WP 2.2 Addressing Objective 2: to identify the features of transitional healthcare that are effective and efficient

Recent reviews have explored the different aspects of transitional healthcare, focusing on the experiences of young people[44, 51] and parents.[83] This work shows how the process of healthcare transition disrupts the lives of young people and their families. Lugasi's[51] review of 46 quantitative and qualitative studies, show how patients describe child services as 'a familiar and comfortable environment, and reported feelings of trust toward their health care providers'. As such, they can develop 'attachment' to child services and have problems to 'detach themselves'.[196] Narratives of certainty within child services and uncertainty about what to expect in adult services were confounded by direct or second-hand experiences of sub-optimal care from adult services. The issue of trust is identified, both trust in adult providers' abilities and knowledge to manage young people with their specific condition and trust in child service providers' reports on the competence of adult services. The review also highlights how transfer can be experienced as an 'abrupt event', through lack of knowledge and information about what to expect. Knowledge gained through joint clinics was therefore especially valued, as this

> 'reduced patients' fears and concerns about transition and provided them with an opportunity to create relationships with providers in [adult services], to get to know a familiar face before transfer, and improved transition outcomes'[50]

They argue that such meetings, ideally, over time rather than as a one off event, can help young people prepare for transition. Finally, they highlight, the role of shifting responsibilities, given young people's 'wish for independence'. At times, parents still offer support, but young people also report that parents will not always 'let them' enact such independence.

Lugasi[51] draw on selected elements of Schumacher and Meleis[197] conceptual model of transition in a range of developmental, situational and health-illness transitions contexts. They highlight the need to focus on: positive meaning; managing expectations; increasing knowledge and skills to 'empower' young people; joint planning with young people; and facilitative environments, including such aspects as transition coordinator and young adult clinic. Fegran's[44] review, focuses on 18 qualitative, including many of the 21 qualitative studies reviewed by Lugasi [51] and highlights four similar elements: facing changes in significant relationships; moving from familiar to unknown ward cultures; being prepared for transfer; and achieving responsibility. Again, we see the centrality of 'close relationships' that young people develop in child services and that prior experiences and knowledge is no longer relevant. Also, we again see a narrative of feeling 'unprepared' and so a 'need for guidance and support'. Finally, we see the same focus on developing, enabling and forcing 'movement to towards independence' and problems of 'parents letting go'.

In this way, these reviews, and many of the original studies, echo a core issue of transition, in whatever context, be it tied to the onset of a long term condition, so a transition from health to ill health, to changes in education, from secondary school to college or university.

> At the individual level … periods of transition are characterised by disconnectedness from the individual's current social context, a transient unfamiliarity with a new surrounding environment, the emergence of new needs that must be met, and the replacement of an existing set of expectations with new ones.[198]

Transition is a disruption, or following,[89] a breach in taken-for-granted experiences, knowledge and expectations. It involves people having to adapt to a new set of circumstances, to learn from and develop new experiences, knowledge and expectations.

In much of this literature, the disruption of the healthcare, the movement from child to adult services is characterised by a narrative of the young person as moving from 'dependence' to 'independence'. The figure of the parent is seen as central in this process. Heath's review of 36 qualitative papers about parents' experiences and views on transition highlights the range of work they engage with. The review focus on how parents are central, especially mothers, in supporting the young person. They work to enable gradual 'independence-building' over time, supporting and enabling 'healthcare autonomy' to develop, at times engaging in a partnership approach, at other times 'stepping in to provide respite'. Such work impacts on them, echoing the young people's experience discussed above, in that they feel uncertain and anxious and at times reluctant 'to relinquish control' and this 'delayed the onset of young person autonomy'. Again, as with young people, they too go through a process of transition, from 'managerial role' to a new 'consultant role'.[199] Finally, where transition is sub-optimal we see the same focus on the loss of 'support, resources and trusted relationships'[83] that parents found available through child services.

Aims
To investigate young people's experiences of healthcare transition services.
- Explore young people's experiences of healthcare transition services over time
- Explore the experiences of healthcare transition service provision of lay people who are identified as significant in the young people's transition journey
- Explore the experiences of healthcare transition service provision of health professionals' who are identified as significant in the young people's transition journey
- Describe how healthcare transition services are operationalized in clinical encounters

Methods
A longitudinal multi-method qualitative study was conducted with young people. Young people were recruited from the longitudinal quantitative study (WP2.1). They were also asked to identify a lay person and a health professional significant to their healthcare experience; and a consultation that the researcher could observe.

Data collection took place between June 2013 and June 2016. The recruitment of young people was driven by criterion and theoretical sampling.[85] Young people (n=13) were aged 4-18 at the first interview. Family members (n=14) were identified by young people and included: ten mothers, three fathers/step-fathers and one brother. Health professionals (n=19) included seven paediatric consultants, five paediatric nurses/AHPs, three adult consultants and four adult nurses/AHPs.

The Interview Schedule is at the end of this report.

Thirteen young people were interviewed once, with four of them interviewed again at least eighteen months after first interview. The young people were interviewed on their own or with a relative if they wished. Fourteen family members were interviewed once, with eight of them twice, at least eighteen months after first interview. We also interviewed thirteen health professionals, nine from paediatric services and four from adult services. We undertook first interviews with 40 people (see Table 19). With thirty of these interviews, the young person had yet to transfer, with twelve, the young person had transferred. We also observed seven consultations, four whilst the young person was in paediatric services and three post-transfer in adult services. Twenty participants took part in interviews only, six in observations only and twenty took part in interviews and observations.

Table 19: Participants recruited for the study by condition, identity and method of data collection

		Diabetes	Cerebral palsy	ASD	Total
Participants for first interview	Young people	4	5	4	13
	Family member	4	6	4	14
	Health professionals	4	4	5	13
	Total	**12**	**15**	**13**	**40**
Participants involved in observations	Young People	3	2	2	7
	Family member	3	3	2	8
	Health professionals	6	3	2	11
	Total	**12**	**8**	**6**	**26**

Observations were recorded in contemporaneous field notes. Formal interviews were audio-recorded, transcribed, edited to ensure respondents anonymity and then analysed alongside anonymized field notes. All analysis was conducted according to the standard procedures of rigorous qualitative analysis.[86] We used procedures from first-generation grounded theory - coding, constant comparison, memoing[87] - and from analytic induction - deviant case analysis.[88] Data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored in subsequent ones. We undertook independent coding and cross checking, team data sessions and data triangulation (different times and persons) and between-method triangulation (interview, observation).

Analysis
All names below have been altered to ensure anonymity and maintain confidentiality.

As one parent outlined, the actual process of transfer from children's to adults' services, 'takes five minutes' (Angela, Family). However, crossing this organisational boundary takes practical, cognitive and emotional work, work that young people, family members and health professionals engage with, often over a long period of time. The young person has usually been in a specific child service for some time, often since early childhood. The family, especially the mother, have developed good working understandings of the best ways to support the management of the young person's specific health condition(s), and importantly, how to effectively navigate, manage and engage with the child health service system. The health professionals often have significant knowledge of the young person and their wider psychosocial context. Centrally, they have all worked to build relations of trust. The organisational process of transfer ends those relationships and calls the young people and their families' expectations, knowledge and practices into question.

All the services worked to support and effectively manage the range of transitions that the young person goes through, including the healthcare transition. They were aware of the implications of an 'unsuccessful' transition and how people can 'drop off the system' (Carlos, HP) or 'disengage' (Pete, HP). As one health professional noted

> And I, I suppose that's my biggest problem with, with transition is, is that I feel that I'm transitioning them to something that isn't actually going to meet their needs if they're vulnerable, or at risk, or not robust. And many young people aren't. (Redgrave, HP)

Some health professionals felt that some young people were not always 'robust', not always ready to transfer when they reached a specific chronological. Given this context, they all had some kinds of formal or informal plans and procedures for transition and transfer that sought to prepare the young person and their family. In what follows, we will outline the practical experience of young people, families and health professionals, we will explore the informal and formal plans and procedures that were implemented within and across the services. This will be structured by focusing on each of the proposed beneficial features (PBF). Table 20 offers an overview of implementation issues.

Table 20: Summary of evidence for and determinants of implementation of the proposed beneficial features

Proposed beneficial feature	Evidence of implementation	Determinants of implementation
Age-banded clinic	Limited: only seen in diabetes services	Often not feasible due to logistics of managing appointments, spatial restrictions or low numbers of young people. In practice, situated alongside other adult clinics, with parent's frightened by visibility of ill adults and health professionals aware of visibility 'problem'. Young people report 'not being fussed'.
Meet adult team before transfer	Variable: some services offer single joint meeting or shared appointments	Dependent on relations with adult team(s). In services that provide, meetings do not always happen or are effective. Problematic when low frequency of meetings, young person moving away (e.g. University), adult practitioner not person who will provide care, or general practitioner is missing (e.g. transfer to primary care).
Promotion of health self-efficacy	Variable: some services provided but in a very informal, ad hoc way.	Can occur in context of long term, trust-based, relationships with specific health professional. Minimal without continuity of personal, with low frequency of visits, and when not part of service culture.
Written transition plan	Very limited: one service offered formal plan.	One service had implemented as part of research project, but withdrew due to lack of resources and motivation to continue. Some practitioners resisted a written plan, as saw interaction is key over more forms and that such forms get forgotten or lost. Informal practices can lead to lack of awareness, knowledge and understanding of process.
Parents engaged appropriately	Extensive: all services report engaging parents.	Interdependence as service norm for some practitioners and so seek to enable appropriate involvement. Some see interdependence as demonstrating problematic attachment, and seek to minimise, often referring to legal issues around patient confidentiality.
Key worker	Variable: services may report designated key worker, but young people and parents often unaware.	In practice, most young people and families name 'their' de facto key worker – someone they trust, seen consistently, highly supportive and accessible. In practice, a parent – usually mother – takes this role.
Coordinated team	Variable: some services demonstrated aspects.	Largely dependent on service structures. Collaboration and coordination between team members can occur formally and informally.
Holistic life skills training	Very limited: few services provided elements albeit in a very informal, ad hoc way.	Some services had not considered, others had not considered it their responsibility. Education, social services, charities, and family were already providing this – or, if not, young people, parents and services felt they should be. All felt young people should be signposted to relevant services outside NHS.
Transition manager for clinical team	Very limited: one service reported recent introduction.	One service introduced, as realised need, but still developing remit for role. Many services would like to implement, but dependent on resources, managing workload and competing demands.

