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 moved from children’s to adult services in Cheshire and Merseyside.

Nick Medforth and Elaine Huntingdon
April 2015
Good transition support for young people with long term conditions has long been a national policy objective and strategic priority for Cheshire and Merseyside Maternity, Children and Young People Strategic Clinical Network (C&M MC&YP SCN).

It is over a decade since the National Service Framework for Children, Young People and Maternity Services highlighted the importance of safe, effective and timely transition between child and adult health services. Yet all too often, young people still experience transitions that are poorly planned and coordinated which can make their conditions even harder to manage for individuals and for families. The result of poorly developed transition services is that sometimes young people are left with no help when they need it. The gains made from contact with children’s services may be diminished or lost as a result of inadequate or failed transition to adult services. This not only lets young people down but it is expensive when additional or crisis care or respite is required.

Numerous reports have repeated the same messages to commissioners and service providers. Transition can be improved by early planning, listening to and involving young people and their parents and carers, and through providing appropriate and accessible information. Joint planning and commissioning can help ensure that services become seamless and developmentally appropriate.

I would like to thank Nick Medforth, Elaine Huntingdon from Liverpool John Moores University, and all members of the Long Term Conditions Special Interest Group from the C&M MC&YP SCN who worked hard to produce Real People, Real Lives. Their excellent report sets out the challenges facing strategic partners and their recommendations are for commissioners, service providers and the young people’s workforce in health, education and social services.

The authors suggest that new models of care provision and new ways of working are essential for success. They challenge strategic partners to adopt new technologies which may contribute to solutions. They call for an integrated approach to meeting the transition challenges and better quality assurance mechanisms to help ensure that young people’s experience of transition improves.

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
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive Summary</td>
<td>5</td>
</tr>
<tr>
<td>Background</td>
<td>14</td>
</tr>
<tr>
<td>Introduction to the project</td>
<td>17</td>
</tr>
<tr>
<td>Methods</td>
<td>18</td>
</tr>
<tr>
<td>Case Studies: the transition experiences of Kyle, Emily, Kelly, Ben, Holly and Sarah</td>
<td>20</td>
</tr>
<tr>
<td>Analysis, Discussion and Emerging Themes</td>
<td>47</td>
</tr>
<tr>
<td>Conclusions</td>
<td>48</td>
</tr>
<tr>
<td>Recommendations</td>
<td>56</td>
</tr>
<tr>
<td>References</td>
<td>58</td>
</tr>
<tr>
<td>Appendices</td>
<td></td>
</tr>
</tbody>
</table>
The authors would like to thank Cheshire and Merseyside Children, Young People and Maternity Strategic Clinical Network Long Term Conditions Special Interest Group and their partners for commissioning the project, their support in recruiting interviewees to enable completion of the Case Studies, and their commitment to develop strategic approaches to improving the transition experience of young people and their families.

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.
Executive Summary

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 and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems. The guidance document builds on previous versions which illuminated some of the challenges and problems experienced by young people whose needs were overlooked or only partially met as they transitioned from children’s to adult services.

Transition has also been a key focus for the Council for Disabled Children (2011) who’s Aiming High for Disabled Children Transition Support Programme report focussed on learning from success and identifying key principles and actions supporting positive change for children, young people and families. Five focus areas were identified as a basis for local activity in addressing the challenges for transition support:

1. Strategic joint partnership working
2. Participation of disabled young people and their families
3. Effectiveness of personalised approaches
4. Joint assessment processes within children’s trusts and adult services.
5. Realistic post-16 opportunities for living life.

Despite examples of good practice and effective models the experience of transition to adult services is by no means a universally positive experience. In his foreword to the Care Quality Commission (CQC) report From the Pond into the Sea (2014) Professor Steve Field (Chief Inspector of Primary Medical Services and Integrated Care) expresses his frustration that 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...the system is fragmented, confusing, sometimes frightening and desperately difficult to navigate. Too often instead of helping young people and their parents it adds to their despair.”

Professor Field reminds us that there is plenty of guidance on what makes for good transition planning and good commissioning of care, but that the CQC found a significant shortfall between policy and practice leading to confusion and frustration for young people,
their families and the staff caring for them. Even worse, young people can find themselves without essential care or equipment because of the different ways services are provided, or while funding arrangements are resolved.

He reminds us that it need not be like this, but that system-wide change will be required to achieve a joined up approach, ensuring that care is coordinated around the individual (Kennedy, 2010.) This will be essential to provide the best possible experience of transition to adult services for those young people who need ongoing care, particularly the increasing number of young people with serious illnesses and disabilities who are surviving into adulthood. It will involve careful consideration of a number of aspects of service provision including commissioning; transition planning; funding and budgets; involvement and choice; supporting carers; working across different settings and professional boundaries; training for professionals; transfer between services and learning from best practice to provide holistic integrated care.

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 and have chosen to make this a special priority focus in their work stream. The starting point is to gain deeper insight into the recent transition experiences of local young people and families and their key workers with a view to identifying further areas for research and service development in light of recent best practice guidance and standards.

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

- Young people who have common long-term conditions such as Diabetes and Epilepsy which are predominantly self-managed at home, with oversight from centres with specialist expertise.
- Young People who have long term conditions which require intermittent or regular hospital-based intensive support such as those who are technology dependant or require frequent admissions for acute or specialist care.
- Young people who have disabilities and complex needs.
- Young people who are receiving support from Child and Adolescent Mental Health Services.
- The intended outcomes were to provide the Special Interest Group with insight into how strategies to improve the experience of transition in Cheshire and Merseyside could be informed by the lived experiences of:
  - Young Service Users who had recently undergone transition from children’s to adult services
  - The viewpoints of their parents and carers
  - The perspectives of lead professionals involved in planning, coordinating and supporting the transition process.

Six Case Studies were constructed following face-to-face semi-structured interviews with young people, parents and carers representing the above groups. The young people involved had experienced the transition from children’s to adult services within the past six months to three years. Where it was possible to identify and access a lead professional who was involved in planning and co-ordinating the transition their perspective was also sought through separate face to face and telephone interviews before inclusion within the appropriate case study.
Emerging Themes

1. Understanding Transition

The Case Studies demonstrate that parents have a good understanding of what Transition means, and have endeavoured to explain this to their children. One parent, however commented “How can young people with learning disabilities be expected to negotiate transition when they don’t even know what that means?” Some parents and carers were aware of policy guidance and expectations, for example the recommendation that planning should start during the early teenage years. This is not necessarily what they have experienced themselves. 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.

2. Variable Transition Plans and Experiences

Two of the case studies (Kelly and Kyle) illustrate that transition can work well when planning starts in a timely manner, is informed by policy guidelines and sector standards, is clearly and appropriately 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 in regular planning meetings and a willingness to challenge traditional ways of thinking about, commissioning and delivering services. The majority of families interviewed, however, were unable to identify a lead professional who took on this role.

Ideally Transition Teams will include representatives from children’s and adult health and social care services; schools and colleges; finance advisors and commissioners and representatives from advocacy groups and the community and voluntary sector. Kyle’s Case Study in particular illustrates the positive outcomes which may result from integrated Education, Health and Care planning. This is in stark contrast to the experiences of Ben, Emily and Sarah. Some of the families and practitioners also highlighted variability in the complexity of cases and consequent complexity of transition planning.

3. Still “Lost in Transition”

Several of the case studies indicate that Transition Plans for some young people are “in the ether” rather than documented and may sometimes be confused with Care Plans – in one case (Emily) a parent had to devise and type her own in an attempt to ensure that her child’s needs were appropriately assessed. This can lead to fear and anxiety in both young people and parents as also illustrated in Holly’s case.

At worst it may lead to detrimental outcomes as a result of poor communication and discontinuity in management, as in Sarah’s case, which illustrates how one young person can have two very different transition experiences even when receiving care under two consultants within the same hospital. Kelly’s case illustrates how within the same family one young person may have a well-supported and co-ordinated transition experience whilst their sibling may be “left hanging.”

4. Involvement in Decision-Making

Kyle’s case indicates that 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 dependant, however, on the attitudes, values, knowledge and skills of individual practitioners, or alternatively the young person having an informed parent or professional available who can mediate or advocate on their behalf. Other Case Studies (Emily, Ben and Holly) illustrate how young people may be completely or partially excluded from decision-making. This may be either because practitioners and professionals are not skilled or confident in communicating with young people who have learning disabilities and...
speech and language difficulties, or because their traditional ways of practicing means that they overlook the need to work in partnership with young service users even when language and communication is not a barrier.

Some practitioners may fail to consult with parents too, or fail to continue to involve families once initial assessment has been carried out, as illustrated in the case of Emily, whose mum raised concerns that once funding assessments had been carried out these may not always be shared with parents before they are submitted to approval panels. Rita (Kelly’s Gran) also reported discontinuity in the allocation of Social Workers had led to incomplete assessment of needs.

Some of the parents interviewed highlighted that choices regarding future services were variable (for example no choices regarding the accessibility of respite, but some choice regarding attendance at youth clubs and young people’s groups.)

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

Different models of service delivery between children’s and adult services may impact on the availability of appropriate services, for example CAMHS services may be based on a children / young person – centred developmental model, but Adult Mental Health services based on a medical, diagnostic or therapeutic models (as indicated by the professional involved in supporting Kelly’s transition to adult mental health services.)

Integrated Commissioning appears to work in some cases up until 18, but then becomes fragmented once young people enter the adult sector. Holly and Kyle’s cases, for example illustrate how some essential services may be cut following transition to adult services. Holly’s case in particular illustrates how care became fragmented as commissioners and service providers worked in isolation, or one when one agency decides to withdraw services and funding. A further barrier to continuity of service provision may be geographical or local authority boundaries. One parent commented that

“Budget holders have freely admitted they are saving money by cutting resources wherever they can, but austerity doesn’t help when you are sick or in danger.”

The majority of the families interviewed reported that they experienced a completely different approach when they had moved to adult services, which were no longer arranged to centre on the needs of the child or young person. In the worst cases services cited did not encompass a philosophy of listening and responding to young people and failed to acknowledge the need to work in partnership with parents. Younger siblings can have their support withdrawn when the older sibling moves to adult services. These concerns are particularly illustrated by the experiences of Holly and her family.

6. Training Needs

The Transition Team Manager involved in co-ordinating Kyle’s transition to adult services acknowledged that practitioners in adult services may have training and support needs if they are to understand the transition needs of young people and families and to confidently and competently provide effective services young people. This is understandable when many adult service providers will have a case load of predominantly older people, however their training needs must be met if they are to be able to effectively provide an equitable level of service to young service users.

The Transition Practitioner involved in supporting Kelly highlighted some good practice in developing and delivering multi-agency training focussing on awareness-raising; underpinning values; expectations and minimum standards in supporting young people’s transition to adult services and complex case management.

Kyle’s mum also highlighted the need for less well informed parents to receive training on understanding transition (something she provides through her parent support group.)
7. Fearful young people and “battle weary” parents and carers

All of the families interviewed indicated that often the transition experiences may be chaotic or overwhelming, resulting in fear, confusion or distress for the young person involved. Many of the parents felt that they had had to “fight” to ensure that their child received the best possible services, even when they knew that they were unlikely to win some battles. They feared that if they didn’t fight the result would be unsafe or compromised services for their child once they had moved over to adult services. For some parents who are already exhausted by struggling to meet their child’s care needs, the battle is continuous. Parents of two of the young people used the term “nightmare” to describe their experiences.

Parents valued or desired 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.

Parents perceptions of the effectiveness of Transition Plans vary from non-existence to resulting in improved outcomes. Others say that life has changed since the transition; becoming a “nightmare” involving constantly chasing things that are not in place and feeling “abandoned.” Some parents and young people feel they have “fallen through a crack” and it is easier for busy, stressed professionals to let that happen, particularly in community settings. Holly’s mum, for example perceives practitioners on the ground 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. This perception is mirrored by several of the other parents interviewed. At worst parents report that adult-focussed practitioners may not understand the importance of sharing information with parents, or listening to and involving them, even in emergency situations – this can lead to dangerous scenarios which compromise the safety of young people or leads to detrimental clinical decisions being made. (This was a concern for both Holly and Sarah’s parents.)

One example of an unintended consequence is Holly’s 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. The Impact of Transition to adult services

The Case Studies illustrate that when transition is well planned and coordinated it can lead to positive outcomes for the young person, however this may be dependent on the severity of the young person’s condition and confidence of their family. Some parents feel they have to choose their battles and let some poor practice or service provision go, and there appears to be a resigned acceptance that some families will receive a diminished or reduced level of service once under adult care.

Parents perceptions of the effectiveness of Transition Plans vary from non-existence to resulting in improved outcomes. Others say that life has changed since the transition; becoming a “nightmare” involving constantly chasing things that are not in place and feeling “abandoned.” Some parents and young people feel they have “fallen through a crack” and it is easier for busy, stressed professionals to let that happen, particularly

9. Loss of Services

Several of the families indicated that they had lost services they had had previously as a result of the Transition to Adult Services. These included

- Loss of a key contact to call if you are worried or need help in an emergency
- Loss of an trusted consultant or practitioner who co-ordinates and oversees care
- Loss of continuity (in medical management and clinical decision-making)
- Loss of Physiotherapy
- Loss of Hydrotherapy
- Loss of specialist equipment (for example Hoists needed in Education settings)
- Loss of Social Care funding and Social Work services
- Loss of individualised Education support
- Loss of social support leading to isolation
- Loss of Respite services
- Loss of support for siblings and parents or carers
There were also some gains acknowledged, for example, Holly now has access to a Counsellor which she didn’t have previously and Kelly now has a Mental Health Practitioner who is supporting her to get back to college, whilst Mary has been able to gain support from excellent Care Assistants due to Emily’s Direct Personal Payments.

10. **Key Messages from Families**

What is most important?

- The most important person is the young person and 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; an identified coordinator (Key Worker or Lead Professional) should manage the Transition process and facilitate integrated commissioning and services.
- 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 person’s perspective include having to get to know new people; 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 what you will be losing or gaining; anxious and unsafe about your future; having limited or little choice.
- Concerns from a parent / carer perspective include recognition that transition planning should start earlier (before 18.)

**Communication, planning and process**

- Practitioners could improve communication and understand systems and processes better – visual materials and developed Transition Plans and Pathways would help to explain things. Transition Plans should be in place for everyone so no-one gets lost, particularly the more vulnerable families who may not have the confidence to fight for services.
- Keep parents informed of outcomes of assessments; development of plans, what is happening and when actions have actually been completed.
- Improve communication with other professionals, the involving young person, parent and carers; 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!

**Services and Support**

- Involvement of Advocacy services would be helpful, particularly to support involvement of young people with severe learning disabilities.
- Improved training is needed for families to help them understand transition and related processes; Parents Forums (local and national) 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
- Training should be available for parents to help them understand the transition process and enable them to actively participate in decision-making.
Conclusions

1. Transition services across Cheshire and Merseyside include some areas of good or developing practice as well as some examples of inadequate transition 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.

4. The Clinical Strategic Network is in a privileged position to make some transformational changes to benefit young people, parents and carers – to achieve this they may need to be courageous in rethinking delivery models and the relationship between services designed to meet the needs of children and adults. This is likely to involve working in partnership with other Clinical Strategic Networks and Clinical Commissioning Groups.

5. There are some good examples of effective practice, but transition planning often starts late and may be vague and fragmented, have gaps or fail to adequately involve young people parents and carers in decisions.

