Development of the Children With Disabilities Algorithm

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Abstract

BACKGROUND: A major impediment to understanding quality of care for children with disabilities (CWD) is the lack of a method for identifying this group in claims databases. We developed the CWD algorithm (CWDA), which uses International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes to identify CWD.

METHODS: We conducted a cross-sectional study that (1) ensured each of the 14,567 codes within the 2012 ICD-9-CM codebook was independently classified by 3 to 9 pediatricians based on the code’s likelihood of indicating CWD and (2) triangulated the resulting CWDA against parent and physician assessment of children’s disability status by using survey and chart abstraction, respectively. Eight fellowship-trained general pediatricians and 42 subspecialists from across the United States participated in the code classification. Parents of 128 children from a large, free-standing children’s hospital participated in the parent survey; charts of 336 children from the same hospital were included in the abstraction study.

RESULTS: CWDA contains 669 ICD-9-CM codes classified as having a ≥75% likelihood of indicating CWD. Examples include 318.2 Profound intellectual disabilities and 780.72 Functional quadriplegia. CWDA sensitivity was 0.75 (95% confidence interval 0.63–0.84) compared with parent report and 0.98 (0.95–0.99) compared with physician assessment; its specificity was 0.86 (0.72–0.95) and 0.50 (0.41–0.59), respectively.

CONCLUSIONS: ICD-9-CM codes can be classified by their likelihood of indicating CWD. CWDA triangulates well with parent report and physician assessment of child disability status. CWDA is a new tool that can be used to assess care quality for CWD.

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Dr Chien obtained funding; conceived and designed the study; acquired, analyzed, and interpreted the data; and drafted and critically reviewed the manuscript; Dr Kuhlthau conceived and designed the study, analyzed and interpreted the data, and critically reviewed the manuscript; Dr Toomey obtained funding; conceived and designed the study; contributed to the acquisition, analysis, and interpretation of the data; and critically reviewed the manuscript; Ms Quinn contributed to the acquisition, analysis, and interpretation of data and critically reviewed the manuscript; Drs Houtrow, Kuo, Okumura, and Van Cleave contributed to the acquisition and interpretation of data and critically reviewed the manuscript; Mses Johnson, Mahoney, and Martin contributed to the acquisition and analysis of data; Dr Landrum provided statistical support to the study design, contributed to the analysis and interpretation of data, and critically reviewed the manuscript; and Dr Schuster obtained funding; conceived and designed the study; contributed to the acquisition, analysis, and interpretation of the data; critically reviewed the manuscript; and provided overall supervision.

WHAT’S KNOWN ON THIS SUBJECT: There are no validated claims-based algorithms for identifying children with disabilities (CWD) to facilitate larger-scale studies of care quality for CWD.

WHAT THIS STUDY ADDS: This study develops the CWD algorithm, a claims-based algorithm for identifying diagnostic codes with a ≥75% chance of indicating CWD, and triangulates the algorithm against parent report and physician chart abstraction.
Little is known about health care quality that children with disabilities (CWD) receive. Most of what is known comes from pediatric case reports,1,2 studies of adults with disabilities,3,4 and descriptions of severely affected children with special health care needs (CSHCN).5,6 A first step toward being able to rigorously assess care quality for CWD is to be able to identify CWD in claims data and to examine care quality for CWD using existing claims-based measures of pediatric care quality (eg, well-visit rates, receipt of recommended screenings). This and the ability to compare care quality for CWD against that for non-CWD would allow physicians, practices, and insurers to better design or target interventions to improve the care of CWD. A claims-based algorithm identifying CWD would allow stakeholders to assess the relative prevalence of CWD across health care systems and to describe the degree to which CWD are reaching the “equalization of opportunity” goals set forth by the United Nations (UN), which directs nations to address whether “persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.”

Disability concepts and definitions have evolved significantly over the past half century, with disabilities being defined as an interaction between persons and their environments as opposed to an inherent feature of individuals.7,8 As detailed in the 2001 International Classification of Functioning, Disability, and Health (ICF)7 and the 2006 UN Convention on the Rights of Persons with Disabilities,8 “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.”

