

Moving on: transitions out of care for learning disabled young people in England and Sweden

Learning disabled care leavers' transitions

Abstract

Background

Learning disabled young people are frequently underrepresented in research accounts. This paper aims to describe the pleasures and challenges experienced by young people transitioning out of the care system.

Methods

We looked at the scholarly and grey literature in English and Swedish for first hand accounts, and interviewed 4 learning disabled young people transitioning from the English care system.

Findings

Grey literature and campaigning literature from charities are more likely than the academic literature to include the voices of service users, but even then the voices are more likely to be those of carers rather than young people. Both the literature and interviews demonstrated young peoples' awareness and understanding of the social as well as financial benefits of work. Good foster care could be precarious, and young people in unhappy placements lacked direction. We found gaps in relation to appropriate accommodation, and the prevention of exploitation around a young person's housing and finances. There was evidence of threshold issues in terms of access to services.

Conclusions

Despite an NHS commitment to listening to the voices of users, our extensive searches identified few studies reporting learning disabled care leavers' own words. Our data add to the voices of a group frequently silent or silenced. We found good evidence of resilience and hope as well as difficulties and frustrations. The accounts in the literature and our interviews provide data on what it can be like to try to operate 'the system.' Those we spoke with were thoughtful and engaging

Accessible summary

- **When young people with learning disabilities leave the care system, they can experience a lot of problems**
- **We don't spend enough time listening to what young people can tell us**
- **Here we describe some of the problems they experience and what they do (or would like us to do) to improve things**
- **These are not always the same things that professionals or carers want**

Introduction

[For] young people with learning disability ... we have this very difficult situation at the moment whereby you'll be a young adult, you'll be through school, it'll be very well recognised you have learning needs [but]... if you have an IQ above seventy, you don't meet the criteria for getting a service... And if you don't meet their criteria where do you get your support from ?

Designated children looked after doctor

In 2015 we carried out a participatory study on the multiple transitions out of the care system of young people in an inner city local authority in England. We found that two groups – learning disabled youngsters, and unaccompanied migrants faced more than their fair share of challenges.

This paper sets out what we learned from a follow up study with learning disabled young people, supplemented by accounts from the literature. Although a major focus of this study was transition from paediatric to adult care, it soon became evident that 'health' was viewed much more broadly by both the young people and professionals we interviewed. Their accounts tended to focus on what they need to be healthy rather than health conditions.

There are relatively high numbers of looked-after children with special educational needs and disabilities (SEND) in the care system in England (Baker 2011) and like other young people, they need to transition rather than simply transfer from care. Whilst the Charter for Care Leavers ([Department for Education 2012](#)) emphasizes their rights to participation,

learning disabled young peoples' rights to protection, as interpreted by adults, may trump their right to participation ([Winter 2006](#)). As a result, not all gatekeepers welcome studies which ask young people with a learning disability whether they would like to participate (Feldman, Battin et al. 2013). Where learning disabled young people *have* been consulted, supportive friends and opportunities for social inclusion are emphasized as important, and it has been noted that their views may differ significantly from those of carers and professionals (Rabiee, Priestley et al. 2001) (Kelly, McShane et al. 2014).

People with learning disabilities have poorer health than their non-disabled peers (Emerson, Baines et al. 2011) and learning disabilities are strongly associated with mental health problems (Moss, Emerson et al. 2000, Robertson, Hatton et al. 2015). The Longitudinal Study of Young People in England shows that for boys and girls with mild/moderate learning disabilities, exposure to common determinants of poor health such as poverty and bullying at age 13/14 was associated with poorer health outcomes at age 14/15 (Emerson, Baines et al. 2011). In the Millennium cohort, at age seven girls (but not boys) with learning disabilities were at greater risk of obesity and boys (but not girls) with learning disabilities were at greater risk of multiple accidents (Emerson, Baines et al. 2011).

We included Sweden in our literature search of young peoples' accounts on the basis of their good record in relation to equalities and their distinct approach to welfare provision. 'Care leavers' still less 'learning disabled care leavers' are not a familiar categories in Sweden, which limits what can be found from administrative data. But it seems to be the case that despite the generally good record of Nordic welfare systems in addressing

inequalities, children placed in out of home care have do not seem to benefit from universal provision to the same extent as children in families ([Vinnerljung and Sallnäs 2008](#)).