6. Transition outcomes for young people and families can be positive, however the researchers found several examples of diminished service provision to the detriment of service users.

7. Where transition planning has worked well this has been because there has been a dedicated Key Worker, named Lead Professional or Transition Team who have developed expertise; are able to coordinate regular meetings and bring together multi-disciplinary/multi-agency teams; effectively involve service providers and users and develop creative solutions to overcome barriers in order to meet the individual needs of young people and their families.

8. The planning process needs an approach which bridges divisions between children’s and adult services; health, social care and education; hospital and community settings; geographical boundaries - service provision needs to develop to match this approach.

9. Training, resources, and pathways need to be developed for both practitioners and families involved in developing and implementing Transition Plans.

10. New models of care provision and new ways of working will be essential to success; new technologies could contribute to solutions.
Recommendations

In view of the above findings and conclusions drawn from the six Case Studies in light of the best practice guidance available the authors make the following recommendations for careful consideration by the project commissioners:

1. 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 when planning and implementing the transition of young people with long term conditions and disabilities from children’s to adult services.

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. Specialist Transition Practitioners will need to have knowledge and skills which will enable them to work across different settings and professional and geographical boundaries, manage complex cases and support families by overcoming barriers to successful transitions. 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 to ensure
   • that the service-user experience is enhanced rather than compromised
   • service provision centres on the needs of the young person and family rather than the needs of services and current models of provision, drawing on effective models of provision which are established in children’s services.

• Service design is informed by current published sector standards and guidance, established models of best practice and is consistent with recent Special Educational Needs and Disability (SEND) reforms.

4. Establish a Young Person and Family Reference Group to enable service development and re-design which is 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 guidance, protocols, Transition Plans and Pathways which ensure a standard level of timely, integrated and seamless service provision, but which could be adapted or differentiated to meet the personalised needs of individuals or shared needs of specific groups of young people (for example those who have specific long term conditions who are transitioning to the care of an adult hospital; young people with mental health difficulties; young people who have special educational needs and complex disabilities.)

7. Explore how local good practice can be built upon to meet the Training, Communication, Information and Continuing Professional Development needs of a) Parents and carers
   b) Lead professionals involved in planning and co-ordinating transition
c) Professionals and practitioners in adult services who may not have the understanding, confidence or competence needed to provide effective and responsive services to young people and their families.

d) Education providers who may not have the full understanding of the support needs of young people with long term conditions, disabilities or mental health difficulties.

8. Consider how new technologies, for example Social Media, Web-based resources and Electronic Transition Plans 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.)
In late modern culture the transition from youth to adulthood is increasingly non-linear and heterogeneous. Social and geographical location can make different pathways to adulthood more or less accessible (Furlong and Cartmel, 1997; Thomson, 2000). The traditional focus on the move from school to work has been replaced by an exploration of the relationships between a range of transitional ‘strands’: education, employment, training, housing, family, income, consumption, and relationships (Coles, 1995; Jones and Wallace, 1992). Transitions do not necessarily occur at the same rate along each of these strands and people may, for example, be independent in some spheres of their lives, but dependent in others (Griffin, 1993; Jones and Bell, 2000).

Thompson, et al (2002) emphasise “critical moments” in the transition of young people from adolescence to young adulthood and how they may vary from individual to individual according to numerous interacting factors relating to life course experiences shaped by family; wellbeing and illness; education; rites of passage; trouble; leisure and consumption; moving and relationships. These incredibly complex interactions between competing factors interplay to make transition something which is individually experienced. For young people with complex health needs these “critical moments” are compounded by the need to move between health, education and social care services focussing on the needs of adults.

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 significant 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.

Young people face numerous challenges when preparing for adult life. For the 40,000 children and young people with complex physical health needs, there are many additional hurdles. In many cases, the health needs of these young people will have been met by the same people who have looked after them for as long as they can remember. However, one of the changes as they reach adulthood is the transfer to an adult environment where they may need to consult several different health teams, therapy teams, and adult social care services. (Care Quality Commission, 2014)

Katon and Kagan,(2007) for example, compared the transition experiences of young people with moderate learning disabilities with other vulnerable young people and their non-disabled counterparts and found that in many cases young people who are vulnerable or disabled may experience “rushed” transitions, which are more stress-full and difficult and may also lead to social exclusion. At the same time, out of necessity, they will often have to grow up much more quickly than their non-disabled counterparts. A key pressure is negotiating uncoordinated and unresponsive services which they have little involvement in.
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 and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems. The guidance document builds on previous versions which illuminated some of the challenges and problems experienced by young people whose needs were overlooked or only partially met as they transitioned from children’s to adult services.

The current document draws on contemporary and systematically reviewed research evidence (Crowley, et al., 2011) as well as good practice guidance (Department of Education and Skills, Department of Health (2006.); Royal College of Paediatrics and Child Health (2013); Children and Young People’s Health Outcomes Forum (2012); National Network of Parent Carer Forums (2013). It highlights how children and young people experience many significant transition points between health care services, as well as those between schools, university and other educational settings. All these transitional phases can have an impact on adherence to therapeutic regimes and retention by supportive health care services.

The publication aims to provide health professionals who work with children and young people with information on the principles of good practice in arranging transitions, key workers’ roles in supporting effective transitions; young people’s involvement; processes and protocols. It includes a list of recommendations for both service providing organisations and individual practitioners to make the transition for children and young people to adult services smoother. Standards focus on providing services which are seamless, flexible and based on the needs of the young person, rather than focused on the needs of the service. They also recognise that young people’s needs are paramount and involve key workers with appropriate specialist skills and knowledge and who are able to listen to and respond to the needs of young people.

The report relates to young people who have long-term conditions; mental health and well-being challenges, complex needs and learning disabilities.

Transition has also been a key focus for the Council for Disabled Children (2011) who’s Aiming High for Disabled Children Transition Support Programme report focussed on learning from success and identifying key principles and actions supporting positive change for children, young people and families. Five focus areas were identified as a basis for local activity in addressing the challenges for transition support:

1. Strategic joint partnership working
2. Participation of disabled young people and their families
3. Effectiveness of personalised approaches
4. Joint assessment processes within children’s trusts and adult services.
5. Realistic post-16 opportunities for living life.

Some models of effective transition planning and support have emerged. One such example at an operational level is the *Ready, Steady, Go Transition Programme* which has been implemented at the University Hospital of Southampton (2015) for children over the age of 11 who have a long-term medical condition. This is a three-stage programme to help young people to get ready and feel confident to move to adult services at their own pace when they are around the age of 18. The programme is supported with young person friendly documentation which includes an introductory Information Leaflet, a Parent Plan, a Transition Plan and Questionnaires to assess the young person’s progress at each of the three (Ready, Steady, Go) transition points. The model has generated considerable interest and has been adopted or adapted by other children’s trusts.

*Yorkshire and the Humber Children’s and Maternity Strategic Clinical Network* (July, 2014) have attempted to identify principles of best practice at a strategic level and provide guidance in relation to the following key themes:
• Commissioning (including funding / budget)
• Integration and Multi Agency Working (including Local Authority, Social Care and Mental Health Services)
• Transition Process and Transition Plan
• Involvement of children, young people, parents and carers and including Self-Care, Social Media and other methods
• Professional Workforce Development
• Health Settings and Services, including Primary Care
• Guidance and Protocols
• Quality, Data, Performance and Outcomes (including children and young people service experience measures)
• Communication and Information

Despite examples of good practice and effective models the experience of transition to adult services is by no means a universally positive experience.

In his foreword to the Care Quality Commission (CQC) report *From the Pond into the Sea* (2014) Professor Steve Field (Chief Inspector of Primary Medical Services and Integrated Care) expresses his frustration that 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…the system is fragmented, confusing, sometimes frightening and desperately difficult to navigate. Too often instead of helping young people and their parents it adds to their despair.”

Professor Field reminds us that there is plenty of guidance on what makes for good transition planning and good commissioning of care, but that the CQC found a significant shortfall between policy and practice leading to confusion and frustration for young people, their families and the staff caring for them. Even worse, young people can find themselves without essential care or equipment because of the different ways services are provided, or while funding arrangements are resolved. He reminds us that it need not be like this, but that system-wide change will be required to achieve a joined up approach, ensuring that care is coordinated around the individual (Kennedy, 2010.) This will be essential to provide the best possible experience of transition to adult services for those young people who need ongoing care, particularly the increasing number of young people with serious illnesses and disabilities who are surviving into adulthood. It will involve careful consideration of a number of aspects of service provision including commissioning; transition planning; funding and budgets; involvement and choice; supporting carers; working across different settings and professional boundaries; training for professionals; transfer between services and learning from best practice to provide holistic integrated care.
Introduction to the Project

The Cheshire and Merseyside Children, Young People and Maternity Strategic Clinical Network has established a Long Term Conditions Services Special Interest Group. The Special Interest Group members 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 and have chosen to make this a special priority focus in their work stream. The starting point is to gain deeper insight into the recent transition experiences of local young people and families and their key workers with a view to identifying further areas for research and service development in light of recent best practice guidance and standards.

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

- Young people who have common long-term conditions such as Diabetes and Epilepsy which are predominantly self-managed at home, with oversight from centres with specialist expertise.
- Young People who have long term conditions which require intermittent or regular hospital-based intensive support such as those who are technology dependant or require frequent admissions for acute or specialist care.
- Young people who have disabilities and complex needs.
- Young people who are receiving support from Child and Adolescent Mental Health Services.

The intended outcomes were to provide the Special Interest Group with insight into how strategies to improve the experience of transition in Cheshire and Merseyside could be informed by the experiences of

- Young service users who had recently experienced transition from children’s to adult services
- The viewpoints of their parents and carers
- The perspectives of lead professionals involved in planning, coordinating and supporting the transition process

Six Case Studies were constructed following face-to-face semi-structured interviews with young people, parents and carers representing the above groups. Young people involved had experienced the transition from children's to adult services within the past six months to three years. Where it was possible to identify and access a lead professional who was involved in planning and co-ordinating the transition their perspective was also sought through separate face to face or telephone interviews, before inclusion in the relevant case study.
Methods

C

Case study has been chosen as the method of data collection for this pilot because the approach helps develop explanations of social-psychological and social structural processes and significantly provides opportunity to explore the context in which a phenomenon is occurring (Eisenhardt, 1989.) As an approach to data collection Case Study is valuable in providing knowledge through the systematic production of exemplars to contribute to the understanding of a particular phenomenon or the developing knowledge of a discipline (Flybjerg, 2006.) This methodology is recognised to be particularly effective in evaluation projects and will therefore be helpful in illuminating the experiences of transition from the perspectives of the people involved, taking account of the complex interactions between competing individual, family factors and service delivery models at this “critical moment” for the young person involved.

A Purposive Sampling technique was employed to identify what Bernard (2002) describes as an effective type of non-probability sampling, often used in Anthropological research. It is considered to be most useful when one needs to study a certain cultural domain with knowledgeable experts within. The inherent bias of the method contributes to its efficiency, and the method stays robust even when tested against random probability sampling. Choosing the purposive sample is fundamental to the quality of data gathered; thus, reliability and competence of the informant must be ensured. In terms of this project, the approach meant that the participants were recruited through the Clinical Strategic Network and it’s partners who acted as gatekeepers for the project. The gatekeepers distributed information about the project and invitations to participate to families they knew who:

- had a young person with a long term condition or disability representative of the four identified groups
- had recently experienced the transition from children’s services to adult services
- has received services within Cheshire and Merseyside

Collectively the participants in the case studies represent young people who have experienced receiving services in Chester, Flintshire, Liverpool, St.Helens and Wirral.

Ethical implications of the project were carefully considered as the case studies involved interviews with potentially vulnerable young people, all of whom were interviewed in the presence of their main carer. Face to face interviews were carried out in a location which assured safety for both the interviewees and researchers, and participants had the option of being interviewed over the telephone if they felt this would be more appropriate. As the project was a service evaluation NHS Ethical approval was not sought, however a submission to the Liverpool John Moores Ethics Committee was approved on 20th January 2015 (Reference 15/EHC/010) This ensured that that all participants

- Were fully informed before agreeing to participate
- Had the opportunity to ask questions, or for further information at any time
- Were asked to give informed consent
• Has the right to withdraw without prejudice at any time without having to state a reason
• Were assured of anonymity and advised how data would be stored and destroyed following completion of the project
• Were not unduly distressed during interviews
• Understood how the information they shared would be presented
• Recognised that they may not personally benefit directly from participating in the project, other than having the opportunity to tell their stories, however the findings would be used to benefit young people and families undergoing transitions in the future.

Examples of Gatekeeper and Participant Information Sheets and Consent Forms can be found in the appendices.

**Authenticity** is a key issue in assuring the quality, trustworthiness and validity in Qualitative Research such as this case study-based pilot (Seale, 1999.) It is one of the three primary criteria which are used for establishing the validity of qualitative research alongside **credibility and criticality** (Whitmore, Chase, and Mandle, 2001.) It is important that researchers seek assurance that the conduct and evaluation of the research is genuine, credible and reflects both the lived experiences of the participants and the political and social implications of the research (Given, 2008.) This includes considering whether the research is worthwhile. The researchers in this study are confident that the case studies are authentic, trustworthy, and credible and reflect the stories the participants wanted to tell. Once written in draft they were returned to the participants who were invited to make any corrections or amendments, before the final drafts were included. These have been taken into account and the case studies presented are versions which reflect any amendments suggested by the participants. The fact that the participants volunteered to be involved once they were fully informed about the aims of the project indicates that they recognised the potential value of the research in informing future improvements to services for young people with long term conditions and disabilities.
Case Studies

The following Case Studies were developed following the interviews with young people, parents and carers and (where identifiable and accessible) lead professionals involved in co-ordinating the young person’s Transition Plan and process. Please note that names have been changed in order to protect anonymity of the participants.
Kyle’s Story

Kyle is a 20 year old young man who lives with his mum Pam, dad Carl, brother Jack (17) and dogs Bruno, Smudge and Hattie. Kyle has multiple complex needs, which include Cerebral Palsy, Epilepsy and Cortical Blindness. Kyle uses a wheelchair and has communication difficulties, but is able to respond to questions and indicate his thoughts, ideas, needs, wishes and feelings when people take the time to listen. Kyle’s mum and dad are his main carers and advocates and are skilled in supporting his communication and ensuring that his rights are maintained. They continually battled to ensure that decisions made on Kyle’s behalf are always in his best interest. Kyle needs support to get ready in the morning, with bathing and feeding and with turns overnight.

Kyle understands that the term “Transition” relates to the movement from Children’s to adult services and this involves Education, Health and Social Care. Whilst Kyle’s mum and dad provide most of his care they both have their own deteriorating health problems, and require support which is jointly funded by Health and Social Care Commissioners. Although Personal Budgeting has worked well for Kyle when things are going smoothly, difficulties arise when carers go off sick and there is no replacement, so the family feel that it is best to arrange care through an agency so that there is back up should problems arise.

Kyle’s parents have been firm in their view that Kyle deserved more than just following the path that was expected. They wanted what was best for him, so following his attendance at a Special School during his primary years, Kyle was dually registered at both the Special School and the local Comprehensive. Maintaining attendance at the Special School meant that Kyle could continue to access essential Speech and Language support, Physiotherapy and Hydrotherapy and sustain his friendship with his best friend, Peter. Attending the High School two days a week enabled Kyle to make new friends in his local community. Although since leaving school he no longer sees them regularly, they still stop and say “Hi” when they see him in the street.

