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Running title: Reasonable adjustment in health assessment

TITLE OF MANUSCRIPT

Making reasonable adjustment to enable and support people with intellectual disability engage in objective health measures in a research study; The Health Fair in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.

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Acknowledgments

Grateful appreciation to the participants, their families and support carer's for their contribution to this study. The authors would also like to acknowledge the Health Research Board and the Department of Health for their continued funding and support for the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing.

Abstract

This observational cross-sectional study presents methods employed in designing and undertaking a suite of 8 health assessments, purposely named '*The Health Fair*', as part of Wave 2 (2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) study. Overall 604 persons of all levels of intellectual disability, aged 40 years and above and in different living circumstances, participated. The Health Fair process was mobile and overcame barriers such as communication challenges or access that people with intellectual disability face. This protocol could support researchers and practitioners in clinical practice to guide and improve the health assessment of people with intellectual disability to facilitate a better understanding of their health pathways and improve health care delivery and services.

Key words: Reasonable adjustment, health assessment, objective health measures, intellectual disability research.

Making Reasonable Adjustment to Enable and Support People with Intellectual Disability Engage in Objective Health Measures in a Research Study; The Health Fair In The Intellectual Disability Supplement To The Irish Longitudinal Study On Ageing.

Introduction

People with intellectual disability have increased health risks as they age (Burke et al., 2017; Kinnear et al., 2018). Frequently individual's health needs go unmet or overlooked (Cooper et al., 2006). Considering the growing ageing population of those with intellectual disability, efforts to understand the contributors and determinants of health and wellbeing are critical. Large longitudinal studies such as the Health and Retirement Study, in the United States, or The Irish Longitudinal Study on Ageing (TILDA), in Ireland, are mapping these determinants among the general population. However due to these studies methodologies, people with intellectual disability have been unintentionally omitted. Fundamental to the provision of appropriate health care is the establishment of determinants of health. The identification of these determinants is strengthened with the inclusion of objective health measures. In Ireland, The Intellectual Disability Supplement to TILDA (IDS-TILDA) was established to specifically follow a cohort of individuals with intellectual disability replicating the protocol of the general population study TILDA. *IDS-TILDA is a longitudinal study investigating the health and wellbeing of those with intellectual disability as they age. In Ireland the National Intellectual Disability Database (NIDD), under the management of the Health Research Board, collates information on the usage and need for disability services for national service planning. The NIDD formed the framework from which IDS-TILDA were granted permission to randomly select 10% of those over the age of 40 years, across all levels of intellectual disability and residing in a variety of living settings such as at home with family, in a community group home or in a residential setting. Invitation packs to the selected candidates were sent to the NIDD regional database controllers who acted as gatekeepers and posted the invites to the candidates. Only on return of their consent did the IDS-TILDA study*

know who was participating. Experienced and trained field researchers contacted the participants and set up a face-to-face interview. A pre-interview questionnaire was sent to the participants a minimum of one week prior, this allowed time for the participant to seek assistance from their key worker/carer to complete. Examples of the data collected includes healthcare utilisation, physical health conditions, medications, community participation, mental health and employment. Key to the inclusion of people with intellectual disability was their involvement at every stage of the study, the design of the accessible material that supported each aspect such as the questionnaire, consent and protocol, sitting on the steering committee and engaging in dissemination of the results. An international scientific board also reviewed and advised on content and process. Ethics approval was granted by the Faculty of Health Sciences Trinity College and all participating service providers. (McCarron et al., 2011, Carroll et al., 2014). Data is collected every three years and in the second Wave [2014] of data collection objective measures of health were included.

Integrating objective health measures into population studies promotes validation of self-reported health data and provides objective identification of risk factors of ill health. Objective measures can also promote more sophisticated analyses of disease pathways. However many issues influence the success or failure of engaging people with intellectual disability in research objective measurements. The literature is replete with examples of challenges and difficulties individuals experience; from gaining consent, communicating the process adequately to ensure understanding, to engaging individuals with minimal distress. Objective measures were new to the IDS-TILDA study introduced in Wave 2, influenced by results from similar studies (TILDA; English Longitudinal Study on Ageing) that suggested most participants found completing objective measures to be a positive experience. The aim of this paper is to describe the adjustments that enabled people with intellectual disability

engage in objective measurement in a longitudinal research study and identify the inhibitors and promoters of engaging this cohort.

Methods

The Design Philosophy

Designing a health assessment process for any large scale longitudinal research is complex and challenging and can require additional planning when participants have intellectual disability. Literature on health disparities is filled with examples of failed initiatives, imperfect understanding of how health care and health assessments may be successfully delivered and, paternalistic rather than inclusive intervention and research efforts (Chew, Iacono, & Tracy, 2009; Emerson, 2011; Taggart & Cousins, 2014). The differences in health experiences, the challenges in communication and tolerance of assessment for people with intellectual disability require a different approach. To that end, the key fundamentals of *Emancipatory Research Design Philosophy* (Oliver, 1992) were applied to The IDS TILDA Health Fair, that is, social engagement, reciprocity, gain and empowerment, in order to build an accessible model of health assessment delivery. The social engagement element incorporates interaction and exchange between the researcher and participant. The focus is on the activity or shared task, integrating the perspectives of both parties working together as equal partners. Supporting this is the second element of emancipatory research, namely reciprocity, which represents a research environment of mutuality and respect, contributing to both persons gaining an understanding of the value in the exchange that takes place. This blends almost translucently with the ethos of mutual benefit which refers to gain. The research and researcher seek to integrate the knowledge gained with interventions, policy and social change, to improve the health and quality of life of the research participants. Finally, the integral component of the philosophy – empowerment - is the promotion of the

participants, endorsing them as the most imperative factor in the process. Empowerment shares decision-making of all phases of the research process and transforms the locus of control from the researcher to a more shared endeavour, enabling the participants to articulate their views, contribute to the experience and be true partners in research. See Figure 1 for the operationalisation of these principles in the study.

