Brief Reports

A practical example of an open disclosure process for people with intellectual disabilities in the Republic of Ireland

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Abstract

Literature pertaining to open disclosure predominantly refers to acute care settings; this is the case in, for example, the UK, Republic of Ireland, Australia, Korea and the USA. There is, however, a dearth of literature regarding open disclosure related to people with intellectual disabilities. A practice example of open disclosure is presented here, following a serious adverse event in an organisation supporting adults with intellectual disabilities. The aim of the process was to openly disclose in a meaningful way to adults with significant intellectual disabilities and communication difficulties. An apology pathway was developed by a multidisciplinary team based on individual communication needs. A suite of resources was developed including easy read-picture agendas and sign language to support increased understanding of the apology. Service users received the apology first, followed by meetings with their families. This practice example has positive implications for service providers for people with intellectual disabilities.

Keywords

open disclosure, error disclosure, intellectual disability, innovative resources, communication difficulties

Introduction

Open disclosure is a communications approach focusing on immediate and honest disclosure to patients and service users following adverse events in health settings (Lee and Kim, 2020). Increased incident reporting and open disclosure are recognised as being indicative of a stronger

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safety culture for patients and service users both nationally and internationally (McCullagh, 2019). Internationally, while sometimes referred to using other terms such as *error disclosure* (Cole et al., 2013) and *reconciliation disclosure* (Martin, 2018; Moore and Mello, 2017); in Australia, New Zealand and the Republic of Ireland, the term most commonly used is *open disclosure* (Australian Commission on Safety and Quality in Health Care, 2013; HSE, 2019).

Open disclosure is defined by the Irish Health Services Executive (HSE) as:

> an open, consistent, compassionate and timely approach to communicating with patients and, where appropriate, their relevant person following patient safety incidents. It includes expressing regret for what has happened, keeping the patient informed and providing reassurance in relation to ongoing care and treatment, learning and the steps being taken by the health services provider to try to prevent a recurrence of the incident. (HSE, 2019: 7)

While open disclosure is a practice that has taken place in healthcare over decades, and is not a new concept (Mathews, 2020), it is only in recent years that policies have begun to support this practice (HSE, 2019). The Republic of Ireland's National Open Disclosure Policy was updated in June 2019 and was seen as a very positive development. Evidence highlights the benefits of open disclosure for the patient and service user experience, while transparency and honesty can aid in the reduction of litigation claims (HSE, 2019; Iedema et al, 2009; National Patient Safety Agency, 2005).

This paper will firstly explain adverse events in healthcare, reporting and open disclosure with a focus on people with intellectual disabilities. The impact of adverse events on this group of people is then detailed, followed by a practical example of how a process of meaningful open disclosure was conducted in a service for people with intellectual disabilities in the Republic of Ireland. Reflections are shared that provide suggestions to aid in ensuring open disclosure is a success while conclusions include a call for further research in this area.

Adverse events in health care

Patient safety incidents have been a major concern since the emergence of research relating to the harm and impact that adverse events have on thousands of people every year (World Health Organisation, 2009).

In the United Kingdom, a national reform took place in the UK's National Health Service (NHS) in 2016, in an attempt to build a culture that fostered transparency and openness between staff and patients. This emerged following the findings of the Francis Inquiry into the Mid-Staffordshire NHS Foundation Trust, whereby between 400 and 1200 patients died as a result of poor standards of healthcare (Toffulutti and Stuckler, 2019). Each day, the NHS deals with the aftermath of healthcare adverse events, however this phenomenon is an issue experienced globally in healthcare settings (Anderson-Wallace and Shale, 2014).

In Australia, the cost of the implementation of their national open disclosure programme is reported to have been in excess of 50 million dollars over the course of 5 years (Kondro, 2001). While initial implementation appears expensive, the cost of healthcare errors vastly exceed the cost of this implementation; a recent study in primary and secondary healthcare settings estimated costs to the NHS of definite avoidable adverse drug errors alone to be £98.5 million annually (McCullagh, 2019).