The prevalence of CWD (0- to 18-year-olds) in the United States has increased from 2% to 8% over the past 50 years.9-11 Many ascribe the rise in CWD prevalence to the rise in mental health–related disabilities and significant functional problems (eg, feeding impairment, learning difficulties) among those surviving with conditions previously considered untreatable (eg, extreme prematurity, congenital heart disease, HIV).9,12-14 Societal costs of CWD appear to be growing: federal spending on children in the Supplemental Security Income program, the main governmental program supporting CWD with low-income backgrounds, has increased by 55% over the past 13 years.15,16 Furthermore, CWD may use health care up to 8 times more frequently than their counterparts without disabilities.17

The 2009 Children’s Health Insurance Program Reauthorization Act has created an unprecedented opportunity to address the long-standing gap in our understanding of care quality for CWD.18 The Children’s Health Insurance Program Reauthorization Act required the Agency for Healthcare Research and Quality and the Centers for Medicare and Medicaid Services to establish the Pediatric Quality Measures Program; the Center of Excellence for Pediatric Quality Measurement at Boston Children’s Hospital was assigned to address care quality for CWD and developed the CWD algorithm (CWDA) so that the proliferating number of available claims-based measures could be applied to the study of care quality for CWD.

CWD are a distinct subset of children7-11 with long-term functional impairments stemming from a wide range of clinical diagnoses (eg, severe burns, gastrostomy dependence). CWD have specific needs within the health care system, but the quality of the care that is being delivered to this population is poorly understood. Existing algorithms based on

International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes have allowed for refined assessment of quality for specific subsets of the pediatric population, but do not specifically identify CWD.19 Studies using other algorithms have provided important insight into aspects of pediatric care quality, such as access to palliative care, so we anticipate that an algorithm aimed at identifying CWD would similarly highlight the particular health care needs of CWD.19-24

Thus, the main objectives of this study were to (1) create CWDA using pediatric disability experts to classify ICD-9-CM codes according to their likelihood of indicating CWD, and (2) triangulate CWDA with the parent perspective of disability and physician assessment of patient charts. The goal of CWDA is to identify a population of children with a high likelihood of having a disability based on their diagnoses found in claims data.

**METHODS**

**Disability Concepts and Definitions**

We based all aspects of CWDA development on the disability concepts and definitions detailed by the World Health Organization (WHO) ICF and the UN.7,8 We continually and consistently referenced these concepts and definitions with our code classification participants and chart abstractors and when selecting existing survey items to assess parents’ perspective on their child’s disability status.

**Study Design**

In the first phase of CWDA development, we used consensus methods developed by Glaser26 and 4 steps to ensure that each of the 14 567 codes within the 2012 ICD-9-CM codebook was independently reviewed by 3 to 9 pediatricians (average of 4) and ultimately thought to have ≥75% likelihood of indicating
CWD. In the second phase, we triangulated CWDA’s identification of CWD against whether children were considered to have a disability according to (1) parents via a parent survey, and (2) physicians via patient chart abstraction. We included parents because they have intimate knowledge of their child’s functioning in nonclinical settings; we gathered physician assessments because physicians care for children with a wide range of impairments and are able to make comparative assessments of functional ability. The study was reviewed and approved by the Boston Children’s Hospital Institutional Review Board.

**Code Classification**

The 4-step code classification process began with all 14,567 codes in the 2012 ICD-9-CM Codebook (Fig 1).

In Step 1 (the Pre-sort), the goal was to reduce the volume of codes for detailed review by removing those that were very unlikely to indicate CWD (nonetheless, these codes were reviewed a second time as described later in this article). We used existing ICD-9-CM algorithms for CSHCN and complex chronic conditions to designate 2738 codes as having a $\geq 10\%$ likelihood of indicating CWD.20,21 We then used 2 fellowship-trained general pediatricians with $>10$ years of clinical experience caring for CSHCN to independently review the remaining codes to determine if they met the $\geq 10\%$ threshold. If these 2 reviewers disagreed, then 3 additional general pediatricians (also with advanced training) resolved the disagreement. These reviewers designated an additional 1226 codes as having a $\geq 10\%$ likelihood of indicating CWD. During this step, we also excluded codes that were inapplicable to the pediatric population ($n = 56$; eg, senile dementia) or could not be used for primary diagnoses ($n = 1291$; ie, E-codes).