Although this universal provision in Nordic welfare systems reduces stigma, a consequence can be insufficient specialist service provision for looked after children and care leavers (Vinnerljung, Hjern et al. 2006, FORTE: 2015). Being taken into care is itself associated with poor health. Significant unmet need including immunization and dental care have been reported (FORTE: 2015). Former care residents are a high-risk group for mental health problems (Vinnerljung and Hjern 2014) and exclusion from the labour market (Vinnerljung, Brännström et al. 2015).

This paper aims to describe the pleasures and challenges experienced by young people transitioning from the care system.

Methods

In order to gather data on young peoples' experiences of transitioning out of care, in our initial 2015 study we conducted five research meetings and 16 individual interviews with a total of 24 young people. In addition to discussion and interview techniques, we used pictorial and other participatory methods.

The care leavers were ethnically diverse, aged 16-24 and included both young women and young men. Two of those we interviewed, and whose words we include here, a young man and a young woman, had learning difficulties. In 2016, we interviewed two young people – 'Betty' and 'Martin' whom we had first interviewed in 2015, and two more, 'Jules' and 'Kip'

(both young men) were interviewed in 2016 only. We provided easy read consent forms and each young person had a code name which we use here. In discussion with our gatekeepers, we provide the minimum of identifying data on individuals. Those in the study consented to their words being used, and those who came to feedback sessions enjoyed seeing their words used.

Our initial analyses began when we listened to our first interviews and reflected on the interview fieldwork notes. All interviews were read several times and initially coded by at least two team members with similarities and differences between us discussed.

Although we had originally planned a scoping review based on systematic review principles, the majority of the (still slender) literature in Swedish and English we refer to below was identified by following up citations in scholarly and grey literature, contacting experts including the authors of relevant papers for further recommendations, and from books which tend not to come up in conventional search strategies. Our studies received ethical approval through the HRA social care ethics committee 15/IEC08/0009.

Findings

In reporting young peoples' own views, we draw on both the interviews we conducted in an English inner city and the relevant studies we found.

Despite a commitment in health and social care to listening to the voices of service users, our searches identified few studies reporting learning disabled care leavers' experiences, particularly in Sweden despite their lead in relation to the rights of children and young people. Grey literature and campaigning literature were more likely than the academic

literature to include the voices of service users, but even these tended to be carers rather than young people. The accounts of young people suggest gaps in relation to transitions in mental health, general practice and dental services and also in relation to appropriate accommodation, and finance. A review by Dowling et al (Dowling, Kelly et al. 2012) reports much the same paucity of 'voice' studies as we found and Lavalley et al (LaValley, Payne et al. 2012) also struggled to find care leavers' own accounts. One study reported young people feeling that they not been listened to by medical staff (Cameron 2007) resonating with our own interviews where receptionists could be experienced as hostile, and delays before being seen by a doctor or a nurse described as a problem.

Kelly et al (Kelly, McShane et al.) identified a UK study (NFCA 2000) where young people with learning disabilities prioritized leisure and social opportunities; relationships, sex and sexuality; employment; education and training and accommodation, and found few opportunities to make friends outside of service settings. Restrictions to practical support and funding for transition to adult services added to their exclusion. Kelly et al (2014) describe young people wanting to pursue work ambitions ranging from motor mechanics to hairdressing following college courses.

Rabiee et al (2001) interviewed 28 care leavers, most of whom were viewed as having a learning difficulty. They were more concerned than professionals about relationships and independence, and focussed on how they could make friends, where they would live and if they would have enough money. Those who stayed in the same long-term foster family had more opportunities to stay in contact with friends than those who moved placement.

From Sweden, despite a long tradition of upholding the rights of children, the representation of children and young peoples' views in the Swedish residential care system has been limited (Pålsson 2015). The family-centred nature of the care system means that research on transitions has tended to refer to young people living with their families (e.g. (Bjorquist, Nordmark et al. 2015, Bjorquist, Nordmark et al. 2015)) although behavioural difficulties (which may be linked to the frustration of having a learning disability) are described as the main reason for being placed in out of home care. Young people whose parents advocate for them have been described in research from their parents' perspectives, but when parents do not deal with the authorities on behalf of their children, young people with disabilities drop from professionals' view. One research respondent said *'We know very little about how they are doing, how they live and sometimes we do not even know who they are'* (Ringsby Jansson and Olsson 2006: 25). For this professional, young people with disabilities are visible to professionals through their parental representatives, but otherwise unknown and, it is implied, unknowable.