While clinical incidents are inevitable in complicated, dynamic environments such as healthcare settings (Martin, 2018: 34), Howell et al. (2015) found that there were reduced rates of litigation claims in hospitals that had increased reports of patient safety incidents and open disclosure to patients and service users.

Additionally, there is a growing body of literature emphasising how increased reports of patient safety incidents in hospitals leads to reduction in lawsuits (Howell et al., 2015; Iedema et al., 2009; National Patient Safety Agency, 2005).

Reporting and open disclosure

Critically, Harrison et al. (2017) cited as little as 30% of harmful events being disclosed to patients in acute health care settings. Under-reporting of incidents is echoed in other literature, often due to perceived negative repercussions (Ock et al., 2016; Wagner et al., 2012; Waller et al., 2020). Duffy (2012) reported in her quantitative study of healthcare staff in the Republic of Ireland (n = 192), that approximately 50% of respondents indicated barriers to disclosure including fear of blame, litigation and disciplinary concerns. More recently, in their cross-sectional study on nurses' perceptions of open disclosure in cancer care, Waller et al. (2020) found that nurses' perceptions of the number of patients informed of errors in a timely manner, and receiving an explanation for why they occurred, were much lower than what was reported by patients in previous studies (Bryant et al., 2017; Carey et al., 2019). They state that this is attributed to the professional and organisational barriers that exist due to perceived negative implications on reputation (Waller et al., 2020).

For people with an intellectual disability, it is likely that they face greater barriers with regard to reporting of adverse incidents. Factors relating specifically to the individual's disability, combined with societal factors, may decrease their opportunities for reporting incidents themselves (Wacker et al., 2008). There is also the possible assumption by carers that the person lacks understanding, and therefore may not understand the apology following an adverse event; often, having an intellectual disability can affect an individual's understanding of spoken language and this may also impact upon one's ability to express oneself with oral language (Learning Disabilities Association of America, 2020). Such an assumption has the potential to negatively impact people with an intellectual disability, as professionals or family members may incorrectly perceive that the service user may not understand the open disclosure, or fear upsetting the service user. Consequently, service users may be less likely to receive an apology to which they are entitled. An assumption that the service user may not understand can also lead to a missed opportunity by the service provider in acknowledging the adverse event and affording the person the opportunity to ask questions.

While much of the research on this topic relates to acute settings, McCormack et al. (2005) in their 15-year longitudinal study in Ireland, found that 42% (n = 118) of confirmed allegations of abuse were reported by people with intellectual disabilities. In addition to this figure, they estimated that many more cases were under-reported due to the nature of the person having a disability, with limited opportunity or ability to be understood or communicate the abuse. Northway et al. (2013) also reported that incidents of sexual assault are underestimated, as under-reporting is likely to be higher among people with intellectual disabilities. Additionally, Curry et al. (2011) claimed that service providers seldom ask people with disabilities about abuse or create opportunities to disclose (Curry et al., 2011).

In a study by Vermeulen et al. (2007), it was found that a higher percentage of children with intellectual disabilities living in residential settings suffered abuse, compared with children who lived at home. Wissink et al. (2015) conducted a narrative review of studies relating to sexual abuse of children with intellectual disabilities and found that children in residential institutions are at an increased risk of sexual abuse. In 2018, Wissink and colleagues conducted a further study in the Netherlands, of reports of abuse of children with intellectual disabilities. These findings were significant, as they identified that most of the reported cases of abuse were disclosed by children themselves (67%), and a significant number of cases were reported by staff members who identified signals of distress from a service user.

This highlights two very important factors. Firstly, the reports from children with intellectual disabilities were from those who could verbally report the abuse. However, these findings also bring to light those people with intellectual disabilities living in care settings who are unable to communicate, thus indicating that incidents could be far higher for individuals with intellectual disabilities and complex needs. This may be further compounded by the fact that people reported to have severe or profound intellectual disabilities living in residential care facilities often do not have family members or significant others to advocate for them (Bigby, 2008; McCausland et al., 2016). Secondly, this study outlines the need for training for staff to recognise the signals of abuse, especially in those who cannot verbally report for cognitive or confidence reasons, and to ensure that appropriate supports are implemented and assured to the service users following the events.

