Schönweiler B, Eckardt A, Ptok M, Tränkmann J, Hausamen JE. A retrospective study of hearing, speech, and language function in children with clefts following palatoplasty and veloplasty procedures at 18–24 months of age. *Int J Pediatr Otorhinolaryngol*. 1999;50:205–217.

Schröder L. Untersuchungen zu psychosozialen Problemen bei häufigen angeborenen Fehlbildungen am Beispiel der Lippen-Kiefer-Gaumen-Segelspalten. Marburg: Görich & Weiershäuser; 1997.

Schultz JR. Psychosocial aspects of cleft lip/palate and craniofacial anomalies. In: Kummer AW. *Cleft Palate and Craniofacial Anomalies—Effects on Speech and Resonance*. New York: Delmar; 2008:279–295.

Schweininger MU. *Untersuchung erwachsener Patienten mit doppeltseitigen LKG-Spalten, doppelseitigen Lippenspalten, Gaumenspalten, Velumspalten und Uvula bifida unter besonderer Berücksichtigung ästhetischer, funktioneller und sozialpsychologischer Aspekte*. Berlin: Freie Universität Berlin; 1991. Dissertation.

Sell D, John A, Harding-Bell A, Sweeney T, Hegarty F, Freeman J. Cleft audit protocol for speech (CAPS-A): a comprehensive training package for speech analysis. *Int J Lang Commun Disord*. 2009;44:529–548.

Semb G, Schwartz O. The impacted tooth in patients with alveolar clefts. In: Andreasen JO, Petersen JK, Laskin DM, eds. *Textbook and Color Atlas of Tooth Impaction*. Munksgaard: Mosby; 1997:331–348.

Shprintzen RJ, Bardach J. *Cleft Palate Speech Management—A Multidisciplinary Approach*. St. Louis: Mosby; 1995.

Simeonsson RJ, Lollar D. ICF-CY next steps: Developmental core sets. Presented at the American Public Health Association 134th Annual Meeting and Exposition; 2006; Boston, Massachusetts.

Slifer KJ, Amari A, Diver T, Hilley L, Beck., Kane A, McDonnel S. Social interaction patterns of children and adolescents with and without oral clefts during a videotaped analogue social encounter. *Cleft Palate Craniofac J*. 2004;41:175–184.

Smith DM, Vecchione L, Jiang S, Ford M, Deleyiannis FWB, Haralam MA, Naran S, Worrall CI, Dudas JR, Afifi AM, et al. The Pittsburgh fistula classification system: a standardized scheme for the description of palatal fistulas. *Cleft Palate Craniofac J*. 2007;44:590–594.

Speltz ML, Endriga MC, Hill S, Maris CL, Jones K, Omnell ML. Brief report: cognitive and psychomotor development of infants with orofacial clefts. *J Pediatr Psychol*. 2000;25:185–190.

Stock N. Measuring psychosocial adjustment in cleft across the lifespan. Paper presented at the European Craniofacial Congress (ECC2011); 2011; Salzburg, Austria.

Strauss RP. The organization and delivery of craniofacial health services: the state of the art. *Cleft Palate Craniofac J*. 1999;36:189–195.

Stucki G, Ewert T, Cieza A. Value and application of the ICF in rehabilitation medicine. *Disabil Rehabil*. 2002;24:932–938.

Stucki G, Konstanjsek N, Ustün B, Cieza A. ICF-based classification and measurement of functioning. *Eur J Phys Rehabil Med*. 2008;44:315–328.

Suzuki K, Yamazaki Y, Sezaki K, Nakakita N. The effect of preoperative use of an orthopedic plate on articulatory function in children with cleft lip and palate. *Cleft Palate Craniofac J*. 2006;43:406–414.

Tate RL, Perdices M. Applying the *International Classification of Functioning, Disability, and Health* (ICF) to clinical practice and research in acquired brain impairment. *Brain Impair*. 2008;9:282–292.

Threats TT. The ICF and speech-language pathology: aspiring to fuller realization of ethical and moral issues. *Int J Speech Lang Pathol*. 2010;12:87–93.

Threats TT. The World Health Organization's revised classification: what does it mean for speech-language pathology? *J Med Speech Lang Pathol*. 2000;8:xiii–xviii.

Threats TT, Worrall L. The ICF is all about the person, and more: a response to Dunchan, Simmons-Mackie, Boles, and McLeod. *Adv Speech Lang Pathol*. 2004;6:83–87.

Tobiasen JM, Hiebert JM. Parents' tolerance for the conduct problems of the child with cleft lip and palate. *Cleft Palate J*. 1984;21:82–85.

Topolski TD, Edwards TC, Patrick DL. Quality of life: how do adolescents with facial differences compare with other adolescents? *Cleft Palate Craniofac J*. 2005;42:25–32.

Trindade IE, Manço JC, Trindade AS. Pulmonary function of individuals with congenital cleft palate. *Cleft Palate Craniofac J*. 1992;29:429–434.

Trost J. Articulatory additions to the classical description of the speech of persons with cleft palate. *Cleft Palate J*. 1981;18:193–203.

Trotman C-A, Barlow SM, Faraway JJ. Functional outcomes of cleft lip surgery. Part III: measurement of lip forces. *Cleft Palate Craniofac J*. 2007a;44:617–623.

Trotman C-A, Faraway JJ, Losken HW, van Aalst JA. Functional outcomes of cleft lip surgery. Part II: quantification of nasolabial movement. *Cleft Palate Craniofac J*. 2007b;44:607–616.

Trotman C-A, Faraway JJ, Phillips C. Visual and statistical modeling of facial movement in patients with cleft lip and palate. *Cleft Palate Craniofac J*. 2005;42:245–254.

Tunçbilek G, Özgür F, Belgin E. Audiologic and tympanometric findings in children with cleft lip and palate. *Cleft Palate Craniofac J*. 2003;40:304–309.

Ueda S, Okawa Y. The subjective dimension of functioning and disability: what is it and what is it for? *Disabil Rehabil*. 2003;25:596–601.

United Nations (UN). Convention on the rights of the child, 1989. Available at http://www.cirp.org/library/ethics/UN-convention. Accessed October 30, 2011.

United Nations (UN). Convention on the rights of persons with disabilities, 2006. Available at http://www.un.org/disabilities/convention/conventionfull.shtml. Accessed October 30, 2011.

Viswanathan N, Vidler M, Richard B. Hearing thresholds in newborns with a cleft palate assessed by auditory brain stem response. *Cleft Palate Craniofac J*. 2008;45:187–192.

Warren DW, Dalston RM, Mayo R. Hypernasality and velopharyngeal impairment. *Cleft Palate Craniofac J*. 1994;31:257–262.

Warren DW, Hairfield WM, Dalston ET. The relationship between nasal airway size and nasal-oral breathing in cleft lip and palate. *Cleft Palate Craniofac J*. 1990;27:46–52.

Webb ACC, Watts R, Read-Ward E, Hodgkins J, Markus AF. Audit of a multidisciplinary approach to the care of children with unilateral and bilateral cleft lip and palate. *Br J Oral Maxillofac Surg*. 2001;39:182–188.

Weinberg SM, Neiswanger K, Martin RA, Mooney MP, Kane AA, Wenger SL, Losee J, Deleyiannis F, Ma L, Salamanca JE, et al. The Pittsburgh Oral-Facial Cleft Study: expanding the cleft phenotype. Background and justification. *Cleft Palate Craniofac J*. 2006;43:7–20.

Wermke K, Birr M, Voelter CH, Shehata-Dieler W, Jurkutat A, Wermke P, Stellzig Eisenhauer A. Cry melody in 2-month-old infants with and without clefts. *Cleft Palate Craniofac J*. 2011;48:321–330.

Wermke K, Hauser C, Komposch G, Stellzig A. Spectral analysis of prespeech sounds (spontaneous cries) in infants with unilateral cleft lip and palate (UCLP): a pilot study. *Cleft Palate Craniofac J*. 2002;39:285–294.

Wetmore RF. Importance of maintaining normal nasal function in the cleft palate patient. *Cleft Palate Craniofac J*. 1992;29:498–50.

Whitehill TL. Assessing intelligibility in speakers with cleft palate: a critical review of the literature. *Cleft Palate Craniofac J*. 2002;39:50–58.

Whitehill TL, Chau C. Single-word intelligibility in speakers with repaired cleft palate. *Clin Linguist Phon*. 2004;18:341–355.

World Health Organization (WHO). *International Classification of Functioning, Disability, and Health, Children and Youth Version*. Geneva: WHO; 2007.

World Health Organization (WHO). *International Classification of Functioning, Disability, and Health* (ICF). Geneva: WHO; 2001.

WHO Work Group 2006. ICF-CY: Representing children's and adolescents' functioning, disability, and health. Available at http://www.venetosociale.it/icf-cy. Accessed October 30, 2011.

Willadsen E. Influence of timing of hard palate repair in a two-stage procedure on early language development in Danish children with cleft palate. *Cleft Palate Craniofac J*. In press. doi:10.1597/09-120.

Willadsen E, Albrechtsen H. Phonetic description of babbling in Danish toddlers born with and without unilateral cleft lip and palate. *Cleft Palate Craniofac J*. 2006;43:189–200.

Willadsen E, Enemark H. A comparative study of prespeech vocalizations in two groups of toddlers with cleft palate and a noncleft group. *Cleft Palate Craniofac J*. 2000;37:172–178.

Wohlleben U. *Die Verständlichkeitsentwicklung von Kindern mit Lippen-Kiefer-Gaumen- Segel-Spalten. Eine Längsschnittstudie über spalttypische Charakteristika und deren Veränderung* [*Development of intelligibility in children with cleft lip and palate. A longitudinal study of cleft type characteristics and their changing*]. Idstein: Schulz Kirchner; 2004. Dissertation.

Wyatt R, Sell D, Russell J, Harding A, Harland K, Albery E. Cleft palate speech dissected: a review of current knowledge and analysis. *Br J Plast Surg*. 1996;49:143–149.

Yamashita RP, Trindade IEK. Long-term effects of pharyngeal flaps on the upper airways of subjects with velopharyngeal insufficiency. *Cleft Palate Craniofac J*. 2008;45:364–370.

Yamashita Y, Michi K. Misarticulation caused by abnormal lingual-palatal contact in patients with cleft palate with adequate velopharyngeal function. *Cleft Palate Craniofac J*. 1991;28:360–368.

Yang FF, McPherson B, Shu H, Xie N, Xiang K. Structural abnormalities of the central auditory pathway in infants with nonsyndromic cleft lip and/or palate. *Cleft Palate Craniofacial J*. In press. doi:10.1597/11-014.

Yazdy MM, Honein MA, Rasmussen SA, Frias JL. Priorities for future public health research in orofacial clefts. *Cleft Palate Craniofac J*. 2007;44:351–357.

Zajac DJ, Mayo R, Kataoka R, Kuo JY. Aerodynamic and acoustic characteristics of a speaker with turbulent nasal emission: a case report. *Cleft Palate Craniofac J*. 1996;33:440–444.

Zheng W, Smith JD, Shi B, Li Y, Wang Y, Li S, Meng Z, Zheng Q. The natural history of audiologic and tympanometric findings in patients with an unrepaired cleft palate. *Cleft Palate Craniofac J*. 2009;46:24–29.