Northumbria Research Link

Experience Sampling Method and the Everyday Experiences of Adults with Intellectual Disability: A Feasibility Study

Background: Experiences of people with intellectual disability ~~(ID)~~ are often reported by proxy, excluding the person's own perception. To ~~better~~ assist people with intellectual disabilities ~~ID's~~ ~~to~~ ability to communicate their own experiences~~have their say~~, the current study explored the feasibility, reliability and validity of Experience Sampling Methods (ESM) for people with intellectual disability~~ID~~.

Method: After a training session, 19 participants carried a mobile device for 7 consecutive days, answering a survey when prompted 7 times daily. Participants were interviewed at the end of data collection.

Results: Excluding incomplete entries, the response rate was 33.8%, varying by living arrangement and employment. Split half reliability and correlations among logically linked internal experiences demonstrated strong reliability and validity. Illustration of the context of responses supported face validity. Technological and content difficulties were discussed in interviews.

Conclusions: ESM is feasible for some people with intellectual disability~~ID~~, providing valid and reliable information. Future research is needed to further improve feasibility and evaluate reporting accuracy.

Keywords: Experience sampling method, intellectual disability, reliability, validity, feasibility

Running title: Feasibility of ESM for people with intellectual disability~~ID~~

Introduction

For many, having an intellectual disability ~~(ID)~~ can mean that pragmatic language skills, expressive communication skills, and comprehension can be a challenge. In particular, communicating with others about internalised perceptions and feelings of subjective experiences and emotions has been referred to as being 'incongruous' with having an intellectual disability~~ID~~ (Bradshaw, 2001). The process of making truly informed decisions and exercising personal choices, especially more complex decisions, can be made difficult when a person with intellectual disability~~ID~~ has difficulties accurately expressing their feelings and perceptions. In addition to such possible communication difficulties, there are two major barriers to ~~this reality~~making independent decisions uniquely facing people with intellectual disability~~ies~~~~ID~~: proxy decision ma~~de~~king by others based often on the principles of best interests (e.g., Bigby, Whiteside & Douglas, 2017), and the reported tendency toward acquiescing to others to not only be agreeable, but also to avoid saying the wrong thing (Finlay & Lyons, 2002). Countering these barriers has been the focus of many scientific and advocacy endeavours over the decades, yet problems persist in finding ways to accurately help people with intellectual disability~~ID~~ self-report their feelings and experiences (Stancliffe, Wilson, Bigby, Balandin & Craig, 2014). This study reports feasibility data using a novel approach, *Experience Sampling Method* (ESM) using mobile devices, which may be a method for allowing individuals with intellectual disability~~ID~~ to self-report.

ESM (Hektner, Schmidt, & Csikszentmihalyi, 2007), an ecological momentary assessment (Shiffman et al., 2008), allows individuals to report actions, thoughts and feelings in real time across naturalistic contexts through repeatedly completing a survey designed by the researchers and tailored to the research questions. Often using electronic mobile devices, such as smart phones, participants are prompted at multiple times throughout the day and across the entire data collection period to respond to a survey to collect their external (e.g.,

what they do in real life) and internal experience (e.g., thoughts and feelings). Hence, this method can produce unique data regarding the dynamic relationships between internal and external experiences of research participants that may not be captured, or at least not as well, by the use of standardised questionnaires or lab-based methods (Shiffman et al., 2008). Consequently, data collected through this method have increased ecological validity. As participants are prompted to enter data 'as it happens', using ESM can reduce the risk of recall problems, a noted major issue for people with intellectual disability~~ID~~ while using retrospective measures such as interviews or global questionnaires, even ~~though~~ when augmentative communication techniques were applied (Stancliffe et al. 2014). Further, the wording of the ESM survey questions should be straightforward and definite, satisfying the participants' reading comprehension levels. This methodology is less cognitively demanding than retrospective approaches (Trull & Ebner-Priemer, 2009).

ESM has been used to collect unique data in different populations to address a range of research questions, such as assessing behaviours and experience in daily life, the impact of symptoms on behaviours and emotions, or investigating quality of life (Shiffman et al., 2008; Trull & Ebner-Priemer, 2009). For example, Whalen and colleagues (2002) used ESM to measure health behaviours in adolescents, including drinking, smoking and stress. Myin-Germeys and colleagues (2003) used ESM to understand emotional reactivity to daily life stress in participants experiencing psychosis. ~~. Using these methods, they were able to~~ collecting ~~data related to participant's' current context and their relating mood, appraisal and thoughts. Similarly, data has been collected regarding the use and effect of emotion regulation strategies in response to stressors for people with Post-Traumatic Stress Disorder (Short, Boffa, Clancy & Schmidt, 2018). ESM has also been used to measure perceived quality of life in children with neuromuscular disorders (Bray, Bundy, Ryan & North, 2010). A particular benefit of this method was it allowed the participants themselves to report their

experiences, rather than relying on proxy or parent data. ESM has also been used to measure health behaviours in adolescents, including drinking, smoking and stress (Whalen, Jamner, Henker, Delfino & Lazano, 2002). While ESM ~~was~~ has predominantly been used as an assessment tool, incorporating ESM into intervention ~~as a momentary intervention~~ is also promising to address behaviours at critical moments in the participants' ~~real~~ life (e.g., Hare, Gracey, & Wood, 2016).