Kyle enjoyed attending High School, and his mum explained that this was because the School were good at “differentiating the curriculum” and were not constrained by perceptions of his disability. Kyle agreed that one example was a Design and Technology project focusing on the construction of Trainers; Kyle was able to make a collage using the actual materials used in the manufacture of Trainers with the support of a designated Teaching Assistant. Whilst at High School Kyle also discovered that he enjoyed Shakespeare.
Kyle now attends a Day Centre 2 days a week and his local Further Education College on 3 days where he is continuing his learning and development. The classes he attends include independent living skills, micro enterprise café and community access. Kyle's mum explained that the longer term aspiration is to support Kyle to channel his enjoyment of painting to contribute to a micro-enterprise involving decoration and production of mugs and calendars. (Kyle is supported to make colour choices using a tray device similar to an egg-box.) A downside for Kyle is that he can no longer access Physiotherapy and Hydrotherapy, which means that he experiences more muscle pain and joint stiffness.

Kyle felt that he was asked what he thought about his Transition Plan and his mum recalls that a particular Social Worker was very patient and took the time to listen to his views and understand his wishes and feelings. Kyle says, however, that he would have liked more choices, and to have had an opportunity to do more of the things he enjoys (including more painting and dancing.)

Pam’s View

Pam understands that transition should involve a smooth transfer from children’s to adult services. She describes it as a *holistic handover* in which nothing is missed, and involves the integration of Education, Health and Social Care services. Pam says that she *made it happen* by approaching the Special School Kyle attended when he was in Year 9. At that time transition planning focussed on the 14-19 age range, however Pam recognised that recent Special Educational Needs and Disability reforms mean that this is now extended to 25.

The initial meeting at the Special School involved Kyle’s parents, Kyle himself, his Teacher, Teaching Assistant, Speech and Language Therapist and Physiotherapist. The meeting drew upon Kyle’s School and Social Care reports, but Pam feels that the transition planning process for Kyle was very much “*driven by Education*” with additional input being provided by the Residential School Nurse at the school and Kyle’s therapists.

Kyle’s Health Transitions were staggered in order to make them more manageable and his General Practitioner has also played a co-ordinating role. Kyle’s parents feel that this has been a relatively smooth process, for example enabling him to have an Orthopaedic operation as an inpatient at the large regional children’s hospital at 18, before transferring to adult services. Kyle’s Epilepsy was also originally managed through specialist services at the children’s hospital, but he has now transferred to a specialist adult Neurological Centre. Kyle’s Dental care is now overseen by the Dental Hospital.

Pam identified three people in co-ordinating roles who were key to putting Kyle’s Transition Plan into place. These were

- The co-ordinator of Post 16 Education for young people who have Special Education Needs
- The Manager of the Social Care Transition Team
- The Children’s Transition Commissioner in the Health service

All of these professionals were prepared to work together and “*not let funding be a barrier*”; looking for new solutions which were in Kyle’s best interests.
Pam feels strongly that the role of the Children's Transition Commissioner in the local Primary Care Trust was essential to ensuring that Kyle had a "cohesive" transition experience bringing together Schools, College, Health and Social Care Services. Pam is concerned that this role no longer exists following the introduction of Clinical Commissioning Groups (CCGs) with the consequence that support from Health Services is diminished as changes to funding models have resulted in having "no-one to pull it all together" from a Health perspective. An example Pam cited was the year she spent trying to access training for Care Assistants, who were able to bath Kyle, to be able administer his epilepsy recovery medication. Previously the Children's Transition Health Commissioner would have sorted this out. However it was not until Pam complained to the CCG through the Patient Advice and Liaison Service, copying in everyone she could think of and citing guidance from the National Institute for Clinical Excellence (NICE) that the issue was resolved. Kyle's parents found this exhausting alongside meeting his care needs themselves and are concerned that other parents may not have the skills, confidence or energy to fight for what they have a right to expect.

Pam identified Kyle's transition to the care of the Adult Neurologist as a positive aspect of the transition experience. The Consultant Neurologist visited Kyle twice at the Children's hospital and took time to get to know him, gaining Kyle's trust and confidence before he attended the Adult Neurology Service.

One example of a big decision the family was involved in during transition planning was Kyle’s progression to the Day Centre and College. Kyle's parents had initially intended for him to attend a Specialist Residential Centre in the South of England and always said that he would go to a Day Centre "over their dead body." Kyle was initially reluctant to go too, even after a two day overnight assessment; but was also unsure about the residential college. Pam acknowledged that it was not until Jack enabled them to see the Day Centre from the perspective of a young person that they changed their view. Jack visited the Day Centre and recognised that rather than just sitting around people were happy there and doing things that Kyle might enjoy. These include Art, Pottery, Karaoke and visits to the local Library. The day centre also makes a recognised contribution to the local community by growing "Incredible Edibles" (vegetables that anyone can pick and take home.) Kyle attended a few times with Jack in the beginning, realised that he liked it and recognised that attending could work in tandem with attendance at the Further Education College. Pam now recognises that Kyle may not have been ready to attend the residential college in another part of the country and attending the day centre has enabled Kyle to contribute as a member of the local community.

Overall, Pam feels that the Transition experience for Kyle has been a good one; taking a person –centred approach and involving Kyle throughout. Pam, recognises, however, that this is not everyone’s experience and runs a support group for other parents going through a similar process and may not be as well-informed about how the system works. One example she uses to illustrate this is the fact that Adult Social Care Transition Team members do not always explain their role as Case Workers rather than Social Workers and it is difficult for parents to gain a full understanding of Fair Access to Care once they have transferred to Adult services.

Pam feels that thinking about Transition and understanding professional roles can be overwhelming for parents, some of whom may not fully understand what it means or prefer to "bury their head in the sand" until it happens without adequate and well-coordinated support. One of the biggest challenges from Kyle's parent’s perspective is that your parental role, perspective and focus is suddenly expected to change. In the past parents have had to focus on all of the problems and negatives to ensure that they get the best services for their child, and no-one may have recognised that the young person's future was even a possibility. When
transition is on the agenda the focus changes; parents are now forced to make a significant adjustment and think about their child’s future in terms of gifts, aspirations and what they are good at. This is a “huge switch” for parents.

Pam’s recommendations for practitioners, commissioners and service providers are that

1. The young person must be involved throughout the Transition Plan and process.
2. Transition Teams need to be multi-disciplinary and stay together.
3. Special Educational Needs Co-ordinators (SENCOs) in schools and colleges need better training to ensure effective planning from age 14, rather than 16 or even older, particularly when colleges may underestimate health needs and support required.
4. Better provision for young people with complex needs (for example proper hoists in Education settings; continuity of Hydrotherapy and Physiotherapy.)
5. Parents are provided with training and support which will enable them to recognise what the young person can do so that they are able to take part in a positive, aspirational Transition planning meeting.

Pam has learned from providing Training and support to other parents that Transition can be a very positive experience as many parents have lost sight of their child in all of the daily challenges they have to face. Saying the positive things can be the hardest thing for parents but when you have to do that “it makes your heart sing...parents will have different feelings and it can be scary seeing your child go out into the adult world, but it’s like that for all parents…”

Patrick is Manager of a Transitions Team which is employed and managed through Social Care services, but is located within an NHS building in a community setting. The team is made up of experienced Social Workers who have expertise in both children’s and adult services. The team pick up responsibility for managing the cases of young people with complex special needs who are 16 plus and have been supported through the Children’s Disability Service. The young people Patrick’s team work with are within their last two years of Childhood and the team’s initial role is to carry out a Needs Assessment with the aim of supporting a seamless transition to adult services.

He describes two distinct phases for a young person’s transition. The planning and transfer of care and support across departments at 18 years followed by preparation for most young people they support for leaving school at 19 years plus, pertinent to the Special Educational Needs System. Once a “settled situation” to transfer the young person over to the appropriate
Adult Locality Team within the Local Authority.

Transition planning will involve consideration of

- Where the young person will live in the future
- Continuing Education for those young people who will benefit
- What will happen post-education (for example possible paid employment or volunteer work)
- Continuing Health and Social Care support
- Financial Arrangements and Personalised Budgets for Care Packages

Patrick met Kyle when he was 16 and a half, during a Transition Planning Meeting at his Special School. The meeting was very helpful in enabling Patrick to understand what Kyle enjoyed and didn’t like about school. Patrick was aware that Kyle had very supportive, well-informed and pro-active parents. Pam was particularly well informed about multi-agency contribution to the transition process and person-centred planning having provided training to other parents locally.

At that time Kyle’s parents had very clear views that they wanted Kyle to go to a specialist residential college in another part of the country, and were prepared to challenge the Local Authority on a number of occasions to make sure that decisions taken were in Kyle’s best interests. The Transitions Team and other agencies were, however, able to support them to explore other options which might be available locally and would be able to meet his specific needs and interests. This was particularly important as Kyle would not have been eligible for the residential college until he was 19, therefore there was a potential gap in his continuing education.

The role of the Transitions Team is to identify and source funding from the Local Authority and/or Health services to meet the assessed needs of the young person. They were able to put together a package which would meet the needs of Kyle and his family and enable him to stay at home whilst continuing to benefit from education and learning. Kyle’s Special School had developed a specific bespoke timetable of Arts-based activities and Patrick was able to negotiate with the local Further Education College to provide a similar timetable which would enable him to progress his interests.

As Kyle has additional 24 hour care needs. Transition planning also involved co-ordination of Health and Social Care services and funding to establish a Personal Budget which supports direct payment of specially commissioned services. These provide the support needed for Kyle at home, as well as when he attends College and the Day Centre.

The Transition planning process is carried out according to a local model, which is currently being revisited in light of the new requirement for integrated Education, Health and Care Plans as a result of recent Special Educational Needs and Disability reforms. The local protocol is also informed by work done by the Council for Disabled Children, which Patrick considers proves to be an excellent framework to follow. Patrick’s Local Authority has also strategically organised services into a “Team Around the Child” model to facilitate inter-agency working which puts the child and his or her needs at the centre. Regular (monthly) Transition Planning Meetings take place. These are hosted by the Transition Team with representatives from up to 20 partner agencies including Health, the Children’s Continuing Health Care Team and Community Matrons; Education, Finance, Connexions, Housing and Advocacy organisations. These enable the tracking and monitoring of Transition Plans for all young people with Long
Term Conditions and Disabilities. Social Workers within the team are able to ensure that young people and families are kept informed of progress and are consulted regarding any decisions to be made.

Some of the challenges Patrick acknowledges that Health commissioners are working towards resolving include:

- Excellent “wrap around” Health Services exist for children and young people up to the age of 18; however, this is not mirrored in adult services; a Health Transition Process is to be developed to match and support that of Social Care.
- The development of Health support services such as Community Matrons; this group is more frequently involved in providing services to older people and may need support and training to develop their confidence in dealing with young people who have complex needs and disabilities.
- A full range of appropriate services is not always available meaning that there is “no-one to let go to” for Children’s Health services.

In addition, recent government funding cuts mean that Local Authorities have had to reduce the range of services available locally. The Transitions Team are continuously working to identify new service providers and develop a Directory of Local Services on their 'Local Offer' web-site. Patrick’s advice to practitioners and service providers would be to:

1. Recognise that parents are very often very anxious about their child’s future and will want to be involved in the planning process at every stage.
2. Each young person is an individual and there is the need to develop your processes to effectively support them through this potentially difficult life phase.
Emily’s Story

Emily is 18 years old and she lives with her mum, Mary, dad Barry and brother (Harry) aged 15. Emily has a health condition which means that she has a complex learning disability, severe communication problems and long term health needs. She needs support with all of her daily activities including washing, dressing, eating, mobilising and going to the toilet. Emily attends a school for children with disabilities and she is settled into school with her peer group. Due to her condition Emily is reliant on adult support and guidance for every aspect of her life and to maintain her safety, therefore she is a very vulnerable young adult. She has attended various appointments at the local tertiary centre since her birth. Transition has been mentioned by a couple of people but it hasn’t happened yet in terms of health appointments.

Due to the nature of her condition Emily is unable to converse much through speech, however she is able to indicate if she was happy or sad or in pain or discomfort. Mary explained that she has tried to engage with professionals in order to try and elicit some information from Emily through the use of Picture Exchange Communication Systems (PECS). This would probably be a useful process, as within school, home and during time spent with her personal carers this and other methods of communication are used. Because of Emily’s communication difficulties, for the purpose of this report, Emily’s story is interpreted through her mum’s response to Emily’s eyes and voice.

Mary’s View

Mary’s understanding of “Transition” is moving from children’s to adult services. Parents have also discussed transition in relation to their children moving from nursery to reception and reception to junior school. Mary has been asking about “Transition” since her daughter was 14 as she understood that this is when the process should start. A Consultant and Nurse Specialist had mentioned “Transition” but Mary has not been aware of this happening. This word has never been used in school until suddenly she was asked to undergo a “Transition Assessment” last year (March 2014) by Children & Young People’s Services. Mary was relieved at this point because the process had finally started to happen and she thought that there was still plenty of time for it to take place. Initially the Family Support Worker from Social Care was going to complete the assessment however due to Mary’s in-depth knowledge in caring and meeting her daughters needs Mary actually completed the assessment herself on her computer. This was then reviewed by the Social Worker. Mary felt that due to the amount of information she had provided the Social Worker recognised that there would be much more work involved.
Mary did not receive a copy of the assessment; she requested a copy and this was eventually received in September 2014. After the initial assessment the Social Worker and Family Support Worker reviewed Emily’s needs and this was taken to “panel.” Mary was not consulted about this and she hadn’t seen the “Care Plan” before it was submitted to the Adult Care Panel. She was then informed by Social Care that some of the support had been refused and she was upset about this because at the same time Emily’s needs had started to increase. Mary requested a meeting with the manager of Adult Disability Services where discussion took place regarding how complicated it was moving from adult to children’s services and that no further support was available. At this time Emily started to wake up very early in the morning, sometimes to go to the toilet and mum would have to get up to ensure Emily’s safety and as a result of this mum became very tired. One morning Mary did not hear Emily and Emily had a fall sustaining a serious head injury. Emily was admitted to the local children’s tertiary centre who are her main care provider.

Mary accesses her local Carers Centre. One day after Emily’s fall Mary shared her frustration and feeling of helplessness with the staff there. Shortly after this Mary received contact from the Social Worker saying that a mistake had been made and additional support was now going to be available. This made her feel that again there was poor and conflicting communication between all services. Shortly after Emily’s 18th birthday the Continuing Health Care Team also carried out another full assessment of needs and Mary wonders “Why can’t this be done at the same time instead of separate assessments asking the same questions?”

Mary was not provided with any information following this assessment; she feels that a copy of the assessment should be discussed with her before this plan is submitted to the Health Care Panel. Mary also would like to be invited to meetings where professionals are discussing her daughter’s needs as her daughter has no voice of her own to express her needs regarding health, education and social care.

Emily had received respite care from a local young persons respite centre for many years and as part of the change from children’s to adult services enquiries were made to look for alternative respite provision. From the outset of this proposed change Mary had explained that due to the nature of Emily’s learning and physical needs one to one support is required in order for Emily to be cared for appropriately. This has been a lengthy process and plans have been made and changed a couple of times due to inadequate staffing and lack of awareness of Emily’s needs despite Mary providing the information required. This obviously has an impact on all of the family. With regard to respite there was no choice of provision within adult services, however there was a choice regarding youth clubs and the continuation of Direct Payments. This has enabled the provision of “very good” Personal Support Assistants who are able to meet some of Emily’s social and health care needs.

