

Reasonable Adjustments Across the Learning Disability Annual Health Check Pathway: A Co-designed Qualitative Study

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Abstract

Background

Annual health checks are structured primary care reviews for people on the learning disability register, intended to identify unmet health needs, support preventative care, and reduce health inequalities. Despite this, people with a learning disability continue to experience persistent health inequalities and avoidable mortality. Although reasonable adjustments are a legal requirement to remove barriers to care, their implementation in primary care remains inconsistent.

Method

Qualitative study conducted in the North West of England, co-designed with patient and public involvement partners. Six workshops with 43 people with a learning disability and two interviews with healthcare professionals were conducted. Data were analysed thematically.

Results

Three interrelated themes described how reasonable adjustments were implemented across the annual health check pathway. Personal factors centred on communication and autonomy, including whether individuals were spoken to directly and supported in accessible ways. Professional factors related to workforce capability and confidence in recognising and applying reasonable adjustments. Organisational factors reflected systems that enabled or disrupted access, such as appointment booking and follow-up processes. Together, these factors meant that reasonable adjustments were often applied reactively rather than anticipatorily, reducing their effectiveness. Where adjustments were identified, recorded, and reviewed in advance, annual health checks and preventative care were more effectively delivered.

Conclusion

Reasonable adjustments are not confined to a single point of care but accumulate across the annual health check pathway. Improving access requires a shift from reactive responses to proactive, system-level implementation embedded within primary care.

Background

People with a learning disability experience significant and persistent health inequalities [1], including higher rates of preventable illness, delayed diagnosis and premature death [2–13]. These disparities are linked to systemic factors, including such as diagnostic overshadowing, insufficient accessible communication, and the failure to make reasonable adjustments (RA) to meet individual needs [8–18].

Under the Equality Act 2010 in the United Kingdom (UK), public sector services have a legal duty to provide RA to remove barriers to accessing healthcare [18, 19]. These adjustments should be personalised for each person in line with the Mental Capacity Act 2005, which requires that individuals are supported to make decisions about their care [20]. In practice, this may include longer or flexible appointments, continuity with known healthcare professionals, accessible information (e.g., easy read, large print, symbols or pictorial formats), and proactive communication such as reminders or alternative booking routes [14].

This legal obligation was reinforced with the introduction of the Accessible Information Standard (AIS), in 2016, under the Health and Social Care Act 2012 [21]. The AIS requires the National Health Service (NHS) to identify, record, flag, share, meet and review the person's communication requirements [22].

Figure 1 provides a broad overview of the legislation, key reports, policies, and guidance that have been developed over time regarding RA for people with a learning disability. Please note this is not an exhaustive list; other policies and initiatives may be available.

Annual health checks (AHC) were introduced into general practice (GP) in England in 2008 to address the unmet healthcare needs of people with a learning disability [23, 24]. AHC are associated with the improved management of long-term conditions [25, 26], improved care and reduction of preventable admissions to hospital [27], and the reduction of mortality in people with Down syndrome [28]. Delivering high-quality AHC, requires accessible communication, continuity where possible, and effective follow-up from healthcare practitioners. Despite this, the uptake and quality of AHC remains inconsistent [27].

People with a learning disability are more likely to have co-morbidities [25], lower rates of cancer screening [29–33], poorer management of long-term conditions [17, 26] and overall, have poorer access to preventative healthcare compared to the general population [34]. Incomplete or inaccurate GP learning disability registers can further limit access to AHCs and the necessary RA they may need [35]. The effectiveness of AHC is dependent on whether RA are consistently applied within practice [24, 36]. Without them, AHC may be inaccessible or incomplete, increasing the risk of missed preventative healthcare interventions [14, 27].

In 2013, the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) reported that many people with a learning disability had significant unmet healthcare needs and died, on average, 16 to 20 years earlier than the general population, often from avoidable causes of death, linked to missed screening, and a broader systemic failure to provide RA [9].

