Real People, Real Lives

A small-scale pilot project exploring Case Studies of the Transition experiences of young people with Long Term Conditions and Disabilities who have recently transferred from children's to adult services in Cheshire and Merseyside

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"Opening the door to improved outcomes for patients and carers"

Defining Transition

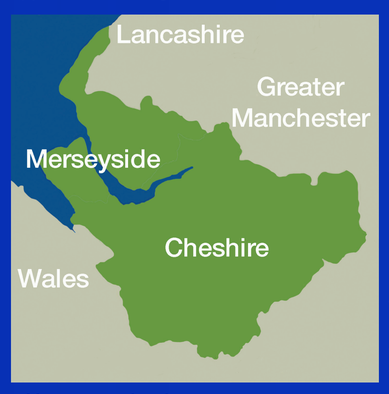
- The journey from adolescence into adulthood is a particularly challenging time for all young people from biological, social and psychological perspectives; for young people with any form of disability, long-term or life-limiting condition or mental health problem, this is made even more difficult. As they move between different health care services, they will find significant differences in the expectations, style and culture of these services, while their own care needs will be evolving at the same time.
- The report Lost in Transition. Moving Young People between Child and Adult Health Services (Royal College of Nursing, 2013) defines Transition, as the purposeful, planned movement of adolescents from child-centred to adult-orientated health care systems.
- The Council for Disabled Children (2011) highlight five key areas in addressing the challenges: strategic joint partnership working; participation of disabled young people and their families; effectiveness of personalised approaches; joint assessment processes within children's trusts and adult services; realistic post-16 opportunities for living life.

Are we "Getting it Right?"

Despite plenty of guidance, good practice and effective models the experience of transition to adult services is by no means a universally positive experience. Despite a vast majority of highly competent, deeply caring professionals and practitioners.

"we have a health and social care system that is not working, that is letting down many desperately ill youngsters at a critical time in their lives…" (Care Quality Commission, 2014)

It need not be like this, but system-wide change will be required to achieve a joined up approach, ensuring that care is coordinated around the individual (Kennedy, 2010.)



The Cheshire and Mersey Experience

The Cheshire and Merseyside Children, Young People and Maternity Strategic Clinical Network Long Term Conditions Special Interest Group are well aware of the complex challenges for both commissioners and service providers in "getting it right" for young people with complex health needs and disabilities.

Project Aims

The aim of this pilot project was to carry out Case Studies which will explore the different transition pathways and lived experiences of young people representing the following groups:

Young people who

- have common long – term conditions which are predominantly self-managed at home.
- have long term conditions which require intermittent or regular hospital-based support.
- who have disabilities and complex needs.
- who are receiving support from child and adolescent mental health services?

Methods

Case study was chosen as the method of data collection. The approach is broadly consistent with the principles of Realist Evaluation which provides an alternative to empiricist evaluation techniques, acknowledging that a critical approach to the underlying social and political context is fundamental to developing an understanding of the effectiveness of policy and process. (Pawson & Tilley1997)

Case Studies help to develop explanations of social, psychological and structural processes and provide opportunity to explore the context in which a phenomenon is occurring (Eisenhardt1989.)

The Six Case Studies involved

- Face-to-face semi-structured interviews with young people, parents and carers.
- Young people involved had experienced the transition from children's to adult services within the past six months to three years.
- The perspective of a lead professional involved in planning and co-ordinating the transition their perspective was also sought and included.

Emerging Themes

The Case Studies demonstrate that parents have a good understanding of what Transition means, and have endeavoured to explain this to their children. Some reported that they only started the process at 17 or 18 and feel that it was too late; some have had transition mentioned at a timely point, but not fully explained and followed through.

1. Variable Transition Plans and Experiences

Transition can work well when planning is timely, informed, is clearly documented and where there are dedicated Transition Practitioners or Transition Teams to coordinate the planning process. Where this works best it involves multi-disciplinary, multi-agency involvement and a willingness to challenge traditional ways of thinking.

The majority of families interviewed, however, were unable to identify a lead professional who took on this role.

2. Still "Lost in Transition"

The Case Studies indicate that Transition Plans for some young people are "in the ether" rather than documented. This can lead to fear and anxiety in both young people and parents. At worst it may lead to detrimental outcomes as a result of poor communication and discontinuity in management.

3. Involvement in Decision-Making

It is possible to involve young people in decisions made about their future, even when the young person has severe communication difficulties. This may well be dependent on the attitudes, values, knowledge and skills of individual practitioners, or the young person having an informed parent or professional available who can advocate on their behalf. Some practitioners may fail to consult with parents too.

