

Still Lost in Transition?

Key Words: disability; mental health; long-term condition; transition; young people

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Abstract

Numerous policy directives highlight the need for planned and well-coordinated support to enable young people with long-term conditions and disabilities to negotiate the transition to adulthood, including making the leap between children-orientated to adult-centred health services. The journey is complex and multi-dimensional. For young people with a disability, long-term condition or mental health problem there are additional challenges when transitioning between services with differences in expectations, delivery and culture. This article explores findings from six case studies of young people who have recently experienced transition to adult health and care services, triangulating inter-related perspectives; those of young people, parents and carers and where possible the professionals involved. One of the case studies illustrates how the challenges are actually experienced. Analysis of emerging themes across the case studies leads to key messages from families to inform strategic development of services and practice.

Introduction

In the report *Lost in Transition. Moving Young People between Child and Adult Health Services* (Royal College of Nursing, 2013) *Transition* is defined the purposeful, planned movement of young people with chronic physical and medical conditions from child-centred to adult-orientated health care systems. Previous versions of the report highlight that often young people's needs are overlooked or partially met. The issue is progressed in contemporary and systematically reviewed evidence (Crowley, et al , 2011) and a range of good practice guidance documents (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).

Young people's transitions to adulthood are non-linear, complex and shaped by a range of factors and circumstances. (Furlong and Cartmel, 1997.) These include personal situations, social and geographical locations and negotiating transitions in several parallel trajectories; education, employment, training, housing, family, income and relationships (Coles, 1995; Jones and Wallace, 1992). Transitions do not necessarily occur at the same rate along each aspect of young people's lives and young people will experience unequal and diverging paths into adulthood. (Jones, 2002.) Thompson, et al (2002) emphasise "critical moments", shaped by family; wellbeing and illness; education and rites of passage. The wider social and cultural environment including citizenship, leisure, consumption, geography and relationships interplay to make transition an individual experience.

For young people with a disability, long-term or life-limiting condition or mental health problem the challenges are compounded by the need to move between health, education and

social care services because significant differences in expectations, style of service delivery and culture are confronted. At the same time their own care needs will be evolving. In many cases, vulnerable or disabled young people may experience rushed transitions, which are stressful and lead to social exclusion. (Caton and Kagan, 2007.) The same people who have looked after them for as long as they can remember will have often met young people's care needs. 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 guidance on good practice in supporting effective transitions, including young people's involvement in the process to make the transition to adult services smoother. Standards define the need for 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.) Ensuring that young people's needs are paramount requires key workers with appropriate skills and knowledge and an ability to listen and respond to the needs of young people, whatever their level of ability. Effective transition to adult services is not a universally positive experience as there is frequently a shortfall between policy and practice. The result is confusion and frustration for young people, their families and the committed staff caring for them. Young people can find themselves without essential care or equipment because of the different ways services are provided, or while funding arrangements are resolved. (Care Quality Commission, 2014.)

“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.”
(Care Quality Commission, 2014.)

A Clinical Strategic Network in the north- west of England commissioned the project reported in this article. Aware of the challenges in getting transition planning and support right for young people with complex health needs and disabilities, the aim was to identify areas for service development by gaining deeper insight into the recent transition experiences of young people and families and the professionals involved. Four cases highlighted problematic transition experiences and two illustrated that despite numerous challenges effective transition planning, co-ordination and support can lead to positive outcomes for young people. This paper focusses on problematic aspects of the transition process.

Research Question

How can the experiences of young people, parents and professionals inform commissioners and service providers of the unmet challenges in providing effective models of support to enable 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 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 particularly effective in evaluation projects (Flybjerg, 2006.) Narratives within case studies can also empower participants to tell their stories and frame their experiences.

Semi-structured interviews with young people, parents and carers took place in their own homes to form the basis of the case studies. The perspective of a lead professional involved in planning and co-ordinating the transition process in partnership with the young person and their family was included where available.

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 order to inform future service development.

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, 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 main inclusion criteria for the study was young people who had experienced transition to adult services during the previous six months to three years. The young people lived within the sub-region covered by the Clinical Strategic Network and represented the following groups:

- Young people who have common long – term conditions such as diabetes and epilepsy, which are 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 hospital admissions
- Young people who have disabilities and complex needs
- Young people who received support from Child and Adolescent Mental Health Services.

