Ensuring meaningful access to easy-to-read information: A case study

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Accessible Summary: This article is about easy-to-read information and how to make sure that it is really accessible for people with intellectual disability. We carried out research in a day centre and spoke to service users and staff about how they use easy-to-read information. We found that there are a lot of factors which influence the lives of service users with intellectual disability and the use of easy-to-read documents. Background: This article presents research on the use of easy-to-read documents to ensure meaningful access to information for persons with intellectual disability. The research questions focus on the factors that influence the use of easy-to-read documents and what needs to be considered to ensure that these documents are used meaningfully. Materials and Methods: A case study was carried out in a day centre for persons with intellectual disability in Malta, using a focus group, an interview and an observation session as research tools. Thematic analysis was used to analyse the data, in conjunction with the social model of disability and an adapted version of Bronfenbrenner's ecosystem model. Results: The research found that the effectiveness of

easy-to-read documents is contingent on a multiplicity of factors which interact with one another. Conclusion: Easy-to-read forms can become more meaningful if these factors are attended to within the wider context.

Introduction

The Convention on the Rights of Persons with Disability (United Nations, [29]) is aimed at ensuring 'individual autonomy including the freedom to make one's own choices, and independence of persons [with disability]' (Article 3a). Amongst others, this aim is achieved through access to information, as set out in Article 9. Therefore, providing easy-to-read information for people with intellectual disability is one way of safeguarding their rights. However, as seen below, literature about easy-to-read information indicates that, on its own, its usefulness is limited.

This article presents a case study of one organisation that provides day services for persons with intellectual disability in Malta. This organisation uses easy-to-read information to enable service users to make informed choices about specific activities. This case study uses an adapted version of Bronfenbrenner's (1979) ecosystem theory to discuss the part played by easy-to-read information within the ecosystem in conjunction with other factors that impinge on the lives of the service users. The research is informed by a social model understanding of disability, distinguishing between cognitive impairment and the socially constructed disabling barriers that create obstacles in the lives of persons with intellectual disability (Williams, 2011).

The central research questions of this study are as follows:

- What factors influence the use of easy-to-read documents in service provision for people with intellectual disability?
- What factors need to be considered to ensure the meaningful use of these documents?

¹ 'Easy-to-read' refers to information that is presented in a way that is accessible for persons with intellectual disability. See, for example, the standards developed by Inclusion Europe (undated).

By addressing these questions, this study aims to contribute to a greater understanding of the contexts in which easy-to-read information is used and to shed light on those factors that affect its usefulness.

Background

Whilst the importance for people with intellectual disability to have access to information is acknowledged in the research literature, its impact and usefulness are also questioned. Chinn and Homeyard's (2017) meta-review refers to questions about its impact in meeting 'personalized health information needs for people with intellectual disability' (p. 1,189), a question that is also raised by Goodwin, Mason, Williams, and Townsley (2015) regarding information about research. Likewise, Anderson et al. (2017) note that the production of easy-to-read information is not equalled by evidence that supports the effectiveness of its use. Chinn and Homeyard (2017) also highlight concerns about whether its symbolic value is greater than its usefulness. A related concern is when the production and use of easy-to-read information is tokenistic, what Walmsley (2013) calls 'a cosmetic device' (p. 17).

Producing easy-to-read documents for persons with intellectual disability is therefore not enough (Walmsley, 2013). Oldrieve and Waight (2013) focus on the importance of starting with screening for the support needs of individuals with intellectual disability in a structured manner in order to establish the adaptations needed for the service users to comprehend the information. The authors argue that one needs 'to modify the content and the method of delivery so that it has value and meaning for people with learning disabilities' (p. 6).

