Brief Report:

Beating the Barriers: Recruitment of people with intellectual disability to participate in research

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DOI: http://dx.doi.org/10.1111/j.1365-2788.2005.00618.x
Abstract

**Background:** The health status of people with intellectual disability is poor, yet very little research has been done on their health needs. There are several barriers to performing this research. Our aim was to examine the significant barriers encountered in recruiting adults with intellectual disability to participate in research.

**Method:** Our project was a randomised controlled trial aiming to improve health advocacy of people with intellectual disability. We approached many organisations to recruit participants and kept records of our results. Recruitment was very low for the first four months. Then we adopted two new recruitment strategies— in-service telephone recruitment and meetings with prospective participants. We then monitored the subsequent recruitment rates. We also questioned participants about the difficulties they encountered when considering recruitment.

**Results:** Initial recruitment of participants yielded less than one-third of the expected number. Additional strategies implemented were partially successful. Significant barriers to recruitment included several sectoral issues and the challenges arising from the research process.

**Conclusions:** Whilst this population is a difficult one to reach for research, attempts to do so should not be abandoned, since the potential health benefits for this underserved group far outweigh the recruitment barriers experienced.

**Keywords:** Barriers; recruitment; intellectual disability; health; general practice.
Introduction

There are few large epidemiological studies about the health of adults with intellectual disability, despite the evidence of poor health status in this group (Beange, et al. 1995; Lennox, Beange, & Edwards, 2000). The reasons for this lack of information include poor access to sufficient numbers of people for participation in research and problems with their recruitment.

For researchers the identification of sufficient numbers of adults with intellectual disability from data sets is generally not possible. The few researchers who can do this include those performing record linkage studies such as the ones in Western Australia, and those with access to files that are regularly used and maintained (Bittles et al., 2002; Cooper, 1999; Cooper, 2001; Leonard & Wen, 2002). As well as identification of potential participants, recruitment problems in large trials include the frequent need for substituted decision-making; the occasional limited literacy of both person and carer; and organisational ‘gate-keeping’ practices (Lee, 1993; Siegel, 1985).

Identification and recruitment are inherent difficulties found in research with all minority populations, such as indigenous groups and the elderly, and they are well documented (Anderson, 1995; Lewis, 1998; Neufeld, 2001). There is no published work on recruitment for these populations for randomised controlled trials (RCTs).

There is also little published information available on recruitment issues specific to people with intellectual disability. One exception is a limited, brief survey of 42 researchers in the field of intellectual disability (Siegel, 1985). Eleven of these researchers reported challenges. These included difficulties in securing consent (or “assent” as used in the UK) within a short time period and organisational policies and procedures. These procedures restricted access to the study group, as recruitment was often dependent upon the goodwill of organisations. They also reported a suspicion of outsiders they considered related to the threat of litigation, as well as anti-intellectualism and an insistence upon immediate local gains from the research (Siegel, 1985).

The obtaining of consent is of primary importance when doing research in the population of people with intellectual disability. The first step in the hierarchy of consent is the initial contact with the most senior staff within an organisation. Taking this step runs the risk of receiving merely token cooperation from subordinates. One strategy to deal with this is the early identification of key workers within the organisations who may become allies and assist the researcher. They may have day-to-day contact with the group of interest and save time and resources (Lee, 1993).
The experience of research on sensitive topics has indicated that organisations and support workers can effectively block access to potential participants by 'gate keeping' (Lee, 1993). In some research frequent attempts were made by gatekeepers to frustrate and circumscribe the studies, while in others the gatekeepers has preconceived notions of the appropriate methodology and refused access to the study population (Lee, 1993).