ESM has recently shown appropriateness in understanding social participation in certain populations that may experience exclusion, including people with disabilit~~y~~ies or developmental disorders. Using the ESM approach, Hintzen and colleagues (2010) found that adults with pervasive developmental disorders, on average, responded 43 times out of a possible 60 prompts (71.6%) about their social ~~spent~~participation. Using ~~this~~these data, Hintzen and coleagues (2012) found that participants with development disorders spent more time with family than a ~~healthy~~ control group without a developmental disorder, whereas those in the control group spent more time with friends or acquaintances. The feasibility of using ESM has also been examined to understand everyday experiences of people with Autism Spectrum Disorder (ASD; ████████████████████████████████ ██████████). An average response rate of 71% and a short completion time of the survey supported the feasibility in this population. Further trials gave insight into understanding the activities participants performed throughout the day, how they felt about such activities and who they preferred to spend their time with ██████████████████████████████████. The feasibility of ESM has also been tested in typically developing children aged between 5 and 7 years ██████████████████████████

Of note is that these methods have not yet been used in participations with intellectual disability~~ID~~. Currently, we know that people with intellectual disability~~ID~~ are often excluded from social and economic participation, are vulnerable to isolation and often have strictly

controlled social or leisure activities (Dusseljee, Rijken, Cardol, Curfs & Groenewegan, 2001; Milner & Kelly, 2009; Stancliffe, Lakin, Dalianac, Byun & Chiri, 2007). However, ~~these types of~~ research mostly ~~rely~~ relies on retrospective methods, such as interviews or surveys, or proxy reports from parents or carers. There is a significant gap in the literature in allowing people with intellectual disability~~ID~~ to ~~have their say~~self-report about their social participation, experiences and feelings. It is important to understand how people with ID feel about their own social participation, including what they like and do not like, and to understand this from the person's perspective, rather than through proxy. Although the body of literature about mobile phone use and people with intellectual disability~~ID~~ is scant, what we do know is that many people with intellectual disability~~ID~~ do use mobile phones, ~~with~~ and have functional and reading ability ~~related to~~compatible with phone use (Bryen, Carey & Friedman, 2007). However, barriers to use include features such as the small size and complexity of app icons and phone functions (De Urturi Breton, Hernández, Zorrilla & Zapirain, 2012). Provided these access barriers can be overcome, ESM may provide a method to capture the daily external and internal experiences of social participation for people with intellectual disability~~ID~~.

The purpose of this study was to examine the feasibility of ESM using mobile devices for exploring everyday experiences in adults with intellectual disability~~ID~~. First, we examined signal response rates in survey completion and gathered feedback from each participant to determine the acceptability of the method. Further, we examined internal reliability and validity through consistency of the data and internal logic of responses reflecting internal experiences.

Methods

Design

Feasibility of ESM for people with ~~intellectual disability~~ID

This observational study used a single-group descriptive design to determine if ESM using a mobile device was feasible in adults with intellectual disability~~ID~~.

Ethical considerations

This study was approved by the ███████████████████████████████

███████████████████████. A modified participant information statement and consent form was developed using plain English and images to enhance the accessibility of the research recruitment material for people with intellectual disability. ~~Consent was completed where the participant lived with a family member.~~ All participants provided written informed self-consent; where the participant lived with a family member, ~~they~~the main family caregiver also co-si~~n~~gned the consent form, along with the researcher, to formalise shared understanding of the consent process. Participants were offered a $50 gift voucher at the end of their week of~~'s~~ participation to recompense them for their time. Although the participants were advised to actively report any negative experience to researchers over the course of the study, no adverse events were reported and there were no withdrawals from the study.

Development of the ESM survey

The ESM survey was adapted for use by adults with intellectual disability~~ID~~ from the surveys developed by the second and last authors in studies with children and young adults with ASD (███████████████████). The survey comprised 12 questions to identify the external and internal aspects of experiences when signalled. For the purpose of this study, external experiences included what they were doing and people they were with, while internal experiences were explored against ~~the~~ two domains: quality of experience (e.g., liking the engaged situation, having fun, perceived difficulty, desires to do something else, and preference for being alone)~~,~~ and emotions (e.g., feeling anxious and feeling lonely). The format of items included multiple choice~~s~~ for external experiences and dichotomous

responses for internal experiences. The Flesch-Kincaid readability test (Kincaid, Fishburne, Rogers, & Chissom, 1975) showed that the grade level of the survey questions was 0.8. To accommodate for literacy skills of adults with intellectual disability~~ID~~ and to help counter the mobile device access issues noted in the literature (De Urturi Breton et al., 2012), we specifically used an ESM survey application mEMA (Ilumivu, 2017) that allowed the use of images to assist the understanding of questions and response options; Figure 1 provides an illustrative example of the types of questions and the use of images in the survey. A full copy of all survey items and images are available from the corresponding authors upon request.

<INSERT FIGURE 1 ABOUT HERE>

Instruments

The WoodCock Reading Mastery Tests (WRMT-III; Woodcock, 2001)~~Reading Comprehension Ability~~

The ~~Woodcock Reading Mastery Tests (~~WRMT-III~~;~~(~~Woodcock, 2011) was used to measure participants' reading comprehension abilities to ensure ~~that~~ they could read and comprehend the words presented in the survey. WRMT-III is a psychometrically sound standardised assessment tool consisting of 9 individually administered tests of reading skills for individuals aged between 5 and 79 years. Two subtests, namely *Word Comprehension and Passage Comprehension* were used to identify participants' reading comprehension abilities. The Word Comprehension subtest measures individuals' reading vocabulary by testing their ability to read a word and ~~stating~~ state corresponding synonyms, antonyms and analogies. The Passage Comprehension subtest examines individuals' vocabulary and comprehension skills by testing their ability to identify and fill in missing word in texts ranging from sentences to short passages. Both subtests are combined to provide an overall measure for reading comprehension skills.

Need for SupportThe Inventory for Client Agency and Planning (ICAP; Bruinincks, Hill, Weatherman & Woodcock, 1986)

The Inventory for Client and Agency Planning (ICAP (; Bruininks, Hill, Weatherman, & Woodcock, 1986) was used to measure participants' adaptive and maladaptive behaviour and need for support. The ICAP provides an overview of any adaptive and maladaptive behaviour and produces a Broad Independence Score. To measure adaptive behaviour, caregivers are asked to rate the participant's on 4 subscales: motor skills (18 items), social and communication skills (19 items), personal living skills (21 items) and community living skills (19 items) on a scale of 0 "*Never or rarely*" to 3 *"Does very well"*. These scores produce a total Adaptive Raw Score. Using norm tables, tThe raw scores of each subscale are converted to Domain scores and averaged is also averaged to produce a Broad Independence Score that reflects the participants overall adaptive skills and independent living ability. This score ranges from 306 to 554, with greater scores indicating greater independence. This score can also produce an age-equivalent scores (Year-Month) that range from <0-3 to 36-0.