In Steps 2 and 4 (the Initial and Final Disability Expert Review, respectively), 3 pediatric disability experts independently reviewed the 3964 codes identified in Step 1 as having $\geq 10\%$ likelihood of indicating CWD and further classified them according to whether the code had a $<10\%$, $\geq 10$ to $<75\%$, or $\geq 75\%$ likelihood of indicating CWD.

Pediatric disability experts were also fellowship-trained, had at least 5 years of experience studying or caring for CWD, and had served on CWD-relevant national councils or chapters (eg, the American Academy of Pediatrics Council on Children with Disabilities). In Step 3 (the Subspecialist Review), we obtained input from relevant pediatric subspecialists (eg, 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, neurologist, and rehabilitation physician). The subspecialists reviewed all codes related to their field, including those originally classified as $<10\%$ in Step 1.

In Step 4 (the Final Disability Expert Review), the 3 pediatric disability experts from Step 2 incorporated the subspecialists’ input into their final classification decisions. Ultimately, codes identified as having a $\geq 75\%$ likelihood of indicating CWD were included in CWDA. A total of 8 general pediatricians and 42 pediatric subspecialists participated in the 4-step
We obtained physician assessment of disability status through chart abstraction. We developed a novel chart abstraction tool explicitly for this purpose. 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 (eg, 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?”

Two general pediatricians served as chart abstractors and underwent a day-long, in-person training on disability concepts and the abstraction tool and then abstracted the charts of 336 patients (268 CWD, 68 non-CWD). During the abstraction process, we blinded abstractors to each patient’s CWDA status. We double-abstracted 10% of charts for quality assurance, calculating both inter- and intrarater reliabilities on a weekly basis. The interrater 2-way $\kappa$ was 0.62 (“substantial”); intrarater 2-way $\kappa$ was 0.46 for 1 reviewer and 0.69 for the other (“moderate” and “substantial,” respectively). All disagreements were discussed and reconciled between the 2 abstractors.

Physician abstractors assessed the charts of children who had $\geq$2 encounters anywhere within a large, free-standing children’s hospital (inpatient, outpatient, primary care, and specialty). Between October and December 2013, physicians abstracted the charts of randomly chosen patients with an index visit

Triangulation

Parent Perspective

We gathered the parent perspective on their child’s disability status via survey. We assembled our parent survey questions from 3 previously used parent-report instruments that have been used to establish CWD prevalence in previous national surveys: (1) the Washington Group on Disability Statistics’ Module on Child Functioning and Disability, (2) the 2011 National Health Interview Survey (NHIS) Questionnaire, and (3) the 1995 NHIS Disability Supplement. The Washington Group on Disability Statistics’ questions gather information on the presence and severity of functional impairments in 12 domains (eg, hearing, seeing, walking) and vary by age-appropriate expectations. The survey also asks parents to reflect on functional ability over the previous year and ends with a single item adapted from the NHIS, “Do you consider your child to have a disability?” The parent survey included 34 items in total and was provided in English or Spanish.

We surveyed parents of children actively receiving primary care at a large, free-standing children’s hospital at the beginning of 2014 (February–April). We defined active as having $\geq$2 encounters at the clinic in the 2 years before the survey and 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 designated children as CWD if they had $\geq$1 CWDA code initially in 2012 (because 2013 information was not available at the time of sampling). We oversampled for parents of CWD versus non-CWD and attempted to survey the parent of every CWD 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 e-mail, phone, and conference calls. Reinforcement generally occurred at weekly to biweekly intervals throughout the code classification process. All disagreements were reconciled by discussion or majority vote.

code classification process. We resolved disagreements through consensus.

We drew pediatric disability experts and specialists from across the United States. We also conducted literature reviews on $>500$ conditions to find empirical data to support or clarify classification decisions. We trained all those involved in the code classification process in the WHO and UN concepts and definitions of disability, to apply age-appropriate expectations with respect to functional ability, to gauge whether the disability would be present for at least 12 months (to meet the “long-term” requirement within current definitions of disability), and to think at the population level (ie, to estimate how many of 100 children with the diagnosis code of interest they would consider as having a disability. 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 who possessed a typical capacity for seeking and accessing health care, received treatment that was typically available, and experienced a typical clinical course. 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 e-mail, phone, and conference calls. Reinforcement generally occurred at weekly to biweekly intervals throughout the code classification process. All disagreements were reconciled by discussion or majority vote.

