Day service cultures from the perspectives of autistic people with profound learning disabilities

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Abstract

Background: Service culture refers to the practices, views and values within service organisations. Developing positive cultures has been thought imperative to improving social care, though day services and their cultures remain an under-researched area. For many autistic people with profound learning disabilities, day services are the sites at which they orientate their Monday–Friday adult lives and so service cultures are fundamental to the way they experience adulthood. It was thus the purpose of this study to explore day service culture through the perspectives and experiences of this group.

Methods: This study took a phenomenological approach involving extended participatory observations with an autistic person with profound learning disabilities at their day service, as well as broader ethnographic work within this context. Data was analysed through theory-led thematic analysis.

Findings: The study found that autistic people with profound learning disabilities contribute their customs and values to service culture in everyday life and that space, time and place were important in this endeavour. It highlighted how these customs and values could be adopted or challenged by the service, its staff and their established culture.

Conclusion: It is argued that positive service cultures are ones in which day services acknowledge and respond to the views and values of autistic people with profound learning disabilities. A potential framework is discussed to support services with this aim.

Keywords

at-homeness, autism, day services, inclusion, profound learning disabilities, service culture, severe learning disabilities

Accessible summary

Service culture refers to the views, values and practices within support organisations. Good service cultures can result in positive and fulfilling experiences.
experiences for service members. Poor cultures can result in experiences of exclusion or neglect.

- Many autistic people with profound learning disabilities are members of day services throughout adulthood. The cultures that exist have a big impact on them. However, research has not looked at how this group are part of day service cultures.
- I discuss a study that explored day service culture from the perspectives of autistic people with profound learning disabilities. The research involved spending time with a person from this group at their day service, as well as their peers and support staff.
- I found that autistic people with profound learning disabilities contribute their views, values and customs to service culture in everyday life. The way they used spaces was an important factor. The service and its staff sometimes helped and sometimes did not.
- To create positive service cultures, services must find ways to respond to the views and values of their members. I suggest a potential framework that could support this aim.

## 1 | INTRODUCTION

Since the 1980s, 'day centres' have developed in line with learning disability and autism strategies (e.g., Department of Health, 2001, 2010) and their focus on personalisation and community inclusion. This has meant the evolution of ‘day centres’ into ‘day services’: a contemporary model of Monday-to-Friday support provision that uses one or more buildings as a base for a service organisation, but where support, activities and occupations extend out into regional spaces and facilities. Services are diverse, run by organisations that are public and private, local, national and international. They can be focused on the support of a particular community or have an occupational focus such as art or horticulture, and, across a week, may be accessed from an hour up to its entirety. The Health Foundation reported that autistic adults and adults with learning disabilities aged between 18 and 64 are now ‘the largest group receiving local authority support’ in England, with approximately 50,000 receiving support from day service organisations (Idriss et al., 2020).

For many autistic adults with profound learning disabilities, day services represent the sites at which they orientate their Monday-to-Friday, everyday lives. They are the bases from which they, alongside their peers, pursue their interests and aspirations. The cultures that exist within day services are therefore fundamental to the ways in which autistic people with profound learning disabilities experience adulthood, constituting the customs and practices inherent in a shared community. Despite the apparent importance of day services and their cultures, no studies have explored the role that this group plays in the way they develop or function.

## 2 | SERVICE CULTURE

The Care Quality Commission (CQC, 2016) identified the development of positive service cultures as key to meeting the need to improve social care provision in England. Service culture refers to the practices, views and values that exists within service organisations and is shown to have significance as it guides the actions and approaches of support practitioners (Bigby et al., 2012). Cultures develop and exist in day services as a way of responding to, and coping with, day-to-day events and circumstances (Schein, 1985). They are unique to service organisations, reflecting and containing the views and customs that, over the course of time, they have embedded into their ways of working.

Two organisational culture concepts relevant to disability services are the cultural domains of the formal and informal (Felce et al., 2002). The formal concerns processes controlled by management and outside influence, such as government policy, and relates to staffing, training, working practices and organisational policies (Humphreys et al., 2019). Informal culture recognises that staff work with their own individual ‘values, motivations, competencies and interests’ (Felce et al., 2002, p. 390) and that these amalgamate into shared ways of working. Disharmony between the informal and formal means a culture falls into disarray, leading to staff practice that is incongruous with formal requirements of the role.

