



Contenance Project Working Group

Meeting 1

Thursday 22 June 2017, South Cloisters, St. Luke's Campus

Family Faculty: Annette, John, Julia, Lisa

PenCRU: Chris, Silvia

Overview

- Chris introduced the research project to the Family Faculty working group.
- Family Faculty suggested ways in which families should be involved in this research project, including how to ensure the parents that participate in this research have a sufficient level of variety in terms of child's condition, continence issues and location.
- Family Faculty discussed contextual factors that influence the efficacy and/or implementing toilet training strategies.
- Family Faculty agreed that involving children and young people in this research is not necessary.

What next?

- Chris will work on the funding application for this research project.

Introduction to the research project

- Chris introduced the National Institute for Health Research (NIHR) project on [improving continence in children and young people with neurodisability](#). The research question is: "What is the available evidence for interventions relating to improving continence for children and young people with neurodisability?"
- Family Faculty acknowledged that this is a broad research topic, made more complex by the large variety of neurodisabilities and issues related to continence.
- John suggested that due to parents' dissatisfaction in bowel and bladder services, parents consulted in this research may use it as an opportunity to share complaints rather than helping PenCRU answer the research question. A rating of services, focusing more on positive experiences of what worked well, was suggested as a way to receive feedback from parents that will be more useful to answer the research question. Questions on rating services can include: accessing services; rating the quality of information received.
- Chris explained that the following organisations and individuals are involved in this project: Paediatric Continence Forum (represented by Ann Wright, a paediatrician at Guy's Hospital

and June Rodgers MBE from charity Bladder and Bowel UK); Nick Madden, a retired paediatric neurology surgeon; Jo Thompson Coon and Rob Anderson from the PenCLAHRC's Evidence Synthesis Team; Stuart Logan, Director of PenCLAHRC and Cerebra Professor of Paediatric Epidemiology. Parents also agreed with Chris' suggestion that an Occupational Therapist should be involved in this research project. Julia suggested that PenCRU involve a representative from schools (teacher or teaching assistant) as some interventions to improve continence take place in schools.

How to consult families in this research

- PenCRU should recruit families to participate in this research through the Paediatric Bladder and Bowel Services, special schools, local parent forums and national parent forums.
- The group discussed how to ensure the parents that participate in this research have a sufficient level of variety in terms of child's condition, continence issues and location. Initially, parents could be sent the opportunity to register their interest in completing a survey on the topic of improving continence in children and young people; when they register their interest, they should also be asked to provide information on: contact details, location, child's condition, child age group, and type of continence issue. In this way PenCRU will be able to monitor the types of families that are recruited to participate in the survey to ensure variety of experiences are represented.
- Some parents mentioned that promoting this research project as improving continence in children and young people with *neurodisability* may not be clear to all parents; some parents may not know whether their child has a neurodisability, and therefore may not know whether they're eligible to take part in the survey. It was suggested that the language used to promote this survey should refer to Special Educational Needs and Disability (SEND) instead, which is more widely recognised by parents.

Contextual factors related to toilet training

- Parents were asked to think about what contextual factors influence the efficacy and/or implementing toilet training strategies. This is what the group identified (photos of exercise at end of document):

<u>Service factors</u>	<u>Child factors</u>
- Thresholds: criteria for service access	- Condition
- Lower and upper age limits	- Age
- Parent's lack of awareness of services before the child is entitled	- Gender
- Waiting lists	- Mobility
- Start of services is not automatic: need for referral; GP; paediatrician; key worker	- Understanding, and consequences of understanding
- Accessing services at the right age (early intervention)	- Learning
- Location	- Different continence issues for different disabilities
- Capacity	- Social rules
- Special service for SEN children	- Routine
- Set criteria of how long children can be in service	- Puberty – menstruation
- Discharge and referral	- Behaviour: smearing, eating
	- Home vs school behaviour

<u>Family factors</u>	<u>Setting factors</u>
<ul style="list-style-type: none"> - Working parents - After school childcare - Home vs school behaviours - Parenting style and skills (including patience) - Separation/divorce - Single parent - Priority of continence compared to other issues - Siblings and primacy - Advocacy: services and schools - Parent's desire to achieve continence - Religious/cultural beliefs - Diet 	<ul style="list-style-type: none"> - Appropriate places to go and not go - Triggers and associations - Routine - Equipment: transport outside home; bringing aids with you - School; leisure; shops; town centre; car; transport; train; short break provisions; visiting relatives; visiting friends; swimming; sport; unfamiliar places; not mum and dad; lighting; smell; hand dryers; cleanliness - Home vs school behaviours - Access to toilets - Mainstream or special school

- The group also discussed whether menstruation in girls with neurodisability should be addressed in this research project. Although interventions to “stop” or “improve” menstruation do not exist, PenCRU could address menstruation as an additional complexity for girls with neurodisability within this research.

