RESEARCH PROJECT:
USING EXPERIENCE SAMPLING
METHODS TO UNDERSTAND
EVERYDAY EXPERIENCES
OF ADULTS WITH
INTELLECTUAL DISABILITY
THIS REPORT HAS BEEN PREPARED BY:

ASSOCIATE PROFESSOR NATHAN J WILSON, School of Nursing and Midwifery, Western Sydney University

MS NATASHA MAHONEY, School of Nursing and Midwifery, WSU; School of Occupational Therapy, Social Work and Speech Pathology, Curtin University

DR YU-WEI CHEN, Faculty of Health Sciences, University of Sydney

MS ANNE MARKS, School of Nursing and Midwifery, Western Sydney University

PROFESSOR ANGUS BUCHANAN, School of Occupational Therapy, Social Work and Speech Pathology, Curtin University

ASSOCIATE PROFESSOR REINIE CORDIER, School of Occupational Therapy, Social Work and Speech Pathology, Curtin University; Department of Special Needs Education, University of Oslo

ACKNOWLEDGEMENTS

We would like to acknowledge the participants who agreed to be a part of this project, their families and carers for enabling a research study to be conducted within their homes, work and spare time. In particular, we want to thank Virginia Howie and Vincent Yu, both parents of adults with ID, for introducing us to their local disability networks.

SUGGESTED CITATION

Wilson, N. J., Mahoney, N., Chen, Y-W., Marks, A., Buchanan, A. & Cordier, R. (2019). The feasibility of using experience sampling methods to understand everyday experiences of adults with intellectual disability. School of Nursing and Midwifery, Western Sydney University. https://doi.org/10./5d9539c36d24b

DISCLAIMER

This project was funded by the Endeavour Endowment Challenge Fund.

This project was conducted by researchers from Western Sydney, Curtin and Sydney Universities between 2017 and 2019.

The content of this report represents the views of the authors and do not necessarily reflect the views of the funding organisations. As such, no endorsement by the funders should be assumed.

Every effort has been made to ensure that the information contained in this report is accurate.
# CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>CONTENTS</td>
<td>3</td>
</tr>
<tr>
<td>PREAMBLE</td>
<td>4</td>
</tr>
<tr>
<td>BACKGROUND</td>
<td>5</td>
</tr>
<tr>
<td>PROJECT OBJECTIVES</td>
<td>5</td>
</tr>
<tr>
<td>ETHICAL APPROVAL</td>
<td>5</td>
</tr>
<tr>
<td>THE ADULTS WITH INTELLECTUAL DISABILITY</td>
<td>6</td>
</tr>
<tr>
<td>THE SURVEY</td>
<td>7</td>
</tr>
<tr>
<td>OUTCOMES FROM THE SURVEY</td>
<td>8</td>
</tr>
<tr>
<td>FEASIBILITY</td>
<td>8</td>
</tr>
<tr>
<td>SOCIAL EXPERIENCES</td>
<td>8</td>
</tr>
<tr>
<td>RELIABILITY AND VALIDITY</td>
<td>8</td>
</tr>
<tr>
<td>WHAT DID EVERYONE HAVE TO SAY ABOUT THE SURVEY?</td>
<td>9</td>
</tr>
<tr>
<td>HOW EXPERIENCE SAMPLING SUPPORTED PEOPLE TO HAVE THEIR SAY</td>
<td>10</td>
</tr>
<tr>
<td>WHERE TO FROM HERE?</td>
<td>11</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>11</td>
</tr>
</tbody>
</table>
PREAMBLE

In 2016, a team of researchers led by Associate Professor Nathan J Wilson submitted a grant application to the Endeavour Endowment Challenge Fund. The Endowment Challenge Fund aims to fund research that addresses significant issues for the Australian disability sector and promote positive outcomes for people with disabilities.