An interesting component of the latter study is that Wissink et al. (2018) estimated that every 1 euro invested in the prevention of child abuse in health and social care settings could provide a reduction of 19 euros in litigation and criminal justice costs. This has financial implications on an international scale in health and social care.

The impact of adverse events on people with intellectual disabilities

The repercussions of adverse events in health and social care can have lasting effects upon people who use services, due not only to the experience of the adverse event itself, but also to the manner in which it is addressed by professionals and service providers. Therefore, open disclosure and managing patient safety is a continual process and the aim should be one of ‘continual reduction’ (Berwick et al., 2013). Essentially ‘healthcare is a uniquely human enterprise, with service consequences that can either add to the joy and comfort of the patient being served or conversely, that can contribute to one’s pain and suffering and even death’ (Cwiek et al., 2018: 3).

Ultimately, listening to and reflecting upon the experiences of patients and service users is fundamental to the development of health and social care settings, as ‘information reported directly by patients can offer insights that cannot be identified through other means’ (OECD, 2017: 16).

However, the process of open disclosure is clearly a significant impediment for many people with intellectual disabilities, as the ability to understand can sometimes present as an obstacle (Cheshire and Wirral Partnership, 2016). Therefore, it is vital that the person can understand the information and, undoubtedly, the importance is in how this information is delivered. Crucially, the apology must be genuine and not a tokenistic task – as Mulkeen (2013) claims, it is incumbent upon health and social care practitioners ‘to ensure that service user participation is not tokenistic but committed to sharing power and knowledge’ (p. 95).

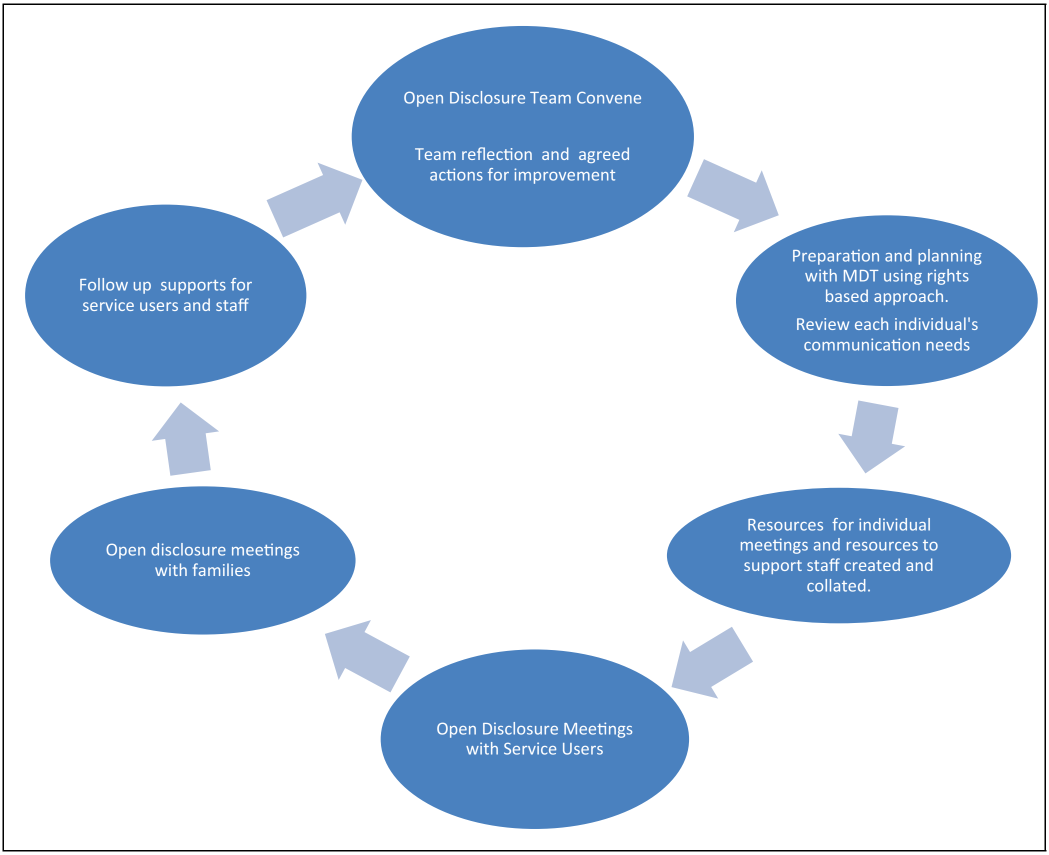

Figure 1. Flowchart of the open disclosure process in a service for people with intellectual disabilities.

