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International consensus on standard outcome measures for neurodevelopmental disorders : A consensus statement

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Authors	Mulraney, Melissa;De Silva, Umanga;Joseph, Andria;Sousa Fialho, Maria Da Luz;Dutia, Iain;Munro, Natalie;Payne, Jonathan M.;Banaschewski, Tobias;de Lima, Cláudia Bandeira;Bellgrove, Mark A.;Chamberlain, Samuel R.;Chan, Phyllis;Chong, Ivy;Clink, Alison;Cortese, Samuele;Daly, Eileen;Faraone, Stephen V.;Gladstone, Melissa;Guastella, Adam J.;Järvdike, Juulia;Kaleem, Sidra;Lovell, Mark G.;Meller, Tamasin;Nagy, Peter;Newcorn, Jeffrey H.;Polanczyk, Guilherme V.;Simonoff, Emily;Szatmari, Peter;Tehan, Caroline;Walsh, Karin;Wamithi, Susan;Coghill, David
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Consensus Statement | Pediatrics

International Consensus on Standard Outcome Measures for Neurodevelopmental Disorders
A Consensus Statement

Melissa Mulraney, PhD; Umanga de Silva, MSc; Andria Joseph, MSc; Maria da Luz Sousa Fialho, PhD; Iain Dutia, PhD; Natalie Munro, PhD; Jonathan M. Payne, DPsych; Tobias Banaschewski, MD, PhD; Cláudia Bandeira de Lima, PhD; Mark A. Bellgrove, PhD; Samuel R. Chamberlain, MB/BChir, PhD; Phyllis Chan, MBBS; Ivy Chong, PhD, BCBA-D, MBA; Alison Clink; Samuele Cortese, MD, PhD; Eileen Daly, PhD; Stephen V. Faraone, PhD; Melissa Gladstone, MB, ChB, MD; Adam J. Guastella, PhD; Juulia Järvdike, MSc; Sidra Kaleem, MBBS; Mark G. Lovell, MBChB; Tamasin Meller, MBBS, MPH, BMus; Peter Nagy, MD; Jeffrey H. Newcorn, MD; Guilherme V. Polanczyk, MD, PhD; Emily Simonoff, MD; Peter Szatmari, MD; Caroline Tehan; Karin Walsh, PsyD; Susan Wamithi, MD, MMed; David Coghill, MB, ChB, MD

Abstract

IMPORTANCE The use of evidence-based standardized outcome measures is increasingly recognized as key to guiding clinical decision-making in mental health. Implementation of these measures into clinical practice has been hampered by lack of clarity on what to measure and how to do this in a reliable and standardized way.

OBJECTIVE To develop a core set of outcome measures for specific neurodevelopmental disorders (NDDs), such as attention-deficit/hyperactivity disorder (ADHD), communication disorders, specific learning disorders, and motor disorders, that may be used across a range of geographic and cultural settings.

EVIDENCE REVIEW An international working group composed of clinical and research experts and service users (n = 27) was convened to develop a standard core set of accessible, valid, and reliable outcome measures for children and adolescents with NDDs. The working group participated in 9 video conference calls and 8 surveys between March 1, 2021, and June 30, 2022. A modified Delphi approach defined the scope, outcomes, included measures, case-mix variables, and measurement time points. After development, the NDD set was distributed to professionals and service users for open review, feedback, and external validation.

FINDINGS The final set recommends measuring 12 outcomes across 3 key domains: (1) core symptoms related to the diagnosis; (2) impact, functioning, and quality of life; and (3) common coexisting problems. The following 14 measures should be administered at least every 6 months to monitor these outcomes: ADHD Rating Scale 5, Vanderbilt ADHD Diagnostic Rating Scale, or Swanson, Nolan, and Pelham Rating Scale IV; Affective Reactivity Index; Children's Communication Checklist 2; Colorado Learning Disabilities Questionnaire; Children's Sleep Habits Questionnaire; Developmental-Disability Children's Global Assessment Scale; Developmental Coordination Disorder Questionnaire; Family Strain Index; Intelligibility in Context Scale; Vineland Adaptive Behavior Scale or Repetitive Behavior Scale–Revised and Social Responsiveness Scale; Revised Child Anxiety and Depression Scales; and Yale Global Tic Severity Scale. The external review survey was completed by 32 professionals and 40 service users. The NDD set items were endorsed by more than 70% of professionals and service users in the open review survey.

CONCLUSIONS AND RELEVANCE The NDD set covers outcomes of most concern to patients and caregivers. Use of the NDD set has the potential to improve clinical practice and research.

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Introduction

Neurodevelopmental disorders (NDDs) are a group of conditions characterized by early-onset symptoms that cause impairments across multiple domains of functioning.[1] This work focused on 4 of the 6 *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition)[1] categories of NDDs: communication disorders (language disorder, speech sound disorder, childhood-onset fluency disorder, and social [pragmatic] communication disorder), attention-deficit/hyperactivity disorder (ADHD), specific learning disorders (SLDs), and motor disorders (developmental coordination disorder, stereotypic movement disorder, Tourette disorder, and persistent [chronic] motor or vocal tic disorder). These NDDs often co-occur (eg, 25%-48% of children with ADHD have a comorbid SLD[2]) and are highly comorbid with other mental health or physical disorders (eg, 92% of adolescents with ADHD have experienced at least 1 coexisting mental health disorder).[3] Given these high rates of co-occurrence, it is important to work transdiagnostically in the NDD field.

