A systematic investigation of intensive support teams (IST) for adults with intellectual disabilities and challenging behaviour

IST-ID Study

Will present

- Background
- Preliminary findings from stage 2
- Reflections

Questions

- What is intensive care for people with intellectual disabilities and challenging behaviour?

- What models of intensive support are currently in operation?

- How do they compare for clinical outcomes and costs?

Study Objectives

- Map and describe the provision of IST services in England.

- Create a typology of IST service models.

- Compare the effectiveness of different IST models for patient outcomes including challenging behaviour, mental health status, risk, satisfaction with care, quality of life, hospital admissions.

- Estimate the costs of different IST models and investigate cost-effectiveness.

- Understand how the ISTs impact on the lives of adults with ID and challenging behaviour, their families and the local services.

NG11

- It recommended further research to examine the ingredients of good close to home care which maintains community placements.

NG93

- Developing services in the community tasking lead commissioner (acting on behalf of local authorities and clinical commissioning groups)

The puzzle of which service

- **Transforming Care** seeks to improve services for people with ID to support people in their community and reduce hospital admissions

- **RCPsych report (2015)** on *Community based services for people with an intellectual disability and mental health problems* found that there is insufficient evidence to suggest a superior model in terms of service user outcome and effectiveness

- **Building the Right Support (2015)** describes a national plan to *"develop community services and close inpatient community facilities for people with a learning disability and/or Autism who display behaviour that challenges, including those with a mental health condition"*

Peripatetic support model - services delivered as part of the model included functional assessment, development of interventions, staff training and role modelling.

However, such teams have been in and out of favour and unclear as to whether their operation is part of a coherent pathway for crisis management and specialist intervention

Intensive Support Teams: recent research

- Some evidence of reduction in challenging behaviour as a result of IST engagement (Inchley-Mort et al, 2014; Hassiotis et al, 2009)

- Limited reporting of stakeholder experiences of ISTs (Inchley-Mort & Hassiotis, 2014; Robotham et al, 2011)

- Davidson et al (2015) described UK wide provision of peripatetic teams for adults and children with ID and challenging behaviour

20/46 teams responded to an online survey

Results showed children were underserved, lack of evidence based practice and reconfigurations resulted in losing these services

ISTs: Function

NHS England proposes that ISTs should be part of **all** community ID services in England.

And should provide:

- Assessment, treatment and support for individuals who display behaviour that challenges
- Specialist support, and training for other agencies supporting those individuals
- Coordination of transitions from inpatient and other settings
- Crisis response

Summary of findings from phase 1

- 73/80 ISTs in England responded

- Independent (Model 1) and Enhanced provision (Model 2)