The first consideration of this design was that the research assessment process would be referred to as '*The Health Fair*'. This was to avoid negative connotations of being tested and promote a more enjoyable interactive experience.

Co-production and collaboration

Seeking additional input reflected a belief that people with intellectual disability are best positioned to identify their own needs and experiences. Initially, the researcher worked with an independent self-advocate to draft the explanatory materials and overall health assessment process including the accessible consent process, explanatory easy read materials for the assessments and the plan for the overall roll out of The Health Fair. The researcher then organised focus group consultations with a number of independent self-advocacy groups throughout the country. Three advocacy groups reviewed and commented on the materials and processes making a number of suggestions which were incorporated into the assessment process. For example, the groups suggested the inclusion of processes to assist people with visual or hearing impairments. The researcher therefore included Lámh, modelling, hand-over-hand as well as visual demonstration. Finally, an independent advocate reviewed the finalised material for user friendliness and ease of understanding. In tandem, the researcher consulted with the IDS-TILDA Scientific Advisory Board who also guided and reviewed the

overall health assessment, the accessible material and the final process of collection. See figure 2 for the overall process employed.

In keeping with the emancipatory design, the researcher developed easy-to-read explanatory and supporting materials that were included in the invitation pack; an easy-to-read letter of invitation and information booklet which explained the process involved, and an easy-to-read appointment card. Each assessment was broken down into 4 or 5 steps using plain language instructions per step and a pictorial representation of the step. These steps reflected prior consultation with people with intellectual disability and were consistent with the participatory approach employed.

Measures included

All equipment utilised in the IDS-TILDA Health Fair replicated the equipment demonstrated to be valid, reliable and utilised in TILDA, supporting direct comparison with this general population study. A fundamental difference was that the researcher who developed the protocol and administered the objective measures for IDS-TILDA had extensive and considerable experience working with people with intellectual disability. This enabled key skills to be applied in developing a process suitable for personnel working in the area of intellectual disability to complete following sufficient training. Assessments included anthropometrics; height and weight (to calculate BMI), cardio metabolic measures; waist and hip measurement (waist to hip ratio calculated), blood pressure measurement (2 sitting and 2 standing to determine orthostatic hypotension), mobility, muscle strength; timed up and go test, grip strength (2 measurements on each hand), and bone health measures were obtained using a quantitative ultrasound of the calcaneus. Table 1 details the full list of the objective

health measures (OM) and equipment employed. As the focus of this paper is on the process, the results of the OM will be reported elsewhere.

Making reasonable adjustment

All assessments were supported by easy-to-read instructions developed through co-production and collaboration (Turner & Robinson, 2011). The easy-to-read principles of reasonable adjustments laid down by the European standards were applied and followed (Inclusion Europe 2016a, 2016b). This included the use of photos to demonstrate the procedure required, the use of plain language, one concept per sentence, short clear and concise sentences, and the provision of explanatory information prior to the day of the health assessment to ensure adequate time was given to the participant to review and consider their attendance. All assessments were conducted at a location and time convenient to the participant where possible. This included participant's service providers, their homes or day services. All participants received an easy-to-read appointment card with the photo and contact details of the researcher, so they knew who was coming to visit them. Alternative measures of the mid upper arm circumference and ulna length measurement were offered and utilised for those who were immobile, afraid, found it difficult, or refused to stand on the stadiometer or seca scale. This provided validated alternative measures of body mass index and height (Brotherton, Simmonds & Stroud, 2012). The researcher initially developed a pilot to test the feasibility of the assessments, time required and test the user-friendliness of the easy read material. This pilot also contributed to developing adjustments and techniques to the individual assessments. These adjustments included:

1. the employment of distraction techniques to draw participant's attention away from the potential discomfort of the automated blood pressure machine
2. allowing the participant to hold the tape when waist measurement was being taken to avoid invading their personal space with inappropriate hugs

3. supporting the participant when stepping onto scales to allay the fear of falling
4. face-to-face support to aid the person mount the standiometer which avoided the person grabbing the upright
5. using a small rubber ball to demonstrate and practice the squeeze action necessary for the grip strength

Identifying contributions and challenges to success on the day of The Health Fair

On the day of The Health Fair, notes and observations were recorded and accurately maintained for each participant detailing their experiences, comments made and observations from the researcher. All verbatim text from the field notes, observations and direct quotes were exported into an excel spreadsheet for thematic analysis. The excel sheet allowed colour coding, grouping and filtering of all the data. Braun and Clarke (2006) framework was applied. This entails a six step approach:

1. Familiarising yourself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Thematic analysis of the text allowed key commentary and opinion on the participant's experience of The Health Fair to be extracted.