Age banded clinic: the organisation of groups or the organisation of clinical mind-sets?
Within our dataset, formalised age-banded clinics are only reported by young people attending diabetes services. We observed the appointments of two young people with diabetes, as they attended age-banded clinics in adult outpatients' wards. Neither of the young people reported this experience as being problematic, one outlining that she's 'not really fussed by that' (Ruth). However, both their parents and health professionals discussed a range of concerns. One parent Judy, described it as 'quite f- frightening I guess is the word', and Ralph (Family) describes it as 'not intimidating but' he thinks that the young people would be 'more comfortable' without seeing such older people. He later describes the ward environment as 'full of fat, old people'. Judy outlined similar concerns

> It is a young adults' clinic, but you go and there's no other young people there. Whether they stagger them. You're sitting with people in wheelchairs, with amputees, the great, big older people that have obviously got type two. It's not a, a young clinic that you sit there and everyone's between 18 and 25. … Everyone's attending other things. So there's amputees there because it's with podiatry. Erm, and then you get the, the lady that can't walk (Judy, Family)

Both parents are concerned about the negative possibilities of such visual interaction with older people with diabetes. The diabetes health professionals raised similar points

> I think what we know is that it can be very off putting for young adults, say, for example, you know, if the waiting room is full of people with a very different demographic, you know, elderly, amputees or blind people, or whatever. Not that they shouldn't see those people, but I think, you know, it's partly it plays on their fears for what the future holds (Redgrave, HP)

Young people are seen by their parents and health professionals as needing protection from the issues they may face as adults with a long term health condition, while at the same time recognising that they should not hide the reality from them.
We see a similar narrative of the problems of visual interaction with accounts of parents of young people with other conditions. For example, Daisy, a parent, recounts their first visit to an adult service

> the whole atmosphere and everything was different to what he was used to. There was a young lad in the waiting room in a prison uniform who was obviously in a bit of a mood and was stomping about and clashing doors and swearing and what-have-you, it was a bit of a shock to the system from what he was used to (Daisy, Family)

However, the young person offers a more pragmatic narrative, that although he 'wasn't used to it' you 'just need to get on with it', that 'everyone's going to need help' (Darryl). In the child services that Darryl visited previously, such age-banded clinics, may occur, but not in any 'structured way', but rather a clinic list may, at times, have 'people of similar ages' (Delia, HP). One group within a service had historically offered age-banded clinics to young people attending specialist schooling and were beginning to expand the service. Another service reported that such an ad hoc, emergent, version occurred in some of the group sessions allied health professionals ran. In these groups sessions

> they have had increased benefits from recognising others with similar needs, feeling part of a group, that they're not isolated, that they're not alone and often it's generated friendships among them (Lucy, HP).

In this way, ideas around peer-support can be enacted in such group sessions. Albeit, we should note the caveat that group sessions often can be poorly attended by young people.
In very general terms all young people reported a preference for the 'idea' of appointments in outpatients wards that are set-up to support young people, over spaces that are designed to facilitate the play of babies and children. Some saw it as potentially offering an opportunity to interact with other young people, people that are 'On the same wavelength about things. So I think … people can socialise better' (Fran). However, we should note that in practice - as reported by young people and as observed in clinic waiting rooms – very little interaction actually occurs between the young people. They are often only briefly in the waiting room, and, in some contexts, they move from room to room, seeing different health professionals throughout their time in outpatients. Some also felt that they could potentially also offer the opportunity for a more young person appropriate space – not one with a 'little kiddie area' (Fran) full of toys and not one, as experienced in some adult services, that are 'completely bare' (Charlie). Finally, some felt that such spaces could begin to enable other young people to

> feel quite comfortable cos they know I'm not the only one whose got a situation going on in my life, there are other people here, I'm not the only, I'm not weird it happens to loads of people (Sarah)

In this way, such visual interaction is seen as potentially working to normalise understanding of conditions, to offer a sense that young people are part of a broader community of young people like them.
In contrast, some young people – as well as families and health professionals - found the idea to be problematic. Some noted that it would create yet another transition, and so potentially create 'a lot more change' (Penelope). Others supported the idea of continuing with mixed spaces, in part so 'other kids' of different ages could see how people are 'getting on' (Lee). Similarly, a parent outlined that

I, I think it'd be much more useful for them to see, say, for example, a pregnant woman coming in [Int: Hmm] and gleaning information from that than just seeing people who are their own age group, either doing it badly or doing it well. … It gives you an understanding of what the expectations are (Amy, Family)

In this way, some preferred the idea of mixed spaces – in terms of age - to normalise understanding of conditions and to outline potential future trajectories.

Irrespective of the different experiences of age-banded clinics, or different ideas about whether or not they may be desirable, young people all valued the quality of the clinical interactions within the clinic room over the physical (and visual) space of the waiting room. They want health professionals they can 'trust', that are 'nice … helpful if I ask any advice' (Ruth) that they can build some kind of 'a rapport' with over time. They want an interaction where the health professional talks to them about issues that matter to them, and strikes the appropriate level of parental involvement. Where feasible, age-banded clinics are also seen by health professionals as useful

I think they work well and I think the reason that they work well is that it focuses your mind on adolescent issues. Erm focuses my mind I don't know whether it works well for the patients but it gets you into a mind-set of thinking about those sorts of things. Whereas if you're going from 18 months old to an 18 year old you sometimes not in the right zone. (Ardo, HP)

In this way, age-banded clinics focus the interactional order of clinical work so health professionals can invoke and sustain the right 'mind-set' to interact with young people as young people.

The idea of offering age-banded clinics – and, for some, running them alongside adult clinics - does appeal to some of the health professionals. However, in practice, they are often not seen as feasible.

it is quite a small waiting room which we, we've- we're trying to address [Okay]. But there's that many people going in and out, I don't know how you would manage it, to be honest. (Dee HP)

Questions about spatial restrictions within outpatients, alongside the distributed physical and organisational geography of services were raised.   Relatedly, the organisational logistics of appointments – the practicalities of coordinating support staff, as well as young people and professionals was a concern. One service had historically offered them, but 'the logistics were hard' as they could not get 'sufficient numbers … because they tend to trickle through at different periods' (Bow, HP). In some contexts and in some services the numbers of young people transitioning at the same period, or within a specific age-band, were relatively low and so coordinating them can be seen as unfeasible.

Meeting the adult team before transfer: first steps in new relations of trust?

In all the services we focused on, the young people moved to an adult service provider with a different set of health professionals that would be offering them care. Given these circumstances, meeting members of the adult team could be key for those that experienced it. When this did occur, it would generally take the form of a single face-to-face joint meeting between specific members of the adults' and children's teams alongside the young person and members of their family.

So what we aim to do, which doesn't always happen, is that, um, we'll have a joint appointment, um, prior to transferring them. So that they will come and see me and my adult colleague, um, so that I can introduce them and they know this new face [Int: Mmm] and that it's not someone completely unfamiliar for when they come (Redgrave, HP)

The young people could meet a single member of the team – often a consultant or nurse specialist – or a range of members of the team, including nurses and allied health professionals. In part, this was about establishing familiarity and trust, and feeling 'you're kind of delivering them into safe hands' (Delia, HP). Some services had a long history of offering this, sometimes this was formalised, and sometimes it was part of the unwritten norms of the culture of the service.

In services that ran young adult and adult clinics alongside one another, where these clinics were physically and temporally co-located, this could offer a range of opportunities for young people. They could become used to the physical and cultural geography of the service – in terms of location in the hospital and the layout, feel and routines of the clinic. They also could offer the young people the opportunity to get to know members of the outpatients' staff – 'they meet our clinic staff start doing their bloods, height and measurements and things' (Jewel, HP). This service also had plans to extend the number of opportunities for the young people to meet the adult team. In one service this co-location could mean a much more extended period of opportunities to meet the new staff

So here we, because we run it alongside the adult clinic, they can meet the adult team several times before they transfer and then we do a transfer appointment where it's either in our clinic or their clinic, er, we see them together. (Ardo, HP)

However, they go onto note that this ideal is not yet representative of other services in the region.

In [Local Town B] they tend to meet the adult doctor and nurse just once at that transfer appointment, er, and as I say in [Local Town A] it doesn't happen at the moment. (Ardo, HP)

And such inequity in access to opportunities to meet the adult team is present across our data set. In a few cases, allied health professionals from both adults' and children's services, may undertake a short series

of 'shared' appointments, and so handover for these specific aspects of the service may be more gradual and occur over time. Such meetings, however, fleeting, offered the potential for both symbolic and practical gains.

Prior to such meetings, child health professionals would introduce the idea of a joint meeting and seek agreement for them to take place. They would, often over time, also seek to explain the norms and expectations of adult services.

> We alert young people to the way adult services are currently provided … 'Unlike in [our service] where if you miss a few appointments we'll still keep trying to contact you, adult services will discharge you rather more promptly.' … I really do feel we have to equip young people (Peters, HP)

Equipping young people with appropriate knowledge about the new service was central. However, what seen as key was enabling young people to actually meet those people whom would be providing them with care.

Young people had, in most cases, a long relationship with a particular service, and so built up, over time, relations of trust with health professionals they regularly saw.

> Because I've had Fiona [HP] for years, and she's been absolutely brilliant like. Honestly she's helped us out and everything and she's always been there, if I've had any concerns, she's been a brilliant doctor. … And I wish I could keep that, and I think it takes a lot to know your doctor, because obviously you trust them with your medical facts and what you do. (Fran)

As another young person noted, going to a new service means 'obviously, it's building relationships' (Brian). For those young people that experienced it, meeting members of the adult team was central to initiating new relationships with members of the adult service, ones that, over time, could develop into new relationship of trust. Charlie outlines his experience of a process he describes as 'nice':

> Charlie   Yeah, well I mean we did meet Crowley [HP] beforehand didn't we?
> Cilla   Yes.
> Charlie   But he was the only person we met beforehand but that was mainly because he wanted to meet me as well as us wanting to meet him. So that was quite nice, cos obviously then before I even went to my first appointment with him I knew his face, I knew a bit about him, he knew a little bit about me. So it wasn't like we went into the first appointment and it was like you had to find out about each other, you could still have a conversation, which was nice.

In such meetings, the young person could share something about themselves and begin to gain some sense of the adult practitioner, as well as the norms and expectations of the service they would be transferred to.

For parents, they enabled them to begin to make sense that their child was being transferred to (another) safe pair of hands. For adult health professionals, it also gave them a chance to 'get to know them'.