An example of a disharmonious service culture was evidenced by Charnley et al. (2019), in a service where support workers understood that they were formally required to facilitate individual leisure activities for those they supported through viewing this type of one-to-one work as dangerous; instead, ‘in learning to cope with its problems’ (Schein, 1985, p. 2), the support worker team commonly used group activities.

The principal service culture researcher is Christine Bigby (Bigby et al., 2012, 2014; Humphreys et al., 2019) who, focusing on residential services, conceptualised culture across five domains. For example, in ‘regard for residents’, a poor service culture emphasises difference between staff and those they support, leading to practices of ‘othering’, while in a positive culture, staff value the interests and lives of service members. As the domains are interactive, Bigby argues targeted improvement in one may bring about change in others.
There is evidence that supports Bigby’s view. For example, a meta-analysis of research examining the effectiveness of staff training in learning disability and autism services (van Oorsouw et al., 2009) concluded that interventions that target improvements in systemic factors, such as staff culture, are beneficial in comparison to targeting behaviours in service members, such as in prevalent intervention training (see Pellicano et al., 2014).

3 | SERVICE CULTURE AND AUTISTIC PEOPLE WITH PROFOUND LEARNING DISABILITIES

The cultural domains framework developed by Bigby et al. (2012) provide clarity to what organisational culture is within support services, though its primary focus is the roles of support workers. Organisational culture is ‘socially constructed, the product of groups not individuals, and based on shared experiences’ (Bellot, 2011). Autistic people with profound learning disabilities may thus contribute to service culture through the groups they are part of, helping to determine services’ customs, values and practices.

Evidence of the ways service members contribute to cultures was presented by Black et al. (2018) in an exploration of a day service in America, Holy Family, which supports people with dementia and Down syndrome. Members designated tables for particular groups, contrasting support workers’ views that anyone could sit anywhere and leading to the inclusion or exclusion of new members. Elsewhere, a member assumed a role of caring for a doll that prompted staff to develop new methods of communication. And of particular prominence was a music culture where members frequently sang, danced and applauded each other in shared performances.

Holy Family members constructed culture through their everyday lives, as a group that would adopt and exclude support workers’ views and customs, leading to patterns of activity, thought and behaviour inherent in any organisational culture (Schein, 1985). Here, members had a role in the way culture developed, exerting autonomy and shaping practices according to their views, values and preferences.

Autistic people with profound learning disabilities are often understood as lacking autonomy and sociality (McManus referenced in Veihmas & Curtis, 2017, p. 508), yet they may, as at Holy Family, shape and contribute to service cultures. Recognising such contributions and the cultures they form could provide insight into this group’s values and preferences and demonstrate how they embed these into their related social groups. Moreover, if developing positive service cultures is key to improving social care provision (CQC, 2016), there must be an understanding of what positive service culture is for autistic people with profound learning disabilities and the types of cultures they wish to cultivate.

This paper reports on a study that investigated day service culture through the perspectives, experiences and involvement of autistic people with profound learning disabilities. The study (1) explored the everyday experiences of an autistic person with profound learning disabilities within the context of their day service; and (2), examined the day service’s broader customs and practices, those involving other autistic people with profound learning disabilities, their peers, and support staff.

4 | RECRUITMENT AND ETHICS

This study was granted a favourable ethical opinion by The Coventry and Warwickshire Social Care Research Ethics Committee (18/WM/0322). All participant names are pseudonyms. To comply with the Mental Capacity Act 2005, a capacity assessment for Ben, the study’s primary participant, was conducted using the two-stage framework in the Mental Capacity Code of Practice (DCA, 2008, p. 41), which involved an accessible information and consent form. Ben was considered to lack capacity to consent, and his parents signed consent forms agreeing to his participation and to be his personal consultants.

Data were also collected more broadly at the day service and so accessible information sheets were distributed across the site. To manage consent and assent for members that could also be considered to lack capacity to consent, senior management gave guidance based on previous capacity assessments and discussions with nominated guardians as to whether they would want to be involved in research. Two members were identified as wanting to be left out and were not included in any data collection.

5 | PARTICIPANTS AND SETTING

Ben was 27 years of age. He communicated through vocalisations, direction and body language, and was provided support at home and 2-day services. Ben had a busy schedule, pursuing a particular plan for each day of the week that included hobbies and interests in and out of the day service building. The service is a local charity based in the North of England providing support to autistic adults with different support needs through day service, outreach and home support. The day service building had between 20 and 30 members and staff accessing it each day. Ben and the majority of his peers would be considered to have severe or profound learning disabilities.