This paper focuses on current barriers to identification and recruitment of adults with intellectual disability into research based on the experiences of researchers from the Advocacy and Health Project (A&H) in Queensland, Australia. The purpose of the A&H project was to evaluate whether more effective advocacy could yield better health outcomes for adults with intellectual disability. The project was a randomised controlled trial designed to test two approaches to health improvement – the comprehensive health assessment program (CHAP) and an educational and advocacy intervention. The health assessment tool had already been evaluated whilst the educational and advocacy intervention was developed and evaluated as part of this project.

The aim of this paper is to describe the barriers we encountered to recruitment of adults with intellectual disability during the Advocacy and Health Project (A&H). We explain the strategies we used to address these barriers and the success or otherwise of these strategies. The conclusion describes the factors that may have influenced recruitment in our study and the implications for future epidemiological studies.

**Methods**

*Purpose:*

As the aim of the paper is to present the difficulties encountered in recruitment for the A&H, a brief description of that project is presented below.

**Advocacy & Health Study**

*Background:*

No data set identifying adults with intellectual disability exists in accurate, comprehensive and accessible form in Queensland, Australia. A national minimal data set has been collected but it was merely an annual one-day snapshot by all government and non-government service providers receiving Commonwealth or State Disability Agreement (CSDA) funding (Black, 1996; Wen, 1997).
This funding provides support services for accommodation, employment, therapies, education, social activities and respite services in Australia.

Based on the research from the snapshot data there appeared to be approximately 1 500 adults with intellectual disability living with their families within the study geographical region of South East Queensland, Australia, in the year of recruitment for the project (Black, 1996; Disability Services Queensland, 2001). This area includes a metropolitan centre, regional and rural communities and has a total population of nearly 3 million people.

**Target Population:**
A recruitment target of 1 000 people was set for the A&H study, based on our previous experiences in other projects. This project aimed to include adults with intellectual disability living with their families, in community housing, or private hostels. It excluded people with high support needs. The recruitment success rate for an earlier study by our Centre in another population of adults with intellectual disability [QCIDD, forthcoming] indicated a potential 70% recruitment rate. This study population had been recruited through one large non-government service provider. An important factor in that project was the employment of a respected, experienced and well known professional from inside this organisation to be directly involved in the recruitment of participants.

**Ethics:**
Ethical requirements restricted direct contact with participants until they or their nominated advocate had signed a consent form. Once that occurred, the person's general practitioner was contacted by one of the authors (also a general practitioner) to gain his/her consent to participate in the trial.

**Advisory group**
We formed an advisory group of nine people with expertise and knowledge of issues around health and intellectual disability. This group included adults with intellectual disability (3), parents (2), support workers (2), an occupational therapist and a professional advocate. We had four meetings during the tool development and recruitment phases, recorded the group’s advice and implemented it where possible.

**Focus groups**
We also conducted focus groups at the beginning of the project. We had 15 focus groups discussions with 104 people, consisting of adults with intellectual disability, parents and support workers. We
recorded all meetings in written form and on tape and later teased out themes from them. We used nearly all of the suggestions from the focus groups in the development of the tool.

Recruitment Strategies

**Initial strategy - Strategy 1.**

In the initial stage, the research team used their knowledge of organisations in the field and organisational listings as a means for contacting potential participants. Effectively, nearly 200 organisations were relevant to this study; and contact was made with 180 (90%), of which 111 (62%) agreed to participate and their key informants were identified (Graphs 1 & 2).

**Graph 1a - Organisations by type - agreed to participate**

**Graph 1b - Organisations by type – Non-respondents**
We received agreements of participation for service organisations from their executive(s), who either took a lead role in that agency or nominated a person within the agency to take this role. We then asked these service organisations to distribute information to potential participants about the study. The information package was developed taking into account advice about readability and visual appeal from disability workers, people with intellectual disability, doctors and advocates. We aimed to present the information to readers who included people who would be either semi-literate or have limited cognitive capacity. The information was either given directly or mailed to potential participants by the participating organisations.