CIPOLD recommended a national mortality review process, which led to the establishment of Learning from Lives and Deaths: People with a Learning Disability and Autistic People (LeDeR) [37] aimed at identifying ongoing health inequalities for people with a learning disability in healthcare.

The 2023 LeDeR report shows that, despite policy and service developments, such as the RA Flag [38] and mandatory training (Oliver McGowen Training, legislated in 2022) [39], people with a learning disability still die around 19.5 years earlier than the general population. Forty per cent of reviewed deaths were classed as avoidable (15% preventable, 25% treatable), and approximately 27% of the people with a learning disability who died did not receive the RA they required when accessing care [7].

Taken together, these findings suggest that while the policy framework for addressing inequalities is well established, implementation in practice remains inconsistent. The persistent gap highlights the need to better understand how RA operates in real-world settings.

Methods

Aim

To explore how people with a learning disability and HCP experience RA within AHC, and to identify opportunities to improve practice.

Study Design

In partnership with our Community Advisory Group (CAG), we used an adapted Experience-Based Co-Design (EBCD) approach [40]. EBCD focuses on collaborative improvement by bringing together service users and key stakeholders (e.g. service providers, carers) to explore their experiences, identify key areas for change, and develop potential solutions. We worked in partnership with Pathways Associates, a community interest group committed to improving the lives of people with a learning disability. This group was central to research design and methods as well as analysis of key findings and co-production of accessible recommendations.

CAG members raised concerns about potential power imbalances within mixed stakeholder workshops (bringing together service users and service providers). They viewed in-person workshops as more inclusive but expressed worries about feeling intimidated or misunderstood in a mixed workshop environment. These views informed our approach to conducting separate workshops for service users in familiar community settings.

With the CAG group, we developed a brief accessible presentation to introduce the study at each workshop for people with a learning disability who may have had autism (Additional Presentation 1). Although some participants may have been autistic, autism was not a specific focus of the study. Workshops explored experiences of health checks (including those who did not attend) and whether RA were made. Participants were asked what worked well or not so well, in terms of receiving RA in an AHC, and what could be improved.

The study adopted an interpretive qualitative approach. While the analysis was inductive with themes generated from participants' accounts rather than predefined categories, interpretation was informed by multiple sociological frameworks [41–43] relating to our focus on exploring experiences and practices regarding implementation and access to RA. This provided a lens to examine how influences shape the implementation of RA in primary care and how these interact across the AHC pathway.

Sampling and Recruitment

People with a Learning Disability

We collaborated with voluntary, community, and social enterprise partners, including Pathways Associates and People First who acted as gatekeepers for recruiting people with a learning disability in the North West of England. Purposive sampling was used to capture a range of experiences of AHCs across different community settings. Individuals were eligible to take part if they had a learning disability and/or autism and were over the age of 18. An information sheet and consent form were provided to eligible participants, who were then invited to a workshop; understanding was checked before consent. Participants were compensated at £25.00 per hour for their time in line with PPIE and ethical approval.

Healthcare Professionals

Health and social care professionals (HCP) were identified through existing in the North West of England. Study information was shared via email and provided at several informal meetings. Written or recorded verbal consent was obtained prior to taking part, and participants were compensated at their hourly rate.

Data Collection

Six workshops (five with people with a learning disability, one with HCP) and two interviews with HCP were conducted between August and October 2024 either in familiar community settings or online. Data collection followed the AHC pathway, covering invitation, booking, consultation, follow-up, and experiences of RA. This approach enabled exploration of where adjustments were introduced, missed, or inconsistently applied. Topic guides were used flexibly and refined iteratively.

All workshops were recorded using secure university devices. Data were anonymised at transcription, with identifying information redacted. Recordings were deleted once transcription was completed.

Data Analysis

Data were analysed using inductive reflective thematic analysis [44]. Early discussions of coding and interpretation involved LG, SG and HG. Transcripts were read in full to support familiarisation, after which initial and open coding was undertaken by two researchers (ND and KH), who independently coded the transcripts before discussing and refining the coding framework. Codes were developed inductively to capture both explicit and underlying meanings, and an example of the coding process is provided in Additional Table 1.