Open disclosure – A practical example in an intellectual disability setting

A process of meaningful open disclosure was conducted, following a serious adverse event in an organisation providing a range of day and residential services for children and adults with intellectual disabilities in the Republic of Ireland (see process overview in Figure 1).

The rationale for conducting open disclosure was based on the key question of the service provider: how can we meaningfully conduct open disclosure with a group of men and women with significant intellectual disabilities and communication difficulties, in a manner that is meaningful and most likely to be understood by each individual, following a serious adverse event? Ultimately, there is an obligation to provide an explanation and an apology to persons with an intellectual disability, for the service provider to reassure them of the actions that have been taken to prevent the adverse event from recurring, and to do so in a manner that the person with an intellectual disability is most likely to understand.

In order to implement the open disclosure meetings, an open disclosure team was convened. The people who used the service were entitled to a full apology for what had happened and to seek assurances from the service provider that this event would not re-occur. Thus, weekly meetings were convened to discuss a strategy for managing the open disclosure in a manner that was appropriate to the needs of the men and women who were affected by the adverse event. This team consisted of several senior directors, a senior social worker, clinical director, senior psychologist, speech and language therapist, middle and senior management and quality and safety team members. Planning was a key component of this process. Using a rights-based approach, each meeting with service users was carefully considered, based on the person's individual and communication needs. Crucial to this, was that capacity was assumed for each person and that each service user had a right to receive an apology, in a manner that they could comprehend and that was meaningful to them. The team carefully deliberated the apology pathway. In addition, as service users were adults and were in direct receipt of the service, it was decided that the meetings to apologise would take place with the service users first and then with their family members.

Practical resources were collated and developed to support the person to understand the apology in a manner that best suited their level of understanding and their communication methods. To this end, speech and language therapy guidelines were reviewed for each individual and the team gathered information such as easy read and picture agendas, Lámh signs (augmented signs for people with intellectual disabilities in the Republic of Ireland) and objects of reference (small objects used to support people to predict events or make choices). Additionally, the team prepared for signs of distress and how this is expressed uniquely by each individual. This planning reflects the recommendation by the Irish National Federation of Voluntary Service Providers Providing Services to People with Intellectual Disabilities (2019) that people with intellectual disabilities are entitled to suitable supports and resources, so that information can be shared in an accessible format suited to the needs of the individual.

For some, picture agendas were prepared to support the person through the process of the meeting. For others who used Lámh; it was paramount that the facilitator refreshed themselves on the Lámh signs prior to the meeting.

The open disclosure meetings took place in an environment in which people felt most comfortable. For example, some of the meetings took place in a meeting room/office space in the service, while others took place in another quiet room or the garden, where privacy could be assured and the person was most comfortable. Individual preferred times were also considered: for example, for some service users who generally needed time to ease into their day; afternoon meeting times were deemed more suitable for them.

Service users' reactions varied across the meetings and, significantly, some service users demonstrated a higher level of understanding than the open disclosure team had anticipated at the outset.

The team also planned for the time immediately after the meetings, and enquired into individual activities that might put the person at ease and signal to them that the meetings were finished. Activities varied depending on individual preferences, such as an appointment with the massage therapist, or trips to the city centre or the park.

Following the open disclosure meetings, supports were commissioned for the service users immediately, and ongoing supports were implemented as required. These supports included psychology and social work input for the individuals. Additional ongoing support was provided for those who required it. Furthermore, staff supports were included for staff members prior to and following the meetings, as it was recognised that staff members are often the second victims involved in open disclosure (HSE, 2019). In addition, support fact sheets were developed by the team, to advise staff working directly with the service users involved in the open disclosure process, on what to expect and how to communicate with people who might be distressed following the meetings. Some items on the fact sheet included a script for staff in response to questions from service users or families. It also advised on what to expect after open disclosure meetings; that service users may be upset after meetings and may need more reassurance, and that family members may call more frequently, ask questions or seek reassurance.

