

Double whammy: transitioning from children's to adult services and transitioning to adulthood

by Marija Trachtenberg

Allan Colver recently gave a talk at the LSE Health and Social Care Formal **Seminar**. His talk is timely and relevant. It coincides and overlaps on the very same issues covered in the recently launched **NICE guideline** on the challenges young people face when transitioning from children's to adult health and/or social care services.

The challenges experienced depend on a range of factors and Allan set out to explore them and how to solve them in a **5-year NIHR-funded Research Programme**.

If you're unfamiliar with this issue there are two main problems that frequently crop up.

Common challenges for young people transitioning from children's to adult services

First, an issue that is most common is that young people may not be adequately prepared to handle new responsibilities that come with using adult services. Adult services, compared to children's services take a different approach in interacting with young people. Adult services tend to assume that these young people will take full responsibility and act appropriately in handling appointments, adhering to their medications, and restrain from risk-taking activity that may harm their health. Children's services on the other hand may be over-involved and may take more responsibility than they should as the young person reaches thirteen or fourteen years old. These problems with preparation by children's services and reception by adult services may mean that young people's health may deteriorate when they transition if it is the case that they don't know how to manage their health with this new responsibility.

Second, young people's brains are still developing and likewise they are developing 'socially' i.e. they are very conscious of their peers. They also like to experiment and seek novelty. Such behaviours are true for everyone but the adolescent brain has a period when the regulation and inhibition of certain behaviours by the front part of the brain tends to be overridden by a rapidly developing part of the brain called the limbic system which determines emotions and reward seeking. This isn't necessarily a problem but it may be a problem if a young person attends a party and wants to drink or smoke to the extent it interacts with their medical condition and affects their health. Or, they may avoid taking medications so that they can party and this could harm their health. Allan Colver highlights the need for practitioners to recognize this as potentially inevitable rather than pretend this won't occur at all. Rather than telling them 'not to do it', practitioners should have honest dialogue and help the young person "do both" (i.e. party and take care of their health).

So if we are to take two lessons from this it is that young people may need some more preparation and support from both services during transition and there needs to be a plan of action to help young people maintain a 'normal' life while managing their health or social care needs.

What's also interesting is that while adult services start when you are 16 or 18 years old, the brain doesn't fully mature until age 25. This means that young people continue to need service providers to understand this developmental phase for longer than had been appreciated.

Why is all of this knowledge important?



Well, there are costs and consequences of being ignorant of the true dynamic of things. Ignoring the fact that young people may need additional help for a few years may result in poor health and wellbeing and this can lead to needing more services when this could have been prevented.

So what has been done to address these problems?

Allan Colver's research Programme is looking into this. The reason why he's researching this is because, unfortunately, there is very little comparative research in this topic.

Allan aims to explore how different approaches can help young people who may have different needs. While it is impossible to capture every individual's experience, there are three broad types. For example, those who may have a chronic health condition where they may mainly interact with health services – in this case Allan's research Programme looks at those with diabetes as an example. Then there are those who have mental health problems and here an example is those with autism and an associated mental health problem. And finally, those who may have multiple needs and use a range of health and social care services – here the example is those with cerebral palsy.

How does the NICE guideline fit in with Allan's research?

PSSRU was involved in the development of the NICE guideline by providing economic input. We were hoping to find economic evaluations that identified cost-effective services, but we found very little and even fewer that were based in the UK. Equally disappointing was the lack of effectiveness studies (studies that focus on outcomes rather than costs). Allan's Programme has research streams that examine both outcomes and the cost consequences of alternative models of provision of transitional care.

The NICE guideline was based on a mix of evidence, ranging from the experiences of the guideline committee as well as other research evidence (views and experiences, quasi-experimental studies, and before and after studies).

While the results of the Research Programme will not be available for a year, Allan thinks the broad NICE guidance is likely to be valid; but he hopes his Research Programme will enable the guidance to become more focused and limited and therefore much easier to commission and deliver. The main improvements will result from getting transition formally addressed by Commissioners and NHS Providers and for this they need concrete suggestions, not just broad principles.

Some of the key NICE recommendations advise practitioners to support transition planning **before** transition and this may require:

- Having a practitioner from adult services meet the young person prior to transfer of services either through joint appointments, joint clinics, or pairing practitioners from both children's and adult services.
- Support from a named worker
- Providing information about what to expect from adult services.

And to support young people **after** transition, which might include:

- Contacting the young person directly or their family
- And if that doesn't work, to contact the named worker who was in charge to try and reach that young person.

Likewise, there must be **joint leadership from senior executives** in both child and adult services to make sure that processes are in place and to establish whether they are working.

What does the way forward look like given cuts in health and social care budgets?



These recommendations will have varying cost implications, at least initially. If we have limited budgets, making sure the right investments are made are important.

The use of support workers may incur a bit more cost but this really depends on how much time is being devoted to the young person. In this case, targeted use of support workers to those who are most in need may be the best use of their time.

However, taking a look at the other recommendations above, we see that most may be very low cost investments. For example, some additional time is needed from one or two staff in terms of meeting the young person or in terms of giving them additional information. Likewise, contacting a young person may take multiple attempts but these cost increases may be very small or even lead to cost savings compared to the probability and the cost of someone's needs being unmet and their condition deteriorating which may or may not lead to preventable service use.

About the author

Marija Trachtenberg is Research Officer within the Personal Social Services Research Unit at LSE, and is involved in economic evaluations for the NICE Collaborating Centre for Social Care.

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