Children with Disabilities Algorithm

Section 1. Basic Measure Information

1.A. Measure Name

Children with Disabilities Algorithm (CWDA)

1.B. Measure Number

0144

1.C. Measure Description

Please provide a non-technical description of the measure that conveys what it measures to a broad audience.

The Children with Disabilities Algorithm (CWDA) identifies International Classification of Diseases, Ninth Revision, Clinical Modification (referred to hereafter as ICD-9-CM) codes that were assessed by expert reviewers as having a 75 percent or greater likelihood of indicating children with disabilities (CWD). With this tool, it will be possible to identify children with a high probability of having a disability in order to:

- Examine care quality delivered to CWD.
- Compare care quality delivered to CWD to that of children without disabilities.

1.D. Measure Owner

Center of Excellence for Pediatric Quality Measurement (CEPQM)

1.E. National Quality Forum (NQF) ID (if applicable)

Not applicable.

1.F. Measure Hierarchy

Please note here if the measure is part of a measure hierarchy or is part of a measure group or composite measure. The following definitions are used by AHRQ:

1. **Please identify the name of the collection of measures to which the measure belongs (if applicable). A collection is the highest possible level of the measure hierarchy. A**

collection may contain one or more sets, subsets, composites, and/or individual measures.

Not applicable.

2. **Please identify the name of the measure set to which the measure belongs (if applicable). A set is the second level of the hierarchy. A set may include one or more subsets, composites, and/or individual measures.**

   Not applicable.

3. **Please identify the name of the subset to which the measure belongs (if applicable). A subset is the third level of the hierarchy. A subset may include one or more composites, and/or individual measures.**

   Not applicable.

4. **Please identify the name of the composite measure to which the measure belongs (if applicable). A composite is a measure with a score that is an aggregate of scores from other measures. A composite may include one or more other composites and/or individual measures. Composites may comprise component measures that can or cannot be used on their own.**

   Not applicable.

1.G. Numerator Statement

The numerator includes children and adolescents aged 1-18 years with at least one ICD-9-CM code with a 75 percent or greater likelihood of indicating a disability.

1.H. Numerator Exclusions

Not appropriate.

1.I. Denominator Statement

The denominator includes children and adolescents aged 1-18 years in a data set that has ICD-9-CM codes.

1.J. Denominator Exclusions

Not appropriate.

1.K. Data Sources

Check all the data sources for which the measure is specified and tested.

Administrative data (e.g., claims data); Survey – Parent/caregiver report, electronic health record (EHR).

If other, please list all other data sources in the field below.

Not applicable.

Section 2: Detailed Measure Specifications

Provide sufficient detail to describe how a measure would be calculated from the recommended data sources, uploading a separate document (+ Upload attachment) or a link to a URL. Examples of detailed measure specifications can be found in the CHIPRA Initial Core Set Technical Specifications Manual 2011 published by the Centers for Medicare & Medicaid Services. Although submission of formal programming code or algorithms that demonstrate how a measure would be calculated from a query of an appropriate electronic data source are not requested at this time, the availability of these resources may be a factor in determining whether a measure can be recommended for use.

We have provided detailed specifications (see Supporting Documents), including (a) the framework used for CWDA, (b) SAS programming, and (c) a list of the ICD-9-CM codes included in CWDA.

Section 3. Importance of the Measure

In the following sections, provide brief descriptions of how the measure meets one or more of the following criteria for measure importance (general importance, importance to Medicaid and/or CHIP, complements or enhances an existing measure). Include references related to specific points made in your narrative (not a free-form listing of citations).

3.A. Evidence for General Importance of the Measure

Provide evidence for all applicable aspects of general importance:

- **Addresses a known or suspected quality gap and/or disparity in quality (e.g., addresses a socioeconomic disparity, a racial/ethnic disparity, a disparity for Children with Special Health Care Needs (CSHCN), a disparity for limited English proficient (LEP) populations).**
- **Potential for quality improvement (i.e., there are effective approaches to reducing the quality gap or disparity in quality).**
- **Prevalence of condition among children under age 21 and/or among pregnant women.**
- **Severity of condition and burden of condition on children, family, and society (unrelated to cost).**
- **Fiscal burden of measure focus (e.g., clinical condition) on patients, families, public and private payers, or society more generally, currently and over the life span of the child.**

- **Association of measure topic with children's future health – for example, a measure addressing childhood obesity may have implications for the subsequent development of cardiovascular diseases.**
- **The extent to which the measure is applicable to changes across developmental stages (e.g., infancy, early childhood, middle childhood, adolescence, young adulthood).**

Children with Disabilities

CWDA is based on the disability concepts and definitions outlined by the 2006 United Nation's (UN) Convention on the Rights of Persons with Disabilities (UN, 2006) and the 2001 International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001). Article 1 of the UN's Convention states, "Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others [article 1, page 4]." At the core of the ICF framework is the concept that disability results from the interaction between the features of an individual's "body functions and structures" and the environment, including social, physical, and attitudinal factors. Therefore, in addition to physical and sensory conditions commonly considered disabilities (e.g., blindness, paraplegia), CWDA also accounts for intellectual and mental conditions that limit children's ability to fully participate in society (e.g., autism, schizophrenia). Consistent with the ICF's disability concepts, the National Health Interview Survey (NHIS) measures the prevalence of CWD in the United States using parental report of activity limitation due to a chronic condition (Houtrow, Larson, Olson, et al., 2014).

Current NHIS findings estimate the prevalence of CWD to be 8 percent (Houtrow, et al., 2014), showing a rising trend from 2 percent in 1960 and 4 percent in 1980 (Halfon, Houtrow, Larson, et al., 2012; Newacheck, Halfon, Budetti, 1986). The rise in CWD prevalence may be due in part to the inclusion of intellectual and mental conditions in this subgroup. It also may be due to greater survivorship for conditions previously considered untreatable (e.g., extreme prematurity, congenital heart disease, human immunodeficiency virus) (Centers for Disease Control and Prevention [CDC], 1999; Institute of Medicine [IOM], 2011) because survivorship can be accompanied by temporary or long-term functional problems (e.g., feeding impairment, learning difficulties) (Chiu, Ijsselstijn, 2012; Wilson-Costello, Friedman, Minich, et al., 2005).