- 22 different terms described the ISTs
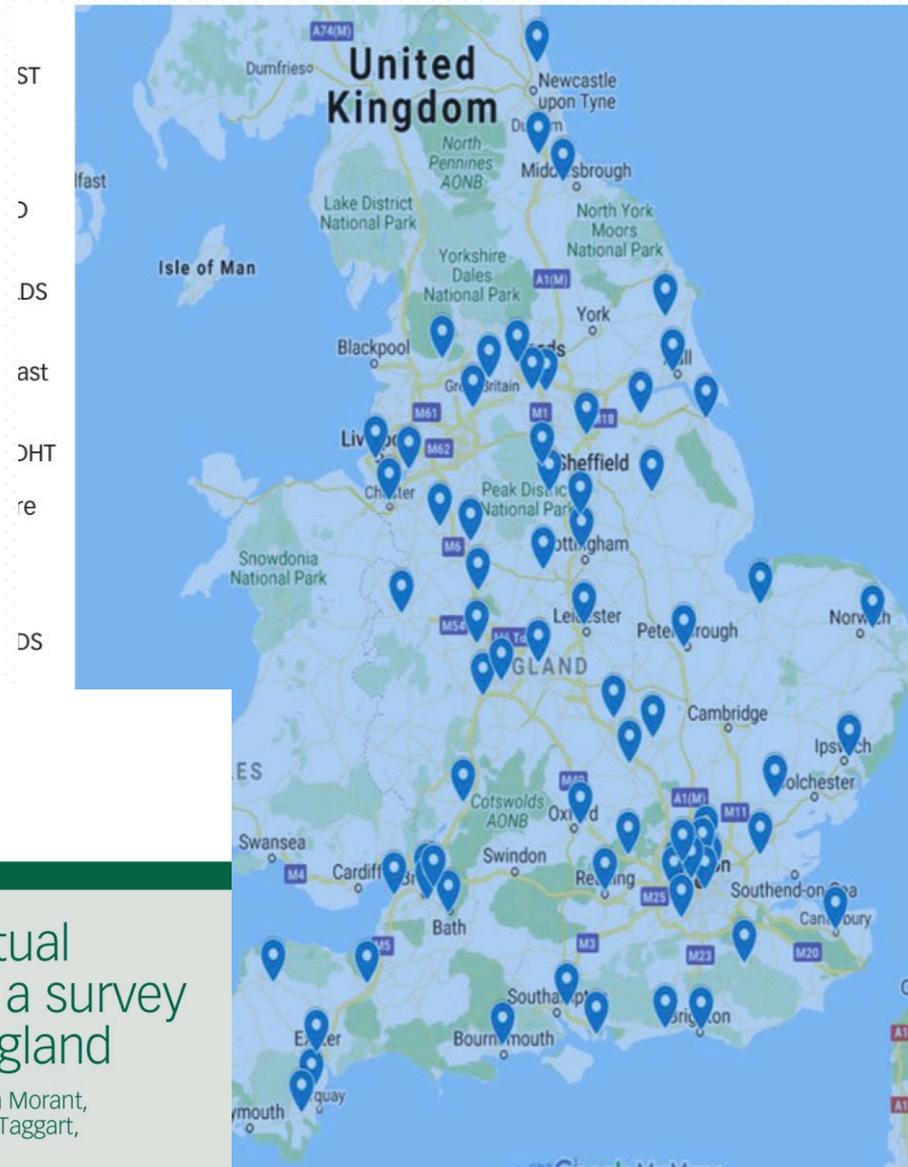
Intensive support for adults with intellectual disability and behaviours that challenge: a survey of provision and service typologies in England

Angela Hassiotis, Amy Walsh, Jessica Budgett, Isobel Harrison, Rebecca Jones, Nicola Morant, Ken Courtenay, Elisabeth Victoria Crossey, Ian Hall, Renee Romeo, Laurence George Taggart, Peter E. Langdon, Victoria Ratti, Vincent Kirchner and Brynmor Lloyd-Evans

ISTs: practice

- Main intervention=Positive Behaviour Support

- Plans to work with local mental health systems to reduce admissions out of hours and provide specialist input

- Role in implementation of initiatives such as antipsychotic reduction (STOMP)

- Operational policies (16 policies for 19 ISTs)

Majority of OPs referred to a crisis plan and a few stated <u>not</u> being a crisis service

Stage 2 Objectives

- Compare the effectiveness of different IST models for clinical outcomes

- Estimate the costs of different IST models and investigate cost-effectiveness.

- Understand how the ISTs impact on the lives of adults with ID and challenging behaviour, their families and the local services.

Measures

Primary Outcome

Challenging Behaviour Aberrant Behaviour Checklist Community Version 2 (ABC-C)

Mental health status: PASADD	Risk: Threshold Assessment Grid (TAG)	Quality of Life: (QoL-Q)	Health related quality of life: EQ-5D (5 level)	Service use: Client Service Receipt Inventory (CSRI)

Other Measures:

- Sociodemographic characteristics
- Clinician recorded Autism and ADHD diagnosis
- Level of functioning (Short Form Adaptive Behaviour Scale)
- Admissions to hospital during follow up period
- Change in accommodation and reasons for it, e.g. placement breakdown.
- Previous treatments received, by whom and outcome (at baseline)
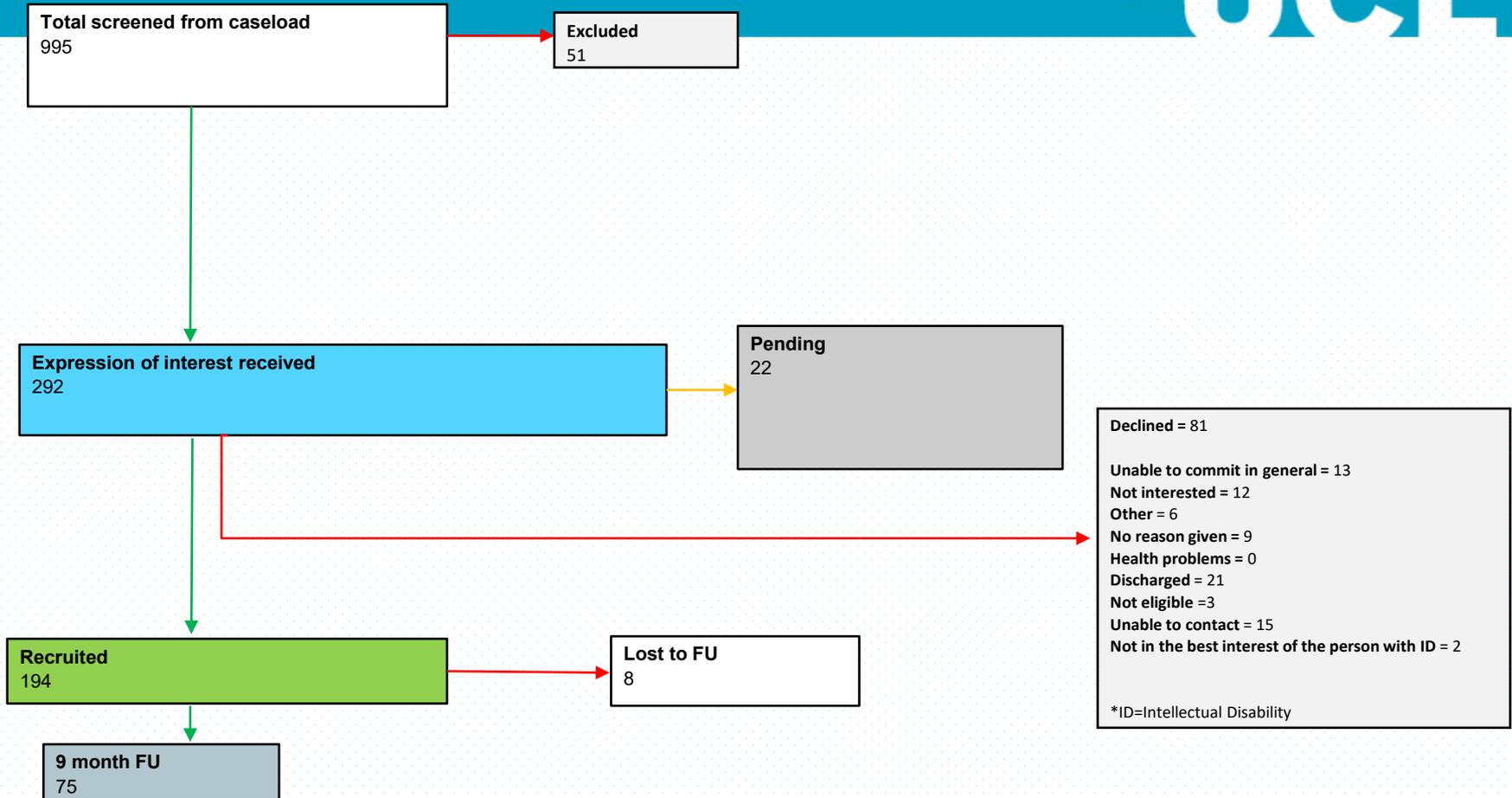
Qualitative exploration

