



LJMU Research Online

Medforth, N and Huntingdon, E

Found in Transition.

<http://researchonline.ljmu.ac.uk/id/eprint/10579/>

Article

Citation (please note it is advisable to refer to the publisher's version if you intend to cite from this work)

Medforth, N and Huntingdon, E (2017) Found in Transition. Comprehensive Child and Adolescent Nursing, 41 (4). pp. 237-254. ISSN 2469-4193

LJMU has developed **LJMU Research Online** for users to access the research output of the University more effectively. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LJMU Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain.

The version presented here may differ from the published version or from the version of the record. Please see the repository URL above for details on accessing the published version and note that access may require a subscription.

For more information please contact researchonline@ljmu.ac.uk

<http://researchonline.ljmu.ac.uk/>

Found in Transition!

N Medforth and E Huntingdon

Acknowledgements: the authors would like to thank all of the practitioners, professionals and partners of the Service Improvement Group focussing on children and young people with long- term conditions and disabilities at the Cheshire and Merseyside Strategic Clinical Network (now the North West Coast Strategic Clinical Network) who contributed to this project. In particular, we acknowledge the young people and families who generously and honestly shared their experiences in the hope that the project would contribute to the continuing improvement of transition support for young people with long-term conditions, mental health difficulties and disabilities.

Abstract

The journey to adulthood is complex and multi-dimensional. Young people may be independent in some spheres of their lives, but dependent in others. For young people with a disability, long-term condition or mental health problem there are additional hurdles. As they move between health and social care services, they will find significant differences in expectations, delivery and culture. At the same time, their own needs will be evolving.

Despite a "*plethora of guidance*" on effective transition support, the Care Quality Commission (2014) highlight a shortfall between policy and practice. The result is confusion and frustration for young people, their families and the staff caring for them. Seamless transition to adult services is by no means a universal experience. Here the authors offer two case studies that triangulate inter-related perspectives; those of young people, parents and carer's and the professionals involved in successful models of transition support. The case studies illustrate how the challenge of transitioning to adult services is actually experienced and how, despite some concerns held by young people, parents and carers, well-planned and co-ordinated transitions can have positive outcomes for the families involved.

Introduction

Transition is non-linear; a range of factors and circumstances make adulthood more or less accessible. (Furlong and Cartmel, 1997; Thomson, 2000). These include personal situations, social and geographical locations and negotiating transitions in several parallel trajectories. Young people may simultaneously be experiencing transitions from education to training and employment or in relation to housing, family, income and relationships (Coles, 1995; Jones and Wallace, 1992). Transitions do not necessarily occur at the same rate along each strand. Whilst transitions are “*critical moments*” in young people’s biographies they contribute to processes of social inclusion and exclusion, with young people recognising their impact on choices, chances and opportunities (Thompson, Bell, Holland, Henderson and McGrellis, 2002.)

The need to move between health, education and social care services compound the challenges for young people with a disability, long-term or life-limiting condition or mental health problem. Young people confront significant differences in expectations, style of service delivery and culture as they move between children centred and adult orientated services. At the same time their own care needs will be evolving. In many cases, vulnerable or disabled young people may experience “*rushed*” transitions, which lead to stress and social exclusion as young people have to “*grow up*” quickly (Katon and Kagan, 2007.) According to the Care Act (2014) if a child or young person is likely to have needs when they turn eighteen the local authority must assess them if it considers there is ‘significant benefit’ to the individual in doing so. This includes young people with long-term conditions, disabilities, mental health difficulties and young carers. There are two key issues in transition: becoming an adult and

achieving independence and changes in the actual services used (Social Care Institute for Excellence, 2014).

