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## **Leaving foster or residential care: a participatory study of care leavers' experiences of health and social care transitions**

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### **Abstract:**

*Background:* Young people in residential or foster care experience multiple transitions around their 18<sup>th</sup> birthday without the long term and consistent support from their family of origin that most of their peers can expect. We report a mixed methods qualitative study of transitions across health and social care services for children leaving care, providing narratives of what young people described as positive, and what they and professionals think might be improved. *Methods:* Data were collected in participatory meetings and individual interviews between young people and researchers (N=24), and individual interviews with practitioners (N=11). In addition to discussion and interview techniques, we used pictorial and other participatory methods. Interviews were coded by three members of the team and differences resolved with a fourth. Our analysis draws on thematic and framework approaches. *Findings:* Health was rarely at the top of any young person's agenda, although gaps in health care and exceptional care were both described. Housing, financial support and education took priority. Young people and professionals alike emphasized the importance of workers prepared to go the extra mile; of young people being able to contact professionals; and professionals being able to contact one another. *Conclusions:* Policy and practice aspirations for care leavers recommend gradual change but transfer rather than transition continues to be described by care leavers. Our data support the need for transition as a long-term process, with children and young people having early opportunities to prepare for citizenship. [238 words]

### **Key messages:**

- Despite a legal framework, policy and practice commitments, and transition guidelines, 'transfer' rather than 'transition' continues to be experienced.
- We found examples of exemplary practice but little by way of someone co-ordinating young people's transitions in the way a parent might.
- Young people may not be aware that after they turn 18 social services and health care providers no longer share information. Without parental support they need to take on the co-ordination of their own care or agree to data sharing, which can be a challenge.
- A commitment to listening to the voices of users is now well-entrenched in the NHS and social care. Ensuring that the expertise of care leavers is used to best effect remains a challenge.

## **Introduction**

Compared with young people living in families, young people leaving foster or residential care are expected to become independent early (National Audit Office, 2015). Their journey from childhood to adulthood is characterized not only by the social expectations of all young people as they mature, but by services changing as they turn 18 (McDonagh & Viner, 2006; Stein, 2012). Health outcomes for this group on average are poor in comparison with the wider population (Botchway, Quigley, & Gray, 2014; Rees, 2013; Stein & Dumaret, 2011). Some of those transferring out of paediatric into adult health care services will transfer across more than one specialty. Those moving out of Child and Adolescent Mental Health Services (CAMHS) may or may not be eligible for adult mental health services (Singh, 2009). Moving home will often require a move to a different general practice (GP).

These processes represent a challenge to all involved: young people may end up with several 'transition' workers and plans across agencies; professionals may duplicate work or believe others are picking up 'transition', and service planners are often restricted by funding streams tied to chronological age rather than individual developmental needs.

The last decade has seen an increased focus on transitions for young people often focused on specific health conditions or particular service users (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014; Reale & Bonati, 2015; van Staa, Jedeloo, van Meeteren, & Latour, 2011). In the UK, transition to independence in social care is underpinned by a legal framework (Stein, 2012) which is structured and experienced through local services, the availability or otherwise of housing, experiences in foster care and experiences of the social care, education and health systems (Barn, Andrew, & Mantovani, 2005; Stein, 2002; Ward, 2005).

Over 3.3 million adults in the UK aged between 20 and 34 were living with a parent or parents in 2013. That is 26% of this age group and a significant increase over the last two decades (The Office for National Statistics, 2014). In comparison, young people in care start preparation for transition around their 17<sup>th</sup> birthday, with the transfer happening at 18. They continue to receive support from a leaving care team until the age of 21, or 25 if they are in education or work (Department for Education and Skills, 2007). In health care, transition to

adult services will also usually happen at age 18, although some services operate with an adolescent service which can delay the age of transfer.

Principles for good transitional care have been set out in policy, legislation and guidance ("The Care Act," 2014; "The Children and Families Act," 2014) . Although there is general agreement on principles of good practice, the translational issues are challenging (Gorter, Stewart, & Woodbury-Smith, 2011; McDonagh & Gleeson, 2011; Shaw, Watanabe, Rankin, & McDonagh, 2014).