4. Different traditions, levels of practitioner confidence and models of service provision

Different models of service delivery may impact on the availability of appropriate services, for example Child and Adolescent Mental Health Services may be based on a children and young person – centred developmental model, but Adult Mental Health Services based on medical, diagnostic or therapeutic models.

Integrated Commissioning appears to work in some cases up until 18, but becomes fragmented once young people enter the adult sector. Some essential support may be cut following transition to adult services when commissioners and service providers work in isolation, or one when one agency decides to withdraw services and funding. A further barrier may be geographical or local authority boundaries. Younger siblings can have their support withdrawn too.

5. Training Needs

Practitioners in adult services may have training and support needs if they are to confidently provide effective young people centred services.

Some good practice was highlighted where multi-agency training focussed on awareness-raising and complex case management. Less well informed parents may also benefit from training to help them understand the transition process.

6. Fearful young people and " battle weary " parents and carers

All of the families interviewed indicated that transition experiences may be chaotic or overwhelming. This resulted in fear, confusion or distress for the young person involved.

Many of the parents felt that they had to "fight "to ensure that their child received the best possible services. They feared that if they didn't fight the result would be unsafe or compromised care for their child once they had moved over to adult services.

Parents valued knowledgeable professionals and practitioners who could advocate for them, co-ordinate services and help them overcome barriers and obstacles by finding new solutions which met the individual needs of their family.

7. The Impact of Transition to adult services

When transition is well planned and coordinated it can lead to positive outcomes. This may be dependent on the severity of the young person's condition and confidence of their family.

Parents' perceptions of the effectiveness of Transition Plans vary.

Some say that life has changed since the transition; they feel they have "fallen through a crack" or have been "abandoned." and it is easier for busy, stressed professionals to let that happen, particularly in community settings.

Practitioners on the ground are seen to be to be doing their best, but decisions about eligibility for services, or cutting services are made by people who don't know the family or have no understanding of their needs.

At worst parents report practitioners may not understand the importance of sharing information, or listening to and involving them, even in emergency situations – this can lead to dangerous scenarios which compromise safety or leads to detrimental clinical decisions.

One example of an unintended consequence was a move from coordinated shared care between three hospitals to fifteen different adult consultants; this has meant appointments in three different hospitals in a single day and unnecessarily repeated painful and costly investigations.

8. Losses and Gains

Several of the families indicated that they had lost valued services as a result of the Transition. Some gains were also acknowledged

- Losses: a key contact to call if you are worried or need help in an emergency; trusted consultants; continuity (in medical management and clinical decision-making); Physiotherapy and Hydrotherapy ; specialist equipment ; Social Care funding and services ; individualised education support ; social support and respite services ; support for siblings and parents or carers.
- Gains: access to a Counsellor; a Mental Health Practitioner who is supporting a young person to get back to college; Direct Personal Payments mean that support from excellent Care Assistants can be accessed.

Conclusions

1. Transition services across Cheshire and Merseyside include some areas of good or developing practice as well as examples of inadequate planning and services to meet the needs of young people who have long term conditions, special educational needs or disabilities.
2. It is not currently possible to conclude that all transition experiences in Cheshire and Merseyside universally meet sector standards and best practice guidance.
3. Families would like those in charge of commissioning services and making financial decisions to hear their stories and understand the challenges they face.

Recommendations

1. Strategic Clinical Networks work with all key stakeholder groups to develop a Business Case to support further developmental work which aims to ensure effective and consistent pathways and agreed approaches.
2. Build on existing local good practice by defining and developing the role of Transition Teams and Specialist Transition Practitioners and modelling Transition Clinics specifically designed for young people where these have been found to enhance the experience of young service users. There is also a case for developing a Specialist Transitions Commissioner role.
3. Work with other Clinical Strategic Networks and Clinical Commissioning Groups to consider how services could be re-designed and re-modelled.
4. Establish a Young Person and Family Reference Group to develop services which are informed by the experiences, needs and aspirations of young service users and benefits from the expertise and experience of parents and carers.
5. Assure an integrated approach involving partnership between commissioners and service providers; children, young people, adult and mental health services; social care; education; local authority, community and voluntary sector services.
6. Work with key stakeholder groups to develop Transition Plans and Pathways which ensure a standard level of timely, integrated and seamless service provision, but which could be differentiated to meet the personalised needs of individuals or shared needs of specific groups of young people.
7. Explore how local good practice can be built upon to meet the training, communication, information and continuing professional development needs of parents and carers; lead professionals involved in planning and co-ordinating transition; professionals and practitioners in adult services and education providers.
8. Consider how new technologies could be utilised to support transition in an accessible and young person friendly way.
9. Develop an advocacy and appeal process which will support young people and parents or carers who are not experiencing transition positively and ensure a prompt and satisfactory resolution of key areas of concern.
10. Develop a quality assurance and enhancement process, which includes collection of transition data and the evaluation of performance and outcomes (including children and young people's service experience measures.)