> It's a one-hour appointment that we have [Int: Okay] with the joint session. So it just gives you chance to get to know them. … They're gonna see somebody who's familiar (Pete, HP)

It also enables them to (re)establish ideas about the norms and expectations of the service, as well as answering any specific questions. Such an event helps young people and their parents to manage potential anxiety and fears and helps to offer more of a sense of certainty about the process.

However, not all services offered such a meeting with the adult team and even in those that did, the meeting did not always happen or were not always effective. In one service, it was seen as 'sufficient' to have a 'joint transition clinic' only once a year.

> Our normal pathway for transition, erm, is that I do an annual transition clinic, with [adult consultant]. So I do that at [Location B]. But we invite in other young people, who are transitioning, simply because, you know, the bulk of them are at [Location B]. But it's sufficient just to have one, one clinic a year. So we've actually got one tomorrow morning, erm, a joint transition clinic. So usually, I would introduce the young person to [adult consultant] face-to-face, in the transition clinic (Carlos, HP)

However, if a young person was unavailable at that time, as 'for some people, it just isn't convenient', they would, therefore, miss out. And this was the case for Carl, whom did not attend the joint transition clinic, and whom felt 'abandoned' by the services. In Darryl's case, the 'handover' meeting, although scheduled, did not take place

> Yeah there was supposed to be a handover but it never really came off. Em, Yeah. I think some in particular do sort of struggle with changes and routine and that kind of thing, so yeah it could help. … I think that would have been really significant had it worked out. So at least we would have been prepared and if nothing else we had a sort of familiar face. (Daisy, Family).

Darryl, the young person, thought that such a meeting would have 'would have helped' and maybe offering 'even like a second meeting'. Such a meeting would have allowed him to 'sort of know where you're going rather than just feeling like you're being dropped into someone else's hands' (Darryl).

Those young people that move away for University are faced with a practical dilemma of whether to stay with their current services, transfer to adult services at the new location, or operate a more shared care model, involving primary and secondary care. Unless well managed and coordinated, they can also miss out on such meetings.

Organisational turbulence, be it in staff turnover or due to staff sickness, could also negatively impact on the process, meaning some young people lost out on the opportunity. Health professionals were aware of the often very practical problems that can emerge when trying to coordinate meetings with adult health professionals.

> There are practical issues, such as, um, sometimes my adult clinic isn't there, so, um, we've got a joint appointment but they're not there so we can't see them. And sometimes they cancel or rebook and then they'll perhaps end up in an adult clinic without having had a joint appointment, in which case one of our paediatric specialist nurses will accompany them on that first appointment so that there is some sort of shared [Int: Yeah] information, um, and handover. (Redgrave, HP)

In such circumstances, the specialist nursing attending the clinic with the young person is not always seen as ideal. The consultant felt that the specialist nurses often did not always have such a long term relationship with the young person as they did and so did not always 'know' the patient as 'well'. In part this was due to this services having a large number of specialist nurses, and any one of them may be asked to attend, and as well in part, due to staff turnover.

In another service, joint transfer meetings only occurred between professionals and 'only … for the really high risk cases' (Peter, HP) were the young person and family invited. However, part way during the fieldwork, this policy had changed to be open to all, although, again, they were aware 'it's not always possible' (Dee, HP). This new service was set up so that

> In the last six months, they'll contact us to arrange an appointment. Erm, and then it, it's normally a joint transfer. … it would be the patient, erm, normally the patient's relatives or next-of-kin comes [Int: Yeah], erm, and it would be the consultant from our team … normally myself, and, and [another AHP] … it's, it's just kind of closing one door and opening another, really. (Dee, HP]

In this way, the young person would meet different members of the team. This is important as we know that in some services the health professional actually meeting the young person in this first meeting was not the health professional they subsequently would routinely being seeing. We know that young people, at the very least, value being able to 'recognise one face, you're not sent into a room full on entirely new people' (Angela).

Finally, a missing figure, especially for those who will be transferred to primary care for all or part of their care, was the general practitioner. For example, one young person visited a range of services and, when he turned 16 his family were told that he was 'in the transition process'. In a consultation his mother outlined how

> I did question, I said, like, 'If, once he does go into adult services what ha- what happens if he needs to see someone?' and they say, 'Oh, go to your GP.' (Beth, Family)

They had never visited the general practitioner in reference to his long-term condition. As they noted, at a later interview

> Brian   I couldn't even, I couldn't even name me GP to be honest.
> Beth   His GP, he sees a different GP every time he's there. Nobody knows him and knows him and knows his history.

Unfortunately, the general practitioner is often someone whom the young people had often had little interaction with over the years, yet is meant to be a central figure in coordinating their health care and access to health services.

Promotion of health self-efficacy: learning how to manage your health (services)?
Health services saw it as their role to help young people develop confidence in making sense of and managing their health condition. Such work is understood as 'kind of always a side-line of the work anyway' (Lucy, HP). For her, and others, this is 'quite often that is a big part of our role' and with her patients

> it might be to work on anxiety, which it tends to be for me, but really part of that is feeling that you're not helpless and hopeless and that you can go forward and that you have got a lot to offer, and so definitely needs that input. (Lucy HP)

However, this was not formalised or based on a specific policy, but rather 'a sort of gradual process rather than a one off education session in a teenage year' (Ardo, HP). As such, supporting young people to develop confidence seemed to occur in an ad hoc way over time in consultations and other interactions with a range of health practitioners, including consultants, nurses, psychologists, physiotherapists, occupational health practitioners and speech and language practitioners. In practice, nurses and allied health professionals were often seen as more central to supporting and enabling this

informal work, in part as they may see young people more often, they spend more time with the young people, and at times the young people are felt to be more 'open' with them.

None of the services reported any form of structured, protocolled, approach to delivery. Such discussions may explicitly be created around specific devices or events. For example, one service used transition questionnaires that included

> elements that ask, you know, 'do you organise your own appointments?' 'Do you organise', er, 'do you know how to pick up your prescriptions? 'How would you', wh-'where would you go if you needed a-advice in an emergency, and your, your mum wasn't around?' [Int: Yeah] That sort of thing. So we, we ask about that, and obviously, if there are gaps in their knowledge, then we try and fill those gaps. But we don't provide them with any training. (Jones, HP)

In this way, in the space of a consultation, such questionnaires' may offer a very brief and focused 'teaching moment'. Another service had offered group sessions, organised meetings for young people to meet outside the space of the clinic, which were led by an allied health professional. These sessions included elements like 'problem solving' around disease management. However, they reported that such extra-clinic sessions often suffered from low levels of attendance. Finally, one service was seeking to transform what they had been doing 'informally for years' to ensure continuity in provision as the team grew. This was part of a broader peer review process, where they were seeking to look at

> 'What do we want them to know by the time they've been educated?' And then looking at the, sort of, that as the curriculum, and then 'how are we going to get to that point?' So starting with what it is we would actually like them to know and then how are we going to teach them that. So they're trying to put some sort of structure around it. And then how do you deliver that and then how do you check whether they actually know if afterwards. (Ardo, HP)

Their aim for was not to develop new questionnaires or develop checklists to ensure the young person has been talked to about a specific topic, but rather to create a more formalised and cross-team culture that ensures an awareness of and action around such issues.

Some of the young people and parents described receiving support in developing health self-efficacy: 'we did lots of different activities. It was never sort of formal' (Penelope). Some young people felt that, at times - 'obviously sometimes' (Sarah) - this was a focus of interactions with health professionals. For some, albeit through informal means, this was 'all the way through' (Amy, Family) their experience of the service. For young people and parents, a context of longer term, trust-based, relationships with specific health professionals seems key to enable them to develop such confidence in making sense of and managing their condition. Often, in discussing this topic, young people would refer to a specific member of their services team as central to offering such support.

However, some young people and family members felt they had not received any formal or informal support in this area. As one parent outlined, this was from her perspective absent, yet 'this is what he needs' (Leanne, Family). Another that

> He hasn't really had any help like that. He has always had, like with Delia [HP] or someone, somebody to talk to. [Int: Yep] The usual checks, height, weight, that sort of thing to make sure that he is not having any kind of adverse reactions to any medications and that sort of thing but no a lot of it has either been down to us or him. (Daisy, Family)

A member of this young person's clinical team, echoes this absence, noting that such work is not always central to the care provided across their service: 'I don't think it is – it's – I don't think it necessarily is done; but I think it would be very helpful if it was.' (Delia, HP). Distribution of the work across teams and services is not always even. As noted above, often nurses and allied health professionals support this work. For some consultants, such work cannot always be taken on

> I think I'm all for assuming responsibility … I'd love to do that. But, um, we are so inundated with managing people. [Int: Yeah] that there is no chance to do that. And ideally that would, is work that was kind of, you know, primordial work (Peters, HP)

The lack of support for self-efficacy, was most marked when young people's appointments were infrequent and where staff and, or the services themselves, were in flux. However, the key work most young people need, alongside support making in sense of and managing their health condition, is in managing services post-transfer.

> Going from Children's Services to Adult Services. There was no one really to talk to who told you what to do, it was just sort of, we've just picked up on it. (Charlie)

As young people are transferred to a new organisational and clinical environment with a new set of health professionals, norms and routines, the core focus they need is support and confidence in the practicalities of managing the adult healthcare system itself.

Written transition plan: gaining awareness of new norms and routines?