Results

Participation

Of the 753 participants who were interviewed nationally for Wave 1 of the IDS-TILDA study [2011], 5.9% withdrew or were deceased prior to Wave 2 commencing. The

remaining 94% completed the Wave 2 computer assisted personal interview (CAPI) and were invited to participate in the objective health assessments (The Health Fair). Of those, 86.3% (n=611) agreed to participate, however seven participants withdrew on the day of The Health Fair, leaving a total uptake of 85.3% (n=604). Of those who participated, 50.8% (n=307) engaged in all elements of The Health Fair and 49.2% (n=297) engaged in at least one element of The Health Fair. Of those who did attend, 47.1% were supported to complete their assessment with the assistance of their support staff/carer. In total, 14.7% (n=104) did not participate in The Health Fair. See Figure 3 for overview of participation.

Demographic profile of the participants

Overall there were more females than males who participated in the study. Predominantly those who participated were between the ages of 50-64 years and reported a moderate level of intellectual disability. Most people lived either in a community group home or in a residential setting. People generally had a positive outlook on their own health with 86.4% self-reporting their health as excellent, very good or good. However in saying that the vast majority of the participants had one or more doctor's diagnosed chronic health condition such as epilepsy, osteoporosis or dementia. Full demographic profile can be viewed in table 2.

Exploring the contributors and inhibitors to success

In total there were 512 observations, comments and/or feedback from participants in The Health Fair. This represents 84.8% of the total Health Fair participants. Through the application of the Braun and Clarke thematic analysis method, the main themes to emerge were categorised into two global themes, the promoters which contributed to the success on

the day and the inhibitors which posed challenges on the day. The themes, meanings and subthemes are summarised in table 3 with detailed categories to emerge presented in figure 4. The comments were documented throughout The Health Fair on a daily basis and enabled the researcher to examine not only what was done that promoted participation, but also provided ongoing experiential learning of how the potential inhibitors were ameliorated and how the process was amenable to the participants, while ensuring the key fundamentals of the underpinning philosophy were maintained. The promoters to emerge included staff support, enjoying the interaction and experience on the day and receiving acknowledgement for their contribution and achievement in the form of a certificate of achievement.

Promoters

Staff/carer support was an important aspect to ensure the researcher understood participants:

Participant was non-verbal however staff said that if she didn't like anything she would push you away. [Field notes; FN]

Participant screamed a lot but staff said this is how she is when asked to do things, guided by staff participant appeared to calm and completed all measures [FN]

It also ensured participant confidence:

'Ah it was ok alright I didn't mind doing it the foot thing was different I never had that done before didn't mind once [named key worker] was with me' [P79]

Support persons also provided feedback to the researcher on the whole process which contributed to improvements:

"I'm 22 years working in this service area and that's the first time I've seen a well explained user friendly procedure with anyone with intellectual disability". [Participant (P) 45] [Staff supporter]

Many of the participants enjoyed the interaction with over 252 comments like the following examples:

“I loved it, I just loved it. I loved everything” [P123]

“It was good, it was excellent and I wouldn't mind doing it again” [P 57]

“Ah good, I liked it, when are you coming again?” [P246]

“Ah, I'd stay here all day that was easy and lovely”. [P2]

Another aspect that promoted engagement was the certificate of achievement, participants were proud of their achievement and delighted with the acknowledgement as reflected in the following quotes:

“Oh that'll go up on my wall so it will - I'll get a wee frame for that” [P27]

“My friend got a cert will I get one, would like to have one of those” [P66]

Inhibitors

Potential inhibitors included being anxious or nervous about what was going to occur, behaviours that challenge, communication challenges and physical health or mobility issues. Many participants were anxious and despite distraction techniques and support they were unable to engage:

I'll just look' [P325] Participant sat and watched the demonstrations staff noted that she was very nervous of new things, became anxious when asked if she would like to do any of the things and would not participate. [FN]

Some would do one aspect and then decide they had had enough:

'it was a bit tingly when the pressure was on, didn't like the blood pressure' [P09]

Overall some of the greatest challenges to engagement were behaviours that challenge, however some staff felt that with familiarisation some participants would eventually engage:

Participant arrived with 2 staff unable to relax, refused to engage and just wanted to pace, attempted to engage to no avail [field notes; FN]

Participant had autism, engaged in some assessments however would not take off shoes, staff said 'if we came back a few times he'd get used to you and you might get more done' [staff supporter]

Other inhibitory aspects noted included communication challenges and reflected partly the level of intellectual disability when a participant found it too difficult to understand the assessment particularly grip strength was a difficult concept for those with more severe to profound intellectual disability to understand:

Unable to understand the assessment or concept [FN]

Participant refused to engage or communicate kept head down wanted to leave [FN]

Some participants talked about their overall lack of education and found that this impacted on their ability to be independent:

Participant noted they couldn't read or write, was sad they couldn't write their own name [FN]

Finally, physical disability impeded some participants from engaging in some aspect of the health fair whilst those using a wheelchair were similarly impacted however alternate measures were used to establish body mass index:

12 Participant had foot deformities unable to conduct the QUS [FN]

Wheelchair users unable to do TUG/Weight/Height [FN]

As a result of the application of the emancipatory philosophy and the inclusionary principles that underpin it, the assessment outcome overall was favourable for participants and the majority of participants were able to engage in at least one part of the Health Fair. The thematic analysis also enabled identification of feedback from the participants in support of these findings which will be expanded through the discussion.