Impact of Disability on Children, Parents, Families, and Society

By definition, the conditions included in CWDA have the potential to seriously impair the ability of children to function. CWD may not be able to move, breathe, or feed themselves without assistance; many of these children will be dependent on technology or the assistance of others for the duration of their lives (Allen, Mulcahey, Haley, et al., 2009; Fauconnier, Dickinson, Beckung, et al., 2009; Sarvey, 2008; Spratling, 2012; Van der Cammen-van Zipp, Janssen, Raets, et al., 2014). CWD may also experience extreme developmental delays, have trouble learning, or be unable to interact socially with their peers (Ginieri-Cocossis, Rotsika, Skevington, et al., 2013; Ikeda, Hinckson, Krageloh, 2014). In addition to their primary disabling condition, CWD may face additional challenges, including chronic sleep disorders, psychosocial impairments, and reduced school attendance (Buckley, Rodriguez, Jennison, et al., 2010;

Ivanenko, Crabtree, Gozal, 2004; Johnson, Giannotti, Cortesi, 2009; Johnson Malow, 2008; Kronk, Bishop, Raspa, et al., 2010; Msall, Avery, Tremont, et al., 2003; Simard-Tremblay, Constantin, Gruber, et al., 2011; Williams, 2004; Witt, Riley, Coiro, 2003). Emotional health is also a concern among CWD (Boyce, Davies, Raman, et al., 2009). Despite these major issues, much can be done to improve the lives of CWD through proper medical care and environmental adjustments that allow CWD to maximize functioning and well-being. Assistive devices, treatments, and technology (e.g., wheelchairs, occupational therapy, cochlear implants) have been shown to improve the functioning of CWD (Duarte, Santos, Rego, et al., 2014; Ervin, Hennen, Merrick, et al., 2014; Lancioni, Singh, O'Reilly, et al., 2012; Rousseau-Harrison, Rochette, 2013; Virbalas, Palma, Tan, 2012).

The impact of childhood disability extends to the family. Parents of CWD face both interpersonal and financial burdens in the care of their children. Parents of CWD experience greater levels of stress and poorer mental and physical health compared to parents of children without disabilities (Halfon, et al., 2012; Hutchinson, Willard, Hardy, et al., 2009; Lopez-Wagner, Hoffman, Sweeney, et al., 2008; Meltzer, 2008; Stabile, Allin, 2012; Witt, Gottlieb, Hampton, et al., 2009). Married couples with CWD are more likely to divorce than those without CWD (Joesch, Smith, 1997; Mauldon, 1992). Furthermore, parents of CWD are more likely than parents of children without disabilities to miss work or be unemployed as a consequence of their child's health care needs (Stabile, Allin, 2012; Witt, et al., 2009). Mothers of young CWD and mothers of children with severe disabilities are less likely to work than their counterparts with non-disabled children (Porterfield, 2002; Powers, 2001; Stabile, Allin 2012; Warfield, 2001). Research also suggests that the negative effects of childhood disability on maternal employment are almost three times as strong among low-income, African American mothers as among high-income, Caucasian mothers (Breslau, Salkever, Staruch, 1982).

Families with CWD also experience direct financial burdens due to expenditures for health care and other out-of-pocket expenses, such as therapy, behavioral or educational services, transportation, and caregivers (Stabile, Allin, 2012). One study estimated that out-of-pocket expenses for CWD consume upwards of 12 percent of a family's annual income (Leonard, Brust, Sapienza, 1992), well beyond the 5 percent cutoff indicating a "catastrophic" financial burden (Newacheck, Inkelas, Kim, 2004). While many families with CWD must carry the full load of these financial burdens, Medicaid and Supplemental Security Insurance (SSI) benefits help to offset the costs for some families with CWD, therefore shifting a portion of the expenditures to the public (Lukemeyer, 2000; McMorrow, Kenney, Anderson, et al., 2014; Parish, Thomas, Rose, et al., 2012).

The societal costs for CWD derive from both the health care and educational sectors of State and Federal budgets. CWD use health care services—inpatient, outpatient, and emergency department—more frequently than children without disabilities (Halfon, et al., 2012; Houtrow, Okumura, Hilton, et al., 2011; Newacheck, et al, 2004). Annual health care expenditures for CWD are on average four times as high as for children without disabilities ($2,669 vs. $676) (Newacheck, et al., 2004). In 2010, the average annual Medicaid cost per child for Federal SSI payments was approximately $7,161, compared to $3,573 in average spending for a child on Medicaid (Centers for Medicare & Medicaid Services [CMS], 2014; Social Security Administration, 2011). A study examining the 1999-2000 school year showed that the total

expenditure on education for school-age students with disabilities was $12,474 per child, compared to $6,556 per general education student (Chambers, Perez, Harr, et al., 2005).

Importance of Identifying CWD for Quality Measurement

Current knowledge of health care quality issues for CWD is based almost exclusively on observational studies and anecdotal reports, both of which are often limited to specific disabling conditions. For example, studies of children with autism (a diagnosis included in CWDA) indicate that providers may not always take the known behavioral needs of autistic children into account during treatment (Megargel, Broder-Fingert, 2012; Nelson, Amplo, 2009). In our estimation, the ability to conduct more rigorous studies has been impeded by the lack of a theoretically grounded, systematically applied, scalable, and affordable method for identifying CWD. Although CWD can be identified by survey methods, the magnitude of the effort needed to identify a target population that comprises less than 10 percent of the total population is usually considered impractical or cost-prohibitive.

CWDA fulfills the need for a theoretically grounded, scalable, and affordable method for identifying CWD. We anticipate that CWDA will vastly increase the rigor and feasibility with which stakeholders will be able to identify CWD for quality assessment and subsequent quality improvement efforts. CWDA will also help researchers to expand our current understanding of care quality for CWD beyond condition-specific observational studies and case studies, potentially revealing systemic issues and more generalizable solutions.

Because stakeholders and investigators can stratify data by disability status to reveal differences in care experiences and quality, CWDA should also enable evaluations of whether CWD receive appropriate differences in care or are at risk for experiencing disparities in quality. Differences can then become the focus of investigations and interventions to reduce and, eventually, eliminate any potential disparities for CWD.

3.B. Evidence for Importance of the Measure to Medicaid and/or CHIP

Comment on any specific features of this measure important to Medicaid and/or CHIP that are in addition to the evidence of importance described above, including the following:

- **The extent to which the measure is understood to be sensitive to changes in Medicaid or CHIP (e.g., policy changes, quality improvement strategies).**
- **Relevance to the Early and Periodic Screening, Diagnostic and Treatment benefit in Medicaid (EPSDT).**
- **Any other specific relevance to Medicaid/CHIP (please specify).**

CWDA is important to Medicaid/CHIP because CWD are disproportionately insured by Medicaid/CHIP based on income qualifications and/or SSI (Szilagyi, 2012; Tu, Cunningham, 2005). CWDA can help Medicaid/CHIP assess the quality of care for its enrollees who are CWD.

3.C. Relationship to Other Measures (if any)

Describe, if known, how this measure complements or improves on an existing measure in this topic area for the child or adult population, or if it is intended to fill a specific gap in an existing measure category or topic. For example, the proposed measure may enhance an existing measure in the initial core set, it may lower the age range for an existing adult-focused measure, or it may fill a gap in measurement (e.g., for asthma care quality, inpatient care measures).

CWDA both fills a specific gap within the pediatric quality measurement field and complements existing pediatric measures. Others have developed survey-based measures that identify the CWD population (CDC, 2011, 1994; Feudtner, Christakis, Connell, 2000), but CWDA is distinct from these measures in that it is claims-based. To our knowledge, no other efforts have been made to develop a system based on ICD-9-CM codes for identifying this unique and heterogeneous population. Other researchers have developed claims-based algorithms for identifying other concerning sub-populations of children: those with complex chronic conditions (CCC) (Feudtner, et al., 2000), children with special health care needs (CSHCN) (Kuhlthau, Beal, Ferris, et al., 2002), or requirements for complex care (PMCA) (Simon, Cawthon, Stanford, et al., 2014). However, existing algorithms omit children with some conditions that make it difficult for them to function in daily life or to gain access to needed health care (e.g., dyslexia, limb amputation) and include children with conditions that are not particularly long-lasting or impairing (e.g., tuberculosis, asthma). CWDA identifies a distinct subset of children based on functional impairments rather than intensity of health care utilization (Halfon, et al., 2012).

