"Information Needs of the End Users Have Never Been Discussed"

An Investigation of the User-intermediary Interaction of People with Intellectual Impairments

Gerd Berget[†]

Department of Archivistics, Library and Information Science
Oslo Metropolitan University
Oslo, Norway
gerd.berget@oslomet.no

ABSTRACT

Many people with intellectual impairments experience challenges searching for information. Consequently, they rely on intermediaries (e.g. caregivers) to solve their information needs. In the field of IIR, little is known about this user-intermediary interaction. More empirical data is therefore needed, both to understand how to support the intermediaries and increase the possibilities for people with intellectual impairments to solve information needs themselves. In this study, 25 people working with adults with intellectual impairments were interviewed about the information needs of the end users and the routines for solving these needs. The purpose was to explore when and how the user-intermediary interaction occurred. According to this study, most end users had limited access to information sources, and relied almost entirely on intermediaries. Further, the technological skills among the intermediaries seemed to affect access to and use of digital devices. Few end users expressed information needs outside everyday life. Moreover, information needs were given very little attention and solving such needs were not part of the routines at most facilities.

CCS CONCEPTS

• Information systems $\rightarrow$ Information retrieval $\rightarrow$ Users and interactive retrieval • Human-centred computing $\rightarrow$ Accessibility $\rightarrow$ Empirical studies in accessibility

KEYWORDS

User-intermediary interaction, Information needs, Information seeking, Information behavior, Intellectual impairments

1 Introduction

According to Dorner, Gorman and Calvert [1], solving information needs is critical for people to satisfy basic human needs. Nevertheless, certain user groups are excluded from information searching. Potential barriers are impaired functional level, limited access to technology or information sources and inaccessible user interfaces. Consequently, not all people can solve their information needs. One such group is people with certain intellectual impairments.

This paper applies the term 'intellectual impairment' when referring to the cohort. 'Cognitive impairment' is a too broad category, comprising several conditions (e.g. dyslexia, dementia, autism and Down syndrome) with very different characteristics. Further, it has been argued that the terms 'learning impairment' or 'developmental impairment' are ambiguous [2]. There may also be differences between nations regarding terminology [3]. 'Intellectual impairment' is the term mostly applied in Norway, where the study was conducted.

The term intellectual impairment can comprise a variety of diagnoses, which occur in many forms. World Health Organization [4] has classified intellectual impairments into different categories in *the International Classification of Diseases* (see Table 1). The cognitive profile of this cohort typically entails some degree of limited language, requirements of support to acquire independent living and often reduced motor skills [4]. Due to limited writing and language abilities, many people may find it challenging to solve and communicate information needs. Nevertheless, this user group has information needs equal to everyone else, for instance health-related issues [5, 6]. This cohort, however, typically have to rely on others to solve their information needs. Examples of intermediaries are family members, teachers or caregivers such as health workers or assistants [7].

Category	Language	Self-care	Requirements
6A00.0 Mild intellectual development	Challenges in acquiring complex language	Mastered by most users	Can acquire relatively independent living as adults, but may require some support
6A00.1 Moderate intellectual development	Basic skills	Mastered by some users	Considerable and consistent support to achieve independent living and employment
6A00.2 Severe intellectual development	Very limited language	May have motor impairments and require daily support	Require daily support in a supervised environment for adequate care
600.3 Profound intellectual development	Very limited language	May have co-occurring motor and sensory impairments	Typically require daily support in a supervised environment for adequate care

Table 1: Categories from ICD-11 [4]

Within the field of interactive information retrieval (IIR), there is much empirical evidence on how people interact with search systems of various types. Further, the systems keep evolving as the needs and behavior of users are better understood. For people with more severe intellectual impairments, however, it is not possible to evaluate the interaction with search systems, since such interaction typically does not occur. Consequently, when evaluating the search behavior of people with moderate to profound intellectual impairments, one has to study the user-intermediary interaction with the caregivers. Important components of this interaction are how information needs are communicated, perceived and solved.