The production of easy-to-read information is also discussed in the research literature, most notably by Anderson et al. (2017). Some of the articles reviewed by Chinn and Homeyard (2017) focus on the production of such information and highlight the value of involving people with intellectual disability in the process. However, Mander (2015) notes that the rate of progress in producing easy-to-read information has not been paralleled by progress in delivering it to its target audience, whilst Townsley, Rodgers, and Folkes (2003) point out that one must facilitate access to easy-to-read information and ensure that the people for whom it is intended can understand it. Walmsley (2013) discusses how simplifying complex ideas can risk misinformation, especially when important material is left out because it is considered too complicated to include in easy-to-read versions of already-existing

documents. In their systematic review, Sutherland and Isherwood (2016) also highlight these issues and point out the importance of attending to each person's support needs in understanding easy-to-read information and to check for understanding.

Guidelines are available for producing easy-to-read information (such as those outlined by Townsley et al. (2003). Some authors also refer to alternative ways of producing and presenting easy-to-read information. Oldrieve and Waight (2013) refer to videos, computer-aided information and easy-to-read websites. The usefulness of video in providing accessible information for persons with intellectual disability is also highlighted by Goodwin et al. (2015).

Therefore, the literature in the area of easy-to-read information indicates that its usefulness emerges when it is individually tailored according to the needs and aptitudes of each person with intellectual disability, and when it is used 'as a process of supporting understanding and comprehension needs and not just a resource' (Mander, 2015, p. 85).

Methodology

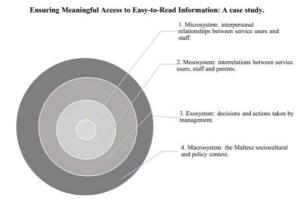
The case-study approach, adopted for this research, 'involves the study of a case within a real-life, contemporary context or setting' (Creswell, 2013, p. 97). The case chosen was a day centre run by 'PromotAbility' where easy-to-read forms are used to enable service users with intellectual disability to decide whether to participate in activities that take place outside the routine programme, including day outings and evening activities. A specific template is followed for these forms. The easy-to-read form about the activity is presented on two A4 sheets, with photographs in the left-hand column and the corresponding text on the right. The text is written in an informal manner, using a sans serif font. At the end of the document, there is a yes/no option where service users can mark their preference.

The research method comprised a focus group with five support workers at the day centre who make use of the easy-to-read forms; an observation session with eight service users who already had experience with using these forms; and a semi-structured interview with a manager within PromotAbility who was involved in initiating the use of the easy-to-read forms—all of which were audio-recorded with the participants' consent. An interview guide was used during both the focus group and the semi-structured interview. Questions revolved on the development and use of easy-to-read forms at the day centre and their personal

thoughts on their effectiveness. Ethical approval was obtained from PromotAbility as well as from the University Research Ethics Committee. The research was carried out according to the ethical requirements of these two entities. All names used, including that of the organisation, are pseudonyms. After transcribing the recordings, a thematic analysis of the research data was carried out, using the six steps identified by Clarke and Braun (2013). We first created tables with three columns: the first for the transcripts—which we broke into small units, placing each one in a separate row; the second for the code derived from each unit; and the third for the themes that we constructed to assemble the codes. We then reviewed the themes and checked them back with the codes and the data before finalising them. These themes were used as headings in the Results section below.

As Braun and Clarke (2012) point out, thematic analysis can be used with various conceptual frameworks. In fact, we used Bronfenbrenner's (1979) ecosystem theory as part of our methodology. As Palareti and Berti (2009) explain, Bronfenbrenner's ecosystem at once takes into account 'distal environments' and 'interrelationships and connections ... that govern the individual's functioning' (pp. 1082–1083). Lerner (2005) notes how Bronfenbrenner's 'ideas ... have stood the test of time' (p. xii). These ideas have in fact been further developed, including by Bronfenbrenner himself (see, e.g., Bronfenbrenner (2005)). Within disability studies, Hollomotz (2009) has used the ecological model to investigate the risk of sexual violence against people with intellectual disability.

