

UP Group's 'Takeover Day Challenge' at the Department of Health, London!



Our young people's working group UP, along with other groups of young people from around the country, were invited to take over the Children's Health and Wellbeing Partnership at the Department of Health, London.

This is an annual event where the Office of the Children's Commissioner sets organisations the challenge of engaging in exciting ways with children and young people to lead and co-produce pieces of work.

UP were invited after being recognised for their '**Transitions Got Talent**' film around developmentally appropriate healthcare. This year's event was focused on children, young people and long term care, including transitions. UP showed their film clip, their work and presented about their research on health passports.

The young people and professionals worked together and agreed goals for the Children's Health and Wellbeing Partnership to carry forward including:

To have a health passport for young people with long term conditions transferable to different settings. The actions for this include disseminating UP's work looking into health passports used by other services.

UP really enjoyed the day, having the opportunity to work together with other groups of young people such as CLIC Sargent and Council for Disabled Children, sharing their experiences and planning together.

They also enjoyed the experience of travelling to London on the train. UP felt that they were really listened to and were treated like adults and gained new skills in team working and communication.



Hi, I'm Kate.

I work as a research assistant on the Transition Study at the Royal United Hospital in Bath, covering Bath, Chippenham, Frome and the surrounding areas. I have been working on the Diabetes part of the study, and will be finishing this year having been part of the study since the beginning four years ago.

I have recently completed a MA and diploma in Psychotherapy and I work in the Adult Diabetes department of the Royal University Hospital as a Psychotherapist. I have really enjoyed working with all the participants in this region and I am looking forward to seeing the results of the study.



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Young People's Newsletter

Issue 5, March 2016

We are now in the final year of the study!

Thank you for continuing to be involved in the research and sharing your experiences with us.

50 of you have already completed the final fourth visit.

All the final visits will be done by the end of October 2016.

We are now working very hard to continue to analyse the huge amounts of data you have given us.

Inside this issue:

- What we have learnt about Proposed Beneficial Features of healthcare so far
- UP Group's Takeover Day Challenge
- Useful Links

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USEFUL LINKS:

- ♦ National Institute for Health and Care Excellence (NICE) published new guidelines on "Transition from children's to adults' services for young people using health or social care services":
<https://www.nice.org.uk/guidance/ng43>
- ♦ **Cerebral Palsy Awareness Month in March**
See CP Teens websites for news, events and blogs: Helping people with Cerebral Palsy & similar disabilities within the UK : <http://www.cpteensuk.org/>
- ♦ **World Autism Awareness Week, 2nd- 8th April 2016**
See some of the events the NAS are putting on to help raise awareness:
<http://www.autism.org.uk/get-involved/world-autism-awareness-week.aspx>



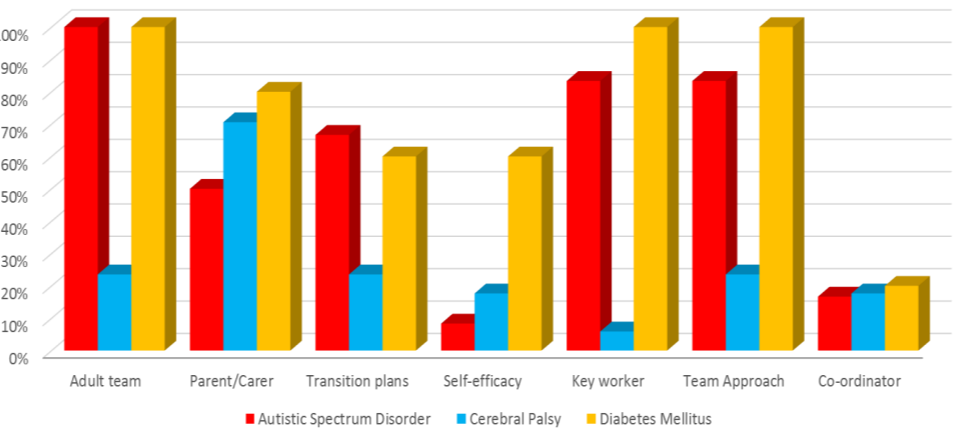
PROPOSED BENEFICIAL FEATURES

Features of health care thought to help with the transition from child to adult services

WHAT SERVICES SAID THEY PROVIDE

We asked the services you attend to complete a questionnaire about which features of care they formally provide to help with the transition to adult services.

Percentage of "yes" responses for each proposed beneficial feature by long-term condition



The most common feature stated to be provided by services was **keeping parents involved in care to the appropriate level (65%)**, while the least common feature provided was **health self-efficacy promotion (20%)**.

How did this compare to what you have reported receiving?

We compared what the services said they provide to what you have described receiving on the Proposed Beneficial Features Summary discussed at your second visit.

Mainly Agree	Moderate	Mainly Disagree
Parent/Carer Involvement (77%)	Key Worker (51%)	Meet adult team (16%)
Health self-efficacy promotion (75%)	Team Approach (55%)	Written transition plan (12%)
	Age-banded clinic (61%)	Transition Coordinator (33%)

Interestingly, many of you reported ‘having a key worker’ (32%) and receiving help with ‘health self-efficacy’ (57%) even when the service stated they did not formally provide these features of healthcare.

FINDINGS FROM THE YETI STUDY

- ⇒ Those of you taking part in YETI have been sharing more details about **your experiences** of these features of health care. We have interviewed 11 young people, 10 family members of the young people and 8 healthcare professionals.
- ⇒ The young people, family members and in some cases the health professionals often do not recognise the proposed beneficial features in the format we present them.

E.g. Age-banded clinics: these may ‘technically’ exist but rather than them being separate spaces or times, they are experienced as consultations where young people can talk about issues important to them and strikes the appropriate level of parental involvement.

- ⇒ Some of the proposed beneficial features are gradually introduced over several consultations rather than there being one identifiable event of when transition was acted on so some of you may not have recognised receiving some of the proposed beneficial features.

E.g. slowly introducing health education to promote young people taking responsibility for their care.

- ⇒ The proposed beneficial features can be seen as ‘artificial’ and do not fit the more complicated experience of these features during transition, as described by one young person;

“Like no one wants to ask for help really, you just want to do it and be independent. But it’s like, **it’s confusing** ‘cause at one point [...], it’s like, **‘Oh ask for help’ and the next point it’s like, ‘Well you need to learn how to do it yourself’**, so it’s like, which one do you do? It’s been like that all me life kind of thing” (YP, Cerebral palsy)

WHAT WE HAVE LEARNT....

- **Similarities and differences** are present between what services say they formally provide and what you have reported receiving.
- Shows we should not just rely on service specifications when evaluating the potential benefits of these features of transition services.
- **Young people’s experiences and perceptions** of these features in their healthcare are very important.
- These interviews have highlighted that the **theory** behind many of the proposed beneficial features is different to what might happen in **practice**.
- Families are mostly interested in **consistency of care** and in a smoother handover from child to adult services.