Collectively, NDDs are the most prevalent mental health or behavioral disorders of childhood[4] and have a significant economic impact.[5] The bulk of the economic costs are not borne by the health care system but instead are associated with increased well-being costs and lost productivity.[6] Because there are effective treatments for NDDs,[7,8] these impacts and costs likely reflect that many children are not receiving treatment and that for those who are, treatments are not optimally managed, with corresponding impacts on long-term functioning and well-being.[7,9,10]

Measurement-based care (MBC) is the use of routine and systematic outcome measurements before and during treatment appointments to guide clinical decision-making at the individual patient level.[11] Although MBC is used routinely in the management of many physical health problems (eg, glycated hemoglobin in diabetes), its use in mental health and neurodevelopmental settings is less well established[12] but has some support in ADHD.[13,14] Although the National Institute for Health and Care Excellence guidelines for ADHD[15] recommend ongoing monitoring of treatment for ADHD, there is limited guidance as to how to measure clinical response and which measures to use, and the use of MBC in neurodevelopmental settings remains limited.[12] Several factors may contribute to the low uptake of MBC within these settings. Outcome measures may be considered time-consuming to use, with clinicians feeling that they do not have adequate resources to administer, score, and interpret these in a busy clinical setting or the knowledge about how to translate the scores into clinical decisions. Furthermore, many measures are available with little advice or agreement as to which should be used and how often they should be administered.

The International Consortium for Health Outcome Measurement (ICHOM) seeks to address these issues through the creation of core sets of patient-centered outcome measures (sets) for a broad range of health conditions,[16] including, more recently, a focus on mental health conditions.[17,18] The ICHOM sets prioritize patient-reported outcome measures (PROMs), which reflect those outcomes seen as most important by clinicians, research experts, and service users. Sets represent the principles of value-based health care, where value is defined as the health outcomes achieved relative to the resources invested, rather than the volume of services delivered.[16] In 2021, the ICHOM established an international working group comprising service user representatives, clinicians, and researchers with expertise in NDDs, with the aim of developing an NDD set. The working group chose to focus on 4 of the 6 *DSM-5* categories of NDDS, excluding autism spectrum disorder (ASD) and intellectual disability (ID) (see Results for explanation). The working group followed the ICHOM principles that focus on measures that track outcomes over time rather than diagnosis or screening. The working group recognizes that the gold standard for assessment of many NDDs involves administration of measures that objectively assess and differentiate a person's performance against normative data. However, these measures are not usually designed to measure change, and many also do not meet the ICHOM preference for PROMs and measures with minimal administrative burden and cost.

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Methods

The standard ICHOM methods for developing sets was followed as per previously published sets[17-19] and are reported in accordance with Standards for Quality Improvement Reporting Excellence (SQUIRE) reporting guidelines.[20] The methods included a combination of research data through systematic literature searches, expert opinion, and lived experience, with decision-making through a combination of working group discussion and modified Delphi surveys. After development, the NDD set was distributed to professionals and service users for open review, feedback, and external validation.

Working Group

The ICHOM sought to recruit a clinically and geographically diverse expert group with a maximum of 30 members who could provide expertise on the 4 disorders included within the scope of the NDD set. Professional working group members were chosen to represent disciplines such as public health, pediatrics, psychology, psychiatry, and psychometrics. Patient representatives were identified through their involvement in public speaking and initiatives on a national level, and professional working group members were identified by the relevance of their online work to this project (eg, journal articles and international conferences) and through recommendations by the working group chair (D.C.). All potential members were invited by an ICHOM project manager (A.J.) to participate in this project. The working group comprised 27 experts and service users from 12 countries. A core project team (M.M., U.d.S., and A.J.) coordinated and facilitated the program of work and undertook the supporting research but did not vote on the modified Delphi surveys. The chair (D.C.) did not routinely vote but could cast the deciding vote on split decisions.

Decision-Making Process

The working group participated in 9 video conference calls and 8 surveys between March 1, 2021, and June 30, 2022. During calls, the working group discussed the results of research presented by the project team. A modified Delphi process was undertaken to make decisions regarding the scope of the set, outcomes and their measurement, and selection of case-mix variables and time points for measurement. Case-mix variables are measured to build risk-adjustment models to ensure fair comparisons are made of outcomes collected across health care professionals when benchmarking. Each decision regarding scope, outcomes, and measurement went through up to 3 rounds of the modified Delphi survey (see eAppendix 1 in Supplement 1 for details).

Selection of Scope, Outcome Domains, Measures, and Case-Mix Variables

Scope | Initially, working group members were asked to define the scope of the NDD set regarding the NDDs included, the age range covered, included treatments, and settings. The NDDs to be selected were based on expert input from the project team and chair and suggestions from the working group during the first call.

