

Minding the Gaps: Improving Medical and Social Care for Young Adults with Cerebral Palsy

Wednesday 6th November 2019, 10:00am-16:00pm &
Thursday 7th November 2019, 13:30pm-16:00pm
Leeds University Business School, Newlyn Business School

Overview

When transitioning from childhood to adulthood, young adults with cerebral palsy (CP) have been shown to experience gaps in the care and support services available to them. The transition to adult care involves changes in service providers as well as the kind of support young adults with CP may receive. It may also imply losing established relationships with care providers and supporters and having to establish a new support network, which can have serious implications to long-term health and well-being.

You are invited to take part in a workshop, which will explore the challenges that young adults with cerebral palsy (CP) face in receiving support and accessing care during transition. The workshop is part of a pilot project developed by the Faculty of Medicine & Health and the Business School of University of Leeds and University of Durham. Engaging activities will provide opportunities for discussion and for the development of novel ideas for improving medical and social care for adolescents and young adults with CP. ***Findings from the workshop will inform the development of a larger research and impact project.***

The workshop will be run in the following way. On the first day (November 6th), we will provide opportunities for small groups to develop ideas on how provisions for young adults with CP may be improved. In the afternoon of the second day (November 7th), participants from workshops will reconvene in a forum to discuss their insights and ideas.

Registration

If you are interested in finding out more about the project/workshop and/or would like to take part, please have contact Joana Pereira (j.pereira@leeds.ac.uk) or Simon Williams (s.c.williams@leeds.ac.uk).

Workshop Programme

Day 1 – Wednesday 6th November 2019, 10:00am – 5pm

Time	Activity	Comments
10:00-10:30	Registration	Participants are assigned to workshops/groups based on their status (what type of stakeholder) and preferences (i.e. participants with CP may choose which workshop they want to join and if they prefer to be in a group with relatives/carers or other participants with CP only).
10:30-10:45	Welcome and introduction	Introduction of the project, overview of the workshop, questions, housekeeping (including consent forms and basic confidentiality rules for participants).

10:45-11:30	Session 1: Stakeholders	Participants work in groups of 4-5. Based on a rough outline of the transition challenge, everyone engages in a brief stakeholder mapping exercise to identify who is involved. Each group then selects a type of stakeholder/user and develops a specific persona (i.e. the description of a user with name, bio, hobbies, a drawing etc. with the aim of encouraging empathetic engagement).
11:30-12:30	Session 2: User experiences	Groups develop empathy maps/matrices that show how their persona experiences, feels, talks and thinks about the transition process (i.e. from the perspective of a patient, parent, nurse, etc. depending on the persona they have chosen). Selection of a critical situation in the transition process and mapping of As-Is-Scenario (i.e. steps how user engages with/ experiences this situation). Identification of specific pain points for persona/user.
12:30-13:15	Lunch	
13:15-14:30 (1h15)	Session 3: Ideation	Ideation – all participants come up with ideas how to address the pain points they have identified. Initially, everyone is encouraged to brainstorm in silence and to come up with some feasible suggestions as well as ‘crazy’ ideas (noted on post-its). Ideas are then shared with other members in the group. Creation of a prioritisation grid where ideas are mapped according to impact and feasibility.
14:30-14:45	Coffee break	(flexible)
14:45-15:45 (1h)	Session 4: Idea development	All groups develop brief outlines of their ideas and how they would envisage implementation. A set of questions or a template helps with the preparation of an output/presentation or the following day.
15:45-16:00	Wrap up	

Day 2 – Thursday 7th November 2019, 13:30pm – 16:00pm

Time	Activity	Comments
13:30-14:00	Participants arrive	Participants arrive. Tea and Coffee available on arrival.
14:00-14:10	Welcome back and introduction	Summary of previous day and overview of programme. Templates provided for the evaluation of/comments on ideas.
14:10-15:15	Presentations	Groups share their persona, the situation and pain points they have identified and their ideas for improvements (about ten minutes per group).
15:15-15:30	Coffee break	
15:30-16:00	Open forum/discussion and Wrap up	

Researchers involved: Prof. Tyrone Pitsis and Dr. Samit Chakrabarty (workshop leaders), Prof, Rory O'Connor, Dr. Joana Pereira, Dr. Josh Morton, Dr. Simon Williams, and Dr. Tabish Zaman.