Six young people, their parents and relevant professionals were recruited through the Clinical Strategic Network and its partners who distributed information and invitations to participate to families who met the inclusion criteria. The participants' names have been changed to preserve anonymity.

Results

Authenticity is a key to assuring the quality, trustworthiness and validity of qualitative research (Seale, 1999.) It is one of the three primary criteria used for establishing validity 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 had opportunity to make corrections or amendments when drafts were returned to them.

Thematic analysis

The case studies were analysed in light themes informed by good practice recommendations listed in the Care Quality Commission report "*From the Pond to the Sea*" (2014.) This report highlights the importance of a good Transition Plan and the use of Health Passports. The importance of a lead professional to support young people and their families through transition; agreed responsibility for funding early in the process and an approach, which is responsive to the needs of young people and their families are also emphasised.

Standards set out by the Royal College of Nursing (2013) also informed the thematic analysis process. The standards relate to three key areas; service provision, process and protocols and the key worker roles. The standards reflect essential principles including the paramountcy of young people's needs, that all services should be accessible and appropriate with genuinely agreed and shared protocols between adult and children's services being properly implemented.

A third reference point was Sir Ian Kennedy's review *Getting it Right for Children and Young People; overcoming cultural barriers in the NHS so as to meet their needs* (Kennedy, 2010.) This highlights an inappropriate division between funding streams for adult and children's services, which, whilst bureaucratically convenient, makes no sense to young people and families and undermine continuity of care.

Understanding Transition

Parents had a good understanding of what *Transition* means, and endeavoured to explain this to their children. One parent however asked, “*How can young people with learning disabilities be expected to negotiate transition when they don’t even know what that means?*” Some were aware of policy expectations, for example the recommendation that planning should start during the early teenage years, however some only started the process at 17 or 18 and feel that it was too late; some had transition mentioned at a timely point, but not fully explained and followed through.

Variable Transition Plans and Experiences

Two case studies demonstrate transition works well when planning is timely, informed and clearly and appropriately documented. A dedicated practitioner or team to coordinate is key and it works best with multi-agency involvement in regular planning meetings. Willingness to challenge traditional ways of thinking about commissioning and delivering services is essential. The majority of families were unable to identify a lead professional who took on this role. Ideally *Transition Teams* 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. This is in stark contrast to the experiences of four of the young people who described their experiences. Some of the practitioners also highlighted variability in levels of need and consequent complexity of transition planning.

Are young people still “Lost in Transition?”

The case studies indicate that documentation of *Transition Plans* for the majority of young people was poor – one parent had to devise her own to ensure appropriate assessment of her child’s needs. This can lead to fear and anxiety; at worst, it may lead to detrimental outcomes as a result discontinuity in management, This was illustrated by the case of one young person whose epilepsy was uncontrolled examination over a clinic appointment and was discharged from the children’s hospital without having attended an equivalent adult service provider. (He had been labelled as a non-attender because he had contacted the clinic to explain he had to prioritise a GCSE examination.) One case study demonstrated that a young person could have two very different transition experiences when receiving care under two consultants within the same hospital. Another 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.*”

Involvement in decision-making

It is possible to involve young people in decisions made about their future even when there are severe communication difficulties. This depends on the attitudes, values, knowledge and skills of individual practitioners or the young person having an informed parent or professional available as an advocate. Four case studies indicate young people may be overlooked in decision –making. This is worse when practitioners are not confident in communicating with young people who have learning, speech and language difficulties. Traditional ways of practicing means the need to work in partnership with young service users may not happen even when language and communication is not a barrier. Some practitioners failed to consult with parents too, or failed to continue to involve families following initial assessment.

One parent raised concerns that practitioners failed to share funding assessments with them before submitting them to approval panels. Another reported that discontinuity in the allocation of social workers had led to incomplete assessment of needs. Some of the parents 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.) Life changes since the transition became a *"nightmare"* for some parents and carers who were *"constantly chasing things that are not in place and feeling abandoned"* or having *"fallen through a crack because it is easier for busy professionals to let that happen."*

Parents perceived practitioners to be doing their best, but some do not know the family or understand their needs when making decisions about eligibility for new services, or removing existing services. At worst parents reported that adult-focussed practitioners may not understand the importance of sharing information with parents, or listening to them, even in emergency situations – this can lead to scenarios which compromise safety or leads to detrimental clinical decisions.