6 | METHODOLOGY

This study’s methodology incorporated the framework of lifeworld fractions (Ashworth, 2016) and the approach ‘thinking phenomenologically while doing phenomenology’ (Berndtsson et al., 2007). The latter phenomenological approach involves a cyclical process of fieldwork and analysis in which a researcher learns about ways participants experience a phenomenon so as to subsequently research that phenomenon by adopting methods and theories relevant to their perspectives. Within this approach, the lifeworld fractions framework was used as an analytic tool as its prompts...
researchers to explore experience from eight perspectives termed fractions, a process that helps challenge assumptions and gain a fuller understanding of the experiences of autistic people with profound learning disabilities (Andrews et al., 2019). Although it was an ethical approach through its attention and response to participants’ communication and perspectives, it is a time-consuming process, which limited the number of people that could be included.

In this study (see Table 1), data collected from the first two periods of fieldwork were explored through the fractions in brief analytic stages, suggesting that the fractions of space and time were significant to the experiences of Ben and his peers and broader day service life. These fractions pointed to relevant phenomenological theory, such as that of Seamon (1979) and Heidegger (1962), which led to the introduction of a ‘fieldmaps’ method (see Figures 1 and 2) in the third fieldwork stage.

### 6.1 Analysis

Two data sets were analysed through theory-led thematic analyses (Braun & Clarke, 2006) using analysis software NVivo. The first focused on Ben’s experiences and was coded through the phenomenological

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| **Stage 1 analysis** | **Method** | **Purpose** |
| 3 weeks | Lifeworld fractions (Ashworth, 2016) | To explore Ben’s experiences and how they relate to broader day-service life |
| | | Ben’s experiences and day service life related to lifeworld fractions spatiality, temporality and sociality |

| **Stage 2 fieldwork** | **Time and location** | **Methods** | **Purpose** |
| 3 weeks | Time and location | Close participatory observations of Ben with note-taking (Simmons & Watson, 2014) | To explore and ask questions of Stage 1 analysis |
| Monday–Wednesday 9 AM to 4 PM | Accompanying Ben in the day service and out in local community | Ethnographic ‘hanging-out’ and note-taking of broader day service | To further document Ben’s everyday life and what he communicates about it |
| | | Collection of archive documents (e.g. Ben’s service file) | To learn about and document the broader day service context |

| **Stage 2 analysis** | **Method** | **Purpose** |
| 3 weeks | Lifeworld fractions (Ashworth, 2016) | To further explore Ben’s experiences and how they relate to broader day-service life |
| | | Spatiality and temporality were significant fractions relating to Ben’s experiences and day service life, leading to the theory of Seamon (1979) and a related fieldmaps method |

| **Stage 3 fieldwork** | **Time and location** | **Methods** | **Purpose** |
| 3 weeks | Time and location | Ethnographic fieldmaps—adapted from van Eck and Pijpers (2017) | To document everyday life and its practices at the service, in a way relevant to the experiences of autistic people with profound learning disabilities |
**FIGURE 1** An example of the fieldmap template. [Color figure can be viewed at wileyonlinelibrary.com]

**FIGURE 2** An example of a completed fieldmap.
framework lifeworld fractions (Ashworth, 2016), which focuses on the subjective ways we experience reality. The second focused on the service’s broader cultural customs and used the concept of Place Ballet (Seamon, 1979) as a theoretical framework, which had been identified through the methodological process and which refers to the ways groups of people experience space and place.

7 | THEMES

Insights into Ben’s experiences guided the research approach in a way relevant to his perspective of service life. They also provided an insight into how an autistic person with profound learning disabilities shapes cultural customs and practices and so are presented here, before the broader analysis of day service culture.

7.1 | The day service from Ben’s lifeworld perspective

7.1.1 | The contextual shifting of identity

Ben found himself in interchanging dyadic relationships with support workers, involving them assuming different roles as they came to know one another. Analysis suggested four aspects of Ben’s identity, each detailed below.

7.1.2 | The supported

When support workers initially met Ben, they drew from his service file and conversations with colleagues to form a concept of who he was and how they needed to act and engage with him:

‘(he)... can use his bus pass: prompt him to place it on the scanner by the driver and wait (sic) until it has registered’ (activity plan).

