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# Transition to where and to what? Exploring the experiences of transitions to adulthood for young disabled people

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## ABSTRACT

Transition to adulthood for young disabled people remains a major policy failure across OECD countries. The support available is often inappropriate, fails to meet young peoples' needs and they fall through the cracks, becoming lost in the system. Much of the work on transition takes a narrow approach, focussing on the shift from paediatric to adult services in health and social care. Drawing on interviews with young disabled people, collected as part of an evaluation of a new cash-based transitions fund, we explore transitions for young disabled people in Scotland. Like the wider personalisation agenda, this fund aims to promote autonomy and individual responsibility. We examine and critique this approach and argue that while the emphasis on young people and their families as *social entrepreneurs* can facilitate transition, it can also act as a barrier by failing to tackle broader structural constraints faced by young disabled people. We argue that whilst it is important to promote individual agency, structural disadvantage and inequality frame the transition process and these also have to be tackled. This is harder, and arguably more expensive, but without it there is a danger that attempts to improve transition for young disabled people will fail.

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## Introduction

The difficulties many young disabled people face as they move into adulthood has long been recognised (Morris 2002; Stalker 2002). The failure of this group to move from school to employment, training, further or higher education or to actively take part in the community once they have left school, has been highlighted as a major cause of their isolation and exclusion across all Organisation for Economic Co-operation and Development (OECD) countries (Ravenscourt, Wazny, and Davis 2017) and more widely (UNCRPD 2014). Evidence suggests that transition arrangements are often absent, or, where present, uncoordinated, young people may not always be involved in the process and suitable adult services are not always available (Kirk 2008). Blame is often laid on the lack of co-ordination between services: while schools provide an institutional

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base from which to co-ordinate services, when young disabled people leave school (UN 2014), they can find themselves either ‘falling through the cracks’ or in a frustrating loop of continual training (Riddell, Baron, and Wilson 2001; Winn and Hay 2009). Policies have therefore failed to address the ‘unique social, psychological, educational and economic needs of youth’ (UN 2014, 2).

The disabled peoples’ movement have called for transition services to be driven by the principles of the of the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD) and the demands for freedom, dignity, choice and control (UNCRPD 2014). Key here is the social model of disability with a focus on the environmental, social and cultural barriers disabled people face (Oliver 1990).

As part of its response to the problem, the Scottish Government produced *Principles of Good Transitions* (Scottish Transitions Forum 2016). These aim to ensure that young disabled people receive person centred support co-ordinated across all services. Young disabled people, it states, should get the support they require and they, and their parents/carers should have access to all the information to help them prepare a single plan that cuts across sectors and services, enabling them make an informed choice of what is right for them. To help meet these aims, the Scottish Government set up *Independent Living Fund (ILF) Transitions* to improve opportunities for young disabled people as they leave school or care, to be more independent and enable a life of equal participation. This commitment formed part of *A Fairer Scotland for Disabled People* (Scottish Government 2016). It is also based on ideas that have emerged from a policy delivery model across OECD countries which has shifted support for disabled people to cash based and personalised models of support over the past 20 years (Pearson 2019).

Whilst there are a number of international examples of using cash based personalised support for disabled adults – notably the *National Disability Insurance Scheme* (NDIS) in Australia (Lakhani, McDonald, and Zeeman 2018) and *Personal Assistance* in Sweden (Westberg 2010) – ILF Transitions is unique in its focus on providing one-off cash payments to young disabled people to facilitate changes into their next phase of life. The move to a more participatory approach on transition support also reflects wider international support in this policy arena. Ravenscourt, Wazny, and Davis’s (2017) research assessed factors associated with successful transition by parents of children with complex additional support needs in 8 European Union countries and found that having an active child-led ethos was the main driver. Yet little is known about the impact of different types of transition services on young disabled people. Lindsay et al. (2019) conducted a systematic review of six international data bases to examine experiences of transitions for young disabled people after leaving secondary education. Their findings – centring on studies in the US, Canada and Australia – demonstrated that whilst there were beneficial influences from a range of interventions for this group, there was an absence of research which highlighted the types of support that work best, how young disabled people viewed these and how they could be delivered.

