

# What do young adults with neurological conditions moving into adulthood want from Leeds Community Neurological Rehabilitation Service? Are we meeting their needs?

Amy McCulloch

Medical Student, University of Leeds

Supervised by Professor Anne Chamberlain<sup>1</sup> & Dr Tamsin Collins<sup>2</sup>

1. Emeritus Professor of Rehabilitation Medicine, Academic Department of Rehabilitation Medicine, University of Leeds.
2. Consultant in Rehabilitation Medicine, St Mary's Hospital, Leeds.

Word Count: 2477 (exc. References & acknowledgements)

## Acknowledgments

I designed and carried out this piece of research as part of the Extended Student-led Research or Evaluation Project (ESREP) module of the MBChB course at Leeds.

I am very grateful for the incredible supervision, expertise and support I have received from Professor Anne Chamberlain and Dr Tamsin Collins at all stages of the research process. I also gratefully received advice and support from Dr Rory O'Connor, Ram Krish and Judy Brantner of the CNRS.

This work has been presented at the 4th Baltic and North Sea Conference on Physical and Rehabilitation Medicine, Riga, Latvia, 16-18th September 2015

## Background

With the introduction of The Children and Families Act in 2014(1), transition services for young adults with disabilities are set to include a more joined up approach between health, education and social care services. Now is the perfect time to find out what young adults and their families want from transition services.

Previous research into the period of transition between childhood and adulthood for young adults with disabilities and complex health needs has covered the challenges of navigating adult services(2,3) and different models of delivering transition services(4–6). Transition into adulthood is an important stage in a young person's life but it can be extremely distressing if not supported adequately.

The government's *2011/12 Disability Prevalence Estimates* state that there are 11.6 million disabled people in Great Britain, of whom 1.1 million live in the Yorkshire and Humber region, and an estimated 5.7 million disabled adults of working age in the UK (7). The numbers are likely to continue to increase as more and more young people survive into adulthood with complex conditions.

This is a small qualitative study which focuses on the young adults with neurological conditions who access the Leeds Community Neurological Rehabilitation Service (CNRS).

## Project Aim

The aim of the project was to find out if young adults and their parents feel that the CNRS is supporting them through the transition period, and if there is more that could be done.

## Methods

### Setting

There has been a service dedicated to young adults with neurological conditions in Leeds since 1988. Previously the service was delivered in the form of a Young Adult Team which produced an almost 3-fold increase in participation in society, when compared to young adults who used ad hoc services(8). There is no longer a separate Young Adult Team, so young adults are referred to the Leeds Community Neurological Rehabilitation Service (CNRS). The CNRS is made up of the Community Neurological Rehabilitation Team (CNRT), the Community Stroke Rehabilitation Team (CSRT), and the Community Neurological Rehabilitation Centre (CNRC - day and inpatient services). The CNRS is a multi-disciplinary service based at St Mary's Hospital, hosted by Leeds Community Healthcare NHS trust.

Young adults with neurological conditions are referred to the service from the age of 16, usually by paediatric services or by their GP. On average, the CNRS receives 18-20 new young adult referrals each year. The team will work with young adults towards mutually agreed goals in a variety of settings, including St Mary's hospital, workplaces, higher education or at home. The team will work with each young adult for varying lengths of time depending on the nature of their goals, but there is now no upper age limit for the service (the previous Young Adult Team had an upper age limit of 25 years old).

## Recruitment

Purposive sampling was used to send 40 invitation letters to young adults at different stages of transition. A physiotherapist from the CNRS checked all potential participants against the inclusion and exclusion criteria (**Tables 1 and 2**) and then letters were sent from him to prevent anyone from the research team viewing patient details before consent had been given. The parents/carers of each young adult received a separate invitation letter and were invited to take part independently of their son/daughter. All participants provided written consent.

**Table 1 Inclusion and Exclusion Criteria for Young Adults**

Inclusion	Exclusion
Aged 18-26	Acutely unwell
Chronic neurological condition	
Referred to CNRS aged 16-25	
Currently accessing the services of the CNRS (minimum of initial assessment) or discharged within the past 12 months	
English as a first or main language	

**Table 2 Inclusion and Exclusion Criteria for Parents/Carers**

Inclusion	Exclusion
Aged 18+	None
Main carer/parent/guardian for a young adult who meets the inclusion criteria above	
Parents/carers can take part individually or as a couple/group	
English as a first or main language	

## Data collection & analysis

All participants took part in a semi-structured interview with the author, which covered access to services, concerns and expectations of the transition period, and the impact of the participant's neurological condition on young adult life (including social life, independence and autonomy, relationships, life skills and future plans). Some participants chose to be interviewed in person in a room at St Mary's hospital whilst others chose a telephone interview.

