

Introduction

- In the UK, Health Care Transition (HCT) between pediatric and adult healthcare services may begin at 14 years of age.
- Carers and young adults with ID characterize HCT by a lack of planning, disjointed services/inter-institutional collaboration, lack of information sharing, and an abrupt binary change. ^{1, 2, 3, 4}
- Individuals with ID and their carers experience
 - Anxiety regarding transition. ^{5, 6}
 - Difficulties with the idea of growing up. ⁵
 - Inadequate support. ^{1, 6}
- There is a need for better material, informative, cognitive, and emotional support to ease anxiety during HCT. ^{4, 5}
- Health Passports provide a model for intervention.
 - Passports are considered helpful ⁹
 - Collaboration with individuals with ID, their carers and staff may improve implementation and buy-in for communication passports ⁸
 - Information these provide can vary widely, ⁷ and staff training prevented misuse. ⁸



Demographics

- Approximately 2.5% of children in the UK have a Learning Disability (Mencap).
- According to ONS statistics, there are approximately 30,500 13- to 14-year-olds in the UK with a learning disability.

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Growing Up and Moving On: A Health Transition Booklet

Aims

- Reduce anxiety of individuals with ID and their carers during HCT.
- Introduce an element of positivity and celebration at this healthcare milestone.
- Create a standard document for the UK context that is flexible enough to reflect individual health needs and potentially be adapted for use globally.
- Include individuals with ID and other stakeholders in the development and implementation of a transition document.

Inclusive Research Considerations

- The main limitation of our work is the current lack of inclusive research. We recognise that without the direct involvement of researchers with intellectual disability, key aims can neither be accurately identified nor achieved.
- Steps we would like to take include:
 - Discussing booklet with a focus group of stakeholders
 - Utilize Cognitive Interview Technique to refine language/items included
 - Involving stakeholders and co-researchers with ID inclusively to design a pilot study for implementation in the UK

Discussion

- Consideration needs to be given regarding the optimal style of trial in which to evaluate the impact of this booklet, in particular regarding young person and carer anxiety.
- We have provided three supplementary documents for people with ID, parents, and healthcare providers to facilitate the implementation of this booklet.
- We will also consider the role of a formally appointed Transition Manager/clinician to facilitate this process.