For young people receiving health services the same people will have looked after them for as long as they can remember. In an adult environment, they may need to consult several new health teams and adult social care services. Young people experience many significant transition points between health care services, as well as between schools, continuing education and employment. All can affect adherence to treatment and retention by services. (Care Quality Commission, 2014.) Professionals have access to a plethora of guidance on good practice in supporting effective transitions by involving young people in the processes, thereby making the transition to adult services smoother. Published standards and guidance focus on services that are seamless, flexible and based on the needs of the young person, rather than on the needs of the service (Royal College of Nursing, 2013; Department of Health 2008; Kennedy, Ian (2010); Social Care Institute for Excellence, 2011; Council for Disabled Children National Transition Support Team (2011.)

Ensuring that the young people's needs and feelings are paramount requires lead professionals or coordinators with skills knowledge and an ability to listen and respond to the needs of individual young people.

The project reported here was commissioned by a *Clinical Strategic Network* in the north- west of England who were aware of the challenges in “*getting it right*” for young people with complex health needs and disabilities. The aim was to identify areas for service development, which would feed into future work streams by gaining deeper insight into the recent transition experiences of young people and families, and the professionals involved.

Research Question

How can the experiences of young people, parents and professionals illuminate effective models of support to enable young people with long-term conditions and disabilities to make successful transitions between child-centred and adult orientated services?

Methods

Data collection.

The chosen method for data collection was *Case study* as the researchers aimed to understand and evaluate the real-world transition experiences of young people, their families and the professionals involved. The case study approach is consistent with the principles of *Realist Evaluation*, which provide an alternative to empiricist approaches. In realist evaluation there is an acknowledgment that a critical approach to the underlying social and political context is fundamental to understanding the effectiveness of policy and process. (Pawson & Tilley, 1997.) In this case, the underlying tensions between policy guidance on how to best support effective transitions and established differences in approach to service delivery encountered in child-centered and adult orientated services provide the context. Case study as a method of data collection enables systematic production of exemplars that contribute to the understanding of a phenomenon or the developing knowledge of a discipline. It is recognised to be particularly effective in evaluation projects (Flybjerg, 2006.)

Separate semi-structured interviews with young people, parents and carers form the basis of the case studies. The viewpoints of young people and their parents or carers are considered alongside the perspective of a lead professional involved in planning and co-ordinating the transition process in partnership with the young person and their family.

Ethical considerations included the provision of easily understood participant information in written format with the opportunity for further explanation as required; establishing informed consent; assuring participant's right to withdraw at any point without

prejudice and safeguarding the anonymity of the participants. These considerations support the intention to provide an authentic voice to the young people, families and professionals who participated in the research in order to enable their evaluation of their own experiences to inform future service development. Approval to proceed with the research was granted following scrutiny by a university Ethics Committee.

Sampling.

Purposive sampling is a non-probability sampling technique often considered useful when one needs to study a certain cultural domain with knowledgeable experts within; in this case, the young service users, their parents, carers and practitioners who planned and supported the transition process. It is the most commonly used sampling method because it allows the researcher to select participants because they are at the right place at the right time. The inherent bias of the method contributes to its efficiency. (Bernard, 2002.) The method however has two significant limitations; firstly, that it is not possible to control variability and bias because the process relies on the judgement of the researcher and secondly results from the data cannot be generalised beyond the sample. (Acharya et al, 2013.) These limitations were not a particular concern for this study as the aims are *idiographic*; seeking a sufficiently small sample of typical cases to enable individuals to have a locatable voice within the study thus enabling an intensive analysis of each case. (Robinson, 2013) This form of *intensity sampling* is acceptable when the objective is to locate an information-rich case chosen specifically to be insightful, articulate and honest. (Miles and Huberman, 1994).

Inclusion criteria.

The inclusion criteria for the study were young people who had recently experienced transition to adult services within the sub-region covered by the Clinical Strategic Network, their parents and professionals involved in coordinating or supporting their transition. The young people represented the following groups:

- Young people who have common long – term conditions such as diabetes and epilepsy, 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.