Recognising that for many care leavers, transitions involve intra and inter-organisational complexities, this study aimed to understand how these are experienced by young people, and some of the key professionals supporting them. We spoke to young people and key agencies involved in their transition between children's (paediatric and social care) and adult services and asked our interviewees what they find helpful during this period and what is challenging in terms of how support is provided. Given the emphasis across UK policy on people's involvement in their own care, we also explored whether young people felt that they had the opportunity to participate in their transition planning as recommended in policy documents.

## **Methods**

Building on the ambition of professionals to listen to the voices of those receiving services, this was a participatory piece of work in which we came to the field with open questions so as to focus on participants' views on the most important issues for them.

### *Recruitment and participants*

The study was conducted in one inner-city local authority in the UK. We recruited young people (N=24) from a participatory project in Children's Services, and the Leaving Care service. All young people use health services to some extent and in our sample of 24, 17 disclosed engagement with paediatric or adult specialist health services, or both. Eleven of the twenty-four had arrived in the UK unaccompanied; six from Europe and five from Africa.

Of the total sample, eleven young people were aged 16/17 and just starting their transitions out of care. A further 13 young people were aged 18-24 and twelve of them had transferred from Children's Services to the Leaving Care Team while one was 'staying put' with foster carers. The sample was ethnically diverse, comprising young people identifying as Black British, White British, Black Caribbean, White Other, Black Other, Chinese and Mixed Race.

The health conditions described by the young people included heart conditions, eye conditions, diabetes, chronic pain, haematological conditions, respiratory conditions, orthopaedic problems, acute and chronic mental health needs and

digestive disorders. Seven young people were or had been involved with CAMHS and two had experienced being sectioned.

Of the ten young people who described receiving specialist health services for a physical condition, seven had moved or were about to move from paediatrics to adult health services and three were diagnosed with a physical health condition while in the process of transitioning into adult health services. Of the nine people who had accessed services for mental health concerns, two were accessing CAMHS at the time of the interviews, two had transferred from CAMHS to adult services, and two had mental health needs first addressed after transition. Three young people had accessed CAMHS but did not transition to adult services.

We interviewed eleven professionals. Four were involved in the leaving care service including two personal advisors (PAs), a strategic manager and an education link advisor. Two were working within CAMHS including a team manager for the CAMHS children looked after team and a transition lead. Two worked within the Children Looked After health team including the designated doctor and a leaving care nurse. We also interviewed a special education teacher with special responsibilities for transition, a specialist hospital nurse and a young person's advocate.

#### *Data gathering*

We gathered data through group meetings and individual interviews with young people, and individual interviews with practitioners. Eight young people attended meeting/s only, nine young people only attended individual interviews, and seven attended both.

We held five participatory meetings (Walker, 2007). The first deliberated the research questions and established a shared agenda for the work. The subsequent meetings covered: 1. young people's understandings of 'transition', 2. their experiences of services, 3. their participation in transition processes, and 4. emerging findings.

We used a number of tools to explore 'transition' (Bolton, Pole, & Mizen, 2001; Broad & Saunders, 1998; Darbyshire, Macdougall, & Schiller, 2005; Kellett, 2005; Kirby, 2004; O'Connell, 2012): young people cut images from magazines and produced collages of their transition experiences and we used visual prompts in group discussions to build up an image of the services they received during this period.

The individual interviews were semi-structured and conversational in nature, focussing on the young person's current situation, the leaving care process, health service transition/s, and reflections on being in 'transition'. Although young men were well represented in group interviews (including the two from which we quote below), they were less willing to participate in individual meetings and this is reflected in the gender balance of our findings below.

The interviews with practitioners were semi-structured and discussed what was working well, and what might work better.

### *Analysis*

The study had a health focus viewed through the lens of young peoples' understandings of transition and participation. The perspectives we have brought to the analysis are informed by our backgrounds as researchers in child public health (HR, KL), health interventions (HR, AI), social care (HR, KL), and childhood studies (HR, KL). CMK is a practising paediatrician in academic training.