Bronfenbrenner's ecosystem comprises the microsystem, mesosytem, exosystem, macrosystem and chronosystem. Since the latter refers to life transitions, we have not included it in our adaptation of Bronfenbrenner's model, as set out in the figure below.



Adaptation of Bronfenbrenner's Ecosystem [Colour figure can be viewed at wileyonlinelibrary.com]

As explained above, the research results presented in the next section are arranged according to the themes elicited during the thematic analysis. The subsequent discussion is informed by our adaptation of Bronfenbrenner's ecosystem and the social model of disability.

Results

This section discusses the main themes which emerged from the focus group with staff at the day centre (John, Jane, Jennifer, Joyce and Jessica), the observation session with service users (including Mary and Martha who are mentioned below) and the interview with Albert, a manager from PromotAbility, with reference to the research literature. The service users involved had different levels of verbal communication skills, with three being able to converse quite easily and the other two responding with one word answers and needing considerable guidance to be able to understand the information presented.

Choices made within structures determined by others

Albert explained that PromotAbility management's decision to implement the easy-to-read forms in day services was prompted by the introduction of standards for residential services for disabled persons which require service users to get involved in decisions concerning them (Working Group of the National Standards for Persons with Disabilities, 2014). Albert said:

when we introduced the forms in the day centres, we organised a meeting with the parents.

The aim of the forms is to inform service users about specific activities and to get them accustomed to accessible information. This approach is in line with Buell's (2018) argument that people with intellectual disability need to continue developing their understanding of easy-to-read information, since comprehension is affected by familiarity with the words used and the ability for the person to link the information with their own experience.

These easy-to-read forms are currently only used for nonroutine activities. During the normal course of the day, different modes are used to offer choices but mainly flash cards and verbal explanation (Jane).

While the ultimate goal is to increase 'the spread of 'easy information' (Goodwin et al., 2015, p.95), service users are largely able to express choices only within structures determined by

others—in this case by PromotAbility staff.

Importance of individualisation

During the focus group, support workers acknowledged that using the same easy-to-read template for each activity fails to cater for the various impairment-related needs of the service users. In an attempt to offset this shortcoming, each form is explained to every service-user on an individual basis:

First we disseminate the easy-to-read form, and then we go through the forms with each client one at a time. (Jane)

This method was observed during the session with the service users. Each explanation differed from the next—there were some service users who could comprehend the pictures, and the support workers went through the form to ensure their understanding. For example, Jennifer is here working with Mary regarding an activity that was being held in hot weather.

Jennifer: What do you need to bring with you for the activity?

Mary: Cap, water and money.

Conversely, other service users had difficulties understanding the easy-to-read form so the support workers provided a full explanation of the activity whilst pointing to the different pictures. Staff were also aware of the need to take a step back and avoid influencing or overriding service users' choices:

Would you want to go to the outing? Yes or no? (Jennifer)

Firstly, the support workers described the overall layout of the form, whilst pointing towards each picture to explain what the activity entails:

here there are the pictures of where we are going and on the other side there are the words (Joyce)

Service users were asked questions that gauged their level of understanding, in order to avoid unnecessary explanations:

if you see this [pointing to a calendar picture], do you understand this? (Jennifer)

Despite these efforts, not all service users could understand the forms and the support workers' explanations. In fact, Martha kept insisting that she would like to go to the activity,

even though she was told repeatedly that this was a practice session. This is in agreement with the findings of Poncelas and Murphy (2007) study that the provision of symbols with text did not always enhance understanding amongst their participants.

The role of support workers

The observation session highlighted the asymmetrical relationship between the support workers and service users. Even though support workers sought feedback from the service users to gauge their comprehension, the latter's responses did not influence the pace of the session. The support workers moved on to the next picture, even though the service users did not always understand the previous one. The pace of the individualised explanation thus remained mainly controlled by the support workers. Chinn and Homeyard (2017) comment on similar observational sessions, where the relationship between the sender (support workers) and the receiver (service users) was 'controlled by the sender' (p. 1196).