A growing number of studies have investigated the information retrieval of people with intellectual impairments [8-10], such as Down syndrome [11, 12] and Autism spectrum disorder (ASD) [7]. Nevertheless, there is still little empirical evidence concerning the information retrieval of people with moderate to profound intellectual impairments. Except for one study of mediated information searching of children with ASD [7], most studies focus on people who utilize search systems themselves, at least to a certain degree. Consequently, there is a particular gap regarding adults who rely on intermediaries for information searching. According to Dowse [13], research on people with intellectual impairments has rarely addressed lived experiences, but rather focused on prevention and care. Access to information, however, may be considered as a basic human need [1] that should also be addressed.

The purpose of this study was to explore whether the needs of adults with intellectual impairments are sufficiently attended to, how to enhance this cohort's access to information and support the intermediaries. A qualitative approach was applied through semi-structured interviews with 25 intermediaries. The assumption was that attitudes towards information needs, time allocation and technological skills among the intermediaries would affect the user-intermediary interaction. The aim was to investigate whether information needs were regarded as a basic need or outside the caregivers' sphere of responsibility, and consequently whether information needs were paid sufficient attention.

2 Background

2.1 Intellectual Impairments and IIR

The term intellectual impairment comprises a variety of conditions, which occur in several degrees and with different profiles. One example is language capacity. Within one impairment type, language might be easily acquired for people with a mild condition, while others may not have any acquired language [14, 15]. Consequently, in certain contexts it might be more purposeful to apply functional level as inclusion criterion rather than condition.

People with intellectual impairments are not frequently included in IIR studies, especially not the most severe categories who rely on intermediaries for solving information needs. Some researchers, however, have studied mild to moderate impairments. Williams [16] reported common barriers experienced online by this cohort, among others finding content from large quantities of text, navigating pages and scrolling. Harrysson, Svensk and Johansson [17] found challenges with query input, result list assessment and extracting useful content. Although some people with intellectual impairments have sufficient skills for information searching, it has been reported that a lack of confidence often results in users requiring help to solve their needs [10].

Salmerón, Fajardo and Gómez-Puerta [18] investigated how 43 adults with intellectual impairments evaluated trustworthy content online, and found that the participants selected trustworthy and relevant information when searching for familiar topics. In contrast, searching and result list assessment were more random for less familiar topics. The authors [18] concluded that one should not overprotect this group when searching for familiar topics, while at the same time provide more support when searching for less familiar topics. Overprotection was also discussed by Williams [3] in the context of recruitment for research projects, where it was reported that people working with this user group may be reluctant to provide access to this cohort for researchers.

Searching has been reported to be demanding for people with intellectual impairments [17]. Nevertheless, searching is suggested to be more purposeful than browsing [11, 19]. Query input has been explored by several researchers. In a study including six participants with different types of cognitive impairments (Down syndrome, ADHD, ASD, Turner syndrome and Traumatic Brain Injury), Nour [12] investigated different forms for query input methods in Google, namely typing and voice searching. Nour [12] found different preferences (which might be related to the variety of conditions included), and advocated a flexible approach in search user interface design. Rocha et al. [8] studied how people with intellectual impairments applied two search engines, namely Google and SAPO. Speech recognition was found to be purposeful, but must be robust and precise enough to handle unclear word pronunciation, which is often a challenge for this cohort.

Hu and Feng [11] explored how people with various cognitive impairments (mainly Down syndrome, but also Cerebral Palsy and Neurological impairment) used a specially designed website called "Mini-Library". Participants were more efficient searching with keywords compared to browsing. According to Williams and

Hennig [20] horizontal browsing structures are more useful than vertical ones for this group, suggesting that scrolling long result lists might be challenging.

Few studies have addressed information seeking and needs. Hanson-Baldauf [9] investigated everyday life information challenges of four people with intellectual impairments and found barriers on several levels related to information needs and practices. The barriers were intrapersonal, physical, economic, social and institutional. More work is needed to understand how to reduce or remove such barriers. Hanson-Baldauf [9], however, emphasizes cognitively accessible information and argues that knowledge level and skills should be considered to better understand the everyday life information needs of this cohort. These findings are coherent with Harrysson et al. [17], who looked into the navigation of people with intellectual impairments, and reported challenges when absorbing information and making selections from large amounts of text due to impaired readings skills.

