

A comparison of two methods for recruiting children with an intellectual disability

Authors: Dawn Adams¹ PhD, Louise Handley^{1,2}, Mary Heald¹ PhD, Doug Simkiss³, Alison Jones¹, Emily Walls¹ & Chris Oliver¹.

Affiliations: ¹Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham, Birmingham, B15 2TT UK; ² Clinical Psychology Doctorate, University of Manchester; Manchester, M13 9PT UK
³Division of Mental Health and Wellbeing, Warwick Medical School, University of Warwick, Coventry, CV4 7AL, UK.

Address correspondence to: Dr Dawn Adams, Cerebra Centre for Neurodevelopmental Disorders, School of Psychology, University of Birmingham, Birmingham, B15 2TT United Kingdom, Europe. Telephone: 0121 414 7206. Email: Papers@DawnAdams.co.uk

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Abstract

Background: Recruitment is a widely cited barrier of representative **intellectual disability** research, yet it is rarely studied. This paper aims to document the rates of recruiting children with **intellectual disabilities** using two methods, and discuss the impact of such methods on sample characteristics.

Methods: Questionnaire completion rates are compared between (a) participants being approached in Child Development Centre waiting rooms (b) one year later, the same participants being invited to take part by phone, email and/or post.

Results: The face-to-face recruitment method resulted in a better recruitment rate (58.5% compared to 18.5%) and a larger sample (n=438) than the telephone/email/post sample (n=40). It also required less hours of researcher time per completed questionnaire.

Conclusions: In-line with previous research, recruitment of participants with **intellectual disabilities** (or their parents/carers) requires significant time and resources in order to get a sample of an acceptable size.

Running Head: Recruiting Parents into ID Research

Keywords: recruitment, intellectual disabilities, questionnaire, response rates

Introduction

Despite the elevated levels of physical and mental health difficulties associated with intellectual disabilities (ID), this population is under-represented in the medical research literature (Feldman et al., 2014). For example, Feldman, Battin, Shaw and Luckasson (2013)'s survey of 533 articles from two well-respected developmental journals note that children with disabilities were excluded from research in 90% of studies, with 74% of the studies not providing justification for their exclusion. Consequently, there remains a lack of both large epidemiological studies and randomized controlled trials (Hassiotis, 2009), with difficulties in recruitment consistently being identified as a key barrier (e.g. Lennox et al., 2005; Nicholson et al., 2013; Oliver-Africano et al., 2010).

Difficulties in recruiting to **intellectual disability** research are well described but little studied (Nicholson et al., 2013). Bonevski et al. (2014) conducted a systematic review of 116 papers that focused on increasing recruitment rates or identifying barriers to conducting research in 16 different "socially disadvantaged" groups. Whilst difficulties in recruitment are not specific to the field of **intellectual disability**, Bonevski et al. clearly identified a lack of literature focusing upon methods of enhancing recruitment within this population. Out of the 116 papers reviewed by Bonevski et al, only one paper (Lennox et al., 2005) focused upon methods of enhancing recruitment amongst individuals with an **intellectual disability**. Interestingly, there were only two other populations in which Bonevski et al. identified only one paper;

mental health difficulties and sex workers. In other groups, the number of papers identified was much higher for example, ethnic/racial groups (N=40), African American (N =19), Substance abusers (N=14) and Indigenous People (N=8). This disparity highlights the paucity of published information on recruitment and recruitment issues within the field of **intellectual disability** research (Lennox et al., 2005).