On the other hand, the support workers highlighted some shortcomings of the easy-to-read forms, such as the small font size and black and white pictures. Furthermore, they questioned the value of using easy-to-read forms with service users who are able to comprehend instructions and verbally communicate their wishes:

if the clients can understand and can communicate verbally, there is no need for the easy-to-read because you can sit next to them and chat. (John)

Powerlessness of staff and service users

As noted in the Introduction, access to information is a human right, and this was also recognised by the support workers:

it's a fundamental right of every human being. (John)

Although PromotAbility introduced easy-to-read information to empower personal decisions amongst service users, both support workers and the manager strongly emphasised that the service users' answer is not a final one:

a choice is being offered but the choice is not 100% yours. (John)

At times, parents overrule their son or daughter's wish either due to disagreement with their choice or due to other practical limitations, as seen later. Such overturning of decisions already taken reinforces feelings of powerlessness amongst both service users and staff.

service users are guided to make a personal choice which is subsequently not respected. Staff, on the other hand, are aware of the conundrum but are unable to contest the parents' decisions:

whatever we do, parents still take the final decision. (Albert)

Staff attributed this behaviour to the fact that parents do not always fully understand the purpose of the easy-to-read forms:

I take the decision and sign for my son and not him. (John quoting a particular parent) The support workers claimed that this is especially true of elderly parents, who are used to acting as their child's advocate and deciding on his/her behalf (Franklin & Sloper, 2009).

Provision of information and its use

When parents alter the service-user's decision, the easy-to-read form is reduced to a source of information about an upcoming activity rather than a tool which facilitates choice. Similarly, the benefit of the form is diminished when it omits details which service users might deem important. For instance, the forms do not mention if an activity is being held in a very noisy environment. Consequently, the information provided may be deceiving as it 'only pictures the positive aspect of the activity' (Joyce) and excludes negative information which can result in unmet expectations:

I feel that if we are going to inform the clients, we have to prepare them to the full and not saying only the positive side and then they find a different reality. (John)

The support workers also questioned the extent to which the concepts of time and place, which underlie all the easy-to-read forms, are grasped by certain service users. Walmsley (2003) claims that persons with intellectual disabilities may fail to understand easy-to-read forms that describe abstract concepts, potentially making these forms confusing. This highlights the importance of individualisation and of attending to context in order to promote the empowerment of service users with different impairment-related needs.

Practical issues and alternatives to easy-to-read forms

Support workers claimed that one of the main drawbacks of the easy-to-read forms is that they are time consuming to produce:

the forms can be used for all the activities we do at the day centre but their production requires a lot of time. (John)

Other issues arise from parents' struggles with logistical matters, such as transport, cost and timing. Staff are aware that, unfortunately, parents may overrule their adult child's decision because PromotAbility cannot accommodate for the needs of each and every family:

some opt out of the activity because of financial problems ... (Jessica)

Another issue of concern to the staff revolved around nonverbal service users, as they remain unable to communicate their decision through the system used and thus depend entirely on the choices of their parents. Incidentally, no mention was made on the use of augmentative and alternative communication. Staff who participated in the study by Mander (2015) also claimed that there is the need for more resources, such as time and communication aides, to make easy-to-read information more effective.

Staff members in this study believed that other alternatives to easy-to-read forms may be more effective. Videos or visual images provide more information about the venue and its facilities:

a video can facilitate understanding. (Jessica)

Videos are also recommended by Goodwin et al. (2015). It was suggested that easy-to-read forms could be presented on a screen rather than printed out. This measure was favoured by the staff because it provides flexibility in changing the details provided, the font and picture size, and is eco-friendly.

