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Davison, J., Maguire, S., McLaughlin, M., Simms, V., & Bunting, B. (2023). Exploring the psychometric properties of the Intellectual Disability versions of the Short Warwick-Edinburgh Mental Wellbeing Scale and Kidscreen10, self-reported by adolescents with intellectual disability. *Journal of Intellectual Disability Research*, 67(5), 415-426. <https://doi.org/10.1111/jir.13016>

[Link to publication record in Ulster University Research Portal](#)

### Published in:

Journal of Intellectual Disability Research

### Publication Status:

Published (in print/issue): 31/05/2023

### DOI:

[10.1111/jir.13016](https://doi.org/10.1111/jir.13016)

### Document Version

Publisher's PDF, also known as Version of record

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# Exploring the psychometric properties of the Intellectual Disability versions of the Short Warwick–Edinburgh Mental Wellbeing Scale and Kidscreen 10, self-reported by adolescents with intellectual disability

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## Abstract

**Background** There are no validated self-report measures that can be used to assess health and wellbeing in adolescents with intellectual disability (ID).

**Method** The aim of this study was to explore the psychometric properties of two newly adapted self-report health-related quality of life (HRQoL) and mental wellbeing measures: the Intellectual Disability versions of the Short Warwick–Edinburgh Mental Wellbeing Scale (ID-SWEMWBS) and Kidscreen 10 (ID-Kidscreen10). For this, we used data from a sample of 427 adolescents (aged 11–19) with ID recruited from special school settings.

**Results** Confirmatory factor analysis (CFA) was conducted to validate the factor structure of both measures. Internal consistency was assessed using Cronbach's alpha and test–retest reliability was analysed using intra-class correlation coefficients. The internal consistency measured using Cronbach's alpha was found to be in the range of 0.70–0.78, test–retest reliabilities were expressed using intra-class correlation coefficients that were found to be high for both measures (ID-SWEMWBS, 0.758;

ID-Kidscreen10, 0.723), and the CFA supported the unidimensional structure of both measures.

**Conclusions** The results of this study indicate that the ID-SWEMWBS and ID-Kidscreen10 have very good psychometric properties and can be used as self-report measures to assess HRQoL and mental wellbeing in adolescents with ID.

**Keywords** Adolescent, Health-related quality of life, Intellectual disability, Mental wellbeing, Psychometric properties, Self-report

## Background

HRQoL and mental wellbeing are important concepts for adolescents with intellectual disabilities (ID), given the health inequalities that exist within this population (Hamdani *et al.*, 2018). For example, adolescents with ID are at increased risk of developing health problems (e.g. co-occurring chronic disease and/or mental illness, obesity) (Frey *et al.* 2017), diminished physical health (Frey *et al.*, 2008; WHO, 2018), lower socio-economic status and social exclusion (Allerton *et al.* 2011; Buckley *et al.* 2020; Emerson 2021) in comparison with their neurotypical peers. To address these health inequalities, it is important to measure the HRQoL and mental wellbeing of these young people and

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identify their underlying causes in order to inform effective and timely interventions.

Traditionally measurement and identification of HRQoL and mental wellbeing from adolescents with ID have been assessed via proxy reports, typically completed by parents, teachers or carers (Ravens-Sieberer *et al.* 2005). Other researchers believe that adolescents with ID do not have the capacity to reflect on these domains and thus cannot reliably report their own wellbeing (Shevell, 2008; Longo *et al.* 2017). Many researchers and clinicians are keen to explore the health and wellbeing of adolescents with ID; however, they acknowledge that measurement is a challenge (White-Koning *et al.* 2005). As a result, adolescents with ID are often excluded from directly communicating their health and wellbeing needs with research thus heavily dependent on accurate identification of these by informants (Scott *et al.* 2011). Limitations exist surrounding the robustness of proxy reflection of non-observable internal states (i.e. feelings), particularly in relation to people whose language limitations mean that they have not been able to tell even close proxies what they think (Emerson *et al.* 2013). Every individual has a unique perception of his/her health and wellbeing that is influenced by context, previous experiences and personal values (Noonan *et al.* 2016). This personal perspective can only be obtained through individuals self-report. Therefore, adolescents' views should, where possible, be sought directly rather than being inferred from proxy reports (Upton *et al.* 2008). Further, the United Nations Convention on the Rights of Persons with Disabilities highlights the need to ensure that children with disabilities 'have the right to express their views freely and are provided with appropriate assistance to realise that right' (Article 7).

