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Reporting Children's Development below the Test Floor: Looking Back and Forth to Describe Individual Strengths and Needs

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Abstract

The test floor effects seen in standardised tests lead to a standardised score of 1 or less with a flat profile that hides a child's individual strengths and needs. The Griffiths III community of practitioners requested advice on the reporting of children's development below the floor of the test, so that individual strengths and needs can be described. This paper reports the third phase of research following an earlier Scoping Review and a wider literature review. To confirm quality control, Phase 3 was conducted in a retrospective manner using the same methodology as the earlier phases but in a reverse direction. Peer reviewer comments and key elements from the Scoping Review and keywords from the publications were tabulated. Data analysis included a change of perspective to that of the child and their individual rights with respect to the literature themes already described in Phase 2. These confirmed that there is little specific guidance in the literature, but that computational advances for homogeneous populations and especially disaggregated data offer some solutions. A greater balance between broad biopsychosocial models and standardised models of assessment should be sought by practitioners together with the use of disaggregated data to highlight issues that pertain to individual subsets of results. This will ensure that the child's right for their individual strengths and needs to be described together with a plan for management, may be met.

Keywords

Developmental Assessment, Children with Severe Disability, Disaggregated Data, Pattern and Needs Identification, Below Test Floor

1. Introduction

General developmental assessment is performed for a variety of reasons and for a variety of children, including those children whose development falls below the floor of a test standardised against a group of typically developing children. Developmental assessment for those children is the focus of this paper.

In 2016, the Third Edition of the Griffiths Scales (Griffiths III) was published following a 6-stage process with a guiding plan that included practitioner input at the start, during the stages and following publication, developing a Griffiths Scales community of practitioners [1] [2]. Experienced practitioners continue to ask for guidance and new information on the most appropriate ways to describe an individual child's development when this falls more than 2 standard deviations below their typically developing peers, *i.e.* at the floor of the test. These questions led to a Scoping Review "Reporting a child's development below the floor of a standardised developmental test". Green [3] describes the Scoping Review and a further clinical review of the literature. A Griffiths III Case Study Book for Practitioners was written to provide practitioners with a range of case study examples describing individual adaptations of the test for that individual child and what to do when comparative statistics are inappropriate [4].

The clinical review of the literature produced several themes. The International Classification of Functioning, Disability and Health Children and Youth version (ICF-CY) [5] displayed a paradigm shift from a medical to a broader biopsychosocial model of disability, an approach consistent with children's rights to participate, with a need for measurement to be aligned with the ICF-CY. There are difficulties using a typically developing child standardisation sample for developmental tests as there is sparse comparative data at the tails of the normal Gaussian curve. Another theme was the greater use of computational statistics for homogeneous populations and more disaggregation of data together with avoidance of issues of measurement such as developmental age. This is an average score eclipsing any individual data from that child. There are several guidelines for assessing children with and without disabilities [6] [7] [8]. The APA's 2011 Guideline 14 is non-specific and recommends an approach that is the most psychometrically sound and appropriate for clients with disabilities.

The Scoping Review produced no replicable evidence to answer the practitioners' questions using the Scoping Review methodology of pre-determined research questions. The need for further literature exploration led by clinical knowledge (Phase 2) left the authors reflecting on the many unsettling questions, aroused by the work, on the rights of a severely disabled child. To examine these in more depth and add quality control, this study re-examines the Scoping Review and clinical review of the literature from a retrospective perspective with a particular emphasis on children's rights. These are described in the United Nations Convention on the Rights of the Child [9].

