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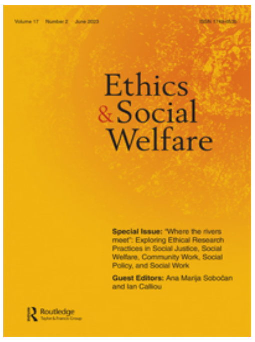

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To Report or Not to Report: The Ethical Complexity Facing Researchers When Responding to Disclosures of Harm or Illegal Activities During Fieldwork with Adults with Intellectual Disabilities

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ABSTRACT
This article draws attention to the ethical complexity researchers may be confronted with during fieldwork should an adult participant with intellectual disabilities disclose that harm or an illegal activity is occurring or has occurred in the past. The need to gain ethical approval and the positioning of people with intellectual disabilities as vulnerable within ethics review procedures can result in the adoption of paternalistic approaches as researchers are encouraged to break confidentiality to report concerns to other professionals. Whilst this may fulfil a researcher's duty to ensure no harm occurs to participants, if it takes place against the participant's wishes it may also violate participant autonomy, reinforce unequal relations of power, and may unwittingly contribute to subsequent harm occurring. Whilst the article begins from our experience as two UK-based researchers working with people with intellectual disabilities, it draws on existing literature and guidelines to expose the ethical tensions which may be encountered. It is intended that the paper acts as a starting point for researchers wishing to reflect on their practice and ethical decision-making, whilst contributing to wider debates on the position of people with intellectual disabilities within society.

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Introduction

It is well known that research has the potential to be harmful. Infamous studies such as the Tuskegee Syphilis Study and Willowbrook demonstrate the abuse and exploitation of people with less power than others that has taken place in the name of research (Iacono 2006; Hardicre 2014; Spellecy and Busse 2021). To ensure the horrors of the past are not repeated, research involving human participants within the UK must be subjected to ethical oversight from research ethics committees (Spellecy and Busse 2021). Their role is to ensure the researchers are acting appropriately. This involves confirming

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that the selection of participants is equitable, participants are respected, harms are minimised in relation to anticipated benefits, informed consent is gained, methods are appropriate, and adequate measures are in place to protect participant privacy and confidentiality (Lynch 2018).

Whilst unethical research has the potential to perpetuate the oppression and marginalisation of disabled people (Oliver 1992; Stone and Priestley 1996), not all research which does so is overtly abusive or comparable to Willowbrook. Research that has gained ethical approval remains in danger of replicating and reinforcing the inequalities that marginalised participants are subjected to outside of the research context. Unequal relations of power thread through all stages of the research process from the research questions asked through to the methods employed and the analysis and interpretation of data (Mullings 1999; Harding and Norberg 2005; Ackerly and True 2008).

In response to unequal power dynamics within research, there is an increasing focus on disability related research that promotes collaboration, inclusion and practices which contest and destabilise traditional power hierarchies. An extensive body of literature exists to support researchers to include participants with intellectual disabilities in an ethical and methodologically sound way (e.g. Cameron and Murphy 2007; Nind 2008; McDonald and Kidney 2012; Carey and Griffiths 2017; Tilly 2020). Additionally, numerous ethical guidelines list the ethical principles that researchers should attend to and set out best practice guidance to encourage researchers to act ethically. However, the focus of the literature concerning ethical practices in research with people with intellectual disabilities tends to be on guiding frameworks and approaches, ethical accountability and how decisions about research participation are made (McDonald and Kidney 2012). Much of this relates to 'procedural ethics', that is ethical issues that are easy to anticipate and addressed before a study commences to gain institutional approval (Guillemin and Gillam 2004). Less is written about 'ethics in practice' or the day-to-day ethical issues that arise during fieldwork: the dilemmas that researchers may be confronted with and the subsequent tensions that can emerge between different ethical principles and value orientations (Guillemin and Gillam 2004; McDonald and Kidney 2012). Whilst it is easy to find guidance on safeguarding participants from harmful research practices, it is harder to find information on navigating safeguarding concerns that may be encountered in the field, such as the decisions that need to be made when researchers gain knowledge of potential harm. Nevertheless, such knowledge may present an ethical dilemma to which the researcher must respond.