Our preliminary analyses began during data gathering. We listened to, and subsequently read transcriptions of the interviews and group meetings, reflecting on fieldwork notes and the collages. At this stage we produced data accounting and summary sheets to consider how the data was addressing our study objectives (Miles & Huberman, 1994). Once data gathering was complete, interviews were coded individually by three members of the team (KL, HR, and CMK) and put onto a coding map. We coded on the basis of our research questions and additional themes emerging from the data. As the coding map grew, overlapping codes were merged and collapsed. The themes were then collated into a narrative and commented by a fourth team member (AI).

A short film presenting some of the findings [<http://www.ucl.ac.uk/cpru/news-events/events/growing-up-happy-in-England/Programme-Systems>] and a short summary were fed back to young care leavers and three members of a Children's Services team for comment.

### *Ethics*

The study was approved by the UK Social Care Research Ethics Committee (15IEC08/0009). In addition to the conditions set out by the ethics committee, our team considered ethics an ongoing concern during fieldwork encounters and worked using the concept of an 'ethical radar' (Skånfors, 2009).

## **Results**

Table 1 below provides an overview of the main themes and codes, and sub-themes that emerged from the analysis of a rich dataset.

<b>THEMES/codes</b>	<b>Quotes</b>
<i>Cross-cutting themes relevant to and informed understanding of all main themes:</i>	
HOUSING: bidding, getting a flat, inappropriate, scary, used by friends, frequent moves	<b>So can you think about if you were to pick a picture of transition what would you choose?</b> Key. <b>A key? Okay. What do people think, a key?</b> Yeah.

	<p><b>What does that symbolise about transition?</b>          So you're moving one place to another place so you're going to have your own set of keys if you know what I mean? Like so you only have, like when I say key having a key to your own house so when you're moving so you've got your key.          Group meeting</p>
<p>ADULT SERVICES: Different culture and changes to communication between services, changing status (implications of being 'adults')</p>	<p>"...with the adult services they just kind of leave you to your own devices... which is understandable, I mean you are an adult and you should know for yourself."          "Mary", aged 20</p>
<p>"Systems" child, stigmatization, judged, failed, drawn into caring type careers, sense of injustice when not believed or when your side of story unheard</p>	<p>"Social Service were talking to [my foster mum], but they never asked me what's happening. And then I.. [asked] them "why don't you ask me? Why are you not talking to me? You make your decisions and you never told me"          "Serena", aged 19</p>
<p><i>Main theme: Transitioning from childhood to adulthood</i></p>	
<p>ADULTHOOD: juxtaposition with childhood          Passport/driving licence/independent housing</p>	<p>"...all your life ...decisions have been made on your behalf so now that you've got to suddenly become an adult and make decisions yourself. You think, am I making the right decision or can I even make a decision, you can doubt yourself."          "April", aged 23</p>
<p>TRANSITION: R-engaging with birth family, reading case notes, uncertainty/anxiety/exiting, not ready, housing, money/budgeting, conflicting status of being a child/adult</p>	<p>"I knew that eventually I'd get a house, I wasn't in a rush to get a house 'cos I knew the responsibilities that came with it, I know a lot of young people are really excited about moving out into their own, I was frightened..          "Kayla", aged 21</p>
<p>SOCIAL NETWORKS: friends, birth family, foster family (previous or current), previous/current workers (teachers, counsellors, social workers), desire for a long term mentor/stable figure/church/college</p>	<p><b>... what else is going on in that period that isn't services but is important?</b>          YP1: I think you're between stages in many aspects, you're a child and an adult all at the same time ... you've got friendship groups changing, you've got all types of relationships changing...          YP2: True.          YP3: Your body might change as well because you're at an age where you're growing up.          YP4: Yeah.          YP1: ... like "Kayla" was saying within them times you're going to have different changes anyway so</p>