2. Methods

Figure 1 displays the methodology of the previous Phases (1 and 2) together

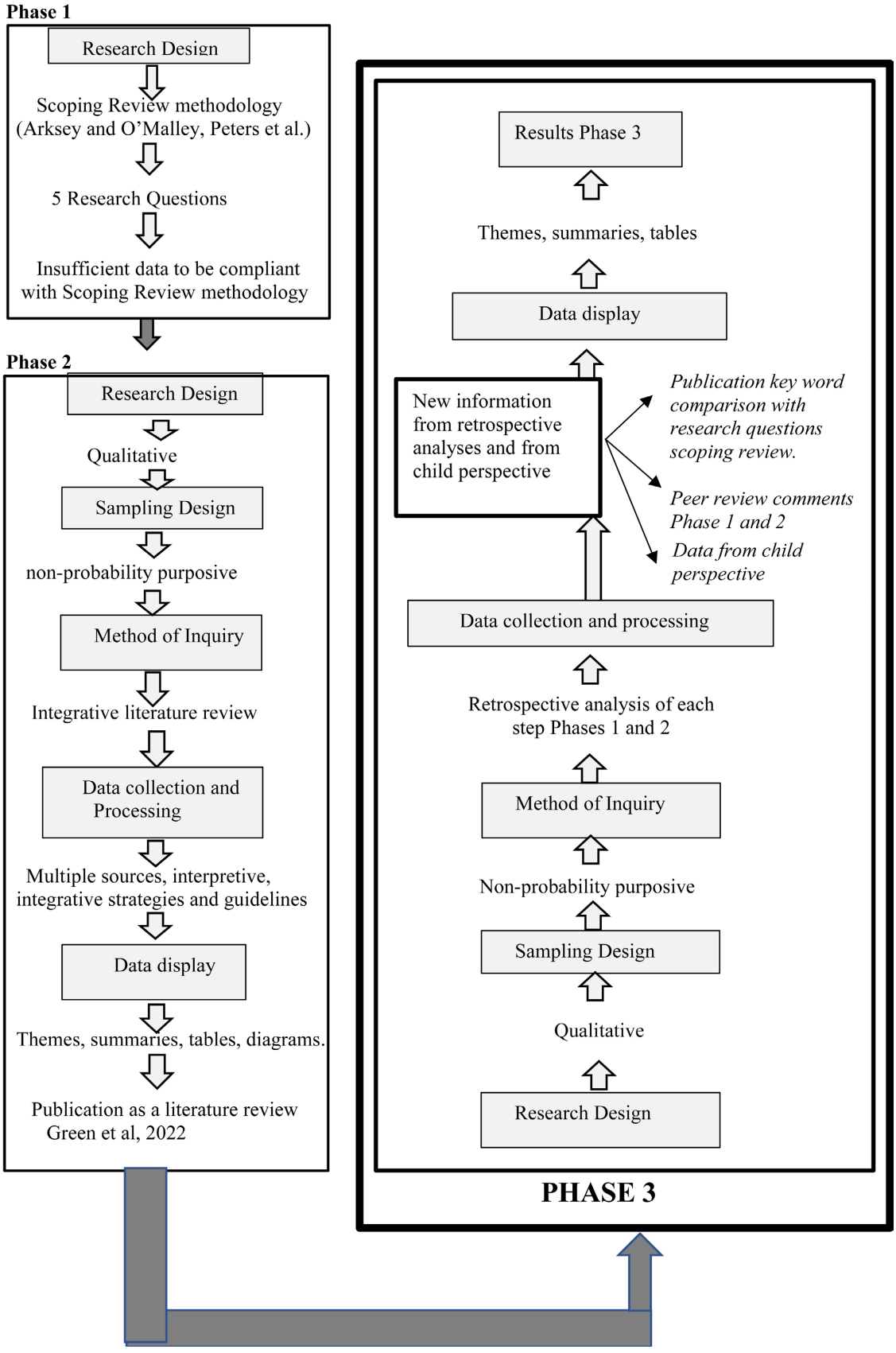

Figure 1. Methodology Phases 1, 2 and 3.

with the methodology of this current Phase 3. The methodology for the initial Scoping Review (Phase 1) was based on the framework described originally [10] and refined with additional guidance [11]. The Scoping Review framework was chosen to examine evidence emerging during the research processes preceding the publication of DSM-5 [12] in 2013 and its recommendations for a more comprehensive view of the individual who falls outside the parametric boundaries of a standardised test. The Scoping Review followed five recommended stages: identifying the research questions, identifying relevant studies, studying selection, charting of data and collating, and summarising and reporting the results. The initial research question was:

"How should a child's development which falls below the floor of a standardised developmental test be reported?"