Clinical Outcomes | Potential clinical outcomes were identified through a systematic literature search, supplemented by a search of clinical trial registries, clinical guidelines, and input from service users. As per the standard ICHOM criteria, the outcomes needed to represent the result of care, not screening or diagnosis; be important to people with NDDs; be feasible to capture; and be modifiable (**Figure 1**; see eTable 1 in Supplement 1 for search details).

Outcome Tools | A second systematic search was conducted in PubMed in October 2021 for each of the included outcomes using the Terwee filter[19] to identify potential outcome measures (eTable 2 in Supplement 1). This search was supplemented by recommendations for tools from working group members during the surveys. The project team identified and compiled information regarding the psychometric properties (reliability, validity, and sensitivity to change), feasibility and acceptability

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(administrative burden, cost, and translation into >1 language), and relevance of the identified measures and shortlisted the tools that best met the criteria. The shortlisted tools were discussed by the working group and the final measures chosen through consensus on the modified Delphi surveys (eTable 3 in Supplement 1 contains information on the psychometric properties of tools).

The project team compiled a list of possible case-mix variables based on relevant articles identified in the search for outcome measures and existing ICHOM sets, including evidence describing the impact of each case-mix variable on the outcomes. The project team also prepared an initial proposal for measurement time points based on existing ICHOM sets and expert knowledge. The final case-mix variables and time points were selected through consensus on the modified Delphi surveys.

Open Review

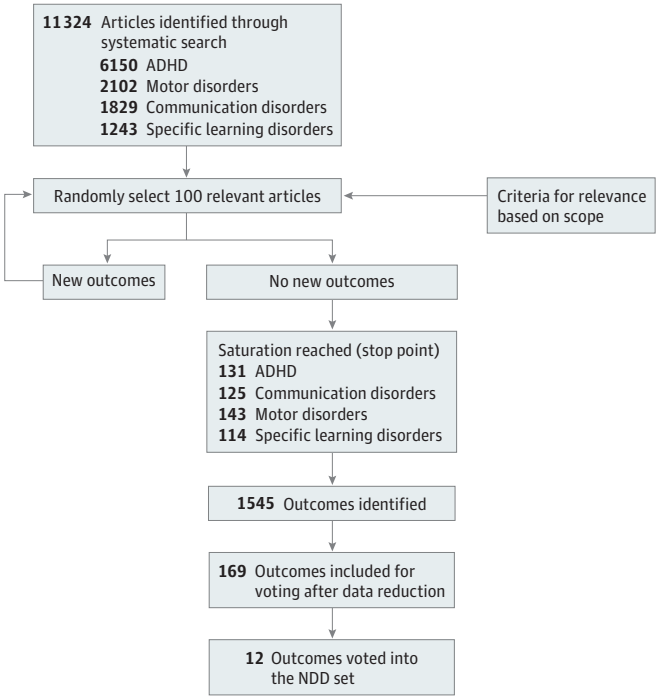
After development, the NDD set was distributed to professionals and service users who were not part of the working group for feedback and external validation. These surveys were determined to be quality improvement and thus exempt from requiring ethical board approval according to the Health Research Authority (UK), The North Star Review Board (US), and the Institute for Evidence Based Healthcare (Portugal). Professionals were invited to provide feedback on the recommended outcomes, outcome measures, reporting sources, and time points for data collection. People 18 years or older with lived experience of an NDD and parents or caregivers of children or adolescents with NDDs were invited to provide feedback on the outcomes in the NDD set (see eAppendixes 1 and 2 in Supplement 1 for details). Consent was implied through completion of the survey.

Results

Scope

The NDDs were defined according to the *DSM-5* categories: communication disorders, ADHD, specific learning disorder, and motor disorders. Although the working group agreed that an ideal

Figure 1. Outcome Extraction and Selection Process



ADHD indicates attention-deficit/hyperactivity disorder; NDD, neurodevelopmental disorder.

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NDD set of outcome measures should include ASD, a separate ICHOM set had already been developed specific to ASD,[19] and it was agreed not to duplicate that work. The working group also voted to exclude ID based on the understanding that the goal of the project was to develop a standard minimum set of PROMs reflecting treatment outcomes, and intellectual abilities are not usually a focus of treatment interventions and are not well measured through PROMs. Furthermore, working group members with expertise in ID argued that ID should have its own set created by a working group with different expertise. All treatment approaches and modalities were considered in scope when reviewing the literature. The working group decided that the age range for the NDD set should be 3 to 20 years. Expert advice from working group members indicated that although many outcome measures would not be validated for the entire age range, most could be used with caution in preschool children and in those aged 18 to 20 years. However, because many of the relevant outcomes change on transition from adolescence to adulthood, the working group limited the scope to clients younger than 20 years. A strong recommendation was made that the ICHOM develop a separate set for adults with NDDs. Children younger than 3 years were excluded because diagnosis of NDDs is less reliable and less stable in this age group.

