

Involving adolescents with intellectual disability in the adaptation of self-reported subjective well-being measures: participatory research and methodological considerations

J. Davison,  S. Maguire,  M. McLaughlin  & V. Simms 

Psychology Research Institute, Ulster University, Coleraine, UK

Abstract

Background The measurement of subjective well-being is challenging with samples of adolescents with intellectual disability (ID) given the cognitive and linguistic difficulties they face in comprehending standardised measures, and as such is primarily based on proxy reports. The lack of appropriate tools needs to be addressed so that adolescents with ID can self-report on their own well-being. The current study reports on the use of participatory research methods to adapt and modify two standardised self-report measures of subjective well-being suitable for completion by adolescents with ID.

Method Two special schools were recruited for this study. At each school, staff ($n = 15$) and pupils aged 11–17 years ($n = 35$) participated. A series of co-design workshops were conducted to adapt two standardised subjective well-being measures: KIDSCREEN-10 and short-form Warwick–Edinburgh Mental Well-being Scale.

Results Specific aspects for measure adaptation were identified: simplifying the item wording and phrasing; inclusion of pictorial communication symbols and visual prompts to represent the meaning of items; changing of tense of questions from past to present; asking questions rather than statements; reducing

5-point Likert scales to 3-point or dichotomous; presenting one item at a time during administration; and developing alternate formats of the survey to ensure inclusivity.

Conclusions This paper illustrates the value of using participatory research methods when working alongside adolescents with ID and offers methodological, as well as practical, guidance in the context of adapting subjective self-report measures for this target group, serving as a guide to fellow researchers and clinicians interested in modifying or developing self-report measures for adolescents with ID.

Keywords adaptation, adolescents, participatory research, intellectual disability, self-report, well-being

Background

Subjective well-being is an important concept for adolescents with intellectual disability (ID), given the health inequalities that exist within this population (Hamdani *et al.* 2018). In comparison with their non-intellectually disabled peers, they are more likely to experience diminished mental health, poorer health, chronic conditions and impairments, reduced wellness, lower socio-economic status, and social exclusion (Allerton *et al.* 2011; Menear *et al.* 2015; Buckley *et al.* 2020; Emerson 2021). To address or prevent these health inequalities, it is important to

Correspondence:

Dr Jenny Davison, School of Psychology, Ulster University, Cromore Road, Coleraine BT52 1SA, UK (e-mail: j.davison@ulster.ac.uk).

© 2022 The Authors. Journal of Intellectual Disability Research published by MENCAP and International Association of the Scientific Study of Intellectual and Developmental Disabilities and John Wiley & Sons Ltd.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

identify children who are at risk of poor outcomes as early as possible so that effective interventions can be put in place. However, measurement and identification of subjective well-being problems can be challenging within this heterogeneous group.

Measurement of subjective well-being

Traditionally, measurement and identification of subjective well-being from adolescents with ID have been assessed via proxy reports, typically completed by parents, teachers or carers (Ravens-Sieberer *et al.* 2005). While some professionals assume that adolescents with ID do not have the capacity to self-report on these domains and cannot reliably report their own subjective well-being (Shevell 2008; Longo *et al.* 2017). Many researchers and clinicians do take the views of adolescents with IDs seriously but acknowledge that it is a huge challenge (White-Koning *et al.* 2005). As a result, this leaves adolescents with ID excluded from communicating their health and well-being needs and 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 well-being, which is influenced by context, previous experiences and personal values (Noonan *et al.* 2016). This personal perspective can only be obtained through individuals themselves. Therefore, adolescent's views should, where possible, be sought directly rather than being inferred from proxy reports (Upton *et al.* 2008). Indeed, 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). Further, recent research has shown that adolescents and parents' perception of health and well-being can differ and that adolescents can reliably report their health and well-being, provided that the measure is appropriate to their age and cognitive functioning (Ingerski *et al.* 2010; Morrow *et al.* 2011). It is promising that recent studies have attempted to develop and use self-report

measures of well-being with adolescents with ID as opposed to typically used proxy measures for this target group (e.g. Boström *et al.* 2018; Boström & Broberg 2018). In adapting such instruments, it is important to consider already 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). Therefore, finding ways to develop or adapt research instruments for use with adolescents with ID is of paramount importance, so that they can provide their own views and opinions about their health and well-being.

Participatory research methods

While it is recognised that it is highly challenging to develop measures for this heterogeneous group, over the past decade, participatory research (PR) methods have rapidly expanded, and the value of involving adolescents with ID as active participants has been well documented (Groundwater-Smith *et al.* 2015; Horgan 2017; Vaughn & Jacquez 2020). Underpinning these methods is the need to understand how adolescents experience the world through ensuring they are at the centre of data collection and analysis and enhance the credibility and trustworthiness of the data by minimising researcher bias. Given that verbal communication may not be the preferred mode of communication for adolescents with ID, PR methods enable adolescents to express their opinions and perceptions in alternative ways (Noonan *et al.* 2016). The foundational principle of PR methods is the value placed on open, honest and meaningful participation, and in particular methods that offer 'the ability to speak up, to participate, to experience oneself and be experienced as a person with the right to express yourself and to have the expression valued by others' (Abma *et al.* 2019, p. 127). Within PR, engagement in each step of the research process includes tools, tasks and structured activities that are used to facilitate participation, shared decision-making and mutual learning (Vaughn & Jacquez 2020).

Recent PR is showing evidence of the capability of adolescents with ID to provide a unique perspective of their own subjective well-being, thereby having a

more inclusive role in research (Ikeda *et al.* 2016). Over the last decade, and in line with the trend of using PR in adolescents with ID, there has been an increase in their use within school-based research to develop, design and adapt self-reported QoL measures for this target population (Foley *et al.* 2012; Boström *et al.* 2016; Ikeda *et al.* 2016; Demkowicz *et al.* 2020). However, a significant limitation of this work is the lack of consultation with young people with ID to adapt the measures and the lack of transparency on what modifications were made, thus limiting the ability of others to build on such work or assess the appropriateness of the measures in these contexts.