With participants' consent, all interviews were audio recorded and transcribed, then thematic content analysis was used to look for key themes in the data. Care was taken to ensure that the clinical team were not made aware of who took part in the study. Specific ages, genders and detailed diagnoses have not been included in this report to further protect the participants from being identified by the clinical team.

Ethical approval was granted by NHS Health Research Authority and Research & Development approval was granted by Leeds Community Healthcare NHS Trust.

## Results

From the 40 letters which were sent, four young adults aged 18-23 and two parents were recruited. This was made up of one dyad of a young adult with a traumatic brain injury and his parent, one parent of a young adult with cerebral palsy, two young adults with cerebral palsy and one young adult with Friedreich's ataxia.

Each participant reported some positive and some negative aspects, however the overall impression of the care provided by the CNRS was very positive.

### Positive experiences

The CNRS was praised by both parents and young adults for a number of reasons. Firstly one young adult felt that the service was "personal" and that they knew a lot about him and his condition. Four of the six participants either said that they were able to get help when they needed it or described an occasion when the CNRS helped them with exactly what they needed, one parent said "I don't think there's ever been a time where I've needed something and not been able to access it straight away".

Two participants also commended the way in which the team worked together saying that they had experienced a smooth transition, that everyone knew what the rest of the team was doing, and that if the person they contacted wasn't able to help they would always find someone who could.

### Change in Role

The most common theme from the data was the change in role for both young adults and their parents as they transitioned from children's to adult services.

Young adults reported having much more responsibility in adult services than they had, had in children's services and felt that there was more pressure on them to make their own decisions about their care. For some young adults this was positive and they felt that the CNRS had listened to their needs but for others this was overwhelming, particularly at first, because they were used to other people making decisions for them. One participant said "I don't really know what I need" and two said that they would still like some decisions about their care to be made by others.

Parents also felt that their role had changed by the time their child was approaching transition and that they had become more expert in their child's condition. One participant said "we know what we're doing" and reported being able to access the CNRS as and when she felt it necessary, in comparison to accessing children's services on a more regular basis.

### Loss of services

Although not all participants reported a loss of services, it was very distressing for those who did. Of those who noticed a difference, they highlighted that children's services were "more comprehensive", had a bigger team involved in their child's care, and that adults services are "just not as on top of everything".

Some participants had pre-existing negative ideas about adult services, with one young adult remembering his parents saying, “we know it’s not as good in adult services”. This caused a lot of anxiety for the young adults and their parents, and in one case the young adult went onto have a relatively smooth transition so this anxiety could have been avoided.

For parents the loss, or potential loss, of services caused a lot of anxiety, “we just got lost along the way”, and concern that any new services may not meet their child’s needs, “adult services don’t know him”. It was also clear that the services should aim to meet the needs of the wider family in order to best support the young adult, with one parent saying very honestly, “maybe it’s me who needs someone”.

“We just got lost along the way”  
- parent

### Young adult life

For three participants the CNRS had played an important role in their higher education. They reported helpful assessments, statements and adaptations to educational facilities, which had allowed participants to access education more easily and develop greater independence. The value of working with young adults in different settings was also seen here with one participant reporting that members of the team visited him at university to offer support and always asked “how have you fitted this into your lifestyle?”.

In terms of difficulties, participants highlighted the impact of fatigue and declining mobility on trying to balance a social life with studies and/or work. One participant said that everything had become a “bit more difficult than it used to be” and another participant said “one day you just kind of think ‘wow I used to be able to do that’”. This difficulty was exacerbated by any conditions which caused pain on a regular basis but was made easier by having supportive friends who understood the impact of their condition.

### Sexual function

One participant raised the issue of sexual function. They reported a lack of reliable information and had sometimes found quite upsetting websites when searching for information online. The participant felt that the issue had never been addressed by a clinician and suggested that if a member of the team offers an advice leaflet to all young adults it just “starts the conversation” and allows patients to ask for more information, if and when they want to.

“Starts the conversation” – young adult

## Discussion

Much of the existing literature focuses on the negative impact of losing services during the transition period. One of the biggest studies is by the Care Quality Commission(2) in 2014 and the report quotes one parent who felt as though “all the people who knew her [daughter] disappeared”. An American study by Cheak-Zamora et al found that the more complex a young adult’s needs are, the less likely they are to receive transition services(9).

Davies et al (3) found that prior to transition, parents were very concerned that their views and experiences of caring for their child would no longer be valued and decisions would be taken out of their hands. A transition clinic involving some of the paediatric team and some of the adult team can help to relieve some of this anxiety and prepare for the changes that will happen (5,3). This is partly because someone is then identified as a point of contact in the adult team to avoid a period of time when the young adult is neither in paediatric services nor in adult services, which can be very distressing(3). It was certainly seen in this study that having someone to contact whenever the young adult needed something, and being listened to by the CNRS team at this point, were hugely important to the participants.