Discussion

Despite the current increase in lifespan, people with intellectual disability continue to die earlier (McCarron, Carroll, Kelly, & McCallion, 2015), present with more complex and adverse health conditions, experience more health challenges (Krahn, Hammond, & Turner, 2006; McCarron et al., 2013) and inequalities engaging in health care and health promotion, with needs often going unmet (Lennox & Kerr, 1997; Robertson, Roberts, Emerson, Turner, & Greig, 2011). IDS-TILDA is concerned with improving the health and well-being of people with intellectual disability as they age. Ageing is evident among people with intellectual disability in Ireland (Hourigan, Fanagan, & Kelly, 2017), however the mortality rate continues to be higher than those of the United States or Australia (Bittles et al., 2002; Janicki, Dalton, Henderson, & Davidson, 1999). The absence of objective measurements of health for people with intellectual disability from intellectual disability population research adds to the lack of health information about this cohort and contributes to marginalising people. To that end, including objective health measures as part of the IDS-TILDA study to assist in the development of a deeper understanding of the ageing process of people with intellectual disability was essential. This ambitious task involved the collaboration of advocacy groups and experts in the field of intellectual disability, the participants, carers and service providers. The success of this current study, whereby over 85% (n=604) of the IDS-TILDA participants engaged in health assessment, demonstrates that it is possible to obtain quality objective measurements with people with intellectual disability. Practice can learn

from the success of this study as the results contribute to building a wealth of empirical knowledge on the health trajectory of those with intellectual disability as they age. This knowledge can be used to underpin and include individuals with intellectual disability in policy development. Coupled with this, in Ireland healthcare delivery for many people with intellectual disability has changed over the last number of years. No longer are individuals attending to their healthcare needs within specific intellectual disability service providers. Instead people are now attending primary care settings, which is a positive step forward for inclusion. However many of the healthcare professionals working at these centres are unfamiliar with intellectual disability, contributing to poorer experiences and perhaps conditions being overlooked, frequently as a result of lack of reasonable adjustment and understanding. The findings from this study informs practice that not only can individuals engage, but provides ‘the how’ to enable this to happen. It is imperative that clinical practice include the need for reasonable adjustments, as demonstrated in this study, in their service policy and practice protocols to enable people with intellectual disability engage fully. Adjustments such as, but not limited to, sufficient time, augmented communication techniques and easy read explanatory information.

The percentage of engagement in The Health Fair indicates the overall success and achievement of the participants, their carers and The Health Fair process itself. An important element in this success, was underpinning the whole process with the key fundamentals of an emancipatory philosophy (Oliver, 1992). This provided the framework through which an infrastructure could be built to make possible the application of novel approaches to each of the assessments and so improve participant involvement, create processes with reasonable adjustments and ultimately promote success. The key fundamentals complement and work together to promote overall reasonable adjustment of each of the assessments, therefore ensuring the process, to a great extent, meets the needs of each participant. As health policies

change and place responsibility for one's health with the individual, recognition is required to ensure suitable accommodation is included for people with intellectual disability so they too can enjoy full health however this will not happen unless awareness is risen within the health provider's domain. This study demonstrates how, through a collaborative process people with intellectual disability can contribute to building this awareness and the knowledge of what needs to happen to support practice to understand how individuals can take that responsibility and be empowered to engage fully in their own healthcare.

Empowerment ensured the sharing of the decision-making through the collaborative process, working with advocacy groups through to ensuring the participant on the day of the assessments retained full independence in their decisions about taking part. The accessible consent was thoroughly explained with the support of pictorial representation. The underpinning framework also ensured information was in a form understandable to all stakeholders and promoted participant's ability to take part through the use of easy-to-read information and explanatory material. Empowerment was supported through the involvement of the participant's carer and service provider and the application of multiple communication methods to ensure full understanding, such as the use of augmented sign language, hand over hand, pictures, demonstrations and carers demonstrating, as well as affording each participant sufficient time to build confidence in the process. All aspects that could easily be adopted by health services to improve the experience of individuals when they engage in assessments in clinical practice.

The carer's support on the day was imperative. Their knowledge of the participant, their support and encouragement and their advice to the researcher contributed greatly to a successful Health Fair. Complimenting empowerment in the emancipatory philosophy is the second key element, namely reciprocity, ensuring respect and dignity to all participants. The researcher ensured choice was respected at all times, for example, although the lay out of The

Health Fair was specific as to reduce burden, it also needed to be flexible enough to ensure it met the choice and interest of the participant. Therefore, if a participant chose to start with having their blood pressure measured, this was facilitated. Flexibility in processes is one aspect that clinical practice needs to pay attention to, all too often clinical appointments are regimental and lack that element of flexibility contributing to failure for the individual with intellectual disability to engage. Participants expressed their satisfaction of the process and enjoyment of taking part indicating that they would not mind doing it all again, another reflection of a successful process. Building capacity was essential to participant success, therefore including surrogate measures and developing alternative techniques and approaches to assessments, such as the technique for mounting the stadiometer (to measure height) or the distraction technique employed when taking blood pressure measurement to reduce anxiety, were all invaluable and again demonstrate avenues of potential for clinical practice to build flexibility in their processes.