Outcome Domains and Measures

Twelve clinical outcomes were ultimately included in the NDD set spread across 3 outcome domains: (1) core symptoms related to the diagnosis; (2) impact, functioning, and quality of life (QOL); and (3) common coexisting problems (**Table 1**). As outlined in **Table 2**, 14 tools were selected to measure these outcomes. The estimated completion time of the full NDD set is 1.5 to 2 hours; thus, it may be prudent to have the initial PROMs completed before clinic attendance.

Core Symptoms Related to the Diagnosis

Attention-Deficit/Hyperactivity Disorder | The set recommends measuring ADHD symptoms using the 18-item versions of 1 of the following measures: Swanson, Nolan, and Pelham Rating Scale IV,[21] ADHD Rating Scale 5,[22] or items 1 to 18 of the Vanderbilt ADHD Diagnostic Rating Scale.[23] These measures are comparable because items map directly onto the *DSM-5* diagnostic criteria and have similar response formats. The working group did not think there was evidence to recommend one tool above the others because they are essentially equivalent.

Communication Disorders | The core symptoms of communication disorders comprise language difficulties, social (pragmatic) communication difficulties, speech sound difficulties, and fluency difficulties. The Children's Communication Checklist 2[24] is recommended to assess language and social (pragmatic) communication difficulties and the Intelligibility in Context Scale[25] to measure speech sounds difficulties. No appropriate PROMs were identified to measure fluency difficulties; therefore, although fluency difficulties were not included as part of the minimum set of PROMs, the working group recommended that, where possible, fluency difficulties could be assessed using the clinician-reported Speech-Naturalness Scale.[26]

Motor Disorders | Core symptom outcomes for motor disorders included fine and gross motor skills and coordination, for which the Developmental Coordination Disorder Questionnaire[27] is recommended. Motor disorders also included tic disorders and severity. Because an appropriate

Table 1. Outcomes Included in the NDD Set

Core symptom[a]	Impact, functioning, and quality of life	Key common coexisting problems
ADHD	Activities of daily life	Aggression or irritability
Communication disorders	Caregiver burden	Anxiety symptoms
Motor disorders	Educational outcomes	Autism spectrum disorder
Specific learning disorders	Family-related, health-related, overall, and psychosocial quality of life	Depression symptoms, emotional lability or reactivity, and sleep problems

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; NDD, neurodevelopmental disorder.

[a] When administering a minimum set, it is recommended that the outcome measures for core symptoms are only completed for disorders for which a child has a diagnosis. However, given the high rates of co-occurrence between the NDDs, it may be appropriate to administer all measures.

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Table 2. Recommended Outcome Measures

Outcome	Measure	Age range, y	Relevance	Feasibility and acceptability			Psychometric properties[a]			
			Domains covered	Administration burden	Cost	Translations, No.	Reliability	Internal consistency	Validated in NDD	Sensitivity to change[b]
Core symptoms										
ADHD	SNAP-IV or ADHD-RS-5 or VADRS	5-17	Inattention, hyperactivity, impulsivity	18 Items related to ADHD core symptoms, 5 min	No (SNAP-IV), yes (ADHD-RS-5, VADRS)	>1	Yes	Yes	Yes	Some evidence
Communication disorders	CCC-2	4-16	Language and social (pragmatic) communication difficulties	15-20 min	Yes	>1	Yes	Yes	Yes	No evidence
	ICS	4-15	Speech sounds difficulties	7 Items, 2 min	No	64	Yes	Yes	Yes	No evidence
	Speech Naturalness Scale[c]	Unclear	Fluency difficulties	Must be administered by a specialist clinician	No	English only	Yes	NA	Yes	No evidence
Motor disorders	DCD-Q	5-15	Fine and gross motor skills, coordination	15 Items, 5 min	No	9	Yes	Yes	Yes	No evidence
	YGTSS	6-17	Vocal and motor tic frequency and severity	25 Items, clinician administered, 10-15 min	No	4	Yes	Yes	Yes	Evidence
Specific learning disorders	CLDO	6-18	Reading accuracy and comprehension, global math ability, and global writing ability	20 Items, 5-10 min	No	English only	Yes	Yes	Yes	No evidence
Impact, functioning, and QOL										
Caregiver burden	FSI	6-18	Caregiver burden	6 Items, 2 min	No	English only	Yes	Yes	Yes	Some evidence
Functioning	DD-CGAS		Overall functioning, ADLs	Clinician-rated measure	No	>1	Yes	NA	Yes	Some evidence
Quality of life	KIDSCREEN-10[d]	8-18	Overall QOL, psychosocial QOL, family-related QOL, health and physical QOL, and ADLs	10 Items, 2-5 min	Yes	28	Yes	Yes	Yes	No evidence
Educational functioning	No measure found	NA	NA	NA	NA	NA	NA	NA	NA	NA
Key common coexisting problems										
Depression and anxiety[e]	RCADS-25	8-18	As per Depression & Anxiety in Children and Young People Set	5-10 min	NR	NR	NR	NR	NR	NR
ASD[e]	RBS-R and SRS or VABS	3-48	As per ASD Set	45-60 min	NR	NR	NR	NR	NR	NR
Emotional lability or reactivity	ARI	6-58	Emotional lability and reactivity, irritability	6 Items, 2 min	No	2	Yes	Yes	Yes	No evidence
Aggression or irritability	SNAP-IV	6-17	Aggression, irritability, defiance	8 Items, 2-3 min	No	>1	Yes	Yes	Yes	Some evidence
Sleep problems	CSHQ	4-13	Difficulty initiating and maintaining sleep, parasomnias, sleep disordered breathing, daytime sleepiness	33 Items, 5-10 min	No	6	Yes	Yes	Yes	Some evidence