The first barriers were identified in the third month of recruitment. They were the complexities and burdens of care faced by family members, and the ‘burnout’ and suspicion towards research felt by workers in the sector. We could not assess or quantify these early barriers. The study team then designed two possible strategies to deal with these barriers and increase the recruitment yield. We consulted the community advisory group about these ideas before acting on them.

**Insider telephone call strategy - Strategy 2**
The second strategy involved the payment of a locally recognised person or ‘inter-agency insider’ to telephone prospective participants via organisations on our behalf. The research team provided the insiders with a short training session on the study protocol and also on telephone techniques. This strategy was not always successful. Some organisations blocked our approach by refusing the nominated liaison person access to client details. These organisations offered to make the phone calls to potential participants themselves in exchange for payment of administrative time. We accepted those offers.

**Information session(s) strategy -Strategy 3**
The third strategy consisted of public information sessions in each of the eight identified sub-regions of the study region. We used these sessions as invitations to potential participants, rather than as a means of securing immediate consent. As a result of this, we needed to extend recruitment time from six to twelve months.

**Results of Recruitment Strategies**
There had been unanimous support for the project from all people approached about it. These included adults with intellectual disability, parents, carers, workers, people invited to the reference
groups, focus groups, and different professionals consulted about the tool. Despite this strong verbal support, the adoption of further strategies, and a doubling of the length of time for recruitment, by the end of the recruitment phase of the project, less than one third (n=265) of the estimated possible eligible participants (n=1000) were finally recruited.

At the beginning of the project, after 3 months of work, 43 individuals had been recruited from a base of 77 interested organisations. A month later 8 more adults had been recruited - giving a cumulative total of 51 people recruited after 4 months of work.

After the initial recruitment strategy proved inadequate we implemented two further strategies; insider phoning at four months, and then information sessions at eight months. The efficacy of the insider phoning strategy over the information session’s strategy was apparent, although some cumulative benefit of initial recruitment efforts would have impacted on both.

![Figure 1: Recruitment Yields Per Strategy](image)

**Graph 2** – Recruitment yields per strategy.

Shortly after implementing the direct telephone approaches (at 4 months), the initial slow trickle of recruits turned into a minor flood, which started to drop off after the eighth month to give a total of 216. Introduction of the information sessions about that time may have helped keep the subsequent
recruitment ticking over faster than in the initial phase. This occurred at a rate of 13 recruits per month for 5 months giving a total of 265 when recruitment was closed (See Figure 1.)

From the viewpoint of costs the principal expenditure was for research staff. In addition 9.3 information packs and 4.2 emails were sent out, and 2.4 phone calls made per eventual participant. This represented a cost of around $AU750 ($US488, €443) per person recruited. Costs per strategy used were impossible to calculate due to the sequential application of the strategies.

Of the final number of participants recruited (Graph 3), 36% (n=103) were recruited from 26 large government organisations, 22% (n=62) from 15 large non-government organisations; 15% (n=44) from 49 small non-government organisations; 12% (n=35) from 15 church organisations; 5% (n=15) from 6 private hostels, and 10% (n=28) from unidentified sources.

Whilst 111 organisations agreed to distribute information to potential participants, only 48 (43%) actually yielded participants for the study. Of the 63 organisations, which did not yield study participants, 60% were small non-government organisations, 18% large government organisations, 14% large non-government organisations and 7% church organisations.

*Graph 3* Yield ratios per organization type. NGO, non-government organization.
Barriers and Complications with recruitment

Barriers and complications with recruitment arose from the nature of statutory requirements in the provision of consent for this population. Adults capable of consenting on their own behalf constituted 11% (n=28) of participants. The remaining 89% (n=237) required another person to consent to their involvement. That party was a parent, guardian or statutory health attorney under Queensland law. In some cases, this third party was not residing with the person with intellectual disability, and was not aware of the nature of their daily activities. In these cases the service organisation was relied upon to mediate the health information to the research team.