Chiner, Gómez-Puerta and Cardona-Moltó [21] suggest paying more attention to the people that support end users with intellectual impairments, since they can facilitate access to the Web. Chiner, Gómez-Puerta and Cardona-Moltó [22] also found a need for training programs targeted at people with intellectual impairments, since this group is exposed to risk and often engage in undesired behavior. There is also a need for more knowledge about the circumstances where the Web is used by people with intellectual impairments [22].

Several researchers [16, 23-24] have reported that in the development of accessibility tools and user studies, people with intellectual impairments have been heavily overlooked. Based on the existing research regarding this cohort, a common finding seems to be barriers towards information searching caused by inaccessible information or search systems. More empirical data is needed concerning which sources this user group actually utilizes. This gap is the foundation for the two first research questions applied in this study:

RQ₁: Which types of information sources do adults with mild to profound intellectual impairments have access to and utilize?

RQ₂: How do technological skills among intermediaries affect the end users' access to digital information sources?

2.2 User-intermediary Interaction

User-intermediary interaction or mediated searching, refers to information retrieval with interaction between a user, a search intermediary and an information retrieval system [25]. User-intermediary interaction is, among others, represented in the research literature in the triadic model by Saracevic, Mokros and Su [26]. This model describes the user, computer and intermediary and the interaction between these three elements. In this model, relevant user characteristics include demographics, question and context, while the intermediary comprises demographics and experience, perception of user question and context. The interaction process covers effectiveness and communication.

In previous research, intermediaries are typically represented by librarians or information professionals. However, other people can function as intermediaries. According to Belkin [27], an intermediary is a human being "*whose task is to mediate between the users' desires, requirements, knowledge [...] and the knowledge resource's content, representation and organization, in order to produce a response to the user*". Belkin [27] discussed, among others, how effective information transfer relies on the communication between the user and intermediary. Further, Belkin [27] studied the cognitive communication system, and emphasized the intermediary's model of the user in the context of knowledge states, problems and problematic situations and goals.

Ellis et al. [25] claim that interaction between the intermediary and the user has clear importance as a means to achieve effective information retrieval, and this interaction affects the search process. Moreover, key elements in the interaction are feedback loops and iterative cycles within the search process [25]. Consequently, both Belkin [27] and Ellis et al. [25] regard the role of communication and information transfer as important in user-intermediary interaction. These components are the focus of this study.

A few studies have addressed the attitudes among caregivers, either family members or staff, towards information seeking. Previous research, however, has mainly addressed issues such as concerns, prevention strategies and training needs when people with intellectual impairments search for online information on their own. Caregivers have been reported to be ambivalent towards the end users being online, expressing concerns about potential risks, while at the same time stating that such technology promotes independence [21].

According to Bohman and Anderson [23], the more severe a cognitive impairment is, the more likely it is that that the user needs a personal assistant for accessing and using the Web. In other words, there is a higher need for user-intermediary interaction as the impairment increases. Nevertheless, IIR studies typically address people who can conduct searching on their own. Less attention has been directed towards users who rely on intermediaries for solving information needs. Consequently, there is a gap of knowledge concerning people with more severe intellectual impairments.

One exception is Bilal [7], who investigated the mediated information needs of children with ASD, collecting data from 17 intermediaries, mostly parents. The main findings were that the participants used several information systems, and acted as information proxies for their children. Children with ASD were therefore regarded as silent information seekers. Moreover, the parents knew little about their children's abilities to search.

This study was inspired by the work of Bilal [7], but directed the attention towards adult end users. Moreover, the intermediaries were not family members, but rather professional caregivers and teachers. Research question three and four are based on how various characteristics among the intermediaries affect the user-intermediary interaction, namely awareness and perceptions of information needs (RQ₃) and routines for solving information needs (RQ₄).

RQ₃: What are the perceptions among intermediaries regarding information needs of end users with mild to profound intellectual impairments?

RQ₄: How are the information needs of adults with mild to profound intellectual impairments attended do?