With regard to Emily and Mary being involved in the plans or decisions being made, Mary feels that she has provided all of the information repeatedly and accurately but has not been involved in any planning, or the “Care Plan” or submission of information regarding her daughter. She had to request this repeatedly. Mary understood that a “Care Plan” was used within hospital settings and that a “Transition Plan” would be in place for the move from children’s to adult services. Mary also reiterates that no attempts to involve Emily have really been made.
Mary feels that she would be the most appropriate person to be involved in supporting Emily's transition from children's to adult services as she knows all of her needs and cares for her every day. Mum also feels that she has to be an advocate and act in the role of a Lead Professional in the absence of one who knows her daughter. It takes a long time to establish a relationship with Emily and the process needs to be started much earlier, with time invested in getting to know her. One suggestion from Mary is that additional Personal Assistant time could be provided in order for people carrying out assessments to get to know Emily better and understand her needs particularly with regard to communication and choice.

In Emily’s position Mary did not feel that there was a Lead Professional involved who knew Emily and the Social Worker who met Emily briefly was not in a position to take on this role. In Mary’s opinion starting the process earlier and improving communication across all areas would improve the quality of care for these vulnerable young adults and their family. Mary felt that professionals were ill prepared to take on this role and they did not fully understand the systems and processes in order to facilitate smooth transition of services for a young person with the degree of disability that Emily has. Therefore she does not see that a “Transition Plan” is in place. Mary also suggests that she has actually facilitated changes in services up to now and a “Transition Plan should be in place well before Emily’s 18th birthday”.

With regard to how the “plan” has worked for Emily, Mary states that “the whole experience has been a nightmare” and has put “a lot of pressure” on the family chasing things up. It is particularly frustrating that Emily was 18 two months before the interviews took place and this “plan” is still not in place. Mary suggests that to try and improve things in future the process should be started earlier, involve an identified co-ordinator who actually co-ordinates instead of Mary and most importantly an advocate is sought to act on Emily’s behalf. Mary has had to repeatedly ask about the outcomes of various assessments and to see plans involving her daughter and she thinks that she should be kept informed of progress as part of the process. Mary suggests that to try and improve experiences for other families Parents Forums both nationally and locally would be one of the most appropriate ways for information to be cascaded out to families with regard to Transition. A national template or standard is also required. This link is provided by Mary, Emily’s mum www.nyas.net and she suggests that this is a useful website for advocacy advice and support for parents and children and young people with all types of disability.

Emily’s dental care was transferred to the adult services and she has had an appointment there and this was one positive experience that Emily and her family have encountered.

Mary’s three most important messages for professionals and final comments:

1. Improve communication with other professions and with the young person and their family liaising and co-ordinating information (if this happened everything else would fall into place). Follow things up and chase information so that parents don’t have to do it.

2. “As a parent I do not want to keep having to fight – this has been a most difficult time for us all.”

3. All areas actually look at producing a proper “Transition Plan” rather than a “Care Plan” which is health focussed.
Finally, in Mary’s words “How can my child with severe learning difficulties find her way around transition when she doesn’t even know what it means?...we need the right tools, the right time, and the right person to do this and I have been asking for this since Emily was 14…Education are isolated in this process! What about joint working?”

It has not been possible to provide the perspective of a Lead Professional in Emily’s Case as Mary was not able to identify one.
Kelly’s Story

Kelly is 18 years old. She lives with her Gran (Rita), her mum Karen, brother (Kevin) (20) and her baby son (Harry) who is 9 months old. Kelly has a complex learning disability which includes ADHD, Dyslexia and Dyspraxia. She has received support from the Child and Adolescent Mental Health Service (CAMHS) at her local children’s hospital for approximately 10 years, where she saw a Psychiatrist regularly on an outpatient basis. Kelly sometimes hears voices and this became more frequent when she became pregnant with Harry. Kelly’s story has been shared by Kelly herself, her gran, Rita, and the lead professional from the Transitions Team who supported her transition to Adult Services.

Kelly found it difficult to remember when “Transition” was first discussed with her, but remembered that it had been raised by a nurse (Paul) who coordinated transitions in the CAMHS team when she attended an appointment at a local Health Centre. Kelly felt “o.k.” at the time about the proposed move to Adult Mental Health services. She can’t recall exactly when the transition took place, but thinks it was somewhere around her 18th birthday. She feels positive about the transition as she feels she receives “a lot more help now” including medication from her G.P. “to help with the voices” and a Community Mental Health Nurse (Sally) who visits her at home and who Kelly describes as a “lovely lady” who goes through things with her and enables her to talk about her concerns.

Kelly thought school was “o.k.” and left when she was 17 to go to a city centre further education College to do a Catering course and courses in Art, Maths and English. Kelly struggled at college, and felt like she was often left “standing around”, without support from her tutors. This was more difficult when she became pregnant, so she decided to leave. Kelly’s suggestion would be that more help could be given to young people to enable them to make the transition to college, and to help the tutors understand the help they need. Kelly’s Community Mental Health Nurse (Sally) has been to the college to talk to the staff there, and Kelly is hoping to go back. She is considering a Hairdressing course.

Kelly feels that she has coped well with the transition to being a mum, with the support of her family and friends. She feels that she has “good” support during her pregnancy, although this was sometimes overwhelming. The birth was difficult and Kelly had a “forceps” delivery. Kelly now sees her Health Visitor (Mary) every two weeks and gets on “o.k.” with her.
Rita’s View

Rita’s understanding of “Transition” is moving Kelly’s support from Children’s Services which were no longer able to meet her needs to Adult Services which would be able to meet her needs much better. She feels that Kelly found it very difficult to talk to the Psychiatrist in the CAMHS service and was “hardly able to say 10 words” during outpatients appointments. It is much better now that Sally (Adult Early Intervention in Psychosis Practitioner) comes to the house; Kelly said more to her in 10 minutes than she had said in all of her previous appointments, for example Kelly had been able to tell her Psychiatrist that she hears voices, but was also able to explain to Sally what the voices said.

Kelly’s pregnancy had been a challenging time for the family. Kelly became pregnant at 17. Her boyfriend was from another culture within which arranged marriages were expected. Kelly went to London to stay with her boyfriend’s family and Rita was concerned that the family were putting Kelly under pressure to agree to marriage. Rita went to London and sought help from the police, but was told that as Kelly was 17 she had the right to make her own decision. Rita was frustrated that Kelly’s learning disability was not taken into account by the Police Officer she spoke to and that they did not take into account Kelly’s limited ability to make decisions. As a consequence Rita thinks that the Police should have more training on managing risks when dealing with young people who have a learning disability and mental health problems. Rita was also frustrated by a lack of support from Social Services, who left it to her, advising Rita that as Kelly was under 18 she should just go to London to get Kelly.

Rita felt that this experience had been traumatic to Kelly “undoing ten years good work” and exacerbating Kelly’s hearing of voices. This led to intensive involvement from both Health and Social Services throughout Kelly’s pregnancy and up to when Harry was about 4 months of age. This meant visits from a Community Midwife, a Family Nurse Practitioner and three Social Workers who had attempted to assess Kelly and the baby’s needs, but had not fully completed the assessment before leaving and passing the case onto a successor. Although Rita recognised that the professionals had “concerns about the baby and how Kelly was going to cope” the level of intervention was often inconsistent and overwhelming. Rita had kept a diary which illustrated one week which had been taken up with visits from different professionals or hospital appointments every day. Rita felt that the intensive intervention had led to an exacerbation of Kelly’s Depression and a fear that the baby would be taken from her. It wasn’t until a new Social Worker came after the baby was born and agreed that the case could be closed as Kelly had a lot of support at home from several adult family members that Kelly felt she was able to bond with her baby. Kelly no longer has contact with the baby’s father.

All of this was taking place with Kelly’s transition to Adult Mental Health Services in the background. Rita felt that it “would all have gone pear-shaped” if it wasn’t for the Transition Practitioner from the Child and Adolescent Mental Health Team and the Adult Mental Health Nurse working together. Rita felt they had done a “fine job” in co-ordinating meetings, “guiding them through” and “packaging it all up.” This was in stark contrast to the experience to that of Kelly’s brother, Kevin, who had also been receiving support from CAMHS but was “left swinging” at 16. Kevin was unable to get medication from his G.P. and as he had left school has no access to other sources of support. Instead used Cannabis to self-medicate, thereby exacerbating his problems.
Rita felt that the outcome of the Transition process had been a very positive one for Kelly and more effective than the support she had previously received to make the transition from school to college. Kelly had also gone back to College too soon (4 months after having Harry) and this had led to further Depression. Paul was no longer involved apart from the occasional phone call and Sally was now helping Kelly to decide what she wanted to do with her life. She was also offering some practical help and was looking into getting Kelly a bus pass; arranging a place in a Day Centre to build up her confidence and had made contact with the community focussed activities of a local football team to help Kelly pursue her interest in Sport.

Rita has 30 years’ experience of “looking after kids” and her advice to professionals and service providers would be

- More people like Paul are needed in the Transition Coordinator role.
- Make sure that every young person leaving Children’s Services has one 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.

The Transition Practitioner’s Perspective

Paul is employed as a Transitions Practitioner with a background in Early Intervention and Psychosis. The post was set up in response to Commissioning for Quality and Innovation (CQUIN) and is jointly funded by the Adult Mental Health Trust and the Children’s Hospital Trust. There are 2 Transitions Practitioners in the team who support transitions in young people who have Mental Health difficulties and Learning Disabilities. For Paul the term “Transition” means “a period of movement from one place to another; a process of change… We are in a really good position to keep the young person in mind.”

Paul didn’t know Kelly and her family until Kelly’s Consultant Psychiatrist asked the team to facilitate Kelly’s transition to Adult Mental Health Services when Kelly was 17. (In CAMHS Teams young people have a Lead Professional to co-ordinate care ; in Kelly’s case this was her Consultant Psychiatrist, however the role could be taken on by other professionals such as a Mental Health Practitioner or Clinical Psychologist. (In Adult Mental Health Teams a Lead Professional role could also be taken on by an Occupational Therapist or Social Worker.)

Kelly’s Psychiatrist recognised the value of Paul’s role and was keen to get to know more about it ; what it involved and how bridges could be built and communication improved between children’s and adult mental health services. Paul was also asked to contribute to “Child in Need” meetings which focussed on the needs of Kelly’s unborn baby.

For Paul the key aspects to supporting Kelly’s transition were

- Keeping the young person and family at the centre and making sure that they did not get lost in politics, processes and policies.
- Gaining consent to share information, for example past history in CAMHS, with the new care co-ordinator in the adult community mental health team.

Paul first met Kelly when she was 17. She was pregnant when he first received the referral. Although there is a Perinatal Team in the Adult Mental Health Trust, Paul felt that the transfer
of Kelly’s care would be inappropriate at this point, due to the psychosis risks associated with pregnancy and the post-natal period, so Kelly was not formally referred to adult services until she had had a 3 month period of stability after Harry was born. An additional consideration at this point was that Kelly did not have a Social Worker, although Paul had been involved with the previous Social Care assessment process and was able to make the Adult Care Coordinator aware of this and the need to monitor any ongoing Social Care needs.

Paul did not consider parallel education transition at this point as he understood that Kelly had been doing a Catering course at college and was intending to go back after the birth of her baby. Kelly did not have a Health Passport to support the process as these tend to focus on physical health needs.

Paul is confident that Kelly was involved in decisions made on her behalf and made some choices in how and when her care would be handed over. This was key to her acceptance of Adult services and her developing trust in Sally, who is an adult Mental Health Nurse working within the Community Mental Health Team.

The challenges in supporting the transition of young people like Kelly from CAMHS from Paul’s perspective include

- Often when a young person is on anti-psychotic medication G.P.s will be happy to prescribe them, but not monitor them so although the young person may be doing well they may also require access to a secondary Mental Health Team in order to have their medication reviewed.
- There could be a risk of Post-Birth Psychosis and 3-6 monthly reviews by a Psychiatrist may be required.
- Commissioning of services may be tri-partite in Children’s Services, involving Health, Education and Social Care; integrated commissioning may not be possible in the “different world” of adult services.
- Children’s services often are based on a child/ young person-centred developmental model and a psychological approach to understanding distress, however adult services may be built around alternative medical, diagnostic or therapeutic models. This might mean that young people who are showing symptoms associated with trauma or abuse are re-assigned diagnostic labels such as “Personality Disorder” to make services accessible to them; young people are made to fit the service rather than the service respond to their needs.
- Some adult-focussed practitioners see young people as “not for us.”
- Young people who already have a diagnosis such as a psychosis may experience a smoother transition; for example the relatively straightforward transferring of a young person who has a previously diagnosed psychosis from CAMHS directly to an Adult Early Intervention in Psychosis Team.
- Some Transitions may be “disjointed” ; for example, when a young person has been discharged from CAMHS before reaching the point of planned transition and then resurfaces in Accident and Emergency or adult services with recurrent problems ; these young people may also benefit from Transition Support Services.
- Young People who are considered to be “High Risk “ and are receiving care in specialist or private settings may not be able to access equivalent Adult services because they are not commissioned ; there is very limited provision locally for young people with inpatient needs, even through private provision.
- For young people with very complex psychological difficulties, turning 18 can be a very significant challenge and involve numerous safeguarding issues. On some occasions
their needs have not changed but the fact that they are 18 means that they must move to an adult service which may not be set up to meet those needs. Some cases can involve a review of the safeguarding arrangements. An 18 year old who stays on an adolescent unit is viewed by some providers as an adult on a children’s ward. Some young people are required to be supported on 1:1 observations because they are defined as adults on adolescent wards.

- Young people who do not have a confirmed diagnosis, or who have mild to moderate learning disabilities, or have a primary diagnosis of Autistic Spectrum Disorder may be receiving support through CAMHS but may “fall through the gap” and not receive community support from adult services as their conditions are not considered severe enough to meet Intake Criteria for Adult Mental Health services.
- Neighbouring boroughs with different commissioning arrangements may lead to different services and expectations; Transition Practitioners are learning to navigate these, however other people may find them a barrier.
- Through involvement in providing transition support to young people like Kelly Paul has learned that
  - Providing information about what to expect significantly helped Kelly and her family cope with the transition to adult services.
  - It is essential to give young people “a voice” in the process; opportunity to express anxieties; ask questions; have a sense of relief and feel valued, fully consulted and reassured.
  - 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.
  - Care coordinators and lead professionals involved in transition cases should regard the process as a journey and not just a ‘one off event’; a holistic approach should be taken which takes into account the whole range of needs.
  - The presence of a Transitions Co-ordinator at the first appointment with the Adult Psychiatrist can be an essential source of reassurance for the young person and their family.
  - For complex cases bi-monthly Transfer of Care Meetings may be necessary; these often involve senior professionals from CAMHS; Learning Disability Services; Tier 4 services and Social Care; Adult Mental Health Services.
  - Transition Policy in CAMHS and Adult Services should mirror each other and be embedded in the management of transition for under 18 service users.
  - The CAMHS Partnership as well as Tier 4 Services may make a useful contribution to Transition Planning.
  - Paul’s Team currently deliver Transitions Training to practitioners from both CAMHS and Adult Mental Health Services. This can be either a full or half day and content includes
    - Awareness raising regarding the transition process
    - Key Values underpinning the provision of transition support
    - Expectations and minimum standards
    - Complex Case Work to illustrate some challenges and practical solutions when planning and coordinating transitions

The team are currently developing Transition Checklists for practitioners and involving young people at the heart of these developments.
Ben is a 19 year old young man who Ben lives with his mum Sharon and his dad David. Ben was born with the condition Spina Bifida. This is a condition that can occur in varying degrees of severity. It is a congenital condition in which Ben’s spine did not develop properly in utero, leaving Ben with no feeling or sensation in the lower part of his body. Ben is a bright and articulate young man who has attended a mainstream primary and secondary school with support regarding his mobility. Since then Ben has attended 6th form at a local college and he is now undertaking a programme in Computer Graphics within the same college. Initially Ben was seen by a Consultant Paediatrician at a local District General Hospital where he was born. He attended the local tertiary centre regularly for routine appointments with regard to his mobility, bladder management and neurological development and he had several lengthy operations on his spine whilst growing up. These appointments continued until Ben was 16. He is a determined young man who prefers to mobilise within college with the use of crutches rather than use a wheelchair. If he walks too far he can quickly develop pressure sores on his heels and feet and these take some time heal further limiting his mobility. His mum Sharon now manages this with some previous support from the local District Nursing Service. Ben also needs to be able to go to the toilet urgently as due to his condition he only has half of the size of a normal bladder and he has been prone to severe urine infections in the past. Fortunately Ben has a good circle of supportive friends both inside and outside of college.