Factors influencing survey or questionnaire participation within the general population include societal-level factors (e.g. perceived legitimacy or benefit of the research), survey design (e.g. topic and length of survey), demographic factors of the responder (e.g. age, gender, income, and health status of respondent), researcher characteristics (e.g. age, gender, perceived confidence) and responder-interviewer interaction (see Groves, Cialdini & Couper, 1992, for a review and discussion). Possible reasons for difficulties with recruitment that are more specific to minority groups, especially people with **intellectual disabilities**, include identification and engagement with potential participants, motivation to engage with the study (from the individual with **intellectual disabilities** or their carer), previous experience with research, quality of relationship with that (or other) “professionals”, obtaining ethical approval, obtaining informed consent (including consideration of reading, writing and cognitive difficulties) and ongoing consent. Consent for adults with **intellectual disabilities** is a largely discussed area (e.g. Arscott, Dagnan & Kroese, 2010; Cameron & Murphy, 2007), with some proposing that individuals with **intellectual disabilities** are limited in their capacity to consent as they have limited decision-making opportunities in real life (Jenkinson,

1999; Suto, Clare, Holland & Watson., 2005). Dye, Hare and Hendy (2007) suggest that altering the presentation of the consent information to each individual's particular cognitive needs may help to increase comprehension and informed consent. Discussed in Rabiee, Sloper & Beresford (2005), "they don't understand" often means "I can't think how to explain it to them" or perhaps reflects the unsuitability of the presentation of materials or research methods chosen.

The sample of participants recruited into research **within** a given population has a clear impact upon the external validity and generalizability of the findings. A surprisingly small number of papers within the field of **intellectual disabilities** and other "hard to reach" populations explicitly report the numbers and characteristics of individuals that did not respond to an invitation to participate in research, refused participation at recruitment, or dropped out of any study (Beadle-Brown et al., 2012). Consequently, it is not possible to assess whether the methods of recruitment employed within these studies impact upon the final recruited sample and whether the "preferred" methods in **intellectual disability** research are the same or differ from other "hard to reach" populations. Beadle-Brown et al. (2012) question why such core data remain underreported and posit that this may be due to publication bias; where a study has (or reports) high levels of refusals, drop-outs or general non-response, outcomes may well be equivocal or considered inaccurate, thus the likelihood of publication is reduced.

Research aiming to recruit and include people with **intellectual disabilities** as participants can be logistically challenging and resource intensive but without a strong **intellectual disability** specific evidence base to guide practice, people with **intellectual disabilities** will be even further disadvantaged compared with the general population (Nicholson et al., 2013). More research on the comparative hours and cost of recruitment methods is needed within these hard to reach populations in order to promote more representative research. It is clear that allowing more time increases recruitment, but it is not clear from the literature how much more resource intensive these recruitment methods are and what the return is on the investment with respect to recruitment and representativeness (Beadle-Brown et al., 2012).

The main aim of this paper is to describe two recruitment methods used for recruiting young children with **intellectual disabilities** or global developmental delay. The first method was face-to-face data collection, which was undertaken as part of a large cross-sectional study of challenging behaviour in young children. The second method describes the recruitment rates of contacting participants from the first cross-sectional study by remote methods (email, phone, letter) approximately one year after they were first recruited. The paper then discusses the impact of such methods on the sample characteristics.

Method

The initial stages of the project required establishing close links with an active researcher (co-author DS) in the Child Directorate in the local NHS Trust, who

then discussed and developed the idea with the clinicians. This allowed for the development of a project that collected research-quality data through a method that was practical and acceptable within the clinics setting, and importantly, did not alter standard clinical practice. The time taken between initial meetings and submitting the project to the ethics committee was nine months (with one PhD student working full-time on liaison and study development and one post-doctoral research fellow assisting in the ethics application).

Ethical approval was received from the **Integrated Research Application System** (IRAS) Ethical Committee, the appropriate Local Research Network (on behalf of the Healthcare Trust) and the University <removed for anonymity> Research Ethics Committee. The time taken between first submission to IRAS and receiving ethical approval and appropriate NHS approvals was three months.

For both recruitment methods, target participants were children with a diagnosis of an **intellectual disability** or global developmental delay. Due to their age and level of ability, all children were recruited through their parents or carers. Each parent or carer was given a detailed information sheet and given as much time as required to read through the information and ask questions before deciding whether to participate. Following this, each parent who wishes to participate completed a written or online consent form prior to completing any questionnaires.