The baseline interview afforded opportunities to seek participants' views on difficulties in recruitment. Qualitative analysis showed that 75% (n=198) responded that they had no difficulty enrolling in the study; specific difficulties with understanding what the study was about 7% (n=18) and filling in the consent forms 6% (n=16) were stated.

We also asked people about what they expected to gain from being in the study. Of the ones who answered, 36% (n=96) said increased knowledge and awareness for them, 26% (n=67) said they wanted to help others including their particular adult with intellectual disability. An example of a particular gain included “What I could get out of it. Learning more about advocacy”.

Discussion

The key finding was that the recruitment of a large population of adults with intellectual disability faced a number of barriers. Recruitment was best achieved through direct contact from a member of staff of a service provider to the adult with the intellectual disability and their caregivers. In hindsight we should have used this strategy from the beginning. We found that even though there was universal positive regard for the research project by self-advocates and caregivers, this was no guarantee of recruitment and, without the use of an “insider” in each organisation, success was very limited.

The retrospective examination of the recruitment process presented above, and discussed below, inevitably must be viewed with some caution, as there is a considerable risk of recall bias. While acknowledging this limitation we consider an exploration of the factors, which may have influenced the process of recruitment, would be timely and useful. Experience with epidemiological studies in
adults with intellectual disability is very limited and there is an increasing demand of governments for empirical evidence from such studies to inform policy and practice.

After some consideration of the recruitment process, we broadly classified the major barriers to recruitment into two groups - sectoral or the research process. The following discussion of the nature of these barriers aims to provide a framework to assist realistic planning for research in this population and in other similarly marginalised groups.

**Intellectual Disability Sectoral Barriers**

In our experience, the intellectual disability sector has a wide set of barriers lying in the path of the researcher. Some barriers include those related to support organisations, the lack of accessibility to people and funding constraints. Other sectoral barriers are the demands of caring and various issues related to consent. These sectoral barriers and our experiences dealing with them are discussed here.

**Organisational Barriers in the Disability Sector**

The barriers in large organisations can be related to numerous tiers of management. This stratification leads to internal inertia, cultures of discontent and blocked communication (Hatton et al., 1999). In one organisation, 17 levels of management were counted between the nominated liaison person for the project and the potential participant. This organisation did not yield any participants for the project. It was not possible to determine at which level the organisational blockers to the recruitment for the project were to be found, or obtain any information about them. In a previous epidemiological study conducted by this Centre with a large organisation, a respected “insider” was assigned to recruit participants and a much higher enrolment rate was obtained (not published).

In the smaller organisations the barriers are different. Many of them are community organisations and workers generally face complex and often overwhelming workloads. They are characterised by adherence to ‘community development approaches’ requiring participation by all people concerned (LGCSAA, 1999), so decisions have to be made by consensus by all stakeholders. These practices are very time consuming, labour-intensive, and slow. There is little time available for research.

**Accessibility Barriers in the Disability Sector**

Accessibility to populations varies across regions and countries. For example, the United Kingdom has regional registers of adults with learning disabilities (Cooper, 1999). These have been used in
research and for policy-making, target setting, contracting and evaluation (McGrother et al. 1996). In Australia however, there is currently no accessible regional register of adults with intellectual disability that can be used in intervention studies. Without such a register, it is difficult to accurately identify and access populations of sufficient size to perform these studies.

Locating people can be difficult. Adults with ‘mild’ intellectual disability may live independently in hostel accommodation and become elusive through their mobility. Older adults with intellectual disability living in the family may have had little funding support and are unknown to service organisations. In New Zealand it was found that 19% of all people with intellectual disability born before 1940 were unknown to relevant services (Hand, 1993; Hand & Reid, 1996).

Accessibility is better where there is co-ordination of services. In achieving flexibility, co-ordination of service delivery may be lost, and people become less accessible (OPA, 2001). In this project, in one extreme, one person had seven service providers - all unaware of each other. Another person had no service provider and thus was 'invisible' on service files, ‘invisible’ in statistics derived from funding sources, and ‘invisible’ to researchers. The ‘invisible’ participants in this project were reached through unknown sources, and on the whole, appear to be family based.