Plans about transition can be offered, experienced and valued in different ways. Several services stated that they had formal plans or procedures for transition and transfer of young people. However, in all but one service, health professionals reported that 'written transitions plan' were not used. In an

already bureaucratic culture, there was some scepticism about the place of such documents. As one practitioner noted 'I'd like to see patients and facilitate effective transitions, not be filling in plans' (Peters, HP). Another outlined that

> I think unless it's been, sort of, discussed with the young person it's, sort of like, completely hopeless. … It's, it's one of those things that people look at when it's written and then never again. And actually does anyone pay any attention to it? I don't think prof – health professionals do. And I don't think the young people do. So I'm sceptical about the utility of transition plans, um, I have to say. (Redgrave, HP)

Issues of time, resources and practicalities of fitting into on-going consultations were also seen as barriers. One service had implemented it as part of a research project, but then withdrawn it when that additional research resource was no longer available. However, two positioned them as an 'aspiration' (Brown, HP) or a 'target' (Delia, HP). For most health professionals, plans around transition were again seen as occurring over a series of consultations. Services also outlined that they then recorded such discussions in clinic letters. Discussions are

> laid out in the kind of letters, which I write to the young person and their parent … And transition is part of that, we don't have a separate piece of paper that's called transition, it's, it's everything weaved into their clinic letters (Carlos, HP)

Some patients reported experiencing plans about transition over time – 'It was more just something we talked about, there wasn't really anything written down' (Darryl). As we will outline below, such an informal approach was not always effective

Unsurprisingly, none of the young people were aware of ever having been offered any sort of 'written transitions plan' or access to 'health passports'. Sarah did remember discussing plans for specific aspects of her transfer in her recent consultation, but when asked about whether she received any type of written documents about any aspect of the process she noted that 'Hmm I don't think so but if I have I don't remember'. Another young person reported having 'got loads of transition plans' (Fran) centred on her move from school to college, but nothing from her health services. However, in one case, a written plan was reported, albeit that only the young person's mother was aware of it. As the topic was initiated in the interview, Jane, Jonah's mum said 'It's here somewhere' and then pulled a crumpled document – entitled a 'transition planner' - from under a large pile of other documents. Jane said to the interviewer that 'Jonah should have filled it in' and then turned to her son and said 'You've only had it about a year to fill in'. In all the other cases, none of the families of the young people had ever heard of such documents. Overall, the young people although less enthusiastic about the concept than family members. The young people were aware of some potential benefits, as well as problems, especially around there ability to 'loose' such documents. Family members and health professionals also shared this concern, health-related paper documents do and will get lost.

The lack of awareness did not only extend to such documents, but also about some aspects of the transition and transfer process itself. Albeit a more extreme case, a mother noted,

> Well we have nothing at all to the extent that I don't even know when she goes over. I'm assuming it's eighteen but I don't know. (Amy, Family)

Another noted that 'anything would have been useful … just to give us some direction' (Beryl, Family). In this case, the family had to actively arrange elements of the transfer of services themselves.

> Remember at the time, I had to write to all of the individual services, and say, 'Ben is now 18. What do we do?' [Bob: Yeah] And a, a couple of them, I think physio being one of them, I had to chase up a couple of times, to just get letters back saying, 'Right, you just ring them.' And that was it, literally. So nobody even sort of came to see us, to say, 'Bye bye, this is where you go.' It was just literally nothing, and we had to write to everybody to say 'Ben is now 18. Can you point us in the right direction?' (Beryl, Family)

This service had 'no real formal processes … or leaflet or anything like that' (Brown, HP) for transition. They discharge most patients from child services, but offer 'that safety net of the adolescent clinic to come to if and when they need it' (Brown, HP) – and these clinics are described as 'occasional'. Young people and their families have to then get themselves referred back into services. In such a context of a lack of awareness, families stressed the potential value of the concept behind such written plans for young people and, as well as them also receiving information about the process. For Paul, brother of Penelope, 'it seems pretty obvious really, like, that you would need something like that'. He notes that

> There was literally no plan … this letter was meant to be sent, this letter wasn't received … she was just lost. She was just lost in that middle area. That, that, well obviously that transition … Um, I think the most important thing is just clarity for the young person, for the parent, for the family … as long as people say what they're going to do, and, you know, be organised and make sure that there is something in place (Paul, Family)

In this case, the young person and the family lacked basic information about the process, they were 'lost'. His sister also outlined the kind of very fundamental and basic information she felt she needed

> Basically just knowing what's going to happen [Int: Mmm]. Knowing when it's going to happen. Knowing the process. They should tell you, not us chase them … Instead of just leaving you in the dark. They should tell you all this. (Penelope)

In part, this lack of awareness was a product of a service in flux, with regular changes of staff – and regular changes in whom Penelope would see - and no specific person coordinating information to her about the transfer process. In Penelope's case, her family were very active in contacting services and seeking the appropriate information; they had sufficient cultural health capital to actively manage the situation.

Some young people, and their families, who had transferred felt unprepared and unsure about many aspects of the new service.

> Connie   None. We've had no word from nobody. Nothing, have we?
> Carl   No.
> Connie   It's like you've suddenly, you've reached that age and you're written off. … So we've had no word from not one of them. And at the day we went to a meeting, must be two years, and basically they were all saying, 'Right, you're, you, you're moving onto now to adult services [Int: Mhm], you will hear from them in due course' and we've had nothing. Absolutely nothing.

In this case, the young person – Carl - and his family felt 'abandoned' after transfer. They were not, as far as they or a representative of child services whom we had also interviewed were concerned, transferred to primary care. They had visited adult services once, but since that point, had received no further contact, appointments or offers of support. They were unsure about what exactly to do or about whom to contact to effectively manage this situation. As such, they felt abandoned both by adults' and children's services.

It appears that such factors as informal practices and organisational turbulence can lead to a lack of awareness, knowledge and understanding of process. As noted above, young people are transferred to a new organisational and clinical environment with a new set of health professionals, norms and routines. They really need to be able to develop an adequate awareness of the transfer process itself and the people, norms and expectations of adult services.

Parents engaged appropriately: enabling interdependence?

At the heart of transition is an ambition to shift the work of managing health and health services from parents to the young person. Central to enabling such 'independence' is the support of family members, especially mothers (or if a mother was not present or able to play such a significant role, the person who takes on that role). However, in practice, this is not about a move from a discrete position of 'dependence' to 'independence', but rather about supporting and enabling the young person's autonomy, so a relational autonomy, where interdependence is central. As Fran noted, 'at the moment I think I like me mum coming to appointments with us, because I still think I need her guidance' (Fran). Family members, in particular, play a very significant role and contribute often invisible labour to the negotiation of the multitude of transitions the young person experiences, especially the healthcare transition.

They are the central mediators in young peoples' experiences of health and healthcare services. At different times, over the trajectory of transition, there is a fluidity to their involvement. They routinely act as key workers both within the clinic and home. Daryl, in conversation with his mother, positions the support his had in terms of his healthcare as 'from you and dad mostly'. Importantly, families provide the young person with some continuity of care and a point of reference and contact. In reference to his new appointments in adult services Charlie outlines what he would prefer.

> I'd have rather mum was included cos I just come home and I'll tell mum everything anyway or I'll end up bringing her to the appointment so she's there anyway. But it's sort of all the letters just all of a sudden got sent to me and I'll open them and I'll be like 'Well, what's this? First I've heard about it' and mum will end up having to deal with it anyway, so if she's contacted as well, even if it's only for sort of the first year of it happening, until they know I'm a hundred per cent confident with what I'm going to be doing (Charlie)

Charlie positions his mother, as a central part of care. He seeks to actively involve her in his care, sharing information about the trajectory of consultations and other information coming from the service. He is clearly aware of her knowledge and abilities in supporting him and values this, especially at time when he is unsure about the practicalities of his care.

Family can also act as advocates for young people in negotiations with healthcare and other services. Ben's parents, Beryl and Billy are aware that some of the adult services Ben engages with do not want them to continue to be involved in his care. In reference to Ben's contact with social services about providing support for an aspect of his long term condition, she notes that

> I'm not just being shoved to the side-lines so they can go and bully him like they do, or like they try and do when it comes to organising the things that they're currently making a mess of organising for him. Unless they think they can get away with it if I'm not there (Beryl, Family)

Most had experience, over the years, of 'fighting to make sure he has the best of everything' (Daisy, Family). Their experiences with services meant that

> I've learnt over the years that I need to ask these questions because I never feel anything's really offered, you always have to ask for the information rather than it being offered. (Cilla, Family)

All the families in this study would seek to be actively involved in obtaining access to the best care they could get for their young person. However, we did have reports of health professionals trying to work with unengaged parents, the 'reality also is that we have lots and lots of families where parents, you know, just aren't involved for love nor money. (Peters, HP).

Families can offer practical support in managing health and facilitating access to services, and cognitive support in terms of prompting or asking questions, doing research, providing information and checking understanding.

> em my mum is my major leaning post for memory and all appointments and what's been said and such … If my mum didn't know the answer the doctor would or if the doctor didn't mum would (Sarah)

Other young people described family members enabling such distributed cognition. Family members were often the focus for the practical coordination of appointments, with many young people having to coordinate contacts with different services or organisations. Daryl's mother took a very active role.

> If I know it is an appointment and it's addressed to him I will open it and then as soon as he shows his face downstairs or whatever I'll say 'this has come for you. Obviously I haven't given it to you cos it'll get lost somewhere in your bedroom. It'll never be seen again so your appointments are here, we'll get them marked up on the calendar'. At least everyone in the house knows what's happening and when. (Daisy, Family)

Alongside such informational and coordinating work, they can also offer emotional support, providing reassurance, comfort and encouragement.

The young people and health professionals are very aware of the work of their families in supporting and enabling them. The young people recognise, request, and at times, require and celebrate this support. Penelope notes that her mother has 'always just been involved … um, she's just always helped us with everything'. One of her professionals offers a related narrative

> Her mother is really her champion. Uh, very creditable parenting style and ability. She knew when to back off and when to champion Penelope. … She was pushed, but she wasn't told where to go [Int: Yeah] by her mum, or where she needed to be. Wherever she was, that was celebrated, and yet masterfully pushed. (Peters, HP)

Family members are generally seen as enabling young people's autonomy over restricting it. Practitioners are aware that often 'they're heavily reliant upon their parents still' (Pete, HP). However, parents can, at times, be seen as shifting between being understood as supportive and enabling to potentially over-invest. For example, a health professional describes Amy, Angela's mother in the following ways

> So we're trying to give Angela a bit of independence but maintaining the support from her Mum who is very, very supportive. [Int: Yeah] Her parents are very supportive. They've had some erm bad experience of [long term condition] … erm I think she will always find it hard to erm let go … what we've tried to say to her is that actually the best way of avoiding that is to teach the girls how to look after themselves cos she's not going to be around forever. … I'm sure she finds it hard cos' she's that sort of mother who erm is very involved, and not all, all, parents are that supportive but she is. (Ardo, HP)

Parents are very aware of the potential to move from being cast as supportive to being understood as 'very involved'. As with all young people with or without long term conditions, parents have to work to negotiate with the young person, and with themselves, about how best to enable and support moments of 'independence'. For example, an interviewer's question, about whether child services ever asked to see Daryl alone for part of a consultation triggered a new conversation between Daryl and his mother Daisy.