Service users' lack of agency

The service users' general lack of agency in their daily lives was another matter of concern both for Albert and for the support workers. Whilst the activities at the day centre aim to empower service users by offering them informed choices and promoting independence, at home, they tend to adopt a passive role. Thus, although support workers strive to encourage service users towards a pro-active approach in their lives, these goals are not being fully attained:

when you place the responsibility on the person, the skills flourish, but when you remove such responsibility he/she becomes dependent on their surroundings. (Albert)

The support workers remarked that such attitudes find their roots in various causes, including lack of time on the part of family members or their fear of the service-user sustaining an injury.

Support workers and parents must therefore promote service users' participation in all their day-to-day decisions:

this idea still needs to become ingrained in our mentality as an agency and also in the persons involved with the service users. (Albert)

These findings show that PromotAbility's introduction of the easy-to-read forms resulted in limited success in enhancing the active contribution of persons with intellectual disability in decision-making. Other factors need to be taken into consideration for the forms' potential to be fully realised. Consequently, the results presented above are now discussed with reference to the ecosystem within which the forms are used.

Analysis of the Ecosystem

As mentioned above, Bronfenbrenner's ecosystem theory was used to shed light on how the various factors impinge on the effectiveness of the easy-to-read forms and how they intertwine with one another. This approach fits well with the social model of disability since it focuses on the barriers that exist in the environment in which the service users are situated. Moreover, the ecosystem's range from the micro to the macro enabled us to consider not only the micro-interactions between staff and service users, but also the immediate and wider settings in which they occurred. We could thus analyse the results of our small-scale study within the context of the overall decision-making processes and of the wider environment, including the systemic barriers that it presents.

The schema presented above is focused on the relationships that affect the lives of people with intellectual disability and that were identified as having a role in ensuring the effectiveness of using the easy-to-read form as a tool for decision-making. The following discussion focuses on these factors.

The microsystem

From the observation session, it was clear that the staff and service users enjoy warm relationships with each other. However, interactions between them were typically initiated by

the staff and service users mainly responded to questions posed to them. This situation reflects the power imbalance that is inherent in most relationships between people with intellectual disability and adults, as also noted by Williams (2011).

It is true that the context in which we carried out our observation was purposely created for research purposes; however, the aim of the session was to recreate the way in which the easy-to-read form is used. Thus, even in a context where staff were actively seeking to give service users more control over what they do during the day, the opportunity for them to voice their opinion was still restricted in scope. Within the microsystem, there is an imbalance of power between service users and staff, with the latter being very much in charge of interactions. The reasons for this situation need to be sought beyond the microsystem itself.

The mesosystem

Whilst the scope of our research did not include the parents of service users as participants, they repeatedly feature in the focus group with staff as well as in the interview with the manager. Parents emerge as an important reference point in the lives of service users and interactions with staff. Thus, the mesosystem is tripartite: service users, staff and parents. The fact that parents feature in this system without being directly involved in the research, or in the activities held at the day centre, highlights the important role they play in the lives of people with intellectual disability, including within the context of the day centre.

Within this tripartite mesosystem, there are the interrelations between staff and parents, and between service users and parents to consider. Ultimately, it is the parents who decide what activities their adult children with intellectual disability are involved in. The motivations for the parents' own decisions are also affected by various factors including, as noted above, the timing of certain activities, the family's ability to pay for the activity and other practical arrangements.

The exosystem

Whilst parents exert control over the lives of persons with intellectual disability, they too experience constraints in their lives. For example, if it is due to lack of money that a parent refuses to let their son/daughter pay to attend an activity, that lack may be due to various reasons, including lack of skills in managing the household budget, the outlay of money to

pay for activities is not considered justifiable, or because the family does not have extra cash to pay for leisure activities. Such constraints can be considered to be part of the exosystem. However, this study focuses on an aspect of the exosystem which is directly related to the use of the easy-to-read forms. As seen in the diagram above, the management of PromotAbility is considered part of the exosystem. In fact, it was at this level that change was brought about through the introduction of the forms. Decisions taken at the exosystem level affect the meso-and microsystems, with the latter two responding to these decisions. Therefore, the potential of the easy-to-read forms to promote choice for service users is limited by the structures of the larger system in which the forms are used. What activities are carried out and what happens during the day is mostly decided by management. These decisions are in turn influenced by other decisions taken at a higher level and by what happens at the macrosystem level.