**Funding Constraints in the Disability Sector**
Inadequate funding is always one of the strongest barriers to progress. Compared with the national average of $AUS4071 per person per annum, Queensland receives $AUS2413 per person per annum (OPA, 2001). With such limited funds available compared with the rest of the country, individuals with intellectual disability in Queensland and the people who support them (principally family) receive barely adequate services.

**Demands of Caring in the Disability Sector**
Carers often find daily survival wearisome, and we found this a common barrier to participation (Briggs, 2000; Henwood, 2000; Schofield, 1999; Todd, 1996). Advocacy will not occur for an individual unless their paid workers or parents have the capacity to undertake it. For example, elderly parents phoned the research team to say that they had an adult daughter living at home with high support needs, that they got fewer than ten hours per week in paid support, and that they would have liked to participate in the study but simply did not have the energy. Commitments perceived as an optional additional load, such as research participation, become a low priority.
Consent Issues in the Disability Sector

Consent issues include the level of intellectual disability and need for substituted decision-making; there was some evidence of limited literacy of either or both person and carer, and a minor level of suspicion of what the nature of the research was. Many adults cannot consent to participation themselves, and a third party is needed to give consent on their behalf. Identifying that person, who may not play a role in daily health care, can be difficult and this forces extensions of the length of the recruitment phase. It was not possible to determine why people might have not wanted to give consent.

The Research Process as a Barrier to Recruitment

There were three main barriers related to the research process. These were how the notions of “advocacy” were perceived, the inability of the research to address some important healthcare concerns and ethical constraints.

The first research process barrier - the perception of the word “advocacy”, was a problem for some. The nature of public advocacy organisations in Australia is to focus more on systems approaches rather than individual advocacy; eg, to lobby governments for changes in hospital systems. Individual advocacy, whereby a paid advocate is employed by a person to advocate on their behalf for their rights on a certain issue, eg: access to housing, is less common. Whilst “advocacy” is a familiar concept for professionals, it is unfamiliar to families. For families who are isolated from services, many cannot see the sense in systems advocacy, and in some cases, perceive individual advocacy as interference in their parenting (Stone, 1999).

For the second research process barrier we could not offer any solutions. This barrier related to the problems that most concerned people around health systems and medical specialists, especially the experience commonly expressed in the focus groups of being discriminated against by specialist practitioners and hospital staff.

The third research process barrier in this area was related to ethics. Ethical limitations prevented a direct approach to potential participants. This safeguard, while protecting adults with intellectual disability, may also act to deny them, or their guardians, the right to hear about and be included in the research. In our attempt to protect this vulnerable population we also may, inadvertently, deny them their rights to be included as participants in research. On balance, this outcome, which arises
from conflict between the right to protection from unscrupulous researchers and the right to inclusion, may be quite appropriate, however it needs to be recognised, acknowledged, and the implications thought through.

One consequence of the difficulties encountered on recruitment is that clinicians and policy makers are forced to make judgments about the effectiveness or otherwise of interventions, such as the introduction of a medication or a specific therapy or new service, which have not specifically been trialled in adults with intellectual disability. In healthcare there has been an increased emphasis on decision making on the basis of the best available evidence, where the level of evidence is based on the number and quality of studies, with randomised controlled trials (RCTs), systemic reviews and meta-analyses of trials being generally accepted as the highest level of evidence (MacIntyre, 2001). If such trials are unable to recruit sufficient numbers of participants, then adults with intellectual disability will receive interventions based on inferior quality information.