- How IST care is experienced by service users and family carers
- Benefits, limitations and functioning of each IST model.
- Differences between IST models service delivery,
- Facilitators and barriers to achieving IST objectives
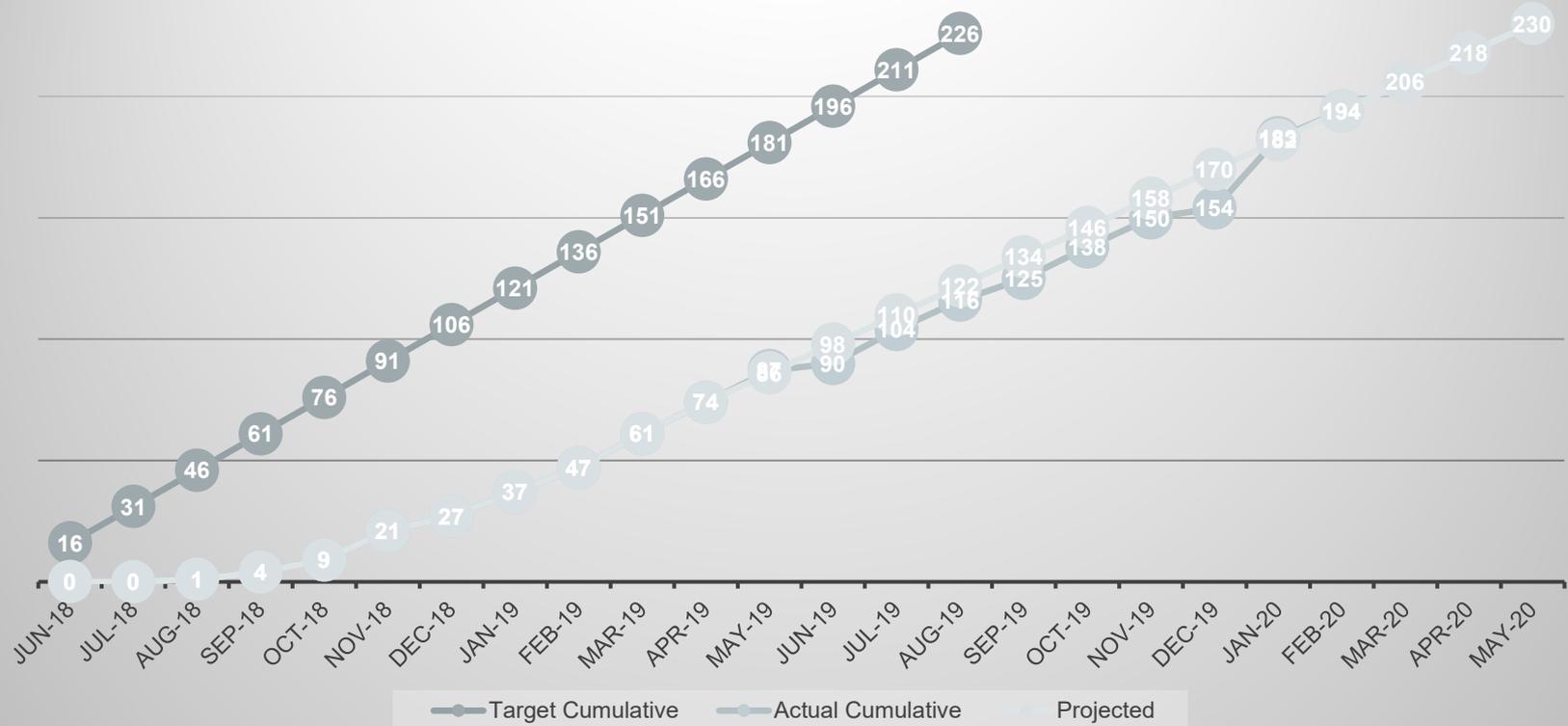
Stakeholders