Participants were recruited through the Clinical Strategic Network and its partners who distributed information and invitations to participate to families in which a young person had experienced the transition from children’s services to adult services within the previous six months to three years. Six young people, their parents and relevant professionals agreed to participate. Four highlighted problematic transition experiences. These are fully reported in the original project report. (Medforth and Huntingdon, 2015.) The two *Case Studies* reported here illustrate that despite numerous challenges effective transition planning, co-ordination and support can lead to positive outcomes for young people. The Case Studies illuminate the experiences of young people and families who fell into one or more groups: a young person who has multiple *disabilities and complex needs* and a young person who is receiving support from *Child and Adolescent Mental Health Services*. To preserve the anonymity of the names of participants have been changed.

Results

Authenticity is a key to assuring the quality, trustworthiness and validity in qualitative research (Seale, 1999.) It is one of the three primary criteria used for establishing validity research alongside credibility and criticality (Whitmore, Chase, and Mandle, 2001.) It is essential that 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 (James, 2008). Research should also be worthwhile. The authors are confident that the case studies reflect the experiences the participants wanted to share as the participants were invited to make corrections or amendments when drafts were returned to them.

Illustrative Case Study 1: Kelly's story

Kelly is 18 years old. She lives with her Gran (Rita), mum Karen, brother (Kevin, 20) and her baby son (Harry) who is 9 months old. Kelly has a complex learning disability, which includes *Attention Deficit Hyperactivity Disorder (ADHD)*, *Dyslexia* and *Dyspraxia*. She has received regular support from the *Child and Adolescent Mental Health Service (CAMHS)* and *Psychiatrist* at her local children's hospital for 10 years. Kelly sometimes hears voices, which became more frequent when she became pregnant with Harry. Kelly herself, her gran, Rita, and the lead professional from the Transitions Team who supported Kelly's transition to adult services, shared their experiences.

Kelly found it difficult to remember when "*Transition*" was first discussed, but remembered that it had been raised by a nurse (Paul) who coordinated transitions in the CAMHS team when she attended an appointment. Kelly felt "*o.k.*" about the proposed move to adult mental health services somewhere around her 18th birthday. She feels positive about the transition. Kelly feels she receives "*a lot more help now*" including medication from her G.P "*to help with the voices*" and an *Adult Early Intervention in Psychosis Practitioner* (Sally) who visits her at home. Kelly describes her as a "*lovely lady*" who goes through things with her and enables her to talk about her concerns.

Kelly thought school was "*o.k.*" She left when she was 17 to go to a city centre college to do courses in Catering, Art, Maths and English. Kelly struggled, and often felt she was left "*standing around*" without support from her tutors. This became more difficult when

she became pregnant, so she decided to leave. Kelly's suggests more help should be given to young people to enable them to make successful transitions to college, and to help the tutors understand the help they need. Sally has been to the college to talk to the staff there, and Kelly is hoping to go back to complete 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 to adult services, which would be better able to meet her needs. 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 comes to the house. According to Rita, Kelly said more to Sally in 10 minutes than in any of her previous appointments. Kelly had been able to explain that she hears voices and what they say.

Kelly's pregnancy at 17 had been a challenging time for the family. 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, who told Rita that as Kelly was 17 she had the right to make her own decision. Rita was frustrated that they did not take into account Kelly has limited ability to make informed decisions. 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 expressed her frustrated at a lack of support from Social Services too. Rita felt that the

experiences had been traumatic to Kelly “*undoing ten years good work*“, exacerbating Kelly’s hearing of voices.

The family experienced 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 on to 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 kept a diary, which illustrated one week taken up with visits from different professionals or hospital appointments every day. Rita felt that the intensive intervention led to an exacerbation of Kelly’s depression and a fear that the baby would be taken from her. Kelly felt she could not bond with her baby until a new social worker agreed that the case could be closed as Kelly had a lot of support at home. Kelly no longer has contact with the baby’s father.