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ADHD-RS-5, ADHD Rating Scale 5; ARI, Affective Reactivity Index; CCC-2, Children's Communication Checklist 2; CLDO, Colorado Learning Disabilities Questionnaire; CSHQ, Children's Sleep Habits Questionnaire; DD-CGAS, Developmental-Disability Children's Global Assessment Scale; DCD-Q, Developmental Coordination Disorder Questionnaire; FSI, Family Strain Index; ICS, Intelligibility in Context Scale; NA, not applicable; NDD, neurodevelopmental disorder; NR, not reported; QOL, quality of life; RBS-R, Repetitive Behavior Scale–Revised; RCADS-25, Revised Child Anxiety and Depression Scales 25; SNAP-IV, Swanson, Nolan, and Pelham Rating Scale IV; SRS, Social Responsiveness Scale; VABS, Vineland Adaptive Behavior Scale; VADRS, Vanderbilt ADHD Diagnostic Rating Scale; YGTSS, Yale Global Tic Severity Scale.

[a] See the eAppendix in Supplement 1 for detail on psychometric properties.

[b] No evidence indicates we were unable to find any research about sensitivity to change; some evidence, we are able to infer the tool has sensitivity to change based on data from trials; and evidence, there is formal research reporting on the sensitivity to change for the tool.

[c] No appropriate patient-reported outcome measures were identified to measure fluency difficulties; therefore, although fluency difficulties were not included as part of the minimum set, it is recommended where possible to assess fluency difficulties using the clinician-reported Speech-Naturalness Scale.

[d] KIDSCREEN-10 should be used to inform both the functioning and quality-of-life outcomes.

[e] It is recommended that the measures from the International Consortium for Health Outcome Measurement sets for depression and anxiety in children and young people and autism spectrum disorder be administered to collect this information.

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PROM was not identified to assess vocal and motor tic frequency, the working group recommended the clinician-reported Yale Global Tic Severity Scale.[28]

Specific Learning Disorders | The SLD outcomes included reading accuracy and comprehension, global math ability, and global writing ability. The working group recommends assessing these outcomes using the Colorado Learning Disabilities Questionnaire.[29]

Impact, Functioning, and QOL

There are considerable conceptual overlaps among the domains of impact, functioning, and QOL, and these domains are often measured using similar tools. Thus, the working group chose to collapse these into a single broad category for the purpose of the NDD set.

For assessment of caregiver burden, the Family Strain Index[30] is recommended. The KIDSCREEN-10[31] was chosen to track the QOL outcomes and activities of daily living. The clinician-reported Developmental-Disability Children's Global Assessment Scale[32] is recommended as a complement to the KIDSCREEN for assessing activities of daily living.

Although educational outcomes were recognized as important, these are not easy to assess via PROMs, and there is considerable variation in educational systems worldwide. We were unable to identify an appropriate PROM for educational outcomes within the health literature, and so no recommendation is made at this time.

Key Common Coexisting Problems

Three of the 6 included outcomes under the domain of common coexisting problems are the focus of existing ICHOM sets. Thus, for anxiety and depression symptoms, the Revised Child Anxiety and Depression Scales (part of the ICHOM Depression & Anxiety in Children and Young People set[18]) is recommended. For symptoms of ASD, the Repetitive Behavior Scale–Revised and Social Responsiveness Scale or Vineland Adaptive Behavior Scale (as part of the ICHOM ASD set[19]) are recommended. The Affective Reactivity Index[33] and Swanson, Nolan, and Pelham Rating Scale IV[21] are recommended to measure emotional lability/reactivity and aggression/irritability, and the Children's Sleep Habits Questionnaire[34] is recommended to measure sleep problems.

Case-Mix Variables and Time Points

An important aim of an ICHOM set is to facilitate the benchmarking of outcomes and comparisons across settings. This goal requires the collection of additional case-mix variables that can be used for risk-adjustment across varying populations and settings. The working group agreed that services should record the demographic information, baseline health status, clinical and historical factors, and treatment-related factors outlined in **Table 3**. Many of the case-mix variables can be measured using the Current View tool.[35]

Because the time points for clinical contact are likely to vary considerably across services and clinicians, the NDD set recommends the minimum time points for measuring outcomes and case-mix variables outlined in **Figure 2**. However, the working group encourages the measurement of outcomes as frequently as is needed to optimally inform clinical decision-making. For example, it may be prudent to measure outcomes when children face changes in familial or social circumstances. It is recommended that outcomes are measured at least every 6 months or, for those taking medication, before initiation or change of medication and end of titration.