3   Methods

3.1 Procedure

In the period March to May 2019, 25 semi-structured interviews were conducted with professional caregivers and teachers in Norway. The inclusion criteria were as follows: the participant had to be above 18 years of age and have worked closely with end users with intellectual impairments for at least two years. Moreover, people were recruited to represent different categories of intellectual impairments, based on the ICD-classification [4].

The interviews were based on a semi-structured interview guide asking questions related to access to information sources, perceptions of and attitudes towards information needs and how information needs were solved. The interview guide had been piloted, to ensure that no questions violated the professional secrecy. The interviews were recorded. The recorder was not turned on until the participant had received extensive information about the study and signed an informed consent form. Each interview lasted on average for 38 minutes. The dataset comprised 15 hours and 48 minutes of recordings. The interviews were transcribed and coded using thematical analysis, based on the main topics in the research questions.

3.2 Participants

The participants comprised 21 females (84%) and 4 males (16%). This corresponds with the gender distribution in this sector in Norway, where 83.6% of the health- and social workers are female and 16.4% are male [28]. Participants were aged 29 to 64, with an average age of 48.4 years. The average experience with this user group was 18.6 years. The participants worked in five different counties and represented various facilities, namely upper secondary schools, sheltered workshops, activity centers and group homes. Sheltered workshops refer to workplaces especially designed for people with impairments to provide a safe environment and purposeful everyday activities. Activity centers provide various activities and interaction with other people, but with less focus on work-related tasks. A group home is an alternative to institutional care, organized as private residences, providing professional caregivers to support independent living.

The participants had different professional backgrounds, such as social workers, teachers and welfare nurses, and were working both within civic services and in the private sector. Parents or other family members were deliberately not included in the study for two reasons. First, it was a purpose to understand whether the needs of adults who rely on daily support to acquire independent living were sufficiently attended to within the healthcare system. Second, family members may be more subjective, and it was an aim to get a more objective perspective on the end users. A possible limitation in this study is overprotection, which is reported for both family members and professionals [3, 7, 18]. Consequently, this is an issue that one has to be aware of during data collection and analyses.

3.3 Ethics

The project was ethically screened and approved by the Norwegian Centre for Research Data (project number #561020). The participants signed consent forms and all data was anonymized. No participants had any previous relations to the researcher and could withdraw from the study or terminate the sessions at any time without justifying this decision. The end users i.e. the users with intellectual impairments remained anonymous to the interviewer, and the professional secrecy was not violated.

4 Results

The participants were asked about various aspects of the information seeking and information needs of their users (hereby referred to as "end users"). The main interview topics were access to information sources in general (RQ₁) and digital resources in particular (RQ₂), awareness and perceptions of information needs (RQ₃) and how information needs were solved (RQ₄).

4.1 RQ₁ Access to Information Sources

The end users' access to information sources comprised both printed and digital resources, from cookbooks and atlas to digital devices and online search engines. The access to information sources varied with the type of facility (e.g. schools versus activity centers). However, the overall access was very limited. In the group homes, there were typically few or no information sources available in common rooms (except for cookbooks in certain common kitchen areas), neither printed nor digital sources. The residents typically had such materials in their apartments, and relied on acquiring materials such as books and tablets themselves or through family members. Few end users had acquired printed materials. In the sheltered workshops and activity centers, information sources were absent, both in printed and digital format. Few end users visited the library, and almost none borrowed books. In contrast, the two participants representing upper secondary schools reported that the end users had access to various information sources.

In total, 14 participants said that some of the end users with mild impairment had access to technological devices such as mobile phones and tablets, and some applied them frequently. Information searching was not a common activity, however. These devices were typically not used as information sources, but for playing music, watching films, gaming and social media.