Recent research has shown that adolescents and parents' perception of health and wellbeing can differ and that adolescents can reliably report on these domains provided that the measure is appropriate to their age and cognitive functioning (Ingerski *et al.* 2010; Morrow *et al.* 2011; Davison *et al.* 2022). In adapting such instruments, it is important to consider identified limitations from previously conducted research with adolescents with ID, particularly in relation to understanding (e.g. determining the meaning of questions), cognitive processing (e.g. recalling information, ordering

information or making comparisons) and expression (e.g. articulating a response). This has led to the development of various self-report health and wellbeing measures with an ID adolescent population (e.g. Well-being in Special Education Questionnaire: Boström *et al.* 2016; Modified Czech version of the children self-report Quality-of-life Measure for Children with Epilepsy: Cui *et al.* 2008, 2010; Children's Assessment of Participation & Enjoyment; Intellectual Disability version of the Short Form of the Physical Self-Inventory: Maiano *et al.* 2009, 2011). Despite attempts to develop measures that are suitable for this understudied group, those that have been developed require further validation before they can be recommended for use by adolescents with ID (Maguire *et al.*, 2023). Therefore, developing or adapting research tools and methods for use with adolescents with ID is of paramount importance, not only so that they can provide their own views and opinions about their health and wellbeing but also to aid their participation and inclusion in research of this nature.

In response to the highlighted issues, our research team has used co-production principles and participatory research (PR) methods to adapt two self-report measures that had previously been validated for neurotypical adolescents [the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) and Kidscreen-10], providing a validated framework for others seeking to adapt self-report tools for adolescents with ID (see Davison *et al.* 2022). Kidscreen10 is a valid measure for neurotypical children and adolescents aged 8–18 years (Ravens-Sieberer, 2010), and the SWEMWBS is a valid measure for neurotypical populations from 11 years of age (Melendez-Torres *et al.* 2019). Both measures are established HRQoL (Kidscreen10) and mental wellbeing (SWEMWBS) measures widely used with neurotypical children and adolescents in cross-sectional and longitudinal surveys worldwide (i.e. Ravens-Sieberer *et al.*, 2014; Melendez-Torres *et al.* 2019; Lereya *et al.* 2022; Wiedemann *et al.* 2022). However, to our knowledge, neither have been completed as self-report among adolescents with ID. Having recently adapted these measures with this target group (Davison *et al.* 2022), the current study aimed to explore the psychometric properties of the ID-SWEMWBS and ID-Kidscreen10 in a sample of adolescents with ID.

## Method

### Adaptation of measures

This section briefly summarises the co-production process involved in the adaptation of two self-report measures; full details are published in Davison *et al.* (2022). Using key principles underlying co-production, research advisory groups were set up in two special schools with staff ( $n = 15$ ) to involve key stakeholders in the adaptation process of two HRQoL and mental wellbeing measures (SWEMWBS and Kidscreen10) and to work alongside academic researchers in an advisory capacity. Applying a participatory research approach (Shier, 2010), a series of co-design workshops were conducted with adolescents ( $n = 35$ ) aged 11–17 years ( $M$  age = 14.19 years;  $SD = 1.93$ ) to improve the suitability of these measures for self-report completion by adolescents with ID. At each school, one measure (SWEMWBS and Kidscreen10) was co-adapted, with both adapted measures piloted together during the final workshop. During the co-design workshops, specific aspects for measure adaptation were identified: (1) simplifying the item wording and phrasing; (2) inclusion of pictorial communication symbols (PCS) and visual prompts to represent the meaning of items; (3) changing the tense of items from past to present; (4) asking questions rather than statements; (5) reducing 5-point Likert scales to three-point; and (6) presenting one item at a time during administration (Davison *et al.* 2022). Utilising participatory research offered a meaningful and feasible method to include adolescents with ID in the adaptation of self-report HRQoL and mental wellbeing measures, with the aim of generating a set of items that this target group would be able to interpret and provide a response.