The search was limited to the years 2005-2020.

The methodology for Phase 2 was a qualitative design with an integrative clinical literature review as shown in **Figure 1**. All aspects of the choices available within the Scoping Review methodology were reviewed in conjunction with the findings of the clinical literature review in Phase 2.

Phase 3 was a retrospective review of all the data from Phases 1 and 2, following the same methodology but each phase in a reverse direction. The retrospective review included new data such as key words provided by the authors of the clinically useful publications in Phase 2. These were assembled and compared with the key elements of the research questions of the Scoping Review. Key words were used as a gauge of the background and interests of the authors. The comments from peer reviewers from draft publications were also included in the retrospective review. The themes raised in the published paper [3] were re-examined from the child's perspective as well as for scientific detail.

3. Results

3.1. Retrospective Review of the 3 Phases of Research

1) The Phase 1 final 16 research questions using different iterations of the initial research question produced no data meeting the inclusion criteria, including that of age. This was for content relating to children under 11 years assessed on a standardised developmental test or measure and performing around or below the floor of the test.

2) No further data was found in the repeated literature review using the original time frame 2005-2020.

3) No relationship was noted between the key elements of the Phase 1 research questions and Phase 2 key words from the literature review papers. **Table 1** shows the key elements from the Scoping Review questions and key words associated with the publications chosen from the clinical review of literature.

4) The peer review comments which did not relate to the structure of the paper describing the Phases 1 and 2 included 3 anonymous reviewers' perceptions of both the research focus and the lack of data in the literature.

Table 1. Scoping review key elements and clinically useful publications' keywords.

Key elements Scoping Review research questions	Key words clinically useful publications			
	Related to assessment	Related to Outcome	Related to evidence base, standards	Type of impairment, medical diagnosis/group
Child development	Functional assessment	Outcome	Guidelines	Language impairment
Below floor of standardised test	Dynamic assessment	Prediction	Early childhood education	Young children
Children with developmental delay and disorder	Ecology of development		Developmentally appropriate practices	Motor impairment
Reporting	Special educational needs		Standards	Visual impairment
Children with developmental delay and disorder	Barriers to learning		Best practices	Cognitive impairment
Assessment less than DQ50	Inclusive education		Program evaluation	Pre-term
Scoring below floor of test	Action and needs based assessment		Early childhood standards	Bilingual speakers
Intellectual delay	ICF-CY		Evidence-based practice	Language disorder
Evaluation	Portfolio assessment		Clinical trials	Low IQ
Scales and development	Curriculum-based assessment		Arbitrary metrics	Autistic spectrum disorder
	Conceptual shift		Clinical significance	Fragile X syndrome
	Alternative assessment		Prejudice	Intellectual disability
	Authentic assessment			Down Syndrome
	National surveys			Intelligence
	Online surveys			FMR1 gene
	Testing			FMRP
	Validity			IQ
	Linking assessment & curriculum			Mental retardation
	Classification			
	Developmental assessment			
	Non-verbal test			

Continued

Standardised test
Reliability
Floor effects
WAIS III
WISC IV
Outcome measures
Intelligence
Assessment
Implicit Association test
Cognitive assessment

"*A thought-provoking work*."

"*This important work addresses the common clinical challenge of extracting more meaningful information from a test result than the blank statement of an intellectual disability*."

"*A compendium* (*short but complete account*), *as well as a review*, *of the area about which almost nothing is known*."

3.2. The Child's Perspective: Main Themes from the Literature Review

1) *The ICF-CY paradigm shift* from a medical to a broader biopsychosocial model of disability is helpful, but some testing needs to continue to demonstrate individual areas of strength, and where more support for the child is required.

2) *The test floor effects* seen in standardised tests lead to a standardised score of 1 or less thus displaying a flat profile that hides a child's individual strengths and weakness/needs [13]. An individual child therefore is grouped together with other children who may have very different needs and abilities. Computational solutions have been shown to be effective for homogeneous samples of children with Down Syndrome, Fragile X and mucopolysaccharidosis [14] [15] [16] but there is no evidence that this solution has been used for a wider group of syndromes.