Chamberlain and Kent(4) highlight sexual health as an important aspect of the key health maintenance skills required for a successful transition. Sawyer and Roberts(10) found that around 30% of their study sample of 51 young adults with spina bifida had discussed “sexuality issues” with a doctor. However, more interesting is that all of the young adults who had not discussed sex or sexual function with a doctor reported that “they ‘would definitely’ have discussed these issues if the doctor had initiated the conversation”. This mirrors the responses of one participant in this study who wanted a clinician to start the conversation.

The support offered by the CNRS in the higher education setting, and the contribution this made to increasing independence, was one of the main areas for positive feedback. This is very important when government statistics show that people with disabilities are around half as likely to hold a degree-level qualification compared to those without a disability (14.9% compared to 28.1%), and at working age, 19.2% of people with a disability do not hold any formal qualification, compared to 6.5% of people without a disability(11). When describing the Young Adult Team as a method for delivering services, Chamberlain and Kent(4) describe working with young adults in their “own social context” instead of in the hospital. Working with young adults at their place of education has clearly been valuable for a number of the young adults in this study.

## Limitations

This is a small study with a small sample size. Although it was explained in the information leaflet that the author was separate from the clinical team, the fact that some of the interviews took place in the hospital could have led to a perceived lack of impartiality and biased some of the results. The sample also lacked participants with intellectual disabilities and was only made up of young adults who were already accessing the service, it would have been beneficial to include those coming towards the end of their time in paediatric services. Some participants were interviewed by telephone and some in person. There was only one dyad so triangulating results between parents and young adults could not be done. Finally, only the author was involved in carrying out the interviews and analysing the data.

## Conclusion

In contrast to the negative experiences reported in the literature, the CNRS is clearly supporting young people with many of the issues of transition. The main areas where the CNRS has had a positive impact are in higher education, promoting greater independence, listening to young adults and their families, and providing a team which is easily accessible when needed.

The results show that even with the smoothest of transitions, there will always be some anxiety as young adults leave a team that they trust and have grown up with. Some of this anxiety can be alleviated by ensuring that the team really gets to know the young adult and their needs. It is also important not to underestimate how daunting it might be for a young adult to move into a service where they have much more responsibility and will be expected to make far more decisions about their care.

This study has shown that the key areas for improvement are closer working with paediatric services and a focus on improving services to address sexual function. Since carrying out this project, the CNRS team are beginning to address sexual function as part of the service they provide and transition clinics have been established with local paediatricians.

## References

1. Children and Families Act 2014. (c.6). London: The Stationery Office.
2. Care Quality Commission. From the Pond into the Sea. Children's transition to adult health service [Internet]. 2014. Available from: [www.cqc.org.uk](http://www.cqc.org.uk)
3. Davies H, Rennick J, Majnemer A. Transition from pediatric to adult health care for young adults with neurological disorders: parental perspectives. *Can J Neurosci Nurs* [Internet]. 2011;33(2):32–9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21977770>
4. Chamberlain M a, Kent RM. The needs of young people with disabilities in transition from paediatric to adult services. *Eura Medicophys*. 2005;41:111–23.
5. Binks JA, Barden WS, Burke TA, Young NL. What Do We Really Know About the Transition to Adult-Centered Health Care? A Focus on Cerebral Palsy and Spina Bifida. *Arch Phys Med Rehabil* [Internet]. 2007;88(8):1064–73. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0003999307003255>
6. Camfield PR, Gibson PA, Douglass LM. Strategies for transitioning to adult care for youth with Lennox-Gastaut syndrome and related disorders. *Epilepsia* [Internet]. 2011;52:21–7. Available from: <http://doi.wiley.com/10.1111/j.1528-1167.2011.03179.x>
7. Department for Work and Pensions, Office for Disability Issues. Official Statistics Disability facts and figures [Internet]. Disability prevalence estimates factsheet. 2014 [cited 2015 Dec 30]. p. 1 & 3. Available from: <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures>
8. Bent N, Tennant A, Swift T, Posnett P, Scuffham M, Chamberlain MA. Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study. *Lancet* [Internet]. 2002 [cited 2015 Dec 30];360(9342):1280–6. Available from: [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(02\)11316-X.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(02)11316-X.pdf)
9. Cheak-Zamora NC, Yang X, Farmer JE, Clark M. Disparities in Transition Planning for Youth With Autism Spectrum Disorder. *Pediatrics* [Internet]. 2013;131(3):447–54. Available from: <http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2012-1572>
10. Sawyer SM, Roberts K V. Sexual and reproductive health in young people with spina bifida. *Dev Med Child Neurol* [Internet]. 2007 Feb 13 [cited 2015 Dec 30];41(10):671–5. Available from: <http://doi.wiley.com/10.1111/j.1469-8749.1999.tb00521.x>
11. Department for Work and Pensions, Office for Disability Issues. Official Statistics Disability facts and figures [Internet]. 2014 [cited 2015 Dec 30]. Available from: <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures>