Regular Article

International Journal of Qualitative Methods
Volume 22: 1–17
© The Author(s) 2023
DOI: 10.1177/16094069221146992
journals.sagepub.com/home/ijq
SAGE

Transformative Inclusion: Differentiating Qualitative Research Methods to Support Participation for Individuals With Complex Communication or Cognitive Profiles

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Abstract

Recent decades have seen an increase in the use of qualitative research methods within disability research, often seeking to include the voices of individuals with disabilities in research informing policy and service provision. However, such cohorts of participants often present with diverse communication profiles, leading to negative assumptions about their capacity to participate in traditionally common forms of qualitative data collection, such as interviews or focus groups. This effectively marginalises them from participating in research relevant to their lives and social inclusion. The current paper argues that, despite the existence of a range of participatory methods, there remain barriers across methodological approaches to the inclusion of participants with complex profiles within qualitative research. In particular, there is a lacuna within the literature regarding how to specifically differentiate or appropriately adapt qualitative methods to support access. An additional lack of guidance regarding the selection of methods and planning of research is also an issue. Drawing from a transformative perspective, this paper proposes adopting Universal Design for Learning (UDL) principles to guide researchers in in how to differentiate the planning, designing, and conduct of research with participants with disabilities presenting with complex communication profiles. While UDL is not being proposed as an alternative to existing research methodologies, its principles provide a framework for researchers to select from existing methods or approaches in a flexible manner depending on the profile of participants they will be working with. A range of existing approaches and methods are discussed with examples that illustrate how they have been used to support participation and inclusion within qualitative research studies.

Keywords

inclusion, transformative, universal design for learning, qualitative methods, disability, elicitation

Introduction

In recent decades, there has been a greater emphasis in research on including the perspectives and lived experiences of individuals with intellectual disabilities and supporting the participation of a range of stakeholders. This has, understandably, led to a noted increase in the use of qualitative methods within disability research (Elliot et al., 1999). Most recently, there has also been a significant evolution in research involving individuals with disabilities presenting with complex communication and cognitive profiles (CCCP) as participants within qualitative research (Beail & Williams, 2014). Such cohorts are diverse and include, for example, individuals

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Correction (March 2023): This article has been updated with minor grammatical correction since its original publication.

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with moderate or severe intellectual disabilities, Autistic individuals, people with neurological conditions or acquired traumatic brain injuries (Shiels et al., 2021), and those with neurodevelopmental differences which lead to significant communication differences. This is both an important and positive development as research making space to hear the lived experiences of these participant cohorts is in line with movements towards a more inclusive pluralist perspective in conducting qualitative research (Smith et al., 2021).

Given that qualitative research is generally concerned with the individual, their views and perspectives, and traditionally data focuses on the analysis of a text corpus, it is important to recognise the central role of language competency and/or discourse preferences of participant cohorts (Beail & Williams, 2014). Individuals with CCCPs often present with significantly different communication and cognitive profiles relative to the general population, thus emphasising the need for differentiation or adaptation of qualitative research methods to support access and inclusion (Beail & Williams, 2014; Goodall, 2018). Perhaps, unsurprisingly, this cohort of participants have been historically under-represented within the qualitative research literature (Beail & Williams, 2014; Fayette & Bond, 2018; Vaughan et al., 2020). Indeed, the literature regarding how qualitative methods can be adapted or differentiated also remains sparse within disability-focused research, (Beail & Williams, 2014) as is discussion regarding approaches to the differentiation within existing research methodologies to support access and participation to individuals with CCCPs. Similar gaps are also observable with literature on participatory and co-research methodologies (Nind et al., 2016; Vaughan et al., 2020). As a result, while such inclusive and transformative research methodologies have become more common within disability, community development and health research, they remain underutilised within research with participant cohorts with CCCPs (Vaughan et al., 2020).

The current paper proposes adopting an approach informed by Universal Design for Learning principles (CAST, 2018) to provide guidance to researchers regarding differentiation in planning, designing, and conducting research with CCCP participant cohorts. The paper also presents an overview of the available literature regarding such approaches and specific exemplars where they are operationalised within studies involving cohorts of participants with CCCPs. While acknowledging that there is an existing literature focused on participatory and non-language based qualitative methods, this paper does not suggest UDL as an alternative to existing methodologies, but as a framework to support researchers in planning, designing, and conducting disability research with participant cohorts with CCCPs.

This paper is presented in three main sections: *firstly*, an outline of the theoretical framework and rationale for the use of adapted methods to support fully inclusive engagement for all participants in qualitative research; s*econdly*, a detailed discussion of existing appropriate approaches to planning research with CCCP cohorts emphasising the importance of flexible practices on the part of researchers to ensure accessibility (Smith et al., 2021); *and thirdly,* an exploration of adapted data collection approaches, inclusive of a range of elicitation methods to support participant access and engagement in all aspects of data collection.

Theoretical Framework

Given the role that research plays in the shaping of policy, development of theory, and design of services, the focus of this paper is on supporting flexible practices among qualitative researchers to facilitate access and participation for those with disabilities. Practicing fully inclusive research which engages marginalized individuals with CCCP can be examined through the lens of a transformative paradigm (Mertens, 2007). This theoretical lens recognises that social justice should be incorporated into the parameters and design of research as a means of valuing the voice of people who may be discriminated against or marginalised, on the basis of race, ethnicity, religion, gender, sexual orientation, socioeconomic status, age, and disability (Mertens, 2007). An approach to disability research which is informed by the transformative paradigm views the primary aim of such research is to facilitate change by promoting equality and societal accessibility, empowerment of individuals/communities with disabilities, and an aim to bring about positive, real-world service outcomes for these individuals. This approach can be understood as a form of ‘engaged’ inquiry within research (Chevalier & Buckles, 2019). From this perspective, the criteria for evaluating studies are framed in terms of the difference a specific study makes in relation to service provision or to social needs/objectives identified as being meaningful to individuals with CCPs and their communities (Smith et al., 2021).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD: United Nations, 2006) Article 2 states that “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (p.4). However, the concerning reality is that, until relatively recently, the voices of people with CCCP and/or disabilities has been sparse within the qualitative research literature, with little consequent impact on policy development (Beail & Williams, 2014; Fayette & Bond, 2018). In a review of approaches to utilising qualitative research methods in disability-focused research, Beail and Williams (2014, 93) found that, while the number of studies reporting data from people with CCCP had increased from historically very low levels, the only adaptation to standard qualitative methods was “that the interviews with people who have intellectual disability were shorter”.

It should be noted that there is an existing broad literature of flexible and participatory research methodologies that have been used within a wide range of diverse participant cohorts (Minkler and Wallerstein, 2011; O'Toole et al., 2003; Paterson & Peacock, 1995; Grant & Humphries, 2006). These participatory and co-production approaches and methods have many advantages and align closely with the transformative research paradigm. For example, there has been an increase in widely recognized branded research methodologies in community and public health where Community-Based Participatory Research (CBPR: O'Toole et al., 2003; Minkler and Wallerstein, 2011) cooperative inquiry (Paterson & Peacock, 1995), and appreciative inquiry (Grant & Humphries, 2006) have become more common. A key principle underpinning the numerous methodologies falling under the umbrella of Participatory Research is an emphasis on direct engagement with the priorities or perspectives of participant cohorts (Cornwall & Jewkes, 1995; Vaughn & Jacquez, 2020). All such research methodologies and frameworks provide systematic approaches for engaging collaboratively with participant cohorts who are directly affected by the study topic for the purpose of action or change (Cargo & Mercer, 2008). Participatory research within a transformative paradigm allows for differing degrees of involvement or participation on the part of participants and stakeholders (Mertens, 2007).