### Testing the psychometric properties

#### Sample

At time one, participants were 427 adolescents (69.3% male and 30.7% female) aged between 11 and 19 ( $M$  age = 13.83 years;  $SD = 1.59$ ) and identified as having mild to severe ID. The sample comprised 17 adolescents (4%) with mild ID, 236 (55.3%) with moderate ID and 174 (40.7%) with severe ID. At time two, of the 427 participants who participated at time one, 154 participants were re-tested after a 2-week

period ( $M$  age = 13.72 years;  $SD = 1.42$ ), comprising 101 males (65.6%) and 53 females (34.4%) (see Table 1).

#### Procedure

As both measures are protected by copyright, registration of a non-commercial licence to use WEMWBS was obtained from Warwick Medical School, and a collaboration form approved to use the Kidscreen10 by the KIDSCREEN Group prior to this study commencing. Ethical approval was obtained from Ulster University Research Ethics Committee (reference number REC/21/0052). Data were generated in two phases. A list of all special schools in Northern Ireland (NI) was obtained from the Department of Education NI (DENI) website. An invitation to participate detailing the aims, objectives and procedures of the study was emailed to each selected school. Of the 31 schools contacted, 22 agreed to participate (response rate 70.9%). Headteachers provided written consent for their school to participate after which they were provided with information sheets and consent forms to distribute to parents and pupils. Parents and pupils were required to provide written consent prior to participating in the study. Data collection was carried out in schools using pen-and-paper methods. Questionnaire administration (ID-SWEMWBS and ID-Kiscreen10) by the research team lasted between 8 and 18 min and was administered within a teaching context, either in the classroom or in small groups, depending upon the needs of the participants and schools. Items were read aloud by the researcher, and participants were then asked to respond in their questionnaire booklet using a pencil. A PowerPoint presentation was utilised to visually guide participants through the questionnaire accompanied by verbal instructions. Gender, date of birth, free school meal (FSM) entitlement, level of ID and additional diagnosis of each participant were collected by a socio-demographic questionnaire completed by each participant's teacher.

#### Measures

The ID-SWEMWBS included seven items designed to measure hedonic and eudemonic components of mental wellbeing. The ID-Kiscreen10 included 10 items regarding adolescent's general health-related quality of life, specifically focused on domains of

**Table 1** Characteristics of participants

Characteristics		Time 1 (n = 427)n (%)	Time 2 (n = 154)n (%)
Gender	Male	296 (69.3)	101 (65.6)
	Female	131 (30.7)	53 (34.4)
Age	Years	Mean = 13.83 (SD = 1.586, range 11–19)	Mean = 13.72 (SD = 1.417, range 11–17)
Level of intellectual disability	Mild	17 (4)	7 (4.5)
	Moderate	236 (55.3)	100 (64.9)
	Severe	174 (40.7)	47 (30.5)
Additional diagnosis	Only ID	18 (4.2)	9 (5.8)
	ASD	178 (41.7)	62 (40.3)
	ADHD	78 (18.3)	27 (17.5)
	Physical disability	28 (6.6)	4 (2.6)
	Learning disability	159 (37.2)	52 (33.8)
	Visual disability	8 (1.9)	1 (.6)
	Down syndrome	44 (10.3)	18 (11.7)
	Cerebral palsy	13 (3)	1 (.6)
	Epilepsy	20 (4.7)	5 (3.2)
	Diabetes	8 (1.9)	2 (1.3)
	Behavioural	47 (11)	15 (9.7)
	Difficulties	10 (2.3)	1 (.6)
	Severe health	14 (3.3)	6 (3.9)
	Difficulties	8 (1.9)	2 (1.3)
	Hearing difficulties		
	Mental health issues		
FSM entitlement	Yes	255 (59.7)	96 (62.3)
	No	172 (40.3)	58 (37.7)

ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; FSM, free school meal; ID, intellectual disability.

physical wellbeing, moods and emotions, autonomy, parent relations and home life, social support and peers and school environment. Both measures asked respondents to consider their experiences ‘today’ and respond on a 3-point coloured pictorial rating response scale (yes, no, sometimes). Items were supplemented with pictorial communication symbols (PCS) symbols and imagery to guide understanding of the meaning of items (see Data S1). Negative items were reversed scored. Summed scores were generated for each scale with higher scores indicating better mental wellbeing and HRQoL.

#### Data analysis

To verify the validity, construct validity and criterion validity assessment methods were employed. CFA was conducted on the default hypothesised unidimensional structure of the ID-SWEMWBS (Tennant *et al.* 2007) and ID-Kidscreen10 (The KIDSCREEN Group Europe, 2006) with six residual

covariances to represent the dimensions from which the items were derived. Recommendations of Comrey and Lee (1992) were adopted to determine the perceived strength of factor loadings (i.e. fair = > 0.45; good = > 0.55; very good = > 0.63; excellent = > 0.71).

To examine the criterion validity, Pearson correlation analyses of the ID-SWEMWBS and ID-Kidscreen10 were performed between time points. The correlation was classified as low and weak (0.10–0.29), moderate (0.30–0.49) and high and strong (greater than 0.50) (Akoglu 2018). *T*-tests and one-way ANOVAs were performed to compare the groups based on gender, age, level of ID and socio-economic status (using free school meal entitlement as an indicator).

The one-factor models, for both ID-SWEMWBS and ID-Kidscreen10, were restricted to be equal across both occasions, that is, the factor loadings were invariant within a given construct. In the case of the ID-Kidscreen10, a series of residual covariances were



set to be invariant for the six subcomponents (physical wellbeing, moods and emotions, autonomy, parent relations and home life, social support and peers and school environment) within the factor. A one-factor model was seen as appropriate because the 10 items of Kidscreen10 are frequently analysed as a single entity, with an acknowledgement that the items are a representative sample from six different components of the larger measure (i.e. Kidscreen52). To fit the final Kidscreen10 model, a residual covariance was introduced between items representing 'parent relations and home life' and 'social support and peers'.

### Process evaluation

A light-touch process evaluation ran alongside the adolescent survey to provide data on questionnaire implementation and to capture the perceptions and experiences of stakeholders in relation to observed questionnaire administration, content and format.

At time one, all participating schools were asked to complete a short survey. The survey comprised 10 closed questions which required respondents to answer questions on pupils understanding of the questions and response options, questionnaire content, administration, length and format across a 5-point Likert scale: *very good*, *good*, *average*, *poor* and *very poor*. Areas of strength and suggestions for improvement were also sought via two open-ended questions. The survey was completed by 44 class teachers and assistants who were present in the room during questionnaire completion, from the 22 participating special schools.

Descriptive statistics were computed on the closed questions, and the open-ended questions were thematically analysed using Braun and Clarke's (2006) six-step thematic approach. Patterns within the data are presented.

## Results

### Content validity

#### *Asking respondents about relevance*

Using a participatory research approach, a series of think-aloud questions were asked to a sub-sample of pupils ( $n = 54$ , all severe learning difficulties) to gather feedback regarding questionnaire completion.

Pupils were asked to identify items that were difficult to answer or any discrepancies within the questionnaire. Of the sample, 92.6% enjoyed completing the questionnaire, and 90.7% found its layout easy to follow. Whereas the majority of pupils reported to understand the questions (90.7%) and response options (96.3%), 87% of pupils acknowledged the usefulness of the pictorial communication symbols and visual imagery to aid understanding for self-reported completion. No pupils reported misunderstanding of any of the items.