To measure maladaptive behaviour, caregivers are asked to rate the frequency (0-*"Never"* to 5 *"One or more times and hour"*) and severity (0- *"Not serious; not a problem"* to 4 *"Extremely serious; critical problem"*) of the following categories of behaviour: Hurtful to self, hurtful to others, destructive to property, disruptive behaviour, unusual or repetitive habits, withdrawal or inattentive behaviour, socially offensive behaviour and uncooperative behaviour. If the participant experiences any behaviour that falls into any of the above category, the caretaker is asked to rate that category as a whole. Such scores are used to calculate four Maladaptive Index scores: Internalized, Asocial, Externalised and General.

The ICAP provides a matrix that using the General Maladaptive Index score and Adaptive Behaviour raw scores are used to determine the participants total service needs score, This assessment comprises a total service needs score that reflectsed the level of care a

participant requires, ranging from 1 (total personal care and intense supervision) to 9 (infrequent or no assistance for daily living).

The ICAP has a test-retest reliability of 0.87 to 0.98 and an inter-rater reliability of 0.83 to 0.94. As the ICAP is an informant-rated measure, only those participants with a regular informant in their lives were asked to complete the ICAP.

Participants

Recruitment of participants with mild to moderate intellectual disability was particularly challenging and time-consuming. At first, our approach was to use existing networks within the disability services sector to disseminate information about the study to people with intellectual disability. This proved a challenge; anecdotally researchers reported that service providers denied disseminating information about the study. This was in relation to the new individualised funding environment of the National Disability Insurance Scheme (NDIS) in Australia, as service providers only receive funding for providing a specific support and time spent supporting research is not viable for many services facing the financial disruption of NDIS. Sectorial barriers to recruiting people with intellectual disability has been noted in other research (e.g., Lennox, Taylor, Rey-Conde, Bain, Purdie & Boyle, 2005). Our next strategy was to approach people with intellectual disability and their families directly via social groups and support networks; this proved to be a more successful approach. Once a small number of people with intellectual disability had been recruited, their friends heard about the project and many subsequently asked to participate. Thus, participants were recruited using a combination of convenience, purposive and snowball sampling over a 12-month period between early 2018 and early 2019.

We recruited 29 participants with self- or caregiver-reported mild to moderate intellectual disability; however, the data for 10 participants were missing due to software, data uploading and/or mobile device issues. For these 10 participants, we confirmed

with the participants and parents of the parents that the participants have did completed a number of surveys and followed the specified procedure to retrieve the data. However, we were not able to upload any of this data, thus we concluded these missing data were due to technological flaws as opposed to issues with the individual being able to complete the measures. Hence these participants are excluded from the study analysis as it appeared to be an issue with the technology we selected and not specifically with the ability of individuals with intellectual disability to complete ESM. In total, demographic data from 19 participants living in four different Australian states were collected, the majority of whom were male (62.5%) and lived with family (74.0%). Of the seventeen participants whose caregiver completed the ICAP (Bruininks et al., 1986), the lowest service scores was 6 ($n = 2$), indicating regular care or supervision. The remainder scored between 7 and 9, indicating limited or infrequent care. Most maladaptive scores were within the 'normal' range, with three participants exhibiting internalised behaviours in the 'marginally serious' range. Broad Independence Scores, reflecting overall adaptive behaviour and independence, ranged from 361 to 533, indicating independence in most domains. The age equivalence (Year-Month) of Broad Independence Scores ranged 7 months old to 17 years and 10 months, with an average age equivalence of 10 years and 3 months. The participants' word, passage and reading comprehension abilities determined by the WRMT-III were at least at Grade 1.3, which is higher than the reading level of the ESM survey. Thus, all participants had sufficient word, passage and reading comprehension to complete the surveys (Woodcock, 2011). Table 1 provides an overview of the aggregated demographic data.

<INSERT TABLE 1 ABOUT HERE>

Procedures

Prior to the data collection, a 45-60-minute training session was conducted with the participants and parents at their venue of choice, either at their home or a quiet place. The survey was delivered to the participants using either an iPhone/iPod Touch® or Android® mobile device. The device signalled participants to complete the survey, time stamped the responses and stored the data ready for analysis. The training included a demonstration of how to use the mobile device and instructions on how to access and use the mEMA App to complete the survey. Each survey question was accompanied by images and explained in detail to ensure the participants understood the available responses. The participants were asked to read out the questions and choose a response based on the situation they were in during the training in the presence of the researcher, to ensure there were no difficulties in reading and understanding the survey. Several surveys were then completed using the mobile device by pretending they were in different contexts until the researcher was confident in the participant's ability to respond to the survey and use the device. This process relied on researcher judgement. On average, four practice surveys in differing scenarios were conducted. If the researcher judged that the participant was independently answering survey questions according to the differing scenarios, they were deemed ready to participate. Researchers focused on the internal aspects of experiences during the training of the survey to ensure the participant was able to understand the meaning of each item. This again relied on researcher judgement and interaction with the participant. Internal aspects, such as emotions, were often related to how the individual participant understood that emotion (e.g. when I'm happy, I smile). The researcher would then apply this understanding to differing scenarios to ensure understanding that emotion in context (e.g. "Would being at work make you smile?"). If the participant was able to answer questions about internal aspects consistently across differing scenarios, they were deemed ready to participate. The mEMA App was configured to provide three signals separated by one minute at each randomised

timeslot to remind the participants to complete the survey; surveys remained accessible for a period of 10 minutes after the first signal.