Recruitment Strategy One: Face-to-face

Parents of children with an **intellectual disability** or a diagnosis of global developmental delay were approached whilst in the waiting room for appointments with consultant paediatricians in five Child Development Centres (CDCs) within a single community healthcare trust in the United Kingdom. Parents were also approached through multidisciplinary assessment groups for global developmental delay or social communication difficulties held at the CDCs. Children are referred to these centres by professionals such as GPs and health visitors, as a result of concerns about progress towards developmental milestones in at least two areas of development.

Participants were recruited by six different researchers (one PhD student and five undergraduate psychology students) across five different CDCs. These researchers attended clinics over a total period of 31 weeks (excluding school holidays) and attended for approximately 575 hours of clinic time.

The questionnaire pack was three pages long (plus the information sheet and consent form) and consisted of the Self-injury, Aggression and Destruction Screening Questionnaire (SAD-SQ: <removed for anonymity>) and Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). So as to limit any potential disruption to normal clinic timetables, a strict limit was imposed on the length of the questionnaire pack so that it could be completed

in less than ten minutes. This meant that data were only collected on child factors and no data were collected on demographics of the parents.

Recruitment strategy two: Remote (telephone, email or post)

Of the 438 parents who completed the questionnaire in the face-to-face recruitment method (after being approached in CDC waiting rooms by a PhD or undergraduate student), 216 consented to take have their names stored on a database in order to be contacted about future research. Twelve to eighteen months following their initial recruitment in Child Development Centre waiting rooms, these 216 parents were telephoned and emailed by a post-doctoral student and invited to participate in a brief questionnaire study consisting of the two same measures described above (HADS and SAD-SQ).

Results

The resulting sample numbers for both recruitment methods are summarized in Figure 1.

++ Insert Figure 1 about here ++

Recruitment Strategy One: Face-to-face

In total, 755 parents or carers were approached in Child Development Centre waiting rooms or groups and invited to take part in the study. Parents or carers could choose to complete the questionnaire in the waiting room or take it away and return by post. Every parent (n=427) who chose to complete the questionnaire in the waiting room returned it to the researcher. Although 101

parents chose to take the postal questionnaires, the return rate was only 10.9% (n=11). In total, 438 parents consented to take part and complete the brief questionnaire, a recruitment rate of 58%. This equates to 1.31 hours of time spent in clinic per participant recruited and questionnaire completed.

Parents who had completed the questionnaire were then contacted via telephone to complete a 20-minute telephone call comprising a measure of adaptive behaviour and a measure of service use. These calls were made within one month of the parent completing the questionnaire. Of the 438 parents who completed the questionnaire, 293 (66.9%) participants completed the telephone interview. A total of 22 (5.0%) participants could not be contacted due to provision of an incorrect contact telephone number, 15 (3.4%) participants no longer wished to complete the interview, 1 (0.2%) participant withdrew their consent for the study, and the remaining 107 (24.4%) could not be contacted at a convenient time to complete the interview following at least three attempts at different times of day (this covers times when the parent/carer requested to be called back at a different time and times when the telephone was not answered).

Recruitment strategy two: Remote

Of the 216 parents who were recruited through recruitment strategy one (Child Development Centre waiting rooms) and consented to their names being stored on a database for future research studies, contact was made with 116 (53.7%). Of the 100 who could not be contacted, 37 (17.1%)

participants had incorrect contact details and 63 (29.2%) were not contactable after at least three attempts at different times of the day.

Of those who were contacted, 16 (13.8%) did not want to participate, 12 (10.3%) indicated that they wanted to complete the questionnaire over the phone, 85 (73.3%) indicated that they wanted to take part online and three (2.6%) indicated that they wanted to take part by post.

In total, 40 (18.5%) completed the questionnaire following the remote recruitment method.. The completion rates for the telephone interview was 50%, online 38.8% and post 33.3%. One post-doctoral researcher worked on this project for a total of 75 hours over 14 weeks. This equates to 1.89 hours of time spent per participant recruited and questionnaire completed, which is higher than the 1.31 hours per participant for the face-to-face recruitment method.