Sharon and Ben’s Perspective

Sharon understands that “Transition” means moving from children’s services to adult services as children mature. She recalled that someone at the local tertiary children’s hospital did mention this to her and Ben when he was about 16 years old but she doesn’t remember this happening. Both Sharon and Ben were worried about having to get to know new people as they felt that they trusted the staff at the tertiary centre.

Ben had always attended regularly for his Neurology, Urology and Orthopaedic appointments, however during 2012 – 2013 a number of his appointments were cancelled by the hospital. Sharon did telephone to query this and she was told that new appointments would be sent out but they were not received. Prior to this Ben had also cancelled a couple of appointments due to being on holiday or taking exams. Sharon sent letters to explain why Ben did not attend but when she rang to query why a new appointment had not been sent out she was told that he had not attended his appointments. Sharon became upset because she had written and explained the situation. Ben was discharged from the consultant he saw regarding his mobility and his Urologist said that he would see Ben at a nearby District General Hospital, however this did not happen. It was at this time that Sharon and Ben felt awkward
about subsequent appointments and they both felt that he was well and they could manage on their own. Sharon reflects that this was a crucial time for this family and yet a vital link was lost and no formal plan was in place to inform Ben and Sharon of what was to happen in the future. Therefore although “Transition” had been mentioned this did not formally take place and neither Ben nor Sharon had the opportunity to be involved in any of the planning, choices or decision making for the proposed transfer of his care.

With regard to assessments taking place, Ben had a Statement of Educational Needs in place within school up until the age of 16 years old and he had a regular assessment for this within school. Once he was 16 and he attended college these were discontinued. Until then they had involvement in all aspects of care and decisions. There were no assessments or formal discussion with regard to “Transition”.

When asked who would be the most important person in supporting Ben’s “transition” he and his mum Sharon felt that his neurology consultant at the tertiary centre would probably be the most significant person to be involved in this process.

Sharon has suggested that improvements could be made if “Health” could arrange a meeting with representatives from each speciality involved in providing care to coordinate information to see through the “Transition” process. In spite of the fact that they did not experience a planned transition process both Sharon and Ben are keen to engage in this pilot study in the hope that sharing their experience will improve services for the future for other young people and their family. Sharon has felt abandoned during this process and as she states

“Ben actually appears when he is sitting down at his computer that he has no additional needs and it is only people who know about this condition who have empathy and understanding of his physical needs inside and outside of college”.

On transfer to a local college Ben felt that only a couple of people understood his physical needs and if they were off there was no communication with regard to support for his physical and elimination needs. There was also little in the way of a contingency plan if the lift breaks down and he is unable to reach his class room or toilet in a timely manner. He is also concerned that people with a learning disability are allowed to be dropped off at the college door by a mini bus however he has to struggle to walk from the drop off point. Sharon and Ben have felt lost over the past couple of years and have not known who to approach with regard to any future health issues apart from their own G.P.

Sharon and Bens three most important messages for professionals and final comments:

1. Better communication between all services and people following through things they have discussed and not leaving them to chance.
2. Developing some telephone consultation or review with services rather than attending numerous appointments on different days which can interfere with educational attainment.
3. Appointments being cancelled by the hospital and by Sharon caused some difficulty in continuing with appointments as when Sharon rang she was just told that they hadn’t received her letters. Some improved co-ordination and record keeping of information regarding missed or cancelled appointments would be beneficial in preventing this situation from happening again.
Holly is now 23 years old. She lives with her mum, Jackie, dad Pete and brother Ross (12) and Guinea Pigs Smudge and Rommel.

Holly became unwell at 13 and was referred to the regional Oncology Unit at a large children’s hospital. Holly’s treatment was successful in inducing a remission of her Leukaemia, however she has been left with multiple problems as a consequence of her treatment. These include the fact that she is restricted to life in a wheelchair, has Diabetes, a heart condition and is dependent upon assisted ventilation overnight. This means that Holly is dependent upon 24 hour care and lives a very restricted lifestyle with consequent anxiety and low mood. Despite this Holly demonstrates amazing courage and resilience. Although Holly was told that she has “the mental age of a 12 year old”, she went back to her High School after a 2 ½ year gap. Her attendance was part-time once she had access to a part-time carer at School who was able to meet her health support needs. (Her parents “had to fight” for this, but were only able to gain support to enable Holly to attend on a part-time basis.) Her friends helped her to take notes and she left at 17 having successfully achieved G.C.S.E.S in English Literature, English Language, Maths, Business Studies and Advanced Computing.

Whilst Holly is now somewhat socially isolated when compared with her peers she maintains her own record of current affairs and endeavours to research for herself things that are going on in the outside world using her PC.

Holly understands Transition to mean “moving from one thing to another” however she is unable to identify a Lead Professional who co-ordinated her Transition to adult services, but recognised that several Consultants were involved. She reports that she had no transition meetings other than

1. Health – Holly’s Consultant told her at a clinic appointment that she was moving over to adult services when she was 18 or 19. She went for a visit to a ward at the Adult General Hospital where she met one of her new Consultants and was advised of their new Emergency Admissions Procedure. This left her feeling that she had gone from having Health support and Education support to just having Education support.

2. Education – Holly is unable to recall any discussion – she just left school and then went for a meeting at her local college, but was left feeling very aware that they didn’t want her to go.
3. Social Services – initially Holly had a meeting with an Adult Social Worker, but was told she couldn’t be allocated a Social Worker because her “health needs were too high.”

4. Community Health – meetings involved Diana Nurses, a District Nurse and Agency Staff, but Holly wasn’t involved.

This made Holly feel scared – “I didn’t know what I was losing or gaining – I was Anxious and felt unsafe about my future… I didn’t know anything (other than what is described in the points above) …nothing was written down”.

Holly didn’t feel that she was enabled to make any contribution to the transition planning process “…it went on around me (I said if I didn’t like carers.)”

Holly’s mum helps her to understand what is happening; they discuss things and her mum helps her to express her views, but Holly feels that she still “doesn’t have much choice in anything.” …It just happens …no stopping it …the most important person to help me is my mum ; she explains things correctly so I don’t get too upset. Holly worries about her dependence on her mum who “never sleeps.”

Holly’s experience is that transition was “chaotic”, leaving her feeling that if it wasn’t for her mum she would have “fallen through the crack”, with no-one noticing her. She also feels overwhelmed in group meetings, so whilst she thinks all agencies should be involved she would like to talk to them separately.

“I think there should be a process that is followed for everyone so things have to happen and are not just forgotten.” She also recommends that transition is staggered so that it is not overwhelming, for example education transition at 17; social services at 18; health between 18 and 19 years of age.

There have been numerous outcomes for Holly following her transition to adult services, most significantly she describes feeling “(even more) lonelier now – things have gone and nothing is there in its place.”

Health:

• Holly reports that she has gone from attending 2 hospitals to 6 and from having medical care being provided by a small number of consultants to more than 15 consultants and their support staff. This includes crossing both regional and national boundaries. “I became a tree…I don’t fit into the jig-saw!” Holly was even initially advised that in an Oncology emergency she would have to travel a four or five hour journey to a specialist centre because of this, although a specialist centre with a shorter travelling distance has now been agreed.

• Holly says that consultants find it hard to talk to each other in one hospital so it is even harder across numerous hospitals; it doesn’t happen and mistakes happen as a consequence leaving Holly feeling that it is only her mum who really knows what is going on.

• Whist there is no continuity of care Holly acknowledges that she is receiving more specialist care, from the range of consultants who are now involved, for example Neurology; Cardiology; Orthopaedics; Spinal; Gastrology and Orthoptics. This is a potential benefit.

• Different departments made transition easier or harder; Urology and Oncology were “Good” and Endocrinology was “Goodish.” What made Urology “good” was that the Consultant had clinics in both the children’s and adult hospital and there was a Teenager
Group so Holly did not feel that she was entirely on her own.

- Holly felt that she had “lost” people she was confident in and was expected to trust lots of new people at one time. That scared her as she had to attend lots of hospital appointments all of which carried out new or duplicate tests and scans with no co-ordination.

- “They think I am an adult and I can handle things, but I can’t – I need my parents but red tape means people make it harder” Holly often relies on her mum to explain things she struggles to understand, however this is often not understood by adult service providers, one of whom even reminded Holly and Jackie that they were no longer in the Children’s Hospital when Jackie offered information that was essential to Holly’s safety.

Social Services:

- As a child Holly had a Social Worker and although there were problems she knew who to ring.

- “Now I don’t have anyone, so there is no-one to turn to… it’s down to money again – no-one cares except my family.”

Education:

- Holly “just wanted to go to college.”

- Holly had part-time “Health Support in School, however this wasn’t available in college and she recalls that they “didn’t want me, even though I had the qualifications for the course and there was a spare place.”

- When Jackie offered to come into the local college (which is just a few minutes from her house) to support Holly whilst she was there the college advised that that wouldn’t be necessary. Holly was finally admitted halfway through the year on a part-time basis and on the proviso that Jackie was never more than 5 minutes away and could be called at any time.

- Holly met some very enthusiastic and supportive people in the college but she left as there were still problems. One example she described as “Jug Gate” in which one particular Care Assistant persistently refused to pass Holly the plastic-wrapped jug she needed to empty her urinary catheter. (Holly was unable to reach this from the Ruck Sack on the back of her wheelchair. The justification was that the Care Assistant was from Education and that was a job for Health!

Community and Voluntary Sector:

- Holly regularly attended a Children’s Hospice and has been a “Young Ambassador” for them, however she is no longer able to attend due to her age. This has contributed to Holly’s social isolation.

- The philosophy of family-centred care at the Children’s Hospice is not the same at the Adult Hospice so Holly and her parents feel that transition there would not be appropriate at present.

- There are consequences for Ross too, who is very distressed at having to leave behind his friends in the Siblings Club.
The three most important issues for Holly are
1. *I want people to visually show me what is happening and going to happen; meetings provide too much information so it helps to write things down so I can go back to it later.*
2. *Stagger Transition so it is not overwhelming – I like to deal with one thing at a time*
3. *I now feel lost, isolated and lonely as an adult and I don’t know where to go for help. It’s a lot to do with money and cuts. One day I was a child and people cared, then I was an adult and not important.*

**Jackie’s View**

Jackie feels that other people read reports on Holly and think “Oh my God”, not realising what the family are capable of. Jackie feels there are some “amazing people on the ground”, but even so she and Pete have continually had to fight for everything. Due to exhaustion they have had to learn to choose their battles. They have learned not always to fight for what they know is right, but for the battles they can win and which are in Holly’s best interests. (This is what always must come first.)

Jackie finds Holly’s hospital – based care to be completely un-coordinated since her transition to adult services, with no sharing of information between consultants. This means that on one occasion Holly had to attend appointments in 3 different hospitals in a single day and that she is often subjected to repeated painful investigations because different consultants “like to do their own, even though this may be a waste of precious N.H.S. resources.” The most worrying thing for Jackie is the fact that lack of information-sharing can sometimes put Holly’s safety and well-being at risk, so she feels that it is necessary for her to be constantly vigilant, share information, advocate for Holly and sometimes intervene. This is difficult when adult hospitals do not always have a culture of working in partnership with parents.

Jackie and Pete are concerned that Community Services are very limited – “They can get round reasonable adjustments if they want to.” Any equipment required can no longer be provided without a formal application and consideration of the request at a meeting, leading to delay even when agreement is reached. “We have to fight for everything – even Conti-sheets.” Holly has been refused Direct Payments and Jackie feels that her care needs are compromised by lack of money; lack of knowledge and lack of resources.

Carer support for Holly is now limited due to a split in funding which was previously provided through a combined contribution (50% from Health and 50% from Social Care.) Now that Holly has transitioned to adult services she receives only Health (CHC) funding because Social Services have now withdrawn support and taken away funding with it. The consequence of this is that despite having 24 hour care needs Holly has 2 carers each day between 9 and 11 and 6 “Social Hours” on Saturday, with the possibility of a further 4 “Social Hours” during the week. Holly’s carers were originally co-ordinated by the Children’s Community Nursing Team, however now there is only one District Nurse as a single point of contact. This leads to anxiety because carer support is reliant upon agency staff and Jackie and Pete can never be completely certain whether they will be there or not.

A range of services have been withdrawn from Social Care. One day a Social Worker called to tell them that they no longer had a Social Worker as they did not meet the Eligibility Criteria. This was not the only service which was taken away as a consequence of Holly’s transition to adult services; she no longer has access to an Occupational Therapist, although she does have access to a Counsellor once a month.
The most worrying thing for Jackie is Holly’s social isolation, as she is dependent upon her parents for 24 hours a day. Jackie worries that this is not appropriate for a 23 year old young woman. Whilst Holly still talks to some of her school friends over the internet occasionally, their lives have now diverged. Holly was initially reluctant to go to the Children’s Hospice, however this has been the biggest loss for Holly now that she is considered too old to go as she has lost many of the friends she had made there.

Jackie and Pete feel that their lives have totally changed and are now “up in the air.” They worry about more vulnerable families who could go through a similar experience. Transition for them has been totally un-coordinated – Jackie explains that no-one gives you a book explaining this is how it is going to happen and there are no Pathways in place which integrate Education, Health and Social Care Transition Plans.
Sarah’s Story

Sarah is a 16 year old young woman who lives with her mum Rose and her younger sister Emma. Sarah has Epilepsy and she has been under the care of a local tertiary children’s hospital. Sarah has been on regular medication to control her Epilepsy and was seen by her Consultant Neurologist and the Epilepsy Nurse Specialist in clinic twice a year. After an Electroencephalogram was carried out last summer Sarah and Rose were informed by the consultant that her Epilepsy had gone and she could begin a plan to slowly reduce then stop her medication over a period of time during the school holidays. A letter was received by Rose and she and Sarah followed the advice provided.