The team proposed a unique method to further understand the experiences of people with intellectual disability (ID), which are not often understood from the person’s own perspective. The team believed that, in order to improve participation and inclusion for people with ID, we need to understand experiences from their point of view. The team proposed to do this using a unique method that may allow people with ID to have their own say, and to explore the appropriateness of this method.

In early 2017, the team was awarded the Endeavour Endowment Challenge Fund and approved to conduct the proposed research. In the following year, adults with mild to moderate ID and their parents and carers across Australia were engaged in the study to answer questions about their social experiences; how they spend their time, what they enjoy and do not enjoy, who they spend their time with and what could be improved. This report summarises the outcomes from this work.
People with intellectual disability (ID) are often excluded from social participation and can often have strictly controlled social or leisure activities. However, the experiences of people with ID are often understood by proxy, usually from the point of view of their parents and/or carers.

This can exclude the person’s own perception about their experiences and own preferences for social participation. The process of making informed decisions and exercising personal choice relies upon the ability of the person with ID to accurately express their feelings and perceptions. Overcoming these barriers and finding ways to help people with ID self-report their experiences was the focus of this study.

The team worked to examine the feasibility of using a method called Experience Sampling Method (ESM) to better assist people with ID to have their say. ESM uses electronic mobile devices, such as smart phones, to prompt users to respond to survey questions throughout the day, for several days. This means information can be collected in day-to-day settings and include both content and context of someone’s experiences “in the moment”. If suitable, this method could assist with better understanding social experiences, as well as many other experiences of people with ID.

**PROJECT OBJECTIVES**

The project had the following objectives:

1. Explore the appropriateness and feasibility of using experience sampling method (ESM) in people with mild-moderate ID

2. Highlight the context-dependent motivations for adults with ID and help inform future promotion of social inclusion

**ETHICAL APPROVAL**

The research project was approved by the Western Sydney University Human Research Ethics Committee on the 23rd October, 2017 (Project ID: HI2374). No adverse events were reported.
The participants were 19 adults with mild to moderate intellectual disability (ID), living across 4 Australian states. The average age was 27 years, and 14 of the participants lived with their family. Most of the participants worked part-time, while some worked full-time or were unemployed. On average, most participating adults needed limited support with personal care and supervision, however two needed more regular support for personal care and supervision. All adults had a reading level that was suitable for the survey.

Recruitment of adults with ID for this study was a particular challenge. The first approach of using existing networks within the disability service sector proved a challenge, in relation to services not being directly funded under the NDIS to support research activities. Our next strategy was to approach people with ID and their families directly, via social media and social groups. This was more successful and those who had already participated told their friends and families about the study. This word-of-mouth approach, or snowball sampling, allowed for us to reach even more people.
THE SURVEY

The team had previously used the Experience Sampling Method in a study with children and adults on the autism spectrum (Chen et al., 2014; 2015; 2016). The survey was adapted for use by people with ID. The survey had 12 questions that participating adults were asked to answer whenever the phone beeped. These included questions about external experiences (e.g. what they were doing and who with) and internal experiences (e.g. enjoying the activity, wanting to do something else, emotions felt during the activity). Adults completing the surveys could choose from several options for each question, with pictures to help interpretation.

Before starting the survey, the adults and their parents and/or carers received 45 to 60 minutes of training with a member of the team. The team member showed the participating adult how to use the device (usually an iPhone or iPod Touch) and how to answer questions. Each question in the survey was explained to ensure the users understood the available responses, and they had a chance to practice answering while pretending to be in different situations (e.g. at work, at home).

After the introduction to the survey, adults carried the device with them for seven consecutive days. During these days, the device would prompt or beep seven times, randomly between 8am and 8pm. At the beep, they would unlock the phone and be presented with the survey to answer. If they were not able to complete the survey at the time of the beep, they were instructed to wait until the next beep. After the seven days, participating adults and their parents and/or carers met with the team member again to talk about their experience with the survey, to clarify their experiences with the device and anything they found difficult.
OUTCOMES FROM THE SURVEY

FEASIBILITY
The overall response rate to the surveys was 40.1%, ranging from 4.1% to 100%. The response rate was highest for adults who lived independently than with family, and for those who were unemployed compared to employed (Wilson et al., under review).