### *Response bias*

Of those who responded, 400 (93.7%) fully completed ID-SWEMWBS, and 388 (90.9%) fully completed ID-Kidscreen10. Partial responders were more likely to have an additional diagnosis ( $P < .005$ ) and were younger ( $P < .001$ ). No differences were observed according to respondents' gender ( $P = .545/.955$ ), level of ID ( $P = .687/.482$ ) or free school meal entitlement ( $P = .370/.374$ ), for ID-SWEMWBS and ID-Kidscreen10, respectively.

Within the statistical models, missing data were assumed to be missing at random, and hence, a model-based approach to missing values was adopted (Muthén & Satorra 1995), based on pairwise present data. The model was estimated via weighted least squares, mean and variance (WLSMV).

### Reliability

Cronbach's alpha coefficients were calculated to measure the homogeneity of both scales. Internal consistency estimate values ranged from  $\alpha = 0.70$  to  $0.78$  and so demonstrated good levels of internal consistency for items (see Table 2).

Inter-item homogeneity was assessed via an examination of the item-total correlations. The correlations between the seven items ranged between  $r = .339$  and  $.698$  (ID-SWEMWBS) and between  $r = .074$  and  $.637$  for the ID-Kidscreen10.

Test-retest reliability was assessed using intra-class coefficients using data collected from a sub-sample (time two) of the overall sample (time one). At 2 weeks, test-retest reliability for ID-SWEMWBS was  $0.758$  ( $P < .001$ ) and for ID-Kidscreen10 was  $0.723$  ( $P < .001$ ), indicating a high reliability/reproducibility for the scale.

Table 2 Reliability statistics

Scale, item	% proportions T1 (T2)	Alpha	T1/T2 R
<b>ID-SWEMWBS</b>			
Do you feel excited about what is happening next?	87.2 (86.8)		
Do you feel helpful today?	90.2 (90.7)		
Do you feel relaxed today?	88.5 (87.3)	.73 (T1)	.758**
Do you know what to do when you have problem?	89.9 (86.5)	.78 (T2)	
Are you good at thinking today?	93.2 (93.5)		
Do you like to be with other people today?	93.2 (95.4)		
Have you made your own choices today?	95.4 (94.0)		
<b>ID-Kidscreen10</b>			
Do you feel fit and healthy today?	94.6 (92.8)		
Do you feel full of energy today?	80.8 (82.5)		
Do you feel sad today?	85.6 (86.2)		
Do you feel lonely today?	84.5 (87.5)		
Will you have enough time for yourself afterschool?	92.9 (88.9)		
Will you do the things you want to do afterschool?	89.6 (94.1)	.70 (T1)	.723**
Are your parents being good to you today?	98.1 (97.4)	.74 (T2)	
Are you having fun with your friends today?	96.5 (94.1)		
Are you getting on good at school today?	95.7 (95.4)		
Are you good at listening today?	91.6 (94.2)		

\*\*Significant at 0.01.

T1, Time 1; T2, Time 2.

### Internal validity

A one-factor measurement model based on prior research was tested in Mplus (version 8.6) using weighted least squares estimation. CFA was conducted on the default hypothesised unidimensional structure of the ID-SWEMWBS (Tennant *et al.* 2007; Stewart-Brown *et al.* 2009), which confirmed a one-factor model that was equivalent across time one and two (see Table 3). Factor loadings and threshold values were constrained to be equal on both occasions. All factor loadings were statistically significant ( $P < .001$ ) ranging from 0.541 (item 4) to 0.819 (item 3), thus deemed in the *good* to *excellent* ranges. Fit indices for the model provided an adequate description for the data with a significant chi-squared statistic (CFI = 0.985; TLI = 0.985; RMSEA = 0.014; 95% CI = 0.00–0.032; SRMR = 0.151;  $\chi^2 = 95.525$ ,  $df = 89$ ,  $P < .001$ ).