Unfortunately after three weeks of stopping the medication Sarah’s seizures came back with a vengeance and neither Rose nor Sarah knew what to do. Rose rang the Neurologist’s secretary for some advice, requesting that Sarah was seen and for some medication and a plan to be provided. Sarah and Rose were both understandably very worried at the sudden return of the seizures with no medication or plan to guide them. As Sarah was 16 her Neurologist stated that he could not see her and advised that she seek advice from her G.P. Sarah saw her G.P (who was under the impression that care was to be provided by the tertiary centre until Sarah was 18) and he referred her to the local specialist adult Neurological centre. For four weeks until services were accessed via her G.P. there was “no support, no medication, and no explanation” for Sarah and Rose.

When Sarah and Rose arrived here for the appointment no information had been received regarding her medical history or transition from her previous care provider, however they were seen and advised that Sarah should have transferred over to the specialist Neurological centre via the Young Person’s Clinic. Sarah was also seen subsequently by an Epilepsy Nurse Specialist who provided advice, information leaflets and support and explained about different types of appropriate choices of medication for young people with Epilepsy through adolescence and adulthood.

During this time Sarah was also being treated for excessive vaginal bleeding and lower abdominal pain and she was seen by Karen, a Nurse Consultant at the tertiary centre. Karen intervened regarding the lack of information regarding Sarah’s Epilepsy at the specialist Neurological centre, ensuring that all of Sarah’s past medical history and appropriate letters were transferred there. Sarah is currently in the process of being transitioned across to services at the specialist Gynaecological centre for the long term management of this problem with the support of Karen from the children’s tertiary centre.
With regard to “Transition” Sarah did not understand this term until she met Karen. For four weeks until services were accessed via her G.P. there was “no support, no medication, and no explanation” for Sarah and Rose from the tertiary centre. This was not fully discussed by the Epilepsy team who had initially mentioned about “transitioning” her care from children’s services to adult services in view of her age when she became 16. At this time Sarah was not aware of what this word meant and she was concerned because she had had a good rapport with her consultant. However he left and another consultant took over her care and several appointments were cancelled by the hospital. When Rose queried why they hadn’t received any further appointments she was informed that she “did not attend” for her appointments and both Sarah and Rose were upset because they felt that they had been blamed for a situation which was not their fault. This made them both anxious and uncomfortable when attending future appointments. Sarah described that she felt as though she had been “pushed to one side” in relation to the management of her primary condition (Epilepsy).

Sarah and Rose had not had any experience or discussion with regard to the “Transition” of services or of a “Transition Plan”. Consequently this period of time was very worrying for both Sarah and Rose. However in the course of attending clinic for her Gynaecological problem Sarah has been able to commence the “Transition” process now and she feels that she has been fully involved with all aspects of this process, including the decision making and choice of services. Sarah feels that with regard to this particular health issue the Nurse Consultant, Karen, and her mum, Rose are the most appropriate people to be involved in the “Transition” of her care to adult services. At the moment the plans are going a step at a time and Sarah feels comfortable with this and everything has been explained fully to her and Rose. Sarah and Rose feel much more secure now that they understand the process and now that the epilepsy care has been “Transitioned” also they feel much happier with regard to this.

Rose’s View

With regard to the experience of initial limited transition planning at the tertiary centre and the ineffective “transition” of Sarah’s Epilepsy care, Rose’s feelings are very similar to Sarah’s; that they felt abandoned and that no one was willing to help despite her being under their services for many years. Rose also felt very responsible as this was her young daughter having several seizures a day and she was unable to control them. This was understandably a very worrying and negative time.

However Rose is much happier now that Sarah is being seen at the specialist Neurological centre and they have confidence in this service’s ability to manage her Epilepsy.

As no “Transition” planning initially occurred there was no involvement, choice or participation in the process and this caused worry and frustration for both Rose and Sarah. As Karen, is now leading the “Transition” of Sarah’s care to the specialist Gynaecological Centre Rose feels much more involved and confident about the future care that Sarah will receive. This is thanks to the input from Karen who is currently supporting this process.
Real People, Real Lives

Sarah and Rose's Final Comments and messages for Professionals

Both Sarah and Rose now feel that they have experienced poor and very good transition of services and they are keen to take part in our pilot study in order to highlight some of the experiences that they have shared so that they can support other families in the future. They have suggested that where possible future “Transition” would be good if information could be provided at home with a person who has been involved in their care and they know they can trust.

In addition to this there are some further concerns from Sarah and Rose with regard to her medication for her Epilepsy and the associated gynaecological problems that she has also encountered. These have now been discussed and the appropriate support has been provided. They both would like other young people to be able to access advice earlier regarding appropriate medication for young girls of childbearing age. Sarah has undergone many investigations due to prolonged anaemia and they are relieved that this is also now being addressed.

1. Please consider how people are feeling if they are discharged without care being transferred appropriately; they can feel abandoned and alone.
2. Don’t treat a child like a number - if someone has suddenly had a 16th birthday they still need care to be provided particularly in serious situations and should not be turned away due to an age-defining number.
3. An opportunity should have been provided for mum and Sarah to know what to do if her Epilepsy came back instead of them having to repeatedly approach services who were not willing to see her.

The Nurse Consultant’s Perspective

In this case the Lead Professional is the Nurse Consultant, Karen who met Sarah and Rose at a routine Gynaecology clinic appointment at the local tertiary hospital. In view of Sarah's age Karen recognised the need to “Transition” her care over to her adult colleagues. Within this service the nurse consultant Karen is considered as the Lead Professional and the most appropriate person (despite knowing them for a short time.) Sarah and Rose also recognise this.

Karen is in the process of compiling the plan with Sarah and Rose. A “Health Passport” to support Sarah’s “Transition” will probably be started in order to include important information for the new service and for Sarah and Rose to refer to. As the Nurse Consultant is aware of the recent failures with regard to Sarah’s Epilepsy she is keen to ensure that this family are provided with the correct information whilst services are transferred to adult care.

Regarding the use of a pathway to support a “Transition Plan” Karen is aware of national guidance and utilises the “Southampton” model developed six years ago. This incorporates awareness of need, readiness for change, discussing appropriate conversations, issues regarding education and employment. Also included is the correct advice to provide employers with the information that they need and to maintain privacy and manage information that does not need to be disclosed. Conversations with Karen were led by Sarah and Rose in order to
make sure that they were listened to and involved in the decision making process. Sarah had already been transferred to the appropriate local services for her Neurological problem and she is in the process of transitioning to the specialist centre for her Gynaecological care under the guidance of Karen.

As a Lead Professional there are some of the key documents that Karen currently uses to support the development of “Transition plans.”

- From the Pond into the Sea (Care Quality Commission, 2014)
- Transition to adult care: Ready, Steady, Go! (University Hospital of Southampton, 2015)
- Strategic Clinical Networks and Senate Yorkshire and the Humber Children’s and Maternity (2014) Transition Key Themes & Principles

These documents are instrumental in advising and guiding professionals to support families during the “Transition Process.” Karen describes the guiding principles for supporting a successful transition as “working collaboratively, being open and honest, having the patient at the centre and as we all work in one NHS this can be achieved.” When asked about the challenges she faced in implementing “Transition Plans” she described some of the difficulties she experienced regarding to trying to understand politics, policy and lack of understanding about sharing information.

“Letters are sent regarding the child/family and they are not involved at all. People need to understand the legality of sharing patient information.”

Karen recognises successes within Sarah’s transition experience. She was instrumental in putting Sarah and Rose in touch with the right people, who have the right information with regard to her Epilepsy and that this has worked well for them. However whilst considering what could be improved Karen feels that she needs a better overview and greater understanding of services for young people at the local specialist Gynaecological centre. It has been suggested that a Deposit Box could be used in clinic in order for people to have the opportunity to make suggestions and provide ideas of how services can be improved. Karen also strongly emphasises that

“Transition is everyone’s business and even if you come into contact with a young person who is outside of your field of speciality we all have a responsibility to ensure that people have access to the right information from the right people. We can find this out by asking our colleagues”.

Karen’s advice to other practitioners who may be supporting families is

“Utilise policies, pathways and the opportunity to discuss concerns with young people and their families and make the time to do it well”.

Within the local tertiary children’s hospital at the present time a group of people led by the “Transition co-ordinator” are working with lead practitioners and services from inside and outside of the organisation to develop support systems and training for those professionals who will take on the role of Lead Professional within the context of “Transition”.
Analysis, Discussion and Emerging Themes

The Case Studies have been subjected to a thematic analysis in light of the key recommendations listed in the Care Quality Commission Report “From the Pond to the Sea” (2014.) The Criteria which set out what are considered to be “elements of good practice” in the report are:

1. There should be good planning for transition
2. There should be a good transition plan in place
3. Health passports should be used more widely
4. There should be a lead professional to support young people and their families through transition
5. Health care settings and services should be responsive to the needs of young people and their families when transferring to adult services
6. The needs of parents as carers should be assessed and addressed
7. Responsibility for funding should be agreed early in the process

In addition to these elements of good practice the Standards set out by the Royal College of Nursing Report “Lost in Transition” (2013) were also applied. These include standards already set alongside recommended standards. They relate to three key areas; Service Provision, Process and Protocols and the Key Worker’s Roles in Transition.

Standards Relating to Service Provision:
- young people’s needs are paramount
- transitional points are set as recommended in the English and Welsh National Service Frameworks
- some flexibility is built in to meet individual needs
- young people can access children and young people’s specialist and mental health services, whatever their educational status
- where children and young people are admitted to adult inpatient areas, full consideration is given to child protection issues
- all services use means of access and venues which suit young people, in tertiary, secondary and primary care settings.

Standards Relating to Process and Protocol Standards:
- There should be a shared protocol between children’s and adults’ services, which is a genuinely shared arrangement, and is properly implemented.
- A transition should appear as seamless as possible to the young person.
- If possible, the young person should have the opportunity to visit the clinic in advance or meet the team who will take on their care.
- They should be given time and support to adjust to the transition, and the opportunity to say goodbye to staff
and friends connected to the children’s service before they leave.

- staff are designated within specialities to handle transitions. Such positions must be reallocated when the staff member leaves
- receiving team or staff member is identified in adult services to welcome and support young people entering their care to ensure effective and seamless transition, each health care area has agreed, accessible and known transitional care arrangements
- the timing and duration of transition is negotiated with the young person and agreed by all relevant parties
- care is handed over in a planned and collaborative way, through meetings between at least one key professional from both services and the young person (and their parents/carers if appropriate)
- services should consider the possibility of adopting a mentoring scheme where a young person who has already undergone the transition may be able to offer help and support to other new arrivals
- a comprehensive written summary of the CAMHS notes is available to the receiving service, with appropriate consent for the receiving service to help provide an overview of past mental health issues

Standards Relating to Key Worker’s Roles in Transition:

- services should designate a key worker or lead professional to work with a young person, their family and relevant services to plan the transition.
- making transition a significant part of a professional’s job description will ensure that the transition phase is not overlooked.
- transition roles are built into job plans, with role descriptions and selection processes
- all professionals and voluntary organisations are aware of each other’s role in transition and the services offered
- staff in both services are aware of the anxiety that the transition may create for young people and parents, and that sometimes young people’s mental health may suffer as a result
- parents or carers will have varying degrees of contact with, and responsibility for, the young person. It is important for key workers to understand this level of contact and also to agree appropriate communication channels in collaboration with the parents/carers and the young person. These discussions must include issues of confidentiality
- the young person understands how and when therapeutic contact will come to an end in one service, and agrees this with transition key workers.

A third reference point was Getting it Right for Children and Young People; overcoming cultural barriers in the NHS so as to meet their needs - A review by Professor Sir Ian Kennedy (September 2010) which highlights that

- Currently, there is a division of funding between services for adults and those for young people. While it may be bureaucratically convenient to draw a clear line between the two streams of funding, it makes no sense at all to the young person. Future arrangements must ensure that there is a greater flexibility, allowing for greater continuity of care even into early adulthood.
- Funding for the health and healthcare of children and young people and for ‘transition’ to adulthood must be identified, separated from the funding dedicated to the care of adults, and transferred to the responsible government department for further distribution to organisations at local level.
- The commissioning of all services, including those of the NHS, called for by the Local Partnership’s agenda and plan must be carried out in such a way as to ensure that the services
are complementary and efficiently delivered.

- Those commissioning health services for children and young people should use their influence through commissioning, contracting and funding to require providers to design services around the needs of children or young people, establish a single portal of access, ensure that care is delivered in line with the normal pathway of care, and require the collection, analysis and dissemination of information.

- Arrangements must be agreed, regarding funding and other matters, to address the changing needs of children and young people as they mature, including greater continuity of care into adulthood. Ensuring a smooth transition between children's and adults' services should be a priority for local commissioners.

Finally recent *Special Educational Needs (SEN) and Disabilities* reforms through the Children and Families Act 2014 place new legal duties on Local Authorities to revise the way support is provided for children and young people with special educational needs and disabilities. Edward Timpson MP (*Parliamentary Under Secretary of State for Children and Families*) wrote to Lead Members, Chief Executives and Directors of Children's Services in November 2014 to highlight the aim to enable every child and young person with SEN or a disability to develop their potential and live happy and fulfilled lives. The Act places the views, wishes and aspirations of children, parents and young people at the heart of the system and requires a culture change in the ways in which professionals work with families and with each other. Whilst the challenges are not underestimated it is recognised that many Local Authorities have made a good start in implementing the new duties and involving parents and key partners in local decision-making. This will be essential to achieve the effective introduction of integrated *Education, Health and Care Plans* by the required target date of 2018. Whilst it would be unfair to highlight the fact that integrated Education, Health and Care Plans have not yet been implemented universally, the spirit of this requirement has informed the author's thinking when analysing findings from the Case Studies.

The six Case Studies demonstrate that is not possible to conclude that the above standards are being universally met across Cheshire and Merseyside. Whilst there are some examples of good practice, for example established Transition Practitioners and Case Work Teams who are able to develop Transition Plans with parents and young people and co-ordinate financial arrangements and services to make the plans a reality these are by no means universally accessible. Several of the Case Studies indicate that families are unable to identify Lead Professionals or Key Workers who co-ordinated the young person's transition to adult services.

Four of the six Case Studies suggested transition planning which was either non-existent or inadequately followed through, or was commenced too late. None of the families or professionals interviewed mentioned the use of Health Passports and written plans were not in place for the majority of the young people who had already experienced transition to adult services.

Two of the case studies (Kyle and Kelly) illustrated how settings and services were able to be responsive to the needs of young people and their families when Transition Practitioners and Case Workers were able to assess and communicate the young person’s needs. Whilst commissioning challenges remain, these case studies illustrate that when responsibility for funding is agreed early in the process it is possible to effectively provide services which comprehensively meet the needs of young people, parents and carers. This is dependent upon co-ordinated planning which brings services across sectors together, and involves children's and adult services working together. *Established Transition Practitioners* or teams with clearly defined roles in supporting young people’s transition to adult services have,
however, been effective in overcoming barriers and finding solutions when it initially appears no appropriate services are available. Where practitioners with specialist roles in supporting transition are not available young people and families may fall through gaps in service provision or divided funding and commissioning arrangements (as illustrated in the cases of Holly, Sarah, Ben and Emily.)