What does it mean to transition?

Care leavers, including those we interviewed, have often experienced a series of transitions, encountering a range of professionals and carers. As was the case in our own interviews, health priorities identified by young people in the qualitative studies we found were more frequently about factors which might determine good and poor health than clinical care or health services as such. All of the learning disabled adults in Streeter's (2015) study spoke of problems, and transitions are frequently poorly managed – though as one pointed out, transitions is part of everyday life for all of us:

I don't know, I don't think that you ever fully grow up, I think you're always learning about things and how to handle things, because when I had to handle my first carer on my own, I didn't really deal with it very well so you know, I think you're always learning, you're always learning from your mistakes ... because you're an adult, it doesn't mean that you don't learn things.' - Young woman in her 30s

(Streeter 2015)

Mental health, loneliness and family life

Another young person in Streeter's work spoke of mental health difficulties, one describing how s/he did not know about psychology services as a child. Another spoke of the risks of not being busy: *there's nowhere to go, what do I do?*

The health dangers of loneliness are well recognized in the elderly – but less so in young people leaving care, and particularly those who may be under-occupied as a result of leaving school or college with little else to do: *If I am alone too long, I self harm... and stuff. I try to keep my days and nights busy 24/7* (Barnado's 2014). Biehal and colleagues, interviewing a young man with learning difficulties, found that the highlight of his week was seeing his grandmother. He was painfully aware of his limitations (Biehal, Clayden et al. 1995): *I can't see much future ... sometimes I get depressed. I think there's no future for me.*

Loneliness was also a problem for two of the learning disabled young people we spoke with. Kip, on the cusp of transition, told us that the best thing that had happened in the last 6 months was to *get to sleep over at Mum's*. When he is not with his brother, who lives with his Mum, he feels lonely. He told us that if he was sad he would speak to friends. His social

worker had organised for him to go to the Child and Adolescent Mental Health Services (CAMHS) with his carer when he was 13 or 14 and he told us that he had liked it, and it helped his reading and writing. He saw a man there, played games with him and they talked together. He doesn't know why he stopped going. Kip had problems in his last foster placement and at school, where he loved sports, but sports stopped when he left school. In school he *mucked about* with his friends because some of the lessons were boring. He used to get told off or be put in a room to calm down and then went back to his class. Sometimes he got angry when he was told off for not focussing. It happened a lot. He was told that school was not for him, which made him upset as he had a lot of friends there. He used to play football, row, do the javelin, 200 metres, 100 metres. He told us that his social worker is going to try to find places where he can do sports again.

If he was organizing services for other young people it would involve:

taking them to places, and like seeing people eating healthily and stuff and that - probably to get out more cause now it is getting dark and most people aint allowed out, they are stuck indoors sitting indoors eating...

Jules spoke of depression:

Well, it's like sometimes, when I'm really depressed, when someone's really really bombarding me ... moaning in my ear... swearing .. giving me all this raving and shouting in my face, it just makes me feel like what am I going to do next ?

But later, he told us:

I don't really have depression... when I'm upset, everybody helps. ...When I'm upset I just have a glass of water.

AI: Do you speak to anybody about your feelings?

Friends, family.

AI: Do you go to the doctor?

No. My doctor's is all the way in [another borough].

When we first interviewed Martin in 2015 told us that he had hay fever, depression and asthma. He was too old for a social worker:

[Social worker] said I'm too old to have her ... so she just passed me onto the duty social team and took it from there basically.

[initials]: Was it planned in any way?

Just like I went up there one day, spoke to the duty team, boom, I was out, on the same day. it was quite annoying. Because you don't know what social worker you're going to be talking to. You don't know if they can sort your problem out always different ones.

He told us that he had been bullied at college, so he left ... *so like when the time came for classes to finish, I walked out.* He described staff encouraging him back, but his mind was made up: *They said 'oh, but can you please just come back.. we can sort this out.'* *I said no and I put the phone down...*

When it came to his support worker:

I told her that I'd left college because of the reasons and she said, okay then, that's your choice at the end of the day, you're eighteen, you're an adult so you make your own decisions in life now, if you want to leave the college you leave the college, we can't make you go back .. we can't force you to go to college, it's your decision, we just can advise you. The social worker said I was too old to have a social worker.

In exercising his autonomy, he has lost the possibilities that a parent might have encouraged him to take up again. He was living in supported accommodation, and knew what he needed to do to live independently.

