

Cultural affordance, social relationships, and narratives of independence: Understanding the meaning of social care for adults with intellectual disabilities from minority ethnic groups in the UK

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Objectives: To explore the perspective of adults with intellectual disabilities from minority ethnic groups, on their relationship with social care services.

Methods: Thirty-two adults took part in semi-structured interviews. Transcripts were analyzed within a Pluralist framework, adopting the structure of Template Analysis and then drawing on phenomenological, narrative, and discursive approaches.

Results: Our participants were generally positive about the services which they received, which they evaluated primarily in terms of their continuing good relationship(s) with specific workers. Our respondents were sophisticated users of cultural resources and identities; the concept of 'cultural affordance' may be useful alternative to 'cultural competence'. We discuss three distinctive narratives about independence (Stability; Progress; Resistance). Each highlights the importance of maintaining connectedness to others, and the crucial role played by ownership of decision-making.

Conclusions: We have developed a set of resources which service providers (and researchers) can use with people with intellectual disabilities, in order to support mutual understanding, service planning and delivery.

Keywords culture, independence, ethnicity, social care, pluralist, interviews, relationships

Introduction

Previous research with families of people with intellectual disabilities from minority ethnic groups in the UK (particularly South Asian British families) has captured their frustration at having to 'fight' to access social care services. This literature has also tended to report that minority communities are often under-represented in social care services (compared with prevalence levels; e.g. see Durà-Vilà and Hodes 2012), and that often families are disappointed by those services they do receive (e.g. see Bonell *et al.* 2012).

The importance of engaging with the complexities of culture and ethnicity is illustrated by Hatton *et al.*'s (2010) study. In interviews focused on health services, and conducted with seven minority ethnic and seven majority ethnic family members (all caring for an adult with LD, almost all sons or daughters), Hatton and colleagues explored their perceptions of support for challenging behavior. The

reduced social capital and increased exposure to racism among minority families appeared to be connected to their skepticism and anger about the motivations of service providers. Among the majority ethnic family members, feelings of anger and cynicism were expressed with much less force. Constructive relationships between families and services were able to be preserved in these cases. While shortcomings of services were acknowledged, these family members felt able to continue to struggle within service systems, in order to improve the situation for their families. Hatton's study gives an important insight into the role which might be played by prior social experiences and by cultural identities in the context of negotiating complex care systems. Indeed, given the fragility and fragmentation of social care services compared with health care services, we might expect such dynamics to be even more important for families seeking social support. It is worth noting too, that it does tend to be families who seek and broker much of this support: service users themselves may be protected from some of the stresses, in this respect.

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Very few peer-reviewed studies (we are aware of: Bonell *et al.* 2012, Pestana 2011, Azmi *et al.* 1997, Raghavan and Waseem 2007) have presented qualitative analysis of care experiences based on verbatim data from adults with intellectual disabilities themselves. This reflects a pattern in the intellectual disability literature for a range of topics (Beail and Williams 2014); the perspectives of people with intellectual disabilities are under-represented even in specialist journals. Existing studies also tend to have focused more on health care than on social care. When they have worked with families, they tend to have interviewed the families of children, rather than adults: this is important because social care needs extend into adulthood.

A wider literature which attempts to evaluate people's satisfaction with intellectual disability services has been criticized by Copeland *et al.* (2014) for failing to give proper consideration to what 'satisfaction' might mean, or how it might best be studied. Satisfaction in this sense has shrugged off its original association with satiety, but is not an adequate substitute for a stronger positive endorsement, such as 'happy' — or even 'pleased.' It is a mild and rather uninformative evaluative term, which can hide many ambiguities. One good reason for conducting a qualitative study which focuses on the perspective of people with intellectual disability is that it gives us the opportunity to explore this issue in different terms. We can aim to find out — as we did in this study — what social care services mean to the people who receive them.

We can also situate those meanings in the context of people's lives and cultural identities. Given the literature on ethnic minority status and dissatisfaction with services, this contextualisation is important. In our study, we wish to be very cautious about assuming that membership of any particular ethnic group carries with it any sort of consistent identity, while simultaneously recognizing that the fact of being *externally identified* as a member of such a group carries with it the risk of exposure to bias and discrimination. To that end we set out to recruit participants from a range of minority ethnic groups, but then to ask them — in some depth — about what culture and identity meant to them. We aimed to treat this information as data, rather than as a means of describing our sample.

In recent years, so-called 'austerity politics' in the UK have reduced the capacity and coverage of health and social care services. Some services have responded to these pressures by adopting less intensive methods of support, such as focusing on prevention, doing more work through informal carers, or providing self-management options. Sometimes these approaches have genuinely evolved from progressive approaches which have been designed to empower service users. Others represent an opportunistic marriage of pragmatism and idealism, and some are brazen manifestations of the worst aspects of neo-liberalism (e.g. see Friedli 2013). In this context, an examination of some of the assumptions underpinning social care provision to adults with intellectual disabilities

is timely. In this paper, we focus particularly upon understanding how service providers' talk about 'independence' is received by service users. Increased independence for service users is often accompanied by reduced support from services. A skeptical interpretation would link austerity measures with the drive for independence, as a way of reducing service provision. It is therefore important and timely to examine how service users perceive this process.

In answering these questions about the meaning of social care, culture and independence, we draw upon a pluralist framework (Frost and Bowen 2012). Pluralism provides a platform for combining different epistemological lenses in the same study, in order to allow different aspects of the participants' accounts to be illuminated and explored 'depending on their context and situation.' In this study, we use the Template Analysis method as a means of organizing our preliminary analysis, and then expanded this with a series of distinct and more focused analyses (using phenomenological, narrative, and discursive lenses).

Methods

Context

Our study aimed to explore people's perception of social care and its meaning for them, through their relationship with those services, and in the context of their cultural identities.

Sample

We conducted 29 interviews with 32 minority ethnic participants with mild/moderate intellectual disabilities. We endeavored to combine a structured approach to sampling (i.e. seeking to interview participants from the largest non-white demographic categories in the West Midlands, UK), with a more nuanced approach to understanding cultural identity (by making culture the topic of the first part of our interviews).

Three individual interviews were excluded from analysis for ethical and methodological reasons. For example, one of these interviews was conducted with an externally sourced Bengali interpreter, who did not ask the participant the questions which were posed by the researcher.

Participants were given the option of being interviewed individually, or with other participants. Five of the final 29 participants preferred to take part in group interviews, and we ran two of these: one involved three women, and the other involved two men.

The participants were recruited via a range of organizations across the West Midlands including education services, specialist health services, third sector service providers, statutory service providers and charities. At the time of the interview, 16 lived in the family home, five lived in residential group homes, 10 lived independently (with limited support) and one was in a mental health hospital. Ethnic heritage was informed by referrers in the recruitment process as well as self-identification during

the interviews. On the basis of preliminary information provided by referrers, approximately 30% of the sample were identified as Black Caribbean, and a further 25% as Pakistani. The remainder were split evenly between people who were described as Indian, as Bangladeshi, or as ‘Mixed/Other.’

Data collection

Interviews were conducted by GU and KM. Most interviews were conducted in English. Two of the included participants preferred to be interviewed in another language, and KM was fluent in their preferred languages.

Our interviews began with a ‘Culturegram.’ This was a visual prompt (inspired by the work of Congress 1994) which we developed to help participants to tell us about the cultural aspects of their identities, and to place this in the context of their everyday lives. The culturegram allowed participants to situate themselves in relation to ethnicity, culture, and religion in more sophisticated ways than we could capture through a demographic ‘box-ticking’ exercise. Further, we anticipated that some participants might not be able to identify their ethnicity based on UK demographic classifications. Discussion of the culturegram generated verbal data which comprised the first section of the interview.

The interviews proceeded with a series of questions structured to find out about the person’s understanding of ‘support,’ their level of involvement with and experiences of social care (provided by both organizations and individuals), their views of the support they felt they needed, and of any support they received, and the ways in which this fitted in with their goals and priorities in life. The interview guide and the culturegram were devised in consultation with two experts by experience, who advised the project and sat on the steering group.

Participants were given the option of being interviewed on their own or with a carer. Seven chose to have a support worker or family member present. Where a carer was also present, they were reminded that their role was to support the person, and facilitate them to tell their story, but not to speak for them.

The interviews were audio recorded and each lasted around 45 min (range 30–90 min). The audio recordings were transcribed by a professional service. Pseudonyms are used in the extracts reproduced in this paper.

Data analysis

Our pluralist analysis began with the development of a template, using procedures from Template Analysis (King 2012). An initial template was developed using 13 interviews. The initial template was developed using a ‘bottom-up’ approach. These interviews were chosen because they were the longest and ‘richest’ (in terms of the depth of description and level of reflection provided by the participant). They were coded (by ML and GU) with

a preliminary focus on experiential claims and concerns, as is consistent with the phenomenological focus of TA. This template was then further developed in line with data from the remaining 16 interviews, which were integrated using a more ‘top-down’ approach (by MI).

The template categories, populated with quotes from across the data-set, provided a detailed map of the data-set. This allowed us to conduct a series of more focused analytic investigations, in order to explore specific issues within the interviews through the most appropriate methodological lenses. In this paper, we report upon further analysis which was conducted on the experiential and discursive aspects of ‘culture and identity’ (conducted by SZ, GU, and ML) and on the narrative trajectories associated with ‘independence’ (conducted by IT, ML, and GU). The team met regularly to discuss these developing analyses.

Analysis and discussion

Cultural affordance and identity salience

Participants in our study made good use of the culturegram, and showed us how they understood their cultural identities in complex ways. We have noted in the Introduction and Method section that we planned our study with a preference for exploring culture via means which are more nuanced than simple demographic categories. In some respects then, having provided participants with an opportunity to demonstrate complexity, we should not be surprised to report subsequently that complexity was indeed demonstrated! However, this would be an over-simplification. Some participants expressed ‘mono-culturally consistent’ positions on issues such as religion, diet, relationships, and family; others drew upon dynamic and overlapping multicultural frameworks. For example, here a range of self-presentational strategies are described by one participant, in the course of reflecting upon her preferred style of dress:

- I: Okay, so because of being Sikh and being a woman, are there certain types of clothes that you might wear?
 R: I wear English clothes.
 I: You wear English clothes?
 R: Yeah.
 I: Would you ever wear Asian clothes, like a sari or salwar kameez?
 R: I do wear like um Punjabi suits, um when [service] had a soiree and we had to have like um pink and black so I wore um a pink trouser suit.
 I: Very nice, that sounds lovely. Um any other kind of clothing that you might wear because of being Sikh?
 R: No, I just wear jeans, trousers, skirts, you know, whatever I feel really comfortable in.

Thus, for this respondent, comfort largely dictated clothing choice, but for special occasions, formal clothing with different cultural connotations might be preferred. In the next example, a participant describes preferences for

cultural engagement which seem to be aligned with two different identities (someone who watches films; someone who doesn't watch films):

- I: Okay, and what about things like, because of, because of your culture, because of being a Pakistani woman, do [service] respect the places that you go to or you don't go to?
- R: They know.
- I: Because I guess you mentioned before you don't go to the cinema?
- R: Yes, some go to the cinema, only I don't go.
- I: Okay.
- R: Or like the other girls go, only I don't go.
- I: How does that make you feel?
- R: ((laughs)) Yes, I get a bit- Everyone, I don't- I don't watch any movies - like I love to go to the cinema, only my dad and mum don't let me go to the cinema. They said films are not good to watch.
- I: So when [service] watch films in here, here, what do you do?
- R: Watch it.
- I: You'll still watch it?
- R: Yeah.

In this extract, each pairing of preference and identity is activated by a different relational context. Conversely, we might say that each context *affords* the performance and experience of a different identity. Thus, we could say that there are different forms of *cultural affordance* at play in the circumstances described by our participants here. These two extracts are examples of a category within our preliminary template ('cultural complexity') which was explored further via the experiential and discursive lenses within our pluralist analysis.

Culture is a good topic for combining these two approaches. Culture provides us with resources for making sense of the world (Bruner 1990, Much 1995), and for understanding our place within it. It is a bridge between the discursive (which analyses resources and practices for making sense which are 'out there' in the world) and the phenomenological (which analyses the world as it is understood from a specific perspective). From this latter, *experiential* perspective, participants told us — as they do above — about a wide variety of things which were important and meaningful to them: for example, food, clothes, music, ritual, performance, spirituality, worship. Some of these things sat clearly within cultural frames which we could associate with a religious identity, or with a sense of one's ethnic or geopolitical origin. Others — just as important to our participants' identities and place in the world — were associated with less easily located forms of culture, such as specific forms of pop music, or — as above — films. In their discursive positioning, what they most often demonstrated was a view of cultural commitments as being context-dependent.

Often, in the literature on culturally appropriate practice, there can be a sense that 'cultures' can be understood as if they are like different *places*, each one having distinct qualities and clear boundaries. Perhaps this arises from

the unexamined assumption that cultures might *originate* in different places. On this view, study participants and service users are often described as if they are speaking to us from 'within' a particular culture. However, as is illustrated in the extracts above, our participants' relationship to culture was characterized by the way that they brought their own *agency* to bear on a series of judgments about *context*. In the extracts, we can see that cultural aspects of identity clearly take on different *meanings* in different contexts (dressing for everyday comfort, or dressing for a special soiree), or in different relationships (spending the evening with friends, or with dad and mum). This does not mean that culture should be ignored by services, of course. One way of thinking about the importance of context-dependence is to consider how service providers are always entering the lives and homes of service users as *outsiders* (even if they might share some cultural identities). Respect for others' preferences remains paramount in such contexts, but that does require that we make the effort to understand those preferences and contexts. Thus, we would argue that culturally sensitive practice should arise from *exploration* and *negotiation* (from a position of curiosity), rather than simply categorization and stereotype. The concept of 'cultural affordance' might be a useful reflection point for services and professionals. Cultural affordance is an analogy drawn from, or perhaps an extension made to, the general concept of affordance. 'Affordance' originates in the Gibsonian model of perception (1979), and is concerned with showing how environments *make possible* particular biological responses. Solymosi (2013) suggests that language, symbols and 'any human artifact or by-product of human activity that becomes a means of affording humans new opportunities for action [can be considered to be] a cultural affordance. Like biological affordances, cultural ones make possible new ways of engaging the world' (p. 602). So for example, in the extract above, we can see that *the availability of trips to the cinema* does not afford our participant the possibility of being *a person who enjoys watching films*, because her family does not approve of her going to the cinema. This is implicitly framed as a cultural barrier. On the other hand, *the availability of films at home* is a much more successful affordance for her, because the participant feels she has the capacity to negotiate the cultural barrier *if* she is not breaking the rule about cinemas. Thus, understanding how such affordances work is not solely a function of the possibilities opened up by the cultural world; it is also a function of a person's capacity to respond.

A subsequent development of the cultural affordance concept by Ramstead *et al.* (2016) is particularly pertinent here, because these authors introduce the secondary concept of *conventional affordance*. This refinement is useful because it includes appears to offer the possibility of incorporating the role of cultural capital and cultural competence into its account of how cultural affordances work:

Conventional affordances are possibilities for action, the engagement with which depends on agents skillfully leveraging explicit or implicit expectations, norms, conventions, and cooperative social practices. Engagement with these affordances requires that agents have the ability to correctly infer (implicitly or explicitly) the culturally specific sets of expectations in which they are immersed—expectations about how to interpret other agents, and the symbolically and linguistically mediated social world. (Ramstead *et al.* 2016, p. 2).

In practice then, when working with people with intellectual disabilities, we might ask ourselves, ‘What cultural possibilities are afforded by the work that I am doing, and the way that I am doing it?’ This aligns very well with increasing commitment to a rights and capabilities perspective for improving the quality of psychosocial care services (Sen 1989, Pūras 2017).