Four of the Case Studies also illustrate that many cultural barriers remain within Health, Social Care and Education services which mean that they are still not consistently “Getting it Right” for either young people or parents when supporting transition to adult services in Cheshire and Merseyside. Examples of shortcomings include failing to recognise the level of anxiety raised for young people and parents and the longer term impact of poor transition experiences and unresponsive services; failing to recognise that young people may not be ready to act as adults in their new settings and may still need to their parents to advocate on their behalf; failing to provide services which focus on the needs of young service users and their families rather than the needs of the service providers; failing to provide services which respond to the unique needs of young people who have Long Term Conditions and Disabilities. Kelly and Kyle’s Case Studies illustrate, however, that “Getting it Right” is possible even where young people have complex needs, disabilities and mental health difficulties, but that this requires creative, individualised solutions and a willingness to overcome traditional barriers or relinquish traditional ways of working.
Emerging Themes

1. Understanding Transition

The Case Studies demonstrate that parents have a good understanding of what Transition means, and have endeavoured to explain this to their children. One parent, however commented

“How can young people with learning disabilities be expected to negotiate transition when they don’t even know what that means?”

Some parents and carers were aware of policy guidance and expectations, for example the recommendation that planning should start during the early teenage years. This is not necessarily what they have experienced themselves. 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.

2. Variable Transition Plans and Experiences

Two of the case studies (Kelly and Kyle) illustrate that transition can work well when planning starts in a timely manner, is informed by policy guidelines and sector standards, is clearly and appropriately 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 in regular planning meetings and a willingness to challenge traditional ways of thinking about, commissioning and delivering services. The majority of families interviewed, however, were unable to identify a lead professional who took on this role.

Ideally Transition Teams will include representatives from children’s and adult health and social care services; schools and colleges; finance advisors and commissioners and representatives from advocacy groups and the community and voluntary sector. Kyle’s Case Study in particular illustrates the positive outcomes which may result from integrated Education, Health and Care planning. This is in stark contrast to the experiences of Ben, Emily and Sarah. Some of the families and practitioners also highlighted variability in the complexity of cases and consequent complexity of transition planning.

3. Still “Lost in Transition”

Several of the case studies indicate that Transition Plans for some young people are “in the ether” rather than documented and may sometimes be confused with Care Plans – in one case (Emily) a parent had to devise and type her own in an attempt to ensure that her child’s needs were appropriately assessed. This can lead to fear and anxiety in both young people and parents as also illustrated in Holly’s case.

At worst it may lead to detrimental outcomes as a result of poor communication and discontinuity in management, as in Sarah’s case, which illustrates how one young person can have two very different transition experiences even when receiving care under two consultants within the same hospital.

Kelly’s case illustrates how within the same family one young person may have a well-supported and co-ordinated transition experience whilst their sibling may be “left hanging.”

4. Involvement in Decision-Making

Kyle’s case indicates that 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 dependant, however, on the attitudes, values, knowledge and skills of individual practitioners, or alternatively the young person having an informed parent or professional available who can mediate or advocate on their behalf. Other Case Studies (Emily, Ben and Holly) illustrate how young people may be completely or partially excluded from decision-making. This may be either because practitioners and professionals are not skilled or confident in communicating with young people who have learning disabilities and
speech and language difficulties, or because their traditional ways of practicing means that they overlook the need to work in partnership with young service users even when language and communication is not a barrier.

Some practitioners may fail to consult with parents too, or fail to continue to involve families once initial assessment has been carried out, as illustrated in the case of Emily, whose mum raised concerns that once funding assessments had been carried out these may not always be shared with parents before they are submitted to approval panels. Rita (Kelly’s Gran) also reported discontinuity in the allocation of Social Workers had led to incomplete assessment of needs.

Some of the parents interviewed highlighted that choices regarding future services were variable (for example no choices regarding the accessibility of respite, but some choice regarding attendance at youth clubs and young people’s groups.)

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

Different models of service delivery between children’s and adult services may impact on the availability of appropriate services, for example CAMHS services may be based on a children / young person – centred developmental model, but Adult Mental Health services based on a medical, diagnostic or therapeutic models (as indicated by the professional involved in supporting Kelly’s transition to adult mental health services.)

Integrated Commissioning appears to work in some cases up until 18, but then becomes fragmented once young people enter the adult sector. Holly and Kyle’s cases, for example illustrate how some essential services may be cut following transition to adult services. Holly’s case in particular illustrates how care became fragmented as commissioners and service providers worked in isolation, or one when one agency decides to withdraw services and funding. A further barrier to continuity of service provision may be geographical or local authority boundaries. One parent commented that

“Budget holders have freely admitted they are saving money by cutting resources wherever they can, but austerity doesn’t help when you are sick or in danger.”

The majority of the families interviewed reported that they experienced a completely different approach when they had moved to adult services, which were no longer arranged to centre on the needs of the child or young person. In the worst cases services cited did not encompass a philosophy of listening and responding to young people and failed to acknowledge the need to work in partnership with parents. Younger siblings can have their support withdrawn when the older sibling moves to adult services. These concerns are particularly illustrated by the experiences of Holly and her family.

6. Training Needs

The Transition Team Manager involved in co-ordinating Kyle’s transition to adult services acknowledged that practitioners in adult services may have training and support needs if they are to understand the transition needs of young people and families and to confidently and competently provide effective services young people. This is understandable when many adult service providers will have a case load of predominantly older people, however their training needs must be met if they are to be able to effectively provide an equitable level of service to young service users. The Transition Practitioner involved in supporting Kelly highlighted some good practice in developing and delivering multi-agency training focussing on awareness- raising; underpinning values; expectations and minimum standards in supporting young people’s transition to adult services and complex case management.

Kyle’s mum also highlighted the need for less well informed parents to receive training on understanding transition (something she provides through her parent support group.)
7. Fearful young people and "battle weary" parents and carers

All of the families interviewed indicated that often the transition experiences may be chaotic or overwhelming, resulting in fear, confusion or distress for the young person involved. Many of the parents felt that they had had to "fight" to ensure that their child received the best possible services, even when they knew they were unlikely to win some battles. They feared that if they didn't fight the result would be unsafe or compromised services for their child once they had moved over to adult services. For some parents who are already exhausted by struggling to meet their child’s care needs, the battle is continuous. Parents of two of the young people used the term “nightmare” to describe their experiences.

Parents valued or desired 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.

Parents perceptions of the effectiveness of Transition Plans vary from non-existence to resulting in improved outcomes. Others say that life has changed since the transition; becoming a “nightmare” involving constantly chasing things that are not in place and feeling “abandoned.” Some parents and young people feel they have “fallen through a crack” and it is easier for busy, stressed professionals to let that happen, particularly in community settings. Holly’s mum, for example perceives practitioners on the ground 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. This perception is mirrored by several of the other parents interviewed. At worst parents report that adult-focussed practitioners may not understand the importance of sharing information with parents, or listening to and involving them, even in emergency situations – this can lead to dangerous scenarios which compromise the safety of young people or leads to detrimental clinical decisions being made. (This was a concern for both Holly and Sarah’s parents.)

One example of an unintended consequence is Holly’s 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. The Impact of Transition to adult services

The Case Studies illustrate that when transition is well planned and coordinated it can lead to positive outcomes for the young person, however this may be dependent on the severity of the young person’s condition and confidence of their family. Some parents feel they have to choose their battles and let some poor practice or service provision go, and there appears to be a resigned acceptance that some families will receive a diminished or reduced level of service once under adult care.

Parents perceptions of the effectiveness of Transition Plans vary from non-existence to resulting in improved outcomes. Others say that life has changed since the transition; becoming a “nightmare” involving constantly chasing things that are not in place and feeling “abandoned.” Some parents and young people feel they have “fallen through a crack” and it is easier for busy, stressed professionals to let that happen, particularly in community settings. Holly’s mum, for example perceives practitioners on the ground 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. This perception is mirrored by several of the other parents interviewed. At worst parents report that adult-focussed practitioners may not understand the importance of sharing information with parents, or listening to and involving them, even in emergency situations – this can lead to dangerous scenarios which compromise the safety of young people or leads to detrimental clinical decisions being made. (This was a concern for both Holly and Sarah’s parents.)

One example of an unintended consequence is Holly’s 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.

9. Loss of Services

Several of the families indicated that they had lost services they had had previously as a result of the Transition to Adult Services. These included

- Loss of a key contact to call if you are worried or need help in an emergency
- Loss of an trusted consultant or practitioner who co-ordinates and oversees care
- Loss of continuity (in medical management and clinical decision-making)
- Loss of Physiotherapy
- Loss of Hydrotherapy
- Loss of specialist equipment (for example Hoists needed in Education settings)
- Loss of Social Care funding and Social Work services
- Loss of individualised Education support
- Loss of social support leading to isolation
- Loss of Respite services
- Loss of support for siblings and parents or carers
There were also some gains acknowledged, for example, Holly now has access to a Counsellor which she didn’t have previously and Kelly now has a Mental Health Practitioner who is supporting her to get back to college, whilst Mary has been able to gain support from excellent Care Assistants due to Emily’s Direct Personal Payments.

10. Key Messages from Families

What is most important?

• The most important person is the young person and 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; an identified coordinator (Key Worker or Lead Professional) should manage the Transition process and facilitate integrated commissioning and services.
• 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 person’s perspective include having to get to know new people; 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 what you will be losing or gaining; anxious and unsafe about your future; having limited or little choice.
• Concerns from a parent / carer perspective include recognition that transition planning should start earlier (before 18.)

Communication, planning and process

• Practitioners could improve communication and understand systems and processes better – visual materials and developed Transition Plans and Pathways would help to explain things. Transition Plans should be in place for everyone so no-one gets lost, particularly the more vulnerable families who may not have the confidence to fight for services.
• Keep parents informed of outcomes of assessments; development of plans, what is happening and when actions have actually been completed.
• Improve communication with other professionals, the involving young person, parent and carers; 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!

Services and Support

• Involvement of Advocacy services would be helpful, particularly to support involvement of young people with severe learning disabilities.
• Improved training is needed for families to help them understand transition and related processes; Parents Forums (local and national) 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
• Training should be available for parents to help them understand the transition process and enable them to actively participate in decision-making.
Conclusions

1. Transition services across Cheshire and Merseyside include some areas of good or developing practice as well as some examples of inadequate transition 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.

4. The Clinical Strategic Network is in a privileged position to make some transformational changes to benefit young people, parents and carers – to achieve this they may need to be courageous in rethinking delivery models and the relationship between services designed to meet the needs of children and adults. This is likely to involve working in partnership with other Clinical Strategic Networks and Clinical Commissioning Groups.

5. There are some good examples of effective practice, but transition planning often starts late and may be vague and fragmented, have gaps or fail to adequately involve young people parents and carers in decisions.

6. Transition outcomes for young people and families can be positive, however the researchers found several examples of diminished service provision to the detriment of service users.

7. Where transition planning has worked well this has been because there has been a dedicated Key Worker, named Lead Professional or Transition Team who have developed expertise; are able to coordinate regular meetings and bring together multi-disciplinary/ multi-agency teams; effectively involve service providers and users and develop creative solutions to overcome barriers in order to meet the individual needs of young people and their families.

8. The planning process needs an approach which bridges divisions between children’s and adult services; health, social care and education; hospital and community settings; geographical boundaries - service provision needs to develop to match this approach.

9. Training, resources, and pathways need to be developed for both practitioners and families involved in developing and implementing Transition Plans.

10. New models of care provision and new ways of working will be essential to success; new technologies could contribute to solutions.
Recommendations

In view of the above findings and conclusions drawn from the six Case Studies in light of the best practice guidance available the authors make the following recommendations for careful consideration by the project commissioners:

1. 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 when planning and implementing the transition of young people with long term conditions and disabilities from children’s to adult services.

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. Specialist Transition Practitioners will need to have knowledge and skills which will enable them to work across different settings and professional and geographical boundaries, manage complex cases and support families by overcoming barriers to successful transitions. 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 to ensure
   - that the service-user experience is enhanced rather than compromised
   - service provision centres on the needs of the young person and family rather than the needs of services and current models of provision, drawing on effective models of provision which are established in children’s services.
   - Service design is informed by current published sector standards and guidance, established models of best practice and is consistent with recent Special Educational Needs and Disability (SEND) reforms.
   - Transition Plans integrate Education, Health and Social Care planning

4. Establish a Young Person and Family Reference Group to enable service development and re-design which is 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 guidance, protocols, *Transition Plans* and Pathways which ensure a standard level of timely, integrated and seamless service provision, but which could be adapted or differentiated to meet the personalised needs of individuals or shared needs of specific groups of young people (for example those who have specific long term conditions who are transitioning to the care of an adult hospital; young people with mental health difficulties; young people who have special educational needs and complex disabilities.)

7. Explore how local good practice can be built upon to meet the *Training, Communication, Information and Continuing Professional Development* needs of
   a) Parents and carers
   b) Lead professionals involved in planning and co-ordinating transition
   c) Professionals and practitioners in adult services who may not have the understanding, confidence or competence needed to provide effective and responsive services to young people and their families
   d) Education providers who may not have the full understanding of the support needs of young people with long term conditions, disabilities or mental health difficulties.

8. Consider how new technologies, for example Social Media, Web-based resources and Electronic Transition Plans 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.)
References


Care Quality Commission (2014) *From the Pond into the Sea: Children’s Transition to adult health services* Care Quality Commission (Online) Available from: [http://www.cqc.org.uk](http://www.cqc.org.uk) [Accessed 35/03/2015]


Kennedy, Ian (2010) *Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs*, London, Department of Health


Strategic Clinical Networks and Senate Yorkshire and the Humber Children’s and Maternity (2014) *Transition Key Themes & Principles*

University Hospital Southampton NHS Foundation Trust Transition to adult care: Ready, Steady, Go University Hospital Southampton NHS Foundation Trust (Online) Available at: http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx [Accessed 06.12.2015]

Title of Project
Pilot Evaluation of the Experiences of Young People, Carers and Lead Professionals involved in Transition from Children’s to Adult Health and Care Services

Name of Researchers
Nick Medforth and Elaine Huntingdon
School of Nursing and Allied Health
Faculty of Education, Health and Community

You are being invited to take part in a small research study. Before you decide it is important that you understand why the research is being done and what it involves. Please read this information and take time to decide if you want to take part or not. Please ask us if there is anything that is not clear or if you would like more information.

1. **Why do we want to do the study?**

We have been asked to do the study by a group of people whose job it is to make sure that young people like you get the health and care services they need. They are interested in improving the experience of young people who are moving from children’s services they have known for a long time to new services designed to meet the needs of adults. They are looking at how Transition (which means moving to adult services) can be planned and done better.

We need to understand the experiences of local young people and families and their key workers. This will help us to learn more about what it was like for you. We are interested in your ideas about how services could be improved to make the transition process the best possible experience for young people.

2. **Do I have to take part?**

It is entirely up to you whether you decide to take part. If you do you will be given this information sheet and asked to sign a consent form. You are still free to change your mind at any time. You do not have to give a reason. Changing your mind will not affect your rights or the treatment or services you receive.

3. **How long will it take and what will I have to do?**

A researcher from Liverpool John Moores University will get in touch. The researchers are also children’s nurses with a lot of experience of working with children, young people and their families like you. They will ask you if you have any more questions about the research and whether or not you want to be involved.
You can choose how you would like to take part. This could be either
• through a face to face interview at a health service or public place near to you
• or at your home with your parent / carer or another adult of your choice present
• or by an interview over the telephone.

Depending on how much you would like to tell us interviews will take between 30 minutes and an hour.

If you decide to take part they will ask you to complete a consent form. If the researchers are meeting you face to face you will be asked to sign it. If we are interviewing you over the phone you will be asked to say that you are happy to continue with the interview.

Please note that what you tell us during the interview may be recorded so that we can make sure we do not miss any of the important things you tell us.