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between July 2011 and June 2012 and abstracted all encounters between the index visit and the 12 months following. We oversampled for CWD, designating children as CWD if they had ≥1 CWDA code in the target abstraction period.

Analysis
For the code classification process, we assessed inter- and multirater reliabilities of the dichotomous classification of codes, <75% or ≥75% likelihood of indicating CWD, by using 3 methods: (1) percent agreement, (2) Cohen 2-way $\kappa$, and (3) Fleiss multirater $\kappa$ then proceeded with consensus discussions.

Because the goal of CWDA is to enable the differentiation of pediatric populations into those with ≥75% likelihood of indicating CWD and those without, we focused on assessing the sensitivity of CWDA (ie, the likelihood that CWDA would be positive when compared with parent report or physician abstraction). A priori, we expect small amounts of misclassification; however, this level of misclassification would not impede comparative studies of CWD versus non-CWD. For informational purposes, we also include the specificity of CWDA, even though the algorithm is not designed to indicate the absence of disabilities.

RESULTS
Code Classification
The code classification process identified 669 codes with a ≥75% likelihood of indicating CWD (see Table 1 for examples, and the Supplemental Appendix for the full list of codes). The percent agreement between any 2 code classifiers was 90% to 91%, which falls into the "nearly always acceptable" range.33 The Cohen $\kappa$ statistic was 0.60 to 0.68 and the Fleiss multirater $\kappa$ was 0.64, both of which fall into the "substantial" agreement range.30

TABLE 1 Example ICD-9-CM Codes in CWDA

<table>
<thead>
<tr>
<th>Non-CWDA &lt;75% Likelihood of Indicating CWD</th>
<th>CWDA ≥75% Likelihood of Indicating CWD</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of codes (%)a</td>
<td>12551 (95.0)</td>
</tr>
<tr>
<td>Examples of codes</td>
<td>250.0 Diabetes mellitus without mention of complication</td>
</tr>
<tr>
<td></td>
<td>277.0 Cystic fibrosis</td>
</tr>
<tr>
<td></td>
<td>296.5 Bipolar I disorder</td>
</tr>
<tr>
<td></td>
<td>314.0 Attention deficit disorder</td>
</tr>
<tr>
<td></td>
<td>495.2 Chronic obstructive asthma</td>
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</table>

Please see the appendix for the full list of CWDA codes. a Of 13 220 applicable codes in the ICD-9-CM Codebook.

Triangulation
Parent Perspective
The parent survey response rate was 61% ($n = 128$). The sensitivity of CWDA when compared with the parent perspective was 0.75 (95% confidence interval [CI] 0.63–0.84) and the specificity was 0.86 (95% CI 0.72–0.95) (Table 2).

Physician Assessment of Patient Charts
We abstracted 336 patient charts. The sensitivity of CWDA when compared with physicians on chart abstraction was 0.98 (95% CI 0.95–0.99) and the specificity was 0.50 (95% CI 0.41–0.59) (Table 3).

DISCUSSION
CWDA is a new algorithm that enables provider networks, health care delivery systems, health plans, hospitals, and state Medicaid offices to assess the quality of care being delivered to CWD. It also enables stratification of claims-based data by CWD versus non-CWD. CWD are a distinct subset of children7–11 with long-term functional impairments who have specific needs within the health care system and for whom no ICD-9-CM–based algorithm exists. CWDA contains a set of 669 ICD-9-CM codes with a ≥75% likelihood of indicating CWD. CWDA is different from other ICD-9-CM–based algorithms designed to identify vulnerable subpopulations of children. CWDA (1) includes diagnoses related to intellectual and emotional conditions with a high likelihood of functional impairment (eg, schizophrenia); (2) excludes chronic conditions with a low likelihood of long-term functional impairment (eg, allergic rhinitis); (3) includes life-threatening conditions with a long-term clinical trajectory (eg, end-stage renal disease) but excludes those with a short-term trajectory (eg, sepsis); and (4) identifies children irrespective of the number of organ systems that might be involved.20–22

Of note, sensitivity of CWDA was 0.75 (95% CI 0.63–0.84) compared with parent report and 0.98 (95% CI 0.95–0.99) compared with physician assessment. We hypothesize that CWDA sensitivity relative to parent report may be lower than that for physician assessment because parents respond according to their own definitions of disability, rather than the WHO/UN concepts and definitions used for CWDA development. Both