> Daisy   But you know, when we're going to your appointments and things like that, if you ever feel that you just want to go on your own, I can always wait in the car you know?
>
> Daryl   I always want you to know what's going on as well cos you know I have an awful memory.
>
> Daisy   Do you know, until you got talking there, it never occurred to me that me being there at every appointment could be too much, but yeah, of course it could, I mean, when I was his age the last thing I ever wanted was to go to the doctors or anything with my mother, I never wanted my mother there by my side.

Two years after the initial fieldwork with Darryl and his family, they then told us that Daryl now only attends appointments on his own. In this way, parents need to learn, over time, new ways to support and enable young people's autonomy.

Creating new routines, norms, and expectations evolves over time. Families and young people can experiment with new ways of being interdependent. Ruth and her father, Rod, had a very collaborative approach to her taking on more responsibility for managing her care as she got older.

> For the last, erm, er, year, 18 months she's been taking on much more of it herself. … I mean when we first started doing this, you know, she did six months of sort of [managing aspects of her long term condition] … You know, not even six months, maybe just six weeks or something, and she said, 'I think I'm getting this all wrong.' You know, 'Can you help me out,' sort of thing [Int: Yeah]. And then we went back to what we were doing before and I [managed her care] and then, erm, er, and obviously she was there as well and then when she got more confident again with it, you know, then she went back to doing it herself, and she has done ever since, you know. (Rod, Family)

Clearly, this involves relations of trust, trusting that the young person will remember to undertake specific actions, or remember specific details, and trusting to them to know when to ask for additional support or information from their family or health professionals. Jack's mother, Judy talked about how her son was taking on responsibility for a new aspect of his care. Specific items needed to be ordered in advance. Jack was supposed to order enough for three months for his time away at university. Initially, Judy reported that she was not going to get involved but she then realised that he did not have enough.

> Erm, and then I said, 'Are you sure you've got enough stuff?' He said, 'Yeah, yeah, I phoned it.' And I looked at it and I thought, 'You've got five boxes. This isn't gonna last you.' I phoned them up, found the number, phoned them up and so I said, 'I know, my son's 18, before you say anything, and he should be doing it himself.' And the woman's like, 'No, I've got a 19 year old.' She said, 'I know what you're talking about.' ((Laughter)) Erm, I said, 'He says he's ordered enough 'til Christmas,' and she says, 'No, he's ordered enough 'til October.' (Judy, Family)

Judy then collected the items and delivered them to her son at university. Judy's involvement, like other parents, is fluid, moving between wanting to be informed, to checking in with health care staff, to supporting Jack in making decisions about his health care - even when she disagrees with some of his choices - to encouraging him to lead an active, independent life. Such work at times, needs to be done with some delicacy, but often families can feel that they are being understood by the young people as doing different work: 'he probably thinks I'm nagging him but it's, it's just trying to encourage him' (Beth, Family).

In some services, or with some health professionals, or with some aspects of the healthcare system, such practices, especially in adult contexts, are seen as examples of 'attachment' or 'dependence' and therefore potentially problematic. Following the incident of Jack not having the specific items he needed to order in advance, Judy describes being told by one of her son's adult health professional's that ' 'You've got to step away'

> The [health professional] is 'But leave him. He's got to sort it out himself.' But it's too late if he doesn't sort it out [Int: Yeah] and he hasn't got the item. … I haven't been in for 12 months. I haven't been to any because it got-the, the [health professional] said, 'Back away,' It was like, 'Right, this year we're gonna back away. [Int: Yeah]. He's gotta build his confidence.' So I haven't been. I haven't been. (Judy, Family)

In Judy's case, they have decided to 'back away' and not go to any appointments, with the hope that her son will develop more (timely) awareness about self-care. They really want to support him in this process but also ask, 'why should he have to think about placing an order [Int: Yeah] when n- no one else his age has to think about that sort of thing?' (Judy, Family).

Some professionals see it as their role to shift the 'locus of control'.

> we try to keep the parents out of [Int: Okay] the consultation but we do offer them, you know, if they want their parents to come in perhaps they could come in at the end of the, the consultation … the sort of parental involved and the, the locus of control in these consultations very much shifts, erm, to the patient [Int: Okay, mm hm], the individual young person, erm, rather than the [service] team and, and the parent team. … Erm, the people who often find it the hardest are the parents [Int: Yes] to go from that position of power come control, er, and they worry desperately about their children, which is understandable [Int: Mhm] … And I think all parents ex- will experience that to a greater or lesser extent. … (Jewel, HP)

This health professional seeks to give young people the 'tools and the knowledge' needed to enable them to 'be empowered to make their own choices' (Jewel, HP). However, in practice, families are always involved, albeit at times feeling they are forced do this work in the background. Since moving to adult services, Charlie noted that that his mother is not included in his care.

> They seem to have left her out, like completely … Yeah, rather than just doing it, actually saying 'Do you want us to cut parents out completely or would you like them to still be involved?' rather than just assuming. (Charlie)

However, as outlined above, Charlie still wants his mother to part of his care, he wants her to because for him, 'having to deal with all of it, is a bit scary'. He still wants his mother 'kept in the loop' and in practice does this work himself.

Part of the narrative of (in)dependence, empowerment and attachment appears to be embedded in a broader narrative of legal independence. A child health professional talks about his own experience of his son's care

> the health practitioners won't speak to me, or engage with me in any way whatsoever, even though he wants me to be involved. Erm, because he's 18, and is deemed to be an adult [That's…], so that is the way of the adult world, and it's, erm, yeah, that's, that's, you know, they, they respect the individual's confidentiality. (Carl, HP)

In this way, working with the family, around communicating issues about appointments of organising aspects of care can become problematic. We have various moments where part of a service will no longer communicate information to family members. For example, Ben's family outline the problem.

> Beryl: everybody's sort of saying, 'You're an adult now, Ben, you're an adult now, you've got to do this yourself.' And everyone was saying, 'You've got to do that yourself, you've got to ask for [service] yourself.' So everything all of a sudden was lumped back on him, [Yeah] and people were starting to say they can't speak, can't speak to me. 'We've got to speak to Ben.' [Yeah] And he was, 'I don't want to speak to them. You just sort it.'
>
> Bob   They said, yeah.
>
> Beryl   And of course they wouldn't speak to me, because they wanted to speak to him, as the adult.

Young people can, at times, be caught in a tension where (legal) independence is thrust upon them, whereas they have a preference for interdependence. Ben notes, in reference to his parents not being able to speak on his behalf that

> I don't know what to say. I'm not even old enough. I'm not experienced to blimmin'... I'm 19 years old. I'm looking out for other things. I don't really know what to say to those kind of people (Ben)

Obviously, for these young people having a long term condition is only one of their identities, one they often want to minimize and only engage with at specific times, when it is necessary. Young people can feel, at times, confused about how to best manage doing being independent

> I want to try and lead like a normal lifestyle. Like no one wants to ask for help really, you just want to do it and be independent. .. But it's like, it's confusing 'cause at one point, I'm like, it's like, 'Oh ask for help' and the next point it's like, 'Well you need to learn how to do it yourself', so it's like, which one do you do? (Brian)

Over the process of the interrelated transitions they face, be that stages of life, healthcare, education, they feel that they can receive conflicting messages about how best manage the rights and responsibilities that are embedded in these transitions.

Some services and health professionals, including those embedded in adult services, understand familial work of supporting and enabling, as demonstrating something like interdependence. Ben notes that one of his health professionals embodies this practice 'He does the both, treats us like an adult but he'll, he'll also include me mam just in case I need her for anything'. (Ben). Similarly as Ruth notes,

> the doctors always said, you know, 'You, you don't have to have your dad here' or, 'You can have you dad here' if he wasn't there kind of thing [Int: Yeah]. And it, it was always more my dad's decision than anything, you know, he would say, 'Look, you know, you should try this on your own' and I would go, 'No, I don't feel comfortable with that yet' or 'yes I would'. And the doctors would go along with it, you know, they'd be [Int: Yeah] supportive if he was there and supportive if he wasn't kind of thing. (Ruth)

An adult health professional outlines, he is aware that with young people 'they, they're in charge of themselves in, in adult services, whereas sometimes they, they still need the guidance and the backup from the parental guidance. (Dee, HP). As such, some services can and do work to recognise, enable, support and accommodate interdependence where possible. One notes that, within their adult service that

> the young people will pretty much always bring, erm, one of their parents or carer with them, yeah. Pretty, pretty much 99% of the time. Yeah [Int: Okay]. Erm, erm, as they get- even- well, even when they get older, they tend to bring partners [Int: Yeah] or, or relatives with them, yeah. (Pete, HP)

Some health professionals are aware that the involvement of others is normal, not dysfunctional. The 'parent team' is, at times, supported in shifting roles to a more 'partnership', 'shared care' or 'consulting' roles.

Key worker: enabling consistent, supportive, relations of trust?
Very few services reported offering a designated key worker. With those that did, the person the services named seemed to differ from the one the young person and family then went onto suggest. For example, one service outlined their practice

> Jones: So they, they have a named specialist nurse … they should know who their named nurse is, and they all know how to get in touch with me, if they need to.
> Int: Okay, okay. So would you find they generally would get in touch with you, or they would get in touch with the diabetes nurses?
> Jones: Mostly with the nurses, and increasingly … the nurses are actually getting in touch with them.

In this service, as with another, the official role is seen as tied to a nurse. When we asked the young person, he responded that person he would contact would be 'Jones normally' (Jack) and not a nurse. Jack's mother, Judy, offers a similar narrative.

> Key worker you see, we don't even see the same nurse, even now … see I always just phone Jones [HP], because he's the main person, you phone the nurses and they are all chopping and changing and they don't work every day ehm and one day 'oh I don't deal with [X], that's so and so she's on this day'

In practice, the young people and their families orientate to a specific health professional as their informal 'de facto' key worker due to such issues of consistency in relationship, knowledge and accessibility. As such, in nearly all the services, young people could identify someone whom they felt acted in the role of a key worker, albeit without a formal title or responsibility.