The final elements to the emancipatory philosophy are social engagement and gain. These were operationalised by offering the assessments at a site convenient to participants where possible, and ensuring the participant and their carers were furnished with information prior to The Health Fair. This material informed them of the study and the potential contribution to the health and well-being of people with intellectual disability, while providing the results and explanations in an easy-read format and highlighting any anomalies for further action. This was appreciated by staff and participants, as some opportunities such as having a bone assessment may not have occurred previously. Many health services do provide easy-to-read information however this is not the norm. Greater effort to have easy read as a fundamental requirement needs to be included in health policy to ensure not only people with intellectual disability are included but all citizens with any literacy challenges can engage in health care.

The participants in this study also received a certificate of achievement on completion of any or all of The Health Fair. The participants expressed pleasure and enjoyment in receiving this and frequently told their friends or proudly displayed their certificate in their homes. Sometimes, it was the delight in receiving the certificate that instilled a pride in their participation. For one participant, support staff noted that anything new or different created anxiety and the participant became very scared, however working through The Health Fair, employing all techniques and promoting relaxation, the participant completed all elements and was thrilled when he received his certificate. The participant was excited and could not wait to go to tell all the staff about what he had achieved.

The emancipatory philosophy contributed to overcoming many of the challenges encountered in engaging people with intellectual disability in health assessment, something clinical practice needs to pay attention to. As can be seen by the success of the process implemented in this study, excuses such as too difficult or people with intellectual disability being unable to do this, are not acceptable. With innovation and a flexible process embedded in an emancipatory philosophy, inclusion of objective health measurement in research is possible for people with intellectual disability. Ensuring '*nothing about me, without me*' (Delbanco et al., 2001) resonates as the pinnacle of shared decision-making in carrying out the assessments in a collaborative manner preventing the sole focus of merely measuring. Evidence based guidelines on engaging persons with intellectual disability in health assessments and health monitoring are limited. To that end this study provides the framework that health services could adopt to underpin practice, a framework co-created with individuals with intellectual disability, to promote success and engagement of individuals in objective health measures therefore contributing to improving health care delivery and ultimately quality of life for people with intellectual disability.

Implication of the study

This study aimed at describing the reasonable adjustments that were included in the objective measures collected in the IDS-TILDA study. It can be seen by the positive response and successful engagement of the participants that these adjustments promoted good involvement and improved participation. These novel and reasonable adjustments are very transferable to clinical practice and offers clinical practitioners the opportunity to improve individual's engagement in everyday health appointments. Along with this, embedding an inclusionary philosophy in practice policy to encompass the development of easy read documentation would further promote the involvement of individuals with intellectual disability however co-production and collaboration with individuals are imperative and fundamental principles that need to underpin such activity. The landscape of care of those with intellectual disability is radically changing in Ireland whereby institutional type settings are expected to close and people living there move to more community integrated settings. Whilst these changes are occurring the shift in the care of people with intellectual disability is moving to primary care. More and more clinical practitioners are being exposed to providing care for people with all levels and complexities of intellectual disability. However many of these practitioners have no previous experience with individuals with intellectual disability. This study presents a practical contribution to the development of an all-inclusive approach to comprehensive guidelines to support these practitioners and provides much needed empirical evidence that people with intellectual disability can be active consumers of healthcare.

Strengths and Limitations

Contribution to the field is multifaceted. Firstly this paper describes the process to ensure people with intellectual disability are embedded in the design of any research being undertaken with them. Secondly, it describes the underpinning philosophy to enhance the promotion of reasonable adjustment lead by people with intellectual disability. Thirdly it provides the reader with a process that is successful and amenable to people with intellectual disability, all of which contribute to demonstrating a strength-based approach to including people with an intellectual disability in research. Although this was primarily designed for healthcare research, the philosophy and learnings can potentially be applied to everyday situations for people with intellectual disability, such as attending the doctor, going to a hospital appointment or having a health check. Through reasonable adjustment, the healthcare experience for individuals can be improved, bridging the gap of disparity frequently referred to in the literature.

Some participants did not engage in all of the assessments. A proportion of participants, especially those with behaviours that challenge and autism had particular difficulty despite employing strategies to engage the participants. It is noted that perhaps due to the longer time required by these particular participants to build familiarity with the processes and assessments, additional time or a couple of visits to desensitise individuals could result in successful engagement in the future. It is also noted that a number of participants did not attend; it is the intention of the researcher to further explore the challenges for these non-attenders. For people with severe to profound intellectual disability, grip strength and the timed-up and go test, for which there are no alternatives, posed particular challenges. However, there was a good overall response rate and every effort was made to encourage and facilitate participation. Those who were ill and in hospital were not included.

Conclusion

In summary, this paper details the assessments, approach, philosophy and structure adopted in undertaking objective measurement with people with intellectual disability. Frequently it is said that engaging people with intellectual disability in research and especially research which involves objective measurements is too difficult, too stressful for the person with intellectual disability or just not possible. Excluding people on these grounds is colluding in the disenfranchisement of people with intellectual disability. As demonstrated in this study, with innovation, adoption of adaptable and flexible guidelines embedded in an emancipatory philosophy, inclusion of measurement is possible for people with intellectual disability. Critically this study provides an evidence base that could easily be transferred to the clinical setting to assist not only the research community, but more importantly the doctors, nurses and multidisciplinary teams, to ensure equity of access to health care for people with intellectual disability. With the right processes and enablers in place, people with intellectual disability of all levels and abilities can engage in objective measurements to provide and contribute to building a robust picture of their health as they grow older. In doing so, they contribute to developing a greater understanding of their health pathways to improve their health care delivery and services now and to the future.