"The authors suggest that new models of care provision and new ways of working are essential for success….

It will be for all Cheshire and Merseyside stakeholders to make sure that the challenges set out in Real People, Real Lives are tackled and that the experience of transition and outcomes for young people with long term conditions improves."

Tim McDougall
Clinical Network Lead: Children & Young People
Maternity, Children & Young People Strategic Clinical Network
Cheshire and Merseyside Strategic Clinical Networks & Senate

Key Messages from Families

What is most important?

- **The most important person is the young person - they should be involved throughout.**
- **Young people need to feel secure that they will receive a service that is at least as effective in meeting their needs as the service they are used to.**
- The next most important is the parent or carer - often they are exhausted and feel they have had to organise everything where no Lead Professional or Transition Coordinator is available.
- The hardest thing for parents of young people with complex needs is reversing your perspective; up till this point people have only talked about your problems, which you have had to focus on to access services – now people are talking about future plans and opportunities and what the young person can do (which can *"make your heart sing"*) but also be a shock or be disconcerting.
- Concerns from young peoples' perspectives include having to get to know new professionals; fears around safety and competence; still needing parents there to explain and reassure.
- Having a young peoples group and special clinics can help to make you feel less alone as transition to adult services can lead to you feeling scared ; unsure; anxious and unsafe about your future; having limited or little choice.

Communication, planning and process

- Practitioners could improve communication and understand systems and processes better – visual materials and developed Transition Plans and Pathways would help, particularly for the more vulnerable families who may not have the confidence to fight for services.
- Keep parents informed of outcomes of assessments; plans, what is happening and when actions have been completed.
- Improve communication with other professionals; all areas should have a proper Transition Plan Document - you need the right tools; right time; right person to be effective.
- It needs Consultants to talk to each other – *"they seem to be able to manage it when they have to in an emergency!"*
- Health professionals can do more to support young people's Education Transitions, particularly where schools and colleges need a better understanding of the young person's health needs.
- Discussions about transition can be overwhelming; it helps to have parents there to support, particularly if you don't understand what is happening; transition between different services should be staggered at a manageable pace.
- Make sure that every young person leaving children's services has a Transition Plan so that no young people are left behind or without services.
- *"Don't promise the Earth and then provide nothing – if you make promises you should follow them through!"*

Services and Support

- Advocacy services would be helpful, particularly to support involvement of young people with learning disabilities.
- Improved training is needed for families to help them understand transition and related processes
- Parents Forums can help promote family awareness of the transition process and enable them to participate in a positive way.
- "*The Transition Team needs to be multi-disciplinary and STAY TOGETHER!"*
- SENCOs in schools need better training for transition from age 14.
- There is a need to develop better provision for young people who have complex needs, for example making hoists and special equipment available in colleges.

Impact

- The report has now been signed off by the Cheshire and Mersey Strategic Clinical Network and they are working with their stakeholders and other Clinical Strategic Networks to respond to the issues raised.
- The report has been circulated to several relevant national organisations and networks and has been well received. These include other Strategic Clinical Networks, the Patient Experience Team, Transition, Mental Health, Diabetes and Quality leads at NHS England, the National Youth Forum, Health Watch and some of the Royal Colleges.

"Well done for commissioning & putting the spotlight on transition and the team & for leading on this. Great work, with powerful narrative, thank you. "

Kath Evans (Head of Patient Experience – Maternity, Newborn, Children and Young People, Nursing Directorate, NHS England.)

"This is a splendid piece of work, very well done! I have forwarded it, if you don't mind, to several of my NHSE colleagues … The trick of course, as we all know, is to take your recommendations and translate them into action with all the partners, the Young Person and family being central to this experience…"

Dr Jacqueline Cornish, OBE (National Clinical Director, Children, Young People and Transition to Adulthood, NHS England)

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The courageous and inspirational young people, parents and carers who generously shared their stories in the hope that they would contribute to the continuing improvement of services to support young people transitioning from children's to adult services in the future.

The forward thinking professionals who enthusiastically contributed by explaining their roles in supporting young people's transitions and illustrated how barriers and challenges can be overcome with willingness to see new ways of working in partnership with others.

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The full report can be accessed at:
http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/maternity-children-and-young-people/children-and-young-people-projects/improving-acute-medical-and-surgical-paediatric-care/