The core attributes around which define someone as an informal key worker for young people seems to centre on relations of trust. For example, when asked if she had one a young person responded that

> I guess it's Redgrave [HP] I trust most out of the people, which I guess isn't really a nurse or anything. But he is the doctor who I trust most to talk to and that (Ruth)

Again, in this service, a nurse was an assigned key worker for Ruth. However, for Ruth and others, knowing someone over time and therefore being known by them is central. Someone whom 'knows me the most' (Fran) emerges from such consistency in relationships. The person also needs to accessible and knowledgeable, often that means in terms of contactable via a specific number or replying to a call within a timely manner. A mother outlined how a specific allied health professional was the person she would always go to if she did not 'quite known who to contact' as they are the person that her son has 'seen the most' (Beth, Family). These informal key workers are often also positioned as someone whom is described as 'brilliant … really helpful' (Daisy, Family). For example, Connie, Carl's mother, remembers someone in child service

> Connie I, actually yeah 'cause she was really good. … So she was good, I mean I tell you what, that woman wants a medal [Int: Mm hm], she really does because she was so good not just at her job but she'd, you know, fit you in somewhere
> Int It's often the [allied health professional] who do, who do all of those things.
> Connie Aye, well there's not many, well honestly all the other ones you used to talk to, 'Yes, but there's naught we can do, goodbye.' You know, [Int: Yeah] and you'd think, 'But you're not saying which way, which route I've got to go.'

Post-transfer, the beginnings of such relationships of trust can be established. Charlie outlines that, the main person I've seen so far is Crowley [HP], he's sort of been really helpful, and he's even given me sort of a mobile contact for him and said 'if there's anything you ever need, just give me a call and ask me anything'. So that sort of made me a lot more comfortable with him and I literally will just give him a call or things like that, so that's sort of been helpful, but with everything else I'm still a little bit lost. (Charlie).

Charlie was in the process of transfer, with a few aspects of his care still situated in child services while most had transferred to adult services. As he notes, he is 'still a little bit lost'. Yet, the person he sees as most useful and accessible, emerges from his brief period of consistent interactions with a specific health professional whom has been 'really helpful' and made themselves easily accessible to Charlie. The centrality of relations of trust is most clear when they are absent. When asked this question about a key worker Ben and his mother, Beryl, responded

> Ben I thought that was what me mam was doing.
> Int Yeah, yeah.
> Beryl I think it's difficult, because I think, not sounding too defeatist, I think the damage has been done and we've just got no faith, well little to no faith, and little to no trust in them. Have we? [Int: Mm] I think they've, they've let us down so many times that we just, we don't trust them. Which is an awful thing to say if you're a health service, but speaking generally again I suppose, but I just don't think we trust them do we? We don't trust them to follow through what they say, they say that they'll do.

In this case the young person and family view of being offered sub-optimal care, in part stemmed from the lack of someone offering 'consistent support' (Beryl) in adult services and being an accessible source of knowledge and supportive over time. Ben had a large number of different people he would see and different services he would visit. The family members went onto outline the need for someone taking on the role of a key worker in one of their own interviews.

> Bob   Yeah, 'cause they always fob you off onto somebody else when you ring up, 'Oh, I don't deal with that. You have to speak to this one.' Speak to them and they go, 'Speak...' There's no direct person you can deal with.
>
> Beryl   It's passed round, mm. …
>
> Bob   They should just have one person you can get in touch with and can sort it out for you. You know, one or two, not ten other people.

The service themselves noted that such support was absent, that it was only offered by 'whoever's working on at the time or with them at the time' (Bow, HP). Whatever the context, whether services are seen as effective or not, mothers are often also understood as another informal key worker. As a health professional commented

> She often said she can't remember who her key worker is. She would call her Mum and her mum would then ring the … nurses up the way er so I think at the moment Angela wouldn't call one of our team, she'd call her Mum (Ardo, HP)

Mothers, or whomever takes on the primary carer role, are central to supporting the young person's interaction with services. As such, they are the central consistent, trusted, knowledgeable resource for the young person. They then often liaise directly with someone whom they feel is a key worker within the service.

As noted above, very few services reported offering a formally designated key worker. Those that did were aware of a range of practical problems they could face. For example, staff turnover could mean that for some young people 'the nurses change several times in the time' (Ardo, HP) they are with the service. Another, when asked if they provide key workers 'Uh, well yes and no'. They noted that:

> We have a named key worker who, for every person under 19, who is one of the specialist nurses. But because there are [X] of them and they all work different hours there can't be just one person they will always speak to [Int: Yeah]. So, um, and some of the nurses have embraced the key worker concept to different degrees. So [Nurse X] … I mean he makes a real effort to work individually with patients of his, whereas some of the others, sort of, like to leave it as a, sort of, more generic role. (Redgrave, HP)

Clearly, this echoes the families' narratives of problems of not being able to contact a specific person given the differing work schedules. It also highlights the awareness of different ways that staff can decide to enact such a formal role, some can 'embrace … the concept', and others may not be so enthusiastic. A service outlined that

> Well, we do in theory, erm [Int: Okay ((laughs))] and we – we should do. And I really, really, really feel, you know, that we've gotta have more attention given to proper key working. I feel that this is one of my regular beefs really. … it's also a problem that er, sometimes people get referred on to [Department X] [Int: Yeah] and then we see the [results] and then the key workers kind of – because they know that they're going to be followed up regularly, the key worker kind of, goes out of the picture a bit but then, the other aspects aren't properly addressed then. (Delia, HP)

As they note, again, the 'theory' is often not enacted in a coherent way. All the services are trying to attend to a large workload, with competing demands for their time and resources.

> We're really just um, ((laughs)), just about manage to get, um, haven't quite got enough clinical staff to do what we're doing , you know, but of course it's a good idea. (Brown, HP)

For those services not providing a key worker, this is not about a lack of being 'committed' to such idea, but often more about 'what they are resourced to do' (Lucy, HP), what is practically possible given the constraints they work within.

Coordinated team: coordination and consistency?
Some services did try to formally coordinate appointments through offering a clinic where different members of a multi-disciplinary team attend, either in separate consulting rooms, or at time, with different members of the MDT in the same room.

> it's very flexible, yeah. I mean we, we, essentially we've got three pr-professionals there in three rooms, and, er, er, we've got two patients coming every half an hour. So there's, there's opportunity for, for – although, if we haven't got the time for each of them to see every member of the team, there's time for some of them to see more than one member of the team. (Jones, HP)

When this can be organised, this clearly enables young people to gain a range of support at single time point, to see 'a selection of people' (Amy, Family). In some services, this is 'not a formal thing, but I try to arrange it that way. (Delia, HP). This is at times positioned as something services informally try to do 'despite all the obstacles managers put in our place we still work as a multi-disciplinary team' (Peters, HP).

For those young people whom have been attending such a service, they see this as the norm, as unremarkable. However, for some, when they experienced a large number of coordinated appointments this was remarkable

> We've been up there sort of a good three quarters of a day cos I've had one appointment, then another appointment, so they've just all seem to have fallen on the same day (Charlie)

They would have preferred them spread over weeks, in part, as this impacted on college. For others, this was never an option, sometimes due to the service structure, or sometimes, as they see 'usually just the one person' (Sarah). Also, different services were at different stages of taking on such a model, some had historically not offered such a coordinated clinic. Some were not as coordinated in terms of information sharing between people or services – 'I know they didn't work as a team very well then, or you'd say one thing and people just didn't know (Judy, Family). Others were attempting to develop this aspect more.

However, at times, potential key figures are missing from these coordinated appointments. Within some services, psychological support can be available at the same time

> Sometimes the psychologist comes as well but usually she's not at the clinic now because she's running her own clinics erm but there's an option to refer to the psychologist (Ardo, HP)

Often such psychological support is offered at separate appointments, at different times, often at different days. It was noted that some services have focused on getting good access to psychological support. However, for others, the psychological support was presented as noticeably absent 'we always talk about the fact that we don't have good access to clinical psychology' (Brown, HP). They noted that

> It really, I mean that's a massive problem in paediatric services and services in transition services: being able to access psychological input, because the funding's just not there. Yeah, so you sort of beg, borrow and steal (Brown, HP)

Alongside this, physiotherapy and occupational therapy was seen as missing, as such services were already seen as 'under resourced' (Brown, HP). However, one offered a service that included a clinic with 'an OT or a physiotherapist in with the doctor as well, [Int: Okay] erm, and we can call a nurse in if nursing issues come up' (Bow, HP).

Such coordination can also be problematic given the range of services sometimes needed by young people. Going through transition and transfer can offer an additional layer of complexity. An interviewer tried to summarise the range of services one young person, Brian, was working with

> Int: so, right, and so some of the people you see at the minute sit in paediatrics, some of them sit in adult care, [Brian: Yeah] some of them sit in adolescent care? Bit of pick 'n mix [Brian: Yeah], pick 'n mix healthcare ((Laughter)).

Distribution of services, especially across different organisational boundaries, can raise practical problems. The distribution can often mean a lack of communication between health professionals. As one family member noted, 'you find going from appointment to appointment you just keep repeating yourself don't you? They're asking the same questions at each appointment' (Cilla, Family). Another noted how

> Well half your appointments wasted because you're going over the same old ground. … Just getting the basics. [Int: Yeah] Instead of concentrating on why you're actually there.[Int: Yeah, yeah] People need, obviously you need a background to be able to treat somebody but you're wasting half your appointment [Int: Mm hm] going through the questions, whereas if they already know about it, they've been introduced to you [Int: Yeah] then you don't have to go over that. (Beth. Family)

Relatedly, such distribution can mean, potentially, a lack of coordination and consistency in information and advice that young people can receive. Even within services that offers an MDT within a single clinic, 'the bigger the team the harder it is to be consistent, and the harder it is to appear to be saying the same things.' (Redgrave, HP). A missing figure, especially for those who will be transferred to primary care for all or part of their care, was the general practitioner. As one service noted

> But we do try to encourage, erm, sort of firming up the relationship with the GP [Int: Yes]. Because for many of these families, the GP hasn't played a very big part (Carlos, HP)

As noted above, the general practitioner is often someone whom the young people had often had little interaction with over the years, yet is meant to be a central figure in coordinating their health care and access to health services

Holistic life-skills training: another service's work?
Very few services within our data-set actually provided any form of holistic life-skill training. One did provide specific elements of Holistic life-skill training, often in the form of talks or group meetings.

> So we normally do an education session in the summer holidays for university leavers. But we need to do more of that. Obviously those staying locally stay under us [Int: Yeah] for a bit longer. Um, and so it's an easier transition and their mums and dads help them do things and navigate, you know, how to change general practitioner and get your repeat prescriptions and things like that. But there are those practical skills they need to learn, actually, just how do you do things? And, um, so for jobs we do talk, if, you know, if they have specific career aspirations (Redgrave, HP)

This service provides some focused support around key issues – going to University, jobs and careers - they feel that the young people face. This service, and some of the others, were aware they could and needed to do more around such issues. One health professional was interested in extending their service to offer a broader range of support through a series of talks, albeit focused around 'self-efficacy', but including aspects around 'managing money, erm, about jobs, about managing my time' (Bow, HP)

> Yeah. Well, it's part of what we see as [core] which is trying to help people, [Int: Yeah] er, achieve [the] maximum [Int: Yeah, yeah] You know, and thinking of … in terms of biopsychosocial. (Bow, HP)

Given the context of a focus on the broader young person, they were currently working on a longer term plan to introduce and implement a formalised Holistic life-skills training. A few parents also felt that such work was going in with health services, albeit in an informal way.