The present study

While a growing body of research highlights the need and importance of developing self-report measures suitable for use with adolescents with ID, there is a lack of guidance on how to do this. This paper addresses this gap by offering methodological as well as practical guidance in the context of using PR methods, for the adaptation of self-report measures for adolescents with ID. This present study is one component of a larger study, which aims to assess the feasibility of including young people with ID in self-report subjective well-being research.

Methods

Design and participants

This study applied a PR approach to ensure that key stakeholders were involved throughout, working alongside the academic researchers in an advisory capacity. Ethical approval was obtained from Ulster University Research Ethics Committee (REC/20/0057). Data collection took place between April and May 2021. A list of all special schools in Northern Ireland (NI) was obtained from the Department of Education NI (DENI) website. Of the 31 special schools in NI that include adolescents aged 11–16 years, a letter detailing the aims, objectives and procedures of the study along with an invitation to participate, was emailed to the principal of five randomly selected schools, one from each education authority area. Of the five schools contacted, four replied with three agreeing to participate. Two schools were chosen to participate (the first two

schools to accept invitation, the third school was placed on our wait-list and will participate in subsequent stages of this study). At each school, key stakeholders (school staff working in various roles and adolescents with differing levels of ID) were recruited. Specifically, one class was selected from each key stage group to participate. Schools were provided with information sheets and consent forms for staff, parents and pupils. All participants were required to provide full written consent prior to data collection.

Staff

A total of 15 school staff members (14 females and 1 male) from two special schools representing various roles: principal ($n = 2$), vice-principal ($n = 1$), head of pastoral care ($n = 1$), speech and language therapist ($n = 1$), teacher ($n = 3$) and teaching assistants ($n = 7$) participated in the study. Their participation was in an advisory capacity. Due to COVID-19 regulations at the time, an advisory group was set up at each school. This enabled academic/researcher–stakeholder partnerships to work together to make choices that best meet the needs of the study and the child participants. Guided by recommendations of the International Association for Public Participation (IAP2), both advisory groups functioned at the ‘consult’ and ‘involve’ levels, providing advice and feedback throughout the process.

Adolescents

Four co-design groups were recruited in total (one KS3 group and one KS4 group at each school) (refer to Table 1). A total of 35 adolescents (17 female and 18 males) participated in the co-design workshops. At the time of recruitment, the adolescents were attending Key Stage 3 ($n = 19$) and Key Stage 4 classes ($n = 16$) and were aged between 11 and 17 years old (M age = 14.19 years). All the participants were in special education classes for adolescents, with moderate ($n = 9$; 25%) or severe ($n = 26$; 75%) ID. The majority ($n = 30$) of pupils had additional diagnosis such as autism spectrum disorder ($n = 7$), Down syndrome ($n = 2$), spina bifida ($n = 1$) and/or other impairments such as speech ($n = 17$), hearing ($n = 3$) and sight ($n = 1$).

Table 1 Co-design workshops sample descriptives

School	Workshop	Key stage (KS)	n	Sex		Age range	Level of ID	
				Female	Male		Moderate	Severe
One	1	KS3	10	8	2	11–14	5	5
One	2	KS4	9	0	9	15–17	4	5
Two	3	KS3	9	5	4	12–13	0	9
Two	4	KS4	7	4	3	15–17	0	7

ID, intellectual disability.

Measures

Established standardised subjective measures for assessing adolescence subjective well-being were selected based on their appropriateness for the age range of the sample and their ability to measure the outcomes of focus. Both measures are widely used in cross-sectional and longitudinal surveys worldwide (Ravens-Sieberer *et al.* 2014). However, to our knowledge, neither have been completed as self-report with atypically developing populations to date.

Kidscreen-10

Kidscreen-10 (The KIDSCREEN Group Europe, 2006) is a 10-item measure of health-related quality of life (HRQoL) designed for use with children aged between 8 and 18 years. Items scored on a 5-point scale—not at all, slightly, moderately, very and extremely—are: ‘thinking about the last week, have you’, ‘felt fit and well’, ‘felt full of energy’, ‘got on well at school’ and ‘been able to pay attention’. Items scored on a 5-point scale—never, seldom, quite often, very often and always—are ‘felt sad’, ‘felt lonely’, ‘been able to do the things you want to do in free time’, ‘had enough time for yourself’, ‘had fun with friends’ and ‘parents treated you fairly’. The Kidscreen-10 has been shown to be reliable with Cronbach’s alpha of 0.82 in adolescents aged 8–18 years ($N = 22\ 830$) across 13 European countries (Ravens-Sieberer *et al.* 2010). It has been shown to function as a good indicator of HRQoL (Erhart *et al.* 2009) and has a unidimensional structure (Ravens-Sieberer *et al.* 2010; Nik-Azin *et al.* 2014).

Short-form Warwick–Edinburgh Mental Well-being Scale (sWEMWBS)

The short-form Warwick–Edinburgh Mental Well-being Scale (sWEMWBS) (Tennant *et al.* 2007) comprises seven items and measures mental well-being, and accounts for both hedonic elements of positive well-being (e.g. I’ve been feeling cheerful) and eudemonic elements (e.g. I’ve been thinking clearly). The scale gathers responses on a 5-point scale (none of the time, rarely, some of the time, often and all of the time) to ‘feeling optimistic about the future’, ‘feeling useful’, ‘feeling relaxed’, ‘dealing with problems well’, ‘thinking clearly’, ‘feeling closer to other people’ and ‘able to make my own mind about things’. The 7-item sWEMWBS has been found to be highly reliable for the assessment of well-being in young people (Clarke *et al.* 2011; Hunter *et al.* 2015; Ringdal *et al.* 2018) and unidimensional in structure (Clarke *et al.* 2011; Ringdal *et al.* 2018; Hoffman *et al.* 2019; Melendez-Torres *et al.* 2019).