Open Review

Forty service users from the UK and Portugal responded to the open review survey (20% patients and 80% parents or caregivers). The service users had lived experiences of all included NDDs, but most (73%) had experience with ADHD. Overall endorsement of the outcomes in the set exceeded the target of 70% (72%-100% across outcomes), with the exception that only 67% of service users agreed that the core symptoms of SLDs covered all important outcomes. Thirty-two professionals

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from 16 countries responded to the open review survey. Once again, experience in all included NDDs was represented, but ADHD was the most common (93% ADHD, 34% communication disorders, 31% SLDs, and 16% motor disorders). Endorsement of the NDD set and its components again exceeded 70% overall (70%-100% across outcomes, case-mix variables, and time points), with the exception that only 60% agreed with the proposed minimum set of outcomes for motor disorders. Review of the written feedback for outcomes that did not meet the 70% threshold indicated that the reasons behind the disagreement had already been discussed in detail by the working group during the NDD set development stage, that the feedback had already been addressed elsewhere in the NDD set, or that the comments were outside the scope of the NDD set.

Discussion

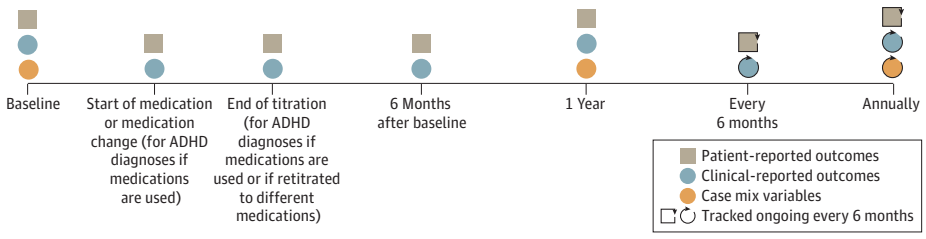
It is increasingly recognized that implementing MBC for mental health conditions and NDDs can improve clinical outcomes. The working group defined a minimum NDD set of outcome measures

Table 3. Case-Mix Factors in the NDD Set

Case-mix factor	Timing	Reporter
Demographics		
Age	Baseline	Clinical record
Sex	Baseline	Clinical record
Gender identity	Baseline; annually	Patient, parent, or caregiver reported
Level of education	Baseline	Parent or caregiver reported
Race	Baseline	Patient, parent, or caregiver reported
Ethnic minority or marginalization	Baseline	Patient, parent, or caregiver reported
Living situation	Baseline; annually	Patient, parent, or caregiver reported
Baseline health status, clinical, and historical factors		
NDD-specific comorbidities (assessed via Current View[35] tool)	Baseline; annually	Clinical record
Intellectual disability diagnosis	Baseline	Clinical record
Psychiatric comorbidities (assessed via Current View tool)	Baseline; annually	Clinical record
Patient family history of NDDs	Baseline	Patient, parent, or caregiver reported
Adverse childhood experiences	Baseline	Patient reported
Hospitalizations in the past 12 mo	Baseline; annually	Clinical record
Prenatal exposures	Baseline	Parent reported
Birth weight	Baseline	Clinical record
Gestational age	Baseline	Clinical record
ADHD subtype (if relevant)	Baseline	Clinical record
Language status	Baseline	Patient, parent, or caregiver reported
Treatment-related factors		
Intervention setting	Baseline; annually	Clinical record
Intervention type	Baseline; annually	Clinical record

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; NDD, neurodevelopmental disorder.

Figure 2. Timeline for Data Collection



Although patients may be seen in clinical practice more frequently, outcome measures or variables should be administered at the indicated time points. ADHD indicates attention-deficit/hyperactivity disorder.

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that are low cost and available in a range of languages and appropriate and feasible to use across a range of cultural and geographic settings. The included outcomes are those that matter most to service users with a *DSM-5*-defined NDD, and the recommendation of a set of standard measures has the potential to improve the quality of care not only through MBC but also by increased harmonization, communication, and benchmarking across services.

The NDD set prioritizes the use of measures that are patient reported, free to use, publicly available, applicable to low- and middle-income countries, and feasible in nonspecialist as well as specialist settings as well as measures that minimize administration burden. This means that in many cases the measures recommended in the NDD set differ from the gold standards for specialist assessment. For example, an assessment of coordination and fine and gross motor skills would ideally involve a skilled clinician observing a patient performing activities related to these outcomes (eg, walking or throwing a ball). However, the included PROMs can capture a patient's perceptions of their functioning across domains, which more closely map onto the ICHOM goal of ensuring interventions are addressing what most matters to patients.

An additional challenge when selecting outcome measures for child populations is the need to consider the views of different informants across different settings (ie, school vs home). The working group prioritized self-report and caregiver-reported measures because it is often less practical or feasible for clinicians to obtain teacher-reported measures. However, it is recommended that, when possible, information should be gathered from multiple informants across multiple settings to fully understand a child's functioning and what adjustments (if any) should be made to treatments to maximize positive outcomes across all areas of functioning.