4. Are there any risks / benefits involved?

Taking part should not mean any risks for you. We hope that you will enjoy taking part. We hope that you will feel that by sharing your experiences you will have had an opportunity to help to make services better for young people and their families in the future.

5. Will my taking part in the study be kept confidential?

What you tell us during the interview will be confidential and only for the purpose of this study. We will only keep an electronic record of your contact details until the study has been finished.

The main things you tell us will be put into a final report for the Cheshire and Merseyside Strategic Clinical Network Long Term Conditions Services Special Interest Group. This will be discussed at one of their meetings looking at how services can be improved in the future.

Your name will be changed in the report. We will take care to make sure that we take out any information such as where you live or the names of services you attend so people reading the report can’t guess who you might be.

The only time we would share specific information with services would be if you said something which made us concerned that you might be at risk of harm or might need more support. We would always discuss this with you first.

This study has received ethical approval from LJMU’s Research Ethics Committee

Reference 15/EHC/010 (20th January 2015)
Contact Details of Researcher
Nick Medforth, RGN/RSCN, BA (Hons) PGCert, MSc, MBPS
Henry Cotton Building, Liverpool John Moores University,
15-21 Webster Street, Liverpool L2 2ER

0151 231 4321
n.medforth@ljmu.ac.uk

If you any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate.

A copy of this participant information sheet is for you to keep.
Title of Project
Pilot Evaluation of the Experiences of Young People, Carers and Lead Professionals involved in Transition from Children’s to Adult Health and Care Services

Name of Researchers
Nick Medforth and Elaine Huntingdon
School of Nursing and Allied Health
Faculty of Education, Health and Community

You are being invited to take part in a small research study. Before you decide it is important that you understand why the research is being done and what it involves. Please read this information and take time to decide if you want to take part or not. Please ask us if there is anything that is not clear or if you would like more information.

1. Why do we want to do the study?

We have been asked to do the study by a group of people whose job it is to make sure that young people like you get the health and care services they need. They are interested in improving the experience of young people who are moving from children’s services they have known for a long time to new services designed to meet the needs of adults. They are looking at how Transition (which means moving to adult services) can be planned and done better.

We need to understand the experiences of local young people and their families and their key workers. This will help us to learn more about what it was like for you as a parent or carer. We are interested in your ideas about how services could be improved to make the transition process the best possible experience for young people and their families.

2. Do I have to take part?

It is entirely up to you whether you decide to take part. If you do you will be given this information sheet and asked to sign a consent form. You are still free to change your mind at any time. You do not have to give a reason. Changing your mind will not affect your rights or the treatment or services you receive.

3. How long will it take and what will I have to do?

A researcher from Liverpool John Moores University will get in touch. The researchers are also children’s nurses with a lot of experience of working with children, young people and their families like you. They will ask you if you have any more questions about the research and whether or not you want to be involved.
You can choose how you would like to take part. This could be either
• through a face to face interview at a health service or public place near to you
• or at your home with your parent / carer or another adult of your choice present
• or by an interview over the telephone.

Depending on how much you would like to tell us interviews will take between 30 minutes and an hour.

If you decide to take part they will ask you to complete a consent form. If the researchers are meeting you face to face you will be asked to sign it. If we are interviewing you over the phone you will be asked to say that you are happy to continue with the interview.

Please note that what you tell us during the interview may be recorded so that we can make sure we do not miss any of the important things you tell us.

4. Are there any risks / benefits involved?

Taking part should not mean any risks for you. We hope that you will enjoy taking part. We hope that you will feel that by sharing your experiences you will have had an opportunity to help to make services better for young people and their families in the future.

5. Will my taking part in the study be kept confidential?

What you tell us during the interview will be confidential and only for the purpose of this study. We will only keep an electronic record of your contact details until the study has been finished.

The main things you tell us will be put into a final report for the Cheshire and Merseyside Strategic Clinical Network Long Term Conditions Services Special Interest Group. This will be discussed at one of their meetings looking at how services can be improved in the future.

Your name will be changed in the report. We will take care to make sure that we take out any information such as where you live or the names of services you attend so people reading the report can't guess who you might be.

The only time we would share specific information with services would be if you said something which made us concerned that you might be at risk of harm or might need more support. We would always discuss this with you first.

This study has received ethical approval from LJMU’s Research Ethics Committee

Reference 15/EHC/010 (20th January 2015)
Contact Details of Researcher
Nick Medforth, RGN/RSCN, BA (Hons) PGCert, MSc, MBPS
Henry Cotton Building, Liverpool John Moores University,
15-21 Webster Street, Liverpool L2 2ER
0151 231 4321
n.medforth@ljmu.ac.uk

If you any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate.

A copy of this participant information sheet is for you to keep.
Title of Project
Pilot Evaluation of the Experiences of Young People, Carers and Lead Professionals involved in Transition from Children's to Adult Health and Care Services

Name of Researchers
Nick Medforth and Elaine Huntingdon
School of Nursing and Allied Health
Faculty of Education, Health and Community

You are being invited to take part in a small research study. Before you decide it is important that you understand why the research is being done and what it involves. Please read this information and take time to decide if you want to take part or not. Please ask us if there is anything that is not clear or if you would like more information.

1. Why do we want to do the study?

We have been asked to do the study by a group of people whose job it is to make sure that young people like you get the health and care services they need. They are interested in improving the experience of young people who are moving from children's services they have known for a long time to new services designed to meet the needs of adults. They are looking at how Transition (which means moving to adult services) can be planned and done better.

We need to understand the experiences of local young people and families and their key workers. This will help us to learn more about what it was like for you. We are interested in your ideas about how services could be improved to make the transition process the best possible experience for young people.

2. Do I have to take part?

It is entirely up to you whether you decide to take part. If you do you will be given this information sheet and asked to sign a consent form. You are still free to change your mind at any time. You do not have to give a reason. Changing your mind will not affect your rights or the treatment or services you receive.

3. How long will it take and what will I have to do?

A researcher from Liverpool John Moores University will get in touch. The researchers are also children's nurses with a lot of experience of working with children, young people and their families like you. They will ask you if you have any more questions about the research and whether or not you want to be involved.
You can choose how you would like to take part. This could be either
• through a face to face interview at a health service or public place near to you
• or at your home with your parent / carer or another adult of your choice present
• or by an interview over the telephone.

Depending on how much you would like to tell us interviews will take between 30 minutes and an hour.

If you decide to take part they will ask you to complete a consent form. If the researchers are meeting you face to face you will be asked to sign it. If we are interviewing you over the phone you will be asked to say that you are happy to continue with the interview.

Please note that what you tell us during the interview may be recorded so that we can make sure we do not miss any of the important things you tell us.

4. Are there any risks / benefits involved?

Taking part should not mean any risks for you. We hope that you will enjoy taking part. We hope that you will feel that by sharing your experiences you will have had an opportunity to help to make services better for young people and their families in the future.

5. Will my taking part in the study be kept confidential?

What you tell us during the interview will be confidential and only for the purpose of this study. We will only keep an electronic record of your contact details until the study has been finished.

The main things you tell us will be put into a final report for the Cheshire and Merseyside Strategic Clinical Network Long Term Conditions Services Special Interest Group. This will be discussed at one of their meetings looking at how services can be improved in the future.

Your name will be changed in the report. We will take care to make sure that we take out any information such as where you live or the names of services you attend so people reading the report can’t guess who you might be.

The only time we would share specific information with services would be if you said something which made us concerned that you might be at risk of harm or might need more support. We would always discuss this with you first.

This study has received ethical approval from LJMU’s Research Ethics Committee

Reference 15/EHC/010 (20th January 2015)
**Contact Details of Researcher**
Nick Medforth, RGN/RSCN, BA (Hons) PGCert, MSc, MBPS
Henry Cotton Building, Liverpool John Moores University,
15-21 Webster Street, Liverpool L2 2ER

0151 231 4321
n.medforth@ljmu.ac.uk

If you any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate.

*A copy of this participant information sheet is for you to keep.*
Title of Project
Pilot Evaluation of the Experiences of Young People, Carers and Lead Professionals involved in Transition from Children’s to Adult Health and Care Services

Name of Researcher and School/Faculty
Nick Medforth and Elaine Huntingdon, School of Nursing and Allied Health, Faculty of Education, Health and Community

As a member of the Cheshire and Merseyside Strategic Clinical Network Long Term Conditions and Disabilities Special Interest Group you may be aware that we have been asked to carry out a small-scale pilot project on behalf of the group. For this reason we are seeking your help in recruiting potential participants in the project. Before you decide it is important that you understand why the research is being done and what it involves. Please take time to read the following information and please do not hesitate to ask us if there is anything that is not clear or if you would like more information. Further information can be found in the attached project proposal.

1. What is the purpose of the study?

As a member of The Cheshire and Merseyside Strategic Clinical Network Long Term Conditions and Disabilities Special Interest Group you will be particularly interested in improving the experience of young people who are going through the transition from receiving support from children’s services they have known for a long time to services designed to meet the needs of adult service users. You will be well aware of the complex challenges in “getting it right” for young people with complex health needs and disabilities. This is why you have chosen to make this a priority in your work stream. You are looking at how transition to adult services can be better planned and managed to meet the needs of young people and their parents or carers. The starting point is to gain deeper insight into the recent transition experiences of local young people and families and the key workers/professional involved in planning and coordinating the transition process. This will help the group to learn more about the transition experiences of local young people, families and lead professionals involved in planning and coordinating the Transition process. The pilot project will explore participant’s ideas about how services could be improved to make the transition process smoother, easier and the best possible experience from the viewpoint of young people and their parents or carers as well as identifying further areas for research and service development in light of recent best practice guidance and standards.

The report will highlight examples of local best practice and effective transition support where possible and emphasise strengths which could be built upon. It will also make recommendations which the special interest group could consider making a focus of their future work stream based upon the different experiences of young service users, carers and practitioners in Cheshire and Merseyside. This could include recommendations for further research as well as insights to be considered when exploring developments in service commissioning, development and delivery.
It is anticipated that the report will be presented by the end of February 2015, however this will be dependent on the accessibility of the participants who will provide the case study data.

2. **Who do we want to invite to participate?**

The intention of this pilot project is to carry out four case studies which will explore the different transition pathways and experiences of four young people from the following groups:

- Young people who have common long-term conditions such as Diabetes and Epilepsy which are predominantly self-managed at home, with oversight from centres with specialist expertise.
- Young People who have long term conditions which require intermittent or regular hospital-based intensive support such as those who are technology dependant or require frequent admissions for acute or specialist care.
- Young people who have disabilities and complex needs.
- Young people who are receiving support from Child and Adolescent Mental Health Services (We do not, however, intend to interview young people where mental capacity is compromised.)

Each of the four Case Studies will ideally involve interviews with

a. A young person from the four groups identified above who have recently undergone the transition from children’s to adult’s services
b. Their parent/carer
c. The key worker involved in their transition planning and support process. Interviews will ideally be face to face, in a location which assures safety for both the interviewees and researchers, but may be conducted over the telephone where this is more appropriate for the interviewee.

As a member of Cheshire and Merseyside Strategic Clinical Network Long Term Conditions and Disabilities Special Interest Group we need your help to recruit participants. We will need your help to assess their suitability to take part, taking account of the above criteria and through discussion with service-providing professionals involved directly in the care and support of the young people and their families. We will need you to share Participant Information Sheets attached with young people who may be interested in taking part, their carers and lead professionals. Where young people, families and lead professionals do indicate their interest in participating you would need to share their contact information with us.

3. **What will be expected of them if they agree to take part?**

They will be contacted by a researcher from Liverpool John Moores University. The researchers are also children’s nurses with experience of working with children, young people and their families. They will ask potential participants if they have any more questions about the research and whether or not they want to be involved.

They will have been given the attached Participant Information Sheet and if they do decide to participate they will be invited to complete the attached consent form if we are meeting them face to face, or give verbal consent if we are interviewing them over the phone.
Participants can choose how you would like to take part. This could be either
• through a face to face interview at a health service or public place
• or by an interview over the telephone
• an interview in the young person / family home with a preferred adult present

Depending on how much you would like to tell us interviews will take between 30 minutes and an hour. Some of what participants tell us during the interview may be recorded so that we can make sure we do not miss any of the most important points shared.

4. **Are there any risks / benefits involved?**

We do not anticipate any risks. We hope that participants will find it beneficial to share their experiences and that they will enjoy taking part. We hope that they may feel that they have had an opportunity to make a positive contribution to the development and delivery of services to young people with long term conditions and disabilities and their families in the future.

5. **Will their taking part in the study be kept confidential?**

What they tell us during the interview will be confidential and only for the purpose of this study. We will only keep an electronic record of their contact details until the study has been completed. The main points of what they tell us will be put into a final report for the Cheshire and Merseyside Strategic Clinical Network Long Term Conditions Services Special Interest Group. This will be discussed at one of your meetings looking at how services can be improved in the future. What participants tell us will be anonymised in the report, however we may use direct quotations to illustrate some key points they thought were particularly important or felt strongly about. We will take care to ensure that we take out any information such as where they live or the names of services which might enable people reading the report to guess who the participants might be.

The only time we would share specific information with services would be if a participant said something which raised a concern that they might be at risk of harm or might benefit from additional support. We would always discuss this with them first.
This study has received ethical approval from LJMU’s Research Ethics Committee (insert REC reference number and date of approval)

Contact Details of Researcher
Contact Details of Academic Supervisor (student studies only)

If you any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate.

A copy of this gatekeeper information sheet is for you to keep.
Title of Project
Pilot Evaluation of the Experiences of Young People, Carers and Lead Professionals involved in Transition from Children's to Adult Health and Care Services

Name of Researcher and School/Faculty
Nick Medforth and Elaine Huntingdon, School of Nursing and Allied Health, Faculty of Education, Health and Community

1. I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights.

3. I understand that any personal information collected during the study will be anonymised and remain confidential

4. I agree to take part in the above interview

5. I understand that the interview will be audio recorded and I am happy to proceed

6. I understand that parts of our conversation may be used verbatim in future publications or presentations but that such quotes will be anonymised.

Name of Participant    Date    Signature
Name of Researcher    Date    Signature
Name of Person taking consent    Date    Signature
(if different from researcher)

Note: When completed 1 copy for participant and 1 copy for researcher

APPENDICES - ASSENT FORM FOR CHILDREN / DEPENDENTS
Title of Project
Pilot Evaluation of the Experiences of Young People, Carers and Lead Professionals involved in Transition from Children’s to Adult Health and Care Services

Name of Researcher and School/Faculty
Nick Medforth and Elaine Huntingdon, School of Nursing and Allied Health, Faculty of Education, Health and Community

Child (or if unable, parent/guardian on their behalf) / young person to circle all they agree with

Have you read (or had read to you) information about this project? Yes/No
Has somebody else explained this project to you? Yes/No
Do you understand what this project is about? Yes/No
Have you asked all the questions you want? Yes/No
Have you had your questions answered in a way you understand? Yes/No
Do you understand it’s OK to stop taking part at any time? Yes/No
Are you happy to take part? Yes/No

If any answers are ‘no’ or you don’t want to take part, don’t sign your name!

If you do want to take part, you can write your name below
Your name ___________________________
Date ___________________________

Your parent or guardian must write their name here if they are happy for you to do the project.
Print Name ___________________________
Sign ___________________________
Date ___________________________

The researcher who explained this project to you needs to sign too.
Print Name ___________________________
Sign ___________________________
Date ___________________________