Comparison of samples

In order to explore whether any child factors differed between those who completed the questionnaires in the waiting rooms and those who completed the follow-up questionnaires on the phone, online or by post, a series of Mann-Whitney U and χ^2 analyses were undertaken using data collected on the questionnaires completed by the parents or carers. Non-parametric analyses were chosen due to the differences in group size. When interpreting the data, it is important to remember that strategy one and strategy two were

conducted 12-18 months apart, so it is possible that diagnoses and behaviours may have changed over that period of time. The data are summarised in Table 1.

++ Insert Table 1 about here ++

The sample of parents who responded to the second recruitment method (remote) reported a higher prevalence of aggressive behaviour and Autism Spectrum Disorder.

Discussion

This paper describes the recruitment rates and child characteristics from two methods of data collection; face-to-face and remote (telephone, email or postal). Such data are important for the planning stages of research studies and estimating researcher time required for projects or grant applications. Using the face-to-face recruitment method, 1.31 hours of researcher time was required to recruit one participant who provided a complete questionnaire which is 0.58 hours less than the time taken to recruit each participant by phone/email/post. These times are solely for recruitment, consent and completion of a 10-minute questionnaire, and do not consider the time taken to plan the study, liaise with the clinical services, complete the ethics application, or data entry and analysis. It is likely that the amount of time required would increase if if parents were requested to complete a longer

questionnaire or participate in a study with higher demands (e.g. interviews, observations) over a longer period of time.

The key finding of this paper is that the face-to-face recruitment method was both more efficient and resulted in a higher recruitment rate than the remote method. The face-to-face method resulted in 58% of eligible parents approached completing the questionnaire and 38.8% of eligible parents approached completing both the questionnaire and a telephone interview. There is also a benefit to keeping the questionnaire short enough (three sides of A4) for parents to complete whilst in the waiting room, as 100% of those who chose to complete the questionnaire in the waiting room completed it, but only 10% of those who chose to take a questionnaire away and complete it at home returned the questionnaire. The reasons for parents choosing to take the questionnaires home were not documented, but could include having to attend their appointment, their literacy levels or having to have their full focus on their child(ren) in the waiting room. This study could have been strengthened by obtaining consent and contact details from parents prior to them taking the questionnaire pack away. This would have allowed for follow-up phonecalls to prompt for the questionnaires to be returned and potentially collection of demographic information from CDC files (if ethical approval had been gained for this) which could have been used to explore differences between completers and non-completers.

Whilst the face-to-face recruitment method required significantly more hours overall, when the researcher time per participant recruited comparison is

made, the face-to-face method required half-an-hour less per participant than the phone, email, postal method. Qualitative interviews with participants have identified the importance of the personal approach in people's willingness to participate in a study (e.g. Nicholson et al., 2013, Zermansky et al., 2007). This personal relationship appeared to last beyond the clinic waiting room, as two-thirds of parents who completed the questionnaires following the face-to-face recruitment method went on to complete a telephone interview within one month.

A key theme that is present both in the **intellectual disability** (e.g. Finlay & Lyons, 2001; Nicholson et al., 2013) and the broader "hard to reach communities" literature (e.g. Zermansky et al., 2007) is the need for increased time to set-up, undertake and complete research. Not only does it take longer to recruit from these populations (Beadle-Brown et al., 2012), but more time is needed to conduct the often complex negotiations of approvals and liaising with organisations or healthcare professionals (Beadle-Brown et al. (2012) before the study begins and staying in contact with parents and professionals during the study itself. The results of this study highlighted the additional time taken to contact parents to complete follow-up interviews. Almost one quarter of parents who completed the face-to-face questionnaire could not be contacted at a convenient time to complete the telephone interview following at least three attempts and a similar proportion (29%) were not contactable following three attempts during recruitment strategy two. It is important that all efforts are made not to lose these participants, as they may be a specific subgroup (e.g. where both parents work full-time) or may reflect parents with

less support networks in place. It may have been beneficial to ask parents to identify convenient times to contact them on the original questionnaire, and have researchers available across all evenings and weekends. Scott et al. (2006) note that it took 20-30 attempts to contact some families in their study and Abbot et al., (2005) report requiring up to ten personal visits to a single participant just to obtain written consent. This increased need for researcher presence is time-consuming both in terms of the actual time taken and in terms of managing the process of who had/had not been successfully contacted, especially when more than one researcher is involved (Scott et al., 2006).