Co-design workshops

Using key principles underlying PR (refer to Table 2), a series of co-design workshops were conducted with the adolescent participants to adapt two subjective well-being measures (Kidscreen-10 and sWEMWBS) to ensure their suitability as self-report measures for adolescents with ID. Following parental consent, the researcher (SM; experienced special education needs educator) visited each school on five separate occasions (1-week intervals between visits) to facilitate the co-design workshops.

All of the workshops were designed in accordance with Shier’s (2010) model of conducting PR with

Table 2 Outline of PR methods used during each workshop

Workshop	PR steps	Summary of methods	Workshop overview
1	Partner Inform Consult	Participants were informed of the study, and their conceptualisations of 'well-being' were established. The draw-and-write technique (Williams <i>et al.</i> 1989) was used to illuminate their understanding of the things, people and places that were good for their well-being.	(1) Participants were introduced to the project and verbal consent obtained. (2) Conceptualisations of the term 'well-being' was explored via group discussion, for example, How can we be healthy? What is good for your well-being? Responses were recorded and presented visually using the interactive whiteboard (IW). (3) Using the IW, participants sorted images into 'good or bad' well-being. (4) Participants created a 'well-being' poster by sketching images and including written language to express their views on what is good for their well-being.
2 & 3	Involve Collaborate Empower	To aid adaption of the items, innovative and creative methods which placed the participants at the centre of proceedings were used (i.e. brain storming, idea generation and, group discussion). Boardmaker picture communication symbols (PCS) and images were co-selected alongside advisory groups to accompany each item to support interpretation of items. Participants identified their favourite image to represent each item and shared their perspective about their chosen images with the group during a facilitated discussion.	(1) Using the IW and a PowerPoint presentation, the original Kidscreen10 and sWEMWBS items were reviewed one by one with participants to check their understanding and suitability. If items were not understood, brainstorming was implemented to determine similar terminology that participants were familiar with and understood. (2) Participants were presented with images that represented each item. Images were discussed in conjunction with each item, and participants selected their preferred image (1 of 3 choices) that they felt represented each item best to support interpretation. The image that received the most votes was used. (3) Boardmaker PCS were applied to support participants to read and interpret items.
4	Consult Involve Collaborate Empower	Researcher-participants focused on co-modifying response options. Individual and group level assessment strategies were used to identify their preferred response option (yes/no), and format/mode of administration (pen-and-paper/electronic).	(1) Using a PowerPoint presentation, participants were presented with the modified items alongside the original 5-point Likert scale supported with boardmaker symbols to gain insight into participants understanding of response options and their ability to discriminate between responses. Through group discussion and brainstorming, participants suggested terminology that they were familiar with (i.e. yes, no and sometimes) to replace and reduce the response options. To check participants understanding of the modified response options, participants practiced answering the items using the modified response options. (2) To decide the most suitable pictorial response option format, participants practiced answering the same item four times using a different response option format each time. Participants were then asked via a worksheet to select their preferred response option format (i.e. thumbs symbol, ✓ or X symbol). (3) The researcher and participants discussed the different modes of administration (pencil-and-paper,

Table 2. (Continued)

Workshop	PR steps	Summary of methods	Workshop overview
5	Disseminate Act	Session five involved a co-pilot of the adapted measures, administered as a participatory group process (i.e. whole-class approach) with support of a PowerPoint administration presentation, and guidance provided by the researcher.	<p>iPad and computer) and participants voted for their preferred mode of administration.</p> <p>(1) A pencil-and-paper version of each adapted measures was administered to all participants using a whole-class approach.</p> <p>(2) Using a PowerPoint presentation, the researcher visually displayed and read each item aloud twice, guiding respondents through the questionnaire by explaining the meaning of items if necessary.</p> <p>(3) Verbal feedback was sought from participants by asking the following questions: Did you enjoy completing the questionnaire? Were there any questions you found difficult to answer? Is there anything you would like to change about the questionnaire?</p>

PR, participatory research.

children, which stipulates five levels: (1) children are listened to, (2) children are supported in expressing their views, (3) children's views are taken into account, (4) children are involved in decision-making processes and (5) children share power and responsibility for decision-making. Each school adapted one measure, with adapted measures piloted in both schools during the final workshop. Each workshop was conducted during the school day and were approximately 45 min in duration, including a 10-min break to facilitate the participants attention spans (Saracho 2013).

Workshop one began with informal conversation and icebreaking activities to build rapport between the researcher and participants (Wilson & Powell 2012) and to enable the researcher to understand participants' individual communication abilities, preferences and requirements in order to employ appropriate PR methods to allow such adolescents to participate. Participants' conceptualisations of the term 'well-being' were explored, and pupils' sorted images into 'good or bad' well-being. The draw-and-write technique (Williams *et al.* 1989) was utilised to enable pupils to become active participants in revealing their world as they see it (Horstman *et al.* 2008). For example, pupils created a questionnaire cover by sketching images and

including written language to express their views on what is good for their well-being.

In workshops, two, three and four participants took on the role of co-researchers; they became the experts in expressing their own lives (Wernick *et al.* 2014) during the co-production of the adapted items and response options. Group brainstorming, open questioning, one-to-one and group discussions were some of the inclusive PR methods applied to engage and communicate directly with participants to facilitate expressing their *own* responses and thoughts in the decision-making processes. For example, item vocabulary was trialled and revised in partnership with participants to determine if words were easily understood (comprehensibility).

The final workshop involved a pilot of the modified measures using a whole-class approach, supported via a PowerPoint presentation to engage the child participants to complete the survey.