The 10 observed items representing the ID-Kidscreen10 were, from a theoretical perspective, taken to represent one factor. To evaluate the factorial invariance of the 10 items at both time points (T1 and T2), the factor loadings were constrained to be equal

across time, as were the thresholds (see Table 4). Due to limited information in certain categories, the model was estimated with a number of empty bivariate cells. These constraints provide for a good description of the data (CFI = 0.999; TLI = 0.997; RMSEA = 0.051; 95% CI = 0.027–0.073; SRMR = 0.016;  $\chi^2 = 37.603$ ,  $df = 18$ ,  $P = .004$ ). The factor loadings from time one and time two maintain a close rank ordering and are in all cases within 0.1 of each other, across time points.

There was consistency between both time-points for scores on the ID-SWEMWBS ( $P < .001$ ) and ID-Kidscreen10 ( $P < .001$ ).

### Criterion validity

As hypothesised, the ID-SWEMWBS and ID-Kidscreen10 total scores showed high correlation among the observed variables at Time 1 ( $N = 427$ ) ( $r = .838$ ,  $P < .001$ ). The correlations between the items representing the ID-SWEMWBS at both time points was 1053, indicating a linear dependency. Because the same measure is implicated on both time points, a high correlation is to be expected and hence the presence of a Heywood case. A similar issue was

**Table 3** Standardised factor loadings for ID-SWEMWBS at time point one ( $n = 427$ ) and two ( $n = 154$ )

ID-SWEMWBS	Factor loadings	
	Time 1	Time 2
Do you feel excited about what is happening next?	.673	.741
Do you feel helpful today?	.743	.818
Do you feel relaxed today?	.744	.819
Do you know what to do when you have problem?	.541	.596
Are you good at thinking today?	.681	.749
Do you like to be with other people today?	.740	.814
Have you made your own choices today?	.741	.816

present between the correlations of the ID-Kidscreen10 measure.

In the overall sample at Time 1, the mean ID-Kidscreen10 total scores were significantly lower for girls than for boys ( $P = .051$ ), and for those in receipt of free school meal entitlement ( $P = .024$ ). The mean ID-SWEMWBS total scores were significantly higher for those with lower levels of ID ( $P = <.001$ ) and for those who were younger in age (i.e. 11–12 years) ( $P = .050$ ).

### Process evaluation

#### Administration

Almost all school staff (97.7%;  $n = 43$ ) rated the administration of the questionnaire with aid of a PowerPoint to support completion as *very good* or

*good*. Administration was qualitatively commended in terms of pupil engagement; pace; provision of researcher support to facilitate pupil understanding; and creation of a supportive environment during administration.

Utilising a whole-class approach for questionnaire completion was perceived as *very good* or *good* by most school staff (90.9%;  $n = 40$ ). However, it was acknowledged that some pupils with severe learning difficulties (SLD) and additional needs require one-to-one support or differentiated into smaller ability groups to aid understanding (Schools 6 and 9).

#### Content and format

Most school staff (90.9%;  $n = 40$ ) rated the relevance of the questions for pupils as *very good* or *good*: ‘very

**Table 4** Standardised factor loadings for ID-Kidscreen10 at time point one ( $n = 427$ ) and two ( $n = 154$ )

ID-Kidscreen10	Factor loadings	
	Time 1	Time 2
Do you feel fit and healthy today?	.908	.821
Do you feel full of energy today?	.698	.684
Do you feel sad today?	.718	.774
Do you feel lonely today?	.710	.769
Will you have enough time for yourself afterschool?	.662	.724
Will you do the things you want to do afterschool?	.859	.908
Are your parents being good to you today?	.903	.859
Are you having fun with your friends today?	.986	.946
Are you getting on good at school today?	.823	.833
Are you good at listening today?	.759	.753



engaging and relevant to the needs of the children' (School 17) and 'very age/ability appropriate' (School 6). The inclusion of the word 'today' in each question was perceived as an area of strength given that pupils with ID tend to have a concrete thinking style and focus on today (exact moments in time) rather than reflecting over a time period.