NVivo 14 was used to support data organisation, comparison across transcripts and development of coding hierarchies. Visual mapping, including NVivo 14 tools and hand-written creative mind mapping (Additional Image 1), supported the interpretation and exploration of relationships within the data. Themes were developed through grouping related codes and reviewed against the full dataset to ensure they fully reflected patterns across participants rather than isolated accounts.

The wider research team (UC, CS, TM, SG, LG) reviewed themes using reflexive dialogue to explore underlying meanings and interconnections, supporting consensus in theme development.

Themes were subsequently organised into three main domains (Personal, Professional and Organisational), reflecting how RA were accessed, experienced and enacted within primary care in relation to AHC. This structure supported the interpretation of how factors interact across the AHC pathway rather than in isolation.

Researcher Reflection

We recognised the power imbalances when working with people who have a learning disability. Reflexive journalling and team discussions were used to examine how researchers' backgrounds and experiences might influence data interpretation, document analytic decisions, and challenge assumptions throughout the research process. This supported an accurate and meaningful representation of participants' perspectives (Additional Image 2).

Study Participants

A total 43 people with a learning disability and eight HCPs consented to participate in the study. Demographic data were collected from people with a learning disability only, to preserve HCP professional anonymity. Most participants with a learning disability identified as "White" (95%). Ages ranged from 25 to 74 years (median age group 45–49). The workshops included 27 women and 15 men; one participant preferred not to state their gender.

Results

Themes

Three interconnected themes describe how RA were recognised and enacted across the AHC pathway (Fig. 2). These themes reflect personal, professional and organisational influences on access to care, and show that adjustments were in many cases in response to immediate need rather than anticipated and embedded within routine practice. Across invitation, booking, consultation and follow-up, participants described how communication, staff capability and service organisation shaped whether AHCs were accessible and effective.

Personal: Communication as a condition of autonomy

Communication shaped whether people with a learning disability could participate meaningfully in AHC. At the invitation stage, standard letters were often difficult to understand, limiting independent engagement with services and increasing reliance on others.

"I don't understand what the letter actually says... I have to ask them to repeat it over and over again" (W4, P3)

Where accessible formats such as easy read or large print were used, participants described greater confidence in responding to invitations and attending appointments. During AHC, communication also affected whether individuals felt included in decisions about their care. Some participants described HCP speaking to carers rather than directly to them.

"They just talk past you... and you just sit there" (W3, P7)

These accounts suggest that communication was not simply a matter of information exchange, but a condition of autonomy. Being spoken to directly and in an accessible way was experienced as respectful and enabling, while being bypassed was experienced as disempowering.

Continuity of care reinforced this. Familiarity with an HCP reduced the need to repeat information and made it easier for RA to be recognised in advance, rather than negotiated each time.

"If you get someone else, you've got to start all over again" (W3, P3)

Participants' accounts suggest that communication needs were most effectively met when they were identified in advance and carried across stages of the AHC, rather than addressed only during the AHC itself.

Professional: Workforce capability and the use of reasonable adjustments in practice

Workforce knowledge and confidence influenced whether RA were recognised and applied in practice. Some participants felt that healthcare professionals did not understand how to adapt care to their needs.

"They don't know how to help someone like me... they just do the same as with everyone else" (W4, P3)

This was experienced as a lack of tailored care rather than the absence of goodwill. HCP themselves acknowledged limited formal training and described relying heavily on experience.

"Most of it you learn on the job" (HCP2, P2)

Mandatory training was viewed positively, but accounts from both people with a learning disability and HCP suggested that one-off training alone was insufficient. RA were more likely to be anticipated where staff had ongoing support, practical experience, or established relationships with patients. Where this was lacking, RA were more likely to be introduced inconsistently and only at the point of the AHC.

These findings indicate that workforce capability shaped not only how adjustments were delivered, but whether they were recognised as necessary in the first place.