Each workshop concluded with a play-based exercise using Makaton to allow participants to unwind and relax before returning to their classroom activities. During all co-design workshops, members of the staff advisory group (i.e. teacher, classroom assistants, and the school's speech and language therapist) were present. The staff advisory group were aware that the co-design workshops were researcher

and pupil led. Any input from staff during the co-design workshops was to facilitate the researcher to provide additional communication support when needed. For example, when the researcher experienced difficulty understanding pupil responses during group discussion, a staff member reiterated what the pupil had said to enable discussion to continue. On completion of each workshop, observational fieldnotes were recorded to document key knowledge-production points and to facilitate post-workshop critical reflection with the research team (Maharaj 2016).

Each co-design workshop built upon the knowledge and learning gained during the previous workshop, whereby items were iteratively revised with participants in response to how they responded to the PR methods. The researcher consistently reflected upon each workshop and incorporated all feedback from participants to adapt both the PR methods and measures, which were refined and developed in co-production with the wider research team (academics and stakeholders).

Results



Through engagement with our advisory groups, this study has found that two commonly used with general populations, standardised, self-report subjective well-being measures are not understood by adolescents with ID to allow self-report completion. In carrying out the present study, a variety of methodological considerations have emerged during the commitment to undertake PR to adapt two standardised subjective measures of HRQoL and well-being to ensure their suitability for use by adolescents with ID. In exploring these considerations, we will offer a brief account of the strategies undertaken to meet the identified challenges. Through our study, we have aimed to address and provide solutions to the following methodological considerations: item content, item structure, response format and mode of administration. The co-design workshops provided insights into specific aspects that required adaptation to make these measures more appropriate for this target population and prompted suggestions for overcoming some of the difficulties experienced in using current measures with adolescents with ID. (Table 3).

Item wording and phrasing

Employing PR methods for this process provided meaningful insight into terminology that required modification to ensure measures were appropriate for this target population. To overcome cognitive and linguistic difficulties experienced by adolescents with ID, the wording of every item was considered collectively during the co-design workshops. Complex words (i.e. optimistic) were substituted with words pupils were familiar with (i.e. excited). Given that adolescents with ID experience difficulty in understanding long sentences (Nakra 2019), a number of item phrases required modification to include vocabulary that pupils were familiar with, for example, item six of Kidscreen-10 'Have you been able to do the things you want to do in your free time?' was reduced to 'Are you doing fun things today?'. Consistent with previous research (Gupta 2017; Nakra 2019), prior to conducting the co-design workshops both advisory groups reported that their pupils struggle to recognise or reflect on their own feelings. Therefore, it was imperative to create short, simple and comprehensible items to facilitate these adolescents to express their emotions. Bell (2007) recommends that questionnaires for adolescents should be short in length, consist of short sentences asking questions rather than statements and use straightforward language. Also, given that adolescents with ID often have working memory deficits, reducing the item length can help their retention in working memory while considering a response (Gilmore *et al.* 2021).

The advisory groups also highlighted that adolescents with ID may struggle to understand a word or phrase that has multiple meanings due to a tendency to make literal interpretations of metaphorical terminology (Coudronnière *et al.* 2018). This tendency interpretative style may present as an obstacle for pupils to comprehend specific terms used in Kidscreen-10 and sWEMWBS, for example, item six of sWEMWBS 'I've been feeling close to other people' may be interpreted as referring to 'a short distance away' or 'apart in space or time' rather than its meaning in the context of the question presented, that is, 'sharing feelings, thoughts, wishes and dreads with someone else'. The co-design workshops confirmed that to support the interpretation of items for adolescents with ID, it is better practice to modify

Table 3 Example of results related to adaptation of items

		Kidscreen10		sWEMWBS	
Results	Description	Original	Adaption	Original	Adaption
Item wording and phrasing	Simplifying the wording of items to aid comprehension. Reducing sentences	Have you got on well at school? Have you been able to do the things you want to do in your free time? n/a	Are you getting on good at school today? Are you doing fun things today?	I've been feeling optimistic about the future I've been able to make up my own mind about things I've been feeling useful	Do you feel excited about what is happening next? Can you choose things yourself today? Do you feel helpful today?
Change of tense to working memory demands	Asking questions rather than statements Replacing words that have multiple meanings Reducing original time frame which respondents were asked to reflect upon	Have you got on well at school? Thinking about the last week ... Have you felt sad?	Are you getting on good at school today? Do you feel sad today?	I've been feeling close to other people Describe your experience over the past two weeks: I've been feeling relaxed. I've been feeling relaxed	Do you like to be with other people today? Do you feel relaxed today?
Pictorial prompts	Use of visual imagery and pictorial communication symbols to support interpretation and meaning of items	Have you felt sad? 	Do you feel sad today? 		
Response format	Replacing 5-point Likert with either dichotomous or 3-point Likert response options	Five-point: never – seldom – quite often – very often – always	Do you feel sad today? Dichotomous: yes – no Three-point: yes – no – sometimes	Five-point: none of the time – rarely – some of the time – often – all of the time	Do you feel relaxed today? Dichotomous: yes – no Three-point: yes – no – sometimes

sWEMWBS, short-form Warwick-Edinburgh Mental Well-being Scale.

the items and use plain language that pupils are familiar with. Throughout the process of modifying vocabulary and item phrasing, the aim of retaining the intent of the original item while simultaneously enhancing comprehension was adhered to.

Inclusion of examples

A finding that emerged early on during the co-design workshops was that adolescents with ID face difficulty comprehending abstract concepts. ‘Abstract’ refers to the inability to perceive directly by the senses. While moving from concrete to abstract thinking is a milestone of typical childhood development (Malik & Marwaha 2021), this cognitive transition from concrete to abstract thinking is less likely to develop in people with ID (Emerson *et al.* 2013). Most items in their original form required the inclusion of examples to support pupils understanding of the items, for example, revised item six of sWEMWBS ‘Do you like to be with other people today’, required the accompaniment of specific examples for ‘other people’. Doing so enabled this item to be more easily understood in its correct context. This finding mirrors that of previous research (Ikeda *et al.* 2016) that suggests that the inclusion of examples related specifically to adolescents’ daily life and contexts is important to aid understanding. In consultation with the advisory groups, examples of ‘other people’ involved in pupils’ lives were sought (i.e. parents, siblings and grandparents), and when needed, personal names of these significant others were recalled upon to support pupils in responding accurately to item six.