- Participants with lived experience of ID
- Paid and family carers
- The managers of all selected IST services
- IST practitioners and practitioners from services that frequently refer to ISTs (i.e. in-patient services, third sector organisations, Early Intervention Services, Community Mental Teams, Transition services)

Preliminary report from Stage 2: Clinical and cost evaluation

- Included 23 ISTs of which 21 were active (Model 1=11; Model 2=10)
- London=5/23
- Recruitment June 2018-May 2020
- N=226 (monitor dropouts)
- 9 month follow up completed for 140 participants
- 36 interviews with stakeholders have been carried out
- Completion of Statistical and Health Economic analyses plans

Total screened from caseload
995

Excluded
51

Expression of interest received
292

Pending
22

Declined = 81

Unable to commit in general = 13
Not interested = 12
Other = 6
No reason given = 9
Health problems = 0
Discharged = 21
Not eligible =3
Unable to contact = 15
Not in the best interest of the person with ID = 2

*ID=Intellectual Disability

Recruited
194

Lost to FU
8

9 month FU
75

Projected recruitment figures

Who are the people seen by ISTs

- Mean age: 33 yrs (sd 13)
- Sex: 69% M
- Ethnicity: 83% W
- Supported living: 61%
- Adaptive behaviour: moderate to severe ID

- ABC-C$_T$: 63 (sd 33)
- Comorbid mental illness: 23% affective disorder
- Risk: 13.7 (sd 4.5)

Risk at baseline (TAG)
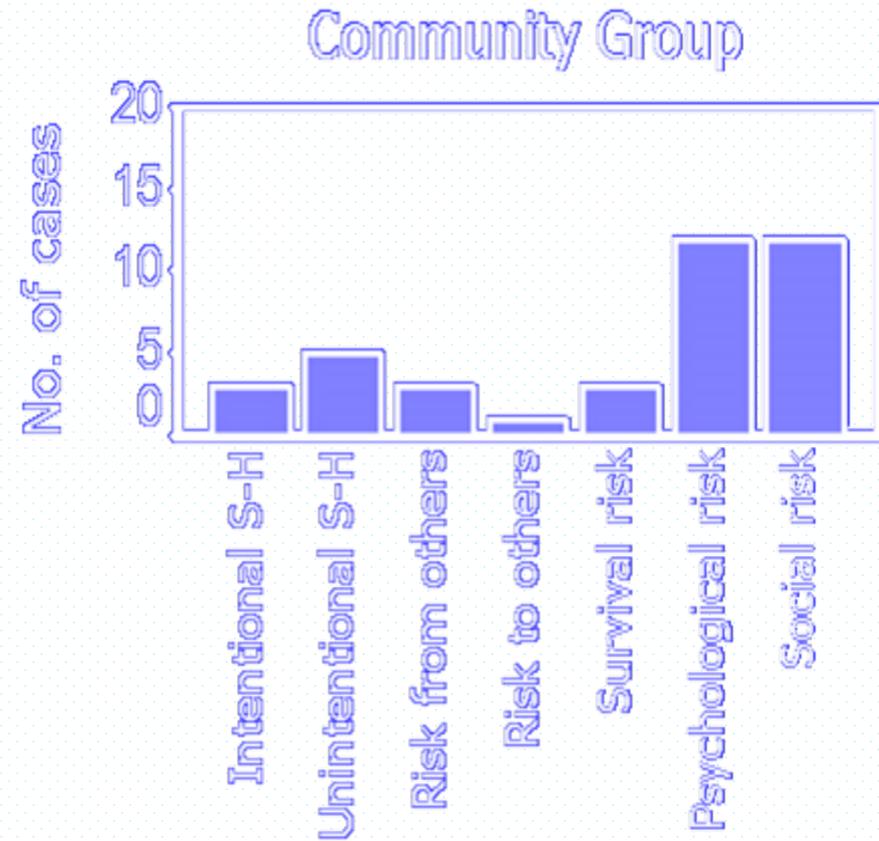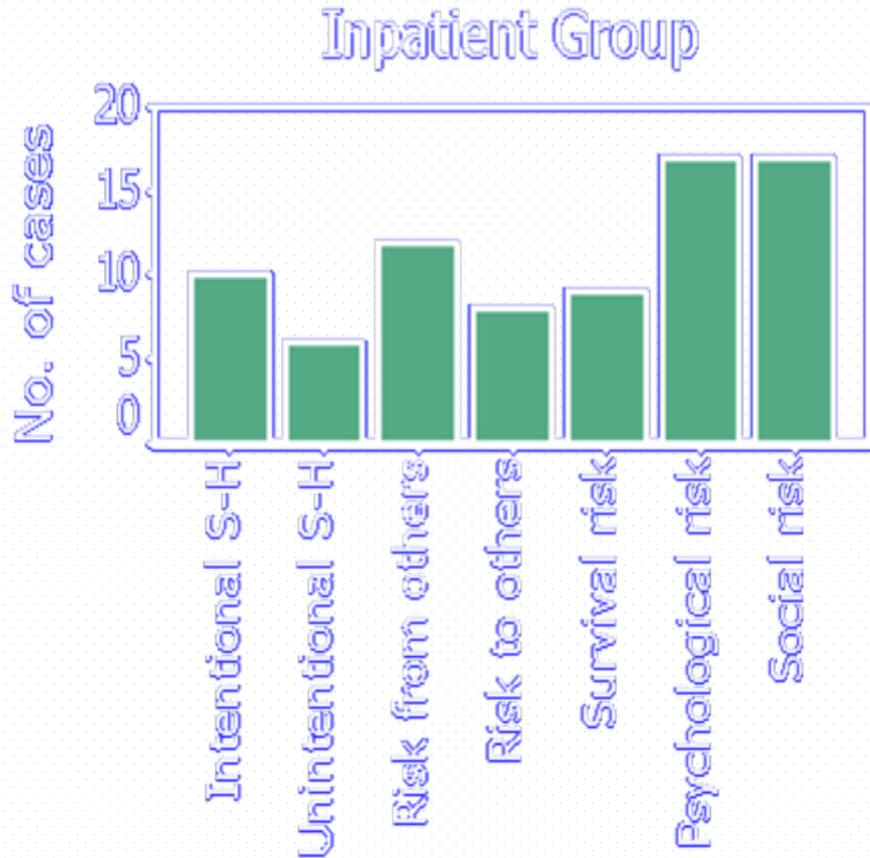
Less risk in community group at baseline t=-4.038; p<0.001

