**Expanding capacity in mental health research in intellectual disabilities**

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**Summary**

Whilst the research base in mental health in intellectual disabilities is advancing, there are long standing barriers which hinder successful completion of funded studies. A variety of stakeholders hold the key to mitigating the challenges and arriving at sustainable solutions that involve researchers, experts by experience, clinicians and many others in the research pathway. Lessons learnt during the COVID-19 pandemic can also contribute to improvements in the conduct of research in the medium to long term. People with an intellectual disability and mental health conditions deserve high standards of evidence-based care.

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**Introduction**

Research evidence is essential in supporting professional decision making for the benefit of patients across Health and Social Care. The benefits of participation in research include better outcomes and more efficient use of resources, with harmful or unhelpful treatments being phased out.

A major driver for funded applied health and social care research is the increase in research capacity, and the completion of high quality studies on priority topics that have been identified by stakeholders including scientists and the public. In the UK, the substantial annual investment of more than £1bn by the National Institute of Health Research (NIHR) supports both projects spanning the range of methodologies and infrastructure to underpin the endeavour.

Recognising the challenges of getting buy-in to research from health and social care organisations, NHS England and the NIHR published a joint report1  which included 12 actions that would help to relieve the bottleneck many chief investigators encounter at the setting-up and recruitment phases. Two major stumbling blocks at the time were setting excess treatment costs with regard to treatment delivery, and research governance; the latter ranges from ethical approval to assessment of local capacity and capability in agreeing recruitment targets.

Whilst progress has been made, these issues which are common in research activity across many different health and social care domains, have not completely resolved 3 years on. In this paper we address a variety of both barriers to research and facilitators of research, with a specific focus on research in intellectual disability services. We argue that such issues may be relevant in research in other hard to reach populations who may or may not have cognitive impairment.

Since the launch of the NIHR in 2006 in the UK, there has been an increase in the number of funded studies investigating a variety of research questions in intellectual disabilities including developing, adapting, and testing interventions in randomised controlled trials (RCTs). The majority of these are trials of psychosocial interventions. However, the portfolio of studies remains small compared with other fields of medicine, estimated at 1.4% of all NIHR funded studies2.

People with intellectual disabilities (global developmental delay evident in childhood which affects adaptive functioning) account for approximately 2% of the population in the UK, and are more likely to suffer with health multimorbidity, higher and earlier mortality and face significant inequalities3. Many participants in research lack capacity and therefore decisions about their participation depend on family and paid carers’ understanding and attitudes towards research projects and research processes. This is because they may be called to act as consultees to enable participation of those most vulnerable. It is therefore essential that people lacking capacity should also be able to take part in and benefit from research specific to people with intellectual disabilities with appropriate safeguards as mandated in the Mental Capacity Act 20054 or equivalent permissions internationally.

## Barriers

Despite the amount of research conducted over time, many challenges which have been reported previously still remain and impact on the completion of studies. Lennox et al (2005)5 described identification of substantial numbers of participants, frequent need for substituted decision-making, occasional limited literacy of both person and carer, and organisational gate-keeping practices as significant barriers to recruitment in a randomised controlled trial of health checks in Australia. More recently, a systematic review of 53 papers reporting RCTs in people with intellectual disabilities published between 2000-20176 identified similar barriers in recruiting to target, participant treatment preferences, engaging with stakeholders, obtaining consent, and staff turnover. Optimistically the authors concluded, “conducting RCTs with people with cognitive disabilities can be challenging, however, with reasonable adjustments, many of these barriers can be overcome”.

People with intellectual disabilities are excluded from research that may be relevant to their health vulnerabilities2, as well as being sceptical about the impact of it on their lives. This is illustrated by the Research Voices project7 which revealed a number of serious concerns parents of people with profound and multiple disabilities harbour about research such as mistrust of health professionals seeking participants for studies, the emotional and time burden of research assessments, frustration with not knowing of the findings or findings not translating to real improvements in practice.

Research infrastructure brings its own multifaceted challenges. The role of Clinical Research Practitioners (CRP) (who are NHS based and able to recruit from services directly) is not fully understood by Intellectual Disability services and there is significant variation among the operations of Clinical Research Networks across the different UK countries. Therefore, professionals in the services may be asked to undertake recruitment in addition to an already busy clinical role. Further, data guarantors are frequently local authorities, who are providers of social care services not directly connected to the National Health Service in England. Finally, Intellectual Disability services being located outside NHS structures have fewer opportunities to be informed of ever evolving research processes, thus remaining unable to utilise available resources to assist them in incorporating and supporting research in their day to day practice.

Clinician factors are also important in maintaining non engagement in research activities including older age, being male and working in the private sector8. Oliver-Africano, Dickens, Ahmed et al9 identified beliefs on drug efficacy, potential ethical conflicts in medication trials and multidisciplinary team processes as having adversely affected recruitment to a clinical trial of antipscyhotics in adults with intellectual disabilities. Delays associated with any of these factors inevitably matter in completing studies which depend on time sensitive research contracts and are likely to hamper the validity of the research findings if under-recruiting.

Finally, clinicians and scientists in general may not make sufficient effort to include participants from underrepresented groups in their studies perpetuating the limited access of people with intellectual disabilities in research. This is particularly important for diseases where it has been demonstrated that there is excess morbidity and/or mortality in this population10.

## Facilitators

Prioritisation of research is likely to confer benefits to both health and Care organisations as shown by views reported in a review of engagement in research11:

*The wider review demonstrated …how collaborative and action research can encourage some progress along the pathway from research engagement towards improved health-care performance. There is also evidence that organisations in which the research function is fully integrated into the organisational structure, out-perform other organisations that pay less formal heed to research and its outputs*.