Change of tense due to working memory demands

Most pupils had trouble interpreting both measures in their original format, as they needed to report about their health and well-being over a period of time (i.e. the last 7 days) and doing so required long-term and short-term memory skills. As Beresford (2012) suggests, this requires a sophisticated level of cognition and self-awareness that may put adolescents with ID at risk of exclusion from well-being research. It is not surprising that the participants in this study struggled to reflect upon and recall past feelings and thoughts, consistent with previous research that found that people with ID have difficulties with working memory skills (Schuchardt *et al.* 2010; Kauffman &

Hallahan 2011). For example, the short-term memory of a young person with Down syndrome is approximately four to five words, the average level of grammatical understanding of a typically developing 3–4 years old (Chapman & Hesketh 2001; Pennington *et al.* 2003). Therefore, for the items to be cognitively ‘accessible’ to adolescents with ID, it was necessary to reduce the original time frame in which respondents were asked to reflect upon: ‘the last week’ (Kidscreen-10) and ‘over the past two weeks’ (sWEMWBS), to a certain time or a certain day (e.g. ‘today’, ‘yesterday’ or ‘Sunday’). As such, pupils are asked about their present states and experiences as opposed to rating their health and well-being over estimates using time frames. This change of tense ensured understanding for adolescents with ID to interpret and respond to the items accurately. However, it is important to note that 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 a child’s health and well-being in one situation (Ikeda *et al.* 2016). Therefore, it may be necessary to utilise ecological momentary assessment in order to accommodate this challenge for adolescents with ID to ensure adherence to the original purpose of both measures, that is, reflecting over the past number of weeks.

Pictorial prompts

Arising from consultations with stakeholders and pupils, the use of visual imagery to support the interpretation and meaning of items was reinforced, to aid understanding of the meaning of words, which is often a difficulty experienced by adolescents with ID (Nakra 2019). In special schools, pictorial communication symbols (PCS) are used to support pupils who experience reading difficulties to help pupils understand and structure the world around them, communicate their thoughts, and learn to read and write. Given that pupils are familiar with these symbol-based visuals and that adolescents with ID benefit from picture and symbol support (Gargiulo & Bouck 2014), we utilised boardmaker PCS in each survey item. Visual imagery was also added to guide understanding of the meaning of words. Using images or PCS alongside words can help adolescents with ID build a direct correlation between words and their meanings much easier and faster (Phelps 2019).

Including attractive pictorial aids also helps to keep participants independently on-task for longer, thereby increasing both the quality and quantity of the data they provide.

Item structure

Typically, Kidscreen-10 and the sWEMWBS measures are administered presenting all items of each scale and response options together. Research demonstrates that adolescents with ID can feel overwhelmed and distracted by too much information presented at one time, resulting in it being difficult for them to comprehend (Hart & Rollins 2011). The co-design workshops highlighted the need for items to be presented one at a time using a clear structure to engage respondents in understanding items. Pupil's ability to understand the items presented one at a time was piloted and determined during the co-design workshops. This format appeared to work well as pupils were able to focus on, and engage with, each item at a time to determine the meaning, recall information and articulate a response.

Response format

During the co-design workshops, the tense of all items changed from past (e.g. about the last week) to present tense (e.g. today); therefore, it was necessary to change the response options to represent this as the original 5-point Likert response options no longer corresponded with the adapted items. Although Likert scales are widely used with general populations as they offer an efficient method for capturing a wide range of response variance (Hartley & MacLean 2006), the pupils in this study found the 5-point Likert scales too complex to be able to distinguish subtle differences in their thoughts and feelings. When children's level of item comprehension is challenged, higher levels of scale granularity may exacerbate the burden already placed upon their cognitive abilities in completing the items (Montserrat *et al.* 2021). The process of interpreting and matching a response category to one's self-evaluation poses multiple cognitive demands that can be challenging for youth with cognitive impairments (Kramer & Schwartz 2017). Due to the cognitive ability of adolescents with ID, key stakeholders also confirmed that it was unrealistic for pupils to understand a 5-point Likert scale. On this

basis, a dichotomous (for profound ID) and 3-point Likert (for mild, moderate and severe ID) scale was co-produced and deemed appropriate for adolescents with varying levels of ID to respond to items reliably and validly. The two diametrically opposed terms that pupils themselves considered comprehensible and were most familiar with was 'yes' and 'no', and the three-point Likert scale included the added option of 'sometimes'. Research also shows that using simplified question wording and response formats frequently minimises cognitive and linguistic difficulties for people with ID (Emerson *et al.* 2013). It is important to note that while some researchers have found that providing simpler response options (e.g. yes/no) is easier and more reliable (Heal and Sigelman 1995), a forced choice between two opposing alternatives may result in acquiescence as an in-between option is not available (Heal & Sigelman 1995).

To aid understanding of response options and in attempting to reduce response bias, pictorial representations of the response options were co-designed for inclusion (Heal & Sigelman 1995). Pupils displayed preference for coloured pictorial prompts (thumbs up and thumbs down) as they were familiar with using coloured communication symbols during schooling.