Until I can prove to them that I can live on my own then obviously they'll have a talk to social workers ... and I'll have a talk to the ones ... on duty and they will compare notes and then obviously I'll have to sign papers ... and once I done that then I'll probably, they'll probably, move me into a house.

He was positive about some of the mental health support he had had in the past:

Like there was a mental health person at [unit name], he prescribed [medication] because he said that would probably help ... not to punch stuff like brick walls and windows and all that lot and believe it or not it has helped.

Interviewed again in 2016, he initially told us that life was good, but went on to tell us about his depression and the ways in which he managed anger:

The depression goes downhill sometimes ... Yeah, basically because someone's made me angry and I want to hurt them but then I think if I hurt them I'm going to get myself arrested so I just hurt myself and then I won't get myself arrested.

Asked who helped him, he told us that it was his girlfriend:

She's like saying to me "Don't do that, please don't do that, it's not, I don't like it, I get worried when you do that because you might die on me ..."

He did go to the doctors, but was embarrassed and never saw the same one. Asked whether he mentioned hurting himself to the doctor, he told us that he hadn't:

but if I did he'd probably put the meds higher, like maybe 150g ... and then take twice a day so like once at night, once in the morning just to see if that helps.

He mostly stayed at his girlfriend's house, but was still in supported accommodation. Asked how many support staff there were, he told us:

Lost count. New staff come in all the time. They employ new staff if like the other staff is busy and they ain't got no one to cover so they just bring the new staff in.

He thought that he was some way off being able to live independently, though he could manage transport. He was depressingly realistic about employment:

I wouldn't like to go with a life on benefits but then again, if I have to because I can't find a job then obviously that's the way I'm gonna have to live my life is benefits.

Leisure activities were a problem because a pass cost “about £19”.

I think because so many people had free leisure passes I think they were crashing, they were going to close down because they weren't earning enough money to pay for the rent of all their facilities.

His ideas for improving services were IT related:

maybe have more staff and have like iPads and stuff in the staffs' hands so then like “Right we're booking your appointment now, right your appointment is now booked for this time. Next person please”.

In relation to Child and Adolescent Mental Health Services, he said: *No, I don't usually go to that. And later: Some of them weren't really listening ... Like I'm explaining something, like they're kind of cutting me out and stuff ...*

On the importance of listening, he added:

Listening is an important skill, it's like you know sometimes a lot of people don't listen because they think, ah this person's talking rubbish, they think they're lying, they think they're doing this, they think they're doing that, they think they're doing that, I don't understand.

He talked several times of the internet as a source of health knowledge:

You can type out the meaning of the word on the internet. You can get information ...

You can go to Wikipedia, it will tell you the whole information.

If Jules were in charge of services:

every child in care should be getting a leisure pass because ... if they get a leisure pass they start going to the leisure centre, they do activities there, it will start developing their skills,

Drinking relationships and cooking

In his interview in 2015, Martin described drinking as a way of being in the world – alone but with others.

Like drinking. I do like going to the pub for a drink, I must admit, it is quite nice and it's relaxing and you can just sit down by yourself, have a drink, relax.

In 2016, he described problems with drinking and smoking. Like the other young people we interviewed, he enjoyed fast food. He only eats salads if it is with a burger, and he goes to Macdonalds once a week. Fast food was a favourite of everyone we spoke with.

Asked how the plans he had had the year before to cut down on alcohol were going, he replied:

I still what they call binge drink. Well not every ... Yeah, well it's not like every week, it's like every two weeks I go out and have a drink.

He smoked 20-30 cigarettes a day and had had advice on quitting from from a GP and a chemist, but:

it didn't really seem to work, I just basically ... crawled back onto them like an hour after it because I got really bad cravings and withdrawal symptoms so I just had to have one.

Relationship support would have been appreciated:

... decent girlfriends and stuff. Yeah, because I've had some really horrible girlfriends in my life ... support with choosing the right friendships, support with choosing the right relationships ...

And

help with cooking, managing money and that's about it really.

Similarly, Jules didn't feel he had been getting support with cooking from his carer, but had learned from his mum:

She [carer] didn't teach me to cook, she didn't even know how ... She didn't teach me to cook and every day, when I'm with my mum I'm always watching her, learning from her, picking up the confidence from her.

He was up to date on worries about sugar:

Yeah. I use the internet for like to check out how much sugar does Coke have ... and basically recently on the news they said a lot of children have 22g of sugar a day.