Follow-up supports were provided on an individual basis. After the open disclosure meetings were conducted, the open disclosure team contacted the staff in the service the following day to check in on both service users and staff. Following this, the members of the multidisciplinary team were consulted where service users showed signs of upset to arrange supports.

Moreover, staff members received coaching and support in preparation for any concerns or queries that they might receive from family members. Additionally, staff members were counselled to expect the possibility that in cases such as these, open disclosure may potentially lead to further disclosures by the service users. Therefore, guidance on the *Safeguarding* and *Trust in Care* policies (National Safeguarding policies in the Republic of Ireland) (HSE, 2005, 2014), was provided as a refresher to equip staff members with the necessary skills and guidelines of the process in such cases.

Reflections following open disclosure

Following the open disclosure and support meetings with service users, family members and staff, the team convened for further meetings to reflect upon the learning gleaned from the process. The team also reflected upon further improvements for the future, such as applying the easy read/picture agenda for the open disclosure meeting, or a personal device for service users who use personal iPads or tablets, as an appropriate media to convey the message in a supportive manner. The team also discussed how the service user might also be encouraged to bring essential oils or personal comfort items (such as a blanket or a fidget bag) used by them to the meeting, to offer further reassurance to the service user. Vital learning from the process included the key insight from families that full disclosure of all the findings is paramount; after all, ‘families can suffer in two ways, first from the incident itself and second from the way it is handled by the healthcare organisation concerned’ (Pinto et al., 2012: 1001).

Significantly, one of the key challenges that emerged during the process was the apparent lack of practical resources or academic literature to guide the team to openly disclose to people with intellectual disabilities. An online search of the literature specifically relating to open disclosure and intellectual disability was conducted on 24 search engines. Further, a member of the team contacted other service providers for people with intellectual disabilities overseas in the UK, United States and Australia to ascertain if they had any accessible resources. Notably this search revealed an apparent lack of available resources for engaging with people with an intellectual disability in an open disclosure process, and critically, in a wider context, knowledge gaps hinder opportunities to better understand and improve performance in healthcare (OECD, 2017).

Therefore, in order to resolve this issue, a toolbox of resources was developed by the team to support the service users and staff of the organisation for any future adverse events. These included picture agenda templates for use with service users in open disclosure meetings, fact sheets and coaching scripts for staff members. In addition, the organisation developed an Accessible/Easy Read Open Disclosure Policy, in conjunction with service users, as this learning has implications for improved practice and learning for intellectual disability service providers on both national and international levels.

Conclusion

While patient and service user safety incidents are unavoidable in the complex field of health and social care, it is the reflection and the corrective actions applied that can provide an improved healthcare experience for the people who use the service.

A process of continual reduction and a commitment to apologise for the harm or distress caused, through meaningful open disclosure, is required to prevent further harm or distress to the person after the event. There are improvements to be gleaned from the benefits of open disclosure and transparency for the experience of those receiving care, and in the reduction of litigation claims for the health care provider.

The growing body of literature on the topic of open disclosure is evident; however, an apparent lack of resources and literature exists for people with intellectual disabilities and their associated service providers. While evidence suggests that a high percentage of patient safety incidents remain undisclosed, it is likely that for people with intellectual disabilities the number is far greater. In addition, there may be a perception that a person with an intellectual disability lacks understanding and therefore may not understand the apology. However, this practice innovation highlights the importance of apologising to people with intellectual disabilities, following adverse events, in a meaningful way and presents an innovative pathway using resources to support people with intellectual disabilities in open disclosure meetings.

It is recommended here that empirical research on the open disclosure process, and specifically on the exploration of experiences for people with intellectual disabilities, takes place to reduce the gap in literature and research.

This practice example of open disclosure in non-acute services for adults with intellectual disabilities has implications for improved practice for non-acute health and social care providers on national and international levels.

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