Section 4. Measure Categories

CHIPRA legislation requires that measures in the initial and improved core set, taken together, cover all settings, services, and topics of health care relevant to children. Moreover, the legislation requires the core set to address the needs of children across all ages, including services to promote healthy birth. Regardless of the eventual use of the measure, we are interested in knowing all settings, services, measure topics, and populations that this measure addresses. These categories are not exclusive of one another, so please indicate "Yes" to all that apply.

Does the measure address this category?

a. **Care Setting – ambulatory:** Yes.
b. **Care Setting – inpatient:** Yes.
c. **Care Setting – other – please specify:** Yes; any setting in which ICD-9-CM codes are used.
d. **Service – preventive health, including services to promote healthy birth:** Yes.
e. **Service – care for acute conditions:** Yes.
f. **Service – care for children with acute conditions:** yes.
g. **Service – other (please specify):** No.
h. **Measure Topic – duration of enrollment:**
i. **Measure Topic – clinical quality:** Yes.

j. **Measure Topic – patient safety:** Yes.
k. **Measure Topic – family experience with care:** Yes.
l. **Measure Topic – care in the most integrated setting:** Yes.
m. **Measure Topic other (please specify):** No.
n. **Population – pregnant women:** Yes.
o. **Population – neonates (28 days after birth) (specify age range):** No.
p. **Population – infants (29 days to 1 year) (specify age range):** No.
q. **Population – pre-school age children (1 year through 5 years) (specify age range):** Yes; 1-5 years.
r. **Population – school-aged children (6 years through 10 years) (specify age range):** Yes; 6-10 years.
s. **Population – adolescents (11 years through 20 years) (specify age range):** Yes; 11-18 years.
t. **Population – other (specify age range):** No.
u. **Other category (please specify):** Not applicable.

Section 5. Evidence or Other Justification for the Focus of the Measure

The evidence base for the focus of the measures will be made explicit and transparent as part of the public release of CHIPRA deliberations; thus, it is critical for submitters to specify the scientific evidence or other basis for the focus of the measure in the following sections.

5.A. Research Evidence

Research evidence should include a brief description of the evidence base for valid relationship(s) among the structure, process, and/or outcome of health care that is the focus of the measure. For example, evidence exists for the relationship between immunizing a child or adolescent (process of care) and improved outcomes for the child and the public. If sufficient evidence existed for the use of immunization registries in practice or at the State level and the provision of immunizations to children and adolescents, such evidence would support the focus of a measure on immunization registries (a structural measure).

Describe the nature of the evidence, including study design, and provide relevant citations for statements made. Evidence may include rigorous systematic reviews of research literature and high-quality research studies.

The evidence that care quality for CWD is less than desirable stems from available research that has looked directly at the CWD population (Perrin, 2002), as well as the broader literature on care quality for adults with disabilities (AWD) and CSHCN.

Care Quality for Children with Disabilities

Available research suggests that care quality for CWD is less than desirable. For example, studies of children with autism (a diagnosis included in CWDA) indicate that medical providers

may not always take the known behavioral needs of autistic children into account during treatment (Megargel, et al., 2012; Nelson, Amplo, 2009). In addition, CWD may encounter difficulties with access to health services. An analysis of the National Health Interview Survey (NHIS) indicated that children with mild or marked hearing impairment are less likely to have access to prescription medications, mental health services, and dental services, with no difference identified for access to routine or sick health services (Boss, Niparko, Gaskin, et al., 2011). Furthermore, parents provide important accounts of their experiences of the shortcomings of the health care system. Parents of CWD report unmet informational needs, including a lack of understanding of how the condition will affect their family and a desire for providers to put them in touch with other parents for support (Liptak, Orlando, Yingling, et al., 2006).

Care Quality for Adults with Disabilities

AWD have been shown to face more challenges in the health care system than their non-disabled counterparts (Office of Disease Prevention and Health Promotion [ODPHP], 2014). For example, if clinics do not facilitate physical accessibility (e.g., wheelchair ramps, height-adjustable exam tables) for patients with mobility impairments, AWD are deterred from seeking recommended care (e.g., primary, subspecialty, or preventive care) (Grabois, Nosek, Rossi, 1999; Iezzoni, McCarthy, Davis, et al., 2000; Lagu, Hannon, Rothberg, et al., 2013; Sanchez, Byfield, Brown, et al., 2000). Studies also indicate that primary care for AWD tends to focus narrowly on patients' underlying disability to the exclusion of preventive health concerns, such as breast and cervical cancer screening tests and discussions about contraception and smoking (Chan, Doctor, McLehose, et al., 1999; Horner-Johnson, Dobbertin, Andresen, et al., 2014; Iezzoni, 2003a; Iezzoni, et al., 2000). CWD may struggle with similar barriers to care quality. CWD and their families may also be deterred from seeking care because of the physical barriers they face, and they may have their preventive care needs similarly overlooked.

Care Quality for Children Who Have Special Health Care Needs

CWD are a distinct population that overlaps with the larger CSHCN population: many (but not all) CWD would also be considered CSHCN. However, compared to CSHCN without disabilities, CWD have longer-lasting functional impairments and more severe activity limitations. Because these populations are similar, we can likely extrapolate care quality patterns described for CSHCN to those for CWD. To date, studies present a mixed picture with respect to the care quality that CSHCN receive. CSHCN have been found to be more likely to receive recommended care than their non-CSHCN counterparts on claims-based measures of preventive and acute care quality (e.g., recommended number of well-child visits, use of streptococcal testing for clinical diagnosis), perhaps due to greater utilization of health care services in general (Chien, Li, Rosenthal, 2010; Chien, Song, Chernew, et al., 2014). However, surveys indicate that CSHCN are more likely to report poorer quality care experiences than their non-CSHCN counterparts in many aspects of medical care (e.g., greater difficulty obtaining referrals, accessing subspecialists, or receiving care coordination) (Chiri, Warfield, 2012; Hill, Freeman, Yucel, et al., 2008; Miller, Macon, Gaboda, et al., 2012; Nageswaran, Silver, Stein, 2008; Houtrow, et al., 2011; Toomey, Chien, Elliott, et al., 2013).

5.B. Clinical or Other Rationale Supporting the Focus of the Measure (optional)

Provide documentation of the clinical or other rationale for the focus of this measure, including citations as appropriate and available.

Stakeholders require an assessment of care quality for CWD in order to begin lauding superior performance or intervening to reduce deficits. CWDA will enable this assessment on a scale not previously possible. Federal awareness is growing regarding the need to identify disparities in quality of care among people with disabilities, specifically CWD.

