

Using User Feedback to Develop Transition Services in South Gloucestershire

Transition to adulthood has been identified as a difficult time for adolescents with disabilities^{1,2}. In addition, transitions are more difficult for young people with learning difficulties³.

Background

A notes audit in 2009 has highlighted that Community Paediatricians in South Gloucestershire were poor at documentation of transition standards when seeing children with moderate learning difficulties. Standards were taken from 'Transition-Moving On Well', and the National Service Framework for Children, Young People and Maternity Services 2004, standard 4.

Following this finding, we worked with Barnados in 2013, in a school for children with moderate learning difficulties. Barnados organised focus groups with young people, and telephone consultations with parents. We found that young people and parents were not happy with information given to them about the transition process. They reported a poor awareness of the transition process, and that the information given during consultations with paediatricians, was not easily understood.

Intervention

As a result of the audit findings in 2009, and feedback from young people and parents in 2013, we set up a 'Transition Clinic' commencing in October 2014. The clinic was held in a school in South Gloucestershire for children with severe learning disabilities.

The transition team was comprised of a Consultant Community Paediatrician, School Health Nurse, and a member of the South Gloucestershire Adult Care team for disabled people.

Young people from 14 years old to 19 years old were seen, along with their parents/carers. The consultation was young person-centred, and needs focused, as recommended by Moving On Well.

The consultation specifically covered:

1. The young person's medical and social needs
2. How these would be met after the young person left school (after their 19th birthday)
3. The professionals that would be involved in the young person's care, after they left school
4. How to access adult services, and who the family should seek for help/support

Feedback

To date, ten young people have been seen. Feedback received directly following the clinic has indicated that parents have found the information given during the consultant was clear, and that they understood the next step in the transition process.

Further information in written form has been requested by two of the ten families. We are currently looking at existing resources to complement messages conveyed during the clinic. Feedback indicated that the clinic is a helpful resource for families with young people with disabilities.

The transition clinic format met all our 2009 audit standards, namely:

1. Transition planning is person-centred
2. The young person plays an active part (where possible) in decisions about their future
3. There is flexibility in the transition process (the plan changes as the young person's needs change).
4. The young person knows how to access adult services
5. The plan reflects on social needs and how these will be met
6. The process involves working together with other agencies.

Conclusion

Feedback indicated that our intervention has led to a positive outcome. We therefore intend to continue to develop this transition clinic by using feedback received. Young people will be seen annually from Year 9 (14 years old upwards) and transition issues addressed in partnership with the young person and their parents/carers. Transition messages will be repeated, and any concerns around transition addressed.

Special thanks to Charmaine Lynch and colleagues from Barnados working with North Bristol NHS Trust

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References in full can be found on the BACCH website www.bacch.org.uk

INTRODUCING HemiHelp



HemiHelp

For Children and Young People with Hemiplegia

Neelam Dongha, Communications Officer, HemiHelp

Whilst it is highly unlikely that you will need an introduction to hemiplegia, you may not have come across our charity, HemiHelp. In this article, I'd like to tell you a bit about what we do and the services we offer to professionals like yourselves. We will then look at the critical time of diagnosis and hear a parent's account of finding out that their child has hemiplegia. Hopefully it will highlight one of the ways we help families and why we would like you all to signpost parents to our services. Together, we would like to work in partnership with you to provide a strong support network to families affected by hemiplegia.

HemiHelp

HemiHelp is a national charity with a membership of over 4,000 families and professionals. Our overriding aim is to support children with hemiplegia and their families, ensure they are afforded the same opportunities as their non-disabled peers and help them to live life to the full. We provide information, support and run events for children with hemiplegia and their families as well as for professionals (medical and educational) involved in their care. Our work benefits professionals in the NHS, social services and schools who work with children with hemiplegia.



Free professional membership

Membership to HemiHelp is free for professionals and allows access to a range of resources. These include regularly updated information sheets, email updates and a popular quarterly magazine which covers a broad range of topics relating to hemiplegia. As a professional member you will have full access to all the information and support



services we offer families, including a helpline staffed by parent volunteers, a home-visiting service, a network of local groups, regular parents' conferences, children's fun days and a range of workshops.

