

Citation for published version:

Jennifer Clegg, Elizabeth Murphy, and Kathryn Almack, 'Liberal Individualism and Deleuzean Relationality in Intellectual Disability', *Philosophy, Psychiatry, & Psychology*, Vol. 24 (4): 359-372, December 2017.

DOI:

<https://doi.org/10.1353/ppp.2017.0053>

Document Version:

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<LRH>PPP / VOL. 24, NO. 4 / DECEMBER 2017

<RRH>CLEGG ET AL. / DELEUZEAN RATIONALITY

<T>Liberal Individualism and Deleuzean Relationality in Intellectual Disability

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<abstract subhead>Abstract

<abstract>Successful critiques of health policies for people with impaired cognition identify a need for alternatives that go beyond individualism. ‘Choice’ policy was examined as young people with severe intellectual disabilities moved from special schools to adult services. We draw on three cases from a longitudinal cohort study to examine the way decisions with and for these young people were made and accounted for. It was not a simple matter of parents and transition workers hearing about these young people’s choices and facilitating what they wanted. The data raise questions about discourses of choice in ID when referring to people with severe intellectual disabilities: Few ‘choices’ could be considered informed nor made by young people with capacity to make them and many decisions were informed by other ethics. Findings were interpreted through a Deleuzean ethical–relational lens. We identify implications for theory and practice to show how Deleuzean thinking can reinvigorate intellectual disability.

<abstract subhead>Keywords

<abstract>Choice, ethics, transition, accounts

<N>The promotion of rights, autonomy and choice reacts against paternalism, an early twentieth-century response to intellectual disability (ID; formerly learning disability in the UK and mental retardation in the United States) that suppressed individual personhood through a combination of resource limitations and poor administration (Thomson, 1998).

These liberal individualist concepts reflect the contemporary zeitgeist of Anglophone nations, although the strength and certainty with which these concepts are expressed in ID policy when compared with policy for other vulnerable groups suggests that they also serve a secondary function. It has been argued that excessive certainty in ID evidences a feared drop into chaos, and holds it at bay (Clegg & Lansdall-Welfare, 2003); and that what ID needs most is more uncertainty (Gleeson, 2010).

Evidence that choice is a foundational concept for English ID services can be found in *Valuing People Now* (Department of Health, 2009). Despite some recognition of population heterogeneity, 4 of this report's 15 policy objectives refer to the promotion of choice as if this is unproblematic. Promotion of the individual's choice is a current requirement of ID services in England (Department of Health, 2012, 2015), echoing similar recommendations for ID made by international groups (e.g., World Health Organisation, 2010).

Yet choice is a slippery concept in ID because of population heterogeneity, in particular variability in the capacity for reflection and communication (Weinberg, 2007). There is concern about polarization between the 'social' model that fits the experience of those with relatively mild ID who can make many choices, and the 'medical' model that allows for the possibility of significant impairment, which means capacity is more limited. The increasing tendency to emphasize heterogeneity (e.g., Grant, Ramcharan, Flynn, & Richardson, 2010) as a prelude to arguing that all degrees of ID need to be taken into account suggests that the two models are increasingly perceived to refer to different types of people. Despite this, papers continue to be published that promote self-determination for all people with ID that fail to consider what this means for those with, say, cognitive functioning below

the 6-month level or additional mental health problems (e.g., Curryer, Stancliffe, & Dew, 2015).

Both Jordan (2005) and Burton and Kagan (2006) argue that policy underestimates the degree to which human services are complex activities based on relationships. For example, strength of choice in research into Person-Centred Planning has been operationalized by staff judging the person's involvement in an activity (Magito-McLaughlin, Spinosa, & Marsalis, 2002). Yet this approach to identifying choice is questioned by Pilnick, Clegg, Murphy, and Almack's (2010) conversation analysis of transition meetings, which found that staff conflated 'is good at' with 'likes,' even when the person with ID resisted this interpretation. Antaki, Finlay, and Walton reached this conclusion about choice policy in ID: "(It) bears little relation to the kind of experiences about which choices are actually available to many people with ID, and no relation at all to the interactional reality of professional interactions ... and the pervasive, not always helpful, influence of basic organizational imperatives" (2009, p. 64).

The view that it is right to prioritize choice for people with ID, however severe their ID or complex their needs, is an ethical claim, yet there has been little dialogue between choice policy and ethical theory. Political analysis of the pros and cons of liberalism (Kymlicka, 1995) identified its defenders as focusing on tolerance, particularly religious tolerance, as a requirement for social and political stability; its critics view it as an ideological justification for capitalism that glorifies self-interest in all spheres of life, replacing the web of mutual obligations that make life worth living.

Philosophical critiques of choice come from five main sources. MacIntyre (1985) argued that too much focus on choice and autonomy damages society by eroding social trust.

Deleuze and Guattari (1987) argued that a focus on choice controls the way that identity can be expressed: everybody has to have an opinion in consumer societies. For Reinders (2000), liberal focus on agency, self-determination and choice blinds us to relational dimensions of existence crucial to people with ID, such as the expression and receipt of care. Mol's (2008) study of another chronic disability, diabetes, criticized focus on the patient's will when so little attention is paid to the actual practice of living with a chronic disease. These patients did not complain about lack of choice, but about services that failed to provide reliable care when needed. Finally, Feder-Kittay (1999) advocated expanding the ethical dialogue about ID beyond choice, autonomy, and rights to theorize the politics and practices of care relationships taking a feminist perspective. These critiques have implications for practice. In particular, Reinders (2000) argued that focus on choice avoids responsibility for deciding what makes a good or meaningful life: it leaves individuals to determine how they should live even when they lack the capacity to make such decisions.

Although the arguments made by these prominent philosophers have found an audience, ID policy remains set in its individualist ways. This differs somewhat from childcare in England where, after a series of scandals, the government commissioned new practice-based research into the potential impact of a European approach to care, Social Pedagogy (Cameron, 2013). This requires ongoing dialogue between theory, practice, and reflection on both rights and limits to rights. Relationships of all types are fundamental to social pedagogy: encounters occur for their own sake, rather than to change behavior or explain rules. Thus, relationships are not instrumental but first and foremost ethical: The significant matter is to establish trust between the vulnerable person and key individuals who support them.

Petrie (2013) summarizes the conceptual challenge that social pedagogy offers to the UK's rights-based framework, and the practice challenge it presents to target-driven care, arguing for a softening and evolution of current policy values. It is not mainstream practice. Nevertheless, a willingness to explore an alternative approach to care for vulnerable children provides an interesting contrast to ID, where the inquiry into abuse at Winterbourne View (Flynn, 2012) elicited a reassertion of neoliberal concern with individual rights, imposed by increased frequency of inspections with increased powers to instigate either compliance or closure (Department of Health, 2012, 2015). Despite policy claims to value innovation no new thinking has been initiated by government, nor are new practices acknowledged in the 'examples of good practice' part of inspection reports. Moreover, ID has previously been shown to maintain interventions even when considerable challenge and change is occurring in related but non-ID mental health research (e.g., bereavement: Clegg & Lansdall-Welfare, 2003).

Where might new thinking come from, and how should creativity be conceptualized? Deleuze is the twentieth-century philosopher and ethicist most concerned with the dynamics of relationships and creativity. He reaches beyond rather than challenges liberal values: "The point in common to all post-structuralist philosophers is that ethics is not confined to the realm of rights, distributive justice or the law" (Braidotti, 2012, p. 173). Deleuze's ethic of affirmation introduces movement and transformation into a "stifling enclosure saturated with unprocessed pain" (p. 182). Although that phrase was not pointed at ID, it does speak to its condition (Clegg & Jones, 2014; Meininger, 2013; Storey, Collis, & Clegg, 2011; Voysey-Paun, 2006). This ethic does not express facile optimism: It seeks to acknowledge and

transform pain, working with the degree of intensity each vulnerable person can take. “It’s life on the edge, not over it” (Braidotti, 2012, p. 179).

Deleuze calls the imposition of established protocols and rules ‘morality.’ By contrast ‘ethics’ emerges from relationships characterized by openness to one another. Deleuze drew on Spinoza to conceptualize interconnected modes of existence that nest people within relationships which unfold across time. “We will not define a thing by its form.... We will define it by its longitude and latitude.... We call longitude of a body the set of relations of speed and slowness, of motion and rest.... We call latitude the set of affects that occupy a body at each moment” (Deleuze, 1988, p. 127). This characteristically opaque description of latitude contains aspects of the more familiar term ‘empowerment,’ but for Deleuze the term is relational (so not concerned with agency over non-human matters) and bidirectional (although not necessarily reciprocal). It refers to the person being able to both affect others and be affected by them. When two beings come into contact with one another, joy results and this is transformative; such joy enables people to overcome the ‘sad passions’ that reduce their ability to act in the world. From this perspective, the task is to construct well-functioning systems where community members can encounter and affect one another to support mutual becoming.

This paper identifies and examines the ethics that were implicit in the descriptions people on the ground of ID gave as they made difficult decisions. It draws on material from three longitudinal case studies drawn from a cohort of 28 school-leavers with ID as these young people made the transition into adult services. It explores the way that parents accounted for the decisions they made, and how they defined and negotiated an acceptable mode of existence with and for their young adult with severe and complex ID.

<A>The Transition Study

<N>Details of the methods, methodology and program of analysis are in Clegg, Almack, and Harvey (2008) with a summary of initial findings in Clegg, Murphy, and Almack (2010). The total database comprises 143 interview transcripts or other substantive pieces of data about 28 young people with ID aged 18 or 19 in two UK localities who were studied longitudinally as they left special schools. The majority of these young people have severe and complex intellectual disabilities. A research team-generated 76-item coding frame was applied to analyze interviews and diaries using the software package Ethnograph.

For this current study, three maximally different cases were selected. They include young people of both genders with different levels of intellectual ability, health need, and challenging behavior as defined by parents, living in different family configurations and situations within different localities. All available data concerning these three cases were read in their entirety before searching Ethnograph for specific coded accounts. Initial systematic analysis of the accounts all parties gave about choices, decisions, and justifications was subjected to further reflection using Deleuze's tools for thought. These aim to "Shed light on other ways of knowing, relating to and creating the world (by) 'noticing' ... different kinds of things that might be happening, or things that might be happening differently" (Coleman & Ringrose, 2013, p. 4). Deleuze-influenced research attends to the affective and experiential; it aims to create concepts that can do things in the world and/or change the problem to which they are addressed.

The Cases

<N>*Tom*.¹ Tom was the middle of five brothers. He lived with his two younger brothers, one with autism, and with their parents whose work was categorized on National Socio-economic

Categories as 'lower managerial' (Office for National Statistics, 2001). Tom had Down syndrome: his mother described him as profoundly intellectually disabled with hearing impairment, autistic traits, and challenging behavior that had worsened with age and physical maturity. He slept poorly, resisted bathing by 'battering' his mother most mornings, and was so focused on food that his mother wondered if he also had Prader-Willi Syndrome. Case study sources were first and second parent interviews (both with Tom's mother), observation of a meeting at home, observation of Tom's first visit to a residential home, researcher notes of monthly telephone conversations, and a final interview with their Transition Worker. The outcome of Tom's transition was placement in a residential home: This was evaluated positively by his parents and their transition worker.

Robert. Robert lived with his mother and her fiancé in a household categorized on NSeC as 'lower managerial.' Robert's epilepsy and profound and multiple ID required a high level of physical care: He mobilized mainly by using a wheelchair. Robert's mother described him as being very developmentally delayed, and only able to walk a short distance if supported. He was incontinent and needed to be fully cared for. He made a few babbling sounds and expressed only negative choices by resisting what he did not want. His mother interpreted Robert's feelings and needs from facial expressions and how active or sleepy he was. Case study sources were first and second parent interviews (both with Robert's mother), researcher notes of monthly telephone conversations, interviews with two transition workers (one a health specialist), and observation of Robert in his eventual day placement. The outcome of Robert's transition was placement in the special needs section of a day center: It was evaluated very negatively by his mother but positively by the transition worker.

Lottie. Lottie was the youngest of three sisters, the only one still living at home: Her mother was a widow with work categorized on NSeC as ‘technical/routine.’ She described Lottie as ‘moderately’ intellectually disabled, with complex epilepsy attributed to a series of strokes in early childhood. Before leaving school, Lottie had been free of seizures for more than 2 years. Lottie was one of the most able young people in our study. She had shown challenging behavior throughout her life, to such a degree that few family members had been willing to sit with Lottie so her mother could have a break. Her mother’s main concern was epilepsy, because occasionally Lottie would enter a continuous seizure that was potentially fatal and required hospital admission. Epilepsy compromised Lottie’s ability to reason and recall. Case study sources were an initial interview with Lottie, first and second parent interviews, observations of Lottie in three different settings, three diaries made by her mother, researcher notes of monthly telephone conversations, observation of two meetings involving the parent, and the final interview with the transition worker. The outcome of Lottie’s transition was a residential college placement that was evaluated variably. Lottie was reported to describe it negatively, but her mother evaluated it positively, emphasizing that although Lottie would prefer to stay at home and do nothing, she was happy when at college and developing well. The transition worker reported being troubled by Lottie’s resistance to the placement.

<A>Findings

<N>These cases identify and analyze the various ways that parents discuss and defend the provision they seek with and for these young people. We examine the degree to which their accounts of what they considered to be the right course of action reflected the goal of enacting each young person’s choices, as expected by liberal individualism, and the degree to

which they were future-orientated and addressed an emotional and relational mode of existence consistent with a Deleuzean ethic.

Choice during the Transition Process: Representation and Consideration

<N>In describing decision making within the family, there were plenty of examples of the young people's desires being presented as choices that were central to decision making. For example, Tom's mother described how the family had accommodated frequent changes to the room Tom wanted to sleep in.

<quote> None of us sleep in the same bedroom, we've all slept in every bedroom in this house trying to accommodate Tom and his moves.... So you move the goal posts on a monthly basis really... we've had to knock through [lounge and kitchen] so that we can sit there and monitor what's going on..... It's all things you wouldn't normally do for an eighteen, nineteen-year-old chap. So yes, he's costing us a bloody fortune (laughs). (Tom's mother, pre-transition interview)

<N>In this situation, Tom's mother described the family's preparedness to tolerate significant and prolonged inconvenience and expense to afford Tom what he desired, even though, given his severe ID, whether or not it is reasonable to call this a 'choice' arrived at by weighing options is debatable. Not only were the needs of his parents subordinated to Tom's wishes, but also those of Tom's two younger brothers. In similar vein, Lottie's mother described accepting Lottie clinging to her because she believed it arose from her daughter's history of epilepsy and loss.

<quote> Before she was 3 years old she was quite poorly and she did not want to leave me.... she was very unsteady on her feet, very frightened all the time she used to

wake with seizures in her sleep screaming hysterically she needed me to hang onto so

I was going to be there. (Lottie's mother pre-transition interview)

<N>Whether this should properly be termed a rational 'choice,' rather than an expression of attachment of which Lottie may or may not have been conscious, is again debatable. Lottie's mother's view of it and of her responsibilities toward her daughter certainly changed by the time of the second interview. Lottie's moderate ID and reasonable language skills provided the means for her to articulate a desire to stay at home rather than return to residential college after the first year. This generated considerable tension between her mother and services and, as Pilnick et al.'s (2010) conversation analysis of transition planning meetings showed, this is a difficult situation for parents to manage. Lottie's mother became less willing to accommodate her daughter's opinion as a legitimate choice, even though life-threatening epileptic seizures that had previously been under control returned when Lottie was at college.

<quote> Part of me ... wants(s) to be there for her as a parent ... [thinks] if the only way of her feeling safe is to stay with me for the rest of her days then that's what I'm going to have to do you know. But then I think to myself well as I get older I won't be able to do this ... it's not going to do her any good. (Lottie's mother post-transition interview)

<N>Here, Lottie's mother weighs her daughter's psychological and physical safety against the decreasing amount of support she will be able to sustain. This mother's rationale balances different considerations both in the here and now and for the future, in a way that Lottie could not encompass or articulate. This shows how 'choice' can be constructed in different ways and with different motivations in a far more complex way than that presented by services. Her

mother seeks to equip Lottie both to be more independent and to accept relationships with others who can support her in the long term.

Constructions of choice made by staff at Robert's adult day center were considered problematic by his mother.

<quote> They often ring me up and say he's not eaten again today, he's not had anything to drink ... all he's wanted to do is sleep. I thought well he's probably got no energy because he's not eaten or drank all day. (Robert's mother, post-transition interview)

<N>The importance of treating choice as only one way to determine ethical action was evident in this account. Although staff apparently constructed Robert's refusal to consume food, drink, or medication as a choice, his mother construed it as neglect. Previously, after Robert was hospitalized for 'bad fits' resulting from severe dehydration, doctors were reported to have instructed her to tip his head and introduce food, drink, and anticonvulsant medication because Robert accepted them after a few mouthfuls. She reported having asked these day center staff to do the same, but that they had refused on the grounds that overriding him was against policy. The English Mental Capacity Act (Department for Constitutional Affairs, 2005) published criteria for determining whether or not a person has the capacity to make particular choices, and what it means to act in the best interests of those who lack capacity. Under the provisions of this act, Robert's failure to take nutrition or medication, and in particular the 8 months it took for Robert to accept a drink at the day center, would not be defined as a choice because he clearly did not have the capacity to understand the implications of non-consumption.

Despite their neglect of his best interests Robert's mother took a generous view of day service staff, locating the problem not in individuals but in their context of work. She observed that the caring for incontinent adults who use wheelchairs was heavy and there were too few staff to do it well, so it was necessary to import extra staff to support mealtimes, even though Robert found it hard to trust strangers to give him food and drink safely. She also observed that staff who had no relationship with Robert would find it hard to judge how long they should persist in pressing him to consume something.

Consideration of Tom's best interests also led his parents to override some of his wishes.

<quote> When Tom wouldn't come downstairs last year, we left him up for ... two and a half days then ... we literally had to push him to the top of the stairs, he was petrified but we knew we'd got to get him down. And when we got him down he hugged us as if to say 'well thank you so much' you know sort of relief.... But now the bugger won't go back up (laughs). (Tom's mother, pre-transition interview)

<N>Although initially his parents had responded to Tom's problematic choice with tolerance and persuasion, the trigger to overriding him was that Tom would otherwise miss the start of the next school term. Continuing to isolate himself from family interaction and from valued experiences outside the home was considered so far beyond his best interests as to justify minimal force. In this instance, Tom's mother reframed acceding to his choice as neglect and, therefore, justifying the intervention described.

Often, the weight given to preferences or choice in the parents' talk depended on whether the situation to be managed was located inside or outside the home. For example, because Tom could be disruptive, his family rarely took him out and when they did they

sought a compromise between Tom's preferences and the risk of causing offense, irritation or inconvenience to others.

<quote> He likes pubs and things but you can't get him out of them (laughs) Tom is like a rhino when he's heading for something, you know he'll see someone with a bag of crisps he'll want to go and take them. And it takes two of us, sometimes three of us to keep him back. (Tom's mother, pre-transition interview)

<N>The solution they found to accommodate Tom was by his father taking him to the pub, but scheduling outings so that they occurred early when the pub was likely to be empty, which minimized the potential for disruption. They adapted to avoid any problems that might result from Tom interfering with other people but, as his mother observed, this compromise did not work well for all family members because drinking in an empty pub was not very sociable for his father.

Tom's parents were clearly thoughtful, but beset by doubt. They described how confidence in their ability to choose well for him was shaken when he became increasingly disengaged from a day service they had selected. It was further damaged by Tom not enjoying a holiday with his family at all, which resulted in one parent having to cut short their own holiday and return home with him. Soon after this, they had the opportunity to place him in a new residential care service that was opening nearby. Its apparently ideal arrangement and location, combined with it having few places that were going quickly, forced them to consider placing Tom out of the family home much sooner than they had originally planned.

<quote> With Tom you'd got no idea whether you're doing the right thing or not....Our worst experience was with [day service] not working out That just gave us, our confidence a bit of a jolt really. So that's the worst thing that happened ...[then] being

made to make the decision [whether to place him out of home or not]. I feel as if we were made to make the decision.... It was make that decision or wobble on for the rest of your life And that's not a life. (Tom's mother post-transition interview)

<N>The struggle to identify the right thing to do was evident in these three mothers' accounts. Parents gave a range of reasons for refusing to accede to some of their son's or daughter's choices. Robert's mother described having weighed up the pros and cons while ignoring his choice, which, she believed, would have been to stay at home.

<quote> I made the best choice I could for him of what was available... the best of a bad lot.... I try not to care which is really hard.... You have to get tough which sounds horrible and it is horrible. (Robert's mother post-transition interview)

<N>She described her distress at having had to choose a poor service, with too few staff to deliver the quality of care Robert had experienced at school, versus no service where she would become even more ill and exhausted.

In sum, these families described the process of deciding on both management and placements as complex, and freighted by tension and difficulty. Decision making at this transition was not a simple matter of hearing about or interpreting these young people's choices and then facilitating what they wanted.

Attending to the Affective and Experiential

<N>Deleuze takes a Spinozist ethical position that a person is defined by the affects of which they are capable, and cannot be separated from multiple relationships and layers of connection with the world (1988, pp. 124-125). We start by noticing how their work affected transition staff and the reports they gave about this. Of the initial 12 transition staff, one-half resigned during the 18 months of data collection and a further 2 had long-term periods of sick

leave. The remaining 4 all reported high levels of stress, not least because their attempts to manage their own workload were undermined by having to cover the work of absent colleagues. With regard to the three young people in this analysis, only Tom was supported by the same transition coordinator throughout the 18-month transition. Robert's worker had a 3-month period of sick leave; Lottie's worker left halfway through, leaving a gap before a new one had to get to know her just 6 months before she left school. Most of the workers responsible for coordinating transitions for the whole cohort reported feeling that the process was difficult, if not impossible. Accepting the possibility that factors other than transition work may also have been in operation, such high turnover and sick leave suggests that the job is stressful and difficult. It resulted in delayed decision making and uncertainty about what was happening for parents and young people.

There were also positive accounts of mutual affect. Text messages from Robert's previous teacher during our study's period of follow-up, asking how he was getting on, had prompted his mother to take Robert back to school. This visit generated a resonant description of affective relationships.

<quote> I was only walking towards the door and one of the ... classroom assistants ... literally ran down the drive, flung her arms around him hugging him and kissing him and oh, it was like, it was like going home. You're making me fill up now. (Robert's mother post-transition interview)

<N>The memory of these encounters made his mother tearful, perhaps both touched by its warmth and saddened by its absence from Robert's experience of adult services. She contrasted her distant relationship with the day center to the acceptance and emotional warmth of this school, and the enduring nature of their relationship reflected by invitations to

social events and seasonal celebrations. A second return visit to the school's Christmas show was described even more positively.

<quote> As soon as we got there: "Hey Robert how do you fancy being in the show with us!" (laughter) and they did, they pinched him again he was in the show with them, joined in ... he was really loving it ... just glad to be back I think for a day.
(Robert's mother post-transition interview)

<N>On both these occasions, the staff were described as taking Robert away from his mother to join their activities as if he was a welcome addition, without any suggestion that Robert might be a burden. Stolk and Kars (2000) found that, when their child is happy or makes others happy, parents of people with profound ID find their own life meaningful: Doubts and questions about the meaning of their life can arise in the absence of such experiences. Bigby and Weisel (2011) point to both the difficulty and the crucial significance of warm social interactions to people with severe intellectual disabilities, which suggests why visiting the school was reported to have been 'like going home' for them both.

Lottie's mother started by giving a positive account of local relationships.

<quote> Lottie loves to travel around the village calling in on the local shop keepers just to say hello and chat, they all loved to see her smiling face and would always look out for her and make sure she was safe, without letting her know she was being looked after. This enabled her to gain in her independence and for me to know I was not alone in protecting and looking out for her.... She did have a problem with money but the shopkeeper knew her well and made sure she was allowed all the time she needed and helped her out when she needed support. (Lottie's mother, diary 2 written 6 months before the final post-transition interview)

<N>Lottie was part of a community that welcomed her, was patient with her, and afforded her meaningful occupation. It provided solidarity for Lottie's mother too: She was 'not alone in protecting and looking out for her.' Lottie described her connection to people and place in equally positive terms.

<quote> I don't like living far away from here.... Round (here) I've grown up with a lot of friends.... I don't really go to a college far away I'd rather go to like a (name of FE College)... cos it's a small college its fine and I know Mum's friends there. (Lottie, pre-transition interview)

<N>Lottie's attachment to her locality bridges the usual gap between people with ID and society identified by research (Forrester-Jones et al. 2006), users (Stewart, 2009), and carers (Smellie, 2009). However, there were also differences between her and her mother as the transition unfolded. Lottie's mother struggled increasingly to achieve the right balance between her and her daughter's preferred lifestyles, because Lottie invited relative strangers into their home.

<quote> It is getting really harder... I never know when I come home from work what I'm going to find... I've just got no privacy whatsoever none ... it's as if this place is hers... I just feel as if I'm a slave [clearing up after meals Lottie made for people she brought back to the house]... when I'm coming in from work I don't want it.... I just feel it's my space that gets invaded all the time. (Lottie's mother post-transition interview)

<N>This mother felt that they both needed a break for Lottie to grow up, and that attending residential college was in her daughter's best interests.

<quote> If I'd agreed to what Lottie says about [residential] college ... then she'd be sat on her backside every day just watching the tellyshe can't see what the college is going to mean for her in the future or what it can offer as in people skills, as in learning to cope and look after herself which are those skills she's going to need in life.... She's started the horse riding [at college] and she absolutely adores it ... they talked about ... finding a [karate] club for her there so she can do it there. So she is starting to get some of her needs met. (Lottie's mother post-transition interview)

<N>Here, Lottie's mother justifies her decision that Lottie should continue attending residential college by considering the beneficial impact on Lottie's future life of her having a wide range of activities and experiences, rather than sitting at home watching TV. She argued that once Lottie could access previously enjoyed activities at college she would also be more content. Her own wish for a peaceful home life is bracketed. Instead, Lottie's mother described the considerable effort she had made to support this distant placement, by describing how she worked with college staff when Lottie had a seizure that required hospital admission, but had then discharged herself against medical advice. Lottie's mother succeeded in persuading transition professionals that Lottie complained about her college placement partly because she was afraid of the return of epileptic seizures and of the constraints these placed on her freedom, both of which the college could and should be managing better. Additionally, and despite what Lottie said to her transition worker during college holidays, when actually there Lottie seemed to be engaged and happy.

<quote> If she was hysterical and screaming the place down and hanging on to me as I left the college then I would think different but ... it's like somebody has flicked a switch, she walks in there, she goes straight to her room, drops all her things and then

goes to find the staff and they're in the kitchen maybe making tea or something so that she's chatting away.... So I know that in my heart of hearts she is comfortable there. (Lottie's mother, post-transition interview)

<N>The account of her 'chatting away' can be interpreted in the context of Lottie having previously refused to speak to a consultant neurologist about her epilepsy, and having walked out of a short-term care establishment she had agreed to stay in while her mother took a holiday. Lottie's mother sought to persuade both her daughter and transition staff that the placement was positive and viable, and that she would do whatever is needed to support it. Mother and staff were creating a dynamic web of supportive relationships, making sense out of different pieces of information and perspectives. However, the college was out of area and Lottie's mother had a job locally. She described having to make difficult decisions about which relationships to invest in as she worked to build effective support for Lottie and a network of staff who accepted her account of the situation.

Tom's parents regarded the residential home he eventually moved into as not simply a collection of tenancies that provided for each person's particular needs, as required by Supported Living, but as a community.

<quote> It took us a long time and thankfully them a long time to realize Tom was going to fit in.... It's taken them over a year to fill that house but they've done it really well because they really get on as a group. (Tom's mother, post-transition interview)

<N>Her repetition of 'really' indicates the strength of their satisfaction. His mother made observations throughout the post-transition interview that indicated how Tom's life had been transformed.

<bullets> • “He’s much calmer when he comes home, he’s not demanding he just looks so well.”

- “He’s lost over 2 stone in weight which is wonderful, he looks so young he doesn’t want to be stuffing his face because he’s not allowed to there.”

- “He seems gentler, not so pushy, verbalizing so much more.”

- “He’s easier to sort out, he can go and stay at mum’s ... he’s a happier, more settled person.”

<N> Moving into this home had affected more people than Tom. According to his mother. his transformation had improved others’ mode of existence too.

<bullets> • “Everybody [Tom’s brother, she and her husband, Tom’s grandmother] has benefited from it.”

- “[Tom’s father]’s a different bloke, totally different bloke. He’s gone out whistling out of here at half 8 this morning.”

<N> Confidence in the placement grew as Tom affected others as well as being affected by them. There could have been conflict between home staff and Tom’s mother, because she phoned or visited many times a day at the beginning of the placement. However, our researcher observed that residential staff worked effectively and cooperatively with her to support Tom’s improving health and development, respecting each other’s different skills and abilities. Tom’s mother reflected on what might have happened to her and her husband’s lives if they had not identified such a good residential home.

<quote> I think we’d have both gone downhill healthwise.... You don’t realize what a massive effect it has on your health.... We were ready for a life back you know.

(Tom’s mother post-transition interview)

<N>Services have been found to express considerable criticism of parents who place their own needs before those of the person with ID (Glendinning et al., 2009). By contrast, a Deleuzian ethic seeks to envisage and encompass future relationships between the young person and significant others as they unfold, as occurred between Tom's mother and his home manager.

So the transition process was not over once an acceptable set of educational or care services had been agreed. Another layer of negotiating relationships was then established to support the health of vulnerable young people like Robert or to hold young people like Tom and Lottie steady, whose behavior could be challenging if the pattern of care did not fit them or its elements did not fit together. The resulting pattern of support and/or care seemed kaleidoscopic. It was made from many pieces and colors, dropping over time into patterns that were more or less coherent and aesthetically pleasing.

Nearly all of these relational negotiations worked comfortably alongside actions and decisions that emerged from a narrative of individual choice, but there was one exception. A transition plan articulated by a group of parents in our cohort that included Lottie's mother clearly ran counter to service expectations and structures. This group proposed that some or all of their seven children might live together when they left college. The young people had attended the same school and developed a shared social life outside school through a range of joint activities. There is considerable evidence that social isolation is a major problem for adults with ID (Bigby & Weisel, 2011; Emerson, 2005; Forrester-Jones et al., 2006) and so Lottie's membership of the group and unprompted reference to them as her friends could have been regarded positively, not least because she had also made relationships with less desirable people in the community who stole from her. Yet their transition worker resisted

this proposal and parents found themselves having to defend this vision of the young people's future lives to both her and her manager. The following field note was made during researcher observations of the second meeting held to discuss this possibility.

<quote> [Manager] noted that social services need to be led by person-centered planning and cannot be tokenistic about that. Parents need to recognize that the young people's idea may differ from what their parents are planning for them.

[Parent] Losing sight of the fact that this idea came from the young people themselves not from parents.

[Manager] suggested that the group of parents nominates two spokespeople and they should write a letter of request as carers. It will then be up to Social Services to construct person-centered plans with the young people and see to what extent those plans 'marry' with parents plans. (Post-transition, meeting observation 2)

<N> Meetings to discuss this proposal confirmed Burton and Kagan's (2006) policy analysis, that services are reluctant or unable to engage with collective solutions to the difficulties experienced by people with ID. The proposal would have been difficult for the transition worker to operationalize because the format for residential services, Supported Living, enacts liberal values by providing solely individual tenancies. This has only recently been identified as a problem by Scottish Social Services staff (discussed in Hall, Simpson, & Philo, 2013) who are exploring how to engender 'Commissioning for Connectivity.'

In sum, accounts given by these participants showed how the young people's experiences of being affected by others, and their ability to affect people around them influenced three different aspects of this process: Decision making at the transition, parents' evaluation of, and involvement with, placements, and parents' plans for the future. Most of

these relational considerations reached beyond rather than challenged liberal individualist focus on choice.

<A>Discussion

<N>This analysis focused mostly on parent accounts, but these were grounded by data collected independent of those parents: interviews with the young person where possible, researcher notes made when observing the young people in their new contexts, and interviews with transition workers.

The findings provide evidence to support Reinders' (2000) assertion that liberal democracies do not have much to offer people with ID. What was most positive did not derive from solely pursuing choice. The only time that Robert was reported to be animated was when he was taken back to school: His mother considered his transition outcome was wholly negative, largely because of resource constraints. Tom initially refused to enter the residential home he ultimately flourished within, creating what became a highly successful placement required energy, courage, and persistence. The contrast between Lottie's opinion of her residential college and her actions when there made it hard for those involved to be sure what she wanted and what was in her best interests but, as her mother emphasized, it was not feasible for Lottie to 'choose' that her mother looks after her forever. The data raise questions about discourses of choice in ID when referring to people with severe ID and complex needs, because few of the 'choices' identified could be considered informed or made by people who had the capacity to make them. Parents trod a delicate line as they reported accepting choice as an expression of personhood, but shaded their responses according to whether a choice was within the young person's capacity or in their best interests when lost opportunity was weighed in the balance.

Choice was rarely the decisive issue informing what these young people did after they left school, but the principle compounded parents' difficulties at a stressful time because they had to defend decisions they made with/for the young person to friends, family and, most significantly, transition workers. In practice, the principle of choice was often no more helpful to these parents than bioethical principles have been found to be for ID staff (Meininger, 2002; Wilson, Clegg, & Hardy, 2008). Parents did not have the reassurance that, if they applied the right rules, they would make the right decision; many of them described the considerable anxiety this transition process elicited.

We found that focus on choice within services could conceal various kinds of physical, social, and emotional neglect, largely through overestimation of capacity. Not only has capacity legislation had no moderating effect on policy promotion of individual choice, in the UK the issue of capacity has been overlooked altogether. For example, the list of legislation compiled as relating to *Valuing People Now*'s (Department of Health, 2009) policy objectives makes no reference to the Mental Capacity Act (Department for Constitutional Affairs, 2005) at all.

Dynamic relationships unfolded between parents and provider staff in what might be termed kaleidoscopes of support. Longitudinal research indicates that both the personnel and style of support they provide changes frequently (e.g., Hubert & Hollins, 2010). Lottie's mother hoped that her daughter would become independent, but also encouraged Lottie to accept support from people other than her. Robert's mother (whose own health was poor) was resigned to a significant reduction in the warmth her son experienced in adult services, and in his ability to affect and be affected by others. Tom's mother had the time and energy to

involve herself with the manager and staff team of his new home from the outset and planned to continue doing so, and this involvement was observed to be welcomed.

Braidotti (2012) has argued that viewing the ethical life as one that involves creating and sustaining affective relationships with others renders liberalism's focus on outcomes for individuals problematic. She elaborates Deleuzian ethics to argue for a triple shift in ethical thinking. This turns away from individual achievements in favor of promoting enduring relationships with networks of people who affect one another, away from applying moral rules and protocols in favor of practical ethical action, and away from negative judgment about people who transgress the protocol in favor of elaborating what it is to live joyfully and affirmatively. She argues that we already inhabit a non-traditional social reality made up of multiple layers of interdependence, interconnection, and encounters, but that we lack the social imagination to bring them into conscious representation.

Of course, Deleuze is not the only philosopher to offer a relational conception of human experience, but he is unique in also theorizing two other phenomena that are significant to ID. He advocates pluralism, and in ID particularly negotiated understandings are crucial because no person or profession holds all the answers. Deleuze also theorizes creativity which, we argued in the introduction, is vital for a conservative field that tends to retain ideas and interventions when practice elsewhere has moved on. Reflecting on Braidotti's ethical triple shift in conjunction with findings from this transition research identified two possible streams of innovation for ID.

First, examination of how rights and relationships can coexist. Although it was possible in most circumstances for parents and services to consider the current choices/preferences of each individual alongside their current and future relationships, the

negative service response to the proposal for a group of friends to explore living together showed how these perspectives can come into conflict. Conceptual and policy work is required to identify how an ethic of the right to choose and an ethic of relationships can coexist. A European approach to childcare (Petrie, 2013) has connected rights and relationality by channeling rights through trusting and reflective care rather than holding them apart from it. Schelly's (2008) reflective ethnography of a year as a personal assistant to a man with ID and autism exemplifies this kind of connected support, while exploring the tensions the worker experienced in delivering it.

Second, a relational perspective opens a rich seam for new research and conceptualization that can reinvigorate services: These are some possibilities.

- <bullets> • Making staff continuity a quality marker for day and residential services. That means slowing the pace of relational 'churn' (a combination of formal turnover, within-organization secondments, and sickness) experienced by people with ID.
- Enabling staff and users to address the start and end of relationships with one another. This is necessary even when care relationships have time to develop and show more continuity. It would contribute to the broader conceptual task of describing realistic modes of existence for adults with severe and complex IDs.
- Identifying the dimensions of effective kaleidoscopes of support: how these are engendered and recognized, how they operate, which aspects are more and less desirable. Miller (1996) provides an example that researched backward from success. From a sample of previously chaotic pupils who had become settled at school, he found they were equally likely to have been helped by behavioral, cognitive, or psychodynamic interventions, but that it was not content per se that created the change. Some method of intervention was needed,

but the crucial dimension was the creation of shared meaning across an effective collaborating system around and with the child comprised of teacher, parents and educational psychologist. In similar vein, ID research should examine how a shared understanding of the needs of a complex individual with ID that drives intervention develops and unfolds between all relevant parties.

<A>Conclusions

<N>We found that decision making at this transition was not a simple matter of hearing about these young people's choices and then facilitating what they wanted; and that focus on choice could be associated with various kinds of neglect, largely through an overestimation of capacity encouraged by this policy. This study responds to philosophers' call to expand ethical dialogue about ID beyond choice, autonomy and rights to also encompass care and support. We noticed that it was usually possible to both attend to individual choice and develop kaleidoscopes of supportive relationships, but that funding needs to be more flexible for Commissioning for Connectivity to become possible.

Deleuzian ethics direct our attention toward the experiential and affective, in open and creative environments. Interpreting findings from this research through Braidotti's 'triple shift' elaboration opened two possible streams of innovation for ID. These show how engaging with Deleuzian thinking brings creativity and innovation into practice.

<A>Acknowledgments

<N>We are grateful to the young people, families, and staff who allowed us to accompany their transitions; special schools supporting the research; Nottingham Mencap steering group; Chris Carter, Val Leyland, Anna Harvey, and Jenny Lapish. We also thank those who commented generously on earlier presentations, and thoughtful PPP reviewers.

<A>Note

<numbers>1. All names are pseudonyms.

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