In 2012, the Agency for Healthcare Research and Quality (AHRQ) reported on the lack of literature capturing the perspective of disabled individuals in regard to health care (Butler, Kane, Larson, et al., 2012). The AHRQ report also noted a lack of literature comparing care quality and outcomes in a disabled population compared to a control group (Butler, et al., 2012). In, 2014 the U.S. Department of Health and Human Services included "Disability and Health" as a topic for improvement in Healthy People 2020. They specified that more opportunities must be available for people with disabilities to "be included in public health activities, receive well-timed interventions and services, interact with their environment without barriers, and participate in everyday life activities (ODPHP, 2014)."

Other programs are ongoing. For example, the Title V Maternal and Child Health Program provides support for CSHCN, including CWD and their families, and promotes family-centered, community-based, and coordinated care (Maternal and Child Health Bureau, 2016). In addition, the National Institute on Disability and Rehabilitation Research (NIDRR), funded through the Department of Education, dedicated over $104 million in 2013 for investigations into topics including rehabilitation services, care coordination, and assistive technology for people with disabilities (NIDRR, 2014). Recent legislation, such as the American Recovery and Reinvestment Act, the Patient Protection and Affordable Care Act, and the reauthorization of the Combating Autism Act, include important investments in research and support services for people with disabilities (American Recovery and Reinvestment Act, 2009; Combating Autism Act, 2006; Patient Protection and Affordable Care Act, 2010).

CWDA will allow investigators to identify CWD populations to implement care quality measures, examine care quality, and look for differences based on disability status. CWDA will therefore serve as a key tool in meeting the Federal priority of building our understanding of care quality for CWD.

Section 6. Scientific Soundness of the Measure

Explain the methods used to determine the scientific soundness of the measure itself. Include results of all tests of validity and reliability, including description(s) of the study sample(s) and methods used to arrive at the results. Note how characteristics of other data systems, data sources, or eligible populations may affect reliability and validity.

6.A. Reliability

Reliability of the measure is the extent to which the measure results are reproducible when conditions remain the same. The method for establishing the reliability of a measure will depend on the type of measure, data source, and other factors.

Explain your rationale for selecting the methods you have chosen, show how you used the methods chosen, and provide information on the results (e.g., the Kappa statistic). Provide appropriate citations to justify methods.

Internal Consistency Reliability

Because CWDA is based on ICD-9-CM codes, we expect the identification of CWD to be entirely reproducible as long as ICD-9-CM coding conditions remain the same. If CWDA is used in datasets different from those we used to develop and test the algorithm, we anticipate that the prevalence of CWD identified by CWDA will vary accordingly. For example, a greater proportion of CWD may be identified in data from hospital-based clinics specializing in the care of complex pediatric patients than in data from community-based general pediatric practices.

We took several steps to ensure that identification of CWD by our algorithm is as reliable as possible. We engaged pediatric disability experts oriented to the purpose of CWDA in a consensus process to specify age-appropriate expectations regarding what constitutes activity limitations and participation restrictions across the pediatric age range (Hagan, Shaw, Duncan, 2008). In addition, following Glaser consensus-building methods (Glaser, 1980), we created a multidisciplinary, multi-step code classification process to ensure that each ICD-9-CM code was reviewed by a minimum of three and up to nine general pediatricians and pediatric subspecialists (average of four), as detailed below.

For all steps of the code classification process, we developed rules and decision-making logic to guide consistent assessment of the degree to which ICD-9-CM codes were likely to indicate CWD. We trained all those involved in the code classification process in the WHO and UN concepts and definitions of disability. We used a 75 percent cutoff for the final designation of CWDA codes. We trained our code classifiers to take a population approach to the code classification process for the 75 percent cutoff. This involved envisioning the features of the population likely to receive an ICD-9-CM code, imagining 100 children with this code, and determining whether 75 or more of these children would meet our criteria for a disability for at least 12 months. Because functional expectations depend on context, we also established key assumptions that children: lived in an environment or setting that was average for the United States in 2012, had families that possessed a typical capacity for seeking and accessing health care, received treatment that was typically available, and experienced a typical clinical course. When there was a question about the typical functional status of children with particular diagnoses or the proportion of children with a given diagnosis who would likely have disabling levels of impairment, we conducted literature reviews and consulted subspecialists to inform the classification decision.

The four-step code classification process (see Figure 5-A in the Supporting Documents) began with all 14,567 codes in the 2012 ICD-9-CM Codebook. We sought to have all codes with a

moderate or higher likelihood of indicating CWD to be reviewed. We first excluded codes that were inapplicable to the pediatric population (n=56, e.g., senile dementia) or could not be used for primary diagnoses (n=1,291, i.e., E-codes) for a total of 13,220 codes applicable to pediatrics.

In **Step 1**, **the Pre-sort,** we reviewed a large volume of codes and identified those with a 10 percent or greater likelihood of indicating CWD. The aim of this step was to allow the code classification process to focus most intensely on the subset of codes with the greatest possibility of identifying CWD. We considered the 2,738 codes in the CSHCN and CCC algorithms as having at least a 10 percent likelihood of indicating CWD because these algorithms were developed to identify populations of children similar to CWD. Next, two fellowship-trained general pediatricians with over 10 years of clinical experience caring for CSHCN independently reviewed the remaining codes to determine if they met the 10 percent or greater threshold. For codes where these two reviewers disagreed, three additional general pediatricians (also with advanced training) helped determine the final classification.

In **Step 2, the Initial Disability Expert Review,** three pediatric disability experts (pediatricians with expertise caring for and studying CWD) independently reviewed the 3,964 codes identified in Step 1 as 10 percent or greater and further classified them into categories based on their likelihood of indicating CWD: less than 10 percent, 10 percent to less than 75 percent, or 75 percent or greater. Pediatric disability experts were fellowship-trained, had at least 5 years of experience studying or caring for CWD, and had served on CWD-relevant councils or chapters (e.g., the American Academy of Pediatrics Council on Children with Disabilities). We resolved disagreements through consensus.

In **Step 3, the Subspecialist Review,** we obtained input from relevant pediatric subspecialists (e.g., codes related to hearing were reviewed by a pediatric otolaryngologist specializing in hearing loss, whereas codes related to intracranial bleeds were reviewed by a pediatric neurosurgeon and a pediatric rehabilitation physician). The subspecialists reviewed all codes related to their field, including those originally classified as less than 10 percent in Step 1.

In **Step 4, the Final Disability Expert Review,** the three pediatric disability experts from Step 2 incorporated the subspecialists' input into their final classification decisions. Ultimately, codes identified as having a 75 percent or greater likelihood of indicating CWD were included in CWDA. A total of eight general pediatricians and 42 pediatric subspecialists participated in the four-step code classification process. Participants were drawn from across the United States. We trained those involved in the Step 1 pre-sort for at least 1 hour, the pediatric disability experts responsible for Steps 2 and 4 for at least 4 hours, and Step 3 subspecialists for a variable amount of time depending on the amount and complexity of codes being reviewed. All initial trainings were conducted in person, and follow-up discussions were conducted by email, phone, and conferences calls. Reinforcement generally occurred at weekly to biweekly intervals throughout the code classification process. Across all four steps, literature reviews (over 500 conditions researched) supported sorting and classification decisions, and all disagreements were reconciled by discussion or majority vote.