During the formal data collection process, adults carried the mobile device for the duration of seven consecutive days. The mEMA App randomly signalled the participant to respond to the ESM survey seven times daily between 8 am and 8 pm. To avoid the signals occurreding too closely or overlapping, the signals were set at least 20 minutes apart. The researchers employed multiple strategies to promote the efficacy of using ESM for adults with intellectual disabilityID, which included: contacting the participants every 2 to 3 days during the survey period to address any technical issues and to remind participants to be mindful of the device and keep it in close proximity. Participants were interviewed about their experiences with the survey at the end of their data collection period to clarify their experiences of participation. For cases where the participant lived with family, parents were also invited to offer any feedback via telephone about the study participation. The semi-structured interview questions consisted of:

1) Can you tell me about yourself and your weekly routine? Where do you go, what do you do, friends and hobbies?
2) What was it like having the smart phone with you all week?
3) What was the easiest thing about answering the questions on the app?
4) What was the hardest thing about answering the questions on the app?
5) Were there any questions you found hard to answer?
6) Is there anything else you'd like to tell us?

Data Analyses

To explore compliance and burden of participating in the ESM study, the signal response rate (i.e., the percentage of signals to which each participant responded over the course of the study) and the response rate of survey completion (i.e., the percentage of number of surveys each participant completed over the course of the study) were recorded (Hektner et al., 2007). Previous researchers suggeststed that the participants had toshould completed at least 33% of

the ESM survey to ensure the data were are valid for analysis (Chen et al., 2014; Hintzen et al., 2010; Myin-Germys et al., 2003). Previous researchers found that that measures of individuals with less than 30% of completed ESM surveys were less reliable (Delespaul, 1995). To identify how individual characteristics impacted compliance, Spearman's rank correlation coefficient (ρ) were calculated to identify the relationships between age, participants' reading comprehension abilities measured by WRMT-III and response rate of survey completion. In addition, Mann-Whitney U tests were conducted to examine the impacts of gender, living status (i.e., living independently vs. living with family) and working status (i.e., employed vs. unemployed) on the response rate of survey completion.

To investigate internal reliability of the method, the split-half reliability was examined to identify the stability of reporting in regard to internal experiences; experiences in the two halves of responses to ESM survey from each participant were expected to be stable (Csikszentmihalyi & Larson, 1987; Hektner et al., 2007). To achieve this, ratings of the internal experience items from each participant in the first half of the responses was compared with those in the second half of the responses using chi-square tests. To determine internal validity, *phi* coefficients for internal experiences were calculated to explore the internal logic of the participants' reporting. All the statistical analyses were performed using IBM SPSS statistics Version 26 (2015).

In addition, the face validity, the degree of consistency between survey items and the purpose of the survey were analysed by comparing the logic of participant responses to questions about the associated internal experiences with their responses to external aspects of their experiences (i.e., what they were doing, with whom). It is expected that participants will have higher levels of positive experience while interacting with familiar people (e.g., friends) but tend to have more negative experience with unfamiliar people (e.g., boss or people at workChen et al., 2014; Hektner et al., 2007; Hintzen et al., 2010).

Results

Feasibility

Overall, the signal response rate, set at least 20 minutes apart, from 19 participants was 40.1% (range: 4.1%-100.0%). After However, we excluding excluded a participant who only responded to the first question of the ESM survey and deleting the incomplete ESM survey entries from other participants (e.g., only responding to the first several questions related to external experience), which did not yield enough data for the examination of internal reliability and validity based on the questions of internal experiences,. Thus, the average response rate of survey completion were 33.8% (range: 2.0%-83.7%) from 18 participants. The analyses showed that the response rate of survey completion was higher for participants who lived independently (Mdn = 34.7%) than for those who lived with family (Mdn = 22.4%), U = 55, p < 0.05. In addition, participants who were unemployed were more likely to have greater response rate of survey completion than those who were employed (Mdn = 69.4%, 24.5%), U = 3, p < 0.05. There were no significant relationships between the response rate of survey completion and other individual characteristics including the reading comprehension abilities.

Participants reported various reasons for not completing the surveys, including being in the bathroom, taking an afternoon nap, not hearing the alert as the tone was too soft in comparison to background noise, leaving the mobile device in a bag, and being at work or a day program where mobile devices were not permitted. Further, equipment malfunctions or technical difficulties were commonly reported during the data collection period, including loss of data due to syncing issues, pictures missing from the survey, devices reportedly failing to prompt or 'beep', and unanticipated updates and changes to the app from developers. When interviewed, most participants considered the mobile device to be easy and enjoyable to use. Despite not being included in the semi-structured interview schedule, all the

participants expressed excitement over their participation and willingness to participate in similar studies throughout the conversation.

Parents were also consulted for their feedback and reported similar technological issues, stressing the lack of prompting from the device made it difficult for participants to remember to complete a survey. Some parents reported the prompt needed to be longer and louder, as their child needed extra time to process the noise and often got distracted. Parents also gave feedback regarding the level of specificity needed for people with intellectual disability~~ID~~ when completing the survey. Even though this was contrary to the training guidelines, two parents reported their child was 'taken out of' what they were doing to answer the survey, resulting in their response to 'What are you doing?' often being related to 'doing a survey' as opposed to, for example, 'watching TV'. To avoid this literal interpretation, questions needed to be more specific with minimal ambiguity. Parents also stressed that some participants with more significant intellectual disability~~ID~~ than participants in our sample may miss out on having their experiences captured, given the eligibility criteria of requiring a particular reading level, and the subsequent need for higher levels of support. Pictographs were recommended as a potential future improvement to the survey to help aid understanding. Participants were often also described as 'people pleasers' by their parents, who worried participants would provide answers that are deemed socially desirable, thus answering according to what they felt they should say. However, parents also reported the survey made participants feel important, responsible and excited.