As two UK-based researchers seeking ethical approval from the Health Research Authority for a project involving people with intellectual disabilities, we reflected on our response should such a dilemma arise. Our ethics application posed the question:

> Will the interviews/questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study. If yes, please give details of procedures in place to deal with these issues. (IRAS, no date a: online)

We felt the pressure to 'pass' the ethics committee, to frame our response within 'ethics-committee speak', gloss over areas of tension, and use phrases that would reassure the committee of our competence (Guillemin and Gillam 2004, 263). Drawing on guidelines, such as The Social Research Association's (SRA) research ethics guidance (2021), we were compelled to state we would make our participants aware of the limits to confidentiality and we would report any concerns appropriately. However, we were left unsatisfied by this broad-brush approach and the power dynamics it evoked; is it right to break confidentiality in the case of every incident of harm? Does breaking confidentiality when faced with a safeguarding concern always protect the participant from harm or is it possible more harm could be caused? Are participants with intellectual disabilities always vulnerable and in need of special consideration? What does it say about the position of the researcher and the power they wield if they override the autonomy of the participant to report a disclosure against their will?

This paper responds to these questions. We draw on existing literature and guidelines to expose the ethical tensions a researcher faces should they gain knowledge of something concerning, such as harm or crime, during their fieldwork. In doing so, we critique taken-for-granted norms in research and draw attention to wider narratives surrounding people with intellectual disabilities. It is intended the paper complements existing guidance and literature and acts as a starting point for researchers wishing to reflect on their role and develop their awareness of ethical decision-making in relation to confidentiality. Although the paper is situated within a UK context, it is envisaged the tensions raised hold relevance further afield. In many countries ethical regulation is not as stringent as it is in the UK (Von Unger, Dilger, and Schönhuth 2016). Nevertheless, the need to engage in ethical reflexivity and reflect on one's role as a researcher, as is encouraged within this paper, is universal.

Maintaining confidentiality

Maintaining confidentiality is a core aspect of ethical research (Greaney et al. 2012; Vanclay, Baines, and Taylor 2013). It is fundamental that the well-being of participants is prioritised, that participants are not harmed by the research and potential risks are minimised (NCPHSBBR 1979). Researchers are obliged to ensure participants should not be exposed to pain or danger but also that no adverse consequences occur for participants due to taking part in the research (Vanclay, Baines, and Taylor 2013). Maintaining confidentiality is one way to minimise risks. Participants often seek assurances of confidentiality before committing to participate in research. Breaching it not only erodes the trust necessary to collect data but can undermine the credibility of the research and risks placing participants and their communities at harm. Limits on confidentiality can act as a barrier to recruitment and lead to the underrepresentation of those fearful of what may be disclosed (Kennan, Fives, and Canavan 2012; Surmiak 2020).

Maintenance of confidentiality comprises two components: anonymity and the protection of information (Surmiak 2020). Anonymity involves concealing the identity of the participant ensuring any identifying information is hidden (Surmiak 2020). The protection of information relates to not disclosing information unless participants consent to its disclosure (Vanclay, Baines, and Taylor 2013). Whilst this can appear straightforward, managing confidentiality is not always easy as each of the two elements presents its own set of ethical challenges. For example, to ensure anonymity, researchers may remove names or allocate pseudonyms to participants. This risks silencing participants who are proud of their contribution, wish to own their story and be named within the research (Swain, Heyman, and Gillman 1998; Nind 2008; Tuffrey-Wijne, Bernal, and Hollins 2008). The protection of information meanwhile is thrown into question should the researcher learn of harm involving the participants or others. Not only must the researcher be careful how they respond in the immediate aftermath of any revelation as their initial reaction has the potential to cause harm (Guillemin and Gillam 2004), but they must decide whether the issue necessitates breaching confidentiality. In other words, alongside deciding what to say and how to say it, whether to stop the recorder or abandon the interview, they must also decide whether they report the matter to someone who has the power to intervene and hopefully prevent further harm from occurring. The justification for this rests on the researcher's obligation to prioritise participant well-being and minimise harm. Therefore, whilst ethical guidelines stress the importance of confidentiality, they also make allowances for it to be broken by making known absolute confidentiality cannot be guaranteed (BSA 2017; SRA 2021; ESRC, online). However, such situations are context-dependent, and it is not possible to regulate for every possible incident. Therefore, in the absence of regulation or definitive guidance, the researcher's judgement is required in determining what constitutes harm and if they are warranted to evoke the limits of confidentiality.

