

# Mental Health Services for People with Intellectual Disabilities: Barriers, Facilitators & Reasonable Adjustments.

Frances Marshall<sup>1,3</sup>, Howard Ring<sup>1,2</sup>, Isla Kuhn<sup>4</sup> & Isabel Clare<sup>3,1,2</sup>

<sup>1</sup>Cambridgeshire & Peterborough NHS Foundation Trust, <sup>2</sup>Department of Psychiatry, University of Cambridge, <sup>3</sup>NIHR CLAHRC East of England, <sup>4</sup>Medical Library, University of Cambridge

## Background

People with intellectual (learning) disabilities (IDs) have higher rates of mental health problems than the general population. They require access to good quality, appropriate, mental healthcare. We need to understand the barriers and facilitators to receiving such care. Now that there has been a move away from specialist services, we need to know how to best provide care in mainstream services, making the 'reasonable adjustments' required by the *Equality Act 2010*.

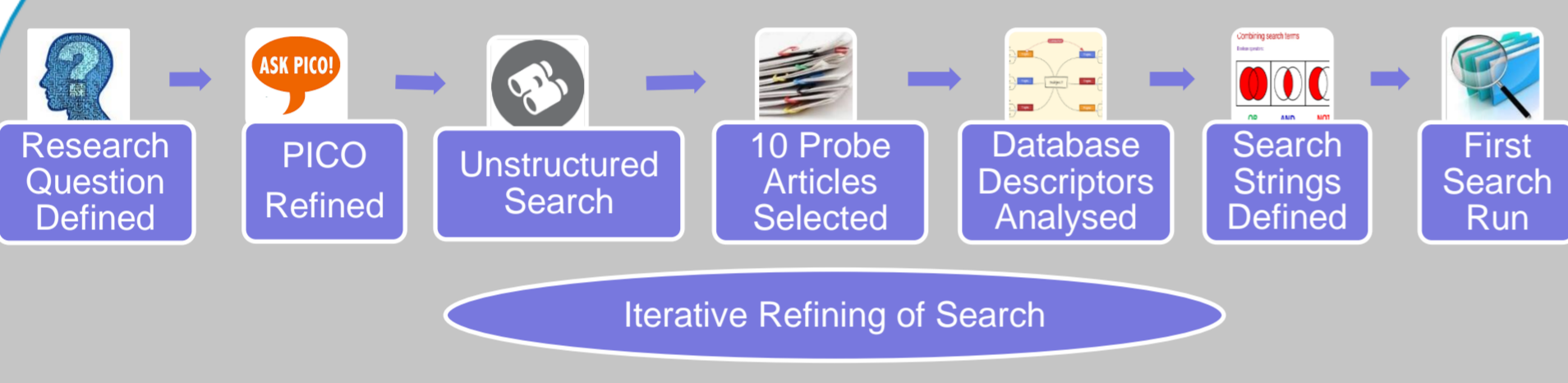


## Study Design

A systematic search of electronic research databases was conducted through the NICE HDAS<sup>1</sup> portal, using a peer checked Boolean<sup>2</sup> search. Studies were included based on predefined inclusion criteria, and reference and citation searches carried out to find further relevant studies. The GRADE-CERQual<sup>3</sup> approach will be used to report the results, enabling judgments to be made about the strength of the findings.



**Fig. 1: Consort Diagram (The Search Process)**



## Evolution of the Study

The original intention was to identify, appraise and synthesise evidence on what modifications of the care pathway might improve or impair the service that adults with IDs receive from mainstream adult mental health services. However, in light of the consultation on learning disability services in the local area, a decision was made to refocus the research project in order to provide feedback for the potential redesign of services.



## Key Preliminary Findings

### Barriers:

- Limited help-seeking by people with IDs;
- Referrals almost always by paid or family care-givers
- 'Diagnostic overshadowing'<sup>4</sup> delays identification of mental health problems
- Referrers' lack of understanding of service systems
- Inconsistent criteria for entitlement to services
- Lack of clear policies and protocols for joint working between ID and mental health services

### Facilitators:

- Good support networks for people with IDs inc. effective advocacy by care-givers
- Clear referral pathways
- Effective multi-disciplinary and inter-agency working
- Consistency in adapting therapies

### 'Reasonable Adjustments':

- Staff education & training
- Interagency collaboration
- Communication support



## Conclusions

There is a small, but directly relevant, literature, based on perspectives from service-users, care-givers, and healthcare practitioners, that addresses the barriers and facilitators to specialist ID & mainstream mental health care for people with IDs. There is broad agreement on the key issues. It is important that this information is used to inform the commissioning, design and provision of community and in-patient care pathways.



## Planned Analysis Strategy

We plan a "best fit" framework synthesis, adopting an existing theoretical model from the research literature and using this to generate codes and themes from the material. This approach supports a comprehensive understanding from descriptive preliminary findings, enabling generalisation. The proposed model is that of 'candidacy'<sup>5</sup>, a concept that, in health services, refers to aspects of the 'fit' between the patient and the service system.



## Recommendations for Future Research

- Research on 'reasonable adjustment' exists, but the term is rarely being included by researchers in their titles, abstracts and key words. We need to raise awareness amongst researchers of the importance of this issue; research we cannot find, we cannot use.
- There are significant gaps in the research literature: in particular the role service policies around diagnosis in gaining access to both specialist and reasonably adjusted services remains under explored.



## Glossary & References

- <sup>1</sup> HDAS: Healthcare Databases Advanced Search: website bringing together key databases of healthcare research <https://hdas.nice.org.uk/>
- <sup>2</sup> Boolean search: user combines keywords with operators such as AND, NOT and OR to further produce more relevant results (e.g. "quality" AND "life") <https://libguides.usc.edu/searching/boolean>
- <sup>3</sup> GRADE CERQual: Grading of Recommendations, Assessment, Development and Evaluations - Confidence in the Evidence from Reviews of Qualitative Research; a systematic method for assessing qualitative evidence syntheses <https://www.cerqual.org/>
- <sup>4</sup> 'Diagnostic overshadowing': attribution of concerns to the impairments that characterise and are associated an ID <http://www.intellectualdisability.info/changing-values/diagnostic-overshadowing-see-beyond-the-diagnosis>
- <sup>5</sup> Methley, A. et al (2016). The value of the theoretical framework of candidacy in exploring access and experiences of health care services. *Health Psychology Update* Vol 25 No 1 Spring