100 Stories – information for new Transition Services Strategy and Action Plan

(Note - prior to this role xx was a Community learning disability nurse and also the Transition link Nurse.)

Main points and issues raised –

1. **CHC (Continued Health Care) funding –**

Childrens CHC : In children's services, the nurse completes the application and panel decide the funding split (it is very straightforward). But in adult's service: Nurse completes the application, nurse and social worker agree a funding split and often this is rejected by CHC (very stressful and panel often disregard the MDT decisions, resulting in application going into dispute. This can make you feel like 'what is the point of having an MDT')

CHC Children's services seems to feel very different to CHC in adult services, including the Children's DST (Decision support tool) Form for CHC Funding very different to Adult DST.

No clear pathway for the funding and its transition from Childrens CHC to Adult CHC

CHC Panel makes key decisions on complex care issues for young people that they don't know – not person centred at all. Some of the funding splits then (when Panel has approved or rejected) can sometimes be unfair – could be 50/50 or even 20/80 and 9 times out of10 your application will be sent back to you and it's not a "fast track process". Social services and BCU can be in dispute who pays for what percentage while the family and young person waits for the decision (as it's always about the health needs of the young person).

2. **Direct Payments –**

In children's services: Young people can have a direct payment and use this to pay for a support worker, in adults, if the young person is fully health funded, the direct payment stops.

It is not clear why health can't contribute to direct payments and create pooled budgets with Local Authorities.

3. **Respite opportunities for young people –**

Respite – Some children go to a facility in Telford, England (not adults), this stops at 18 and there is no alternative in adult services

Adult respite services are normally full of older and unwell patients with complex needs, so even the young people who have had access to children's respite services

over the years are then plummeted to being with much older people and no peers or friends and very little activities suited to young people. (But the older people normally love having them in the respite facilities and look after them as their children, but obviously the young people would rather be in a facility with people their own age)

4. **Example of poor transition services (need consent to share) -**

A very complex young man attends a local Hospital regularly and has epilepsy and required medication. His parents are now concerned about his future health care as recently he's been nursed on an ambulance waiting for 17 hours because there was no room for him in the Hospital ED – and this young person before the age of 18 was used to having direct access to a children's wards for his health emergencies. His parents and the young person were very distressed and had to support with elements of this health procedure (PRN?) due to the long waiting list on that day in the ED department. No transition plan was in place. The expedience caused more seizures and all that needed ere some kind of reasonable adjustments to support his learning disabilities when attending hospital.

5. **Denbighshire Transition Hub (good examples of transition work)**

In her previous post xx used to have a meeting twice a year with the CALDS team, which is the community and adolescent learned disability for Conwy and Denbighshire. The meeting included careers officers, community LD nurses and transition social workers. This service worked very well and dealt with young people younger than 14. If the young person was very complex, this joint working just kept them on the radar, and then also in the Denbighshire team there was a **transition hub**, so everyone could meet quarterly to discuss all the school reviews so that they knew who was coming through in readiness for transition.

6. **Primary care/GP's**

- GP registers - A lot of the young people are not known to their local GP. As a result of their children's needs being managed by a paediatrician and school nurses, they suddenly reach 18 and they've never met the GP before. There has been instances that a young person had to be sent to the local A & E as the GP didn't have a hoist for check-ups and wouldn't come out to the patient's home where she had a hoist!
- Once the young person turns 18 and are placed on a GP register, they are invited for an annual health check (GP's get paid to do these checks). Conwy Connect (local charity) also have an Annual Health Champion within the community and help BCU with their LD Champions Training on e.g how to treat somebody with a learning disability when they come into hospital.
- *BCU "Lab in a bag" project - primary liaison service and they've got project called Lab in the back and they've got link nurse in* each of the six counties and they go out to the community's GP Practices and use iPads to connect to

the GP's system, to capture the people that have not had an annual health check for many years.

- Some medications stop when the young person reaches 18 and is part of adult services. A medication called Concerta, which is prescribed for ADHD and is not being prescribed to young people as it's not licensed for adults. Young people therefore if not registered with a GP could be without medication for many weeks until it has been sorted and a new medication identified.

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7. **Colleges and Transition –**

- More support for young people with learning disabilities is needed especially if they are in a mainstream college and not a specialist college.
- Not every college offers e.g quiet rooms or an ALCO and some students can be expelled or excluded from the college as the staff are not aware that their behaviour issues are part of their learning disabilities [redacted] used to be called in to Colleges in her previous role as some young people were at risk of losing their college placement as a result of their behaviour and they were trying to fit in and be normal, as in their previous specialist schools, they had back-up plans and tools to support them)
- Some young people turn 18 and have to leave home and go straight into residential settings so they miss out on that college experience which is a huge part of growing up and gaining skills and knowledge..

Case study –

Xxx could give an example of a young lady who had to have 1-1 support as a result of her epilepsy, but this affected her confidence and she didn't want the 1-1 support as she felt it made her look different to other young people. So the Specialist College at the time tried to observe her from a distance, but then this made her very vulnerable.

In the end and due to her behaviour she ended up being asked to leave the specialist college – BUT they had managed her in a respite capacity beforehand without any issues and the facility is being paid funding for this respite…..

8. **Suggestions for improvements in transition services –**

- Sort direct payments out - not fair on young people to lose their health worker or their support worker just because of a funding issue.
- BCU should be flexible and continue with the support in children's services, working with social workers and extend this to 25 years of age for children and young people with learning disabilities. This would make such a difference to the eventual transition but it would be fairer at the age of 25.

- CHC – Look at the pathway again – there are separate funding and separate panels to approve CHC funding for children who are transitioning -yet there are some services that remain the same e.g OT for example and they also work with children and adults.
- Support the whole family - we get a lot of very distressed parents during transition periods as while their child (ND/LD or CAMHS) had direct access to a children's ward when they were poorly, once they turn 18 years of age they have to go through Emergency Departments and have to wait for hours like everyone else, and for some obviously this is a challenging and upsetting business especially when they have had years of direct access to children's wards.