The most straightforward approach to the situation is to talk with participants and gain their consent to take the matter further. Indeed, this process is considered best practice within ethical guidelines unless doing so is deemed unsafe or may increase the risk of harm (Dunn 2020; SRA 2021). It is an approach that minimises the researcher's responsibility whilst avoiding disrespecting the participant. However, if the participant refuses their permission, the complexity of the situation intensifies as the researcher may decide they need to break confidentiality regardless – an action which may jeopardise participant autonomy.

A practical, pre-emptive approach suggested to avoid this dilemma and reduce the moral damage caused by breaking confidentiality against the will of the participant or without their knowledge, is ensuring the limits to confidentiality are made known to participants during the informed consent process (Dunn 2020; SRA 2021). Additionally, it is advised that the research protocol addresses the safeguarding procedure in advance, and follows appropriate adult safeguarding or child protection protocols (Dunn 2020; SRA 2021)

However, these steps alone are not enough to ensure the decision a researcher makes is ethical; ethical decision-making involves recognising and negotiating 'inherent dilemmas generated by differing rights, responsibilities, motivations and vested interests of all concerned' (Swain, Heyman, and Gillman 1998, 34). Thus, not only is the problematic nature of informed consent ignored within the recommended steps, but the role and responsibilities of the researcher are oversimplified, and questions of vulnerability and autonomy neglected. These areas are addressed in turn below.

Informed consent

Informed consent is described as an 'indispensable step' in the conduct of ethical work (Dixon and Quirke 2018, 18). It involves providing participants, or a consultee if participants are unable to consent for themselves (DoH 2005), with appropriate information so they gain an adequate understanding of the research and the consequences of participation (Wiles et al. 2008; Vanclay, Baines, and Taylor 2013). The SRA (2021:, 5) provides a comprehensive explanation of informed consent and suggests information should address who is conducting and funding the research, its purpose, who will use the data and for what, what participation will entail, what risks to them (if any) could be reasonably seen as arising from participation and anything else which could be important for helping them decide about participation. For vulnerable, or potentially vulnerable, participants this includes acknowledging the limits to confidentiality (SRA 2021; ESRC, online).

When used to mitigate the moral damage of breaking confidentiality (Dunn 2020), informed consent becomes a 'caveat emptor' (Iphofen and Tolich 2018). Responsibility is deflected from the researcher and placed on the participant to be aware of what they are signing up to. However, it is argued that the amount of information required to be on consent forms and participant information sheets by ethics committees can overwhelm participants with intellectual disabilities and dilute understanding (Wiles et al. 2007). Similarly, participants may be keen to take part and provide consent without considering the full consequences and possible outcomes (Wiles et al. 2007). Indeed, as Swain, Heyman, and Gillman (1998) highlight, it can be impossible for participants to know what the consequences of participation may be as they do not know in advance what they might disclose. Qualitative interviews are designed to foster trust and rapport between researchers and participants to encourage participants to talk freely. Therefore, whilst on the one hand it is suggested participants are in control of how they answer questions and the details of what they disclose, on the other hand, researchers employ 'techniques of listening' designed to encourage participant candour (Swain, Heyman, and Gillman 1998, 26). Accidental disclosures are a possibility and neither the researcher nor the participants can anticipate the different avenues an interview may go down, thus undermining the status of informed consent; is consent informed if you do not know where the discussion may lead and therefore the consequences of participation?

Whilst steps can be put in place to enhance the accessibility of the informed consent process for people with intellectual disabilities and consent viewed as an ongoing process (Cameron and Murphy 2007; Carey and Griffiths 2017), it should nevertheless be treated with caution when drawn upon as justification for breaching confidentiality. Therefore, researchers may wish to consider ways to ensure participants remain in control of the interview content. For example, by providing participants with the research questions in advance to allow time for reflection on what they want to discuss or, more importantly, what they wish to avoid.

The role and responsibilities of a researcher

Deciding how to respond to a concern requires considering what the researchers' primary duties are, the extent of their responsibilities and the boundaries of their role. A researcher who believes the primary purpose of research and thus the researcher is to advance science and knowledge may respond differently to someone who believes the researcher's primary duty lies in the prioritisation of the participant's welfare (Allen 2009).