	<p>like you're going to be doing what a normal girl would do, will go out with friends and stuff like have relationships and stuff like that...</p> <p style="text-align: right;">Group meeting</p>
<p><b>INDIVIDUAL PATHWAYS:</b> Young people emphasizing how every journey differs/depends on the individual, professionals going above and beyond</p>	<p>"It's sort of exciting at the same time as being anxious and sort of, yeah, because it's like I'm stepping into like the stage of adulthood now... theoretically speaking, 18/19 is sort of teenage, but in the adult world, 18's classed as a man, so..."</p> <p style="text-align: right;">"James", aged 17</p>
<p><i>Main theme: Healthcare during transition</i></p>	
<p><b>HEALTHCARE:</b> Health not a priority – yet essential, health-housing issues, GP changes, stigmatisation, lack of service knowledge, CLA nurses, support from adult at first adult appointment</p>	<p><b>What about your general practitioner, your doctor?</b> [No immediate response] <b>No?</b> No-one really goes to the doctors unless you're ill [Laughter]</p> <p style="text-align: right;">Group meeting</p> <p><b>Where's the GP in all of this?</b> Not really seen. <b>GP is not really seen.... ?</b> Invisible person. "Maisy", aged 18</p>
<p><i>Main theme: Social care during transition</i></p>	
<p><b>SOCIAL CARE:</b> Inaccessible/unreliable workers, changing placements/workers, pushing for support, preparation for transition</p>	<p>"...like someone call and say they're not going to be in because they're ill or on annual leave or something, I think that is what they're lacking right now, that communication..."</p> <p style="text-align: right;">"Silvia", aged 20</p>
<p><i>Main theme: Participation in own transition</i></p>	
<p><b>PARTICIPATION:</b> Adult-led, listened to/not heard, surveillance, pushing for support, not engaging, young person centred, choices (limited), are you participating if you are incentivised?</p>	<p>"I just let them do their thing kind of thing... I'm quite an independent person anyway so when I'm being told that this is going to happen with this person and this is going to happen with this person I'm just waiting for it to happen... there's not really much I can do..."</p> <p style="text-align: right;">"Ashley", aged 17</p>
<p><b>PARTICIPATION PROJECT</b> (run by children's services): support/participation/engagement/rights/career opportunities/internships</p>	<p>"I found out everything from either being in [participation project] or from my friend who also comes to [participation project], and who's also in care. <b>Right, what did you find out that you, they hadn't told you?</b> Everything ... about the money ... going to college you can get bursaries ... there's a lot of things even my foster carer didn't know ... I find out new things all the time when I come to [participation project]"</p>

	"Kalenda", aged 17
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[TABLE 1: Themes and exemplary quotes]

The following narrative is structured around young people's understanding and experiences of transitioning to adulthood, young people and professionals' narratives on transitions from child to adult health and social care services, and young people's understandings of their participation in these transitions.

*Transitioning from childhood to adulthood*

Young people aged 16 – 17 looked forward to moving out of foster care and being in charge of their own lives. Being 'adult' was associated with freedom, having their own flat and getting a drivers' licence and a job (Images 1 & 2).



[Image 1: "This is my key to my house... Feel like a car like I'm moving, I'm moving forwards, my transition."]





[Image 2: [used the image of a cake to illustrate his wish for a nice career] "I like the goat but it's got a beard, it's grown-up basically... And the wine on his head is that he's got the freedom to drink..."]

Young people approaching transition and those who had moved on also spoke of a darker side to transition - social isolation and insecurities. Some felt on reflection that they had been too eager to leave, and missed the family environment of foster care once they were on their own. Practitioners also described tensions when young people re-engaged with their birth family, or read their case notes.

Housing emerged as a key contributor to well-being during transition. Some young people spoke of feeling unsafe in semi-independent accommodation, feeling used by friends when they got their own flat, the uncertainty of bidding for flats, and how nervous they felt when first living alone.

"...it was just so fast, so I think they could have given me a bit more time to get my head around it and especially leaving foster care and going into

semi-independent [accommodation]..."

"Shirley", aged 22

### *Healthcare during transition*

Health was rarely at the top of any care leaver's agenda. When asked to map out the services important during transition, health services were missing from suggestions. There was also a gap in understanding of how the healthcare system works. With only two exceptions, GPs were not mentioned by young people as prominent, although some people spoke of complications related to moving GPs when you have a long-term health condition. In some cases, health care was accessed through A&E and voluntary sector agencies.

Most young people who were in frequent contact with NHS providers spoke warmly of their healthcare practitioners, in particular when they had supported them beyond the clinical encounter, for example by writing letters of support for adapted housing.