In relation to alcohol, Kip on the start of his transition pathway said that there were six in the family, and his Dad gave them a drink when they were little. Alcohol no longer featured in his life and he has never tried smoking. He described both of them as bad for you.

Betty, a care leaver safe in a foster family did not mention smoking or drinking. She enjoyed her food (including Macdonalds).

Sexual health

Research suggests that young people with disabilities are at higher risk of abuse than their non-disabled peers (Stalker and McArthur 2010). In a study of running away from home (Smeaton 2015) 17 young people self-defined as having a learning difficulty and described being encouraged to run away and were then sexually exploited. A care leaver in this study spoke positively of a professional who knew how to communicate with her:-

She's worked with young people like me before [...] so she knows what she's doing. [...] She knows not to say too much at one time and not to talk about too many things at once. [...] It's like, now I'm going for a diagnosis [to assess for learning disability], some people have learnt to talk to me a bit different. (Smeaton 2015)

The young men we met were aware of measures to protect sexual health - a credit to them and their support workers.

Housing

Housing, a central determinant of health, was important to all the learning disabled care leavers we spoke to. Two of the young people gave accounts of their housing situation damaging their sense of wellbeing.

Jules arrived at his interview upset after an argument with his carer. Among the problems he raised was feeling that his friendships were under attack. He explained:

If I'm talking to someone very politely, if I'm having a private conversation on the phone [carer] will have to shout and ask me, who's this? And I'm always a bit offended and I can't really talk... And then I'm like ... you have to call me back init because I can't talk right now ... I'm always having a nice conversation with them and she's doing my head in.

He felt hemmed in:

...she's keeping me in the house 24/7 like a dog, when everyone is out I'm just sitting there, bored.

But the alternative offered was, in his view out of the frying pan and into the fire.

they keep saying that I need to go to a hostel and I'm totally disagreeing with them, I know that I don't want to ... they have to understand that I've been through a lot of things, they can't just send me to one place when I've just come out, when I just come out of care and it's a bit ... And I said to them today, it's a bit too much really.

Martin is in a supported living placement, despite problems with a housemate who makes him angry, a changing cast of carers and no agenda for activity after his decision to leave college. His current accommodation is not providing him with the most basic of needs - to be safe.

Kip, at the start of his transition, had recently moved placement and on the day of the interview, had been living with his foster carer for 3 days. He was with a previous foster carer for 6 years. He felt quite upset but is coping 'ok.'

Finally we end with a vignette from Betty, who is less verbal than the other three – but a good communicator. We include it as she illustrates what good reliable and predictable care to a sassy young women can achieve. Betty is in an arrangement which is successful, and provides her with stability, though one which depends on the goodwill of her foster carer. Although all involved were apparently in agreement that she would be staying put whilst suitable supportive housing was found, we were told that payment to the foster carer had been reduced, despite Betty needing the same level of care as in the past.

The account below describes interviews with Betty in 2015 and 2016:

Before interviewing Betty in 2015 [name] liaised with 'Clara,' the Disabled Children's Worker. Betty had just turned 18 and would be staying put with her foster carer for a bit longer. Betty responded well to visual prompts and clear, focussed questions. Clara described Betty loving bees and that it might be helpful to have "bee" breaks during the interview. This involved making buzzing noises for the length of a breath which delighted Betty. The day before the interview, Clara sent printed symbols representing emotions, buildings and people in key positions in Betty's life. On arrival at the house, Betty's foster carer answered the door with a baby in her arms and a toddler in tow. Betty was in the hall. She threw her arms around [name] and hugged Clara. She ran upstairs and came down giggling showing her Ipad which had a row of zzzzzzz denoting a bee buzzing. [Name] went through the information sheet with Betty who signed the consent form. They went through the choices of ethnic background (Betty is Black). She chose Chinese. Clara gently probed but Betty was adamant. Clara used Makaton to communicate with her.

Betty lives with 'Aunty' and 'Uncle.' She goes rock climbing. The best thing thing is living in the house with Aunty. She does not know how long she has lived there. Prompted she said 1 year, but went on to say she has always lived there. She goes to college one day a week and does cooking and painting. She remembered previous social workers names. Clara said that she has had lots of social workers. She likes her Personal Advisor (PA). If she was sad she would ask her for help. The most important person in her life is 'Aunty.' She mentioned her Independent Reviewing Officer (IRO) who comes to see her. She doesn't think that the people who help her talk to one another; they just speak to her, and she was happy about that. Asked if she liked all these people she said yes. On being autistic, she gave a thumbs up sign. She has never been to hospital. When she goes to the doctor Aunty goes with her. She smiled when agreeing that she went to the doctor and dentist and is happy to visit both.