Where there is an unfailing belief in the importance of advancing science and knowledge, concerns have been raised that breaking confidentiality undermines the integrity of the research (Allen 2009). There is a worry that participants may not provide accurate information if they know they may be reported and it may pose a challenge for the recruitment and retention of participants (Becker-Blease and Freyd 2006; Allen 2009;

Kennan, Fives, and Canavan 2012). In line with this, and out of a concern for the harm which may occur if sensitive topics are avoided or excluded altogether from research, Becker-Blease and Freyd (2006, 221) argue it is ethical not to report suspected abuse when five conditions are met. Two of these conditions are that maintaining confidentiality 'has the potential to yield benefits to society and participants' and 'the risks to participants do not outweigh the benefits to society and participants.' In other words, in situations where the knowledge gained through the research has the potential to benefit many people, it may outweigh the risk posed to the individual participants and therefore justify the researcher not acting when abuse is suspected. It is an argument of utilitarianism that Allen (2009) suggests is on dangerous ground, not least because similar utilitarian arguments have been drawn upon to justify abusive research practices. Reflecting on the Vipeholm Dental Caries study spanning 1945–1954 which saw the teeth of children with intellectual disabilities deliberately ruined, one of the original authors wrote 'the end sometimes justifies the means' (Krasse 2001, 1788). Although studies like this relate to harm inflicted by the researchers, Allen (2009) poses the question as to whether this is ethically distinct from a researcher failing to protect their participants from potential harm inflicted outside of the research context.

How researchers view their role impacts the decisions they make in light of knowledge about harm. Surmiak (2020) conducted 34 in-depth interviews with Polish researchers working with 'vulnerable' participants to ascertain their experiences and opinions concerning the maintenance of confidentiality. The perceived role of the researcher was frequently drawn upon to justify maintaining confidentiality. Where there was a belief that the researcher's role was primarily about producing knowledge, disclosing information to authorities about their participants would go beyond the scope of their role. Similarly, prioritising confidentiality enabled the collection of valuable data which may not have been possible otherwise. Many researchers within the study viewed their role as one of neutrality; personal values were to be put to the side as researchers were not in a position to judge participants, to make decisions about what is good or bad and therefore what should be reported.

Whilst it is important to consider the weighting the researcher attaches to the value of knowledge production and their role within this, the role of the research to the participant also needs to be examined. Participants do not simply appear in front of the researcher rather 'they arrive to the research encounter with their own anxieties, hopes, and expectations' (Huysamen 2022, 123). Whilst we are instructed not to overestimate the benefits to individual participants simply by taking part in research (IRAS, no date b) motivations for 'arriving' at research vary and some people may welcome the opportunity to tell someone their secrets and to talk openly about topics they might not be able to discuss with friends and family (Huysamen 2022). Qualitative interviews can provide participants with space to explore their feelings and experiences, and to make sense of traumatic events (Swain, Heyman, and Gillman 1998). Therefore, does value lie not only in the advancement of knowledge, but in giving participants the opportunity to discuss a topic or raise an issue without fear of repercussions or consequences? This may be particularly significant for people with intellectual disabilities where social exclusion and loneliness remain an issue (Tilly 2019) and social networks largely comprise family members and professionals (Lippold and Burns 2009). There may be limited opportunities for people with intellectual disabilities to voice their experiences to someone who is not forced to act due to their position.

Researchers are encouraged to engage in reflexive practice: ‘a continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data but also the researcher, participants and the research context’ (Guillemin and Gillam 2004, 275). Part of this involves researchers reflecting on their positionality and acknowledging how their worldviews, in relation to the social and political context of the research, can influence the research (Holmes 2020). Positionality also shapes how researchers respond to gaining knowledge of harm or illegal activities during fieldwork. This is evident within Surmiak (2020) where researchers who knew about certain illegal activities being committed maintained confidentiality due to their own political beliefs, for example, a belief in the legalisation of drugs. It is, however, no doubt easier to interrogate our beliefs and acknowledge the impact they may have on the maintenance of confidentiality when the researcher believes the issue at hand concerns minor illegal activity as opposed to more serious harms or abuse (Wiles et al. 2008; Surmiak 2020).

Practitioner-researchers occupy a unique place. Alongside taking into consideration their role as a researcher, they must acknowledge their role as a practitioner which brings another layer of complexity to the dilemma (Bell and Nutt 2012). In some cases, it may be that their role as a practitioner, and the related statutory responsibilities and professional standards to which they must adhere, overrides the researcher-identity. The National Midwifery Council’s code of practice, for example, states:

> Raise concerns immediately if you believe a person is vulnerable or at risk and needs extra support and protection. To achieve this, you must […] share information if you believe someone may be at risk of harm […]. (2015, 15)

Therefore, a researcher who is a registered midwife, must act accordingly or risk sanction. Nevertheless, the divided loyalties experienced by practitioner-researchers can prove challenging (Bell and Nutt 2012). To demonstrate this Bell and Nutt (2012) provide an example of when researcher and practitioner obligations clashed: Nutt was carrying out research with foster carers whilst simultaneously employed as a social worker. During her fieldwork Nutt noticed a sexually explicit picture on display in a foster carer’s home. Whilst for many researchers this would not be an issue, Nutt was aware that foster children should not be exposed to potentially sexual messages due to limited knowledge about their previous experiences. Despite wishing to respect her participants and being concerned about possible negative ramifications for them, Nutt felt obliged to act due to her practitioner identity and being bound by the social work code of practice. Acting in accordance with this, which puts the safety of children above assurances of confidentiality, Nutt informed the local authority of her unease and the potential impact the image may have on foster children.

Although social researchers may not be bound by the same professional requirements as practitioner-researchers (Dunn 2020) they too must abide by the law. However, it can be tricky to ascertain where researchers stand in relation to their legal responsibilities; whilst ethical concerns can take a legal form, the role of legislation is rarely discussed (Erikson, HÖglund, and Helgesson 2008) and will vary depending on location. Confusingly, whilst some guidance states researchers are legally obligated to report suspected abuse (University of Sheffield 2020) there are currently no mandatory reporting laws within

England relating to abuse (although it is important to note this is not the case in other countries) (HoC 2020). In the UK, researchers do, however, like other members of the public, have a legal duty to report money laundering and crimes covered by the Terrorism Act 2000. Furthermore, researchers in the UK, as with researchers in, for example, Poland, USA and Canada, may be formally obligated to share information gained through research to support criminal proceedings (Lowman and Palys 2014; Surmiak 2020). Indeed, Lowman and Palys (2014) provide several examples from USA and Canada where this has occurred although they were unable to find examples of it occurring within the UK.

Surmiak (2020) identifies four approaches that researchers took when faced with knowledge of harm: passive, collaborative, caring and balancing. Followers of the passive approach did not take steps to intervene and prevent harm from occurring. This was particularly the case when researchers considered the issue, or harm, to be a private family matter, for example, what they believed to be a harmful way to raise children. This is not dissimilar to the argument of neutrality also raised by participants within their study and mentioned previously; researchers are not in a position to judge their participants and decide what is acceptable or not. Opposite the passive approach stands the caring or paternalistic approach. Here researchers made a judgement as to what is harmful and broke confidentiality to protect the participant's wellbeing. The balancing approach saw researchers balance on the verge of maintaining and breaking confidentiality. An example given by Surmiak (2020) involves a researcher subtly alerting a responsible person, in this case a home manager, that harm was occurring by asking them considered questions in the hope it would draw attention to the issue. In the collaborative approach researchers sought the permission of their participant to intervene. Although this proves problematic when consent is not given (Wiles et al. 2008), researchers taking a collaborative approach worked together with the participant to reach a solution that satisfies them both. This approach relies on researchers being willing and having time and opportunity to negotiate with participants. However, it ensures the participant maintains control over the situation; the more control participants have throughout the research process the less likely the research will infringe on their rights (Swain, Heyman, and Gillman 1998).

In line with the collaborative approach, research which is participatory or co-produced may be in a better position to ensure people with intellectual disabilities contribute to the management of ethical issues. Within participatory approaches, the traditional power imbalances between researcher and researched are undermined as people with intellectual disabilities become involved in all stages of the research process – their views incorporated into what research gets done, how it gets done and how it is implemented (Fletcher-Watson et al. 2019). Therefore, discussions with co-researchers with intellectual disabilities regarding how to manage the reporting of disclosures could take place both before the research commences and as any issues arise thus unsettling the power a researcher may otherwise hold over the situation.

Nevertheless, regardless of the reasons behind a decision or whether the decision making is shared with people with intellectual disabilities, Becker-Blease and Freyd (2006) stress the importance of participants being informed where abuse or harm will not be reported. If not, there is a danger the participant may mistakenly believe their disclosure is a report to an outside agency. Similarly, if a researcher does not report a concern themselves, they should at the very least support, or tell, the participant how they can report the matter themselves (Becker-Blease and Freyd 2006; Kennan, Fives, and Canavan 2012).

Vulnerability and the issue with 'best interests'

In line with the caring approach, researchers within Wiles et al. (2008) broke confidentiality when it was seen to be in the participant's 'best interests'. Although the researchers tried to seek consent before doing so, justification based on 'best interests' is problematic. Best interests is a central principle within the Mental Capacity Act (DoH 2005), which applies to England and Wales, and states that anything done for or on behalf of a person who lacks mental capacity must be done in their best interests. Whilst Section 4 of the Act sets out a checklist of factors to be considered when making a best interest decision, the term itself lacks a definition. It is also a term that is absent from the United Nations Convention on the Rights of Persons with Disabilities where instead a 'will and preferences' paradigm is favoured with the suggestion being that this affords people a higher degree of respect than a best interests framework (Donnelly 2016). Thus, drawing on best interests within the research context raises questions of power; what gives researchers the authority to act in someone else's best interests? The researcher-participant relationship is often a fleeting one so how is it possible to know what is in the participant's best interests if you barely know them?

Labelling people with intellectual disabilities as 'vulnerable' fuels the 'best interests' narrative and provides justification for researchers to take a paternalistic approach (Brown 2011; Gustafson and Brunger 2014; Martino and Schormans 2018). As a term, vulnerability implies weakness and suggests an inability to protect oneself prompting interventions based on 'knowing better' (Wishart 2003; Brown 2011). Therefore, as researchers are told to take 'special care' with vulnerable adults, such as those with intellectual disabilities (BSA 2017; SRA 2021) and are informed by conservative and risk-averse research ethics committees who may act with caution when it comes to participants with intellectual disabilities (Iacono 2006; Martino and Schormans 2018), they are pushed to believe unequivocally that they must report abuse when interviewing people with intellectual disabilities (Wiles et al. 2008).

A label of vulnerability places emphasis on the individual requiring protection rather than on the structural forces that disadvantage disabled people and create and sustain their 'vulnerabilities' (Wishart 2003; Guillemin and Gillam 2004; Brown 2011). Furthermore, the label is homogenising: 'labelling the disability community as vulnerable assumes incorrectly that all members are similarly positioned and therefore disadvantages, at risk, or in need of protection based on a single category of difference, that of living with a disability' (Gustafson and Brunger 2014, 1001). Interestingly, this appears to conflict with the checklist in the Mental Capacity Act (DoH 2005) which says that no decision should be made solely on the basis of a person's age, appearance or other aspect of behaviour that might lead others to make unjustified assumptions. Summing up the issue with vulnerability, Brown (2011:, 316) lists three main concerns: 'it is a paternalistic and oppressive idea', 'it functions as a mechanism of widening social control' and 'calling individuals or groups "vulnerable" can act to exclude and stigmatise them'. As a result, the term needs to be 'handled with care' and evoked with critique. Furthermore, we should acknowledge the 'temporal, situational, relational and structural nature of vulnerability' (Virokannas, Liuski, and Kuronen 2020, 327). Thus, researchers, concerned about how they will manage matters of confidentiality, need to consider the individual and their circumstances rather than relying on blanket assumptions of vulnerability.