Losses and Gains

Several families lost previously valued services as a result of transition to adult services including a key contact to call if you need help in an emergency; a trusted professional who co-ordinates and oversees care. The result is discontinuity in management and decision-making or loss of essential services such as physiotherapy and hydrotherapy as well as specialist equipment (for example hoists needed in education settings.) Other losses included social care funding and services and individualised education support. Social isolation and increased family stress were consequences of the removal of social support, respite services and support for siblings and parents or carers. Families also acknowledged some gains following transition. One young person now has access to a counsellor and another now has a mental health practitioner who is supporting her to get back to college. Another parent has been able to gain support from care assistants (described as *"excellent"*) due to her child with complex disabilities receiving direct personal payments.

Illustrative Case Study: Holly's Story

This case study illuminates the complexity of the challenges faced by young people and their families, and illustrate why they may continue to feel *"lost"* following transition to adult services.

Holly is 23 years old. She lives with her mum (Jackie) dad (Pete) brother Ross (12) and two Guinea Pigs. Holly became unwell at 13 and received care and treatment at the regional oncology unit at a large children's hospital. Holly's treatment was successful in inducing a remission from leukaemia; however, she has multiple residual problems because of treatment. She needs to use a wheelchair due to a spinal tumour, has diabetes, a heart condition and is dependent upon assisted ventilation overnight. This means that Holly needs 24-hour care and lives a very restricted lifestyle, with consequent anxiety and low mood. Despite her problems, Holly demonstrates amazing courage and resilience.

Holly understands *Transition* to mean, “*Moving from one thing to another*” however she is unable to identify a single professional who co-ordinated her transition to adult services, recognising that several consultants and nurses were involved. Holly had no transition meetings. She remembers being told at a clinic appointment that she was moving over to adult services when she was 18 or 19. She then went for a visit to a ward at the district general hospital she would transfer to where she met one of her new adult consultants. Holly was advised of their new emergency admissions procedure.

Holly explains that because of her transition to adult services she now has to attend appointments at six hospitals instead of the two hospitals she attended previously. This involves having to meet more than 15 consultants and a range of other staff, rather than the few she with whom had previously built relationships. Holly says, “*I don’t fit into the jigsaw!*” Accessing adult acute and specialist services involves crossing regional boundaries. Holly was told initially that she must travel a four to five hour journey if she needed specialist oncology services in an emergency but this created considerable anxiety as Holly is unable to sit in her wheelchair for long periods because of her spinal tumour. Her attendance at a specialist centre with a shorter travelling distance was subsequently agreed.

Holly’s mum helps her to understand what is happening; they discuss things and Jackie helps her to express her views, but Holly still feels that she “*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*” because of Holly’s 24 hour care needs.

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 by group meetings, so whilst she thinks all agencies should be involved she would like to talk to them separately. She recommends that transition be staggered so it becomes less overwhelming, for example focussing on education transition at 17; social services at 18; health between 18 and 19 years of age.

“I think there should be a process that is followed for everyone so things have to happen and are not just forgotten.”

There have been numerous outcomes for Holly. Most significantly she describes feeling “*(even more) lonelier now – things have gone and nothing is there in its place.*” Lack of integration or coordination between (and within) health, social care, education sectors and community and voluntary sectors exacerbate Holly’s sense of isolation.

Holly’s health and social care transition experience

Holly says that consultants find it hard to talk to each other in one hospital so it is even harder across several. Mistakes happen because of discontinuity. Holly feels only her mum really knows what is going on. Holly acknowledges that she is receiving more specialist care, from the range of consultants who are now involved, including specialists

in neurology; cardiology; orthopaedics; spinal; gastrology and orthoptics. This is a potential benefit.