Ben was an expert in these interactions, waiting for support workers to fulfill their predetermined roles. This was exemplified at the gym where Ben would wait for support workers to take his membership card out of his wallet and hand it to the receptionist, despite knowing which card it was and correcting them when they got it wrong. Ben’s position as a ‘service user’ affected his support workers into providing the card, highlighting his experience as a supported person. Ben did not mind this though, as it created a consistent way of engaging with support workers even when they changed.

7.1.3 | The supporter

Ben provided guidance to support workers, observing situations so they proceeded as expected, such as when he waited for his cinema tickets:

...Ben keeps his wallet held open, looking at Emma and waiting for the change. She pays while Ben looks over her shoulder (notes).

When veering off course, Ben used verbalisations or body language to help support workers proceed appropriately. His frequent consideration showed them as people who were an intrinsic part of his everyday life, maintaining their respective roles and providing a stable manner of being with each other.

7.1.4 | The Independent

At times Ben confidently pursued his interests whether or not support workers joined, as in the following observation:

He returns and gathers his jigsaws from his locker as he did the previous week... he begins quickly but methodically completing the jigsaws (notes).

As the independent, Ben represented a juxtaposition for support workers as they were aware of his autonomy yet were bound by their roles to act in a supportive manner. Ben would quell their need to support by showing his competence and offering encouraging, gentle high fives to signify that it was going OK.

7.1.5 | The partner

Ben experienced himself as a partner when his comfort and confidence in a support worker grew. A shared etiquette meant they engaged with Ben in a manner that he found polite and expected, such as in a small but delicate interaction when a support worker writes in his diary each week:

...Emma says to Ben, ‘have we had a good day?’ and Ben nods. He then squeezes his eyes closed for a moment... Emma picks up the book, points to the words and begins quietly reading them aloud to Ben (notes).

In such circumstances, Ben and support workers were able to become more open, interested in one another and what each person had to communicate.

7.1.6 | A visceral world

Ben’s intense sensory perceptions meant he interacted with his surrounding environments, manipulating sound, vision, and bodily sensations. ‘He is feeling the noise’ (notes), a support worker said to me as Ben hummed with his fingers in his ears.
The unpredictable nature of people presented a risk for Ben as direct verbal communication could be overwhelming. Ben was observed trying to stop such occasions happening:

...Jeni asks him vocally if he'd like a drink, Ben 'hmmmmms' in a high pitched sound (what I understand to be a negative vocal) (notes).

Because of this, Ben and his support workers conformed to an etiquette in which direct vocal communication was considered tactless, 'he doesn't like too much chit chat' said one support worker (notes). Rather, Ben enjoyed their presence through a proximity in which he observed, listened, and shared situations:

Ben and Katie are both walking on treadmills—next to each other. They walk slowly, in silence, almost in synchrony (notes).

7.1.7 | Living the future through the past

Ben sought to ensure his days followed a very specific order which he has defined over many years, such as when he checks that the exercise bike he uses each week will be available once he's finished on the treadmill:

Ben turns around to look at the bike which he intends to use next. Shortly after, the treadmill begins to slow and then Ben presses stop and quickly jogs over (notes).

The future is filled with unknown potential and so Ben prepared himself, others, and his environments, so it proceeded as anticipated: as he had lived it before. Quite distinctly, Ben wore particular clothes on particular days and in doing so embodied the temporal structure of the week. When support workers enforced unexpected change, such as when one wrote in his communication book before the end of art, Ben was dramatically confronted, physically distressed in the face, and sought to correct it immediately through high-pitched vocals.

The spaces and activities that filled Ben's days constituted a tool with which he situated himself in the temporal world. Each represented an assurance of the next and so to deny one would bring into question the others. Rooted to these spatial and temporal structures, this is where Ben felt sincere belonging. Sincere in that he did not take it for granted, only once each stage had been met did he accept that the space was there for him and that he could live in it as he wished to, with concern for the people and activity in which he was surrounded.

7.2 | Everyday life at the day service

This second part concerns everyday life at the day service: what characterised its culture, customs and practices. Its focus was one main area of the day service building, termed 'The Hall'.

7.2.1 | Spatial and temporal customs

To help manage space in The Hall, an unwritten space hierarchy existed, with members with personal areas at the top (see Figure 3), transient members below, and support workers at the bottom. Support workers and members acted to enforce this hierarchy, directing one another through prompts and gestures. Personal areas were organised around members' particular schedules, while in contrast, support workers remained transient, having primary use of a small office, though ceding this to members during busy times.
The space hierarchy allowed people in The Hall to go about their day-to-day lives with a sense of spatial order laid down by members.

