

Stakeholders' perspectives on the transition from residential education to adult support for young people with learning disabilities/autism

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Context

The “Transition to adult social care from residential educational settings” project

Background – out-of-area adult placements

- Out-of-area residential placements for adults with learning disabilities are receiving increasing scrutiny in the UK
 - National scandals
 - Link to a range of poor outcomes (e.g. Beadle-Brown et al., 2006; Barron et al., 2011; Deveau et al., 2015; Emerson & Robertson, 2008)
 - Policy emphasis on their reduction
- Reasons for use of out-of-area placements are varied, but the presence of **challenging behaviour** is often cited (Mansell, 2007; McGill et al., 2010; Perry et al., 2013), which is also cited as a key reason for seeking a residential school placement for young people

Background (continued)

- Residential school placements in the UK are often located **out-of-area**
 - 230/600 children with ID, and 250/700 children with ASC at residential school were placed out-of-area in 2014 (Pinney, 2014) — likely to be an underestimation
- Increasing recognition that being placed in an out-of-area residential school is **linked to being placed out-of-area as an adult** (LGA & NHS England, 2014; McGill et al., 2010)
- Reasons for this unclear — perhaps due to **transition process?**
- **Existing research relating to transition** (e.g. Heslop & Abbott, 2007, 2008) reports **mixed experiences**, with many families reporting that the process was initiated late, involved variable support for the young person and their family, and was often **exacerbated by the distance** between the school and the young person's home area

Transition to adult social care from residential educational settings project

- Project funded by NIHR School for Social Care Research at the Tizard Centre, University of Kent
- **Aims:**

1

Identify the type and location of adult support settings where individuals who have transitioned from a residential educational setting are placed (findings presented yesterday by Serena Tomlinson)

2

Examine factors which may lead to a young person being placed in- or out-of-area following transition from a residential educational setting

Methodology – Phase 2

- Interviews with relevant stakeholders focusing on their **experiences of the transition process** in order to identify **factors related to subsequent placement being in- or out-of-area**



- The focus today will be on the interviews with **school/college** staff

Most common factors identified by residential school/ college staff related to placement location were as follows:

- Characteristics of young people
- Specialist support required
- The family context
- Student voice
- Specifics of adult social care providers
- The professional context
- The transition process

Characteristics of Young People

- Wide range of need types including autism, moderate and severe learning difficulties, profound and multiple learning difficulties and physical, medical and/or sensory needs
- Need types which may be **more difficult to place** upon leaving an education setting:

- **challenging behaviours**

'...young adults that are easy to manage, tend to have the easiest transitions. The children and young people that have complex needs and challenging behaviours, they're the ones which make difficult transitions because there's--, that--, those placements are a lot more scarce, you know.'

- **physical disabilities**

'I think the biggest barrier for our students is the physical disability, there's very few...future living placements that cater for physical disabilities.'

Location setting based on the young person's needs

- The **type of location** setting required based on the young person's needs may limit the number of available options
- Young people with **sensory processing difficulties** –
may require a less busy and quieter location:
'...their sensory processing needs are...off the scale basically but they need to be able to go and find a quiet space... so... thinking about some of them that have come from tower blocks in the centre of London... you're not going to find open space, let alone the countryside...'
- Young people with **moderate or severe learning difficulties** –
may require access to the local community:
'...they want to be somewhere where they can get to a pub, that there is a day centre, they could go swimming. Because quite often residential homes for example, are very rural and they haven't got access to anything. They're literally left with the countryside which for a young person is not where they want to live.'

Location setting based on the young person's needs (continued)

Daily occupation/ activities

The location of the placement may also depend on local facilities required by the young person, for example:

- Do they need access to a local college and/or continuing educational opportunities?
- Do they need access to the local community or work-based/ vocational opportunities?
- Do they need opportunities to develop their independence skills such as shopping and travel training?
- Does the locality have wheelchair accessible taxis?

'...it's not just about getting the placement it's what are they going to do, what's their week going to look like? You know, what are they going to be accessing during that time?'

Specialist Support

Does the young person require continued access to specialist support such as:

- speech and language therapy
- Augmentative & Alternative Communication Aids (AACs)
- physiotherapy / hydrotherapy
- nursing/medical support?

Is the new provision able to meet the young person's continued needs?

'...most community SLTs [Speech and Language therapists] have never... they don't have the training, they've never dealt with an AAC... We have highly specialised SLTs here so it's not something that can easily be picked up in community... If you're talking about going back to your local area, you are not going to have... an SLT probably who can support you with your communication...'

Family Context

- If the young person returns to their local area there may be more of a pressure for them to **return to live with their family** which may be problematic for a number of reasons including ability/ capacity to support at home:

'...some choose to return home... I'm transitioning a young lady at the moment. She's going to be returning home and her parents have always said that she will never ever go into residential or anything and that concerns me slightly because they're quite elderly parents.'

'... we have a big battle going on with a young man at the moment who wants to go to [X - residential placement] and his Social Worker and the Continuing Care Nurse want him to stay at home with the family, one of whom is very poorly, and manage the care from home with a care package with Carers going in, which hasn't worked for them in the past. And they're having a huge battle. Fortunately, they've got the funds behind them to have the battle...'