Organisational: Systems that enable or disrupt access

Organisational systems influenced whether RA were consistently available across the AHC pathway. At the booking stage, some participants described flexible arrangements, including quieter appointment times and different contact routes, that made access easier. Others described systems that were unable to accommodate their preferred communication preferences.

"They rang me... I said can you not send it on a message... they said no" (W3, P7)

This suggests that even when needs were identified, systems were not always able to respond. Digital booking processes were also described as difficult to navigate, particularly where access depended on literacy or complex interfaces.

Access was further shaped by how practices identified eligibility for AHC. Some people with a learning disability were unsure whether they were entitled to an AHC, while others described being removed from the learning disability register without explanation.

"They said I was taken off the register... no explanation" (W2, P4)

These administrative processes often determine whether individuals entered the AHC pathway at all. Follow-up was similarly inconsistent. Where appointments were cancelled or missed, systems did not always support re-engagement, increasing the risk of people falling out of care.

Taken together, these findings suggest that access to AHC depended not only on the availability of RA, but on whether organisational systems could identify need, communicate consistently, and maintain contact across the AHC pathway.

Interconnection across the AHC pathway

Although presented separately, the themes were closely interconnected. Difficulties understanding invitation letters, inflexible booking systems, and limited staff confidence often occurred together, creating cumulative barriers across invitation, booking, consultation and follow-up. This helps explain why RA were frequently experienced as reactive rather than anticipatory. Information about the individuals' needs was not consistently recognised, recorded or acted on across different stages of care.

Overall, AHC were most accessible when communication needs were understood, staff were confident in adapting care, and organisational systems were flexible. Where these factors did not align, RA depended on individual effort rather than routine practice.

Discussion

Summary

RA in primary care remain inconsistently implemented. This analysis shows how personal, professional, and organisational factors interact to shape access to RA across the AHC pathway. Personal factors centred on communication as a condition of autonomy, including being spoken to directly, receiving information in accessible formats, and continuity with familiar professionals. Professional factors related to workforce capability, particularly healthcare professionals' confidence and understanding in recognising the need for reasonable adjustments and responding appropriately.

Organisational factors reflected the systems that enabled or disrupted access, including appointment booking processes, inclusion on learning disability registers, and follow-up arrangements.

These factors did not operate independently; in many cases, weaknesses in one area compounded failures in others. For example, communication difficulties were reinforced by inflexible booking systems and limited staff confidence. As a result, barriers accumulated across the care pathway rather than occurring as isolated instances. In many cases, care depended on individual effort, with RA introduced reactively, after problems arose, rather than being identified and recorded in advance.

Embedding reasonable adjustments in primary care requires more than individual goodwill. It depends on systems that identify and record needs in advance, supported by HCP who are equipped to respond accordingly. Integrating national policy and legal duties into routine practice is therefore essential if RA are to become standard rather than the exception.

This study extends existing literature by showing how barriers to healthcare access are produced across the AHC pathway rather than occurring at a single point of care. While previous research has identified challenges relating to communication, service organisation and staff knowledge, our findings show how these factors interact and accumulate across invitation, booking, consultation and follow-up.

Participants valued AHCs as an opportunity to discuss their health and feel listened to, however, this experience was inconsistent. Appointments were sometimes described as rushed or inflexible, and digital booking systems excluded some people entirely. Consistent with previous evidence, accessible communication remained central to supporting autonomy [46], yet gaps persisted in identifying and meeting communication needs despite policy requirements under the AIS [48]. Evidence from Mencap reflects this gap, indicating that only 41% of trainee nurses had received training on the AIS, and just one in four had been trained in RA (56). HCP in this study wanted to provide equitable care but often lacked time, confidence, or clear guidance.

While training initiatives, including the Oliver McGowan mandatory training, provide an important foundation [39] for HCP. Participants' accounts suggest that knowledge and training alone do not ensure consistent implementation of RA. People with a learning disability questioned whether the HCP understood their needs, '*...they haven't got a clue*'. These findings are consistent with previous research that the application of RA depends on ongoing support, experience, and organisational context rather than on training alone. Practical, experiential learning is more likely to improve confidence and sustain behavioural change [14,15,17,45,57]. Without reflective practice, mentorship, and local leadership that values inclusion, training risks becoming another procedural exercise.