The importance of continuity and reliability for good relationships and support

Participants had very few complaints indeed about the cultural appropriateness of the services they received — for them, this was not the critical issue for deciding whether a service was good. In some narratives, cultural competency was discussed, but it was discussed in terms of the behavior of specific individuals (key support workers) about whom participants were generally very positive. In fact this typified the way in which participants described their relationships to services. They were often not relationships with ‘services’ at all; they were primarily with *people*. Many respondents described very positive connections with their [current] support workers. Some expressed distress at relationships which had been severed by recent changes to service provision.

Some respondents *did* talk about relationships with services — especially social services, education, and health. Generally, however, relationships with services were located in the past. *Present* relationships were understood in personalized terms. Good support was understood in the same context; it was *personally attuned*. Participants were more able to evaluate support provided by an individual, than to talk about services as whole, and when they did so, the person’s competence and reliability were the key criteria. Underpinning this, maintaining the continuity of a good relationship, once it had been established, was understandably very important:

- I: And so the one person, did you, did you just um, what, was it one person who came and helped you, one particular-?
 R: Yeah, one person. I don’t like changing over.
 I: What do you mean?
 R: Like had to swap person before now, I’ve kept that one now, kept him, understanding me, I just understand him, we clicked on after that, yeah.

For some participants, changes to the welfare system, and the onset of cuts to social care funding, were already

causing distress, because of the loss of access to these relationships:

- R: I don’t want to move from here. At the time mum and dad said they didn’t realize that the tax, the tax was, was going to affect me until that letter came about the benefits, the rent and that you know. So um I’m waiting. I’m waiting to see what the cutbacks are really.
 I: Mm. Sure, so-. Just go back a moment. You mentioned that you used to go the [service]
 R: I enjoyed that because I had a set time to go. I had to go from morning ‘til evening and I really enjoyed it but I got upset when they closed it down. I used to go to college and they closed that down as well.

This sets the scene for a more detailed discussion of the concept of independence in shaping people’s experiences of services in general, and of connectedness, more specifically.

Transitions, goals, and threats: the contested meaning of ‘independence’

Independence was a divisive topic. At times, it was connected to issues related to culture and family, but more typically it was an issue which transcended culture. This was the case for most of our participants. Independence was certainly one of the most important and emotive issues in their relationship with social care services.

For some, independence was a long-term goal (an outcome), and there was a clear pathway to it. Independence as *outcome* could mean different things: it could mean, ‘living independently,’ with little or no support from services, or it could take a more abstract form (related to ‘choice’ or ‘agency’), which might best be summarized as ‘being able to do what you want, when you want.’ The extent to which a person might feel able to meet these aspirations could be a complex and contingent judgment, as in this example:

- I: But so if [support worker] wasn’t there. would you be able to have gone and watched that film?
 R: No.
 I: No.
 R: Or, or I could decide, okay, I’m going. ‘Bye!’ In fact I would like to do that at some stage, like. ‘Bye! I’m going. ‘ Okay, grab my coat, grab my bag, grab whatever I need, ‘I’m off, I’m going, bye! I’m going to buy milk. ‘
 I: Yeah, yeah.
 R: Just around the corner.
 I: That’s something you’d like to do?
 R: There are no shops round the corner.
 I: So if there was a shop would you go? Would you be able to do that?
 R: Yeah, yeah. Because I know my way around, but except the roads, you know, the roads are not good.

Here, the respondent demonstrates that she is motivated to act independently (in the sense of spontaneously choosing to pursue a simple activity outside of the home), and

she does so by describing a hypothetical trip to the corner shop, to buy milk. However, this is purely hypothetical for her, because it is contingent on living somewhere where the roads are *safe*, and where there *are* local shops. Neither of these applied to her current accommodation, and so again we can see the important role played by affordance. There is also resonance with both the social disability model (the barriers to her independence are external, and could be solved by situating the supported accommodation in a quieter area with accessible basic amenities) and the capabilities approach (the participant has the capability for greater independence, agency and problem-solving than her current situation allows). Thus we can see that, in these sorts of outcome-related examples of independence, there is potentially an important beneficial role for social care, *if* that care has a degree of *continuity* (i.e. it involves a service provider who can get to know the service user) and *if* it is attuned to change (i.e. it involves periodic assessment and review of a person's capabilities and motives, in the context of their current situation).

Thus, even in accounts where the focus was on independence-as-outcome, there was also some sense of independence as *process*. This is because new outcomes can be pursued; greater independence can be sought, and so it can be difficult to separate process and outcome. Sometimes, however, the focus on process *was* clearly the foregrounded feature. In this form, independence was often represented as an aspect of personal development. The process of increasing one's independence was discussed as something to be pursued, via acquisition of a *specific set of skills*. For example:

I: So can you tell me a bit more about them [types of support] please?

R: We'll go on the computer. They help me every day to get into what I need to do.

I: Mm.

R: Just to help me with the cooking 'til I could do it myself, shopping 'til I could do it myself and cleaning really, I know I need a lot of prompting but there was this lady who was sick but her- was a really good cleaner, and they used to tell me, 'Oh she can clean her bedroom and everything,' and they used to look at me and say, 'Why can't you do it?' and I say, 'I can do it but I'm slow.'

In this example, the participant describes a process of gradual skill acquisition (i.e. re: computing, shopping, cleaning). The process is slow, but there is progress. He describes how social care staff prompted him to improve his skills, by pointing to what another resident was capable of doing, but he also situates this prompting as something which happened in the past ('til I could do it myself'). In many participants' accounts, this kind of understanding of independence-as-process was explicitly conceptualized as a journey. As will be evident from this extract, the motivation to take the journey, or the speed at which the journey was made, were not *always* determined by the service user.

Our participants were at different stages of their journeys, and some had different end points in mind: not all wanted to be 'independent' of the people supporting them, but most had an idea of what they would like to be able to do more of, or to be making their own decisions about. In order to unpack this, the data relating to independence were further analyzed through a narrative lens, with a particular focus on identifying recurring tropes and structures. In many of the accounts, one of three narrative types demonstrated the participants' relationship to independence. Each of these three narratives (Stability, Progress; Resistance) tells us something distinctive and important about the role of independence in the lives of people with intellectual disabilities. In the following subsections, we draw upon data from those interviews where this typology was clearest, in order to outline these patterns of meaning.

Stability and protection at home

For eight participants (six men; two women), independence was rarely mentioned, and never as a desired goal, because it was implicitly associated with change, separation, and upheaval. These participants were largely happy with their current circumstances. All of them were living in their family homes, albeit with some varied forms of support from social care services. Their self-narratives described an arc toward the future which was stable ('I think stay the same in the future') and secure ('I'd still live with my family'). These participants described their lives, and their preferences to us, and they did so on the basis that they were broadly content with how things were. These were continuity narratives: in their lives the respondents perceived few drivers toward change, and few threats of change. When these participants did describe aspirations for themselves, they tended to pitch them at a different level from their day-to-day lives. They engaged imaginatively with the invitation to think about what they might like to be different about their lives. They tended to 'think big,' and to speak of hopes and dreams, rather than to think about 'next steps,' and to speak about daily life. Their lives were stable, because they did not actively pursue changes. For example, one participant described how he wanted to work for a football team, and another said, 'I just want to be an actor,' but they did not describe these aspirations as goals which they were working toward, but rather as things which they dreamed about.

Making steady progress toward independence

In this narrative, independence is represented as an end in itself; a natural 'good.' For four respondents (one woman; three men), this independence was a desirable goal, but the process of working toward this goal was slow. They made comparisons between how things were (then), and how things are (now), to demonstrate the upward arc of their journey. The expressed pride in their progress ('I've got

big certificate for that’) as their self-narratives described this upward arc (‘In the future, maybe less support and not needing any support and just being independent and doing things for myself.’) What they wanted from ‘independence’ was to have paid work, and to have control over both the important and the everyday decisions in their lives. Often this also included the opportunity to access *some* support, when needed (‘I can still contact [service] and they’ll still be there to support you so if anytime, you know, you’ll be — you know — finding something difficult.’). These participants shared some worries about increasing their independence, where independence is potentially a move away *from* services, or *from* family. For example, Harinder said ‘I might get lonely’ and later offered a reciprocal relationship for his support workers: ‘I’ll cook them [i.e. support workers, if they visit] a meal; I’ll cook them a curry. Really, I don’t want to be on my own, that’s what I’m trying to say.’ However, these participants generally shared their worries in the context of good relationships with their social care providers, who they described as respecting their views. Thus, the view of independence as a desirable goal in and of itself, tended to prevail (‘It’s a positive move for me’). That is, independence was understood as being about something which is good *for* the person, rather as something which can only be achieved by separating *from* others.

Frustrated, frightened, and pushed

Three participants (two women; one man) offered a narrative in which ‘independence’ was introduced as an external threat. These participants described how they felt lonely, and how they needed company and connection with others (‘I do get really, really bored’). Support services were their primary source of contact with others. They valued this contact greatly, but were not being involved in decisions about when and how the support would continue. Talk of their ‘greater independence’ represented a threat to them, and to that very important social contact; there was a sense that support was being withdrawn without negotiation (‘Every single time I wanted like something doing — it was like ‘We can’t do that for you, we can’t do it for you,’ you know?’). The role of the actor in these narratives was thus unlike that of both the easy-going steady-hand in the Stability narratives, and the striving self-improver in the Progress narratives. Instead, the primary goal of these respondents was to retain their current support in the face of this threat (‘I thought, “It’s not right”’). These narratives positioned the central actor as being ‘pushed’ toward independence (‘I used to have my support on Monday afternoon — this one Monday, the support worker never turned up. I had no call, no — eh- nothing to say that she weren’t coming, so I went two to three months with no support’). These participants appeared to be struggling to meet service providers’ expectations of progress, and to be facing a frightening future without the scaffolding which they needed.

These three story structures provide an insight into the way in which context (and particularly connectedness to others) plays an important role in shaping the meaning of ‘independence’ for people with intellectual disabilities. In our study, it seems that the security of one’s relationships to others (including one’s relationship to service providers) could make independence *irrelevant* (as in the Stability narrative), or *desirable* (as in the Progress narrative). But in situations where one’s connections to others are limited and fragile, independence can seem *threatening* (as in the final narrative).

Interestingly, there were also some participants whose narratives drew on a hybrid of these three types. For example, Simon began his story drawing upon the Progress narrative. He participated in decision-making and chose to move out of his residential home into independent living. However, he subsequently found that transition particularly challenging, and described how he had recently decided to return to his previous residential home. He made this decision because of the lost social contact and support. The return to the residential home went well for him: he felt he had made the right decision (‘I knew I had to make this decision and I did’).

By contrast, Fazia wanted to be able to adopt a Progress narrative, but felt that she was being obstructed in her desire to become more independent. She agreed that she needed some support in making this transition, but was told that this support was not available: ‘Can [*peer*] go out by himself? Yes, yes. But I can’t. And that makes me very angry. I thought I was here to learn um independence, independent traveling, but it doesn’t look like it, does it?’ The cases of the participants who — like Fazia and Simon — shifted across the different narratives, serve to illustrate the crucial role played by ownership of any decision-making. Simon tries out the Progress narrative and does not like it, but he is happy with the outcome, because he *is* able to reverse his decision — indeed, it seems he was leading the decision-making throughout his journey. Conversely, Fazia is very angry about her situation. She feels she has been offered the Progress narrative on false pretences; her decision to pursue it is being obstructed, rather than supported.

When we consider these three narratives, and the additional stories of those who switch between them, we are reminded of self-determination theory (Deci and Ryan 2000). This is a model of psychological wellbeing which suggests that people require a balance of *autonomy*, *competence*, and *connectedness* in their lives. In this sense, independence is a form of autonomy (being able to do what you want, when you want), and in another it is a form of competence (developing new skills). Interestingly, the potential withdrawal of services was consistently seen as a threat to connectedness, and consequently, many of our participants were ambivalent about ‘independence.’ Some were *drawn toward* it, through the attraction of increased autonomy and competence. Others felt *pushed toward* it,

by services (however well intentioned some of these may have been). People in both camps worried about the threats to the social fabric of their lives, and in both cases we can see that the meaning of services (as *supportive*, or as *manipulative*) may be determined by this issue.

Summary and implications

Our study provides an in-depth and direct account of the experiences of social care services for adults with intellectual disabilities from minority ethnic groups. The study provides important insights into the ways that individuals view their cultural identity, relationships, support, and independence. We found that our participants were generally positive about the services which they received, and that they preferred to evaluate these in terms of their continuing good relationship with the specific person providing the support. Our study took place during a period of major financial constriction, with significant consequences for many social care services. This may have set a context in which service users were keen to communicate the message that their services were greatly valued. Many of our incidental findings resonate with those which have been reported in previous, less direct studies (e.g. in terms of social isolation and reliance of services for social contact; restrictions on agency and opportunity, etc.).

We observed that our respondents were often much more sophisticated users of cultural resources and identities than they are given credit for by the conventions of cultural competence training, and we have argued that the concept of ‘cultural affordance’ may be useful for service providers in future. Consideration of the relationship between the opportunities (for doing and being) which are made available to the person, and that person’s cultural resources and capabilities, would provide a more personalized and context-sensitive means of assuring culturally appropriate services, than simply focusing on the care provider’s knowledge of cultural tropes and types.

Our analysis describes three distinctive narratives about independence (Stability; Progress; Resistance), each of which highlights the importance of maintaining connectedness to others, and the crucial role played by ownership of decision-making, in providing good care and support to service users. From our work, we have developed a set of resources which service providers (and researchers) can use with people with intellectual disabilities, in order to facilitate mutual understanding, service planning, and service delivery (see [reference redacted for anonymous review]).

Our toolkit, and our analyses, should inform service provision, by emphasizing the importance of sensitive planning regarding any changes to service provision (including changes to support workers, day services, reductions in support), the importance of mutual understanding and good communication in relation to personal and cultural needs, and the importance of continuity of care and a relational perspective on service development.

Reflections

We are mindful that our interviews provide a counterpoint to the previous literature that has tended to draw more heavily on family members’ accounts. It is important not to overlook the reality of families’ struggles to access services, and their own perspectives on the frustrations of service change. Recommendations made to support people with intellectual disability by providing better support to their families remain very important. In addition, our study sample did not include the experiences of new migrant populations, whose needs and experiences are likely to be distinct. With this notable exception, our sample is relatively large, and does capture a good range of diversity for an in-depth qualitative study.

We have been fortunate to benefit from a relatively large and diverse study team and steering group too, in terms of both ethnicities and nationalities, but also methodological expertise. This has been helpful in managing potential biases. Our research team does have a disciplinary skew toward psychology however, and it may be that readers from other disciplines can see features of our account which they would have explored differently.

Recommendations for practice

- It may be **helpful** for services to consider culture as an *integral part* of their assessment the individual and social needs of each of their service users, and to ask themselves what kind of cultural identities are *afforded* by their work.
- It may be **unhelpful** to consider culture and ethnicity as a set of discrete categories, or to make assumptions about people’s needs based on their *apparent* membership of such categories.
- In particular, services may wish to consider service users’ *preferences* in relation to the pace of change, the maintenance of key relationships and activities, and the meaning of ‘independence.’
- We have produced some simple communication tools, based upon our research, which can be used to broker *conversations* about these issues between service providers and service users. These are available at [website redacted for anonymous review]
- The core aspects of good quality care appear to be recognized across cultures, and they develop from the building of *good relationships*.

Contributors

ML, BSK and JR conceived the study, in response to a focused funding call. GU and ML further developed the design, sampling strategy, data collection materials and ethics application, in consultation with the project steering group, which included experts-by-experience. GU and KM conducted the interviews, with supervisory support from ML, BSK and JR. ML and GU conducted preliminary analysis, and MI developed a template which extended this to the remainder of the sample. These findings were discussed at a large stakeholder reference event run by

GU and ML, and co-facilitated by JR, BSK, KM, MI, and IT. SZ and IT conducted the focused secondary analyses presented here, with supervision from ML and GU. KM also conducted a focused analysis at sub-sample level, supervised by JR and ML, and reported elsewhere. ML wrote this paper, drawing on materials developed by the authorship team.

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