One young person with a physical health condition described an exemplary transition to adult services corresponding with principles of good practice (McDonagh & Gleeson, 2011). She had been told about adult services when she was 16. A nurse from adult services held clinics in the paediatric department. This nurse had spoken regularly to her about transfer and the young person herself made the choice to move over. In contrast, another young person had met once with her healthcare team to discuss transition, but the transfer to adult services happened without warning.

"...as soon as I hit their eighteen deadline they wheeled my bed from one floor to the other..."

"Maisy", aged 18

Others spoke of being unprepared for what adult services entailed in terms of changed expectations for their own input, changes in provision, and the different culture in adult services. This was echoed by those transferred from CAMHS to adult mental health services.

"they .. [said] 'it's just like this but just for adults' but when I did go there it wasn't like CAMHS... 'cos I'd see people sitting there talking to themselves and, you know, just doing certain things and it would scare me 'cos I never saw that in the young people service..."

"Shirley", aged 22

Young people appreciated the children looked after health team. In this authority, the Children Looked After nurse would travel to the child's placement for health assessments. A benefit of this was consistency, and a comprehensive health history report on leaving care. Young people got to know the nurses and would approach them for health information during transition. Young people found it

helpful that the looked after children nurse ran a drop-in clinic in the leaving care team, but not all knew of this service.

Some young people did not want their health histories to be known beyond the health care team and there was concern about the stigma of healthcare staff knowing them as care leavers from their case notes. Two suggested that some healthcare professionals need more training, with particular attention to being non-judgemental about this group.

"sometimes... you don't really want people to know you're in foster care because some people just judge you, they don't really know why people are in foster care, they will think that "oh maybe you are a bad person or like your family doesn't want you"

"Hayley", aged 17

That said, some young people felt that they would have preferred more communication between their PAs and their specialist healthcare providers. A specialist health practitioner described how helpful it had been to attend review meetings, and suggested that invitations from social care go to the whole specialist team not just the consultant.

#### *Social care during transition*

A recurrent theme in the interviews was the need for consistent support from a responsive, knowledgeable and easily contactable social worker or PA and some felt that the lack of this had impacted directly on their transitions. The majority had experienced multiple changes in workers, a factor long acknowledged as a problem for young people who need stability and consistency (Held, 2005; Holland, Faulkner, & Perez-del-Aguila, 2005). In turn, practitioners described the challenge of heavy caseloads and paperwork.

Young people and practitioners alike grumbled about the others' time keeping. From the young people, this included PAs or social workers being slow in getting back to them. At one group meeting young people chose the image of a clock to illustrate the slow responding worker.

Yp1: Well my Social Worker...

Yp2: She's just long full stop.

**Q: To what, to do what?**

Yp1: Anything in general.

Yp2: Anything or she never calls me, I always have to call her all the time, like I arrange the meetings, she never ever...

Group meeting

Young people also spoke of not being able to get hold of their PA. Some acknowledged that this could be due to workers having a lot to do, but nevertheless raised it as a concern. This was echoed by leaving care practitioners

themselves who felt pushed for time.

*Participation in own transition*

Whilst young people tended to describe feeling central to the planning of their transitions, their narratives almost always described adult-led transitions. Some described not being able to participate in, or even informed about, important decisions, for example the involvement of a birth parent. Some described going along with decisions rather than actively participating. At the same time, practitioners spoke of opportunities for formal participation into the shaping of services sometimes being taken up, sometimes not:

“The group is open for young people to come to but we’ve never managed to find a time when they could come....”

Practitioner

Since the main avenue of recruitment to this study was through a local social services participation project, many of the young people we spoke to did have experience of participation. They recounted how they were valued for their input, and this was echoed by professionals.

**Discussion**

Transition into adulthood has received considerable attention in recent years for young people inside and outside health and social care services (DeLuca, Godden, Hutchinson, & Versnel, 2015; National Audit Office, 2015; NICE, 2014, 2016). Our study points to the particular complexities experienced by young people who need to engage across and within sectors during their transition into independence. Some participants described themselves as ‘systems children’ and had experienced multiple moves in and out of the looked after system with a range of social workers and foster carers (Sinclair, Baker, Lee, & Gibbs, 2007) in addition to the complexities associated with their healthcare transitions.