There are very few interventions that have been tested using the RCT methodology in adults with intellectual disability. RCTs in studies in the general population have revealed that interventions are often not as good as previously thought (Augood et al., 2003; Hulscher, 2001). These interventions have been used with a low level of evidence of their usefulness because they were thought to be helpful, but in fact RCTs have shown them to be ineffective. If recruitment into RCTs continues to be difficult, adults with intellectual disability will continue to receive therapies and services only supported by inferior levels of evidence.

As Oliver has suggested, new services only arise where there are strong supportive voices. This, however, is the lowest level of evidence and may ignore issues of effectiveness. In healthcare decisions there has been an increased reliance on high quality evidence to support, or otherwise, therapeutic or service interventions. Where an intervention does not have supportive evidence then policy makers and clinicians are increasingly less likely to fund or use the intervention (Oliver et al., 2002).

The effective exclusion of many adults with intellectual disability is commonplace in studies in the general population. In Australia, a major study of women’s health and a national mental health survey excluded this population, as they required literacy skills, a circumstance that is almost
certainly repeated in other countries (Andrews, 2002; Brown et al., 1998). This further hides adults with intellectual disability from the benefits of research.

Over the last 20 years some groups have attempted to move the control of the research process to the adults with the intellectual disability (Walmsley, 2001). Arising from the general disability literature and based on the social model of disability, this shift has resulted in two broad approaches, participatory and emancipators research, where the person with the disability is at least considered an equal partner, expert, and often the researcher (Walmsley, 2001). Direct application of this approach has been achieved in some qualitative studies by and about adults with intellectual disability. There have been reservations expressed by some researchers about this process. These include the need for more time and resources, as well as the difficulty negotiating the power differential between disabled researchers of different cognitive ability and non-disabled researchers. In addition, the expertise of a researcher is not transmissible to some adults with cognitive impairments (Ward, 1998; Walmsley, 2001; Chappell, 2000). Perhaps of most significance is that this approach has not been used in quantitative research studies where large populations are usually necessary. The ongoing and repeated detailed consultation process used in participatory approaches would be extremely time consuming to implement given the numbers of people that need to be recruited for this type of research when compared to qualitative studies. In the highly competitive research grant environment the cost of such high levels of participation would be prohibitive.

Suggestions for Improving Recruitment Yields in this Population

There is no one solution to reducing barriers to study recruitment within this population. Working within the constraints mentioned above is simply dealing with reality and we could see no way to design the study in any other form. However, for the benefit of other researchers, the study has suggested a number of possible strategies, which could reduce some recruitment barriers:

- The provision of more direct access to participants would reduce recruitment time and provide a more participatory consent process for subjects.

- The development of a centralised register of adults with intellectual disability would be beneficial to both researchers and policy makers in providing useable, current and accurate data.
Allowance should be made for the recruitment phases for ‘sensitive’ populations to be longer than other populations and should be matched by appropriate research funding.

Researchers must be aware that distinct service languages exist and should be used to prevent antagonism.

Researchers must be prepared to make home visits and visits after-hours to allow for time constraints of participants and carers.

It is important for adults with intellectual disability and their carers to feel that their stories have been heard, before they can reciprocate and participate in research. Focus group discussions serve this purpose well.

Clear descriptions of eligibility, purpose and benefits of the research are helpful. Our success here was not as much as expected.

This paper describes the barriers to recruitment for research in adults with intellectual disability. The paper also offers suggestions for beating those barriers. We consider that this population is a difficult one to reach and recruit. However, attempts to do so should not be abandoned. The potential health benefits from research for this underserved group far outweigh any barriers experienced.

Acknowledgements
The team acknowledges the financial support of the General Practice Evaluation Program for this research, and the developmental support of Associate Professor Robert Bush of the Centre for Primary Health Care, University of Queensland. We thank the participating adults with intellectual disability, support workers, family members, support organisations and general practitioners; the University of Queensland, the community advisory group who gave their time freely; and the Mater Hospital for its ongoing support. The views expressed in this work are those of the authors.

REFERENCES