She remembers going to the dentist and doctor as a little girl. She doesn't have a pathway plan. Her IRO and PA come to her house, talk to her, ask her how she is, how she is doing at college. She is happy to see them. Her teacher at college is Dora. She does not know who she would go to for help at college. She hasn't needed help. She goes to college in a minibus. She sees a nurse at the doctor's surgery on Wednesdays. She sees the nurse for immunisations. She likes the nurse. When Clara comes to see her they do work. She doesn't remember what they talk about. Prompted by Clara she remembered that they talk about what Betty likes and dislikes. She gets £5 pocket money. She goes with her 5 school friends, (she names some of them) to spend her money at Macdonald's. Asked now that she is getting older where she will live she says "*stay here.*" Asked if her social worker talks to her about where she will live in the future she said yes.

Clara suggests that they use the symbols/pictures so that Betty can point to the relevant picture in answer. Asked when change happens how she feels, she says happy. She is excited when she sees her social worker. She is going to a school prom on Friday and is happy about that. This is the end of school; she is leaving and next year she is going to college to study cooking and painting. She feels confused when she sees her PA. She did not know why. She talks to her about college and plans for the future. That makes her feel happy and confused.

Asked if there were any questions she wanted to ask, she said that she wanted some 'buzzing.' She was about to go on an aeroplane and that makes her happy. She will wear a sundress, look nice and go swimming. No one helps her to do anything there. She can do everything herself. After leaving, Clara explained that Betty had been in many placements and has been in the current one for 2 years. Although 18 she will remain there before moving to supported living.

Betty is totally included in the family, has been on holiday with them, and is looking forward to going again soon. Her home is warm and welcoming. She is happy and is aware of being supported by a social worker, PA, IRO, participation worker, doctor, dentist, nurse and teacher. She said she is happy with change but was very clear that she was "staying here" in future. She is slim, agile, confident, has friends. The most important person in her life is her foster carer.

On a return visit in 2016, the carer welcomed [name] and Clara and a conversation followed around her concerns that the authorities had not yet sorted out Betty's placement. Betty arrived home. She smiled shyly. [Name] looked at her school writing book and was shown an accomplished drawing of a bee superimposed on lines of zzzzzzzzz (buzzing). On the next page was an account of a visit to Primark in neat handwriting. Betty pointed to Clara and [name] and they took it in turns to make buzzing noises. She laughed delightedly. [Name] thanked Betty for letting her come to listen to what has been happening in her life. Betty spoke of a plane journey (short she said), the sun, and said she had stayed in a hotel, had cereal for breakfast and had KFC for lunch. Clara said 'Kentucky Fried Chicken' and Betty smiled and nodded. [Name] asked her about college, reminding her that last year she had been going to college one day a week and school the rest of the time. She no longer goes to college, attends school every day and learns cooking and drawing. She was clear that she prefers school to college and has friends there. She doesn't see her friends outside school but described them all going to Macdonald's as a treat. She plays snooker, cricket and rugby at school. Betty is very much part of a caring family.

She smiled when telling [Name] her social worker's name is Jenny. It turns out that Jenny is in fact Betty's carer's social worker. Ken is Betty's social worker and he is leaving. Asked if the people who come to help her keep their promises, she answered very decisively "yes".

In the kitchen, her carer was cooking supper. 'Betty' is in a different situation from the other care leavers we interviewed. Although her difficulties were potentially more limiting, the care she has had (in part as a result of her limitations) enabled a full and happy life. After the goodbyes, Betty waved shyly and went upstairs. What we learnt from her is what worked well in matters of health, happiness, well being and placement. She was very vocal that she was not ready to move on.

Discussion

A challenge in public policy is identifying the outcomes of most importance to various constituencies with an interest including those experiencing interventions or the absence of interventions.