Internal Reliability and Validity

No significant differences were found when comparing two halves of responses in terms of internal experiences except 'prefer being alone'. These findings suggest that the data are internally reliable (see Table 2). Table 3 summarises the relationships of ratings in quality of experiences and emotions. As can be noted, the relationships between items linked by

theory or logic were significant and with expected strength. For example, 'liking the engaged situation' was positively and significantly associated with 'having fun'. However, both 'liking the engaged situation' and '"having fun' were negatively related to the other ratings of quality of experiences and emotions.

<INSERT TABLES 2 AND 3 ABOUT HERE>

Face validity: Everyday Experience of Engagement in Activities

On average, participants spent equivalent time resting (49.6%) and doing something else (50.4%). The associated quality of experiences and emotions while participating in these two categories of everyday activities (i.e., resting and doing something else) are illustrated in Figure 2. As can be noted, they had similar quality of experiences while resting and doing something else in terms of 'liking the engaged situation' and 'having fun'. However, they more frequently perceived difficulty and felt anxious when doing something else than resting.

<INSERT FIGURE 2 ABOUT HERE>

On average, participants spent more time being alone (55.1%) than talking to someone else (45.0%). Figure 3 illustrates the quality of experiences and emotions associated with social interactions. Participants more frequently had fun, liked the situation, as well as preferred being alone while they were alone than when interacting with people. However, they were more likely to feel lonely when they were alone. When they were interacting with people, they more frequently reported more frequently to havehaving fun and likinge to interact with friends compared to other people. Conversely, they seldom had fun and liked the situation while interacting with a boss or a workmate. Overall, these findings support the face validity of the data.

<INSERT FIGURE 3 ABOUT HERE>

Discussion

This feasibility study has shown that conducting an ESM study using mobile devices is feasible for some people with mild to moderate intellectual disability~~ID~~, allowing them to reflect upon their experiences and feelings 'in the moment' when responding to a survey modified for people with ~~ID~~intellectual disability. Nevertheless, a number of issues require attention prior to application in any future applied studies. These following main issues were identified: 1) the design of the survey content needs to be enhanced to improve its accessibility and comprehensibility, 2) there is a need to find more stable ESM software that can incorporate images and/or pictographs within the platform, 3) there were many technological issues that arose ~~relating~~ related to using an array of different device types with cross-generational software and hardware, and 4) there is a need to develop strategies to increase response rates across multiple environmental contexts of people's day-to-day life. Despite these challenges, ~~given~~ the feedback that participants reported that they enjoyed participating in the study suggests that modifying ways to enhance future participation are worth pursuing.

The average response rate of survey completion (33.8%) was lower than reported in other studies investigating ~~the participants'~~ everyday social experience with similar procedure, such as 47.6% in typically developing young children (Vilaysack, Cordier, Doma & Chen, 2016; Mulligan , Schneider, & Wolfeand colleagues, 2000), 56.8% in children with ASD (Chen et al., 2015) and around 71% in adults with ASD (Chen et al, 2014; Hintzen et al., 2010). However, it was above the suggested acceptable response rate of 33% (Chen et al., 2014; Hintzen et al., 2010; Myin-Germys et al., 2003). Although low, certain factors appeared to impact our participants that may not be as critical in other population groups who, unlike many people with intellectual disability~~ID~~, do not require the support of others to remind them to keep their mobile device close or to be alert for an impending beep. For

example, in the study of four young adults with ASD ~~by~~ who commonly present repetitive patterns of behaviours ██████████, participants were able to switch between their current activity and the survey without problems, even though it is not clear what these participants were doing during the day. By contrast, Vilaysack et al. (2016) reported that some children could use the device while at school if the mobile device was set to vibrate. Such a strategy may not always be possible for most people with intellectual disability~~ID~~ while at work or other vocational activities, for example, one of our participants worked in a kitchen where safety issue precluded the use of a mobile device. As noted by Seekins, Ipsen and Arnold (2007) in their ESM study on people with physical disabilities, certain activities, such as driving, should not be interrupted for any purpose and so missing data is to be expected. Future studies that include people with intellectual disability~~ID~~ who either live at home or are in some form of employment~~,~~ need to find strategies to enable sufficient data collection with higher response rates.

Of note ~~were~~ was the high percentage (55%) of time spent alone and ~~the data suggesting~~ that this common experience wa~~i~~s not associated with negative emotions ~~by participants~~. Although it remains open to conjecture, we suggest that the term 'prefer' and the construct 'alone' are potentially difficult for most people with intellectual disability~~ID~~ to understand. Firstly, a preference implies a choice and the literature is unequivocal that fewer choices are available to people with intellectual disability~~ID~~ and, subsequently, they make fewer choices. Furthermore, many living and vocational contexts can significantly affect the *degree* of choice available to them (Stancliffe & Parmenter, 1999). Secondly, being alone and feeling lonely have entirely different meanings and perhaps these differences were not made clear enough in the survey or during training. Preferring to be alone was negatively correlated with positive emotions (e.g., 'liking' and 'having fun') as would be expected, however, it was positively correlated with negative feelings (e.g., 'anxious' or 'lonely') which is unusual. For

example, it would be logical to assume that if someone who is feeling anxious or lonely would *not* prefer to be alone. This suggests that the construct of 'preferring to be alone' was perhaps too difficult for participants. Of note is that the frequency for 'being alone' was high across all experiences and emotions, suggesting that many people with intellectual disabilityID are alone much of the time as compared with individuals without intellectual disability ID (35% in Hintzen et al., 2010). Research has found that without support to participate in social groups and maintain friendships, people with intellectual disabilityID would may otherwise be alone and have little to do (Wilson, Jaques, Johnson & Brotherton, 2017). These findings contribute to both the intellectual disabilityID-specific literature, in particular studies related to self-reported loneliness (Stancliffe et al., 2014), and also the emerging body of work exploring ESM using mobile devices across different population groups such as children with neuromuscular disorders (Bray et al., 2010). Also, contrary to most published research about anxiety and intellectual disabilityID (e.g., Reid, Smiley & Cooper, 2011), anxiety did not appear to be a commonly reported emotion, regardless of who the participant was with or the situation they were in.