Strengths and Limitations

This study has several strengths. The working group included 2 patient representatives as voting members. The inclusion of these patient representatives in all stages of the NDD set development ensured that they were fully engaged in the decision-making process. To further support this, the working group chair actively solicited input from all members during discussions and sought the views of the patient representatives if they had not yet contributed to a discussion to help ensure diversity of input. Additional feedback from service users and professionals working in the field was also sought toward the end of the NDD set development through the open review surveys. Although the patient surveys were available in only 3 countries and completion numbers for both surveys were relatively low, the responses largely endorsed the NDD set, and feedback reflected points that had already been discussed by the working group. For the open review there was a predominance of experience with ADHD in both the service user and professional respondents. Although this may have impacted the responses, we think this is unlikely because the endorsement of outcomes did not appear to vary by experience.

This study also has some limitations. The scope of the NDD set is limited to young people aged 3 to 20 years with 1 of the specified NDDs. Some NDDs, in some cases, may be diagnosable and treatable before 3 years, and early interventions are ideal. In addition, NDDs are lifelong conditions that often continue to need treatment in adulthood. The NDD set covers several disorders that, although highly comorbid, have distinct symptoms and are quite heterogeneous. Thus, the breadth of the NDD set may come at the expense of depth for a specific disorder. The NDD set is a minimum recommendation of outcomes to measure, and the working group recommends that, where feasible, clinicians complement the NDD set with other outcome measures of importance to each individual patient.

It was difficult to identify appropriate tools to measure the outcomes across several domains. In several cases, no appropriate PROM was identified, so the working group either made no recommendation at this time or was required to recommend a clinician-reported outcome measure. Many of the identified tools were designed to be used as screening measures rather than outcome measures (eg, Developmental Coordination Disorder Questionnaire). Furthermore, many of the tools did not have evidence of sensitivity to change. Most tools do not span the entire age range (eg,

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validated for 6-18 years rather than 3-20 years) and are typically only validated for use in WEIRD (Western, educated, industrialized, rich, and democratic) settings and have few translations available. This was particularly an issue for those measuring SLDs and communication disorders due to the language and cultural specifications across countries and languages. Although the tools are mostly well validated in research, their use in guiding clinical decision-making is less clear and requires further research. There is a need to improve outcome measurement in NDDs, which should include codeveloping PROMs with parents and children to ensure the measures are capturing all outcomes of importance and demonstrating sensitivity to change in measures.

Conclusions

We have described in this consensus statement the development of a standard set of outcome measures for youth with NDDs. The NDD set covers outcomes of most concerns to patients and caregivers, including core symptoms, impact, functioning, QOL, and common coexisting conditions. Use of the NDD set has the potential to improve clinical practice and research. In the future, in addition to monitoring implementation, the working group will take responsibility for updating the NDD set when advances in measurement are made. The widespread implementation of the NDD set will create large databases that will provide a valuable resource for researchers to generate hypotheses for future research.

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Corresponding Author: Melissa Mulraney, PhD, Department of Paediatrics, University of Melbourne, 50 Flemington Rd, Parkville, VIC 3052, Australia (melissa.mulraney@unimelb.edu.au).

Author Affiliations: Department of Paediatrics, University of Melbourne, Parkville, Australia (Mulraney, Coghill); International Consortium of Health Outcome Measures, Boston, Massachusetts (de Silva, Joseph, Sousa Fialho); School of Allied Health, Australian Catholic University, Brisbane, Australia (Dutia); School of Human Movement and Nutrition Sciences, The University of Queensland, Brisbane, Australia (Dutia); Faculty of Medicine and Health, The University of Sydney, New South Wales, Australia (Munro); Murdoch Children's Research Institute, Melbourne, Australia (Payne); Child and Adolescent Psychiatry and Psychotherapy, Central Institute of Mental Health, Medical Faculty Mannheim, University of Heidelberg, Mannheim, Germany (Banaschewski); Institute for Evidence Based Healthcare at University of Lisbon School and Medicine, Lisbon, Portugal (de Lima); Turner Institute for Brain and Mental Health and School of Psychological Sciences, Monash University, Melbourne, Australia (Bellgrove); Department of Psychiatry, Faculty of Medicine, University of Southampton, Southampton, UK (Chamberlain); Department of Neuroscience and Physiology, Norton College of Medicine at SUNY Upstate Medical University, Syracuse, New York (Chamberlain, Faraone); Department of Psychiatry, Queen Mary Hospital, Hong Kong (Chan); May Institute Inc, Randolph, Massachusetts (Chong); Dundee & Angus ADHD Support Group, Dundee, UK (Clink); Centre for Innovation in Mental Health, School of Psychology, Faculty of Environmental and Life Sciences, University of Southampton, Southampton, UK (Cortese); Tees, Esk, and Wear Valleys NHS Foundation Trust, Middlesbrough, UK (Cortese, Lovell); Hassenfeld Children's Hospital at NYU Langone, New York University Child Study Center, New York City, New York (Cortese); Department of Precision and Regenerative Medicine and Ionian Area, University of Studies of Bari Aldo Moro, Bari, Italy (Cortese); Department of Forensic and Neurodevelopmental Sciences, King's College London, London, UK (Daly); Department of Psychiatry and Behavioral Sciences, Norton College of Medicine at SUNY Upstate Medical University, Syracuse, New York (Faraone); Department of Women and Children's Health, Institute of Life Course and Medical Sciences, University of Liverpool, Liverpool, UK (Gladstone); Brain and Mind Centre, Children's Hospital Westmead Clinical School, Faculty of Medicine and Health, University of Sydney, New South Wales, Australia (Guastella); WeMind Suomi, Helsinki, Finland (Järvdike); Department of Pediatrics and Child Health, Aga Khan University Hospital, Karachi, Pakistan (Kaleem); Royal College of Psychiatrists, London, UK (Lovell); Northern Beaches Child and Family Health Service, Sydney, Australia (Meller); Division of Neurodevelopmental Disorders, Bethesda Children's Hospital,