In assessing the initial impact of ILF Transitions, we draw on a set of 37 interviews with young disabled people and/or their parents/guardian who have successfully applied to the new scheme in its first year (2018–19) and an analysis of the application data. Our findings present an insight into how the fund has been received by its applicants, how this has impacted on their broader future plans and aspirations and, in turn, what this tells us about the its wider role in governmental approaches to transitions policy.

The article begins by examining policy in the broader context of youth transitions literature. More recently, Smith and Dowse (2019) have argued for new ways of understanding transition, particularly for young people with complex needs or what they term a 'complexity approach'. They highlight the dominance of a linear approach to transitions for this group of young people, arguing that 'Intersecting and overlapping forms of disadvantage mean that not only do this group experience non-normative transitions to adulthood, they also experience multiple other system and service transitions' (Smith and Dowse 2019, 1328). By contrast, a complexity approach requires that we look at transition not only in terms of the inter-play between complex personal, social and historical contexts, but also through periods of inactivity or inertia. Indeed work around transitions has traditionally ignored the views of younger disabled people, either focusing on other structural inequalities around class, gender, ethnicity or sexuality or by failing to adapt discussions around individual agency to incorporate disabled experiences. Discussion then moves to a more in-depth appraisal of the experiences of young disabled people and/or their families who have used ILF Transitions through a focus on four key themes. We begin by looking at who is applying to the fund, what they are using payments for and what they think about the new scheme. This draws on analysis of the application data and introduces findings from the interviews and links into the second theme which positions the fund in the broader context of transitions policy and austerity. For many, the absence of good transitions planning has left them unready and unprepared for the next stage in their lives. Whilst austerity cuts dating back over the last decade are important, our findings emphasise that a legacy of long-term absence in transition services remains apparent and there are limits as to what this type of policy initiative can achieve. Discussion then moves to examine the fund in the broader context of the personalisation of social care services. This presents ILF Transitions as a highly individualised policy and one which relies on its recipients (or those advocating on their behalf), assuming the role of a *social entrepreneur* negotiating support options in local transition service markets. The possibility of *market failure* in presenting appropriate support underlines the shortcomings of a consumer-led model of transition planning and forms the final article theme.

## Disability, young people and transition theory

The difficulties many young disabled people face as they move into adulthood has long been recognised (Morris 2002). In the United Kingdom 30% of people aged 16–24 who are Not in Education, Employment or Training (NEET) are disabled, compared to 9% of non-disabled young people (Powell 2017). This is slightly higher than the OECD average for the 15–29 age group. Disabled young adults in Scotland are more than twice as likely as their non-disabled peers to be unemployed and in 2016, 20.8% were unemployed (Scottish Government 2016). They are also more likely to stay within the parental home for extended periods compared to non-disabled people, even though their aspirations to leave home are the same (Heath 2008). For example, in Scotland, 69% of people with a learning disability under 35 live with a family carer, compared to 26% of non-disabled adults (SCLD 2016). Young disabled people with learning disabilities and complex needs often transition from residential school straight to care homes because of the lack of suitable alternatives (Ormston et al. 2017).

Youth transitions, for both disabled and non-disabled people, have been traditionally conceptualised as a step-by-step linear process, with a predetermined end (Furlong 2009; Smith and Dowse 2019). This is certainly the case within research on disabled young people, where much of the focus has been on the transition from child to adult services, particularly in health and social care. Understandings of youth and their transitions across OECD countries are still heavily grounded in traditional markers of adulthood such as securing full time work, financial independence, marriage and parenthood (Ravenscourt, Wazny, and Davis 2017). These markers of 'successful' transitions have been criticised as both normative and unhelpful to account for the complexity of contemporary youth experiences (Blatterer 2007; Woodman and Wyn 2014; Woodman and Bennett 2015; France and Threadgold 2015). They are particularly harmful to young disabled people, many of whom face additional and significant barriers to achieving these markers.

The approach presupposes that adulthood is fixed and stable; an end point that can only be achieved after 'a completed set of transitions' (Woodman and Bennett 2015, 6). More recent research on transitions has sought to explore transition to adulthood as non-linear, fragmented, multidimensional and extended, reflecting the complexity of young people's life experiences (Goodwin and O'Connor 2005; Furlong et al. 2005; Furlong and Cartmel 2007; France 2007; Côté and Bynner 2008; Cieslik and Simpson 2013). Changing patterns of dependency (Furlong and Cartmel 2007) as well as the increasing period of time during which a large number of young people remain in a state of semi-dependency have given rise to terms such as 'yo-yo', 'arrested' or delayed transitions (Côté 2000; EGRIS 2001; Biggart and Walther 2006). These types of protracted and delayed transitions have led researchers – in particular in psychological research – to try to define a new 'life phase' between youth and adulthood. Arnett, for example, has coined the concept of 'emerging adulthood' which he describes as a 'new' stage of life-course during which young people are able to 'explore a wide range of different possible future paths' (2004, 7). This has created what Côté (2000) terms a 'dangerous myth', implying that young people are free to choose which direction they want to take. It over emphasises individual choice and responsibility (Furlong and Cartmel 2007; Côté and Bynner 2008; Furlong 2009; Woodman and Wyn 2014).

This model of 'can-do' youth, with its emphasis on young people's individual potential implies that young people are free to act as entrepreneurs who can achieve success provided they have a positive attitude and a good work ethic. It is based on a normative expectation of the type of 'adults' that young people should aim to be (Kelly 2006, 18). It is also grounded in an idea of what young people will be rather than what they are and how they feel in the present. In other words, these conceptualisations of youth view young people 'not as complete individuals now, but as future adults, citizens and workers' (Wood 2017, 1179).

The focus is on individual agency rather than the structural constraints that shape individual life-chances (Evans and Furlong 1997). Responding to the debates around the role of structure and agency, Furlong and Cartmel (2007) have argued that processes of individualisation and social changes have led to an 'epistemological fallacy' in which young people are encouraged to seek individual solutions to structural issues. In other words, even though young people's life-chances and transitions remain significantly structured by social factors, subjective understandings of

transitions and opportunities are increasingly understood and experienced on an individual level. Responsibility is placed in the hands of the young people themselves to take up opportunities and live up to expectations of successful transitions. Individuals are viewed 'as being responsible for conducting themselves, in the business of life, as an enterprise, a project, a work in progress' (Kelly, 2006, 18; see also Harris 2004; Griffin 2004; Kelly 2014). Young women in particular have been understood and positioned as 'successful girls' (Ringrose 2007) and 'can-do women' (Harris 2004). Those who are successful are celebrated for their determination, resilience and confidence (Harris 2004, 1). These narratives, feed and reinforce this epistemological fallacy by putting a great emphasis on individual responsibility, choice, independence and achievement. They overlook the social, cultural and economic constraints that shape not only life-chances, but also perceptions of these chances.

The experiences of disabled young people in much of this work has, to a large extent been ignored, concentrating instead on other identities and social locations such as class, gender, place and ethnicity in shaping young people's transitions. Where disability has been the focus of transition, the young people have been treated as a homogenous group and the impact of these various social locations has been ignored. This paper seeks to start to fill that gap and utilise Furlong and Cartmel's ideas as a framework to understand the views of disabled people and their families at this point of transition in their lives. In doing this, the following section sets out how the policy for ILF Transitions emerged and the background to our evaluation.

### **Disability, transition policy and the emergence of ILF transitions**

In recognition of the problems in transition planning for young disabled people, the Scottish Government used the re-configuration of the original Independent Living Fund (see Pearson 2019) as an opportunity to develop a new service. The scheme was co-produced by the ILF Working Group, with representation from Scottish Government, ILF Scotland, disabled people, carers, disability groups and local authorities. It set a discretionary fund with an annual budget of £5 million, to allocate one off payments to young disabled people (aged 16-21<sup>1</sup>) for projects and/or equipment which enables them to live more independently. Through this, *ILF Transitions* hoped to improve the involvement of young people in planning their future and to better communicate what is important to them. It also aimed to improve their skills in planning and decision-making. The focus is very much on the individual who is supported through a cash payment to resolve the problems they face.

The cash-based focus of the new scheme also draws strongly on the legacy of direct payments and personalisation which has influenced support for disabled people both in Scotland and across OECD countries (see Pearson 2000; Pearson, Watson, and Manji 2018). Whilst the global legacy of disability activism in securing this shift remains important (see Campbell and Oliver 1996), the infiltration of individualism and neo-liberalism in its implementation has been dominant and reflect many of the concerns outlined earlier by Furlong and Cartmel in regard to youth transitions. These broader policy discourses clearly underpin its inception and will be returned to in more detail later in this article. Before doing this, we outline the methods we used in the study.

## Methods and background to the study

The data presented here are drawn from a commissioned evaluation of the ILF Transitions scheme on behalf of the Scottish Government. The data were collected over the first eighteen months of the scheme (January 2018–June 2019). We had access to application data which included the young person's impairment category, benefits received, age, social and geographical location and details of their requested funding. Permission to pass on these details was secured in the initial ILF Transitions application process, where information about the evaluation was included, alongside a request for successful applicants to take part. We were given an email address for the young person or a parent/guardian from all those agreeing to take part. This was the only means used to invite them to participate in the study.

The evaluation set out to examine the impact the new scheme on the lives of those applying over the short and longer term. The first stage of the research was to analyse and document who was applying to ILF Transitions in the first year of operation (January 2018–January 2019), looking at where they were from, their socioeconomic status (Table 1), what they applied for (Table 2) and their impairment categories (Table 3).

Socio-economic status was analysed through the Scottish Index of Multiple Deprivation (SIMD) (Table 1). SIMD is a relative measure of deprivation across 6976 data zones in Scotland (Scottish Government 2020). Deprivation is evaluated across seven domains: income, employment, education, health, access to services, crime and housing. Data zones are ranked from the most deprived (ranked 1) to the least deprived (ranked 6976) In our analysis we worked with quintiles, from the most deprived 20% (ranked 1) to the least (ranked 5).

This was followed by a series of semi-structured interviews with recipients of the scheme and/or their parents/guardians (n=37). We sampled across the five quintiles to

**Table 1.** Successful applications by SIMD Quintile.

SIMD 2016 Quintile	Count of Applicants
1	102
2	88
3	102
4	72
5	67
NA	38
Grand Total	469

**Table 2.** ILF Transitions payment use.

Payment use	1	2	SIMD 3	4	5	Total	% Applicants
Driving lessons	39	24	20	24	17	124	56
Leisure and sport	15	16	11	7	15	64	29
Computers	10	12	5	8	10	45	20
Travel	10	8	5	3	11	37	17
Education/training	9	7	3	8	11	38	14
Assistive technology and ADL	4	6	6	4	8	28	13
Inclusion/support	3	5	6	1	7	22	11
Smart phone	3	1	3	0	1	8	4
Accommodation	0	2	3	0	3	8	4
Transition	0	0	3	3	2	8	4
Treatment/therapy	0	0	2	1	3	6	3
Misc	0	1	0	1	1	3	2

**Table 3.** Applications by impairment category January-June 2019.

	Visual impairment	Hearing impairment	Physical impairment	Speech impairment	Autistic spectrum	Learning difficulty	Intellectual impairment	Mental health	Other
Number	18	19	35	26	79	76	26	72	60
Percent	10	10	20	15	43	42	15	39	28

Note: Many applicants selected multiple impairments.

ensure spread and research participants were contacted 6 months after applying to the scheme (from July 2018 to May 2019). Applicants were emailed and invited to take part in the research. In most cases this involved a face-to-face interview, although where requested by them, these was conducted by telephone or on-line. Six months later, a follow-up telephone interview was conducted with 12 of the original respondents and their families. This included 9 young people and 3 parents/carers.

In our interviews we adopted a barriers approach and, influenced by the social model of disability, did not ask interviewees and/or families directly about their impairment (Oliver 1990). Where impairment was relevant and brought up in the interview, this was recorded and discussed more fully (for example where a young person with autism discussed the barriers they faced when accessing public transport). During the interviews we asked people about current life, where they lived, who they lived with, their hobbies and leisure time activities and their future plans and aspirations. The young people were given the option as to whether they wanted to be interviewed on their own or with a parent/carer present. Where children had more complex needs, parents/carers supported them in the interview process or took part on their behalf. Seventeen interviews were completed with the young people at stage 1 (7 female and 10 male) with 9 parents/carers (of 3 daughters and 3 sons) sitting in on the interview and 8 with parents/carers doing the interview themselves. Of the 12 follow up interviews, 5 were female and 7 male. This offered a detailed insight into their experiences of the scheme and through this an understanding of the transition process.

Ethical approval for the project was received from the College of Social Sciences' Ethics Committee at the University of Glasgow. All interviews were transcribed and independently read by two members of the research team. Data storage, administration and analysis were conducted using QSR NVivo 11. Thematic Analysis (Guest, MacQueen, and Namey 2012) provided the framework and involved initial coding of interview transcripts, identifying key categories. This process resulted in a thematic analytical framework, which was set up and agreed upon within the research team. Each interview was read by two members of the team and coded according to this framework. Through this we were able to explore the key issues identified by young disabled people and their families as they move on from school. In the next section we present these findings and unpack young people's current aims and needs and how these relate to their life experiences.

### Accessing funds and making choices: responses to the new scheme

It is important at the start to stress how popular the scheme was with all those we spoke to. It was easy to apply for, very few people were refused funding and the scheme was well managed, ILF Scotland – the organisation delivering the fund – were responsive to the needs of the applicants and people felt that the money provided was useful. Given the

broader hostile environment facing disabled people, the ten years of austerity and their overall dissatisfaction with current welfare provision (Pearson 2019), any money will be welcome.

Applications varied in both content (Table 2) and size; the average (mean) was £2392. There was also a great deal of variation in the amount of support requested, one applicant, for example, applied for a £23,000 specialist wheelchair, other applications were much smaller, for example £300 for a tablet. Whilst wide ranging in their scope, the type of support requested shows the key areas young disabled people were looking for help in as they leave school. What is noticeable is how few young people were looking for support to leave home, to access work or help them achieve what are seen as the traditional markers of transition.

Driving lessons were by far the most popular item across all socio-economic groupings, with 56 per cent of applicants requesting help with money towards meeting the costs. Although many of the applicants had mobility impairments – which may explain why they need this support – they were also popular with people with other types of impairments, particularly those with autism. Public transport is, for many disabled people, a potential site of violence (Emerson et al. 2016) and many were reluctant to use it for that reason. As Julia commented:

I feel like [the driving] is going well because I feel like once I've got to a stage where I need to be driving and I've passed then I'm going to be independent and I'm going to be able to go out more. 'Cause I really like, don't do well going around places in public transport and stuff 'cause it scares me ...

(Julia, aged 17, driving lessons)

Being independently mobile, for many young people, helped them take more control, gave them greater responsibility and broadened their opportunities, enabling them to take part in more activities. However, this was contingent on having access to a car, and as Natalie told us, without a car being able to drive had not greatly improved her opportunities for participation:

I mean it was quite exciting but now I'm like, oh, because I don't actually have my own car so I just have to ... still walk places.

(Natalie, aged 20, driving lessons)

Funding was also used to enable young people to develop their sport skills and to participate more widely in sporting activities and competitions. This was the second most popular area in which support was sought. Ella for example, who was studying Sport and Exercise Science at University, used her ILF payment to cover a wide range of costs so she could participate more widely in wheelchair rugby and basketball competitions. These included a new sports wheelchair, funds to employ a personal assistant (PA) to accompany her to tournaments and training, travel and hotel costs for her PA and driving lessons and test fees:

It's really a great opportunity for me and it's obviously helping me develop as a player. But it's also giving me a lot of different skills which will in turn help me get a job and do other kind of things later on in my life.

(Ella, aged 21)

Many of the participants, like Ella, felt that the relatively small financial award helped in their transition. There was a general belief from many of the young people we spoke to that what amounted to small changes in either their capabilities or their skills would be able to help them as they seek to move to life after school. The ‘can do’ philosophy, so heavily criticised by, among others Furlong and Cartmel (2007), prevailed among many of those we spoke to.

This is perhaps not surprising, given the financial climate many of the participants have experienced. Austerity and welfare reform have meant that most young disabled people and their families are more used to rejection when it comes to applying for funding and that their support needs are not fully met (Pearson 2019). The positive response made many young people feel valued, impacting on their sense of self and wellbeing. As James told us:

It’s just brought me on tons confidence wise, mentally, everything. It’s just improved.

(James, aged 16 – music lessons and equipment)

The provision of small amounts of money to help young people through the transition process does clearly have benefits. Natalie (aged 20) was typical of those applying for driving lessons in commenting that ‘it’s just something that I wouldn’t have started without it’. People were able to try out new activities and develop new skills. Jane’s parents had successfully applied for funds to cover skiing lessons, music therapy and payment for a therapy trike. For her mother, this was a really positive change after on-going attempts to secure support through adult services:

As she goes into her final year at school, she’s got all these things going on that ... connect her to the adult world.

(Parent of Jane, aged 17)

Yet it is clear from these examples, that the emphasis on spending the money from the fund and exploring service options, relied on individuals – either the young person them self or a family member – to find out what was available in local communities and organise a package of support. In Olivia’s case, the payment had been used for a support worker to accompany her on work placements at the local theatre. However when we spoke to her parents six months later, the placements had not worked out and so in absence of other options, the funding had to be paid back. ILF Scotland had made it clear that they could re-apply at a later stage, but the lack of support from statutory agencies made this quite a daunting task. As her mother explained:

We’re still trying to think what things she might be able to do and what other kind of opportunities there are out there that we could use funding to support her ... We have been trying to do transition planning literally for years, but because she’s not in her sixth year and it’s not absolutely urgent, it’s really difficult to get agencies together and take that on.

(Parent of Olivia, aged 17)

As discussion in the next section reveals, this reflects a wider trend in the provision of social support, whereby responsibility for service options have become increasingly individualised, with the task of finding the right support left to young people and

their families. The key question is how effective is a fund like this as a way of improving young people's transition. It is to an exploration of this that this paper now turns.

## Transitions, personalisation and social entrepreneurship in an age of austerity

One of the key aims of the Scottish Government's transition policy (Scottish Government 2019) is to adopt a person centred approach, founded in the belief that young people, and their parents/carers, are best placed to know what they need. The individual cash payment offered by *ILF Transitions* fits well within that philosophy, as it seeks to help young people take control in their day to day lives and to offer them different experiences and expectations and routines. Individuals are given control of both what they ask for, and to a certain extent, how the money is spent. This emphasis on autonomy and flexibility was welcomed by many of the young people and their families we spoke to. For example, James' mother, was able to use a proportion of their payment for music equipment, despite this not being part of the original application:

I wrote to them [ILF Scotland] and said, is it possible, because we didn't manage to use the money for what we'd originally been awarded it. Was it okay to spend it on this and they said that was fine because it was going to be even more beneficial

(Parent of James, aged 16)

Bob was able to use additional monies from the payment to support his University studies, even though these did not form part of his original application:

I used the IL monies to buy a textbook, which I didn't know about until I'd done the course. So I did the course, I found out about the textbook and now I have it, it will greatly increase my chances of passing.

(Bob aged 18 – books for university course and driving lessons)

The way the fund worked enabled a sense of autonomy and independence not normally experienced in the provision of benefits. As stated earlier, this was particularly significant in the current economic climate where austerity has removed flexibility. However, this is not without costs. It placed responsibility on the individual and there is little emphasis on structural change. If young people and/or their parents wanted to take control, they had to be the main drivers for any change. It was left to them to find out what was available in the local area and to come up with ideas as to what resource to apply for. Some, such as Sophie's mother, spoke positively about this type of approach. Yet it was clear that without her role as a *social entrepreneur* – researching opportunities to access transition – services would be far more restrictive:

So the idea of this being a transition fund is going to give her the opportunity to go out and try working with these people, try making peer relationships in the resource, accessing the building and maybe in the future, build up that knowledge of her likes and dislikes and things like that so when she does leave home, we've got a clear path of what's going to work for her.

(Parent of Sophie, aged 18 – one-to-one language support classes).

Interviewees told us that services were limited in both their availability and the opportunities they afforded to young disabled people. This was the case even when funds were made available to buy more support through ILF Transitions. This was recognised throughout the interviews and perhaps reflected the popularity of using the fund to learn new individual skills such as driving rather than seeking funding to participate in other services:

The message that we're getting is that there are no college placements for people like Olivia when she leaves school because she requires help with personal care and travel ...

(Parent of Olivia, aged 17 – personal assistance for voluntary placements)

The push towards personalisation and the diversion of finances into the hands of individuals and their families, can reduce the service options available to some groups of disabled people (Power and Hall 2018). Our data suggest that there is some evidence that similar gaps are opening in the opportunities for and support to younger disabled people, as Jane's mother told us:

The voluntary organisations - like Sense - are all full up, so when Jane leaves school, there's no spaces in adult services, they've just closed the doors on applicants. There is a real concern about planning for the future, because of a lack of resources.

(Parent of Jane, aged 17 – music therapy, ski lessons, therapy trike)

Social entrepreneurs can choose which service they want to utilise, but for this to work, services have to be available. Rarely do they have the capacity to design or develop their own service.

The changing dynamics of service provision for transition links in with the broader model of cash payments and personalisation which has dominated social care provision and the wider discourse surrounding independent living over the past 20 years. As stated earlier, this has seen earlier activism and ownership from the disabled peoples' movement (see Campbell and Oliver 1996) over policy development, diluted by a push across OECD governments to promote a more individualised and consumer-led model of support (see for example, Howard et al. 2015 for discussion of Australia; Pearson, Watson, and Manji 2018 for Scotland and Christensen and Pilling 2014 for Norway and England).

The social entrepreneur role therefore underlined the broader absence of attempts to develop structures, policies and procedures that enabled good transition planning; the young people and their families were often left without any support in securing services for the next stages of their lives. As Olivia's mother explained:

Olivia's social worker retired in January and apparently another two workers left ... they just haven't got the workers there. But we just got on with it, I've got direct payments, so we just pay the services. But eventually they'll have to get somebody back in, but they really should be planning with us now ... They're the key people 'cause they're the ones who are going to come up with the budget ... So that's a bit of anxiety and I think it's the same for a lot of people.

(Parent of Olivia, aged 17 – funding for personal assistant to support voluntary work placements).

This was a common theme and ties in very strongly with the epistemological fallacy identified by Furlong and Cartmel, whereby the responsibility for transition planning has been shifted from the state to the individual. For this to work, services have to be available that meet their needs and it is a discussion of this that is the focus of the next section.

### Transition services and market failure

The shift to personalisation across social care and wider social policies requires the presence of a diverse and vibrant provider market from which users or their proxies can purchase the appropriate support (Baxter, Glendinning, and Greener 2011). Yet our findings showed an absence of local services to support the young people's needs. Whilst having the cash from the fund was welcomed, it was not always easy to find the right type of service – either because it was not available or was of poor quality.

The main barrier would be finding somewhere that was just right for her, because her needs are quite complex and staff need a good working knowledge of people on the spectrum ... Adult services are pretty grim, there's not very much out there.

(Parent of Sophie, aged 18 – one-to-one language support classes)

The ideals and demands of the disabled peoples' movement and the underlying philosophy of personalisation have been used by the state to reduce their role in the direct delivery of care and support. This has also meant that control and oversight of these services has shifted from the state to other agencies, be they statutory or third sector providers. Lucy, for example, told us that the services she accessed were inadequate to meet her needs:

The service [art class] as a whole isn't really doing what it says it's doing. I think it's just most of the people who are working there aren't really ... I don't know it's they're not qualified or they're not experienced ... They make a lot of noises about what they're going to do and then they don't do it.

(Lucy, aged 21)

As detailed earlier, transition planning is based on the idea that the aim is to transform disabled young people from passive recipients of support to active subjects, empowering to participate in the democratic process and in the assessment and interpretation of their own need. Rather than the state transforming the institutions that provide support, responsibility is placed on individuals to transform them into agencies that will promote and enable their transition. There is little evidence that this is happening. Lewis, for example was at a further education college and was attempting to move from National Certificate (NC) to a Higher National Diploma (HND) and from there on to university. This was met with resistance from the college he was attending:

He was on target to go into the HND after his first year, everything was fine and then at the last moment they [the College] said 'no, you're not getting in' and offered him a third NC ... After spending eighteen months transitioning, Lewis had to choose a course he didn't want to do ... They wouldn't write him a reference to progress to uni or anything like that.

(Parent of Lewis, aged 19-theatre and art courses)

Faced with opposition like this there is little individuals can do. Giving people control to choose the services they wish has both benefits and drawbacks.