> I think this team have, have been doing those kind of issues informally [Int: Yeah, yeah] i- but in a structured manner, in their heads already, without [young people] realising that they've gone … Well, you see, they knew they were going to this. They were invited to attend this driving, [Int: Yeah] erm, seminar and so they met other teenagers the same - a couple of boys the same age as themselves there [Yeah] when they went. (Amy, Family)

Within this service, they had no formal courses or resources which they drew on to support such Holistic life-skills training. Instead, topics, like sex, may emerge or be prompted within the space of consultations. However, the focus appeared to be on the implications of the long-term condition and its potential impact on these topics, over a broader more holistic focus.

Health professionals were aware that such services could be offered and some felt it could be 'really helpful' (Lucy, HP) albeit given the caveats of more time and resources. However, they were aware that other non-health services are already offering this: 'I think it would be something for another service. … they can go to places like [Charity A] and that and, and they'll do social skills there' (Pete, HP). As such, this style of work is not always seen as a core responsibility.

> I think it's a bit over the top to be honest, you know, I think, but, you know, w- there are, there are aspects of what they need to do that's a bit different to the next young person who doesn't have [long-term condition], but that sort of stuff is the same for every [Int: Yeah] young person.(Jones, HP)

Holistic life skills are, given their nature, positioned as something that all young people need to acquire albeit that condition-specific issues will impact in specific ways on elements of their engagement with the world. Rendering this as something tied to health and health services per se can be seen as problematic.

> No, I don't think that should be part of … health [Int: Yeah]. I think it's more social services domain [Int: Okay]. That's just my personal view point. (Peter, HP)

Clearly, there is an element of resistance from some professionals to realign the scope of their work in such a way. This is in part driven by the knowledge that other services the young people encounter are potentially offering such support already and may be better resourced and skilled to provide such training. However, as another health professional noted

> I think it's one of those, this is one of those areas that sort of falls between the agencies; so you could argue that that kind of input could be, erm, part of an education remit; part of a health remit; part of a, you know, social care remit (Delia, HP)

In this way, given the broad focus of such work, a range of service providers could, in theory, offer such support. However, in practice, only some young people are actively engaged with social and educational providers, from across the state, private and charitable sectors.

Echoing the health professionals, young people and families, were aware that such work was already going on through other providers. Some of this work occurred within the school or college environment. This was especially so when the young person was attending college courses tailored to offering such support around topics like 'independent living' or was involved in specialist schooling.

> They had a little flat and it was a little flat where they would teach them how to budget money and day to day sort of living and how to cope and that sort of thing. I thought it was absolutely fantastic. But it came from the school. It came from nowhere else and it was never sort of kept up anywhere else and I really do think that helps to keep him on the right track but I suppose unless you are in a special school you don't get that. (Daisy, Family)

Some young people also were provided with such training and support through groups, events or trips provided by the third sector: 'well I've done sort of similar things but through maybe private charities, things like that' (Charlie). Such charity run specialist groups, sometimes long term condition-specific, or more general, offered as part of their services elements of Holistic life-skills. In some cases, third-sector partners already had good links with the services.

It should be noted that, this work was also seen as something that families are already providing and should be central in. As one young person noted, when asked about such provision, the only person she has received support from is 'My mam, it's only me mam helps us with everything and all that sort of stuff.' (Penelope). Again, echoing some health professionals, a family member also felt that such work should not be tied to health services

> I think probably health departments, they've got enough to do really haven't they? I think that should be down to the, you know, the, the individuals and their families. You know, to sort of sort out. I, I, I mean, I mean if there's any advice there to be given, obviously, or, or asked for it might be handy. But, uh, but I really think, you know, health departments are for the health really aren't they? (Ralph, Family)

The social institution of the family was often seen as a central resource – and note that all these young people had at least one family member closely involved in their healthcare. In this context, a core responsibility of health services was to signpost young people to relevant services outside of the NHS.

> Beryl   Um, yeah certainly signpost to, they'd probably dismiss it as not being their responsibility I would imagine, but
>
> Bob   I think they probably do a lot more things before they'd start doing this [Int: Okay], you know, they need to get other things put right [Int: Yeah] before they thing about [Int: Yeah] taking on more things they cannot do.
>
> Beryl   Yeah, I think so. … I think that's very fair point to raise [Int: Yeah], that they need, they need to do what they're supposed to do best first and foremost [Int: Yeah] before they look at, at taking on more

For those families who felt aspects of the child or adult services were in some way sub-optimal, a focus into other domains of work, beyond a focus on supporting the core medical issues was clearly problematic.

Coordinator at managerial level: an absent idea(l)?
Only one service reported that they had introduced such a coordinator role as they realised the need. However, this was role was newly created

> We have identified one of the nurses as taking a lead for transition and she's the person who's going to be looking at the pathway and the overall thing but they haven't done anything much yet cos they've only been in post a month. So we we've sort of thought about having a person and erm but we haven't got very far with what they're actually doing in that post yet (Ardo, HP)

Other services were also aware of the opportunities that such a role could provide. One health professional noted that 'I would like one. I think that's a really important role' (Redgrave, HP) and discussed a range of evidence they were aware of that demonstrates how it could benefit their service. It was clearly seen as 'useful' (Bow, HP), and offering a range of potential benefits

> Ideas about how to organise these clinics, you know, disseminating ideas, um, information sources – all that sort of thing and I mean, if all the various facets were all given the same message saying the same thing, directing to the same services then yeah, of course. That would be, that would possibly be the single most useful thing to do … if somebody could kind of co-ordinate and pull together what, what is going on across the board, service wide, then that would make that sort of planning easier as well, I think. (Brown, HP)

Despite such enthusiasm, the practical realities of limited resources, managing increasing workloads and competing demands mean that such an ideal seems far from being implemented. For example, in one service, they noted that, they are a 'relatively small area', with few young people transferring, 'So whether that's enough to justify an individual's work' (Barbara, HP). In this way, such innovations will depend on such factors as clinician enthusiasm alongside, more external, policy drivers like developments in guidelines, tariffs and quality standards.

Strengths and Limitations
Conducting serial and triangulated interviews enabled us to confirm stories and capture evolving perspectives. Observing consultations enabled us to compare what people do, against what they said they did in these contexts. Whilst both the form and content of healthcare that is received may differ between the three exemplar groups, the organisation and experiences of the transition and transfer process showed many more similarities than differences.
The findings have face validity as they relate well to the findings in other WPs and other studies in the literature, especially how transition and transfer can be disorientating for young people and their families.[44, 51, 83] This study strongly echoes work on how young people build relations of trust with health professionals and services,[44, 51] especially where those relations are consistent and supportive;[58] as well as work on how the family, especially the mother, have built relations of trust with health professionals and services.[83]

In its nature, qualitative work is in-depth but small-scale; a consequent strength being the richness of data and a weakness being the low number of case examples. We aimed to recruit fifteen families and achieved thirteen. We had difficulties in recruiting young people, with many seeing the breadth and depth of data-collection as an additional burden whilst already taking part in *WP 2.1*. Retention of young people for follow-up and/or post-transfer interviews was poor, so learning about the adult context was limited. We were unable to contact some young people and some of those we did contact declined follow-up interviews. They either withdrew from this aspect of the study, or suggested we speak to their parents or health professionals. Thus, our findings are valid in relation to the data we collected; however, it is possible we did not identify key messages that would have been relevant after transfer to adult services.

Additionally, all the young people had at least one family member closely involved in their healthcare. We therefore lack the perspective of young people with less input from families, including looked-after young people.

Discussion

Our work echoes the reviews of Lugasi, Fegran and Heath[44, 51, 83] that transition and transfer is disorientating for young people and their families. The young person has usually been in a specific child health service for some time, generally since early childhood. They have, over time, built relations of trust with health professionals and services, especially where those relations are consistent and supportive.[58, 144] They have, over time, learnt to make sense of how best to integrate the practical, cognitive and emotional work it takes to be a patient with a long term condition within a specific paediatric health service system. Similarly, the family, especially the mother, have built relations of trust with health professionals and services.[83] They have, over time learnt how best to support their child, how best to support the management of their child's health condition(s) and importantly, how to effectively navigate, manage and engage with the child health service system.

The process of transition breaches[89] the relations of trust. It breaches the relations of trust they have developed with others, with a range of health professionals, services and organisations. It also breaches the relations of trust they have developed with themselves. They no longer know what to practically do, how best to navigate consultations and services, whom best to contact. In this way, it breaches their taken-for-granted expectations, knowledge and relationships. The event of transfer is central to enacting this disruption for young people and their families.

Allen,[58, 144] following and developing the work of Forbes,[200] has focused on how continuity of care be effectively enabled, so as to reduce disruption for young people and so enact a 'smooth transition'.[58] They discuss seven different forms of continuity: relational, longitudinal continuity, managerial, cultural, informational, flexible, and developmental. Importantly, they note that

> Relational and longitudinal continuities are the mechanisms central to transition because they also facilitate management and flexible continuity. They also provide a sense of safety at times of change, obviating the need for informational continuity interventions. Flexible and cultural continuities also emerge as important.[58]

Relational and longitudinal continuities refer to an 'ongoing therapeutic relationship' and 'uninterrupted relationships with service providers over time'.[144] However as we saw above, for these young people and families, relational and longitudinal continuity are breached. In all the services we focused on, the young people moved to a separate adult service provider with a different set of health professionals offering them care. In such a context, Allen highlights that informational continuity – 'the provision of information in order that young people and their families are prepared for transition and understand the new arrangements for their care'[144] – can become central.