Family Context (continued)

- Family carers may **advocate for out-of-area placements** if they think this will better allow their child's needs and aspirations to be met:

'...sometimes parents, there aren't any appropriate services in their local authority and their surrounding areas, so they choose to stay in this area'

- Or they may choose to **move the family house** and follow their child or move to be closer to another suitable provision:

'There are some parents that are saying, it's far better that we get the right placement again for the child and who will move. Some parents have moved to be closer to here, and will more than happily, move again...for them having a contented happy child is vastly more important to the family...'

- **Legal action**

'Well parents are key obviously, and I mean, you have some parents are obviously well educated, very articulate, they've fought for everything all the way through the system and they just keep on fighting, fighting. And you know, they obviously are very instrumental in transition...'

'...one of our parents recently fought, she went back to the courts and made sure she got the education funding up 'til 25 for her son as well.'

Student Voice

What does the young person want?

*'So student voice, when we talk about what they want, they want somewhere where they can have **access to their peer group, to be able to live independently**, with the support that they've put in place. They don't particularly want to go back and live with their parents, where they're relying on them all of the time.'*

*'...the thing that I think is always forgotten in a transition, or isn't given enough precedence, is the **young person's preference**, about whether they want to live alone, whether they want to live in shared housing, where they want to live, do they want to live in the countryside, do they want to live in a town.'*

Are young people's views fully listened to?

'...if you are able to make that decision then local authorities will sit up and notice and recognise that preference a lot more if the young person is able to say it.'

Adult Social Care Providers

- **Are the numbers of places required exceeding those available?**

There appear to be more young people leaving the education system each year than a 'matched' and equal number of places becoming available in the adult sector:

*'.... you think... adult provisions... don't move through beds as quick as we do with schools, we have **more of a foot flow** because you think the longest they're ever going to stay here is 13 years, well they've got a lifetime elsewhere. So it's a case of if we supported every young person that comes through our residential schools, we wouldn't be able to keep up... unfortunately it's going to be an **aging issue**, that we're never going to be able to support all the young people we support residentially in schools.'*

- **Availability of specialist adult places**

If there is a lack of appropriate local school provision for the young person there may also be a lack of suitable adult provision in the locality

- One young person had 17 different organisations come to assess his needs but none of them agreed to accept him

- Another setting described the situation of a young person:

'... absolutely nothing in county whatsoever, parents were very proactive, everything that was suggested they went and visited..'

Adult Social Care Providers (continued)

- **Age-appropriate settings**

*'...it's often **age inappropriate**... the first thing local authority will always expect is for the young person to **return to their local area**... then the offer is quite often just simply not appropriate for that young person. It could be a care home... with maybe the youngest person who is **40/50** and then you've got a **20-year-old** quite often with various complex needs...'*

- **Examples of 'alternative' adult social care provisions:**

- bespoke new builds and bespoke care packages
- '***parental cooperative trusts***'
- schools/colleges creating their own adult services provisions including short-term '***transitions placements***'

The Professional Context

- **Local Authorities** - initial aim and remit to return the young person back to their local area upon leaving a residential setting

*'... it is really about **the local offer** and what the local authority can offer the child, or the young person as well, when that's all very dependent on the location of the family.'*

- **Multi-agency working**

Importance of all relevant professionals - i.e. social workers and education, health and local authority staff - **meeting collectively together** with the young person and family carers at key meetings such as Annual Review meetings in order to **fully understand the needs and aspirations of the young person**.

- **'Changeover' between children's and adults' services**

*'...at 18 it all changes, they're in this real sort of **crossover between teams**, so we... suddenly we have the adult team stepping in and if that hasn't been as a transition stage then those are the ones where things go wrong.'*

The Transition Process

- **Prior planning**

Essential that the transition process is **planned well enough in advance** in order for both the young person and all professionals involved to secure a smooth and thorough transition.

'...last year was the worst year in the ten years that I've been there, in that we had four young people with no one with placement on the day that they left...'

- **Timing of the transition and funding**

*'... colleges are a little easier because obviously they have a September intake, but if it's a residential house **you have to go when there's a bed**, and when there is a bed you need to **secure the funding** and you need to go, because very, very rarely will local authorities do an overlap in funding to allow that transition period.'*

'I mean I think the funding, lack of funding over the last three years is quite apparent now, when it comes to people's transitioning... You know, whereas someone might get five days at a day centre, they'll only get three. Yeah, so I think that's had a massive impact... the amount of money that's available for social care.'

Limitations

- The views expressed are restricted to those of education school and college staff.
- Further interviews with the other three participant groups - young people with a learning disability/ autism, family carers and local authority staff - will provide a broader range of perspectives.
- Comments made by interviewees should be seen as their perceptions and not as factual observations.
- Some of the comments made are likely to reflect the specific experience of some interviewees.

Conclusions from early analysis of Phase 2

- Availability of suitable adult social care provisions may be limited according to the young person's specific needs.
- Young people and family carers may consider out-of-area provisions if they better suit the young person's future needs and aspirations.
- The apparent shortage of adult social care provision is likely to rise as more young people transition from residential educational settings each year.
- Prior multi-agency planning may become even more important in the future in order to avoid a shortage of provision.

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