This conceptualisation for supporting a spectrum of participation has influenced the development of a range of research focused models, from a low level of participation within a consultation role, to a co-production role encompassing participation at all levels of the research process. Hill et al. (2016) refer to six degrees of participation, adapted from Cornwall (2008) and Truman and Raine (2001):

- co-option (research subjects are represented but not actively involved in the research);
- compliance, participants engage in activities but the researchers dictate the research design and procedures);
- consultation (research subjects contribute viewpoints but researchers determine analysis and interpretation);
- co-operation (research cohort work with researchers to consider priorities for the study but researchers control the process);
- co-learning (participants and researchers share knowledge to evolve new thinking and share in the research process); and
- coproduction/collective action (members of the community who are the focus of the research devise and conduct the research independently).

Supporting participant agency and autonomy in choosing the degree of participation, input, and commitment to the process of research also aligns with the UNCRPD (United Nations, 2006) rights-based perspective. Appropriate methodological flexibility or methods are made available to support engagement with the research process (Beail & Williams, 2014). Research design and procedure must, therefore, consider how the perspectives, values, accounts and viewpoints of all can be given equal access or weight. This may be particularly important in the context of research involving participants with CCCPs whose voices have been previously silenced (Blunden & Calder, 2020). Studies which explore the lived experiences of people with CCCP may include experts by experience in the administration, planning and design of the research either as co-producers or advisors.

A key gap in the existing literature related to the use of participatory and engaged research methodologies is that they remain comparatively under-represented within disability research (Nind et al., 2016; Beail and Williams., 2014), and particularly with cohorts with CCCPs (Nind et al., 2016; Vaughan et al., 2020). For example, while there are exemplars of participatory methodologies being used within some studies (e.g., Wilbur et al., 2019), these studies utilise smaller participant cohorts and are less common in the literature. There is, additionally, a relative paucity of evidence examining the intersection of common participatory research methods, such as CBPR approaches, and disability (Vaughan et al., 2020), and less literature exploring how such methods should be differentiated to make them appropriate to the needs of participants with complex CCCPs (Kuper et al., 2021). There are many potential reasons for this absence, with some researchers suggesting engaging in co-produced research as a process can lead to challenges (Stark et al., 2021) or be a 'turbulent' and 'challenging' experience for participants (Worsley et al., 2021). In addition, even in well-funded research with diverse cohorts of participants with disabilities using well established CBPR participatory methods, researchers noted the significantly more planning time and additional resources in budgets and timelines for research was required (Vaughan et al., 2020). Another potential issue, for example, relates to the complex interpersonal dynamics that may emerge within diverse research partnerships involving stakeholders with different backgrounds, experiences, or communication profiles/expectations. In their study investigating the experiences of children and young people in residential special schools, Davis (2009), cited in Hill et al., (2016, 30) advised using a methodology of consultation, co-operation and co-learning whilst also acknowledging the pragmatics of "what is possible within time, ethical and budgetary constraints". While all of these considerations fully align with existing participatory research frameworks, there remains a lack of specific guidance regarding how these processes are to be negotiated by researchers working with participant cohorts with CCCPs. Such considerations are vital if these approaches are aiming to foster engagement and empowerment on the part of such participating within research.

While the extant literature on the use of participatory research methods with diverse populations emphasises the use of "choice points" (Vaughn & Jacquez, 2020: See Figure 1 below) to support collaborative selections of particular approaches at each step of the research process, such analysis does not focus on the specifics of such differentiations

(Vaughan et al., 2020). While this is entirely understandable given the potential diversity within participant cohorts, and there is no “right” way of conducting participatory research (Vaughn & Jacquez, 2020), the specific approaches to engaging with participants are foundational in supporting access for cohorts such as those with CCCPs (Stark et al., 2021). In other words, the barriers observable within qualitative research more generally may also be acting as barriers to the participation of individuals with CCCP within participatory and engaged research also.

From a transformative perspective, people with disabilities have been disengaged from research and policy narratives that directly informed the development of service policy and theory. This has given rise to concerns regarding the potential for epistemic injustice (Chapman & Carel, 2022; Fricker, 2007) in the production of knowledge or development of theory within disability research. Epistemic injustice describes the process within research enquiry whereby one source of evidence or data is privileged over other valid sources (Smith et al., 2021), and has been observed to be highly prevalent in mental health or disability service settings (Crichton et al., 2017). Fricker (2007) identified two forms of epistemic injustice common within qualitative research; firstly, *testimonial injustice*, where a participants account is delegitimised due to who they are (e.g., an individual with intellectual disability). Secondly, *hermeneutical injustice* whereby a participants account is discounted due to a lack expertise or understanding at an institutional or organisational level (e.g., a lack of knowledge of appropriate adaptations to qualitative methodology). To truly hear the voices of people with CCCP, who have been marginalised within disability research and policy, we need focused support for appropriate access within qualitative research. Greater consideration of differentiated methods is warranted given that research with individuals with CCCP would need to be adapted such that functional differences in communication ability do not constitute a barrier.

This article aims to provide guidance to researchers in flexibly and appropriately select methodologies to support the recruitment and participation of individuals with CCCPs in their research. While it is not a research methodology, nor intended as an alternative to existing research methodologies, the principles of Universal Design for Learning (UDL: CAST, 2018) would provide a framework for researchers to adopt a flexible and appropriate stance in the design of qualitative research. In such an approach, the focus is on the researcher to engage with participants or relevant gatekeepers to select from among a range of existing methods depending on the profile of the particular participant cohorts involved. Such an approach

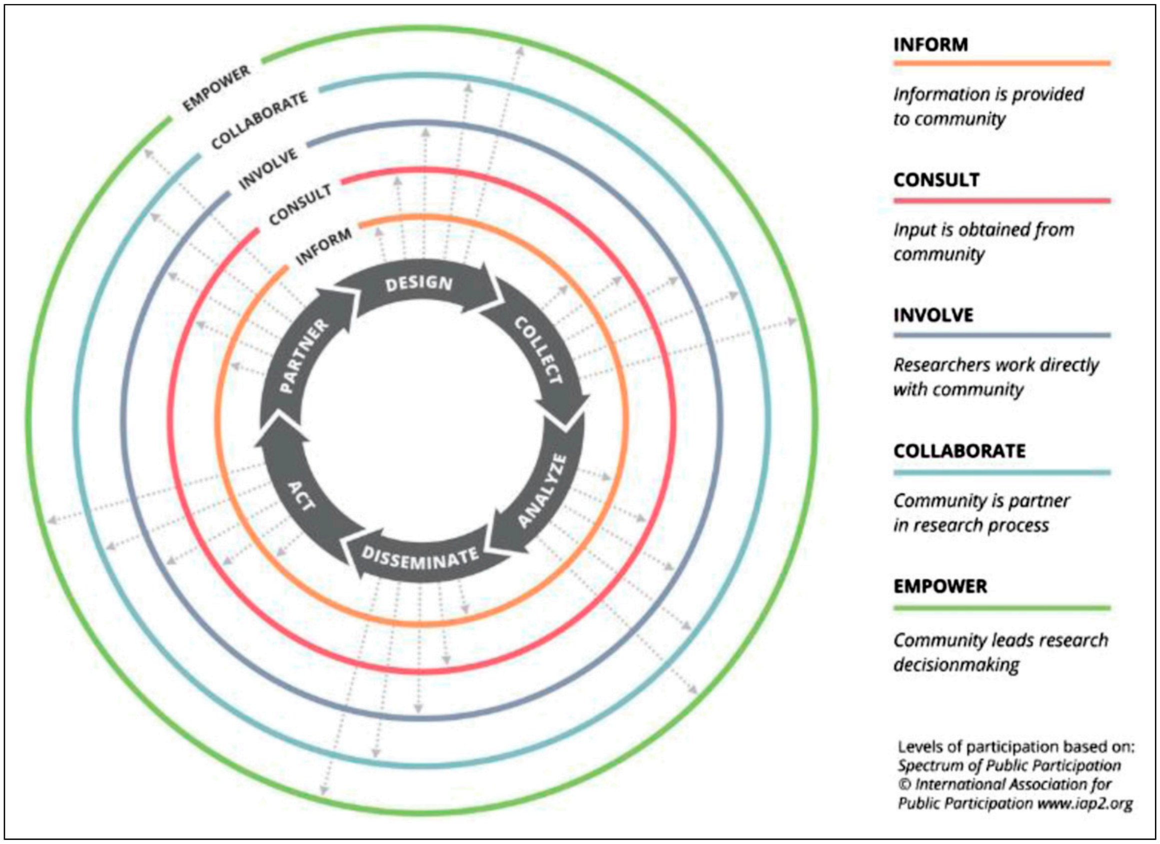


Figure 1. Participant Choice Points at each stage of the research process. International Association of Public Participation IAP2 (2018).

would also afford options to individuals with CCCP to participate to the degree and in the form of their choosing.

Universal Design for Learning (UDL) guidelines (CAST, 2018) were initially designed to support improved accessibility within curriculum design and delivery in the sphere of education and to reflect the reality that diversity of preference, ability or support needs was common among learners in many settings. UDL is not a methodology but, rather, a useful framework that views the fundamental needs of individuals with disabilities as being the same as those of students without disabilities (Lambert, 2021). From a UDL perspective, change in education is essential to support access and participation because "the future is in the margins" (Meyer & Rose, 2005), or participation will facilitate future innovation and development in society into the future (Lambert, 2021). UDL is organised according to a set of principles, in written and spoken communication, which aim to encourage transparent, inclusive, and community-driven learning and to ensure access to all within learning cohort through flexible and individual design.

In summary, UDL advocates for multiple means of engagement to stimulate motivation and learning, multiple means of representation by presenting information in different ways, and multiple means of action and expression by offering differentiated ways of expressing knowledge and understanding to ensure accessibility. This paper will argue that such an approach can (and should) equally be applied to the research process of qualitative research with participants with CCCP. In adopting a UDL informed approach, access and flexibility can be frontloaded into the design process based on informed understanding of participant's profiles or preferences. Such an approach is vital given the diversity of profiles or presentations among cohorts of individuals with CCCP, and to fostering an inclusive and flexible medium for engaging these participants within research. This perspective, however, contrasts with the lack of specific detail or guidance regarding technical knowledge on how to effectively plan or differentiated traditional qualitative methods to support access for participants with CCCP (Beail & Williams, 2014; Fayette & Bond, 2018). This has led to some researchers questioning whether a privileging of "methodolatry"(Frost, 2011) which emphasises adherence to standardised qualitative methods (and research validity) may be functioning as a form of hermeneutic injustice in research (Fricker, 2007).

The following sections discuss methodological approaches to appropriately differentiate the process of planning, designing and conducting qualitative research involving individuals with CCCP. It considers how approaches that facilitate multiple means of engagement, multiple means of representation of information, and multiple means of action and expression of knowledge and understanding can support accessibility (CAST, 2018) within qualitative research methods for individuals with CCCP. These approaches may be used across the spectrum of participation (Cornwall, 2008; Truman & Raine, 2001) where engagement can be considered to reflect transformative participation (Mertens, 2007).

Planning Research with Complex Cohorts

Undertaking transformative and co-operative research with participants who have CCCP requires focused deliberation on appropriate design and differentiation of approach, procedures, methods, and materials employed in research. As a priority, the pragmatics of conducting the study must be fully considered and discussed with all stakeholders in order to assess the feasibility of initiating and completing the study, and delivering the anticipated outcomes (Quinn, 2015). This discussion should focus on designing recruitment procedures appropriate for diverse participant profiles, design of accessible instruments or approaches, and discussions of flexible data collection planning.

In the design of studies where participants choose to engage in the research process without taking an active role in co-producing the study, or where such an approach is not feasible for other logistical reasons, it is essential to establish an inclusive methodology by:

i) understanding the profile and needs of the participant cohort,
ii) adhering to ethical considerations when working with Individuals with CCCPs,
iii) creating clear and understandable materials which communicate the purpose of the research and what participants will be asked to do, and
iv) utilizing a range of materials that provide every participant with an opportunity to express their opinions.

Acknowledging Individual Participant Profiles

Prior knowledge of participant profiles is essential for appropriate and individualised planning across many of the practical aspects of conducting qualitative research involving diverse groups of participants with CCCP. Researchers often enter settings with limited information about individual participants (Parsons et al., 2016). Therefore, a multi-phase process of information gathering may be needed which can be complex and requires intensive planning, although there is a dearth of literature that examines how best to approach these processes with vulnerable cohorts. Such a multiphase approach supports researchers to adopt a flexible approach to research design informed by the principles of UDL for both written and spoken communication to ensure accessibility (CAST, 2018). Access and flexibility are key considerations within the research design and planning process from the outset. Such considerations are fundamentally based on informed understanding of participant's profiles or preferences.

Planning should consider appropriate differentiation based on individual profiles offering multiple means of engagement, multiple means of representation, and multiple means of action or expression. This differentiation relies upon specific knowledge of participants' strengths, preferences, and potential areas for support. Where possible, therefore, it is important to engage with gatekeepers, support stakeholders, and the participants themselves, at an early stage in the planning process to gather information about cognitive, sensory, and communication preferences or profiles. This detailed information can then be used to inform the planning of the research, design of the procedures, selection of measures, and researcher protocols or communication approaches. Firstly, background information on each participant's personal journey across the lifespan allows researchers to position the person in relation to the purpose of the research study. Awareness of individual cognitive profiles (e.g., processing speed, working memory, verbal and non-verbal comprehension) will also inform the way in which information is presented and received. Specifically, in terms of how much time is required for the individual to process questions or instructions, how much time is required to formulate a response, whether and what kind of prompts may be required (auditory and/or visual, human and/or material).

Secondly, understanding the sensory profile of each participant will ensure that their comfort needs are met. This might include, for example, arranging the physical space to allow unimpeded movement, reducing ambient auditory and visual stimuli that may be distracting or stressful, and paying attention to the researcher's personal presentation, for example moderating the tone, clarity, and volume of speaking. Thirdly, familiarity with the communication profile and preferences of each participant frames the method and materials used to gather data, which also requires knowledge and understanding of the fundamentals of accessible information and technologies. These speak directly to the creation of literature for recruitment and engagement in the study which necessarily needs to be transparent and comprehensible, to establish a motivation to participate, and to reassure participants that multiple means of communication are welcomed.

Adopting Inclusive Research Methods

Identifying an appropriate methodology requires the research team to consider multiple techniques to encourage and support participants in sharing information. Discussing co-production with autistic co-researchers, Stark et al. (2021) suggest ground rules to establish full participation and mutual understanding. These can be extrapolated to working with individuals or groups with CCCP who are adopting a range of participatory roles in a research study, but who are not engaged in co-production:

- Valuing the viewpoints of all participants engaged in the research study reflected in verbal and written communication exchanges that are respectful and considerate in tone and content.
- Meeting in fully accessible environments which facilitate the use of individualised supports e.g., sensory aids, personal assistants, assistance animals, assistive technologies.
- Acknowledging preferences for remote meetings and ensuring that digital platforms are suitable for the parameters of the research and meet the needs of the participant e.g., ease of use, clarity, connectivity, anonymity, and opportunities for verbal and written engagement.
- Formulating a "traffic light system" for all participants which sets out preferences and needs for in-person and remote interaction including alternative communication methods e.g., augmented, interpreter, audio, visual, verbal and written.
- Reassuring participants that they are not obliged to respond to a direct question and that their engagement in the research is voluntary and valued.
- Facilitating breaks from the research process if participants are anxious or overwhelmed, or where there is a need for additional processing time to respond to questions.
- Pre-identifying through discussion any potential for distress in the research process or content and note where these may represent a trigger warning.

Underpinning these ground rules is the need to fully understand and plan for the unique needs of every participant, which may require individualised approaches and materials to elicit responses to the research questions.

Hill et al. (2016) note that individuals with CCCP may require flexible methods of eliciting opinions (Nind et al., 2013) which could include the presence of known adults as facilitators (Bellamy et al., 2010). Specifically, Hill et al. (2016) used a range of research techniques to elicit children's viewpoints, including a *graffiti wall* accessed with visual supports and prompts with support from key workers, writing, drawing and symbol communication. *Diamond ranking* of statements accompanied by pictorial symbols to support understanding, but also suggested that *photographic images* representing concepts as opposed to text statements could be used. Hence their study also utilised a sorting activity with preference cards illustrated with Picture Exchange Communication System (PECs) symbols and highlighted the need for these to be specifically and clearly related to each of the research themes to avoid ambiguity or "over-interpretation" (Hill et al., 2016, 35). A more detailed discussion of such flexible elicitation approaches is presented in *Designing effective elicitation techniques* in this article. Evidently, careful thought needs to be given to how research questions are to be shared with participants, and how they are facilitated to respond.

Communicating Clearly With Participants

To establish an inclusive methodology in line with a UDL framework, clear and understandable materials are required which communicate the purpose of the research appropriately. Accessibility considerations within the design and selection of written communication relevant to participant cohorts with CCCP are, obviously, a vitally important consideration (Sharpe et al., 2021). These factors are important for two reasons: i) they may affect a participant's ability to comprehend information that is relevant to their decision making and consent, and ii) effective and appropriate written communication can enhance recruitment and data collection (Nind, 2008).

Informed consent is central to any ethics protocol. However, there is a distinct need for greater transparency and repositioning of how consent is sought from people with CCCP, and this is particularly relevant for children and young people with additional needs (Fayette & Bond, 2018). Before informed consent can be obtained, researchers must ensure that participants are fully informed about all aspects of their involvement in the research. Inclusive recruitment practices use visual information to support written language and effectively communicate information about a research study (Thomson, 2009). While text-based materials are habitually used to disseminate research information, this should also be accessible and relevant to participants using visual methods including symbols, pictures, simplified language, profile-appropriate/differentiated plain language statements and the use of digital technology (Johnson et al., 2017).

A recent example of effective differentiation of participant information in research can be found in Sharpe et al. (2021). In this study, novel approaches to engage young people with SEND are outlined with accessibility being a central concern as the participants, or 'co-researchers', had a range of complex profiles, physical and sensory needs. Initially the authors took inspiration from visual timetables and image-based emotion cards used by the students to convey their thoughts/feelings. However, researchers were aware that the use of over-simplified imagery to convey more intricate information relating to ethical aspects of the research including confidentiality, may be misleading (Parsons et al., 2016). Instead, they opted to create images using a digital drawing-based technology to include in the participant information pack, which were specifically illustrative of the research being conducted. Additionally, they created a vlog style video that recapped key information contained in the participant pack (Sharpe et al., 2021), an approach reflective of the UDL principle of providing multiple means of representation, providing information and content in a variety of ways in order to support understanding (CAST, 2018). The following sections discuss methodological approaches to appropriately differentiate the data collection process for qualitative research involving individuals with CCCP.

Implementing Differentiated Qualitative Data Collection Approaches

Prior knowledge of participant profiles is not only important to consider when sharing information about the research study but is equally important in the design of data collection tools, adapting or differentiating approaches to enable accessibility for individual participants. This is important to support multiple means of participant engagement and expression (CAST, 2018)

Key gatekeepers such as support staff or facilitators provide an important role in planning for inclusive research. Researchers should liaise with gatekeepers in order to ensure that venues, communication, information and transport are appropriate and accessible (National Disability Authority, 2002). Additionally, for participants with CCCP, it may be beneficial to include a third party with whom the participant is familiar to act as an 'interpreter' during the interview or focus group (National Disability Authority, 2002). It is important to highlight however, that the inclusion of a third party may affect how a participant responds to interview questions (see *Analysing Differentiated Data Sets* for more detailed discussion regarding impacts on data analysis process).

Visual representation throughout the data collection process is essential to support engagement and empower participants to express their opinions. Interview schedules that use dense or complex language may be simplified and reinforced using social stories, photographs and pictures. Using symbols or cue cards such as 'stop', 'break' and 'pass' can help to alleviate frustration and guesswork by providing a visual means for participants to end the interview, take a break or skip a question (Goodall, 2020).

Adapting verbal language and communication style is essential where processing speed, working memory, verbal and non-verbal comprehension may be compromised, and will inform the way in which information is presented during the data collection process. In their book Is That Clear? Effective Communication in a Neurodiverse World, Gaynor et al. (2020) outline some considered approaches to using accessible language. These include techniques such as:

- Slowing down the language of requests and instructions: Multiple cognitive steps are involved in understanding and responding to questions including information retrieval, manipulation, and expression.
- Avoiding the insertion of unnecessary 'filler' words that have no meaning or purpose such as 'I suppose', 'what I mean is', 'you might say'. This includes avoiding the temptation to fill silent pauses when the participant is considering their response.
- Speaking clearly and enunciating words to facilitate understanding; running words together as is habitually the case in normal conversation may impede understanding, for example 'plisoffiser' for 'police officer'.
- Breaking down lengthy instructions into smaller segments or steps adds clarity.
- Avoiding ambiguous words and sentences or any implied or hidden meaning.
- Use short, direct questions, and reframing these if necessary.
- Using the person's name at the beginning or end of the question or instruction.

Collecting Data Using Assistive Technologies

The UNCRPD identifies the need to ensure accessibility of Information and Communication Technology (Article 4), and that all information and communication is provided in accessible formats (Article 30). The use of technology also affords access to a range of avenues for UDL informed differentiation in terms of engagement, representation, and engagement within research (CAST, 2018). Therefore, research materials (recruitment, measures, tasks) need to consider far more than use of plain language, they may also need to be multi-modal (print, audio, symbolic, tactile) depending on the needs of the research cohort, and thus personal profiles are essential. Important considerations here include whether the person utilises Augmented and Alternative Communication (AAC) devices to access and respond to research activities. ICT Accessibility is the key to inclusive communication (Accessible Europe: ICT 4 ALL, 2019) and Higher Education institutions universally are major drivers (AHEAD, 2022), meaning that these principles should feed into institutional research. Printed and digital information should consider colours and fonts but must also be readable by assistive technologies, thus documents need to be properly structured. Audio materials should utilise natural human voices, and universal pictures or symbols used to substitute or supplement text.

Inclusive data collection methods that accommodate the needs of AAC users include providing interview questions in advance to allow time for reflection and composition, posing fewer questions, and acknowledging the need for extended wait time for response (Ashby & CaustonTheoharis, 2009). Facilitating communication preferences (Paterson & Carpenter, 2015) requires familiarity with the mechanics of AAC; hardware devices use software based on alphabet boards or picture/symbol grids that allow users to combine these to form phrases or sentences. These use a combination of three approaches: i) single-meaning pictures (one picture, one word) that do not require literacy skills although pictures/symbols may need to be pre-taught, ii) alphabet-based systems (spelling and letter codes) that require a level of literacy, iii) and semantic compaction (multi-meaning icons) using 1-2 symbols per word for which pre-teaching is required.

Devices that are designed specifically for users who are unable to use most of their voluntary muscles due to physical disability use eye movement technology to spell out words or to select pictures/symbols and require physical collaboration between 'the listener' and 'the user'. A shorthand option allows the user and listener to create abbreviations for commonly used terms. Blind or visually impaired participants may use a portable symbol communicator which can store messages and uses removable tactile symbols that allow the user to push a button to create a message. For people who are literate but unable to easily communicate through speech, a small, lightweight screen device permits the user to type a response while the listener is sitting beside them for easy dialogue.

In addition to AAC, apps embedded within common computing software packages can provide text-to-speech voices, voice recognition speech to text, and symbol vocabularies. Thus, the range of supported communication requires researchers to establish literacy levels and communication methods, share subject or topic specific vocabulary with participants and personal assistants/facilitators in advance of interview or focus groups, and may also require the research team to create picture/symbol artefacts to support the data collection process.

Collecting Data Using Digital Platforms and Video Conferencing

The rapid expansion of online and digital platforms has transformed the social, educational and therapeutic space particularly for younger people (Hollis et al., 2020). Since the emergence of COVID-19, digital living is now an integral part of everyday experiences for many people (Bates et al., 2021). Thus, there is growing potential for digital and online platforms to provide opportunities for various cohorts to engage in research.

The National Health Library and Knowledge Service Evidence Virtual Team in Ireland (2020) reviewed national and international literature to explore best practice for technologies to deliver telehealth services to people with intellectual disabilities, neurological and cognitive disorders, mobility and spinal injury, and visual and hearing impairment. Citing Ali et al. (2020, 5), they state that "technological constraints have a stronger moderating effect than behavioural factors", which suggests that researchers need to consider technological barriers rather than assume 'within person' barriers. For Sheehan and Hassiotis (2017) people with CCCP face challenges in adopting digital technology and providing support to enhance technology use creates new opportunities for improving educational, vocational and leisure experiences. For example, Bates et al. (2021) examined telehealth within CAMHS settings whereby assessment and intervention work moved to online conferencing platforms including Zoom and Microsoft Teams. Young service users in this study were already familiar with using smartphones, tablets and digital platforms which are unique in terms of speed of access, capacity for personalisation, and may also support engaging people with a preference for visual stimuli (Bates et al., 2021).

The use of video conferencing within a research context may also be beneficial over alternative approaches such as telephone, email or text as the use of video may create a better connection by allowing a level of familiarity and by facilitating non-verbal communication, facial expressions, gestures and cues. Video conferencing, however, is not without its limitations as technical problems can disrupt the establishment of rapport (Bates et al., 2021) and confidentiality may not be easy to maintain. Practically speaking, unstable internet connections, small screens (e.g., mobile phone, tablet), and the necessity for facilitators or supporters to restart the online session due to technical difficulties, detract from the interview process. Video conferencing as opposed to in-person interaction also throws up unique challenges including; i) limited observation of multiple participants, ii) ability to manage events within the physical context, iii) a greater need to explain, clarify and question, and iv) engagement that centres on sensitive topics or instigates emotional responses is difficult to manage remotely (Oudshoorn Smit et al., 2021).

Designing Effective Elicitation Techniques

Individuals with CCCP may require highly differentiated methods to support them in eliciting opinions (Nind et al., 2013). Rather than depending upon traditional qualitative research methods such as interviews, focus groups, and surveys, the use of inclusive elicitation techniques allows the researcher to incorporate multiple modalities that may be more accessible to individuals who may have limited language or use alternative ways of communicating (Barton, 2015).

Elicitation techniques, sometimes referred to as participatory tools or methods (Clark, 2005; Goodall, 2018) can be described as tasks that encourage research participants to discuss their ideas (Johnson & Weller, 2002) and can include visual, verbal or written stimuli as useful alternatives to direct questioning (Barton, 2015). They have the potential to make research more transparent, comfortable and authentic and may also give participants a greater voice in order to equalize potential power imbalances between the researcher and the research participants (Barton, 2015). Such approaches support access for participants to voice their perspectives and avoid testimonial injustice (Fricker, 2007) within research design.

The use of elicitation techniques in research with young children and participant cohorts with CCCP has been shown to have the potential to maximise research accessibility, mitigate anxiety associated with expressing opinions verbally and ensure that the participant has multiple means of representation (Clark & Moss, 2011; Goodall, 2018; 2019; Hill et al., 2016; Shepherd, 2015). Examples of elicitation/participatory approaches include, but are not limited to, activity-based interviews, photo elicitation/photovoice, drawings, ranking activities, collage making and walking interviews. This type of data collection often results in the creation of bespoke artefacts that may be co-produced or manipulated to support expression. These artefacts, which might include participant drawings, may provide a pathway to understanding participants' meaning making/thought process, worldview or understandings. These artefacts can be analysed as data, or from a meaning making perspective, and used to support or represent the narrative accounts of the young people (Goodall, 2018: See *Analysing Differentiated Data Sets* for more detailed discussion).

As previously noted, implementing bespoke elicitation approaches requires deliberate and intense planning during the design process and is dependent on determinating participant profiles (including information regarding strengths, interests, communication preferences, and cognitive and sensory profiles). This again links researchers adopting a UDL informed approach, specifically by providing participants with; (i) multiple means of engagement, (ii) multiple means of representation by presenting information in different ways and, (iii) offering multiple means of action/ expression by offering differentiated ways of expressing knowledge and understanding (for example, drawings, photographs and collages) (CAST, 2018). Liaising with key gatekeepers at this point may also inform the elicitation approaches so that data collection methods are appropriate, accessible and meaningful for participants.

Elicitation Techniques for Interviews

The mosaic approach (Clark & Moss, 2011) originated from a study which sought to differentiate qualitative methods to appropriately include the voices of young children regarding their pre-school environments. It combines traditional qualitative methods such as interviewing and observation with 'participatory tools' or elicitation approaches which include child conferencing, drawings, photographs, tours, mapping and role play (Clark & Moss, 2011; Tan, 2019). Thus, it aligns closely with and exemplifies the principles of UDL (CAST, 2018) being harnessed to support accessible and appropriate differentiation of research for diverse cohorts of participants. The mosaic approach reflects a practitioner's approach to teaching in the early childhood classroom and takes the theoretical perspective that children are experts in their own lives. Their role alongside adults is acknowledged as co-constructors of knowledge and researchers are also encouraged to explore tools that complement each child's interests. Each 'tool' forms a piece of the child's unique mosaic, and these approaches provide opportunities for children to increase skills, build confidence and explore their own experiences and understandings, therefore each 'mosaic' is unique (Figure 2). This approach supports researchers to collect authentic understandings of participant experiences, and can therefore support participants with CCCPs 'to access and represent different levels of experience' (Bagnoli, 2009, 547). This method is flexible and can be moulded by the researcher to obtain responses that address a specific question (Tan, 2019). The following sections will discuss examples of how activity oriented elicitation approaches have been used in studies with participants with CCCPs (Fricker, 2007).

Activity oriented interviews have also been used effectively across a range of studies with participant cohorts with CCCPs which focus on abstract concepts or topics. For example, one study (Winstone et al., 2014) explored the perspectives of young autistic people about their sense of self-identity through interviews that included a number of concrete and engaging activities. Two weeks prior to the interviews, students engaged in drawing tasks exploring self-identity during an Art class (for example, Figure 3). Students were given a small mirror and asked to describe how they felt and

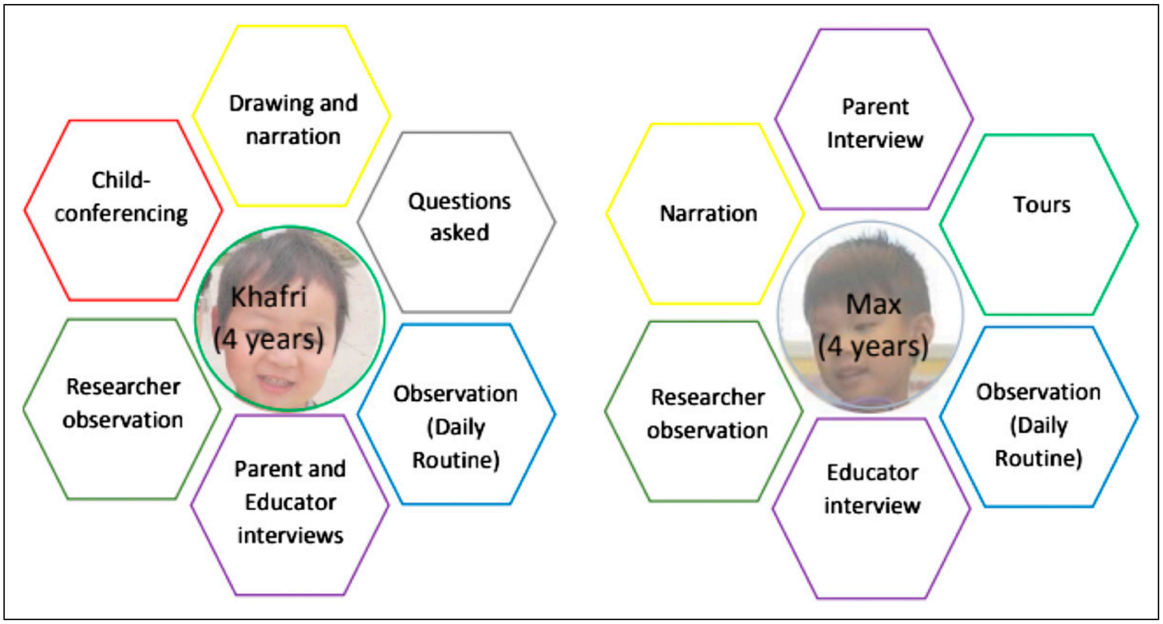


Figure 2. Examples of two children communicating through different methods on a similar research activity (Tan, 2019, 72).

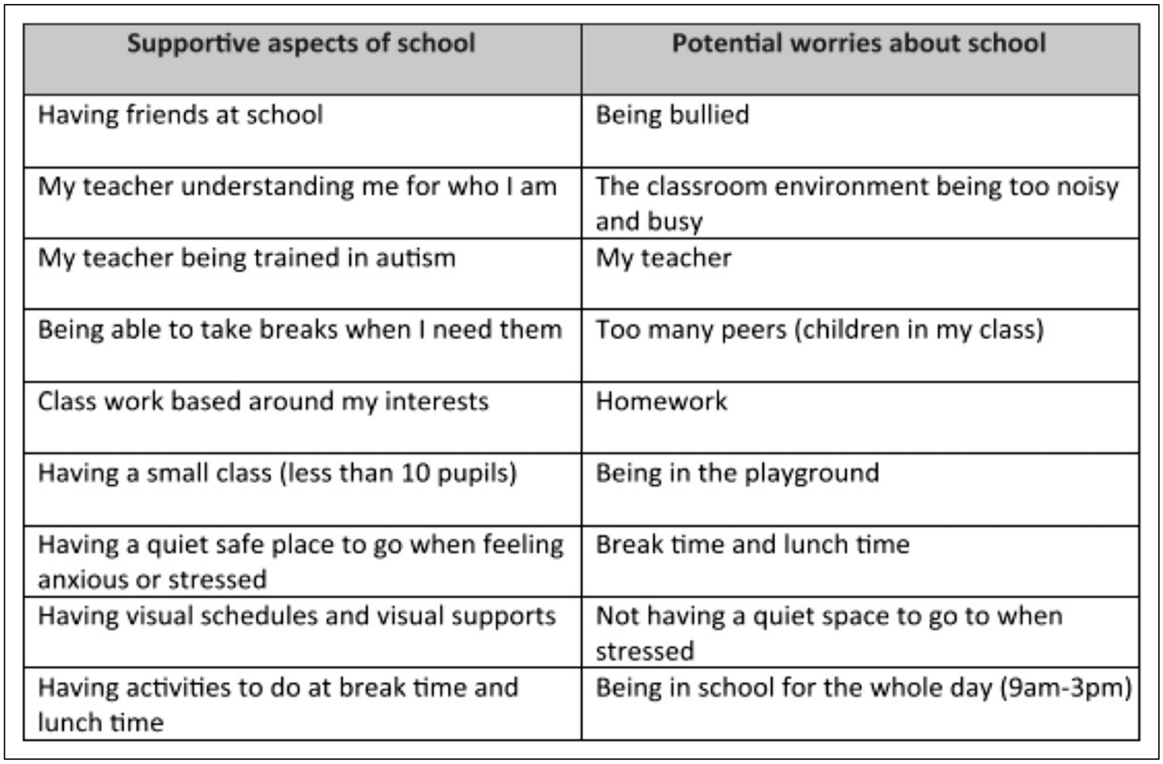
Figure 3. A student drawing of what they would like to be in the future (Winstone et al., 2014, 198).

what they thought other people would see; students were also invited to discuss the artwork they had produced. Thus, through the use of activity-oriented interviews, participants were able to articulate their perspectives in multiple ways.

Goodall (2018) examined the perspectives of a group of autistic young people regarding their school placement, using a number of participatory activities to support the participants in expressing their experiences. The drawing activities asked students to describe a good teacher and a bad teacher by adding drawings and text to two generic outlines of a figure. Participants were also invited to design their own school activity through drawing, and some participants also produced a drawing of themselves in school with added annotations (Figure 4); subsequently, participants were asked to orally describe each of these works. Students also participated in a 'diamond ranking' activity (Figure 5) whereby aspects of school life were ranked from most important to least important. Additionally, students took part in a 'beans and pots' activity (Figure 6) by placing a personalised polystyrene ball into True, False or Unsure pots in response to a number of statements (Goodall, 2018; 2019; 2020).

Figure 4. Student drawing from the drawing activity 'Me at school' (Goodall, 2019, 21).

Similarly, Hill et al. (2016) explored the lived experience of mainstream secondary school for autistic young people. In this study participants were tasked with taking photographs of aspects of school life that were important to them which then formed the focus of discussions. The photo walks were participant led and allowed the students to take an active role



Supportive aspects of school	Potential worries about school
Having friends at school	Being bullied
My teacher understanding me for who I am	The classroom environment being too noisy and busy
My teacher being trained in autism	My teacher
Being able to take breaks when I need them	Too many peers (children in my class)
Class work based around my interests	Homework
Having a small class (less than 10 pupils)	Being in the playground
Having a quiet safe place to go when feeling anxious or stressed	Break time and lunch time
Having visual schedules and visual supports	Not having a quiet space to go to when stressed
Having activities to do at break time and lunch time	Being in school for the whole day (9am-3pm)

Figure 5. Diamond ranking aspects of school (Goodall, 2019, 17).

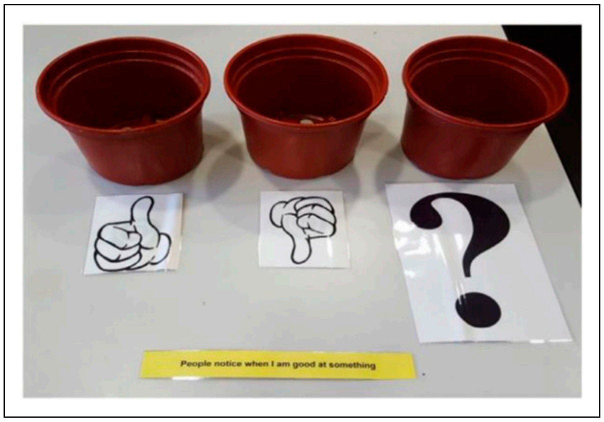


Figure 6. 'Beans and pots' activity (Goodall, 2019, 17).

in deciding the topics for discussion. Shepherd (2015) used a combination of visual methods, using tablet applications and walking interviews to elicit the views and perspectives of autistic young people regarding their transition to further education colleges. Interviews with participants were punctuated by activities that included making a collage representing their interests outside of school (Figure 7) and sorting cards into order of preference using an electronic tablet. Students also participated in a walking interview around the college environments, taking photographs of places that were significant to the individual (Figure 8).

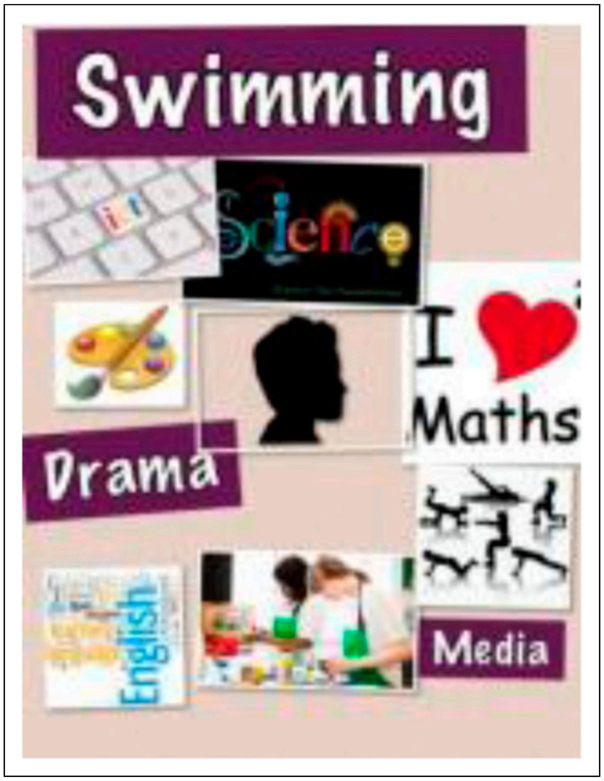


Figure 7. A collage of Jake's interests (Shepherd, 2015, 253).

Figure 8. Student photograph of the learning resource centre during a walking interview (Shepherd, 2015, 254).

One effective and regularly utilised approach to support accessibility and inclusion for individuals with CCCP within interviews is to create a dedicated interview space (Trevisan, 2021). For example, dyadic interviews are conducted in the presence of a person with whom the participant is comfortable or has invited to be present, such as a primary support professional, sibling, or parent (Caldwell, 2014). This strategy has been used with success across a range of qualitative studies with participants who have intellectual disabilities (Llewellyn, 2009). Additionally, the use of adapted and flexible interview protocols which can be differentiated according to the preferences of individual participants (Hollomotz, 2018) provides scope for researchers to adapt the style, questions, or materials in line with individual profiles.

Elicitation Techniques for Focus Groups

In recent years, the use of focus groups with marginalised participant cohorts with CCCP has increased (Trevisan, 2021), for example, research exploring the experience of participants with Traumatic Brain Injury (Koffer Miller et al., 2018) or Autistic participants (Sveen et al., 2013). However, in focus groups, participants are often faced with the additional challenge of an expectation to contribute within more complex social interactions involving the use of pragmatic language skills within reciprocal interactions among peers and the group facilitator (Beail & Williams, 2014). Unsurprisingly, given that many participants with CCCP have limited vocabulary, difficulties with verbal comprehension, and slower receptive language processing (among other differences), standard approaches to conducting focus groups may function as a barrier for inclusion (Beail & Williams, 2014).

Trevisan (2021) suggests a range of strategies for organising accessible focus groups with CCCP such as utilising smaller numbers of participants (typically four to five participants) with support from focus group facilitators. Tassé et al. (2020) conducted focus groups spanning 60–75 minutes involving adults with intellectual disability and their parents/guardians. The number of participants in each focus group was limited to provide equal opportunities to respond and participate and included a moderator, an assistant moderator, and an observer. Where necessary, a member of support staff attended with a participant although they did not contribute to the discussion.

Sampling considerations are also highlighted as being important, with Trevisan (2021) advising that participants with pre-existing friendship relationships be allocated to the same focus groups. An advantage of such an approach is that individual participants feel more confident in expressing their views or contributing to the discussion. In addition, Barr et al. (2003) suggest that the group will be more familiar with the support needs or flexibility requirements of other participants within the same group, leading to a more inclusive group dynamic. However, using pre-existing friendship networks may also lead to less diversity of view or perspective within groups, thus requiring additional consideration within the facilitation and data analysis process (Trevisan, 2021).

Llewellyn (2009) also advises that setting is an important factor in planning focus groups with this cohort of participants, as less familiar or more medicalised settings may lead to responses that demonstrate greater alignment with “the system” or respondent bias (Llwellyn, 2009). This dynamic was not as clear a factor within participant’s responses when focus groups were held in more familiar settings such as home or community support contexts (Tevisan, 2021).

