Research priorities in IDD in England

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IDD and **ALL** types of mental ill-health!

- Life-long disabilities – 2.5% of the population
- Demographics – life expectancy; birth rate, very low birth weight babies, maternal alcohol, Down syndrome
- Mental ill-health – point prevalence 41%
- Multiple comorbidities/polypharmacy e.g. epilepsy 25%
- Health inequalities; premature death

From Prof Sally Anne Cooper OBE
Weaknesses

• Capacity
• Cost
  – Capacity; Helsinki agreement, EU directive, Disability requiring flexibility
  – Dispersed population
• Materials (underpinning research)
• Existing structures of Clinical Research Networks
• Border barriers (what is available in each country)

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Research strengths and opportunities

• Quality of UK research
• Distinct focus on mental health research
  – Aetiology, detection and diagnosis, development of interventions, evaluation of interventions, health and social care services research
• Inter-disciplinary research
  – Only country engaging a range of medical disciplines, as well as psychology, social scientists etc
• Academic leadership in most UK regions/countries
• Relationships with NHS/social services and the charities

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Some priorities

• UK representative longitudinal cohort, to gain a deeper understanding of factors influencing and protecting mental ill-health and its outcomes
• Further capacity building
• Expand learning disabilities translational studies (including proof of concept studies)
• Reduce the existing and growing health inequalities
• Test interventions
Our interventions programme 2005-

- TIME-A Trial
- iCST
- REBILD trial
- TOP-COG trial

- pbs positive behaviour support

- Befriending for depression in ID

- CBT

- EPICC-ID

- IST-ID

- Shape-Up LD
Co-production

- [https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(17)30426-1/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(17)30426-1/fulltext)
- [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5154058/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5154058/)
- PEP for psychotropics; trauma based CBT; pharma