When working with “hard to reach” populations, it may also be beneficial to invest in experienced researchers who are sympathetic to the needs of the parents and can quickly develop rapport, but this is an area that requires further research. Ideally, all studies would have the same researchers in the clinics, completing follow-up calls and working on later studies in order to develop a relationship between the researcher and the participant. In this study, if parents or carers did not want to participate in the study, they were not reproached for ethical reasons. However, Voight, Koepsell and Daling (2003) report that 376 (6.7%) of the 5616 participants who initially refused to take part in a telephone survey later participated when approached after a period of 3-6 months. Their comparison of those who participated immediately and those who initially refused participation identified that the initial refusers were older, had lower levels of education and were more likely to be from a non-white ethnicity than the immediate responders. These

demographic differences highlight the difficulties of aiming to get a large and representative sample whilst maintaining respect for an individual's decision whether or not to participate.

Comparison of child variables between the two samples showed that parents who participated in the follow-up study (and were re-recruited using the remote method) reported a higher prevalence of aggression and Autism Spectrum Disorder than noted in the original face-to-face recruited sample. However, it is important to note that these should be considered exploratory comparisons and the cause of the difference between these samples cannot be inferred from the data. Given that all of the parents who completed the telephone/post/online survey had originally completed the questionnaire following the face-to-face recruitment method 12-18 months before, it is possible that these things had changed during this time period. Alternatively it could mean that parents of children with aggression and/or autism spectrum disorders are more likely to participate in the follow-up study or be recruited over telephone, phone or email. With the method two sample being so small, it is difficult to explore factors predicting completion of questionnaires over phone/email/post, but this should be considered in further, larger studies. These data would be important as it would allow identification of participants who are at-risk for dropping out of follow-up or longitudinal studies and allow researchers to possibly invest more researcher time in maintaining their participation. An identified weakness of this study is that parent demographics were not collected, so it is not possible to explore any

differences in parent factors between the groups. This highlights this as an area for future research.

It is important to recognise that factors other than the method of completing the questionnaire differed between these two recruitment strategies, and so may have influenced the recruitment. Nicholson et al. (2013) highlight the impact of the setting and parents beliefs about the impact of the research. Parents report feeling that studies undertaken in health-care settings will have a greater benefit on their or their child's health, so are more likely to participate. Parents are also likely to be less busy when in the waiting rooms of the Child Development Centres than when at home, so may have felt more able to participate. This suggestion is supported by the low completion rates (10.9%) for the parents who took questionnaires to complete at home from the waiting rooms. It may have been helpful to collect contact details for the parents who chose to take the questionnaires away in order to provide a reminder letter for parents who did not return the questionnaire within a few weeks. Consideration must also be given to the ethical issue of whether parents felt "compelled" to complete questionnaires if researchers are present with them in the waiting room. If this was true, it could be predicted that parents may not give their correct name or address for further contact, but this was only noted in 5% of cases.

All of this needs careful consideration and justification within research grant applications and protocols in order to achieve a sample that is generalisable to the wider population (Nicholson et al., 2013). Beadle-Brown et al. (2012)

identified two papers working with hard to reach populations that provided, or attempted to provide, some idea of the cost of carrying out research with marginalised groups. One paper concentrated on the impact of recruitment, arguing that owing to the multiple recruitment techniques necessary, the cost per recruited participant was £11,000 (Oliver-Africano et al. 2010); while the second estimated that trial research in care homes would cost approximately three times the amount of running a similar trial with older people in their own homes (Zermansky et al. 2007).

This study has a number of limitations. One significant factor that cannot be measured through this study is parent characteristics and whether there were any differences between those who responded to the different recruitment methods. Using multiple recruitment strategies, Rugkasa and Canvin (2011) found that the type of strategy used affected the type of participants recruited. They found that those responding to adverts tended to be service users and/or those with higher educational attainment. They also noted that the range of socio-economic backgrounds was greater in participants recruited through community groups than those who had self-referred. It may be that employing a range of recruitment strategies is the most effective at recruiting a representative sample.