Organisational barriers identified inflexible booking systems, inconsistent follow-up and inaccurate learning disability registers, mirroring the wider evidence on structural barriers to care [14, 29, 49, 50]. These barriers often operated together, increasing the likelihood of disengagement before the AHC occurred. Continuity of care emerged as a critical mechanism for addressing these challenges [15, 51], supporting the recognition of individual needs and reducing the burden on individuals to repeat information. This suggests that these barriers operate together to disrupt access across the AHC pathway.

Continuity is, in itself, a form of reasonable adjustment and has been linked to safer care and better management of long-term conditions [15,59]. People with a learning disability value seeing the same person (58), with evidence suggesting that people with a learning disability who have a preferred HCP could lead to greater uptake of AHCs (42). In this study, continuity of care functioned not only as a relational aspect of care but as a practical mechanism for implementing RA across multiple encounters. Building and maintaining continuity requires a relational approach and leadership and structures that prioritise ongoing relationships rather than one-off appointments.

Together, these findings highlight that barriers to RA within AHC are not the result of isolated failures but reflect interconnected system-level processes determining whether reasonable adjustments are recognised, recorded, and sustained in practice. Despite an established policy framework, RA continue to be delivered reactively rather than anticipatorily.

System accountability and future implementation

Recent developments in system-level accountability reflect growing recognition that reasonable adjustments require organisational, not solely individual, responses. As part of the Care Quality Commission's Single Assessment Framework [52], organisations are now assessed on how effectively they identify and meet communication needs in line with the AIS. This marks an important shift from reliance on individual clinician effort towards organisational responsibility for inclusive care.

However, identification remains foundational. Learning disability registers are one of the primary mechanisms through which people are identified, invited to AHC, and flagged for RA in primary care. As demonstrated in this study, inaccuracies or unexplained removal from registers can prevent individuals from accessing the AHC pathway altogether. Without reliable identification, systems designed to support equity cannot function effectively.

This study was conducted prior to the national rollout of the Reasonable Adjustment Digital Flag [53], and therefore reflects a context in which RA were not consistently recorded or shared across services. While the digital flag offers a mechanism to improve continuity and anticipatory care, its effectiveness will depend on how consistently practices use the system and act on recorded information. Recording adjustments alone is insufficient if this information is not embedded into booking systems, consultation workflows, and follow-up processes.

Wider system approaches may further support proactive implementation of reasonable adjustments. Population health management tools [54] and care coordination roles [55] could enable earlier identification of unmet need, support consistent follow-up, and reduce reliance on individuals or carers to

navigate complex systems. As shown in this study, equitable access to AHCs depends not only on policy mandates, but on how effectively systems are designed to anticipate need and coordinate care across the pathway.

Conclusion

The legal duty to provide RA is clear, and the tools to support delivery already exist. However, consistent implementation in primary care remains uncertain. This study demonstrates that barriers to care are not isolated but arise through the interaction of communication, workforce capability and organisational systems, across the AHC. RA must be delivered as a routine part of care, rather than as an exception. Equity will only be achieved when identification of need, accessible communication, and workforce capability are connected within accountable, everyday systems that anticipate and respond to people's needs.

Strengths and limitations

This study's strengths lie in its co-designed approach, ensuring that issues prioritised by people with lived experience shaped the research. Including both people with a learning disability and HCP provided a detailed account of how RA are accessed, experienced, and enacted, offering insight from both service user and provider perspectives. This enabled a nuanced understanding of how barriers arise and are managed across the AHC pathway.

The findings align with national evidence, including LeDeR data, supporting their relevance beyond the immediate study context. However, the study was conducted in the North West of England, and local service structures may have influenced delivery. Participant groups were limited in ethnic diversity, and information on level of learning disability or co-occurring autism was not collected. As a result, the findings may not fully reflect the experiences of people facing intersecting inequalities or those with severe or profound learning disabilities, particularly where communication needs are more complex.

Further research should explore how reasonable adjustments are implemented for underrepresented groups, including people with severe or profound learning disabilities and those from diverse ethnic or cultural backgrounds, where intersecting inequalities may create additional barriers to care [45, 46]. Inclusive methodological approaches beyond verbally mediated methods are also needed to support wider participation [47].

Recommendations

Improving the access to RA requires system level changes that span across primary care settings. Learning disability registers should be maintained and accurately updated where necessary. Being able to identify who needs an AHC in the first instance must be a priority. Practices where possible should support continuity of care and use the use the Royal College of General Practitioners continuity of care toolkit [56]. Future research should assess the effectiveness of the Reasonable Adjustments Digital Flag, while prioritising underrepresented groups such as people with a learning disability from ethnic minority groups or people who have complex communication needs.

During the co-designed workshops, people with a learning disability identified practical ways to improve access to RA and inclusion within healthcare encounters (Fig. 3).

Ultimately, people with a learning disability want to be seen. These recommendations reflect individual experiences but highlight shared priorities across participants, demonstrating that small, proactive changes can make a meaningful difference:

- **Visible:** To be spoken to directly by HCP.
- **Flexible:** To have various accessible ways of accessing healthcare services.
- **Proactive:** Have follow-up systems in place to reach out to people with a learning disability, especially if appointments are cancelled or not attended.
- **Accessible:** Communicate in a way that the person prefers.
- **Familiar:** Ensure the person with a learning disability has good established relationships with HCPs.

Declarations

Ethical Approval

The study will be conducted in full conformance with all relevant legal requirements and the principles of the Declaration of Helsinki, Good Clinical Practice (GCP) and the UK Policy Framework for Health and Social Care Research 2017.

Consent for publication

Written and verbal informed consent was obtained from each participant for the publication of their anonymised, direct quotes and associated data.

Conflict of interest

The authors declare that they have no competing interests

Other

Microsoft Co-Pilot – used for clarity, proofreading, spelling, and grammar

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Author Contribution

ND contributed formal analysis, data interpretation, visualisation, and writing of the original manuscript draft. KH contributed to methodology, data collection, formal analysis, data interpretation, and manuscript review and editing. LG contributed to methodology, co-facilitation of workshops, patient and public involvement and engagement activities, early initial analysis, data interpretation, and manuscript review and editing. TB contributed to conceptualisation, methodology, data interpretation, and manuscript review and editing. SG contributed to early study design, data collection and early data analysis. CS contributed to conceptualisation, methodology, early initial analysis, data interpretation, and manuscript review and editing. UC contributed to conceptualisation, methodology, data collection, and manuscript review and editing. All authors have read and approved the final manuscript.

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Data Availability

The data generated and/or analysed in the current study are not publicly available because the raw qualitative interview transcripts contain highly personal information that cannot be fully anonymised. Providing access to this data would pose a severe risk to participant confidentiality.

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Figures



Figure 1

Timeline of legislation and crucial reports that have impacted reasonable adjustments for people with a learning disability in healthcare