Mode of administration

During one of the co-design workshops, modes of administration (i.e. pen-and-paper vs. electronic) were discussed with majority preference shown for paper format. Despite electronic devices being frequently used as education tools for adolescents with ID, most pupils outlined that they would be most comfortable using pen-and-paper to complete the survey. However, during the pilot, it was apparent that for those pupils who experience poor fine motor skills, a common difficulty in this population (Vuijk *et al.* 2010; Westendorp *et al.* 2011), using a pen to provide a response was problematic. If a pupil was unable to fill in their own responses, the facilitator or teaching staff scribed for them, which prohibited self-reporting and made it difficult to maintain confidentiality and anonymity of responses. Therefore, future research should seek to incorporate a range of inclusive practices to enable self-report data collection from all adolescents with ID, for example,

using touch screen devices, as they do not require a high level of fine motor skills (Avis 2019).

Discussion

This paper has sought to describe and report the considerations and processes arising from a series of co-design workshops, used to adapt two self-report subjective well-being measures for adolescents with ID. Primarily, through engagement with our advisory group, this study has found that two commonly used with general populations, standardised, self-report subjective well-being measures are not understood by adolescents with ID to allow self-report completion. The study identified key aspects of the measures that need to be adapted to ensure inclusion, specifically: simplifying the wording of items to aid comprehension, inclusion of PCS and visual prompts to represent meaning of items, changing the wording of items from past to present tense, asking questions rather than statements, replacing 5-point Likert scales with either dichotomous or 3-point Likert response options (dependent on level of ID), presenting one item at a time during administration, and developing alternate formats of the survey to ensure inclusivity. The adapted measures maintained the inclusion of both positively and negatively worded items as per the original scales.

Addressing the identified considerations in adapting two subjective well-being measures (Kidscreen-10 and sWEMWBS) has ensured that these measures are better understood by most adolescents with ID in order to self-report on their own well-being. Some of the methodological considerations highlighted in the Results section were surprising, and it is arguable that their significance has only become apparent because of the participatory approach taken. Without the use of PR, would we have realised that adolescents with ID experience difficulty reflecting back on last week or understanding abstract concepts? This study emphasises the critical importance of PR methods when working with adolescents with ID, and it is essential that these participants are fully embedded in the research process to ensure their inclusion and ultimately for their voices and opinions to be heard both through the design process, but also in wider large-scale surveys. The wealth of knowledge and

insight gained from the use of authentic PR methods are evident from this study's results.

Although this paper represents an advance in our understanding of developing and adapting measures to ensure suitability for adolescents with ID, there are limitations that should be considered. This study included only two special schools, and the findings may not be representative of all adolescents with ID. This is particularly important in the context of the wide heterogenous nature of adolescents with ID in relation to cognitive, academic and social skills (Longo *et al.* 2017). Also, this study adopted a PR approach that does not have formal guidance for data synthesis. Therefore, it is worth acknowledging that our co-design workshops were not audio recorded to enable the wider research team to review for triangulation purposes. While this paper highlights practical and methodological considerations, which arose from this project, in order to determine validity of the recommendations, testing the reliability of the adapted measures is warranted. Further research will explore the measures validity and reliability in larger samples of adolescents with ID.

Among strengths, is the PR approaches utilised. This paper reveals the vital importance of sustained efforts of researchers and stakeholders at co-production in research with adolescents with ID. Such work is often more time-intensive, requiring committed and skilled management and support throughout (Baum *et al.* 2006). This paper demonstrates that the benefits of co-production to researchers and stakeholders also extends to participants and to the quality of the research itself. The methodological considerations reported demonstrate that involving adolescents with ID in the research process is of paramount importance in enhancing our research practices with this target group. Future research should seek to create opportunities for PR where adolescents with ID play a full role in the design and execution of the research. Doing so creates opportunities for adolescents with ID to have a voice, exert control, and make decisions in the research process.

Conclusion

Participatory research offers a meaningful and feasible method of including adolescents with IDs in the development and adaption of self-report measures.

This paper has identified methodological considerations that arose in our study and should be considered by future researchers and clinicians when modifying existing instruments or developing new measures for this target population. When selecting standardised self-report measures that have not previously been used with adolescents with ID, we recommend employing PR methods to ensure that items are understood in order to facilitate full participation.

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 TRUST/VC/AC/SG/5662-8764).

Ethics approval

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.

Conflicts of interest

No conflicts of interest have been declared.

Data availability statement

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

References

- Abma T., Banks S., Cook T., Dias S., Madsen W., Springett J. *et al.* (2019) *Participatory Research for Health and Social Well-Being*. Springer Nature, Switzerland.
- Allerton L. A., Welch V. & Emerson E. (2011) Health inequalities experienced by children and young people with intellectual disabilities: a review of literature from the United Kingdom. *Journal of Intellectual Disabilities* **15**, 269–78.
- Avis E. K. (2019) The effects of early technology use on the development of young children. Master of Education Thesis, Northwestern College, Iowa. Available at: https://nwcommons.nwciowa.edu/cgi/viewcontent.cgi?article=1175&context=education_masters (retrieved 10 August 2021).
- Baum F., MacDougall C. & Smith D. (2006) Participatory action research. *Journal of Epidemiology and Community Health* **60**, 854–7.
- Bell A. (2007) Designing and testing questionnaires for children. *Journal of Research in Nursing* **12**, 461–9.
- Beresford B. (2012) Working on well-being: researchers experiences of a participative approach to understanding the subjective well-being of disabled young people. *Children and Society* **26**, 234–40.
- Boström P., Åsberg Johnell J. & Broberg M. (2018) Self-reported psychological wellbeing in adolescents: the role of intellectual/developmental disability and gender. *Journal of Intellectual Disability Research* **62**, 83–93.
- Boström P. & Broberg M. (2018) Protection and restriction: a mixed-methods study of self-reported well-being among youth with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **31**, 164–76.
- Boström P., Johnels A. J., Thorson M. & Broberg M. (2016) Subjective mental health, peer relations, family, and school environment in adolescents with intellectual developmental disorder: a first report of a new questionnaire administered on tablet PCs. *Journal of Mental Health Research in Intellectual Disabilities* **9**, 207–31.
- Buckley N., Glasson E., Chen W., Epstein A., Leonard H., Skoss R. *et al.* (2020) Prevalence estimates of mental health problems in children and adolescents with intellectual disability: a systemic review and meta-analysis. *Australian and New Zealand Journal of Psychiatry* **54**, 970–84.
- Chapman R. S. & Hesketh L. J. (2001) Language, cognition and short-term memory in individuals with Down syndrome. *Down's Syndrome, Research and Practice* **7**, 1–7.
- Clarke A., Friede T., Putz R., Ashdown J., Martin S., Blake A. *et al.* (2011) Warwick-Edinburgh Mental Well-being Scale (WEMWBS): validated for teenage school students in England and Scotland. A mixed methods assessment. *BMC Public Health* **11**, 1–9.
- Coudronnière C., Bacro F., Guimard P. & Muller J. B. (2018) Validation of a French adaptation of the Multidimensional Students Life Satisfaction Scale in its abbreviated form, for 5-to 11-year-old children with and without intellectual disability. *Journal of Intellectual and Developmental Disability* **43**, 407–20.
- Demkowicz O., Ashworth E., Mansfield R., Stapley E., Miles H., Hayes D. *et al.* (2020) Children and young people's experiences of completing mental health and wellbeing measures for research: learning from two school-based pilot projects. *Child and Adolescent Psychiatry and Mental Health* **14**, 1–18.
- Emerson E. (2021) Inequalities and inequities in the health of people with intellectual disabilities. *Global Public Health*.