Participating adults reported various reasons for not completing surveys, including being in the bathroom, taking a nap, not hearing the beep or being at work where phones were not permitted. Equipment malfunctions and technical difficulties were commonly reported. These included loss of data due to syncing issues, missing pictures, devices not beeping and unanticipated updates to the app from developers. These issues made it difficult for some adults to complete all surveys across seven days.

SOCIAL EXPERIENCES
On average, the participating adults spent similar amounts of time resting (49.6%) and engaged in some activity (50.4%). Adults rated these two categories (i.e. resting and doing something else) similarly in terms of liking the situation and having fun. However, they did report greater difficulty and anxiety when doing something other than resting.

Participants spent more time on average alone (55.1%) than talking to someone else (45%). Participants reported having fun and liking the situation more when they were alone, compared to with someone else. However, they reported feeling lonely more often when they were alone. When with other people, participants were more likely to have fun and enjoy the interaction when they were with friends, compared to others. They reported less fun and enjoyment when with a boss or workmate.

RELIABILITY AND VALIDITY
Statistical analysis of the survey responses suggest that the data reliably represented the social experiences of participants. We found that adults had similar responses to survey questions that were related to each other. For example, “liking the engaged situation” was associated with “having fun”. However, “liking the engaged situation” and “having fun” were found to be negatively related to other quality ratings and emotions.
WHAT DID EVERYONE HAVE TO SAY ABOUT THE SURVEY?

When interviewed about their experience with the survey, adults with ID considered the mobile device easy and enjoyable to use. Most adults expressed excitement about their participation and willingness to participate in similar studies.

Parents and carers were also consulted for their feedback. Parents and carers stressed that, due to technological issues, the lack of prompting from some devices made it difficult for participants to remember to complete the survey during the day. Recommendations from parents/carers included making the beep louder and longer, to allow for extra time to process the noise or distractions.

Feedback also involved the level of specificity needed for people with ID when completing the survey. Some parents reported that their son or daughter was “taken out of” what they were doing at the time, to complete the survey. This led to their preferred responses to questions such as “What are you doing?” becoming “doing a survey”, instead of the activity they were engaged in at the time. To avoid too literal of an interpretation, questions need less ambiguity and more specificity.

Parents also stressed that the current format of the survey may exclude people with more significant ID, due to the required reading level and higher levels of support needed. To improve this and aid understanding for all participants, pictographs were suggested to be developed for future use.

Overall, parents reported participating in the study and answering the survey made participants feel important, responsible and excited.
HOW EXPERIENCE SAMPLING SUPPORTED PEOPLE TO HAVE THEIR SAY

Through this project, we were able to explore a method that can better allow people with mild to moderate ID have their say. We found that ESM can provide reliable and valid data about the social experiences of people with ID, including what they engage in, who with, how they feel about it and what could be improved. We can also know how these experiences change within a day, a week or even longer. This means we can hear from people themselves, rather from other sources, and use this information to improve their experiences. With some improvements to accessibility and specificity, ESM can provide a feasible way for people with ID to have their say on a variety of experiences and issues.
Feedback from participants, their parents and carers identified areas of improvement for the survey and mobile devices. Changes such as longer and louder prompts, pictographs and more specific questions can improve the ESM method and allow it to be used with a wider range of people with ID and topics that may impact them.

After incorporating this feedback, we hope to use the information provided from participants to further understand and improve social experiences.

We hope to use ESM to further understand other issues that can impact people with ID. For example, including chronic health management such as being able to better self-report the physical symptoms and feelings that are associated with changing blood glucose levels for people living with type 1 diabetes.

REFERENCES