The technological issues related to the app and the range of mobile device types led to missing data and were a constant frustration for all involved. Of note is that the most modern mobile device used by a participant, a recently released version of a top-selling brand, was just as incompatible as some of the older mobile devices. Future studies must field-test the stability of any ESM app across different mobile device platforms. Using a mobile device to collect ESM data offers many advantages, such as more accurate transfer of data across platforms, having data that is time-stamped, and eliminating the need for recall – a major issue for many people with intellectual disability ID (Stancliffe et al. 2014) – when using a retrospective data collection tool. There is not an obvious solution to the instability of the app across different types of devices. For those participants with a mobile device that was

incompatible with the app, due to age or being an atypical branded device, we supplied them with a brand new mobile device with hardware that was compatible with the app. The solution was not, however, ideal as this meant carrying around and being responsible for two mobiles. Further, it also required learning how to use a different type of mobile device with totally different commands and ways of activating functions (e.g., swiping up, rather than across) and these barriers have been noted previously in the literature (e.g., De Urturi Breton et al., 2012). While literature suggests that mobile phone use is common for people with intellectual disabilityies ((Bryen, Carey & Friedman, 2007)CITE), there may be a level of cognitive functioning necessary to use particular ESM software. Future research is needed to investigate the level of cognitive functioning may be needed to use ESM software and at what point such software may become inaccessible to people with cognitive or communication difficulties. While the technological issues were more common in our study than previous research, future research should may require work closely with the App developer to solve any technological problems promptly or investigate possibilities of using other Apps (e.g., PIEL Survey App; Jessup, Bian, Chen, & Bundy, 2012).

Future studies should focus on improving the survey content, layout, language and use of images. Although we modified previous ESM surveys, for example, using dichotomous rather than sliding scale responses, and as a whole the survey itself proved valid, improvements are needed. Qualitative feedback from parents highlighted specific issues with certain terms and misunderstandings that we may not have otherwise gleaned. F, for example, instances of potential acquiescence and responding as if the survey was 'the event'. Importantly, although many consider acquiescence in people with intellectual disabilityID to be based on a desire to please others by giving the 'correct' response, it also results from misunderstanding what has been asked of the person due to the complexity of the language or constructs being used (Finlay & Lyons, 2002). A standard measure of

acquiescence would enhance the rigour of the current study and future replication. However the reading activity required correct answers and the demonstration of the app likewise required an appropriate response, thus we remain confident this was not an issue in the current study. Consideration for co-design of a future intellectual disability~~ID~~-specific survey with both parents and people with intellectual disability~~ID~~ would be worthwhile. Further, the addition of Augmented and Alternative Communication experts who can assist with modifying the language and matching the images to the underlying construct and meaning would be of benefit.

Future implications

A key finding from this feasibility study is the responses we received to questions about being alone and loneliness. Measuring loneliness in people with ~~ID~~intellectual disability using valid self-report tools is not straightforward and the need to develop intellectual disability~~ID~~-friendly tools and methods has been noted (Stancliffe et al., 2014). ESM could provide a solution to this research problem, in particular ESM has the strengths of ~~the~~ contextual granularity ~~ESM provides~~ across time and ~~that it does not rely~~limited reliance ~~up~~on recall. An area that we believe ESM can have potentially significant implications is in the self-reporting of chronic illness symptoms, most particularly as people with intellectual disability~~ID~~ have a disparate incidence of chronic illness compared to the general population (████████████). Areas of focus could include the self-reporting of pre- and post-ictal seizure symptoms, symptoms of high and low blood glucose levels in people with diabetes, and pain symptoms related to cerebral palsy. More broadly, there is scope to build on the work of Bray and colleagues (2010) in using ESM for self-reporting of health-related quality of life. Notwithstanding the possibilities of these exciting areas for future research, at this stage, ESM using mobile devices is currently limited to people with borderline to moderate intellectual disability~~ID~~ *and* sufficient reading ability. Future application might

enable accessibility to more people with intellectual disability~~ID~~ who have been exposed to years of inclusive school education and/or targeted literacy interventions (e.g., Allor et al., 2013).

Limitations

There are a number of limitations to this study, the main one being the relatively small sample size due to difficulty recruiting participants and missing data. Nevertheless, it should be noted that Hektner et al (2007) has previously suggested that 10-20 participants are sufficient to examine the feasibility of ESM using mobile devices and identify concerns regarding designing and implementing an ESM study with people with intellectual disability ~~ID~~ for a full-scale study. One variable not embedded in this feasibility study was the amount of time spent in survey completion as it was not recorded in the App we purchased (Basic License version). This is another factor influencing the response rates. However, as we did not receive any negative feedback about participation being a time burden, we assume this was not problematic and was not a factor for missed survey responses. Further researchers may consider the mEMA App with the Professional License or other Apps that include the function of recording time spent in survey completion. Although reading ability was mentioned by some parents as an area that might exclude some people with intellectual disability~~ID~~, there must always be some screening measure for such a tool and so future studies should explore the range of ways that function, and therefore participation, can be measured. In addition to the technological issues discussed, it also possible that participants made errors using the software that result~~s~~ed in missing data or impacted the validity of such data. Further, we used the ICAP, and as this was published in the 1980s, it is possible that more current measures of adaptive behaviour could be used. Nevertheless, the ICAP is a robust tool that remains in use by many international researchers. The final limitation was not using an operational definition of personal perceptions or emotions, instead we relied upon

Feasibility of ESM for people with intellectual disabilityID

self-interpretation, which could differ across individuals and contexts. As our indicators of internal validity suggest, the concepts had shared meaning among participants. HoweverThis suggests, there was a strong enough level of common understanding among participants such that varying self-interpretation did not affect the rigour of our findings.