Holly explained that different departments made transition easier, ranging from “good” to “goodish.” What made some services “good” was that the consultant held clinics in both the children’s and adult hospital and there was a group for teenagers so Holly did not feel that she was entirely on her own. Holly felt that she had lost people she was confident in and has to trust many new people at one time. Holly often relies on her mum to explain things she struggles to understand. Adult service providers may not recognise this. One, for example, 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.

“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 recalls a meeting with a social worker from adult services, but felt excluded from the social care transition planning process and left feeling scared and unable to contribute. She was told that she could not be allocated her own social worker because her “health needs were too high.” This led to several community health meetings, which involved Diana nurses, a district nurse and agency staff but again Holly felt she was not part of the process. As a child, Holly had a named social worker and although there were sometimes difficulties, she knew whom to call if she had a problem.

“I didn’t know what I was losing or gaining – I was anxious and felt unsafe about my future... I didn’t know anything...nothing was written down... it went on around me... 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 transition

Holly recalls being told by a doctor that she has “the mental age of a 12 year old” but went back to her high school (after a two and a half year gap) once access to a part-time carer who was able to meet her health support needs was established. Holly’s parents “had to fight” for this, but were only able to gain support to allow 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 seven subjects.

Holly cannot recall any discussion regarding her continuing education. She just left school and then went for a meeting at her local college, but was left feeling very aware that they did not want her to go.

“I just wanted to go to college...They didn’t want me, even though I had the qualifications for the course and there was a spare place.”

She had part-time “health support” in school, however this wasn’t available in college. When Holly’s mum offered to come into the local college to support Holly the

college advised that would not be necessary. Eventually Holly attended mid- way through the year on a part-time basis on condition that Jackie was never more than five minutes away so able to be accessible at any time. Holly met enthusiastic and supportive people in the college but there were still problems, which led to her leaving. In one example, she described a care assistant persistently refusing to pass Holly the plastic-wrapped jug she needed to empty her urinary catheter. (Holly was unable to reach this from the rucksack on the back of her wheelchair.) The justification was that the care assistant was “*from education and that was a job for health.*” Holly is now socially isolated in comparison to her peers, however she endeavours to research the outside world using the internet to maintain her own record of current affairs.

Community and voluntary sector transition experience

As a teenager, Holly regularly attended a children’s hospice and became a young ambassador. Holly’s age means that she is now no longer able to attend and this contributes to her sense of social isolation. The commitment to family-centred care at the children’s hospice is not replicated at the local adult hospice and because Holly is still young, her parents feel that transition there would be inappropriate. There are consequences for Holly’s younger brother too. He is very distressed at having to leave behind friends he made at the siblings club run by the children’s hospice.

The three most important issues for Holly

- 1. I want people to show me what is happening and going to happen visually; meetings provide too much information so it helps to write things down so I can go back to it later.*
- 2. Stagger transitions so they are 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 do not know where to go for help. It is 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 professionals underestimate what the family are capable of when they read reports. She recognises some “*amazing people on the ground*”, but she and Pete have continually had to fight for everything. They are exhausted and have had to learn to choose their battles; not always for what they know is right, but those they can win and which are in Holly’s best interests.

Jackie finds Holly’s hospital care to be completely un-coordinated since her transition to adult services, with no sharing of information between consultants. On one occasion Holly had to attend three different hospitals in a single day and is often subjected to repeated painful investigations “*because different consultants like to do their own, even when a waste of precious N.H.S. resources.*” Poor information sharing can put Holly’s safety at risk.

“It needs Consultants to talk to each other – they seem to be able to manage it when they have to in an emergency!”

Jackie feels that she needs to be constantly vigilant, provide information, advocate for Holly and sometimes intervene. This is difficult when hospitals do not have a culture of working in partnership with parents.

Jackie and Pete are concerned that community services are sparse. Equipment is not made available until approval of a formal application following consideration at a meeting. Even when agreement has been reached delays still occur.