Inter-Rate Reliability

After Step 4, we assessed the inter- and multi-rater reliability of the dichotomous classification of the codes—less than 75 percent (not in CWDA) versus 75 percent or greater likelihood of indicating CWD (included in CWDA)—using three methods: (1) percent agreement, (2) Cohen's 2-way kappa (Cohen, 1960), and (3) Fleiss' multi-rater kappa (Fleiss, 1971), then proceeded with consensus discussions. The percent agreement between any two code classifiers was 90-91 percent, which falls into the "nearly always acceptable" range (Neuendorf, 2001). The Cohen's kappa statistic was 0.60-0.68, and the Fleiss' multi-rater kappa was 0.64, both of which fall into the "substantial" agreement range (Cohen, 1960).

6.B. Validity

Validity of the measure is the extent to which the measure meaningfully represents the concept being evaluated. The method for establishing the validity of a measure will depend on the type of measure, data source, and other factors.

Explain your rationale for selecting the methods you have chosen, show how you used the methods chosen, and provide information on the results (e.g., R2 for concurrent validity).

Construct Validity

CWDA is based on the disability concepts and definitions of the WHO, which are detailed in the 2001 ICF (see Section 2 for further details), and the UN. CWDA also reflects current concepts regarding developmental expectations for the pediatric population (Hagan, et al., 2008).

Criterion Validity

Given that the degree to which disability is present depends on environmental factors (social, physical, and attitudinal), we assessed the validity of CWDA according to (1) the parent's perspective and (2) the physician's assessment of patient charts. We chose to compare CWDA to the parent perspective and to physician assessment of patient charts because there is no "gold standard" for identifying CWD and because parents and physicians have complementary insights that contribute to a more complete understanding of disability. Because the goal of CWDA is to enable the differentiation of pediatric populations into those with a 75 percent or greater likelihood of indicating CWD and those without, we focused on assessing CWDA's sensitivity (i.e., the likelihood that CWDA would be positive when compared to parent report or physician assessment of patient charts) for both the parent report and physician abstraction processes.

Parent Perspective of Child's Disability Status. We developed the parent survey based on questions from three previously used parent-report instruments: (1) the Washington Group on Disability Statistics' (WG) Module on Child Functioning and Disability, (2) the 2011 National Health Interview Survey (NHIS) Questionnaire, and (3) the 1995 NHIS Disability Supplement (CDC, 2011, 1994; Madans, et al., 2011). The WG questions were designed to gather information on functional impairments in 12 domains and the degree of difficulty presented by performing specified functions. Questions vary by age and include items about seeing, hearing, walking, self-care, communication, comprehension, learning, emotions, behavior, attention, coping with change, relationships, and playing. The NHIS questions include a single item that

was designed to ascertain, in a dichotomous fashion, whether parents felt that their child had a disability; parents were asked, "Do you consider your child to have a disability?" with response options of "yes," "no," and "I don't know." The parent survey included 34 items in total.

Between February and April 2014, we targeted parents of all CWD actively receiving primary care at a large, free-standing children's hospital. We defined active as having at least two encounters at the clinic in the 2 years prior to the survey. We designated children as CWD if they had at least one CWDA code in 2012 and updated their status when 2013 information became available. We fielded the survey in the early months of 2014 because the survey questions asked parents to recall their child's functional ability over the 2013 calendar year. We recruited parents 1 week before or after their scheduled clinic visit and provided the option to complete the survey by mail, online, over the phone, or in person. We provided English and Spanish versions of the survey and offered interpreter services for American Sign Language. The survey response rate was 61 percent (n=128).

We compared CWDA ascertainment of CWD status with that of parents based on the NHIS question, "Do you consider your child to have a disability?" (n=114 responses). In a sample that CWDA determined to have 52 percent CWD (n=59), 62 percent of parents (n=71) indicated that they considered their child to have a disability. Percent agreement between CWDA and the parent perspective was 79 percent, and sensitivity was 0.75 (95 percent confidence interval, 0.63-0.84; see Table 6-B in the Supporting Documents).

Physician Assessment of Patient Charts. We developed a novel chart abstraction tool based on the ICF's impairment domains and severity coding schemes (WHO, 2001). Two fellowship-trained general pediatricians with at least 10 years of clinical experience served as our main chart abstractors. The abstraction tool built on the ICF's impairment domains and severity coding schemes and required physicians to abstract clinical information pertaining to 13 domains of potential impairments (e.g., hearing, seeing, moving), to indicate corresponding age-appropriate assessments of impairment severity (mild, moderate, severe, complete, unspecified), and to note whether participation restriction appeared to be present in the home or school settings. The tool also instructs the abstractors to provide a clinical summary for the years' worth of encounters and the item, "Do you consider this child to have at least one disability for the full duration of the target abstraction period?"

Physician abstractors assessed the charts of children who had two or more encounters anywhere within the same large, free-standing children's hospital (inpatient, outpatient, primary care, and specialty) as in the parent survey. Between October and December 2013, physicians abstracted the charts of randomly chosen patients with an index visit between July 2011 and June 2012 and abstracted all encounters starting with the index visit through the following 12 months. We oversampled for CWD, designating children as CWD if they had at least one CWDA code in the target abstraction period. During the chart abstraction process, both reviewers were blinded to the patient's disability status as determined by CWDA. We double-abstracted 10 percent of charts for quality assurance, calculating both inter- and intra-rater reliabilities on a weekly basis. The inter-rater 2-way kappa was 0.62 ("substantial"91); intra-rater 2-way kappa was 0.46 for one reviewer and 0.69 for the other ("moderate" and "substantial," respectively; Landis, Koch, 1977). All disagreements were discussed and reconciled between the two abstractors.

In a sample (n=336) that CWDA determined to have 80 percent CWD (n=268), 62 percent of children (n=208) were considered to have a disability according to the physician chart review. Percent agreement between CWDA and physician assessment of patient charts was 80 percent, and sensitivity was 0.98 (95 percent confidence interval, 0.95-0.99; see Table 6-B in the Supporting Documents).

Content Validity

We considered functional issues of all body systems that could lead to disabling levels of activity limitation and participation restriction. We considered not just sensory and physical functioning, but also cognitive and emotional functioning.

Face Validity

We incorporated face validity checks into our CWDA development process. During the development of the parent survey, we consulted with two parents of CWD and one adult who had a history of being a child with a disability. During the code classification process, we incorporated the expertise of 42 pediatric subspecialists. We also presented the development of CWDA to Boston Children's Hospital's Family Advisory Council.

Section 7. Identification of Disparities

CHIPRA requires that quality measures be able to identify disparities by race, ethnicity, socioeconomic status, and special health care needs. Thus, we strongly encourage nominators to have tested measures in diverse populations. Such testing provides evidence for assessing measure's performance for disparities identification. In the sections below, describe the results of efforts to demonstrate the capacity of this measure to produce results that can be stratified by the characteristics noted and retain the scientific soundness (reliability and validity) within and across the relevant subgroups.

7.A. Race/Ethnicity

We assessed differences in CWDA status by race/ethnicity using our 2008 nine-State Medicaid Analytic Extract (MAX) data set for children and adolescents ages 1-18 years who had been enrolled in Medicaid for at least 11 months (n=2,671,922). Race/ethnicity is recorded in MAX data using the categories white, black/African American, Hispanic/Latino, Hispanic plus other race, Asian, Native Hawaiian/Pacific Islander, Native American/Native Alaskan, more than one race, and unknown race. Race/ethnicity data were missing for 3.6 percent of our sample. For our analysis, we combined the Hispanic/Latino and "Hispanic plus other race" groups into the Hispanic category. We also combined the Asian and Native Hawaiian/Pacific Islander groups into the Asian/Pacific Islander category. We found significant differences in CWDA status by race/ethnicity (chi-square test, $p<0.001$; see Table 7-A in the Supporting Documents).

7.B. Special Health Care Needs

We assessed differences in CWDA status by special health care needs using our 2008 nine-State MAX data set. We used the Pediatric Medical Complexity Algorithm (PMCA) to group patients based on special health care needs status. The PMCA was developed to stratify children based on medical complexity in terms of life expectancy, mechanical dependence, and health care resource utilization (Simon, et al., 2014). For our analyses, we used the more conservative version of the PMCA, in which the identification of complex chronic conditions requires at least two occurrences of PMCA-indicated ICD-9-CM codes during the study period. We found significant differences in CWDA status by special health care needs (chi square test, $p<0.001$; see Table 7-B in the Supporting Documents).

7.C. Socioeconomic Status

Because MAX data do not include information on socioeconomic status, we did not assess use of CWDA to identify differences in CWDA status by socioeconomic status. CWDA potentially could be used to stratify socioeconomic information in a data set where socioeconomic status is documented in a standard and consistent way.

7.D. Rurality/Urbanicity

We assessed differences in CWDA status by residence in rural versus urban areas using our 2008 nine-State MAX data set. We assigned rural-urban commuting area (RUCA) codes to patients based on their five-digit home zip codes. RUCA codes are part of a census-tract-based classification system that uses Bureau of Census Urbanized Area and Urban Cluster definitions together with work commuting information to characterize census tracts by their rural or urban status (WWAMI Rural Health Research Center, 2005). We then used the RUCA codes to assign patients' residence to one of five levels of the rurality/urbanicity classification scheme created by the Dartmouth Atlas Working Group: urban core, suburban, large town, small town, or isolated rural (Dartmouth College, 2007). RUCA codes could not be assigned for 10,423 observations that were missing zip codes. We found significant differences in CWDA status by rurality/urbanicity (chi-square test, $p<0.001$; see Table 7-D in the Supporting Documents).

7.E. Limited English Proficiency (LEP) Populations

Because MAX data do not include information on English proficiency, we did not assess use of CWDA to identify differences in CWDA status based on limited English proficiency. CWDA potentially could be used to examine CWDA status by English proficiency in a data set in which English proficiency is documented in a standard and consistent way.

Section 8. Feasibility

Feasibility is the extent to which the data required for the measure are readily available, retrievable without undue burden, and can be implemented for performance measurement. Using the following sections, explain the methods used to determine the feasibility of implementing the measure.

8.A. Data Availability

1. What is the availability of data in existing data systems? How readily are the data available?

CWDA relies on ICD-9-CM diagnosis codes, which are used by U.S. public and private payment systems, including State Medicaid/CHIP programs, and by care delivery systems, including acute and long-term care hospitals and general and subspecialty practices (Iezzoni, 2003b; O'Malley, Cook, Price, et al., 2005).

2. If data are not available in existing data systems or would be better collected from future data systems, what is the potential for modifying current data systems or creating new data systems to enhance the feasibility of the measure and facilitate implementation?

Not applicable.

8.B. Lessons from Use of the Measure

1. Describe the extent to which the measure has been used or is in use, including the types of settings in which it has been used, and purposes for which it has been used.

We tested CWDA using two domains from AHRQ's Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician and Group Survey and 11 measures from the National Committee for Quality Assurance (NCQA) Healthcare Effectiveness Data and Information Set (HEDIS). Using CAHPS, we assessed outpatient care experience for CWD at the primary care clinic of a large, freestanding children's hospital. Using HEDIS, we assessed outpatient care quality for Medicaid-insured CWD in 2008 MAX data from nine States. CWDA was easy to implement in both instances and with both data sources.

2. If the measure has been used or is in use, what methods, if any, have already been used to collect data for this measure?

Implementing CWDA requires application of the list of 669 ICD-9-CM codes that were identified as having a 75 percent or greater likelihood of indicating CWD. We have created an SAS program that can be used with data organized at the encounter or claims level, as is typical for electronic health records (EHR) and health plan data, respectively.

3. What lessons are available from the current or prior use of the measure?

Overall, CWDA has proven to be extremely easy to implement. Users are not likely to have difficulty implementing CWDA. However, users may face challenges when selecting data sources stemming from the accuracy (whether the data correctly represent the conditions present) and completeness (whether the data cover all of children's conditions) of ICD-9CM data (see Section 12 for limitations of ICD-9-CM codes). For example, it would not be appropriate to use CWDA to measure dental care quality for CWD if dental health benefits are not included in the claims data being used.

When applying CWDA to a specific quality measure, users must determine the appropriate timeframe and data source with which to use CWDA. For example, if users are applying CWDA to a hospital patient experience survey, users should consider whether to determine CWD status

by applying CWDA to data from the duration of the hospital stay only or by also including data from periods of time before or after the hospital stay. Furthermore, the user may choose to use only inpatient data or to also include outpatient data when applying CWDA to such a quality measure.

Section 9. Levels of Aggregation

CHIPRA states that data used in quality measures must be collected and reported in a standard format that permits comparison (at minimum) at State, health plan, and provider levels. Use the following table to provide information about this measure's use for reporting at the levels of aggregation in the table.

For the purpose of this section, please refer to the definitions for provider, practice site, medical group, and network in the Glossary of Terms.

If there is no information about whether the measure could be meaningfully reported at a specific level of aggregation, please write "Not available" in the text field before progressing to the next section.

Level of aggregation (Unit) for reporting on the quality of care for children covered by Medicaid/ CHIP†:

State level* Can compare States

Intended use: **Is measure intended to support meaningful comparisons at this level? (Yes/No)**
Yes.

Data Sources: **Are data sources available to support reporting at this level?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Not applicable.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Other geographic level: Can compare other geographic regions (e.g., MSA, HRR)

Intended use: **Is measure intended to support meaningful comparisons at this level? (Yes/No)**
Yes.

Data Sources: **Are data sources available to support reporting at this level?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Not applicable.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Medicaid or CHIP Payment model: Can compare payment models (e.g., managed care, primary care case management, FFS, and other models)

Intended use: **Is measure intended to support meaningful comparisons at this level? (Yes/No)**
Yes.