Professionals' conferences

HemiHelp also holds conferences for professionals that bring together leading practitioners in the field to share learning and present the latest research and practice. As well as gaining information and knowledge that can improve your skills, attendees also qualify for CPD points.

Our next Professionals Conference 'Developments in the Management of Hemiplegia' is being held on 17th September 2015 at St Georges Centre, Great George Street, Leeds, LS13BR. For details of the full programme and to book your place, please see the contacts section at the end of this article.

Dr Ron Loh - a professional's perspective



Dr Ron Loh is a consultant paediatrician with a special interest in neurology at the Royal United Hospital in Bath. He very kindly chaired a HemiHelp workshop for parents (with 0-5 year old children) last year. Dr Loh made the following comments, "Meeting parents outside of the clinical environment made it very real for me and

gave me a great insight into the condition, which I went back and shared with the rest of my team. I realised that some parents may not feel able to share their experiences in a clinical setting where they are conscious of the limited appointment time. At the HemiHelp event, parents were able to tell me about their practical difficulties and also their solutions to problems. For one family, it was all about negotiating the local educational provisions. For another, they talked about the various therapies that they have purchased from the private sector. It has affected the way I treat patients and I now ask questions about how they cope which I find allows them to talk about wider issues."

Dr Loh has the following advice for other professionals treating children with hemiplegia, "Take advantage of opportunities to meet parents in non-clinical events, such as the HemiHelp parents' workshop I attended."

Diagnosis

For parents, learning that their child has hemiplegia is often an emotionally fraught and difficult time. In most cases, they have never heard of it until the point of diagnosis. At HemiHelp we recognise how vital it is that parents have support at this critical time and would like every doctor making such a diagnosis to signpost parents to our services. We offer a helpline where a trained member of staff can offer guidance, support and direction to parents. All of our helplineers are parents of children with hemiplegia themselves so they can fully empathise with the parents who call them.

Hayley Turner talks about her daughter's diagnosis

Iris is a bubbly, energetic 6 year-old who loves ballet and karate. Her mother, Hayley describes how she learnt that Iris has hemiplegia.



"From about 6 months old I noticed things were not quite right. I took Iris to the Health Visitor a few times over the next few months and told them my concerns but I was always told not to worry. I then went to the GP as I felt that there was an issue with her balance and because she wasn't using her right arm/hand; it would just hang behind her with her hand fistled. On my first visit, they said she simply had a left hand preference. I

thought this was strange and a bit early to have so I went back. This time the doctor showed more concern, explained that it could possibly be Erbs Palsy and referred me to a paediatrician. Iris was about 11 months when she saw the paediatrician who immediately told me it was 'cerebral palsy.' Diagnosis was the scariest moment in my life and these words filled me with shock and horror. I remember briefly hearing him say 'right hemiplegia' and that she would need an MRI to confirm this. I was told of the possibility of Iris not walking, needing a wheelchair, having speech and learning difficulties and after this he kept talking but it is a blur.



Looking back, I think I could have received a bit more support at the time as I left in complete shock and had no real idea what my daughter had just been diagnosed with. The words 'cerebral palsy' are very scary, and the image you have in your head are generally not a true picture. I just remember leaving the room, going to the washroom and staring in the mirror for ages with the words cerebral palsy echoing in my head and the thought of my little

girl being severely disabled. I then walked around town for hours in a state of shock, not even acknowledging what had just happened. Eventually, I rang my husband and told him. I went through a period of wondering if it was my fault and if I could have done anything differently.

The paediatrician had printed off an information sheet and handed it to me before I left telling me about HemiHelp, with a website and basic information. I spent a long time reading all the information on the website. I then rang the HemiHelp helpline and was instantly calmed down by someone who understood. I was given so much information regarding her diagnosis and what to expect. Support from HemiHelp has been invaluable on every step of our journey so far. It has helped me understand my daughter's condition and make sure she is doing her best. There are great fact sheets, excellent get-togethers and events where everyone actually understands and becomes part of 'your world'."

Contacts

If you would like to become a professional member (free) of HemiHelp, attend the next professional conference or are interested in more information, please do contact me at neelam@hemihelp.org.uk

You can also find a downloadable information pack to give to parents at

<http://www.hemihelp.org.uk/professionals/health/diagnosis/>

or if you would like some of our information leaflets to keep in your practice, please do email me.

We look forward to meeting you at one of our events!