“We have to fight for everything – even Conti-sheets... they can get round reasonable adjustments if they want to”

Holly’s application to receive Direct Payments was refused and Jackie feels that Holly’s care needs are compromised as a result. A funding model involving a division between health and social care provides the basis of carer support commissions. Because of the withdrawal of social care support Holly now only receives funding from health commissioners. This means that despite her need for 24- hour care two carers visit between 9 and 11 in the morning. There are four further hours allocated for social support during the week and six hours on a Saturday. Holly’s carers were originally co-ordinated by the children’s community nursing team; however, one district nurse is now a single point of contact. Care support is reliant upon agency staff and Jackie and Pete worry because they can never be completely certain they will be there. Since moving to adult services, Holly no longer receives social worker support because the family did not meet eligibility criteria. This was not the only service taken away because of Holly’s move to adult services; she no longer has access to an occupational therapist.

The most concerning thing for Jackie is Holly’s social isolation. Holly is dependent upon her parents 24 hours a day and Jackie worries that this is not appropriate for a young woman. Whilst Holly talks to some of her school friends on-line occasionally, their lives have diverged. Despite Holly’s initial reluctance to attend the children’s hospice this has been the biggest loss for Holly as she has lost many of the friends she made. However, Holly does now have access to a counsellor once a month.

Jackie and Pete feel their life has totally changed. They are now *“up in the air.”* Transition for them has been totally did-jointed– Jackie says 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.

Discussion, conclusions and key messages from families

Recent reforms through the Children and Families Act (2014) place new duties on local authorities to revise the way support is provided for children and young people with special educational needs and disabilities to enable them to live happy and fulfilled lives. The spirit of this requirement has informed the authors’ thinking when considering findings from the case studies, alongside the wide –ranging guidance provided to define expected standards of transition support from a health care perspective.

Whilst there are some examples, in which transition practitioners and casework teams 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 universal. Several case studies indicate that families are unable to identify a key person who co-ordinated the transition process. Where practitioners with specialist roles in supporting transition are not available, it is evident that the young people fall through gaps in service provision or divisions in funding and commissioning arrangements. Whilst the use of Case Study methodology limits the generalisability of the findings, the depth of insight into the lived experience of the individual participants gained highlights that concerns about the effectiveness and accessibility of transition support and seamless service provision persist. The participants were motivated to share their experience in the hope that this would lead to future service improvements.

Four of the six case studies highlighted that transition planning was non-existent, inadequately followed through, or commenced too late. None of the participants mentioned the use of Health Passports and written plans were not in place for the majority of the young people. Their experiences highlight ineffective collaboration due to persistent cultural disconnections between health, social care and education services.

Recurrent examples of shortcomings include failing to recognise the level of anxiety raised because young people may not be ready to operate as adults in their new settings; they may still need to their parents to advocate on their behalf. Families have to adapt to the needs and culture of services, rather than receiving responsive services that focus on the unique needs of young service users. This means that many young people with specific and complex needs are still *“lost in transition.”* Joined-up thinking, integrated working and remodelling services around the needs of the service user are key to developing and delivering services that respond to unmet challenges. This is by no means a universal reality.

Participants in the project shared their priorities for getting transition planning and support right. Most importantly, the young person should be involved throughout and needs to feel secure that they will receive a service that is at least as effective in meeting their needs as the service that is familiar to them. The next priority was that a key worker or lead professional should manage the transition process and ensure integrated commissioning and services, taking the pressure of already exhausted and battle-weary parents and carers. Young people’s worries include having to get to know new people; fears around safety and competence; still needing parents there to explain and reassure. Having a young people’s group and special clinics can help to make them feel less alone, unsure, anxious, unsafe, or disempowered. Families suggested advocacy services would be helpful, particularly for young people with severe learning disabilities. To help families to overcome some of the barriers and navigate hurdles the support of experienced transition practitioners is essential.

Families recognised that improved transition planning should start earlier (before 18) and is best staggered at a manageable pace. Transition Plans should be in place for everyone so nobody gets lost, particularly more vulnerable families who may not have the confidence to fight for services. They asserted that practitioners should always

- Keep parents informed of outcomes of assessments, development of plans, what is happening and completed actions.
- Improve communication with other professionals, involving young people, parents and carers.

- Have a properly documented Transition Plan - you need the right tools; right time; right person to be effective so that no young people are left behind or without services.

As one parent put it “Above all don’t promise the Earth and then provide nothing” – if you make promises, you should follow them through! The Transition Team needs to be multi-disciplinary and stay together.”

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