Data Sources: **Are data sources available to support reporting at this level?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Not applicable.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Health plan*: Can compare quality of care among health plans.

Intended use: **Is measure intended to support meaningful comparisons at this level? (Yes/No)**
Yes.

Data Sources: **Are data sources available to support reporting at this level?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Not applicable.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Provider Level
Individual practitioner: Can compare individual health care professionals

Intended use: **Is measure intended to support meaningful comparisons at this level? (Yes/No)**
Yes.

Data Sources: **Are data sources available to support reporting at this level?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Not applicable.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Provider Level
Hospital: Can compare hospitals

Intended use: **Is measure intended to support meaningful comparisons at this level? (Yes/No)**
Yes.

Data Sources: **Are data sources available to support reporting at this level?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Not applicable.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Provider Level
Practice, group, or facility:** Can compare: (i) practice sites; (ii) medical or other professional groups; or (iii) integrated or other delivery networks

Intended use: **Is measure intended to support meaningful comparisons at this level? (Yes/No)**
Yes.

Data Sources: **Are data sources available to support reporting at this level?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**

Not applicable.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Section 10. Understandability

CHIPRA states that the core set should allow purchasers, families, and health care providers to understand the quality of care for children. Please describe the usefulness of this measure toward achieving this goal. Describe efforts to assess the understandability of this measure (e.g., focus group testing with stakeholders).

CWDA will allow a variety of stakeholders—parents of CWD, health care providers, insurers, researchers and policymakers— to investigate, understand, and improve care quality for CWD for a broader range of quality measures and at a larger scale than was previously possible.

We have presented CWDA development and use to a variety of stakeholder groups. Parent members of the Family Advisory Council at Boston Children's Hospital understood the goal of CWDA, how it was developed, and how it may help them comprehend how care quality could differ for CWD versus non-CWD. Parents expressed interest in having usable quality data on CWD, especially if the data were presented in a user-friendly format with specific information to direct them to the best care for their child.

Multiple national multi-stakeholder groups, including the Center of Excellence for Pediatric Quality Measurement's (CEPQM) Scientific Advisory Board and National Stakeholder Panel, confirmed the benefits of bringing together extremely heterogeneous diagnoses into a cohesive, identifiable group for care quality assessment. They agreed that valuable applications for such a tool include stratification of data for CWD versus non-CWD comparisons using existing and new quality measures.

In addition, CWDA was reviewed by the Massachusetts Child Health Quality Coalition and the Pediatric Academic Society Complex Care Special Interest Group (local and national multi-stakeholder groups, respectively). Both groups found the CWDA development process understandable and were enthusiastic about the possibility of being able to stratify existing HEDIS and parent-survey-based quality measures by CWD status.

CWDA is grounded in the WHO disability concepts and definition (WHO, 2001; as described in the ICF; see Section 2 of this report), a framework that is easily accessible to individuals engaged in quality assessment, disabilities research, and policy analysis in the United States.

Section 11. Health Information Technology

Please respond to the following questions in terms of any health information technology (health IT) that has been or could be incorporated into the measure calculation.

11.A. Health IT Enhancement

Please describe how health IT may enhance the use of this measure.

Health IT systems potentially could expand the applications of CWDA by automating implementation of the algorithm to identify CWD for various purposes. For example, CWDA could be integrated into IT applications to measure health care quality for CWD or compare quality for CWD versus children without disabilities. As health IT adoption and functionality continue to advance, it likely will become increasingly feasible to incorporate CWDA into these and other activities.

11.B. Health IT Testing

Has the measure been tested as part of an electronic health record (EHR) or other health IT system?

No.

If so, in what health IT system was it tested and what were the results of testing?

Not applicable.

11.C. Health IT Workflow

Please describe how the information needed to calculate the measure may be captured as part of routine clinical or administrative workflow.

Most current health systems already use ICD-9-CM codes as part of routine clinical billing processes (Iezzoni, 2003b; O'Malley, et al., 2005).

11.D. Health IT Standards

Are the data elements in this measure supported explicitly by the Office of the National Coordinator for Health IT Standards and Certification criteria (see healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__standards_ifr/1195)?

Yes.

If yes, please describe.

Currently, the Office of the National Coordinator for Health It Standards and Certification (ONC) requires that EHR technologies be capable of using ICD-9-CM codes or SNOMED-CT terminology (ONC, 2010). Therefore, CWDA could be used in any EHR system that is certified by the ONC.

11.E. Health IT Calculation

Please assess the likelihood that missing or ambiguous information will lead to calculation errors.

It is possible that inaccurate or incomplete use of ICD-9-CM codes could lead to erroneous inclusion or exclusion of patients when using CWDA to identify CWD.

11.F. Health IT Other Functions

If the measure is implemented in an EHR or other health IT system, how might implementation of other health IT functions (e.g., computerized decision support systems in an EHR) enhance performance characteristics on the measure?

Computerized decision support systems that help users code diagnoses more accurately or completely would help increase the performance and sensitivity of CWDA. This could alleviate some of the limitations of relying on ICD-9-CM data.

Section 12. Limitations of the Measure

Describe any limitations of the measure related to the attributes included in this CPCF (i.e., availability of measure specifications, importance of the measure, evidence for the focus of the measure, scientific soundness of the measure, identification of disparities, feasibility, levels of aggregation, understandability, health information technology).

Limitations of ICD-9-CM Codes for Assessing Disability

The main limitation of using ICD-9-CM codes to assess disability is that the primary purpose of these codes is to bill for care according to diagnostic information, not to capture disability (Iezzoni, 2003b; O'Malley, et al, 2005). ICD-9-CM codes seldom describe patients' level of functioning, which is a key criterion in our code classification. To classify codes based on the expected functioning of children with each diagnosis, our pediatric disability experts had to draw upon their clinical and coding experiences, epidemiological studies, and subspecialist consultants' advice (see Section 6 of this report).

ICD-9-CM coding patterns can therefore affect the identification of CWD using CWDA in three key ways. CWDA may under-identify CWD because most health care encounters only require a single ICD-9-CM code to satisfy billing requirements, so practitioners sometimes code for the primary reason for a visit (e.g., fever) and omit underlying information that could provide insight into a child's level of functioning (e.g., intellectual disability) (Kronick, Gilmer, Dreyfus, et al., 2000; Perrin, Kuhlthau, McLaughlin, et al., 1999). CWDA may also over-identify CWD because codes have limited ability to allow practitioners to distinguish suspected conditions from

confirmed ones. Thus, practitioners may devote a visit to evaluating highly concerning conditions (e.g., traumatic brain injury) that subsequently may not be confirmed (De Coster, Li, Quan, 2008; Saligram, Lo, Saul, et al., 2012; Thigpen, Dillon Forster, et al., 2013; Van Walraven, Bennett, Forster, 2011). CWDA also may misidentify CWD if providers respond to reimbursement arrangements by "up-coding" (i.e., choosing the higher reimbursing codes among related diagnoses), even though slightly different diagnosis codes may be associated with very different functional ability (Iezzoni, 2003a; O'Malley, et al., 2005).