Despite a commitment in health and social care to listening to the voices of users, there are relatively few studies reporting the voices of learning disabled care leavers. Grey and campaigning literature is more likely than academic literature to include the voices of service users, but even these have tended to be largely carers' accounts. The accounts of young people suggest that they experience gaps in relation to smooth transitions in mental health and general practice dental services and to areas which are widely acknowledged as the determinants of health, including housing and finance

In an over-stretched system, professionals' efforts in developing pathways for learning disabled care leavers may need to focus on young people experiencing particular difficulties. This can mean that those in good placements and those who care for them are left on a cliff edge.

Three of the four people we spoke with were just about managing their transitions. The fourth, though more vulnerable, was better supported though possibly about to undergo a rude change. A potential weakness of an over-stretched the system is that when things are going well or even muddling along, professionals' efforts in developing pathways are understandably more likely to be focused on those experiencing acute difficulties.

Strengths and limitations

While a strength of our primary qualitative interviews was working closely with an active participation service and a care leavers' service, we acknowledge that we were meeting care leavers who are better supported than many. That even this 'privileged' under-privileged group articulated significant problems suggests that these may be even more prevalent and less well-addressed elsewhere. That these young people had the confidence to speak with us is testimony not only to their own abilities, but also to the contribution of those who encouraged them to participate. A further strength is that while there are few 'voice' studies with learning disabled young people, there are even fewer which re-interview them as they pass through the transition process. Sample size is sometimes raised as a limitation. Prior sets out a number of reasons why a small total number of participants can be useful (Prior 2016). A small sample rarely gives us all the information we need, any more than a cohort study, an RCT or a big administrative data set, but it can provide an important part of a wider picture.

The combination of findings from the 'voice' literature and first-hand accounts from our own sample provide insight to what it can be like to liaise with 'the system.' One young man was receiving medication for anxiety which helped, but he told us that he was still boiling inside. Skilled foster carers could make a real difference, but young people in

unhappy placements could be directionless, with no expectations of getting a job, although capable, computer savvy, and engaging. Young people had a good understanding of the social as well as financial benefits of work.

We found evidence of the threshold issues in terms of access to services described by the children looked after doctor at the start of this article. Self harm and housing were particular problems. The internet was an important tool both for accessing health care and for diversion.

The gap between policy aspirations and reality was spelled out by a health care practitioner in our 2015 study, asking how any system, however good, can replace what a family can offer.

I love the aspiration ... and obviously ... all the years you work in looked after children your thinking's informed by 'how can we be as close as we can be to what the experiences of a young person living and being brought up in a birth family?' and, you know, if you think about your own experiences of still going back to stay with your parents when you were in your thirties, your forties and that, even when you've got your own family, where your parents live is still 'your place' I think, I think it's very hard for a local authority to mimic that because of staff change ...[and] the character of the borough changes through the years.

Designated children looked after doctor.

The provision to care leavers of a personal advisor (PA) is potentially a good means of navigating a complex pathway so long as there are sufficient resources. Practitioners in our 2015 study spoke of an inequity in formal access to support from a personal advisor until

the age of 24, with young people with learning difficulties described as particularly vulnerable to missing out. It was suggested that the cut-off at 24 for care leavers in employment and education could usefully be taken up by all services, including health and CAMHS.

Despite negative experiences and the considerable challenges they face, the way in which young people with learning disabilities describe their experiences suggests both a willingness and the capacity to be engaged. As is the case more broadly, young people valued accessible services with polite, helpful staff who take the time to communicate. Those we spoke to were trying hard to cope; looking for ways to deal with transitions to adulthood whether by finding a partner and seeking happiness within a relationship, making a decision to leave an inappropriate placement or making clear that they wanted to stay put.

Care leavers' experiences of multiple transitions through services can affect their willingness to engage with further, unknown people. Where young people's expectations of service provision have been lowered, and without professionals and carers providing continuity (Bradby, Varyani et al. 2007) it can be hard to flourish.

The bench to bedside mantra in clinical research needs further thought in relation to the wider health, social care and health determinants of vulnerable children and young people. Without powerful commercial and patient interests driving implementation in the less well-resourced engines of social care, listening to service users voices, and putting into effect what is already known including work commissioned by DH in the 1990s (Biehal, Clayden et al. 1995) remains important. It may well be that strengthening services, particularly

investment in pathway planners and pathway smoothers who provide some of the same supports a family might, should be strengthened. In addition decision makers need contextual information and evidence on the ways in which policy interventions play out on the ground ([Cartwright 2010](#), [Cartwright 2013](#)). Qualitative work of the type we provide here serves as a pointer, and adds to the slender qualitative evidence in this area.

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