The lack of availability of services for transition planning was also noticed and there was a clear lack of discussion around long term transition planning, even in the second set of interviews. The young people and their families we spoke to were still thinking very much in the short term, trying to meet relatively simple goals. Nobody we spoke to, for example, talked about either leaving home or moving into full time employment. It may well be, that for younger disabled people at least, the idea of such transition is very far in the future and that their transitions are much more protracted than their non-disabled peers.

## Discussion and conclusions

The experiences of the young people set out in this article opens up some of the key debates on youth transitions. The widely held contention that youth transitions in advanced capitalist societies have shifted from being linear to more complex has been argued since the 1970s (Sanderson 2019). This has seen a re-thinking around the transitional period between childhood and adulthood extended in terms of the move from education to employment, living away from the family home and family formations. For Sanderson (2019) and others, modern transitions are therefore invariably more fluid, complicated, risky, uncertain and prolonged. By looking at the experiences of young disabled people, it is clear that this understanding of the transition period has similar resonance. Transitions for disabled people are, as Smith and Dowse have argued, complex. We are unable to define what a successful transition is for disabled young people. It is an illusive concept and, much like ideas around inclusion, independence and living in the mainstream, lack metrics and is hard to define. What we can stipulate however, are the processes and structures that are required to help people as they leave school and move on into the next stage of their lives. Young disabled people need to be given autonomy and be empowered to make choices, but they also need support to help tackle the systematic and structural barriers that serve to exclude them and deny them opportunities.

It is possible in the short-term to facilitate the process through the provision of one-off payments. We do not want to underplay the potential afforded to young people by the provision of funds to help them achieve their goals and clearly cash based models such as the ILF Transition fund have many benefits. This claim is supported by the broader literature on the personalisation of social care, where there are very real advantages in using cash payments to promote independent living (Stainton and Boyce 2004). However, as Furlong and Cartmel's (2007) notion of an 'epistemological fallacy' makes clear, policies such as this have been framed with an over-emphasis on young people's individual capacity to secure life choices and control their destiny. There is an overemphasis on agency and individual choice, with a failure to address the root causes of discrimination and disadvantage; the barriers that disabled people face and the structures that exclude them remain unchallenged and unchanged. The choices and services available are constrained – even where the resource was available to buy into a new experience, this was often limited by an unresponsive transitions service market. Structural and cultural inclusion are therefore central in transition planning (Ravenscourt, Wazny, and Davis 2017).

The reliance on disabled people acting as social entrepreneurs to negotiate their way through barriers and tackle structures has been replicated across a number of OECD countries. In Australia, the *National Disability Insurance Scheme* (NDIS) was set up with the expectation to ‘fundamentally disrupt traditional service practice and improve disabled people’s lives’ (Kendrick, Ward, and Chenoweth 2017, 1333–1350). Like ILF Transitions and other global programmes of personalised support, the rhetoric of choice and control was used by the Australian Government to promote NDIS to a wide audience. In contrast to similar schemes in Scotland, England and other European countries (Pearson and Ridley 2017), the NDIS has received a long-term commitment to significantly increased government spending (Miller and Hayward 2016). Yet as Kendrick, Ward, and Chenoweth (2017) have observed, increased funding and a reliance on the buying power of service users to stimulate creativity and innovation is unlikely to be enough on its own to transform the landscape of disability support. The role of the social entrepreneur – bypassed from service professionals to young people and/or their families – left individuals charged with the responsibility of negotiating access to transition services. Often this can result in a more individually tailored service, which matched personal interests. However, successful outcomes were reliant on the ability of young people, parents or carers to successfully take on this role and for local markets to have the services available. Rather than tailoring the services to meet the needs of individuals, responsibility for achieving change is placed in the hands of individuals.

Youth transitions for young disabled people are complex and require a multifaceted response that can both promote individual agency whilst also tackling structural disadvantage and inequality. The latter is much harder, and arguably more expensive, but without it there is a danger that attempts to improve transition for young disabled people will fail. Given the extensive disadvantage experienced by disabled young people in all aspects of their lives, this epistemological fallacy is even more relevant to their experiences and it is one that has to be addressed if the limits to their life opportunities are to be removed.

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### Data availability statement

Transition to where and to what? Exploring the experiences of transitions to adulthood for young disabled people.

The authors confirm that the data supporting the findings of this study are available within the article and its supplementary materials.

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