The space hierarchy gave a sense of what people would do within particular areas, at particular times. Spaces were imbued with customs and etiquette, such as one member who conducted the same interaction with staff each morning:

Alfred takes a support workers hand and leads them through to his seat where he initiates a process of seeking confirmation to sit down through small points, hisses and face gestures (notes).

So, while the service provided a general day-to-day schedule of activity sessions, breaks, lunches, and so on, members created a different sense of routine, filling space and time with their activity, expressions and interactions. At times, support workers attempted to reinforce the service’s schedule, such as attempting to persuade a member to eat lunch at ‘lunch-time’, which, in this case, caused distress.

The hierarchy and its related schedule meant people could proceed freely, with little concern for those around them. Occurrences that may usually seem alarming went unnoticed, embedded into the expectations of everyday life, such as the frequent talk of one member:

‘don’t hit me. Now come on. Calm it down. Don’t swear please. Come on. I’ll thump you if you swear’ (notes)

Tradespeople, family members and external support workers came and went; members sang, talked aloud, and jumped on the spot. Members’ spatial and temporal customs thus enabled them and others to act and live with relative freedom and comfort.

7.2.2 | A sense of risk

Support workers imbued risk into everyday life through discussions and interactions, such as when two talked loudly in The Hall:

‘if you’re with another person (Support worker) it doesn’t matter too much, but if your by yourself you need to know them (risk assessments)... the first week you’re on your own is really scary’ (notes).

Such discussions identified risks in the actions and characters of members. Engagement between members was monitored and mediated, with observations showing support workers defining how members could interact with each other. Where engagement could not easily be managed, such as in overcrowded like the kitchen, members required the correct mood to enter—‘we need to be happy before we go in—is Bob happy?’ (notes); or, outside of The Hall (see Figure 4).

By overemphasising risk, support workers by necessity drew attention to areas in which it was also perceived by members, such as Ben’s worry around changes in schedules. This led to ways of acting and behaving that were congruous with the perspectives of those they supported, while also leading to practices of exclusion.

7.2.3 | A place to learn; a place to teach

Daily life in The Hall was a continual process of learning for support workers, assisted by teaching from colleagues and members. They did it without question, whether colleagues asked for or required information, interweaving teaching with social interaction so to not join in would place a support worker outside of social and professional convention (see Figure 5).

Teaching often involved storytelling, as support workers drew from personal experience to improve knowledge of The Hall’s people,
activity and history. In one instance (notes), a support worker pleasingly told a manager of how a member had chosen and enjoyed an afternoon of bowling to which their mum was ‘totes emosh’ (very emotional). The manager understood that it could offer a valuable lesson and asked, ‘do you want to tell the other staff?’, enabling learning without the need for a structured meeting or official direction.

Knowledge of the Hall, its people and its culture offered invitation to its community. It helped support workers to overcome the frequently discussed staff changes and the risks they felt this posed (notes). And joining the community placed one in the customs of members including animated exchanges about blues music, high fives, ear tickling, and idiosyncratic good morning customs. The benefits of community membership were communicated by staff as improving health and bringing relaxation and happiness (notes).

Due to the idiosyncratic communication of many members, storytelling was vital for sharing understanding of how they had contributed to The Hall’s history. It was a personal practice, informing of members’ personalities, lives, families, and friends. And though at odds with the client-professional dynamic that services are framed through, the practice was omnipresent. Storytelling was thus a valued practice, one which recognised and established members as the foundation of The Hall’s community, maintaining a sense of place and history built on their lives and experiences.

8 | DISCUSSION

The findings of this study draw attention to the significance of space and place in the ways that autistic people with profound learning disabilities contribute to and experience day service culture. Contributions that occurred in everyday contexts and interactions became embedded as cultural customs, such as particular forms of etiquette, though these could be hindered by organisational practices. Hence, in this discussion, it is proposed that positive day service cultures are those where the values and customs of service members are recognised and embedded into the use and management of space.

The concept of ‘at-homeness’ will frame this discussion, which refers to the ways we experience places of personal significance (Seamon, 1979). At-homeness has been conceptualised in the context of residential and palliative care (Öhlén et al., 2014), where it is said to rest upon a person having ‘meaningful relations with significant others, things, places, and activities’ (p. 7). At-homeness explores the experience of place on the individual level and by the ‘totality of participants’ (Seamon, 1979, p. 95), reflecting the relationship between individuals and groups within service cultures (Felce et al., 2002, p. 390). Alongside its focus on space, it is argued therefore that at-homeness is a frame for service culture that can include the perspectives of autistic people with profound learning disabilities and the broader service groups they’re part of. Seamon (pp. 78–85) describes the experience of at-homeness through five underlying characteristics:

- **Rootedness**—The pull of the place—it organises one’s life through regular comings and goings. Things, schedules, and activities have fixed places—they are taken for granted.
- ** Appropriation**—Space is possessed and controlled. It is the opportunity to be private. Friends may be welcome, though unexpected guests less so.
- **Regeneration**—The sense of security that allows for physical and mental rest. After a tough day at work, socialising is turned down for it is the home that regenerates.
- **At-easeness**—‘The freedom to be’ (p. 83), to act and behave as one wants without embarrassment. One can sing out loud, dance, eat chocolate spread from the jar.
- **Warmth**—The atmosphere of home is friendly and supportive. It feels cozy. Certain areas may emphasise warmth—a snug conservatory, or a lively dining room—they are nurtured.

Drawing from each of its characteristics, the findings from this study and others will be discussed to explore how day services may facilitate at-homeness through the promotion or hindrance of cultural practices.

8.1 | Rootedness

The Hall enabled rootedness as it gathered people pursuing divergent activity, creating a consistent space which could be defined by members’ habits, interests and schedules. To contribute to one’s community in a way that is valued by other members, and that shapes the community’s space, is a key aspect of belonging for people with profound learning disabilities (Nind & Strnadova, 2020). To maintain such contributions, support workers in The Hall taught one another through storytelling, a practice that could be seen as a ‘disjuncture
between what staff do, and what is formally asked of them’ (Bigby et al., 2012, p. 452), which traditionally could be considered a poor service culture.

At times, support workers challenge organisational practices in the interests of those they work with, to develop positive relations and improve working conditions (Fisher et al., 2021). Storytelling in The Hall helped to share practices and experiences valued by members and challenged issues faced by support staff, such as high staff turnover, though such stories were not evidenced in official service documents. Rootedness requires time to develop (Seamon, 1979, p. 81), and so it is imperative that members’ contributions and narratives are maintained by day services as they contain customs and values which could otherwise be lost. This though may require greater recognition of practices that organisations do not outwardly endorse but that have positive outcomes for their members and staff.

8.2 | Appropriation

The Hall, like other service spaces (Black et al., 2018), was appropriated by its members through a space hierarchy. These spatial customs are representative of the autonomy and choices of members, key tenets of the personalisation agenda (Morgan, 2010), though they could be challenged by support workers who saw risk in members accessing busy areas. The emphasis on risk in service cultures is well documented (Seale et al., 2013), the standardisation of risk assessments, for example, can lead to generalised and exclusionary practices (Hawkins et al., 2011). The underscoring of risk might be better balanced through greater recognition of the positive ways that members share space with one another, so to help support workers understand and promote appropriation. Nevertheless, risk was most emphasised in confined areas where overcrowding was possible. A lack of space in any area, regardless of whether it is a neighbourhood, a school or so on, will lead to the exclusion of certain members at certain times, it is uncontrollable (Seamon, 1979). As one support worker said of the kitchen while blocking entry—it’s full’ (field notes). The emphasis of risk in service culture may hinder members from appropriating space, which requires addressing through organisational approaches such as staff training. However, equally important in fostering appropriation is the space available to services as both members and support workers must respond accordingly.

8.3 | Regeneration

The ways in which small, unexpected events can confront autistic people with profound learning disabilities, as in Ben’s experiences and many others (Caldwell, 2017, pp. 96–97), means that space and time are relied on to offer moments of repose. Such opportunities for regeneration were challenged in The Hall when support workers imposed the service’s schedule of activity, lunch, and break periods over members preferred schedules. This is what Bigby et al. (2012, p. 458) referred to as a ‘misalignment of power-holder’s values’ though they were referring to support workers not adhering to organisational direction, while here support workers were not adhering to the direction of members. ‘Routines’ are often stressed as significant in relation to autism and profound learning disability, though the individual experience of spatial and temporal coherence may be less understood. Ridout (2017, p. 53) states that ‘a general understanding of what being autistic means has a devastating impact on the well-being of many individuals’, as generalised training means generalised approaches to support; ‘what is parasitical to one autistic person may be harmonious for another’ (Rourke, 2017, p. 142). In Ben’s case, regeneration was experienced within the security of previously lived time and space, providing the physical and psychological rest necessary for personal and social development.

8.4 | At-easeness

The most prevalent intervention training in the United Kingdom is Positive Behaviour Support (PBS), which was the case at the participating service, and which directs support workers’ to negative aspects of member behaviour so to promote more appropriate skills and strategies, though outcomes are varied (Bowring et al., 2020; Hassiotis et al., 2018). Ben’s experiences at the day service demonstrate an interesting role reversal in relation to PBS and interventions in general, in that he developed an understanding of support worker actions and communication so to promote more appropriate behaviour in them.

It could be argued that interventions are incongruous with the fostering of at-easeness as they seek to change or adapt member behaviour, challenging the very essence of at-easeness which is to be yourself and ‘fear no repercussions... be as foolish, negative, or loving as’ you wish (Seamon, 1979, p. 83). Some interventions (see van Oorsouw et al., 2009) however, use self-reflection to improve support worker behaviour, as opposed to member, and show some positive outcomes. Findings from the Hall support this, the day-to-day communication between support workers demonstrating a need to gain and share understandings of how they should act towards members. Members had a great deal to teach support workers though this required their time and consideration and the opportunity for support workers to share what was learnt.

8.5 | Warmth

‘Use is one quality prerequisite for warmth’ (Seamon, 1979, p. 85) and so it develops over time, as people care for the spaces they are part of. As Johnson et al. (2012) reported in relation to a person with profound learning disabilities, it was important for The Hall’s members to nurture and shape its space in ways important to them, such as through social and person customs. Learning-disability spaces, such as day centres, are central to building communities for
people with profound learning disabilities as they are not ‘ignorant of structural and discriminatory practices’ (Murray, 2018, p. 304) found in wider society and provide the time it can take to develop positive relationships (McCormack, 2017). Community inclusion is emphasised within services yet it is important to acknowledge the spaces in which community is most likely to be experienced, that which members experience together (Murray, 2018). Despite the significance placed on support workers in contemporary models of service culture (Bigby & Beadle-Brown, 2016; Humphreys et al., 2019), their formal, professional roles may mean they are less likely to initiate the everyday, personal aspects of life that foster warmth. For members in the Hall, the experience of warmth was possible as they had the opportunity to have and share space with one another, to embed customs and life into it that represented their characters and histories.

9 | CONCLUSION

This study highlighted how autistic people with profound learning disabilities have opinions and thoughts on service provision and demonstrated ways these are communicated, expressed, and actioned in everyday life. Members contributed their preferences, customs and characters and instigated patterns of daily life, demonstrating a distinct benefit of day service spaces. Aspects of organisational culture could challenge cultural practices valued by members, such as in the promotion of risk; while at times, support workers demonstrated unorthodox practices that challenged their organisation’s culture in favour of its members.

To develop positive service cultures, day services must be able to understand and respond to the views and values of autistic people with profound learning disabilities. This study highlighted the importance of space and place in this endeavour, and it was subsequently argued that the concept of at-homeness can help draw attention to the ways this group experience their worlds as individuals, as members of social groups, and as part of day service cultures. In this way, at-homeness has potential in assessing how members experience service cultures and whether their views and values are being promoted or excluded. It could represent a framework to guide services in developing positive service cultures, though greater understanding of how this could work practically and effectively is required. Some key considerations are:

- How members views and values could be effectively documented
- How, and in what areas, services can respond to members’ views and values, for example, through environments or training
- How understandings of members’ experiences might impact staff and their practices
- How services can demonstrate how they respond to members’ views and how this could be assessed
- How organisational issues typically associated with social care, for example, high staff turnovers, might challenge or be challenged by practices associated with at-homeness

To summarise, the characteristics of at-homeness offer a way to understand how service culture interrelates with the experiences of autistic people with profound learning disabilities. It can be used to ask whether the spaces in which they situate their lives are in their hands, conforming to their customs and morals and whether this is hindered or encouraged by support worker and formal culture. At-homeness has ‘...a major role in fostering community’ (Seamon, 1979, p. 71) and so service cultures that are able to cultivate its characteristics may take the first steps to creating spaces in society that are truly inclusive of autistic people with profound learning disabilities.

CONFLICT OF INTEREST STATEMENT

The author declares no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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