The macrosystem

The support workers referred to the reluctance of elderly parents to allow their adult children with intellectual disability to decide for themselves. Thus, they are indirectly referring to sociocultural and policy changes that have occurred in Malta over the past decades, which have had an impact on the lives of disabled people and their families. Therefore, whilst none of the research participants referred to sociocultural factors, and only Albert made brief reference to policy, it is important to consider these contexts, which are part of the macrosystem in which the easy-to-read forms are used.

Parents who are now elderly were born at a time when disabled people were mainly seen as a burden. Until the mid-1960s, disabled people were mostly kept hidden by family members (Camilleri & Callus, 2001). However, a Catholic priest, Monsignor Mikiel Azzopardi, brought a sea change in attitudes towards disabled people and worked actively to improve their quality of life. He overturned the discourse on disabled people by speaking of them as angels. As Camilleri and Callus (2001) argue, this terminology 'gave rise to new stereotypes of untouchability which, over the years, have themselves become powerful instruments of oppression' (p. 82). It was within this context that many adults with intellectual disability were raised.

The situation today has improved through the achievements of the disability rights movement, the Equal Opportunities (Persons with Disability) Act (Laws of Malta, 2000) and

the ratification of the Convention on the Rights of Persons with Disability (United Nations, 2006) which have all left their beneficial effects in Malta. Many (mostly state-funded) services support disabled people to be included in mainstream education and in employment and to live in the community (Malta, 2014). However, there remain many areas of concern regarding policy and services, as attested by the Committee on the Rights for Persons with Disabilities (2018) on Malta's state report on the implementation of the Convention.

Some sociocultural factors still impinge negatively on disabled people's lives. Whilst discourse about angels is not as prevalent as it previously was, it is still used (Casha, 2016). Furthermore, disabled people still experience significant degrees of overprotection (Cardona, 2013; Gauci, 2018), especially those who have intellectual disability (Callus, Bonello, Fenech, & Mifsud, 2019). This overprotection is partly caused by inadequate income for disabled people to live independently of their families (Garland, 2015) and insufficient support services for them to be able to take decisions and act on them (Callus et al., 2019). The compound effect of these factors is that people with intellectual disability are seen as being in need of care, which remains primarily the responsibility of the family.

The analysis of our research findings has shown that the interaction between support workers and service users when using the easy-to-read forms is directly influenced by factors which may not be immediately obvious. Attending to these factors is vital if easy-to-read material is to serve the functions for which it is created. It is equally important to consider how the factors interact with each other within the levels of the ecosystem. Each level is influenced by the ones outside it, such that the innermost one is influenced by the most external factors. The location of the person with intellectual disability in this inner level highlights how their lives are controlled by the actions of others. Without addressing these factors, the effectiveness of easy-to-read information remains limited. Even worse, its use can be counterproductive because overturning service users' decisions can reinforce feelings of powerlessness.

Conclusion

Whilst generalisations cannot be drawn from this small-scale study, the research findings are in line with the conclusions reached in the research literature. Using easy-to-read documents is not an automatic guarantee that people with intellectual disability have access to information that affects their lives. Moreover, the very fact that the effect of systemic barriers in the everyday lives of people with intellectual disability emerged even in a study with

limited scope underscores just how significant this effect is, even in micro-interactions between staff and service users and the outcomes of these interactions.

The study therefore highlights the importance of attending to the wider contexts in which easy-to-read documents are used. It throws light on the way in which it is not only persons with intellectual disability who experience constraints in their lives, but also those who live and work with them, who also act within limitations. If the factors that create these constraints are not attended to, easy-to-read information on its own cannot fulfil its potential for empowerment.

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