These lessons whilst not specific to intellectual disabilities are relevant in this context as presenting a justification for embracing research by the multitude of service configurations delivering care to this population.

In other changes to research governance, the new Health Research Authority has halved the time needed to obtain regulatory approvals12 although other milestones along the research pathway remain areas of concern.

Whilst the funding for research in intellectual disabilities may be lower than what is essential for investigating the increased morbidity, mortality and the health inequalities seen in this population group, there is an emerging cohort of completed high quality studies. There are also many committed researchers and health care service professionals and other staff whose enthusiasm and problem solving capacity signal their willingness to engage with the process. These may further promote interest in research by influencing national clinical practice and through targeted dissemination including to people with intellectual disabilities and their carers. Clinician familiarity with academic work, peer support and support from management are likely to also increase positive attitudes towards research. Research that is seen as arising out of patient concerns and that it could lead to tangible benefits in interventions and care improvements is also likely to be supported7.

Recently the NIHR Dissemination Centre published its themed review on Intellectual Disability research, Better Health and Care for All (2020)13. More than showcasing the funded projects it highlighted the meaning of the findings for the care people with intellectual disabilities and their family carers receive. In addition, the collection of studies included in the Themed Review demonstrate that funded research can be conducted successfully in the field of intellectual disabilities but that all the studies have had significant involvement of people with intellectual disabilities and their family carers throughout. These studies are examples of good practice that can be shared between researchers, people with lived experience of intellectual disabilities, their carters and charities supporting them.

## Solutions

A primary area for mitigation lies in Health and Social care professionals’ and people with lived experience of intellectual disability conviction of the importance of research and its wider contribution to the lives and wellbeing of people with intellectual disabilities. A recent course14 which was devised to train people with lived experience of intellectual disability in research methods suggests that learning about conducting research and driving the research process is feasible. Such courses could increase the number of suitably trained people with intellectual disabilities who could be recruited to work as researchers in various projects.

Incentives for encouraging donation of time to research activities by family and paid carers may improve uptake and retention alongside other strategies. Increasingly experts by experience are being asked to interpret and comment on research findings and that is a way in increasing familiarity with research processes as well as consumer feedback.

The well intended efforts of paid carers to protect vulnerable adults where they lack capacity including the personal data protection regulations can, on many occasions, stifle participant recruitment. In England and Wales, this could be addressed by a revision of the Mental Capacity Act 2005. Heywood et al (2019)15 outlined how the Mental Capacity Act 20054 is predominantly focused upon treatment and decision-making within a “best interests” framework, rather than upon research where decisions are not made using the same “best interests” framework. Instead, the sections governing research do not effectively balance protection and empowerment, and researchers may be reluctant to include participants who lack capacity within research projects.

The research community may also need to take some responsibility in providing solutions to the present challenges. Being clear about what the findings mean to the wider group of people with intellectual disabilities, proactive dissemination strategies and other activities in engaging the public with research are paramount in moving forward. Research aims to shape service delivery and to translate advances in science into measurable benefits for the population at large. It is questionable as to whether consumers consider research findings relevant to their health and those who commission services apply the findings to enhance clinical effectiveness and value for money.

An example of fostering closer links between clinical, academic and people with lived experience of intellectual disability is the newly formed RADiANT consortium, a platform that works to increase health and social care staff research awareness and develop research skills and capacity. The consortium is focused upon mental health and behavioural issues within intellectual disabilities, autism and other neurodevelopmental conditions (see [http://radiant.nhs.uk/](https://eur01.safelinks.protection.outlook.com/?url=http%3A%2F%2Fradiant.nhs.uk%2F&data=02%7C01%7C%7C4393ec3c50c8429832dc08d8429c5a22%7C1faf88fea9984c5b93c9210a11d9a5c2%7C0%7C0%7C637332586588177042&sdata=ec%2F5xj%2BRp6pGM%2F4V0R56EU72gEnG9CY3m7UrX7j4RXY%3D&reserved=0) for more information). So far it has produced guidance on how to manage the pandemic in different mental health settings and has delivered several educational activities. Its wider impact remains to be established.

Professional bodies across all professions must also promote research related objectives in training curricula and on public facing fora, e.g. websites, newsletters.

Strengthening health and social care links is an area for further development especially as social care is identified as a domain for research investment. This means extension of the research infrastructure to reach the neglected care sector which is central to accessing participants to take part in research activities as proxy informants.

The coronavirus pandemic has shown that whilst continuing to endorse ethically conducted research, it is possible to do so at pace16. It will be important to remember those lessons as we are coming out of the pandemic and in the event of future public health emergencies. In particular how to carry out remote research assessments and interviews with participants with intellectual disability and ensure that the voice of experts by experience remains central to research activity. In the pandemic people with intellectual disabilities have been disproportionately affected in both their health and social care needs and require high standards of support in both. We must be able to reassure them and their families that being partners in research pays off in achieving those standards.

(2017)

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**Declaration of interest**

Declaration of Interest: None

**Funding Statement**

This work is funded by the National Institute for Health Research (NIHR, Health Services and Delivery Research Programme reference 16/01/24). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

**Ethics Statement**

The manuscript is a special article and does not use any patient data.

**Consent Statement**

This is not applicable to the type of article

**Professional Medical Writer Statement**

No professional medical written was involved in the preparation of the manuscript

**Author Contribution Statement**

All named authors have equally contributed to the preparation and content of the manuscript. AH drafted the manuscript and led the submission process, PL, KC, VC, AK, RR, BLE, AK and IH contributed to the intellectual content via successive iterations of the manuscript. All authors have read and approved the final version.

**Data Availability**

Data availability is not applicable to this article as no new data were created or analysed in this study

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