TABLE 2 Phase 2 of CWDA Development: Triangulation: CWDA Compared With Parent Survey

| Phase 2 of CWDA Development: Triangulation: CWDA Compared With Parent Survey |
|---|---|---|
| | n = 114 | |
| | Disability | Parent Survey a |
| | CWDA | 53 | 6 |
| | No disability | 18 | 37 |
| | Sensitivity (95% CI) | 0.75 (0.63–0.84) | NA |
| | Specificity (95% CI) | 0.86 (0.72–0.95) | NA |

a Parent response to National Health Interview Survey question “Do you consider your child to have a disability?” NA, not applicable.
code classifiers and chart abstractors were physicians trained on the WHO/UN definition. Although chart abstractors were blinded to CWDA status, the common training may have made it much easier for the sensitivity between physician assessment of patient charts and CWDA to be extremely high.

Although CWDA was not designed to identify the absence of disabilities, the specificity of CWDA could be quite high in a population oversampled for CWD. A high specificity would suggest that the absence of a CWDA-qualifying diagnosis might also be aligned with parent report and physician assessment of the absence of disabilities.

CWDA has some limitations. Like all ICD-9-CM-based algorithms, CWDA is based on diagnostic codes and administrative data, so misclassification (eg, due to miscoding) can occur. Another concern is the upcoming implementation of the International Classification of Diseases, 10th Revision (ICD-10), which has 5 times as many codes as ICD-9-CM. We anticipate the development of numerous ICD-9-CM to ICD-10 "crosswalk" resources, which may extend the applicability of the current version of CWDA.44,45 In addition, the methods that we used to develop CWDA form a solid foundation on which an ICD-10 version could be created.

CWDA benefits from our drawing the pediatric disability experts from across the United States, training them to apply population logic based on their understanding of diagnosing and coding practices across the country, and using empirical data to support classification decisions. CWDA also benefits from having been triangulated against both parent and physician assessments of children, although future validation studies would benefit from samples that may be more representative of the US pediatric population as a whole.

CONCLUSIONS

CWDA is a theoretically grounded method for identifying CWD using ICD-9-CM codes that has been triangulated against parent report and physician chart abstraction. By using CWDA, stakeholders can explore health care quality for CWD, which is likely robust in some respects (eg, whether they receive the recommended number of well-child visits in a year),19 yet inadequate in others (eg, whether their sexual health needs are being addressed).4,36 If CWDA is used to examine whether CWD and non-CWD groups receive or experience differential care quality, noted differences can become the focus of investigations and interventions.

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We thank the staff of the Center of Excellence for Pediatric Quality Measurement (CEPQM) at Boston Children's Hospital and Boston Children's Primary Care at Longwood. We thank the members of the Boston Children's Hospital Family Advisory Council, Massachusetts Child Health Quality Coalition, Academic Pediatric Association’s Complex Care Special Interest Group, and CEPQM’s Scientific Advisory Board and National Stakeholder Panel. We thank the participants in our parent survey and code classification process and all the others who contributed to the development and testing of CWDA.

TABLE 3 Phase 2 of CWDA Development: Triangulation: CWDA Compared With Physician Chart Abstraction

<table>
<thead>
<tr>
<th>CWDA</th>
<th>Physician Chart Abstraction#</th>
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<tbody>
<tr>
<td>Disability</td>
<td>204</td>
</tr>
<tr>
<td>No disability</td>
<td>64</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>0.98 (0.95–0.99)</td>
</tr>
<tr>
<td>Specificity</td>
<td>NA</td>
</tr>
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</table>

NA, not applicable.

# Chart abstractor response to “Do you consider this child to have at least one disability for the full duration of the target abstraction period?”

Abbreviations

CI: confidence interval
CSHCN: children with special health care needs
CWD: children with disabilities
CWDA: children with disabilities algorithm
ICD-9-CM: International Classification of Diseases, Ninth Revision, Clinical Modification
ICD-10: International Classification of Diseases, Tenth Revision
ICF: International Classification of Functioning, Disability, and Health
NHIS: National Health Interview Survey
non-CWD: children without disabilities
UN: United Nations
WHO: World Health Organization
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<td>References</td>
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