Respect for persons: respect for autonomy

Respecting participant autonomy is a fundamental component of ethical research. It is at the heart of the ethical principle 'respect for persons' – one of three overarching principles in the Belmont report which is widely regarded as forming the foundation for institutional ethics procedures and governance (Israel and Hay 2006). Similarly, self-determination is a key value within social work practice (Preston-Shoot 2001), whilst choice and independence have been championed within intellectual disability services since the publication of the Valuing People White Paper in 2001 (Fyson and Kitson 2007) and are considered key factors of quality of life (Brown and Brown 2009). Nevertheless, people with intellectual disabilities have a long history of being denied autonomy. Not only have protective and paternalistic approaches been taken, with people with intellectual disabilities viewed as eternal children (Martino and Schormans 2018), but they are often viewed as less than human, not fully deserving of the rights afforded to other adults (Slater 2015; Goodley 2021). The very fact that Valuing People sets out that choice and independence, alongside rights and inclusion, are the government's key principles for people with intellectual disabilities suggests they cannot be taken for granted. Many adults with intellectual disabilities have 'battle scars' from previous experiences of abuse and violation of trust (McDonald et al. 2015); a researcher's violation of participant autonomy does not occur in isolation. Thus, not only does the adoption of paternalistic approaches by the researcher pose an ethical challenge within the research context, but it may contribute to the wider marginalisation and silencing experienced by people with intellectual disabilities. It is perhaps no surprise, therefore, that adults with intellectual disabilities viewed researchers reporting information to the authorities, for example where there was suspected harm, as more harmful than other stakeholder groups (McDonald, Conroy, and Olick 2017).

It can be argued that taking participant autonomy as the guiding principle, is a simplistic approach to autonomy. Not only does it assume freedom to choose between options, ignoring the possibility of a decision being made under duress, but it fails to acknowledge the separation of a person's short-term and long-term interests (Preston-Shoot 2001; McDonald, Conroy, and Olick 2017). It may be more ethical to deny autonomy and cause harm in the short-term to ensure the person remains an autonomous individual in the longer-term (Horne 1999; McDonald, Conroy, and Olick 2017). Thus, whilst participants with intellectual disabilities in McDonald, Conroy, and Olick (2017) considered breaking confidentiality to be harmful, other groups believed it was justified due to the subsequent longer-term benefits of being safeguarded in the future. In addition, the interdependence of humans cannot be ignored; people often require support from others to make decisions and to maintain an optimum level of independence, something which may be lost when too much emphasis is placed on self-determination (Fyson and Kitson 2007). Undoubtedly, however, the clashing of views within McDonald, Conroy, and Olick (2017) poses a problem. Whilst McDonald, Conroy, and Olick (2017) recommend further work to explore the tensions and identify appropriate practices for researchers, it also highlights the importance of participatory approaches and involving people with intellectual disabilities within ethical decision-making processes to ensure decisions remain relevant to those they concern.

A consequentialist approach

Weighing up the participant's short-term harm versus their long-term interests is a consequentialist approach to ethics. That is, someone deciding what action to take based on what will lead to the best and/or least negative results for the participant. When doing so, alongside the harm caused in violating autonomy consideration may be given to other harms which may arise from the reporting of a concern. In cases of abuse, participants may fear retribution from the perpetrator or losing the support of caregivers, particularly if dependent on their abuser for care. The fear of losing access to services, their home, or independence due to heavy-handed paternalistic interventions is, for some, very real (Digman 2021). Similarly, adults with intellectual disabilities in McDonald et al. (2015) worried about the backlash they may face from their support providers and the loss of privacy should researchers break confidentiality.

An example of this approach, where the researcher considered the different harms which may befall their participant, is provided in Surmiak (2020). The researcher in question had learned of abuse perpetrated by staff towards their participants within a homeless shelter. However, they decided not to act as they feared reporting the abuse could lead to greater harm should the shelter close due to the abuse being uncovered.

To support researchers in responding to such dilemmas, Buchanan and Warwick (2021, 1092) suggest engaging in 'ethical triage' to ascertain an appropriate course of action. Their approach is not dissimilar to a consequentialist stance as actions taken within 'ethical triage' should,

> prioritise the well-being of the participant, both in terms of preventing immediate and longer-term harm; adhere to the stipulations made when the ethics application was approved; be aligned with the aims of the research and serve the purpose of the research itself; and involve choosing the action that can bring about the greatest good.

Moving forward

There are no clear answers to the question of how a researcher should respond to the dilemmas discussed within this paper. Researchers cannot predict all possible consequences of their actions, or lack of action, and it can be difficult to weigh up and compare different outcomes (Swain, Heyman, and Gillman 1998; Surmiak 2020). Harm is subjective and future harm unknowable and unpredictable. Mistakes may be made if researchers over or under-estimate the importance of negative consequences related to the protection of an informant's wellbeing (Surmiak 2020).

Alongside proposing 'ethical triage', Buchanan and Warwick (2021) take a three-step approach to minimising harm amongst their participants suggesting attention is paid to actions taken before, during and after data collection. The prioritisation of the participant's well-being and endeavouring to reduce the inherent power relationships between the researcher and the researched underpin each step. In line with this we outline some actions researchers may wish to consider before, during and after data collection to help them navigate the ethical complexity should a concern arise during their fieldwork. We add to the underpinning principles the need for critical reflexivity. It is paramount researchers address their positionality and interrogate their beliefs, the 'norms' within research processes to which they subscribe, and the language used in connection to people with intellectual disabilities. Doing so will help researchers be mindful of the nuances within ethical guidelines, the areas where principles can clash and the discourses surrounding people with intellectual disabilities that perpetuate inequalities. Drawing on the awareness and knowledge gained by engaging in critical reflexivity will help develop and deepen ethical literacy and enhance ethical decision-making. Doggedly following rules or research 'norms' must not replace a commitment to exposing and exploring the ethical complexity which arises during fieldwork and working out the right course of action during fieldwork (Dixon and Quirke 2018). Likewise, ethics committees would also benefit from reflecting on their role to ensure they promote a reflexive and ongoing engagement with ethical issues and facilitate opportunities for discussion and learning rather than encouraging a 'tick-box' approach to ethical approval (Von Unger, Dilger, and Schönhuth 2016).

Before data collection

- Reflect on potential issues which may arise and the different ways they could be addressed whilst considering the subjective and contestable nature of harm.
- Identify any legal, practitioner, or funder obligations you have in relation to reporting information which may be non-negotiable.
- Compile a list of useful resources, such as the contact details of organisations, that could be shared with participants if appropriate. (This is particularly important if the decision is made not to break confidentiality but to support the participant to seek help themselves.)
- Consider putting in place a safeguarding protocol or 'safe working interview plan' (Buchanan and Warwick 2021) bearing in mind who the document is intended to protect: the institution, the participant, or the researcher? (Martino and Schormans 2018).
- Seek informed consent from participants whilst being mindful of its problematic nature and the importance of treating consent as an ongoing process. (For researchers in England and Wales, refer to the Mental Capacity Act 2005 guidance for participants who may lack capacity to consent.)

During data collection

- Pay attention to positionality and take steps to minimise power hierarchies remembering that the more control participants have over the interview the less likely their rights will be violated.
- Pay attention to your initial reaction to a disclosure as the immediate response has the potential to cause harm.
- Do not make any immediate promises regarding confidentiality if you require time to process the information or wish to seek the advice of others.

After data collection

- Provide participants with the opportunity of a debrief after the interview or a follow-up after-care call should they become upset.
- Ensure the researcher can have their own debrief with a member of the research team or supervisor/principal investigator.

- Before taking any action, it may be helpful to seek advice and support from colleagues or institutional safeguarding leads to share the burden of decision-making.
- Seek out opportunities to discuss ethical issues with other researchers, people with intellectual disabilities and interested parties to ensure continuous learning and reflection.

Conclusion

We have outlined several tensions which can emerge when a researcher, working with participants with intellectual disabilities, gains knowledge of information they may wish to share with another person to protect the participant's or someone else's wellbeing. If it is not possible to gain the participant's consent, researchers are faced with a dilemma as they must decide whether to maintain or break confidentiality and respect or override the participant's short-term autonomy. Due to the context-specific nature of the dilemma, guidelines are limited in the advice they provide, and they should be approached with caution, with researchers critiquing academic 'norms' and the narratives they may perpetuate. Whilst it may be necessary to report some concerns, maintaining a critical reflexive approach and reflecting on the key areas outlined in this paper will support researchers to present considered arguments for the value of one course of action over another (Preston-Shoot 2001). It will also encourage more nuanced responses which move away from paternalistic actions based on flawed assumptions about the vulnerability of people with intellectual disabilities. We end by encouraging researchers to share the ethical dilemmas they have faced, presenting the steps ruled out, alongside those which were taken and the justification for each. Doing so will allow opportunities for learning and discussion and build a body of evidence which can be drawn on when other researchers find themselves in similar positions.

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