3) *Issues of mismeasurement*.

Some quantitative metrics have definite issues for children with developmental disability, including ratio developmental quotients which are not comparable at different age levels because the standard deviation of the ratios does not remain constant. Moreover, confidence intervals vary tremendously. The pace of an increase in a given developmental construct changes at different ages as well [17].

Developmental Age Equivalents (AEs) represent the average age that a raw score is typical rather than presenting accurate information about the child being as-

sessed and, as a result, falsely imply that abilities increase at a constant rate from year to year [18]. Unlike standard scores, which follow an equal-interval scale, AE scales are ordinal, with a flattening of the curve as age increases [19].

4) *Disaggregating data* is a critical step to gaining increased knowledge from collective or aggregated information. In a standardised test, data is aggregated to produce a statistical comparison with the standardisation sample. Developmental age uses aggregation using a mean value. Disaggregating data involves delving more deeply into a set of results to highlight issues that pertain to individual subsets of results. Qualitative and descriptive analyses are also ways to disaggregate test data [3]. Disaggregation of data has been shown to be effective in Aboriginal Health [20], to display race when in smaller numbers in a group [21], and during a Pandemic [22].

4. Discussion

A retrospective re-examination of the data using the same methodology as in Phases 1 and 2 produced little new information for Phase 3 apart from some related peer review comments and lists of key elements from the Scoping Review questions and key words from publications sourced in Phase 2. The peer reviewers support that little information is available on the Scoping Review research questions. Phase 3, that of retrospective review in a reverse direction to the original reviews, confirmed the absence of data for the scoping review and the data collected in Phase 2. It provided some quality control for the research, which had proved hard to achieve by more usual methods.

There are several well-recognised issues related to the developmental assessment of children with or without disability. Measuring child development is fraught with challenges due to its dynamic nature with individually complex and inter-related developmental domains. Children tend to develop in spurts rather than in a linear fashion, developing rapidly yet also slipping in and out of 'normality', particularly at a young age [23].

Tests of child development are often standardised on a population of typically developing children whilst they are used mostly to assess children whose development is thought to be atypical. Addition of children with disabilities to the norming group can negatively impact a test's discrimination accuracy or its ability to differentiate between typically developing children and children with disability [24] [25]. Standardised instruments for such children assume a developmental process that is only quantitatively, and not qualitatively, different from typically developing children. However, the hallmarks of developmental disorders are disrupted developmental timing and slow acquisitional pace [26].

The strength of standardised developmental tests lies in their objectivity, norm-referenced scores, and psychometric properties, but these characteristics and aggregated data may make the scored standardised test inappropriate for children with severe disability. Many test developers warn against their use for this group of children. Numerical measures of developmental status compared with

typically developing children continue to be demanded in some areas such as in the measurement of treatment effects, progress planning and monitoring despite significant barriers to accurate normative measurement. Where numerical estimates of development below the floor of standardised tests are stated, many are inaccurate such as ratio developmental ratios and developmental age equivalents thus producing an inaccurate assessment of the child's real abilities and needs.

Whilst not directly related to the research questions of this study, the iterative process of the Scoping Review identified evidence that children for whom an accurate numerical score is not achievable are excluded from many research studies. Whilst this is understandable from a research methodological perspective, it means that decisions, for example the effects of treatment, are taken without data from some of the population investigated. The children with disability who do not score within the boundaries of a parametric test become invisible as well as their needs.

The results demonstrated that each of the themes examined, the ICF-CY paradigm shift from a medical to a broader biopsychosocial model of disability, the test floor effects seen in standardised tests, issues of mismeasurement and the use of aggregated data have the potential to impair the individual rights of disabled children. A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.

The UN Convention on the Rights of the Child, 1989 [9], Article 29, 1. states that… the education of the child shall be directed to the development of the child's personality, talents and mental and physical abilities to their fullest potential. Article 23, Section 3 states "Recognizing the special needs of a disabled child…, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development".