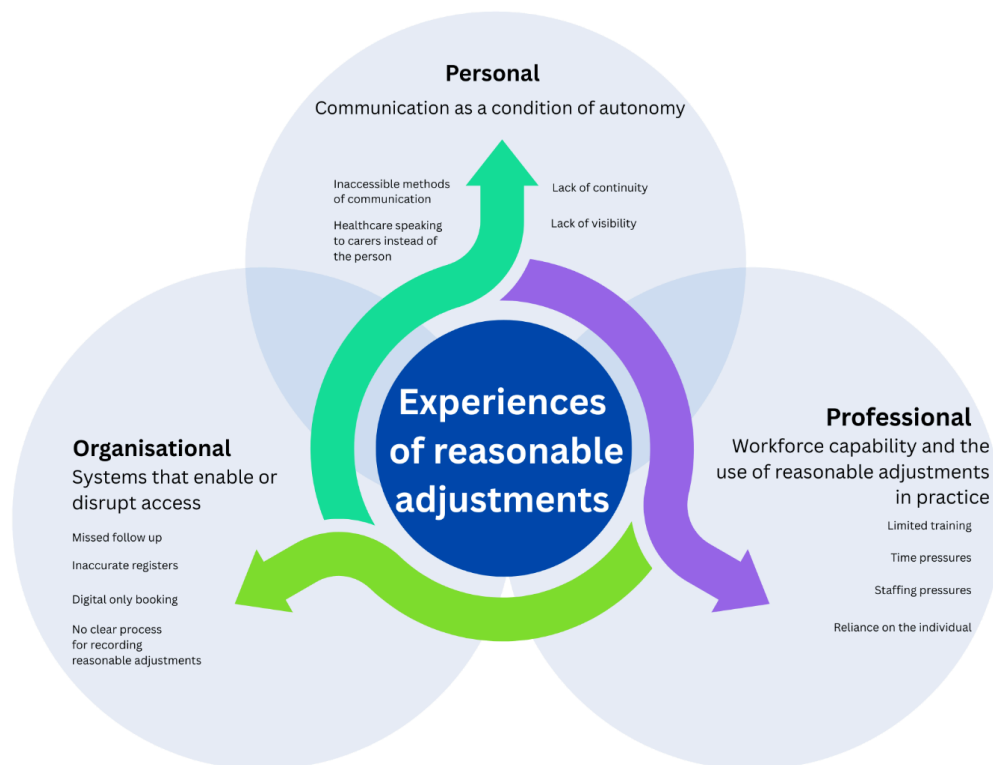


Figure 2

Themes interact to either enable or constrain the implementation of reasonable adjustments.

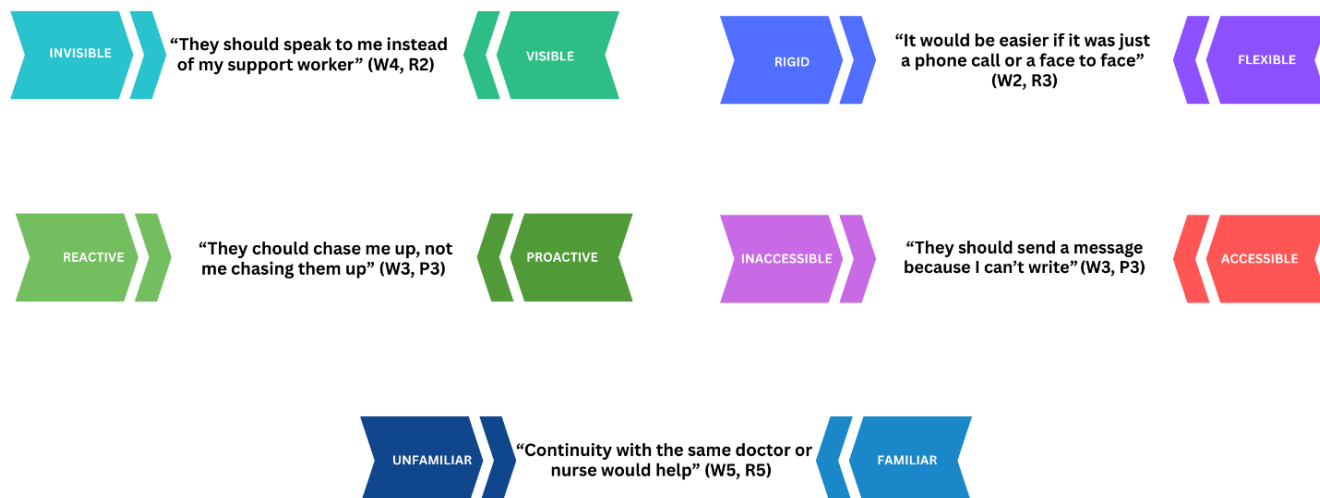


Figure 3

People with a learning disability: Suggestions to improve accessibility to healthcare.

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