We have seen that systems, processes and practices that work to help people make sense of and minimise these disruptions are more likely to be effective for young people and their families. In Allen's[58, 144] terms, informational continuity is a central resource through which effective transfer takes place within our data set. Quite simple and mundane practices, like being very clear about the processes in discussions and documents, are key, as is exploring how adults' and children's practices and procedures actually differ, exploring the new norms and routines. When there is informational discontinuity, young people and families can become lost, abandoned and feel there is no one to turn to. Similarly, organisational turbulence, through things like staff or services changes, prior to transfer, can led to informational discontinuity and so create confusion and uncertainty. As young people are transferred to a new clinical and organisational environment with a new set of health professionals, norms and routines, the core focus they need is support and confidence in the practicalities of managing the adult healthcare system itself. We have also seen how, undertaking joint clinics and meetings with members of the adult team which the young person will actually be seeing, can be central. Following Allen,[58, 144] this enables the possibility of the initial steps towards 'relational continuity'.

Finally, we have seen that systems, processes and practices that work to recognise, enable, support and accommodate interdependence and relational autonomy are more likely to be effective for young people and their families. Interestingly, in the reviews,[44, 51, 83] and in nearly all the papers they worked with, the figure of the parent is cast as, albeit for good reasons, in some ways holding back the young person's move from dependence to independence. Allen's[146] work is a notable exception, in that they problematize the myth of independence, highlighting how 'the individualized focus of adult services does not reflect the realities of young people's lives, which are characterized by interdependencies'. As ethics of care work[201, 202] has repeatedly outlined, interdependence, or rather 'relational autonomy', is a routine feature of everyday life. The involvement of others is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members should be supported in shifting roles to a more 'partnership', 'shared care' or 'consulting' role.[83]

May et al[203] argue that, over time, patients with long term conditions, especially those with multiple morbidities, have increasing 'workloads', a burden of treatment. The everyday work of living with a long term condition includes work that is delegated from health professionals to patients. This includes managing and coordinating multiple appointments, treatment regimes, self-care and self-monitoring. This work disrupts everyday life. Through the process of transition, and especially the process of transfer, we are increasing that burden for young people and their families. Following May et al,[203] we need to support and enable a minimally disruptive transition.

Conclusion

Transition and transfer is disorienting for young people and their families. It has practical, cognitive and emotional impacts. Importantly, it disrupts their often hard-earned knowledge of how best to navigate the child healthcare system effectively. Health professionals need to focus on helping young people and their families make sense of these disruptions. They can minimise them through actions like: being very clear about the process in discussions and documents; exploring how adults' and children's practices and procedures actually differ; undertaking joint clinics and meetings with members of the adult team the young person will actually be seeing; and including family members in the process. Transition is about supporting and enabling young people to become responsible for their own healthcare. However, family members remain crucially important in this process. The involvement of others is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members should be supported to shift roles to be more 'partnership', 'shared care' or 'consulting'.

Interview schedule: Young person

Schedules for parents and health professional are similar – not reproduced here

Young Person Interview Schedule – Time 1

Note: The interview schedule is developmental. The questions will need to be tailored to the specific answers of each interviewee. The interview schedule given here is therefore a general topic guide for the one-to-one qualitative interviews.

Plan of interview

1. Introduction
2. About you
   - Education; Employment; Leisure/hobbies; Health/Mental Health
3. Proposed Beneficial Features/Things that might be part of your transition
4. Transition/discharge plan
5. Becoming an adult
6. Feedback

Setting

- Young people will choose setting – mainly their home, could be their school/workplace/college etc
- Time 1 interviews to take place in 2012/2013
- Newcastle University lone worker policies will be followed

Introduction

- Explain purpose of the study and this interview and that it is the first of two:
  - Won't affect the care you receive whether you take part or not
  - What you tell me will not be discussed with your health professionals/parents/carers or anyone else outside of the research team without your permission. (Unless you tell me that someone is hurting or harming you, in which case I will have to tell someone to make sure that you are safe)
  - We're looking at the experiences of young people with complex health needs as they move from child to adult health services
  - No right or wrong answers – not a test of your knowledge
- Consent – written.
- Explain interview recorded but details will be confidential I am not a clinician, but [appropriate clinician] who is involved in the study can speak with you or facilitate an appointment with your general practitioner
- Questions or concerns?

About you

Firstly can you tell me about yourself (things like how old you are and who you live with)?

Points they might cover:

- ❖ Age
- ❖ Current living arrangements
- ❖ With who?
- ❖ Plans to move?
- ❖ If yes – When?
- ❖ Where?
- ❖ Who with?

About your health/mental health care

Can you give me a brief description of your current health/mental health care (things like who you see and if they are helpful etc.)?

Have any plans been made about what might happen after you leave children's services?

Have you met anyone to talk about what might happen after you leave children's services?

Do you know if you will need to be followed up in adult services?

Have you talked to anyone about adult services and what might happen there?

Tell me about your current health/mental health appointments

Points they might discuss:

- ❖ Helping to make decisions about your care?
- ❖ Attending appointments (or part of your appointments) by yourself?

  Do you think there is anything that could be changed about your health/mental health appointments to make them work better for you? (The things you like and the things you would like to improve)

Points they might discuss:

- ❖ Timing
- ❖ Location
- ❖ Professionals talking to you more
- ❖ Professionals talking to your parents more
- ❖ Language used

Education

Tell me about your education/school/college

- ❖ Where
- ❖ Subject(s) and level(s)
- ❖ Continue on to sixth form/college/university?
- ❖ Future studies?

Have you discussed education with your health/mental health professional(s)?

- ❖ If no – do you think this would be helpful?
- ❖ If yes – Tell me about it
- ❖ Helpful/useful to you?

Employment

Have you thought about what you might like to do for work/career?

- ❖ Specific career plans?
- ❖ How to do that

Have you had any support/advice about planning for your future career?

Points they might discuss:

- ❖ Who (Connexions/school careers advisor/transition employment support officer/similar)
- ❖ Tell me about this
- ❖ What did they say
- ❖ Helpful/useful to you?
- ❖ How could it be more helpful/useful to you?

Have you discussed this with your health/mental health professional?

- ❖ If yes – Tell me about it
- ❖ Was this helpful?
- ❖ How could it be more helpful/useful to you?

Leisure/hobbies

What do you like to do in your spare time?
Do you need any support with this/these?
Points they might discuss:
- ❖ Get any support?
- ❖ Tell me about your support
- ❖ Who
- ❖ Is it helpful/useful to you
- ❖ How could it be more helpful/useful to you

Have you discussed this with your health/mental health professional?
- ❖ If yes – Tell me about it
- ❖ Was this helpful/useful for you?
- ❖ How could it be more helpful/useful?

Proposed Beneficial Features/Things that might be part of your Transition
Here are some things that some people have said might be useful to help them move from children's health services to adult health/mental health services. You will have this list in your health contacts diary from the other research assistant who is working with you.
What would work for you, why, what would not work for you?
Go through each of the 11 features and find out if they have experienced them (in conjunction with health diary and information from clinical notes obtained from relevant local RAs) (See also Health Diary Piloting)
Things that might be part of your transition:

Number	Questions to think about
1	Was the clinic you attended **separate from the children's clinic**; therefore just for young people or young adults?
2	Have you been **introduced to people in the adult team** who will take on your care in due course?
3a	Did anybody ask you **formal questions or ask you to complete a questionnaire about whether you are a confident type of person**. This does not mean how you appear to other people; rather whether inside you appreciate yourself, can deal calmly with difficulties or unexpected events etc
3b	Did anybody in the clinic team work with you to become more confident in **looking after your health condition** and your health generally?
4	Did anybody ask you formal questions or ask you to complete a questionnaire about whether you felt **ready to move to adult services**?
5	Do you have any document completed by you and the clinic team with information about you and your condition; a document you can share with any new health staff you meet? This might be a **health passport or a transition plan.**
6	Did you think your **parents were involved and consulted** to the right amount about your healthcare?
7	Is there one person in the clinic or team working with you who you feel knows you well and is identified as your **'key' worker?**
8	Do you know if there is a person **(a co-ordinator)** whose job is to make sure services are well co-ordinated as you move from child to adult services (you may not know the individual personally)?
9	Did you think the doctor, nurses and other healthcare staff involved in your care **work together as a team?**
10	Do you or your parents receive an **'individualised budget'?** This is a sum of money you or your parents receive to buy your health care which previously was provided free by the health service.
11	Did you receive from staff in the clinic any **training such as watching a video or attending a course** on preparing for your future? So it would cover such things as: • Planning for training or work or more education • Looking after your health • Making good and happy relationships • Looking after you finances

For each of those they have experienced:

Tell me about it

Potential prompts/areas they might discuss:
- ❖ What happened?
- ❖ What was discussed?
- ❖ What was done well?
- ❖ What could have been done better?
- ❖ What could have been done differently
- ❖ Do they think this was helpful?

If they do not think they have experienced them discuss the idea:
- ❖ Do they think it could be helpful/why

Ask them about any other ideas they have which might be helpful and use prompts if needed:
- ❖ Other ways to organise your health care
- ❖ Other training that might be useful to you

Transition/discharge plan

What do you think should be on a transition/discharge plan?
- ❖ Education
- ❖ Employment
- ❖ Leisure/hobbies/spare time
- ❖ Independent living skills
- ❖ Condition related needs
- ❖ Health/Mental health

Do/did you have a written transition/discharge plan?

If yes, tell me about it

Points they might discuss:
- ❖ helping to write it
- ❖ Anything extra should be on
- ❖ Anything should be taken off
- ❖ Do you have a copy?
- ❖ Was/is it helpful/useful to you?
- ❖ How could it have been more helpful/useful to you?

Who was involved?

Potential people involved:
- ❖ You
- ❖ Education
- ❖ Health
- ❖ social services
- ❖ parents/carers
- ❖ other family members
- ❖ friends
- ❖ Anyone else

What was on your plan?

Potential areas covered:
- ❖ Education
- ❖ Employment
- ❖ Leisure/hobbies/spare time
- ❖ Independent living skills
- ❖ Condition related needs
- ❖ Health/Mental health

If no do you think it would be/have been useful?

Becoming an adult

Do you feel like a 'grown up' or an 'adult'?

What do you think will make you feel like a 'grown up' or an 'adult'?

When do you think someone becomes a 'grown up' or an 'adult'?

> Discuss, then show them the list adapted from Arnett[204] and discuss whether or not they think each item contributes to being an adult. Can be simple yes/no.

Finally, we need to understand whether the kinds of questions we are asking actually relate to the issues that you think are important?
- o Are we asking the right questions?
- o Did these questions allow you to talk about what was important for you?
- o Is there anything else you would like to tell me?

Thank you for taking part
Remind them that you will be contacting them about the arrangements for the diary exercise in 2-3 months' time.