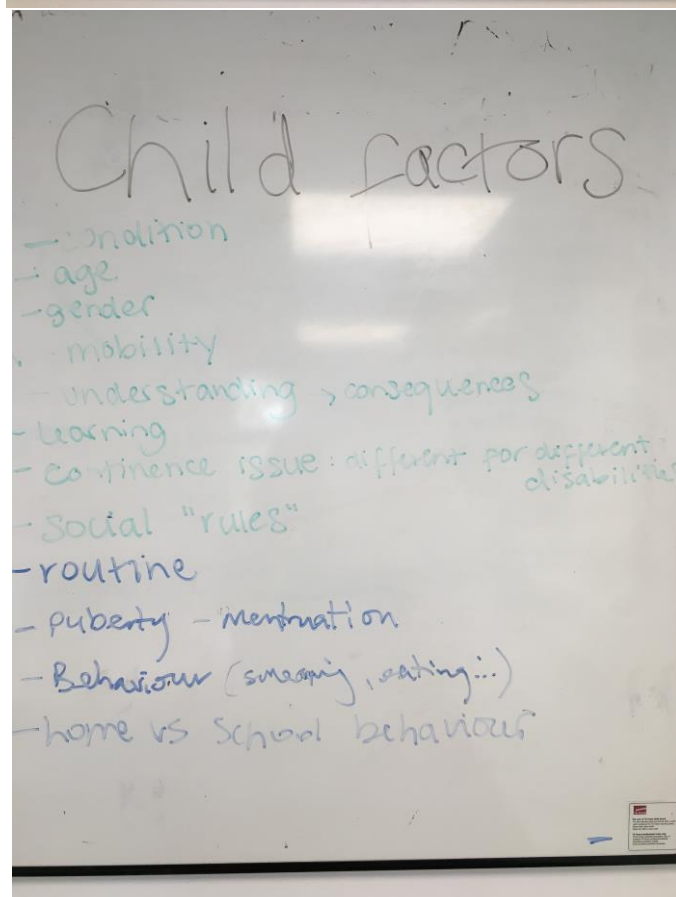
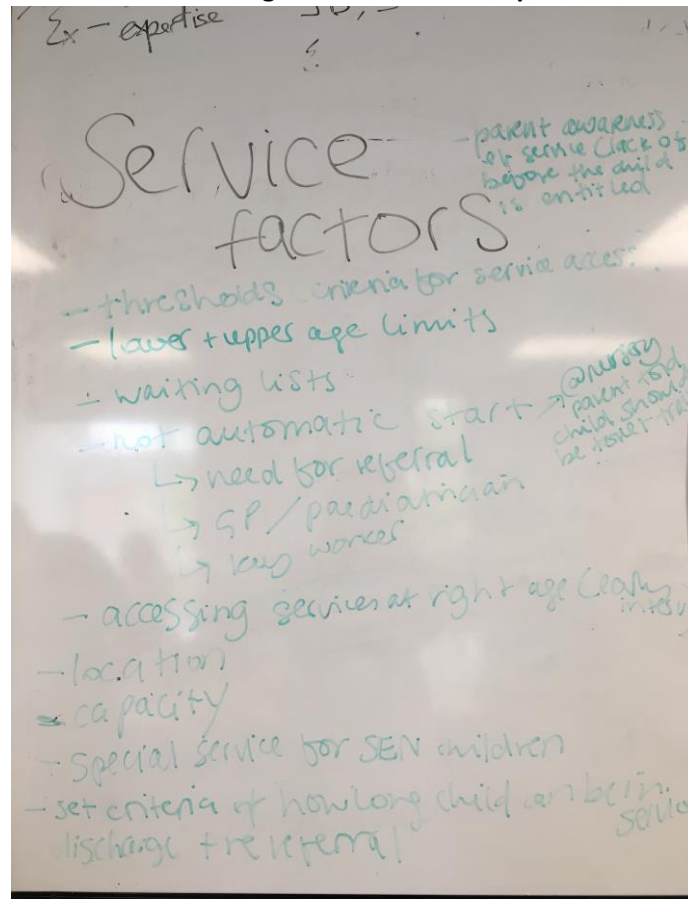
Potential consultation of children in this research

- Overall, the Family Faculty felt that involving children and young people in this research is not necessary. Parents said that some children may not be able to express their experience, involvement may cause embarrassment, and generally parents are able to explain the experiences and preferences of their children. A question could be added to the survey sent to parents asking whether their children have anything else to contribute.

Perception of readiness of toilet training

- Julia explained that mainstream nurseries and preschools require that children are toilet trained, at least in the daytime, before they start. This causes significant pressure on parents.
- Some parents explained that children have various ways in which they express their readiness of toilet training.

Contextual factors related to toilet training exercise – exercise photos



Setting factors

- appropriate places to go
- changing places to go
- triggers and associations
- routine
- equipment: transport outside home
bringing aids with you?
- school, leisure, shops, town centre, car,
transport, train, short break provisions,
visit relatives, friends, swimming, sport,
unfamiliar places, not mum + dad, lighting,
smell, hand dryers, cleanliness
- home vs school behaviours
- access to toilets
- mainstream or special school

Family factors

- working parents
- after school childcare
- home vs school behaviours
- ^{familiarity} parenting style + skills
- separation/divorce
- single parent
- priority compared to other issues
- siblings and primacy
- patience of parents
- advocacy: services and schools
fighting to stay/shouting
- parent's desire to achieve confidence
- religious/cultural beliefs
- diet