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Budapest, Hungary (Nagy); Department of Psychiatry, Icahn School of Medicine at Mount Sinai, New York, New York (Newcorn); Department of Psychiatry, Faculdade de Medicina, Universidade de São Paulo, São Paulo, Brazil (Polanczyk); Department of Child and Adolescent Psychiatry, King's College London, London, UK (Simonoff); Centre for Addiction and Mental Health University of Toronto, Toronto, Ontario, Canada (Szatmari); The Royal Children's Hospital, Melbourne, Australia (Tehan); Division of Neuropsychology, Children's National Hospital and The George Washington University School of Medicine, Washington, DC (Walsh); Department of Paediatrics, Child & Adolescent Health, Aga Khan University Medical College, Nairobi, Kenya (Wamithi).

Author Contributions: Drs Mulraney and de Silva had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: Mulraney, de Silva, Joseph, da Luz Fialho, Banaschewski, Bandeira de Lima, Bellgrove, Chamberlain, Chan, Chong, Faraone, Guastella, Järvdike, Nagy, Newcorn, Polanczyk, Simonoff, Szatmari, Tehan, Walsh, Coghill.

Acquisition, analysis, or interpretation of data: Mulraney, de Silva, Joseph, da Luz Fialho, Dutia, Munro, Payne, Banaschewski, Bandeira de Lima, Bellgrove, Chamberlain, Chong, Clink, Cortese, Daly, Faraone, Gladstone, Guastella, Kaleem, Lovell, Meller, Nagy, Newcorn, Polanczyk, Walsh, Wamithi, Coghill.

Drafting of the manuscript: Mulraney, de Silva, Joseph, Dutia, Munro, Bellgrove, Chamberlain, Chong, Faraone, Guastella, Järvdike, Kaleem, Nagy, Wamithi, Coghill.

Critical review of the manuscript for important intellectual content: de Silva, da Luz Fialho, Munro, Payne, Banaschewski, Bandeira de Lima, Bellgrove, Chamberlain, Chan, Chong, Clink, Cortese, Daly, Faraone, Gladstone, Guastella, Järvdike, Lovell, Meller, Nagy, Newcorn, Polanczyk, Simonoff, Szatmari, Tehan, Walsh, Coghill.

Statistical analysis: de Silva, Joseph, Bellgrove, Chan.

Obtained funding: da Luz Fialho.

Administrative, technical, or material support: Mulraney, de Silva, Joseph, Dutia, Payne, Bellgrove, Chong, Cortese, Daly, Guastella, Kaleem, Meller, Simonoff, Szatmari, Tehan, Walsh, Coghill.

Supervision: de Silva, Joseph, da Luz Fialho, Bandeira de Lima, Guastella, Simonoff, Szatmari, Coghill.

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in Autism, *Clinical Child Psychology and Psychiatry*, *British Journal Of Psychiatry*, *Advances in Mental Health and Intellectual Disabilities*, and *Developmental Medicine and Child Neurology*; and authoring textbook chapters for Oxford University Press and Pavilion Publishing outside the submitted work. Dr Nagy reported receiving nonfinancial support from Egis Pharmaceuticals and personal fees from Medice outside the submitted work. Dr Newcorn reported receiving personal fees from Adlon, Cingulate Therapeutics, Corium, Hippo T&C, Ironshore, Lumos, Medice, MindTension, Myriad, Otsuka, Rhodes, Shire/Takeda, Signant Health, Supernus, the National Football League, and Klingenstein Third Generation Foundation outside the submitted work. Dr Polanczyk reported receiving personal fees from Apsen, Aché, Abbott, Medice, and Takeda outside the submitted work. Dr Coghill reported receiving grants from Takeda/Shire; personal fees from Takeda/Shire, Medice, Novartis, and Servier; and royalties from Oxford University Press and Cambridge University Press outside the submitted work. No other disclosures were reported.

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SUPPLEMENT 1.

eAppendix 1. Supplemental Methods
eTable 1. Search Strategy to Identify Outcomes
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eReferences
eAppendix 2. ICHOM NDD Open Review Survey
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SUPPLEMENT 2.

Data Sharing Statement

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