- Emerson E., Felce D. & Stancliffe R. J. (2013) Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellectual and Developmental Disabilities* **51**, 333–48.
- Erhart M., Ottova V., Gaspar T., Jericek H., Schnohr C., Alikasifoglu M. *et al.* (2009) Measuring mental health and well-being of school-children in 15 European countries using the KIDSCREEN-10 Index. *International Journal of Public Health* **54**, 160–6.
- Foley K., Blackmore A., Gidler S., Donnell M., Glauert R. & Llewellyn G. (2012) To feel belonged: the voices of children and youth with disabilities on the meaning of wellbeing. *Child Indicators Research* **5**, 375–91.
- Gargiulo M. R. & Bouck C. E. (2014) *Special Education in Contemporary Society. An Introduction to Exceptionality*. SAGE Publications, Inc, USA.
- Gilmore L., Campbell M. & Shochet I. (2021) Adapting self-report measures of mental health for children with intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities*, 1–19.
- Groundwater-Smith S., Dockett S. & Bottrell D. (2015) *Participatory Research with Children and Young People*. SAGE, London.
- Gupta N. (2017) *Major Issues & Challenges in Special Education in India*. Horizon Books.
- Hamdani Y., Yee T., Rowland E. & McPherson A. C. (2018) Examining wellness in children and youth with intellectual and developmental disabilities: a scoping review. *Current Developmental Disorders Reports* **5**, 165–96.
- Hart R. & Rollins J. (2011) *Therapeutic Activities for Children and Teens Coping with Health Issues*. John Wiley & Sons, Inc, New Jersey & Canada.
- Hartley S. L. & MacLean W. E., Jr. (2006) A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research* **50**, 813–27.
- Heal L. W. & Sigelman C. K. (1995) Response biases in interviews of individuals with limited mental ability. *Journal of Mental Retardation Research* **39**, 331–40.
- Hoffman S., Rueda H. A. & Lambert M. C. (2019) Confirmatory factor analysis of the Warwick-Edinburgh Mental Wellbeing Scale among youth in Mexico. *International Social Work* **62**, 309–15.
- Horgan D. (2017) Child participatory research methods: attempts to go deeper. *Childhood* **24**, 245–59.
- Horstman M., Aldiss S., Richardson A. & Gibson F. (2008) Methodological issues when using the draw and write technique with children aged 6 to 12 years. *Qualitative Health Research* **18**, 1001–11.
- Hunter S. C., Houghton S. & Wood L. (2015) Positive mental wellbeing in Australian adolescents: evaluating the Warwick-Edinburgh mental wellbeing scale. *Australian Educational and Developmental Psychologist* **32**, 93–104.
- Ikeda E., Krägeloh C., Water T. & Hinckson E. A. (2016) An exploratory study of self-reported quality of life in children with autism spectrum disorder and intellectual disability. *Child Indicators Research* **9**, 133–53.
- Ingerski L. M., Modi A. C., Hood K. K., Pai A. L., Zeller M., Piazza-Waggoner C. *et al.* (2010) Health-related quality of life across pediatric chronic conditions. *The Journal of Pediatrics* **156**, 639–44.
- Kauffman M. J. & Hallahan P. D. (2011) *Handbook of Special Education*. NY and London, Routledge.
- Kramer J. M. & Schwartz A. (2017) Reducing barriers to patient-reported outcome measures for people with cognitive impairments. *Archives of Physical Medicine and Rehabilitation* **98**, 1705–15.
- Longo E., Badia M., Orgaz M. B. & Gómez-Vela M. (2017) Comparing parent and child reports of health-related quality of life and their relationship with leisure participation in children and adolescents with cerebral palsy. *Research in Developmental Disabilities* **71**, 214–2.
- Maharaj N. (2016) Using field notes to facilitate critical reflection. *Reflective Practice* **17**, 114–24.
- Malik F. & Marwaha R. (2021) Cognitive development. In: *StatPearls*. StatPearls Publishing.
- Melendez-Torres G., Hewitt G., Hallingberg B., Anthony R., Collishaw S., Hall J. *et al.* (2019) Measurement invariance properties and external construct validity of the short Warwick-Edinburgh mental wellbeing scale in a large national sample of secondary school students in Wales. *Health and Quality of Life Outcomes* **17**, 1–9.
- Menear K. S., Preskitt J. K., Goldfarb S. S. & Menachemi N. (2015) Correlates of wellness among youth with functional disabilities. *Disability and Health Journal* **8**, 223–30.
- Montserratt C., Savahl S., Adams S., Grigora B. A., Bacter C. & Bălătescu S. (2021) Childrens perspectives on scale response options of subjective well-being measures: a comparison between numerical and verbal-response formats. *Child Indicators Research* **14**, 53–75.
- Morrow A. M., Hayen A., Quine S., Scheinberg A. & Craig J. C. (2011) A comparison of doctors', parents' and children's reports of health states and health-related quality of life in children with chronic conditions. *Child: Care, Health and Development* **38**, 186–95.
- Nakra O. (2019) *Children and Learning Difficulties*. India, Notion Press.
- Nik-Azin A., Shairi M. R., Naeinian M. R. & Sadeghpour A. (2014) The health-related quality of life index KIDSCREEN-10: confirmatory factor analysis, convergent validity and reliability in a sample of Iranian students. *Child Indicators Research* **7**, 407–20.
- Noonan R. J., Boddy L. M., Fairclough S. J. & Knowles Z. R. (2016) Write, draw, show, and tell: a child-centred dual methodology to explore perceptions of out-of-school physical activity. *BMC Public Health* **16**, 1–19.
- Pennington B. F., Moon J., Edgin J., Stedron J. & Nadel L. (2003) The neuropsychology of Down syndrome:

- evidence for hippocampal dysfunction. *Child Development* **74**, 75–93.
- Phelps D. (2019) Developing visual supports for individuals with intellectual disabilities who are non-verbal to enhance communication in the home, school, & community. *The Omnipedia Review* **1**, 1–5. Available at: <https://digitalcommons.longwood.edu/cgi/viewcontent.cgi?article=1004&context=omni> (retrieved 11 October 2021).
- Ravens-Sieberer U., Erhart M., Rajmil L., Herdman M., Auquier P., Bruil J. *et al.* (2010) European KIDSCREEN Group. Reliability, construct and criterion validity of the KIDSCREEN-10 score: a short measure for children and adolescents' well-being and health-related quality of life. *Quality of Life Research* **19**, 1487–500.
- Ravens-Sieberer U., Gosch A., Rajmil L., Erhart M., Bruil J., Duer W. *et al.* (2005) KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert Review of Pharmacoeconomics & Outcomes Research* **5**, 353–64.
- Ravens-Sieberer U., Herdman M., Devine J., Otto C., Bullinger M., Rose M. *et al.* (2014) The European KIDSCREEN approach to measure quality of life and well-being in children: development, current application, and future advances. *Quality of Life Research: an International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation* **23**, 791–803.
- Ringdal R., Bradley Eilertsen M. E., Bjørnsen H. N., Espnes G. A. & Moksnes U. K. (2018) Validation of two versions of the Warwick-Edinburgh Mental Well-Being Scale among Norwegian adolescents. *Scandinavian Journal of Public Health* **46**, 718–25.
- Saracho N. O. (2013) *An Integrated Play-based Curriculum for Young Children*. UK & NY, Taylor & Francis.
- Schuchardt K., Gebhardt M. & Mäehler C. (2010) Working memory functions in children with different degrees of intellectual disability. *Journal of Intellectual Disability Research* **54**, 346–53.
- Scott J., Wishart J. & Currie C. (2011) Including children with intellectual disabilities/special educational needs into national child health surveys: a pilot study. *Journal of Applied Research in Intellectual Disabilities* **24**, 437–49.
- Shevell M. (2008) Global developmental delay and mental retardation or intellectual disability: conceptualization, evaluation, and etiology. *Pediatric Clinics of North America* **55**, 1071–84.
- Shier H. (2010) Pathways to participation revisited: learning from Nicaragua child coffee workers. In: *A handbook of children and young peoples participation* (eds N. Thomas & B. Percy-Smith), pp. 215–27. Routledge, Abingdon.
- Tennant R., Hiller L., Fishwick R., Platt S., Joseph S., Weich S. *et al.* (2007) The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. *Health and Quality of Life Outcomes* **5**, 1–13.
- The KIDSCREEN Group Europe (2006). *The KIDSCREEN Questionnaires: Quality of Life Questionnaires for Children and Adolescents Handbook*. Lengerich: Pabst Science Publishers.
- Upton P., Lawford J. & Eiser C. (2008) Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Quality of Life Research: an International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation* **17**, 895–913.
- Vaughn L. M. & Jacquez F. (2020) Participatory research methods—choice points in the research process. *Journal of Participatory Research Methods* **1**, 1–14.
- Vuijk P. J., Hartman E., Scherder E. & Visscher C. (2010) Motor performance of children with mild intellectual disability and borderline intellectual functioning. *Journal of Intellectual Disability Research* **54**, 955–65.
- Wernick L. J., Woodford M. R. & Kulick A. (2014) LGBTQ youth using participatory action research and theater to effect change: moving adult decision-makers to create youth-centered change. *Journal of Community Practice* **22**, 47–66.
- Westendorp M., Houwen S., Hartman E. & Visscher C. (2011) Are gross motor skills and sports participation related in children with intellectual disabilities? *Research in Developmental Disabilities* **32**, 1147–53.
- White-Koning M., Arnaud C., Bourdet-Loubère S., Bazex H., Colver A. & Grandjean H. (2005) Subjective quality of life in children with intellectual impairment—how can it be assessed? *Developmental Medicine and Child Neurology* **47**, 281–5.
- Williams D. T., Wetton N. & Moon A. (1989) *A Way In: Five Key Areas of Health Education*. Health Education Authority, London.
- Wilson C. & Powell M. (2012) *A Guide to Interviewing Children. Essential Skills for Counsellors, Police Lawyers and Social Workers*. Taylor & Francis.

Accepted 20 April 2022