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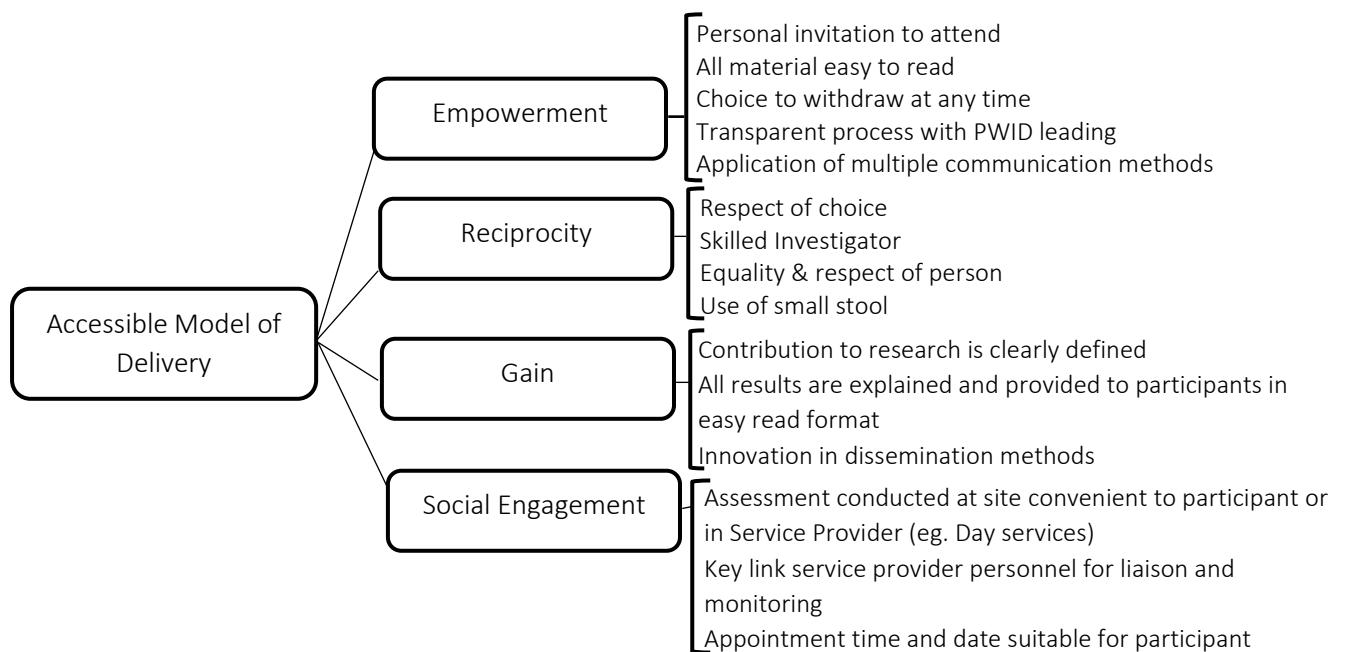


Figure 1.0: Operationalising the emancipatory research design to the health assessment process

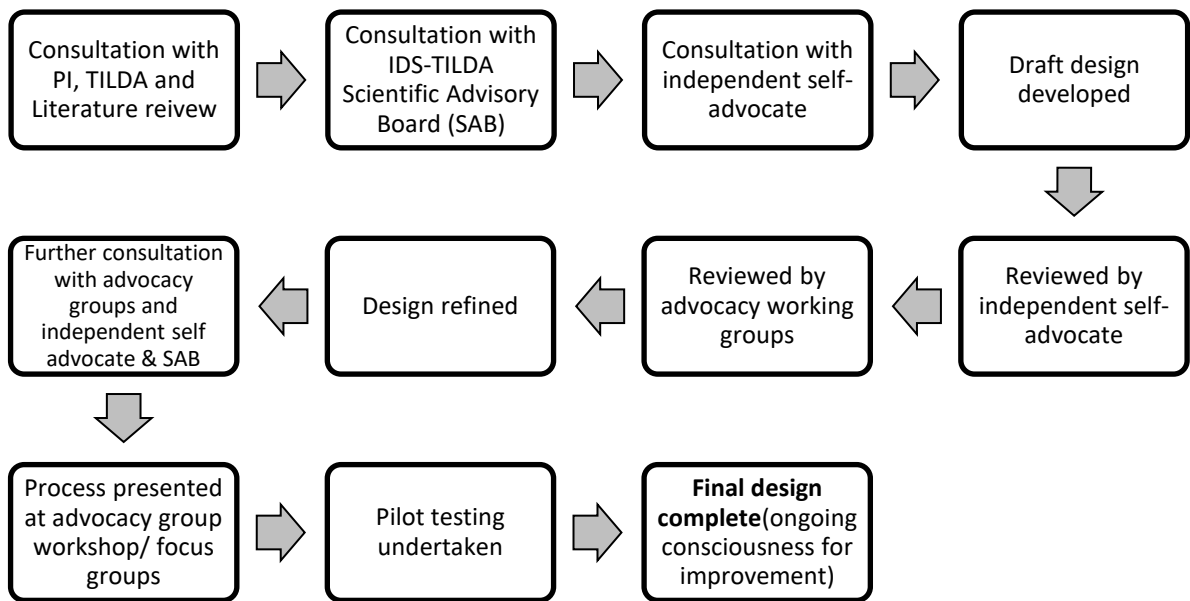


Figure 2: Collaborative and consultative process in designing the Health Fair.