Teachers highlighted that given the cognitive ability of some SLD pupils is poor, further simplification of the items to improve understanding may be warranted: 'more simple/direct/closed questions, e.g. Are you happy?' (School 9).

86.4% ( $n = 38$ ) of school staff observed pupils to have a 'very good' or 'good' understanding of the response options (*yes, no, sometimes*). It was suggested by school staff that 'more capable' pupils (referring to those with moderate learning difficulties) could potentially report across a 4-point or 5-point Likert scale.

The use of visual cues to support comprehension was rated as *very good* or *good* by most school personnel (95.5%;  $n = 42$ ). The use of pictures and symbols was highlighted as aiding pupils to understand the questions and response options: 'Pupils understanding of the questions was very good because of great visuals' (School 16).

The suitability of the questionnaire format was rated as *very good* or *good* by 88.6% ( $n = 39$ ) of school staff. The layout of the questionnaire (use of visual imagery, colour, one item per page) was identified by many as an area of strength. For example, 'meant children could focus on one question at a time' (School 17), and 'the colour copies were very helpful, and the large print with pictures was excellent' (School 2). Also, 90.9% ( $n = 40$ ) of school staff felt the questionnaire length was suitable for pupils with ID: 'not too long, which was great' (School 6). In offering suggestions for improvement, two SLD schools (Schools 9 and 20) recommended presenting the questionnaire in A3 (as opposed to A4) to aid pupils with visual impairments.

## Discussion

This study aimed to assess the psychometric properties of the ID-SWEMWBS and ID-Kidscreen10 in a sample of adolescents (aged 11–19) with ID. The ID-SWEMWBS and ID-Kidscreen10 were found to be valid and reliable across repeated administrations.

Both measures demonstrated good levels of internal consistency, suggesting that adolescents with ID were able to report on their HRQoL and mental wellbeing in a coherent and reliable manner. The high test–retest reliabilities demonstrates stability of responses over time and supports the measures as accurate representations of the constructs being measured (HRQoL and mental wellbeing). In relation to the factorial structure of the scales, CFA for the ID-SWEMWBS and ID-Kidscreen10 supports one-factor models, a finding that aligns with the results of other validation studies (i.e. Ravens-Sieberer *et al.* 2006; Matos *et al.* 2012; Nik-Azin *et al.* 2014; Haver *et al.* 2015; Smith *et al.* 2017; Ringdal *et al.* 2018; Anthony *et al.* 2022; Fung 2019). High factor loadings were observed for each measure, and these were stable across time, indicating that the factors strongly influence the variance among the items and that each factor accurately represents the items that it is comprised of.

## Implications of findings

When selecting existing measures that have not previously been used with ID populations, we suggest sustained efforts of researchers and stakeholders to utilise co-production principals and participatory research approaches with this target group in the adaption process (Davison *et al.* 2022). Our present study indicates that doing so improves the accessibility, reliability, validity and utility of measurement instruments for adolescents with ID. Although we recognise that our recommended adaptation method is not the only valid approach, we encourage other researchers to include adolescents in the instrument development or adaptation process while outlining clear steps so that they can be used by research teams and enhance our research practices with this target group.

A reliance on proxy reports has hindered progress in assessing adolescent health and wellbeing in ID populations to date. We need to move towards using valid and reliable self-report measures for this understudied population as their health and wellbeing needs are unknown. Also, to develop effective and timely interventions, children and adolescents who are at risk of poor outcomes need to be identified as early as possible (Parry 1992). Thus, the use of appropriate self-report measures (i.e.

ID-SWEMWBS and ID-Kidscreen10) should facilitate earlier and more accurate understanding of their health and wellbeing needs so that we can begin to address the growing health inequalities that exist among this group.

### Limitations of research

This study has some limitations that need to be considered. Firstly, the ID-SWEMWBS and ID-Kidscreen10 were adapted and validated among adolescents with ID in Northern Ireland. Our sample ( $n = 427$ ) was not randomly selected and therefore may not be representative of the overall population of adolescents with ID in Northern Ireland. Also, the results reported here were obtained from data collected exclusively from adolescents attending special schools; adolescents with ID attending mainstream school settings were not included. Thus, the next step in evaluating the robustness and generalisability of the ID-SWEMWBS and ID-Kidscreen10 would be to verify the applicability and validity of these measures with larger, representative samples of adolescents with ID in other countries and across cultures to further examine their psychometric properties.