Despite the limitations of ICD-9-CM codes, they are ubiquitous in health care and routinely used for quality measurement and improvement (Goto, Ohl, Schweizer, et al., 2014; Iezzoni, 2003c; O'Malley, et al., 2005; Williams, Shah, Myers, et al., 2013). Furthermore, validation studies demonstrate that ICD-9-CM-based quality measurement can be as reliable as other sources of information (e.g., chart abstraction, laboratory confirmation) (Angier, Gold, Gallia, et al, 2014; Ramanathan, Leavell, Stockslager, et al., 2014; Reeves, Garcia, Kleyn, et al., 2014).

Limitations of the Algorithm

Our pediatric disability experts and subspecialist were instructed to consider impairment in four main domains: Mobility, Communication, Learning, and Self-Care. They were also directed to consider the degree to which particular diagnoses may lead to activity limitations in two main settings: (1) home (e.g., ability to meet age-appropriate expectations regarding feeding, bathing, and dressing oneself) and (2) school (e.g., ability to participate fully in academic, social, and physical aspects of school life). These domains of impairment and activity limitations were based on the ICF (WHO, 2001). We considered but ultimately excluded other domains of functioning (e.g., the ability to participate fully in extracurricular life or sexual relationships, be able to reproduce, or transition to adulthood).

Additional limitations arise from assumptions that we asked our pediatric disability experts and subspecialist consultants to make. We asked the classifiers to consider that the children: (a) live in an environment or setting that is average for the United States, (b) have families that possess a typical capacity for seeking care, (c) have average access to health care compared to other children in the United States, (d) receive treatment that is typically available today, and (e) experience a typical clinical course. Thus, the setting of use and pace of health care changes dictate the generalizability and validity of CWDA.

During the validation of CWDA, we compared the algorithm's performance with the parent's perspective through a survey and with the clinical perspective through chart abstraction. Future efforts should include the child's own perspective.

Section 13. Summary Statement

Provide a summary rationale for why the measure should be selected for use, taking into account a balance among desirable attributes and limitations of the measure. Highlight specific advantages that this measure has over alternative measures on the same topic that were considered by the measure developer or specific advantages that this measure has

over existing measures. If there is any information about this measure that is important for the review process but has not been addressed above, include it here.

The prevalence of children (ages 0-18 years) with disabilities (CWD) in the United States has increased from 2 percent to 8 percent over the past 50 years (Halfon, et al., 2012; Houtrow, et al., 2014; Newacheck, et al., 1986). CWD use more health care services and have higher health care expenditures than children without disabilities (Newacheck, et al., 2004; Perrin, 2012; Stabile, Allin, 2012). Societal costs of CWD also appear to be growing—Federal spending on children in the Supplemental Security Income (SSI) program, the main governmental program supporting CWD with low-income backgrounds, has increased by 55 percent over the past 13 years (Social Security Administration, 2000, 2013). Costs are also high for families of CWD; parents of CWD disproportionately leave or reduce their participation in the workforce (Breslau, et al., 1982; Chung, Garfield, Elliott, et al., 2013; Chung, Garfield, Elliott, et al., 2007; Porterfield, 2002; Schuster, Chung, Elliott, 2009; Stabile, Allin, 2012; Witt, et al., 2009) and experience greater levels of stress and poorer health compared to parents of children without disabilities (Halfon, et al., 2012; Hutchinson, et al., 2009; Lopez-Wagner, et al., 2008; Meltzer, 2008; Stabile, Allin, 2012; Witt, et al., 2009).

CWD may encounter multiple obstacles in the health care system, including lack of adequate primary and preventive services, barriers to subspecialty care, limited care coordination, and uneven research attention (Houtrow, et al., 2011; Liptak, et al., 2006; Megargel, Broder-Fingert, 2012; Perrin, 2002; Raddish, Goldmann, Kaplan, et al., 1993). Although problems are evident, research on care quality for CWD is largely anecdotal or observational and is often limited to specific disabling conditions. A major impediment to a more complete understanding of care quality for CWD has been the lack of a theoretically grounded, systematic, yet scalable and affordable method for identifying CWD using administrative claims data. As such, we created CWDA to identify CWD using ICD-9-CM codes. Most current health systems use ICD-9-CM codes as part of routine clinical billing processes (Iezzoni, 2003b; O'Malley, et al., 2005), thus making the use of CWDA highly feasible and widely applicable.

CWDA is based on the disability concepts and definitions articulated by the WHO in its 2001 ICF and the United Nations (UN, 2006, 1994; WHO, 2001). During the development of CWDA, over 40 experts were involved in an extensive process to classify each of the 14,567 ICD-9-CM codes based on their likelihood of indicating CWD. ICD-9-CM codes with a 75 percent or greater likelihood of indicating CWD were included in CWDA. Our three pediatric disability experts were health services research-trained general pediatricians who had at least 5 years of experience researching or clinically caring for CWD and additionally served on CWD-relevant national councils or chapters (e.g., American Academy of Pediatrics Council on Children with Disabilities).

We compared groups of children identified by CWDA to children identified as disabled through two alternative methods, a parent survey and a chart abstraction. CWDA had a sensitivity of 0.75 when compared to a survey question about whether the parent considered their child disabled and 0.98 when compared to physician assessment of disability status based on chart abstraction.

We anticipate that CWDA will vastly increase the rigor and ease with which stakeholders will be able to conduct quality assessment and subsequent quality improvement related to care for CWD.

CWDA will help researchers to expand current understanding of care quality for CWD, potentially revealing systemic issues and more generalizable solutions. Because CWDA allows users to stratify data by disability status, CWDA should also enable evaluations of whether CWD experience appropriate differences in care or are at risk for disparities in quality. Differences can then become the focus of investigations and interventions to improve health care quality for CWD.

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Section 14: Identifying Information for the Measure Submitter

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The CHIPRA Pediatric Quality Measures Program (PQMP) Candidate Measure Submission Form (CPCF) was approved by the Office of Management and Budget (OMB) in accordance with the Paperwork Reduction Act.

The OMB Control Number is 0935-0205 and the Expiration Date is December 31, 2015.

Public Disclosure Requirements

Each submission must include a written statement agreeing that, should U.S. Department of Health and Human Services accept the measure for the 2014 and/or 2015 Improved Core Measure Sets, full measure specifications for the accepted measure will be subject to public disclosure (e.g., on the Agency for Healthcare Research and Quality [AHRQ] and/or Centers for Medicare & Medicaid Services [CMS] websites), except that potential measure users will not be permitted to use the measure for commercial use. In addition, AHRQ expects that measures and full measure specifications will be made reasonably available to all interested parties. "Full measure specifications" is defined as all information that any potential measure implementer will need to use and analyze the measure, including use and analysis within an electronic health record or other health information technology. As used herein, "commercial use" refers to any sale, license or distribution of a measure for commercial gain, or incorporation of a measure into any product or service that is sold, licensed or distributed for commercial gain, even if there is no actual charge for inclusion of the measure. This statement must be signed by an individual authorized to act for any holder of copyright on each submitted measure or instrument. The authority of the signatory to provide such authorization should be described in the letter.

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