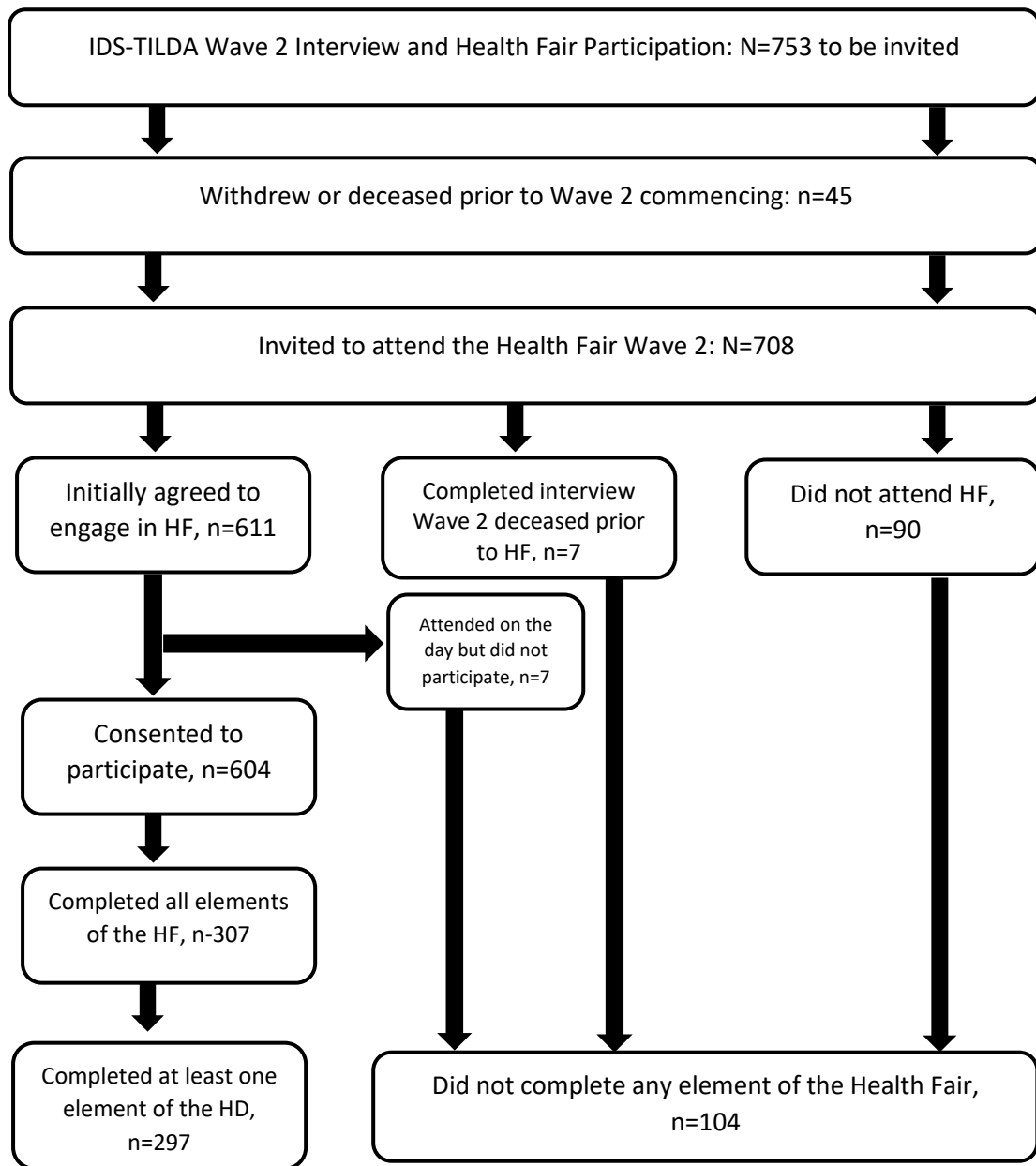


Figure 3: Participation in Health Fair Flowchart

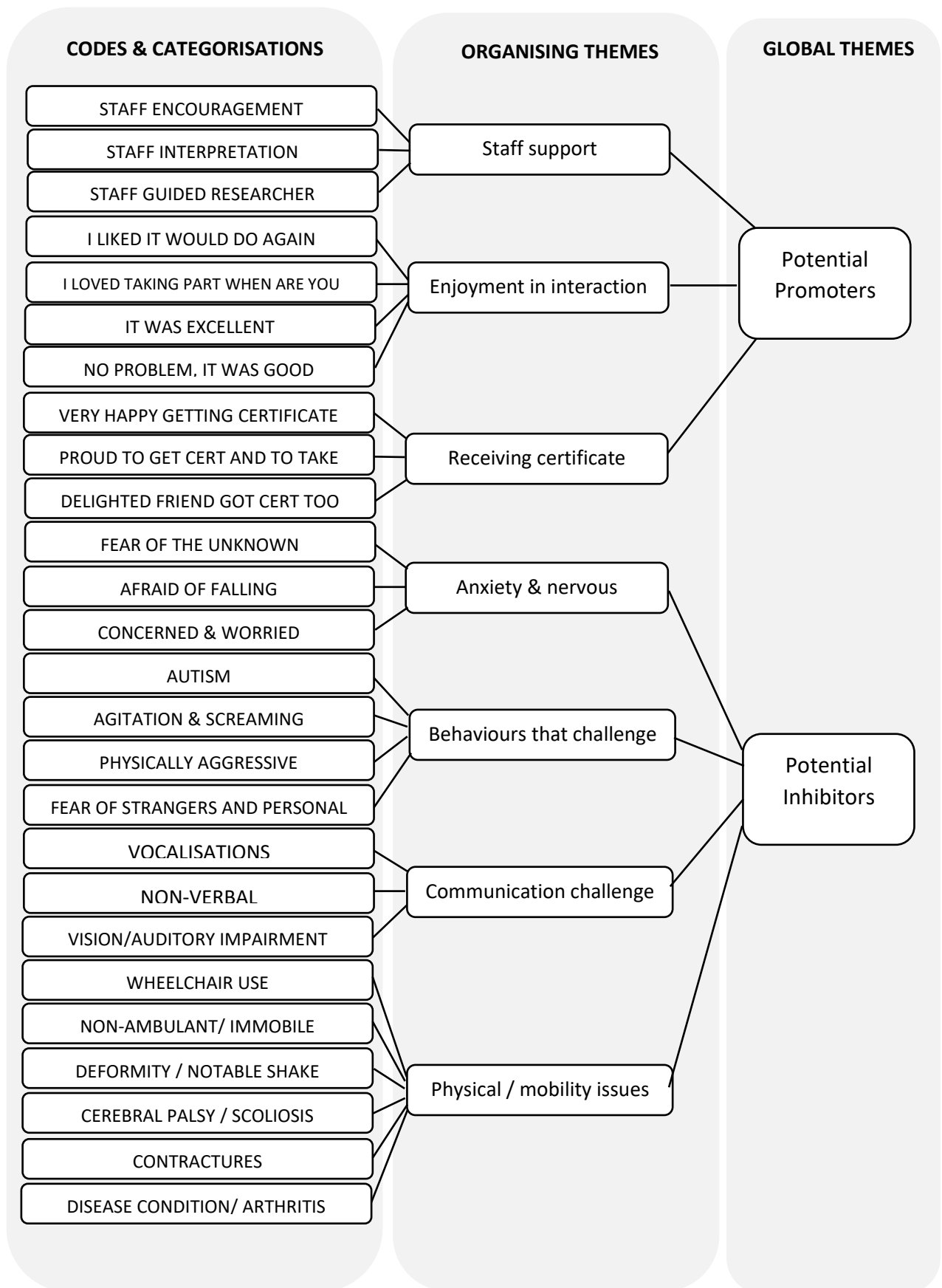


Figure 4: Potential inhibitors and contributors for participant's engagement with the Health Fair

Table 1

Objective health measures included in the IDS-TILDA study

Objective health measurement	Number of measurements	Equipment or test used
Height	1	Seca 217 portable stadiometer
Weight	1	Seca 803 digital scale
Waist size	2	Seca tape
Hip size	2	Seca tape
Blood pressure	4 (2 sitting and 2 standing)	Omron M10-
Grip strength	4 (2 on each hand)	Jamar Hydraulic Dynamometer
Timed up and go	1	Standard chair (45 cms), tape measure, high visibility tape and a stopwatch
Bone assessment	2 (both heels scanned)	GE Lunar Achilles Ultrasound

Table 2

Demographic description of the health fair participants (N=604)

Demographic variable	%	n	total
Gender			604
Male	42.2	254	
Female	57.8	350	
Age			604
<50	28.5	172	
50-64	51.5	311	
65+	20.0	121	
Level of Intellectual Disability*			563
Mild	22.9	129	
Moderate	47.4	267	
Severe/Profound	29.7	167	
Living Circumstance**			602
Independent/Living with family	14.8	89	
Community Group Home	43.5	262	
Residential Service	41.7	251	
Self reported health***			588
Very good/good	86.4	508	
Fair/poor	13.6	80	
Chronic health conditions (CHC)			604
≤ 1 CHC	13.7	83	
>1 CHC	86.3	521	

NOTE: *Not all participants verified their level of ID missing values 41

**Not all participants provided their living circumstance missing values 2

***Proxy respondents did not answer self reported questions missing value 16

Table 3

Themes, meaning and subthemes

Global themes	Meaning	Sub-themes
1. Potential promoters	Agents, means or drivers that promoted the engagement of individuals in the health fair	<ul style="list-style-type: none"> (i) Staff support (ii) Enjoyment in the interaction (iii) Accessible information & receiving certificate
2. Potential Inhibitors	Causes or factors that prevented the individuals engagement in the health fair	<ul style="list-style-type: none"> (i) Anxiety and nervousness (ii) Behaviours that challenge (iii) Communication challenges (iv) Physical/mobility issues