Kelly’s transition to adult mental health services was taking place at the same time. Rita felt it “*would all have gone pear-shaped*” if it wasn’t for the *Transition Practitioner* from the Child and *Adolescent Mental Health Team* (Paul) and the *Adult Early Intervention in Psychosis Practitioner* (Sally) working together with the family. They did a “*fine job*” in co-ordinating meetings, “*guiding them through*” and “*packaging it all up.*” This was in contrast to the experience 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, he used Cannabis to self-medicate, thereby exacerbating his problems.

Rita felt that the outcome of Kelly's mental health transition process had been very positive and more effective than the support Kelly had previously received to make the transition from school to college. Kelly had gone back to College too soon (4 months after having Harry) and this had led to further Depression, but she is now receiving support to return to college at her own pace. Paul is no longer involved apart from the occasional phone call and Sally is now helping Kelly to decide what she wants to do with her life; offering some practical help; looking into getting Kelly a bus pass and arranging a place in a day centre to build up Kelly's confidence. Sally has made contact with a local football team to help Kelly pursue her interest in sport through their community programme.

The Transition Practitioner's Perspective.

Paul works 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*. The Adult Mental Health Trust and the Children's Hospital Trust jointly fund it. Two *Transitions Practitioners* in the team support young people who have mental health difficulties and learning disabilities. For Paul

"Transition is 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 first met Kelly when he received a referral during Kelly's pregnancy. Although there is a *perinatal team* in the adult mental health trust, Paul felt that the transfer of Kelly's care would be inappropriate, due to the psychosis risks associated with pregnancy and the post-natal period. Kelly was formally referred to adult services after she had a 3-month period of stability after Harry was born. Paul had been involved in the previous social care assessment process and was able ensure that ongoing social care needs continued to be monitored. Paul did not consider parallel education transition at this point, as he understood that Kelly was intending to go back to her Catering course after the birth of her baby.

Kelly did not have a *Health Passport* to support the transition 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 developing trust in Sally and adult services.

Through providing transition support to young people like Kelly Paul has learned that providing information about what to expect and giving young people “*a voice*” in the process is essential. Young people need opportunity to express anxieties; ask questions; have a sense of relief, feeling valued and fully consulted. They need to be reassured they will receive a service that is at least as responsive and effective as the service that they are used to. The process is a journey, not just a ‘one off event’ so requires a holistic approach taking 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 involving senior professionals from *CAMHS; learning disability services; Tier 4 services* and *social care and adult mental health services*. Transition policy in children’s and adult services should mirror each other. Paul’s team currently deliver transition training to practitioners from both CAMHS and adult services. Content includes values underpinning the provision of transition support; minimum expectations and standards and complex case work to illustrate challenges and practical solutions. The team are currently developing *Transition Checklists* for practitioners and involving young people at the heart of these developments.

Illustrative case study 2: Kyle's story

Kyle is a 20-year-old young man. He lives with his mum (Pam), dad (Carl), brother Jack (17) and their three dogs. 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, skilled in supporting his communication and ensuring his rights are maintained. They battle 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. Whilst Kyle's mum and dad provide most of his care, they both have their own deteriorating health problems, and require support, funded jointly by health, and social care commissioners. Although *Personal Budgeting* has worked well for Kyle, 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 understands that the term "*Transition*" relates to the movement from children's to adult education, health and social care services. 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 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. 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 high school. His mum explained that the school was good at “*differentiating the curriculum*” unconstrained by perceptions of his disability. Kyle agreed that one example was a design and technology project focussing on the construction of Trainers. Kyle was able to make a collage using 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 is continuing his learning and development by attending a *Day Centre* two days a week and *Further Education College* on three days. Classes 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. 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 confirmed he was asked what he thought about his *Transition Plan* and his mum recalls that a particular social worker was very patient, taking time to listen to his views and understand his wishes and feelings. Kyle says 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 - a “*holistic handover*” in which nothing is missed. Pam “*made it happen*” by approaching the special school when Kyle was in Year 9. (At the time transition planning

focussed on the 14-19 age range; however, 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 was "*driven by education*" with additional input from the school nurse and Kyle's therapists.

Kyle's health service transitions were staggered in order to make them more manageable. His *general practitioner* 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 originally managed through specialist services at the children's hospital, but he has now transferred to a specialist *adult neurological centre*. Pam identified this as a positive aspect of the transition experience because the *consultant neurologist* visited Kyle twice at the children's hospital, taking time to get to know him, gaining Kyle's trust and confidence before he attended the adult service. Kyle's dental care is now overseen by the dental hospital rather than the children's hospital.

Pam identified three people who were key to putting Kyle's *Transition Plan* into place and were prepared to work together and "*not let funding be a barrier*" instead looking for new solutions which were in Kyle's best interests:

- *The Post 16 Education Coordinator for young people who have Special Education Needs*
 - *The Manager of the Social Care Transition Team*
 - *The NHS Children's Transition Commissioner*

Pam is concerned that the role of *NHS Children's Transition Commissioner* no longer exists following the introduction of *Clinical Commissioning Groups (CCGs)* meaning support from health services is diminished. Changes to funding models have resulted in

having “*no-one to pull it all together.*” An example Pam cited was the year she spent trying to access training for *care assistants*, who were able to bath Kyle and 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.

One example of a big decision for the family 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 bodies.*” Kyle was 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 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 college. Pam now acknowledges that Kyle may not have been ready to attend the residential college in another region 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 that this is not everyone’s experience and runs a support group for parents going through a similar process and who may not be as well informed. Pam says 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 the perspective of Kyle’s parents is that your 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 and parents are 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 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. Hearing people saying positive things about the young person’s future can be the hardest thing for parents to hear but when you do...

“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...”

Transition team manager’s perspective.

Patrick is manager of a *Transitions Team* delivered through social care services. It is located within an NHS building in a community setting. Patrick’s local authority has strategically organised services to facilitate inter-agency working which puts the young person 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 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. The *Transitions Team* is made up of experienced *Social Workers* with expertise in both children's and adult services and are able to ensure that young people and families are kept informed of progress and are consulted regarding any decisions to be made.

The team pick up responsibility for managing the cases of young people with complex special needs who are 16 and 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. This involves co-ordinating multi-agency support, bringing together community health services, social care and education to plan for what is going to happen when the child turns 18. Ideally, the planning process will have commenced from 14 years so Patrick's team work with other agencies to consolidate plans initially started by children's services. Transition planning follows a local model, informed by the requirement for integrated *Education, Health and Care Plans* required in light of the *Children and Families Act (2014)*. Patrick also considers *Transition Guides* produced by the *Council for Disabled Children Transition Support Team* (2011) to be excellent frameworks to follow.

Patrick 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 required by most young people with special educational needs for leaving school at 19 years and transferring over to the appropriate *Adult Locality Team*. Planning involves 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
- 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 enabled Patrick to understand what Kyle enjoyed at school and what he was less keen on. Patrick was aware that Kyle had supportive, well-informed parents, who had clear views that they wanted Kyle to go to a specialist residential college in another part of the country. They 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 able to work with them to explore other options available locally to meet Kyle's specific needs and interests. This was particularly important to avoid a potential gap in his continuing education, as Kyle would not have been eligible for the residential college until he was 19.

The role of the *Transitions Team* is to identify and source funding from the local authority and health services to meet the assessed needs of the young person. They were able to put together a package to would meet the needs of Kyle and his family and enable him to stay at home and continue to benefit from education. Patrick was able to negotiate a bespoke timetable of arts-based activities with the *Further Education College* to enable Kyle to progress his interests.

As Kyle has additional 24 hour care needs transition planning involved co-ordination of health and social care services and funding to establish a *Personal Budget* that 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.

Discussion: analysis of emerging themes and key messages from participants

Interpretation of the data involved a process of Thematic Analysis – a method of identifying, analysing and reporting patterns in the data flexibly. (Braun & Clarke, 2006) Through a process of familiarisation with the data, searching for, naming and reviewing themes it was possible to provide detailed description of key messages without being constrained by a specific theoretical framework.

Working towards better outcomes and making sure that no young person “falls through the gap.”

Four of the case studies from this project highlight that despite a range of policy guidance young people and families face numerous challenges and dis-jointed practices during the transition process with resulting poor outcomes, including the overlooking of safety and safeguarding concerns. These are transparent in the original project report, which has since been used by the Strategic Clinical Network to inform developmental work to improve young people’s transition experiences (Medforth and Huntingdon, 2015.) Kyle and Kelly’s stories illustrate that poor outcomes need not be the case. Whilst some challenges persist and young people and families continue to regret the loss of some services, overall outcomes can be positive and built upon to ensure continuing service improvement.

Participants highlighted the need for professionals to ensure that no young people leaving children’s services fall behind or are without services when gaps between children’s and adult’s services emerge. To achieve this it is necessary for Transition Teams to be multi-disciplinary, stay together and consist of experienced Transition Coordinators. Parents need to be able to rely on them to manage the transition process and facilitate integrated commissioning rather than leaving it to already exhausted parents. A priority for young people was the need to feel secure that they will receive a service that is at least as effective in meeting their needs as the service that they are used to. Professionals involved highlighted that timely transition planning is essential to avoid “disjointed transitions” for examples

when a young person resurfaces in accident and emergency or adult services because they were discharged from children's services prematurely.

Focussing on the young person as an individual

The young people, parents and carers interviewed were clear about the central importance of the young person who must be involved throughout the transition planning and implantation process. Involvement of advocacy services would be helpful, particularly to support involvement of young people with severe disabilities. This is essential if particular issues relating to provision for young people with complex needs arise.

Professionals who are experienced in supporting young people's transitions recognise that each young person is unique and will have individual support needs. Parents are often very anxious about their child's future and will want to be involved at every stage.

For young people with complex difficulties, turning 18 can be a 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 must be ready to meet those needs effectively. Collaborating with other service providers is an important element of the role of the transition team, for example, when ensuring that health needs are not under-estimated in educational settings; proper hoists are available when required and hydrotherapy and physiotherapy continue to be provided.

Navigating challenges.

Professionals experienced in supporting young people's transition to adulthood are learning to navigate differing arrangements across neighbouring boroughs and may have expertise to overcome challenges other professionals find to be a barrier. The transition experience can be positive for all concerned when care is co-ordinated by lead practitioners who are experienced in working across organisational boundaries to overcome barriers and

have the confidence and experience to help young people and families to explore new solutions and navigate alternative transition pathways.

The experienced professionals who participated in the project highlighted the numerous challenges they face. Firstly, some adult- focussed practitioners see young people as “*not for us*” and need support and training from professionals experienced in supporting young people to develop their confidence in working with a group who make up a small percentage of their clients. Secondly, commissioning of services may be tri-partite in children’s services, involving health, education and social care. Integrated commissioning can be more challenging in adult services, but commissioners should work towards addressing this imbalance. Professionals reported excellent “*wrap around*” health services exist for children and young people with complex needs and disabilities up to the age of 18; however, this is not mirrored in adult services. A health transition process needs to be developed to match and support that provided by social care services.

Supporting the transition of young people with mental health difficulties may present professionals with particular challenges. Child and Adolescent Mental Health Services are based on a developmental, young person- centred model and a psychological approach to understanding distress whilst adult services are built around medical diagnostic or therapeutic models. This means that young people who are showing symptoms associated with trauma or abuse are re assigned new diagnostic labels to make services accessible to them. The service needs to respond to the needs of young people rather than expect them to fit the current model of service delivery. A more person-centred approach could achieve this.

Young people who do not have a confirmed diagnosis, or who have mild to moderate learning disabilities may be receiving support from CAMHS but “*fall through the gap*” *because* their conditions are not considered severe enough to meet intake criteria for

adult mental health services. Criteria to determine young people's eligibility for services needs to be revisited.

Commissioners need to address the problem that young people who are considered to be "*high risk*" in terms of mental health and receive care in specialist or private settings may not be able to access equivalent adult services.

A full range of appropriate services is not always available meaning that there is "*no-one to let go to*" in adult health services- something which needs to be carefully considered by service providers and commissioners. Recent funding cuts mean that local authorities have had to reduce the range of services available locally. *Transitions Teams* need to continuously work to identify new service providers and develop a shared directory of local services offered locally.

Sharing experience through training.

Transition teams may also play an important role in training others, for example, to enable *Special Educational Needs Co-ordinators* in schools and colleges to make an informed contribution to transition planning when a young person reaches the age of planning from age 14. Training in transition support can help promote better understanding of underpinning values; provision of transition support; minimum expectations and standards and practical solutions in complex transition case work. This may benefit practitioners in both children's and adult services across agencies and sectors.

Parents need training and peer support to enable them to recognise what the young person can do so that they can take part in an aspirational transition planning process, but caution the need to avoid promising the earth then failing to follow through.

Conclusion

Established benchmarks may be used to evaluate the validity of interview-based studies. These are sensitivity to context, rigour, transparency, coherence and impact and importance. (Robinson, 2008; Smith et al 2009; Yardley 2000; Robinson 2013.) The authors acknowledge that this study is limited in terms of generalisability as the sample size was small and therefore it is only possible to illuminate the experiences of participants chosen at a specific point in time. This does not detract from the value of the case study approach in transparently providing young people, parents and professionals with an authentic and credible voice through which their experiences can be shared.

The project has achieved its aims, enabling the researchers to highlight emerging models of support, which can enable young people with long-term conditions and disabilities to make successful transitions between child-centred and adult orientated services. These are contingent on complex interacting factors including the individual circumstances, needs and aspirations of young people along a number of trajectories such as progress towards independent adulthood, friendships and social support networks, health and well-being and meaningful education or employment . These should be considered in the context of the young person's family, location and the current culture and models of service delivery and commissioning arrangements. Parents and siblings will also need to be included and supported through the experience. The underlying political and social context may provide additional hurdles to overcome.

Key to success is the development of expertise in specialist transition practitioners and teams who are skilled in focussing on the unique needs of each young person they work with. They need to be able to support young people as individuals and their parents; plan and co-ordinate a timely transition process; collaborate with others to ensure that no young person falls through gaps in service provision; have the courage to navigate challenges and overcome barriers and be willing to share their expertise through the provision of training.

It will only be possible to demonstrate impact of the project if the emerging issues and messages highlighted lead to further research, practice or significantly influence future service developments, including new models of delivery, which enable seamless transition between services centred on the holistic needs of the service user rather than the needs and traditions of the service.

References

- Acharya, A.S., Prakash, A., Saxena, P. & Nigam, A. (2013). Sampling: why and how of it? *Indian Journal of Medical Specialities*: 4, (2), 330-333
- Bernard, H.R. (2002) *Research Methods in Anthropology: Qualitative and quantitative methods. 3rd edition*. Walnut Creek, California: Altamira Press,.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2), 77-101. doi:10.1191/1478088706qp063oa
- Caton, S. & Kagan, K. (2007). Comparing transition expectations of young people with moderate learning disabilities with other vulnerable youth and with their non-disabled counterparts. *Disability and Society*, 22, (5), pp 473-488
- Care Quality Commission (2014) *From the pond into the sea: children's transition to adult health services*. London, England, Author: Retrieved from <http://www.cqc.org.uk>
- Coles, B. (1995). *Youth and social policy: youth citizenship and young careers*. London, England: UCL Press.
- Children and Young People's Health Outcomes Forum (2012). *Recommendations to improve health of children and young people*. London, England, Author: Retrieved from: <http://www.gov.uk>
- Council for Disabled Children National Transition Support Team (2011) *Information and learning from the aiming high for disabled children transition support programme: a summary*. London, England, Author. Retrieved from http://www.councilfordisabledchildren.org.uk/media/136250/information_and_learning_from_the_ahdc_tsp_report_summary.pdf
- Department of Health (2008) *Transition: moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*. London, England, Author. Retrieved from http://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf

- Flyvberg, B. (2006). Five misunderstandings about case study research. *Qualitative Inquiry*, 2 219-245. Retrieved from <http://flyvbjerg.plan.aau.dk/Publications2006/0604FIVEMISPUBL2006.pdf>
- Furlong, A. & Cartmel, F. (2006) *Young people and social change: New perspectives*. (2nd ed.) Maidenhead, Berkshire, England. McGraw-Hill Education.
- James, N. (2008). Authenticity. In L. Given (Ed.), *Book Title: The SAGE Encyclopedia of Qualitative Research Methods* (pp. 45). Thousand Oaks: SAGE Publications, Inc.
- Kennedy, Ian (2010) *Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs*, London, England, Department of Health. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216282/dh_119446.pdf
- Medforth, N. & Huntingdon, E. (2015) *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*. Warrington, England, North West Coast Strategic Clinical Networks. Retrieved from http://www.nwscnsenate.nhs.uk/files/4014/3834/8138/Real_People_Real_Lives_Report_April_2015.pdf?PDFPATHWAY=PDF
- Miles, M.B. & Huberman, A.M. 1994. *Qualitative data analysis: an expanded sourcebook*, (2nd ed.) London, England : Sage.
- The National Network of Patient Carer Forums (2013) What good integrated care looks like in transition. London, England, Author. Retrieved from: <http://www.nnpcf.org.uk/what-good-integrated-care-looks-like-in-transition>
- Pawson, R & Tilley (1997). An introduction to scientific realist evaluation. In
- E. Chelimsky, & W.R. Shadish (Eds.), *Evaluation for the 21st century: A handbook*, (pp. 405-418). Thousand Oaks, CA, US: [Sage Digital Editions version]. doi 10.4135/9781483348896
- Robinson, O.C. (2014) Sampling in interview-based qualitative research: a theoretical and practical guide. *Qualitative Research in Psychology*. 11, (1) 25-41. doi:10.1080/14780887.2013.801543
- Thompson, R., Bell, R., Holland, J, Henderson, S, Mc Grellis, S. & Sharpe, S. (2002) Critical moments: choice, chance and opportunity in young people's narratives of transition. *Sociology* 36 (2) 335-354. doi 10.1177/0038038502036002006
- The Royal College of Nursing/ & the Royal College of Paediatrics and Child Health (2013) *Lost in transition: Moving young people between child and adult health services*. London, England. Author (Online) Retrieved from: https://www.rcn.org.uk/__data/assets/pdf_file/0010/157879/003227_WEB.pdf

- Seale, C. (1999) Quality in Qualitative Research. *Qualitative Inquiry*, 5 (4) 465-478. doi : 10.11460.3511
- Social Care Institute for Excellence. (2014) *The Care Act: Transition from childhood to adulthood*. London, England. Author online. Retrieved from <http://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/>
- Social Care Institute for Excellence. (2011) *Planning and practice in transition: how to support effective transitions*. London, England. Author online. Retrieved from <https://www.scie.org.uk/publications/guides/guide44/planningandpracticeintransition/support-effective.asp>
- Smith, J.A, Flower, P & Larkin, M. (2009). *Interpretative phenomenological analysis: theory, method and research*. *Qualitative Research in Psychology*. 6 (4) doi: 10.1080/14780880903340091
- Whittemore, R., Chase, S.K. and Mandle, C.L. (2001) Validity in Qualitative Research. *Qualitative Health Research* 11 (4) 522-537. doi : 10.1177/104973201129119299
- Yardley, L. 2000. Dilemmas in qualitative health research. *Psychology and Health* 15: (2) 215–28. doi: 10.1080/14780880008400302