What works and what does not

- Collaborative ethos and carer involvement
- Personalised care
- Need to systematically collect data on outcomes

- Unclear operational lines/pathways of referral (e.g. too late, person in crisis)
- Lack of skilled providers
- What is the IST role?
- Are ISTs visible?

Challenges in study progress

- Estimation of potential participant pool and flow into the study

- Clinical Research Network reach poor in some areas

- Response to coronavirus

- Speed at which research governance processes were completed

- Extreme gatekeeping by paid carers and confusion over GDPR

What is crisis care?

•Crisis care has to be person centred.

•Tailored arounds the strengths and assets available individually or within the family unit

•As flexible as possible, aiming for minimal coercion where possible

•Service options made available that allow for assessment to ensure the immediate and short term support is tailored to the crisis at hand.

•Actively seeks feedback from service users and their carers to see what works well, and what doesn't.

•Encourages self-management in the long-term.

https://www.mentalhealth.org.uk/a-to-z/c/crisis-care

Mental Health Crisis Care Concordat (2014)

It focuses on four main areas

• Access to support before crisis point

• Urgent and emergency access to crisis care

• Quality of treatment and care when in crisis

• Recovery and staying well

Reflections

- So what? (clinicians, commissioners, NHS England)

- Research processes in ID

- Adaptation of research processes for public health emergencies

IST-ID research team

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Thank you

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https://www.ucl.ac.uk/psychiatry/research/epidemiology/pis/hassiotis-research-portfolio/intensive-support-teams