The system aims to care for these young people so that they reach adulthood ready to live independently. Health and social care is intrinsically linked, and their health and well-being depends on good support so they can influence their own life trajectories. This is mirrored in our findings, and others’, where housing, financial support and education took priority in young peoples’ narratives of health and well-being (Dixon, 2008; Liabo, 2016; Wade & Dixon, 2006) A key question for health policy and organisation is how we can retain the person-centredness of children’s services into adult services, and through multi-agency work achieve a holistic approach to transition (Beresford, 2004).

A recent NICE guideline refers to the need for transition to be ‘purposeful and planned’, and a process rather than an event (NICE, 2016). Practitioners in our study also spoke of the importance of preparation for transfer, and support

afterwards, including a gradual process, so that young people could learn to make safe decisions and take responsibility for them. Looking at these findings in the context of the wider transition literature over several decades, it is clear that these are enduring messages (Fegran et al., 2014; Gorter et al., 2011; Stein, 2006). Our findings further point to the need for young people to be prepared for the implications of turning 18 in terms of understanding their new role as coordinators of their own health and social care. They require support to use this role wisely, particularly if they are unable to draw on wider family or other support.

The children's rights literature argues for a balance between protection and participation, recognising that without participation it is difficult to achieve adequate protection (Winter, 2006). This becomes particularly evident during transition. If young people are not prepared and given gradual opportunities for participation in their health and social care decision-making, they can no longer be protected once they turn 18 and are treated as decision-makers in charge of their lives and health decisions.

In regards to provision, practitioners spoke of inequities in formal access to support from a personal advisor, and felt that the 24-years formal cut-off should be taken up by all services, including health and CAMHS. Some studies have indicated that it might be beneficial for young people to stay in care beyond the age of 18 (Courtney & Dworsky, 2006; Munro, Lushy, The National Care Advisory Service, Maskell-Graham, & Ward, 2012). In our sample, some young people were not only surviving but thriving through transition. Others were struggling, which suggests that cuts-offs related to a young person's individual development is more appropriate than a chronological cut-off.

### **Strengths and limitations**

A strength of this study is that while policies are made nationally, they are implemented (or not) locally. We were able to interview care leavers and professionals in one metropolitan borough in order to explore how things are working on the ground. Two feedback meetings with young people we interviewed, others in the same situation, and some practitioners, helped us to hone our findings. The strength of the study is also a limitation. This study was undertaken in one area where services are acknowledged as good, and health and social care for children in the care system are co-located. The young people were recruited through a participatory service run within children's services and the service contacts shared with us. This means that this is not a population sample. However, since even in this relatively well-served population, problems were identified, it is likely that if anything, this study may be an under-estimate of the kinds of challenges faced by young people and services. Finally, this work may be less salient in countries without well-developed child welfare systems or health systems free at the point of use.

## **Conclusion**

The fine-grained data collected here highlights how policy developments in the care-leaving system, and aspirations in health and social care for user involvement are experienced by users. Our data supports an understanding of transition as a process encompassing preparation, transfer, and settling in. Descriptions of 'good' transitions included each of these steps, with consistent and planned support from one or more adults. As such, it is not just a matter of care leavers transferring well into adult services, but managing the process of becoming an independent adult.

These findings point to the importance of early and gradual introduction to participation in health and social care decision-making. Whilst person-centred care in paediatrics will invariably include parents, for children in care, the involvement of social workers or foster carers is less straightforward given placement moves and worker turnover. The 'child' herself may, in some cases, have extensive pre-care experiences of 'taking charge' of herself and others from an early age, but may need additional encouragement in applying participatory skills as a young adult.

In regards to getting transition 'right' for this group, our data suggest that what is required may not be *additional* services, but more manageable caseloads, more housing options, service co-ordination and personal support during transition, and recognition of the centrality of young people's active participation. There is clearly scope for enhancing children's capacities for participation in decision-making from very early on in life so that that they can be prepared for what the world expects of them, what they can expect of others, and how they might impact positively on the world as adults.

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