Analysing Differentiated Data Sets

In qualitative research, the researcher endeavours to actively understand and explain a range of social phenomena to solve “the intellectual puzzle” (Mason, 2002a, 2002b, 18) of shared understandings through dialogue with informants. This paper has discussed a range of approaches to support participation and foster access for individuals with CCCP, which are underpinned by a diverse range of highly differentiated methods to elicit their expression of experiences or perspectives. However, the use of elicitation approaches within a highly individualised data collection process, such as the Mosaic approach (Clark & Moss, 2011), may lead to the creation of a range of non-traditional data traces or artefacts of meaning. The obvious challenge this creates with the data analysis process is that it may require a highly flexible approach to the data analysis process itself. In effect, researchers may need to move their analysis beyond language/written forms and be more flexible in exploring other modes of expression. The researcher, in analysing data, may need to “relearn other languages” (Clark, 2005, 26) that do not usually comprise a traditional formulation for the analysis of qualitative data.

The Mosaic approach (Clark, 2005) provides a framework for data analysis within which each data collection method, or tool, forms an aspect of the data collection “mosaic” included within the analysis process (alongside traditional voice-based data). Rinaldi (2005) describes the process of documentation as visible listening through the construction of authentic *traces* of participant expression, which includes documentation and interpretation. This approach to data analysis allows for an active participant role as documenters, initiators, photographers, and creators, with the outcomes of their participation becoming traces or participatory artefacts of meaning. Traces might be photographed outcomes of elicitation methods previously discussed in *Elicitation Techniques for Interviews*. By using this mode of participant expression, the danger of researcher misinterpretation or bias overwhelming the perspective of participants is reduced. By including these trace*s* within the data analysis process, it affords participants multiple modes of expression and access (CAST, 2018) while also minimising any danger of testimonial injustice (Fricker, 2007) within the analysis process.

The inclusion of outcomes from the elicitation methods requires that the analysis process moves beyond a verbal/text (audio/transcription) format that traditionally comprises most qualitative data analysis. The participatory or democratic aspect of the Mosaic approach, therefore, can involve a fundamental role reversal for both the researchers and the participants, with the latter playing an active role within data collection and leading the medium within which data emerges and is analysed (Clark, 2005). Including the outcomes – traces of meaning - of differentiated data collection methods within the analysis process provides robust access for participants with CCCPs and helps to control for epistemic injustice (Fricker, 2007) within the research findings.

The inclusion of visible traces or artefacts of meaning also has the advantage of contributing to the rigour and credibility of study as the collection of participants' visible contributions over the process of data collection, and their transparent interpretation within the data analysis process, can contribute to the audit trail of the study (Lincoln & Guba, 1985). Audit trails document the course of development of the completed analysis where there is an accessible account of research decisions and activities throughout the study (Koch, 1994). The trustworthiness of a qualitative study can be established through observation of the events, influences, actions and decisions of the researcher (Koch, 1994). The existence of a transparent and rich trail of visible information, artefacts or decisions, represents a means of assuring quality in qualitative studies (Akkerman et al., 2008).

Another feature of differentiated data collection approaches for participants with CCCP that may complicate or impact on the data analysis process is the inclusion of a third party acting as an interpreter during the interview or focus group (NDA, 2002), therefore responses contributed by participants and those of a third party must be signposted in the coding process. More seriously, however, the inclusion of a third party to support access or "interpret" may also impact how a participant answers questions. For example, in a study by Llewellyn (2009) adult service users with intellectual disabilities were supported to participate in focus group discussions by paid staff members within the service with whom they were familiar. This arrangement was intended to support participation, however, support staff became 'secondary participants' due to the nature of the support that they provided. The author describes how one support staff member demonstrated a desire to discuss positive aspects of the self-advocacy service in which they were employed (Llewellyn, 2009). Researchers should be aware of this possibility and 'openly acknowledge the nature of supporters' influence on the data obtained' (Llewellyn, 2009, 846).

Conclusion

Taylor and Balandin (2020) point out that individuals with CCCP must be facilitated to participate in research to provide authenticity to the lived experience of disability, and in recognition of social inclusion under the UNCRPD (United Nations, 2006). They argue that negative assumptions about capability, capacity, and ability to give informed consent means that researchers often exclude those with CCCPs, effectively removing opportunities for them to voice their experiences.

Whilst interviews and focus groups are traditionally used to capture the perspectives of participants, it could be argued that both methods have functioned, perhaps unintentionally, as barriers to the participation of individuals with CCCP (Beail & Williams, 2014; Fayette & Bond, 2018). While there exist a range of non-verbal language based data collection approaches also available to include those with differences in communication profiles, such approaches remain relatively underutilised compared to more traditional data collection approaches within research involving those with CCCPs (Beail & Williams, 2014; Vaughan et al., 2020). Furthermore, ethical review boards have tended to view research involving these participant cohorts as posing some degree of "risk" to be approached with caution owing to perceived participant vulnerability (Trevisan, 2021). This conservative but laudable culture of caution may stem from an intention to protect vulnerable individuals but has also led to their marginalisation and disempowerment within qualitative research that informs policy priorities relevant to their interests (Trevisan, 2021).

Including the perspectives and lived experiences of individuals with CCCP has resulted in greater efforts within qualitative research communities to reach out to these potential participants (Beail & Williams, 2014). Making space to hear the lived experiences of participant cohorts that are unheard accords with an inclusive pluralist approach to conducting qualitative research (Smith et al., 2021). Pluralism acknowledges that there is no single perspective or truth that is universally valid (Rescher, 1995) and is particularly relevant where researchers engage with populations whose realities are often neglected (Fayette & Bond, 2018; Preece & Jordan, 2010). Indeed, Taylor and Balandin (2020) argue that as a result of these negative assumptions, researchers often exclude those with CCCPs, effectively silencing their voices. If we accept this as a potential instance of epistemic injustice (Fricker, 2007), we must also consider the scale of social injustice, where 15% of the global population are disabled.

Individuals with CCCPs require differentiation or adaptation of qualitative research methods to support their right to participate as valued members of the community (Beail & Williams, 2014). Practicing fully inclusive methods in research can be achieved using a transformative paradigm (Mertens, 2007) where social inclusion is incorporated into the parameters and design of research as a means of valuing the voices of all people. This engaged inquiry (Chevalier & Buckles, 2019) requires a pluralist approach to designing research artefacts and processes, adopting research objectives and questions which are meaningful to the researched population (Smith et al., 2021). While co-produced research is most closely aligned with a democratic ethos in transformative research (Mertens, 2007), such levels of involvement are not always preferable or desirable for participants, nor logistically achievable due to time or budgetary limitations.

This paper proposes adoption of Universal Design for Learning principles in the planning, designing, and conduct of research with participant cohorts with CCCPs. Selecting from across a range of existing research approaches in a manner informed by the principles of UDL has the potential to support the design of accessible and inclusive qualitative research. Providing researchers with a range of extant methods and strategies informed by the profiles and preferences of participants (Trevisan, 2021) supports increased accessibility and expanded modes of involvement for individuals with CCCP. In turn, ths approach fosters and encourages engagement in research that can inform policy and avoid testimonial injustice (Fricker, 2007). In summary, adhering to typical qualitative methods may constitute a barrier to participation for many people with CCCPs, and therefore guidance and protocols for inclusive qualitative methods can open the door to richer understandings and potentially transformative findings.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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