Within all populations where there are potential difficulties with recruitment, consent, measurement and interpretation of data, it is important to recognise that that representativeness can be threatened at various stages of the research process. Researchers must remain mindful of whom they may be

excluding (purposefully or unintentionally) in the design and implementation of each studies and employ strategies to avoid this happening (Bonevski et al., 2014). Generation of research findings that are representative of all social groups will allow development of an evidence base that can be used by service providers and policy makers to deliver programs and policies that reduce health inequalities.

Conclusion

This study aimed to describe the effectiveness of two recruitment methods; face-to-face and telephone based. Overall, the face-to-face recruitment method resulted in a **higher recruitment rate (58.5% of those approached)** and required 1.31 hours of researcher time per completed questionnaire. The telephone recruitment method resulted in a **poorer recruitment rate (18.5% of those approached)** and required 1.89 hours of researcher time per completed questionnaire. This supports the previous research highlighting that recruitment of participants with **intellectual disabilities** (or their parents/carers) requires more time and resources, and researchers should plan and justify for this in their grant applications using published data and figures.

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Table 1: Demographics and characteristics of children and parents recruited

		Recruitment	Recruitment		
		Method 1	Method 2	U/ χ	p
		(Waiting	(Phone/Email/		
		Rooms)	Post)		
<i>n</i>		438	40		
Gender	Male N (%)	330 (75.3%)	29 (72.5%)	.16	.69
Age of Child	Mean (SD)	5.1 (2.6)	5.6 (2.9)	8586	.33
Possible ASD	N present (%)	81 (18.4%)	16 (40%)	10.5	<u>.001</u>
Presence of genetic syndrome	N Present (%)	27 (6.2%)	1 (2.5%)	.86	.35
Challenging Behaviour	N Present (%)	328 (74.9%)	31 (77.5%)	.32	.57
Aggression	N Present (%)	391 (68.7%)	29 (72.5%)	9.67	<u>.001</u>
Destruction	N Present (%)	234 (53.4%)	24 (60%)	.64	.43
Self-Injurious Behaviour	N Present (%)	154 (35.1%)	13 (32.5%)	.11	.74
Parental anxiety score	Mean (sd)	9.03 (4.65)	8.73 (5.14)	8880	.82
Parental depression score	Mean (sd)	6.99 (4.13)	7.15 (4.4)	8867	.82

Study 1: Face-to-Face Recruitment

Project staff recruit children and parents from Child Development Centres, waiting rooms 755 parents/carers approached
Total time: 575 hours

517 parents/carers wished to participate

Requested to complete questionnaire in waiting room
N=427

Requested to return questionnaire by post N=101

Returned completed questionnaire N=427 (100%)

Returned completed questionnaire N=11 (10.9%)

Completed questionnaires = 438 (84.7%)

Expressed interest in future studies
N=216 (73.7%)

Called within one month

**Completed telephone interview
N=293 (66.9%)**

Did not completed telephone interview
N=145 (33.1%)

Could not be contacted at suitable time
N=107 (24.4%)

Incorrect telephone number
N=22 (5%)

Did not wish to participate
N=15 (3.4%)

Withdraw consent
N=1 (0.2%)

Approached by phone, email and letter and asked to complete questionnaire N=216
Total Time: 75 hours

Study 2: Remote Recruitment

Contact Made N=116 (53.7%)

Could not be contacted N=100 (81.5%)

Requested online N=85 (73.3%)

Requested call N=12 (10.3%)

Requested post N=3 (2.6%)

Did not consent N=16 (13.8%)

Completed online N=33 (18.5%)

Completed call N=6 (50%)

Completed post N=1 (33.3%)

Could not be contacted after 3 attempts
N=63 (63%)

Incorrect telephone number
N=37 (37%)

**Total completed questionnaire
N=40 (18.5%)**