Conclusion

Importantly, what we have shown is that the ESM using mobile devices can beis feasible in this population. Despite a low response rate, the response that were received were found to be valid and reliable in most areas. as some participants showed valid and reliable responses in most areas. However, we did experience feasibility issues in the domains of technological issues and potential misinterpretation of some of the items. Although low, the signal response rate illustrated ESM methods can be useful for people with Iintellectual dDisability. As participant understanding of the survey relied on researcher judgement, the replication of the current study in other populations is limited. Further research is needed to address the issues encountered with this method in order to further improve feasibility for this population. ESM methods were also found to be reliable and have strong face validity in this population for individuals who completed the surveys. Findings suggest ESM should be further evaluated as a method to understand both internal and external social experiences of people with intellectual disabilityID.

References

Allor, J.H., Gifford, D.B., Al Otaiba, S., Miller, S.J. & Cheatham, J.P. (2013). Teaching student with intellectual disability to integrate reading skills: Effects of text and text-based lessons. *Remedial and Special Education, 34*(6), 346-356. DOI: 10.1177/0741932513494020

Bigby, C. Whiteside, M. & Douglas, J. (2017). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services, *Journal of Intellectual & Developmental Disability*, DOI: 10.3109/13668250.2017.1378873

Bradshaw, P. (2001). Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of Intellectual Disability Research, 45*(3), 233-243. https://doi.org/10.1046/j.1365-2788.2001.00318.x

Bray, P., Bundy, A., Ryan, M. M., & North, K. N. (2010). Feasibility of a computerized method to measure quality of "everyday" life in children with neuromuscular disorders. *Physical & Occupational Therapy in Pediatrics, 30*(1), 43-53. doi: 10.3109/01942630903294687

Bruininks, R. H., Hill, B. K., Weatherman, R. F., & Woodcock, R. W. (1986). *Inventory for Client Agency and Planning*. Chicago, IL: Riverside Publishing.

Bryen, D. N., Carey, A. & Friedman, M. (2007). Cell phone use by adults with intellectual disabilities. *Intellectual and Developmental Disabilities, 45*(1), 1-2. Doi: 10.1352/1934-9556(2007)

██

██

███

███████████████████

██

███

████████████████████████████████████

██████████████████████

Csikszentmihalyi, M. & Larson, R.W. (1987). Validity and reliability of the experience-sampling method. *Journal of Nervous and Mental Disorders, 175*, 526–536.

De Urturi Breton, Z., Hernández, F., Zorrilla, A. & Zapirain, B. (2012). Mobile communication for intellectually challenged people: A proposed set of requirements for interface design on touch screen devices. *Communications in Mobile Computing, 1*(1), 1-4. Doi: 10.1186/2192-1121-1-1

Delespaul, P. (1995). *Empirical studies in ESM reliability and validity*. In: M.W. de Vries (Ed.), Assessing Schizophrenia in Daily Life: The Experience Sampling Method. Maastricht University Press, Maastricht, The Netherlands.

Dusseljee, J. C. E., Rijken, P. M., Cardol, M., Curfs, L. M. G., & Groenewegen, P. P. (2011). Participation in daytime activities among people with mild or moderate intellectual disability. *Journal of Intellectual Disability Research, 55*, 4-18. doi: 10.1111/j.1365-2788.2010.01342.x

Finlay, W.M.L. & Lyons, E. (2002). Acquiescence in interviews with people who have mental retardation. *Mental Retardation, 40*(1), 14-29. https://doi.org/10.1352/0047-6765(2002)040<0014:AIIWPW>2.0.CO;2

Hare, D. J., Gracey, C., & Wood, C. (2016). Anxiety in high-functioning autism: A pilot

study of experience sampling using a mobile platform. *Autism*, *20*(6), 730-743.

Hektner, J. M., Schmidt, J. A., & Csikszentmihalyi, M. (2007). *Experience sampling method: Measuring the quality of everyday life*. Thousand Oaks, California: Sage Publications Inc.

Hintzen, A., Delespaul, P., van Os, J., & Myin-Germys, I. (2010). Social needs in daily life in adults with Pervasive Developmental Disorders. *Psychiatry Research, 179*(7), 75-80. doi: 10.1016/j.psychres.2010.06.014

IBM Corporation. (2015). IBM SPSS Statistics 26. Armonk, NY: IBM Corporation. Available from: http://www-01.ibm.com/software/analytics/spss/

Ilumivu. (2017). *mEMA: Mobile ecological momentary assessment*. Retrieved 21 September 2017, from

https://ilumivu.com/solutions/ecological-momentary-assessment-app/

Jessup, G., Bian, S., Chen, Y. W., & Bundy, A. (2012). *Manual of P.I.E.L Survey Application [iPhone/iPod Touch/iPad/iPad Mini Application]*. Retrieved from: http://pielsurvey.org/

Kincaid, J. P., Fishburne, R. P., Rogers, R. L., & Chissom, B. S. (1975). Derivation of new readability formula (Automated Readability Index, Fog Count and Flesch Reading Ease Formula) for Navy enlisted personnel. Memphis, TN: Naval Air Station.

Kimhy, D., Delespaul, P., Corcoran, C., Ahn, H., Yale, S. & Malaspina, D. (2005). Computerized experience sampling method (ESMc): Assessing feasibility and validity among individuals with schizophrenia. *Journal of Psychiatric Research, 40*, 221–230, doi:10.1016/j.jpsychires.2005.09.007

Lennox, N., Taylor, M, Rey-Conde, T., Bain, C., Purdie, D.M. & Boyle, F. (2005). Beating the barriers: Recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research, 49*(4), 296-305.

https://doi.org/10.1111/j.1365-2788.2005.00618.x

Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society, 24*(1), 47-62. doi: 10.1080/09687590802535410

Mulligan, C.B., Schneider, B., & Wolfe, R. (2000) Time use and population representation in the Sloan Study of Adolescents. Unpublished manuscript, Alfred P. Sloan/University of Chicago Center for the study of Working Families.