It appears to be a straightforward argument that a child who has severe disability but who nevertheless can access, for example, a communication system or play with their peers should not, without further assessment, be grouped together to receive the same service as a child with disability who experiences the world through their sensory system. DSM-5 and its recommendations for a more comprehensive view of the individual who falls outside the parametric boundaries of a standardised test has achieved a greater breadth of assessment but, unless assessment of children's strengths and needs at an individual level is included, other DSM-5 recommendations cannot be met.

Accurate assessment of intellectual ability is a necessary component in interpreting results from autism diagnostic instruments in a comprehensive ASD differential diagnosis [27]. DSM-5 states explicitly that the disturbances in social communication and repetitive behaviour must not be better explained by ID or

global developmental delay [12]. In practice, this means that the behaviours found deviant on assessment must be abnormal for peers at the child's general developmental level, not for chronological-age peers [28]. For a child with specific instructional needs, knowledge about the child's use of vision and hearing, language comprehension and learning ability are essential.

The data gained from the wider literature review comes from a wide-ranging field, demonstrated by the extensive list of key words from these publications. It is striking how few key words were placed in the "outcome column". This may reflect the exclusion of children with severe disability from many outcome studies. The extensive list of key words does not suggest a group of researchers or clinicians aiming at the same goal, particularly that of outcome. It appears that a mind-shift and a change of practice by professionals working in the child disability field may be needed to ensure that a child's needs are both acknowledged and described so that individual barriers to function and learning are lowered where possible.

With the current emphasis in UK child services on screening rather than comprehensive developmental assessment, children with disability receive an aggregation of scores to delineate their broad level of disability. Whilst this is reasonable for those children who can fulfil the requirements of a standardised test, this obliterates any information on an individual child's strengths and needs, thus preventing timely intervention. Segregation based on scoring is reasonable when extrapolated to planning for services, but not for individuals who need disaggregation of finer detail. Some education professionals need the support of their colleagues in medical services to achieve this with information about an individual child's strengths and needs.

There are ways to achieve a less discriminatory service for this vulnerable group of children. Many forms of childhood disability have a mix of dysfunction rather than in one developmental area. For example, many children who display difficulties with the autistic spectrum have other developmental difficulties which would benefit from treatment more immediately than a long waiting list for a specialist service allows. There could well be a cost benefit with lower numbers of children needing mental health services in the future as a result if children's needs are kept central in their management plans.

An excellent example of the benefit of detailed evaluation of cognitive and adaptive development plus modern methods of score analysis is that of children with treated mucopolysaccharidosis. Studies proved the need for earlier intervention at national level such as new-born screening and innovative intervention [29] [30] [31]. Although norm-based data detailing the natural history of untreated MPS I was collected [32], the test floor of 50 of the standardised developmental tests used meant that the lowest end of the developmental trajectory was truncated without revealing the true nature of the profound impairment possible. Re-examination of the data [16] using a modern method of score analysis [33] revealed the full range of cognitive functioning beneath this cut-off of

50 and uncovered new information about the rapidity of decline and the profound impairment in these children.

Another way to achieve less discrimination is the use of disaggregation of data relating to the child with disability. Since the Covid-19 pandemic, the strengths of disaggregation of data to highlight the specificities of smaller groups hidden by aggregating statistics has been both recognized and utilised. The Pan American Health Organization and the World Health Organization have produced a Digital Transformation Toolkit [22] which details further links which provide technical information and work dating back to pre-pandemic. Every attempt should be made to disaggregate data relating to the child. For our research and clinical practitioner community using Griffiths III, a qualitative assessment of skills and needs is recommended for children who display a flat developmental profile because the parametric test is not appropriate for them. The analysis is possible at the individual item level enabling assessment of the child's ability at items of differing constructs. Whilst not numerical, the method does show developmental change over time.

5. Conclusion

This research has confirmed that there are methods to describe accurately the development of children with disability who perform below the floor of a standardised test. These are to consider modern computational solutions for research involving a homogeneous group of children and for other children to disaggregate data and use descriptive analysis. Without this consideration, discrimination by omission occurs and the standards of the UN Convention on the Rights of the Child are not met.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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