Secondly, the ID-SWEMWBS and ID-Kidscreen10 require respondents to rate their present states and experiences as opposed to rating their health and wellbeing overestimates using time frames. However, when the context of each item is precisely determined by specific information of a person, time and place, the measure may provide only a limited snapshot of an individual's health and wellbeing in one situation (Ikeda *et al.*, 2016). Therefore, it may be necessary to utilise ecological momentary assessments (EMA) to ensure adherence to the original purpose of both measures, that is, reflecting over the past week. Although time consuming, research indicates that EMA can enable more detailed measurements of phenomena (e.g. HRQoL, mental wellbeing) over a period of time and is less susceptible to recall and cognitive biases (Kwasnicka *et al.*, 2021).

Finally, almost all participants completed the questionnaires solely via self-report. However, a small number of participants with complex needs required adult assistance, and therefore, these participants completed the questionnaires with individually tailored help and support. Although it is important to

obtain responses via self-reports to enable this target group to provide their own views and opinions, we recognise that this may not be a straightforward process for all adolescents with ID as many adolescents with ID have co-morbid or co-occurring conditions such as autism spectrum disorder (ASD) which affects how the brain functions, learns and processes information (Williams and Minshew 2010). To ascertain their individual perspectives of their HRQoL and mental wellbeing, some adolescents with ID may require additional help and support.

### Future research

Given that these measures have been adapted and validated for adolescents with an intelligence quotient less than 70, it is probable that these measures can be used with neurotypical younger children. Therefore, future research should investigate the applicability of these self-report measures (ID-SWEMWBS and ID-Kidscreen10) to young children.

The reliability of the ID-SWEMWBS and ID-Kidscreen10 measures could be explored further by firstly calculating the inter-rater reliability expressed as intra-class correlation coefficients among pupils and teachers and pupils and parents to measure the degree of agreement and enable comparisons between the different rating subgroups (pupil–parent and pupil–teacher). Secondly, it would be valuable for future research to investigate the extent to which the ID-SWEMWBS and ID-Kidscreen10 measure the same constructs as the original measures. One method of doing so could be to recruit a sample of adolescents with mild ID and ask them to complete both the original and ID versions of both measures. Thirdly, future research should be undertaken to explore if these adapted measures are sensitive to change by administering them before and after an intervention. Finally, future studies could translate, adapt and assess the cross-cultural validity of the ID-SWEMWBS and ID-Kidscreen10 measures to better understand the usefulness of these measures across cultures.

### Conclusion

Modifying self-report measures previously validated for neurotypical adolescents allowed the research team to test their applicability to adolescents with ID.

In summary, the ID-SWEMWBS and ID-Kidscreen10 display very good psychometric properties: high stability during a two-week test–retest interval, good models of fit, good levels of internal consistency and acceptable validity in this sample. Despite the limitations mentioned above, this study indicates that the ID-SWEMWBS and ID-Kidscreen10 are valid and reliable measures for assessing HRQoL and mental wellbeing among adolescents with ID.

### Acknowledgements

The authors would like to acknowledge the schools, their staff and pupils, who gave their time to participate in this research.

### Source of funding

This work was supported by The Baily Thomas Charitable Fund, United Kingdom (Grant Number: TRUST/VC/AC/SG/5662-8764).

### Conflict of interest

No conflicts of interest have been declared.

### Ethics statement

This study obtained ethical approval from Ulster University Research Ethical Committee (reference number REC/21/0052). The study was performed in accordance to the Declaration of Helsinki.

### Data availability statement

All data and materials associated with the current study is available from the corresponding author on reasonable request.

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Accepted 24 January 2023

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## Data Sr. Supporting Information