Myin-Germys, I., Peeters, F., Havermans, R., Nicolson, N. A., de Vries, M. W., Delespaul, P., & van Os, J. (2003). Emotional reactivity to daily life stress in psychosis and affective disorder: An experience sampling study. *Acta Psychiatrica Scandinavica, 107*(2), 124-131.

Reid, K.A., Smiley, E. & Cooper, S.A. (2011). Prevalence and associations of anxiety disorders in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 55*(2), 172-181. doi: 10.1111/j.1365-2788.2010.01360.x.

Seekins, T., Ipsen, C. & Arnold, N.L. (2007). Using Ecological Momentary Assessment to measure participation: A preliminary study. *Rehabilitation Psychology, 52*(3), 319-330. DOI: 10.1037/0090-5550.52.3.319.

Shiffman, S., Stone, A. A., & Hufford, M. R. (2008). Ecological momentary assessment. *Annual Review of Clinical Psychology*, *4*, 1-32.

Short, N. A., Boffa, J. W., Clancy, K., & Schmidt, N. B. (2018). Effects of emotion regulation strategy use in response to stressors on PTSD symptoms: An ecological momentary assessment study. *Journal of Affective Disorders, 230*, 77-83. doi: 10.1016/j.jad.2017.12.063

Stancliffe, R.J. & Parmenter, T.R. (1999). The Choice Questionnaire: A scale to assess choices exercised by adults with intellectual disability. *Journal of Intellectual and*

Developmental Disability, 24(2), 107-132.

Stancliffe, R. J., Lakin, K. C., Doljanac, R., Byun, S.-Y., Taub, S., & Chiri, G. (2007).

Lonelieness and living arrangement. *Intellectual and Developmental Disabilities,*

45(6), 380-390. doi: 10.1352/1934-9556

███

██

███████████████████████████████████████

███████████████████

Trull, T. J., & Ebner-Priemer, U. W. (2009). Using experience sampling methods/ecological

momentary assessment (ESM/EMA) in clinical assessment and clinical research:

Introduction to the special section. *Psychological Assessment, 21*(4), 457-462. doi:

10.1037/a0017653

███

███

██

████████████████████

Whalen, C. K., Jamner, L. D., Henker, B., Delfino, R. J., & Lozano, J. M. (2002). The

ADHD spectrum and everyday life: Experience sampling of adolescent moods,

activities, smoking and drinking. *Child Development, 73*(1), 209-227.

███

███

██████████████████████████████████████

███

███

██

Woodcock, R. (2011). *Woodcock reading mastery tests, 3rd ed* (WRMT-III). San Antonio,

Texas: Pearson Education, Inc.

Table 1. Participant demographic data ($N = 19$)

	M	S.D.	Minimum	Maximum	Frequency (%)
Age	27.2	7.7	18	43	-
ICAP					
Broad Independence[a]	493	37.8	361	533	-
General Maladaptive[a]	-2.5	3.3	-11	0	-
Service needs[*]	7.8	1	6	9	-
WRMT-III					
Word comprehension[b]	71.0	18.6	55	112	-
Passage comprehension[b]	63.3	14.3	55	112	-
Reading comprehension[b]	66.4	15.6	55	113	
Gender					
Male	-	-	-	-	12 (63.2)
Female	-	-	-	-	7 (36.8)
State					
Western Australia	-	-	-	-	7 (36.8)
Queensland	-	-	-	-	7 (36.8)
New South Wales	-	-	-	-	4 (21)
South Australia	-	-	-	-	1 (5.4)
Accommodation					
With family	-	-	-	-	14 (74)
Independent	-	-	-	-	5 (26)
Employment					
Full time	-	-	-	-	3 (15.8)
Part time	-	-	-	-	12 (63.2)
Day program	-	-	-	-	1 (5.4)
Unemployed	-	-	-	-	3 (15.8)

Note: General Maladaptive scores between -10 and +10 are considered normal. Service needs scores are as follows: 1-2 (Total personal care and intense supervision); 3-4 (Extensive personal care and/or constant supervision); 5-6 (Regular personal care and/or close supervision; 7-8 (Limited personal care and/or regular supervision); 9 + (Infrequent or no assistance for daily living)

[a]based on 17 participants

[b]Standard scores evaluated by WRMT-III

Table 2. Comparisons of internal aspects of experience between the two halves of the ESM data.

ESM questions	1st half of week Count (%)	2nd half of week Count (%)	χ^2	p
Quality of experiences				
Liking the engaged situation	143 (93.5)	141 (97.9)	3.51	0.06
Having fun	143 (93.5)	131 (91.0)	0.65	0.42
Perceived difficulty	6 (3.9)	4 (2.8)	0.30	0.59
Desires to do something else	21 (13.7)	17 (11.8)	0.25	0.62
Preferring alone	67 (43.8)	42 (29.2)	6.83	<0.01
Emotions				
Feeling anxious	8 (5.2)	10 (6.9)	0.38	0.54
Feeling lonely	34 (22.2)	40 (27.8)	1.22	0.27

Table 3. Relationships (phi-coefficient) between the quality of experience and emotions.

	Liking	Having fun	Perceived difficulty	Desires to do something else	Preferring alone	Feeling anxious	Feeling lonely
Liking	--	0.25**	-0.23**	-0.36**	-0.08	-0.22**	-0.07
Having fun		--	-0.44**	-0.37**	-0.17**	-0.50**	-0.30**
Perceived difficulty			--	0.31**	0.13*	0.50**	0.11
Desire to do something else				--	0.20**	0.36**	0.21**
Preferring alone					--	0.24**	0.34**
Feeling anxious						--	0.24**
Feeling lonely							--

* Significant at the 0.05 level (2-tailed).

** Significant at the 0.01 level (2-tailed).