A great potential in various technological devices was reported by 12 participants, but this issue was not sufficiently attended to. The underestimation of users was commented on by one participant as follows (when referring to users with mild impairments using Google): "*They typically manage more than we think*" (P07). Another participant elaborated on the same topic and put forward the argument that one should try various devices: "*One often thinks for them. Why not test and see what happens? Then, at least, one has the foundation to conclude that it was too advanced*" (P17). Another caregiver said, when asked about the technological skills among the end users: "*I don't know, because we haven't really tested that*" (P23). Moreover, one caregiver reflected upon the lack of renewal in her sector, and how this could

negatively affect the end users: "*If there is a user group that falls behind, it is these users. There seems to be a 'this is the way we always have done things' kind of thinking with these users. Can't we try something new?*" (P25).

Only a few end users applied digital devices to search for information, mainly Google. In addition, some people with moderate to profound impairment had access to Gridpads. However, these tablets were only used for communication purposes, and may therefore not be regarded as an information source in this context. Except for in educational settings, the end users relied almost exclusively on informal information sources, represented by caregivers or family members.

4.2 RQ₂ Technological Skills among Caregivers

Technological skills among caregivers were reported to impact access to and utilization of digital information sources. It was mentioned by six participants that young end users often had much higher skills than their caregivers. For instance, one participant said: "*Now we have some challenges related to the users with mild impairment. They are younger, so they use mobile phones, they have Facebook and other social media. We are not used to this at all!*" (P05). This statement was supported by one of the teachers who confirmed that technological skills and digital literacy were now specific areas of commitment at school: "*The goal now is to get more pupils to get their own ipad (…) we are going to find suitable apps that the pupils can use, and increase the competence in the entire academic environment*" (P24).

It was typically the end users in the mild to moderate impairment categories who had access to digital devices. Creating accounts and inputting passwords were tasks that some end users would acquire help with, while using apps would be manageable. This issue was discussed by a nurse: "*I see that many users get smartphones, but it varies how much they can use them, and I am not sure how much help the staff can provide them with*"   (P16). Consequently, lacking skills among the staff represented a serious barrier, especially for young end users. Insufficient skills were also mentioned as affecting the acquisition of technological devices. Caregivers typically assisted the end users when buying phones, and sometimes they ended up with feature phones that could not connect to the Internet. Apparently, certain caregivers thought such devices were most suitable. This was reflected upon by one of the participants as follows: "*Large, accessible buttons and no content! That hinders us caregivers, as well*" (P16).

Regarding the young end users, one participant elaborated on how their limited access to technology caused a digital divide, where the end users missed out on an important aspect of being a teen: "*It is a bit coincidental whether the staff is interested in introducing the technology (…) I have teenage kids at home, and their everyday life is very different from most of the users at activity centers*" (P04).

One participant addressed elderly people, and said that few of these end users were introduced to technology. This digital divide was explained as follows: "*There is a problematic theory that has never been proved, that people with intellectual impairments above a certain age cannot learn new things, and then there is no point in teaching them anything. Should we then remove all stimulus because they cannot learn anymore?*" (P05).

4.3 RQ₃ Information Needs

The interviews comprised various questions concerning the information needs of the end users. Key topics were whether users with intellectual impairments actually expressed information needs and how these needs were perceived by the caregivers.

4.3.1 Do the End Users Express Information Needs?
When asked whether their end users often expressed information needs, 22 answered yes, while three said no. Typical examples of information needs regarded activity- and shift schedules, which were typically described as "*personal information needs*" (P20). One of the participants elaborated on this issue: "*It is mostly about here and now with these users*" (P13). Another referred to the information needs evolving around "*the same old rut, in the bubble they are living in*" (P16).

All participants except for five people said that everyday information needs occurred on a daily basis. There was only one participant who had never experienced any information needs being expressed, and related this to a fear of disclosing insufficient skills: "*Some of these users are in the upper level of intellectual impairment (…) they don't want that diagnosis, so they conceal that they don't know the time, cannot read bus schedules etc.*" (P11).

When asked about other types of information needs, not concerning daily routines, 21 participants claimed that such information needs never occurred. For instance, one participant said: "*These major things, like society and such… I am thinking that they do not want to get any information about that. However, their everyday, and who will be at work, are things they need to a considerable degree. So it's mostly about what affects them there and then in the moment, really*" (P23). Another referred to the information needs as follows: "*They have only asked simple questions*" (P19). In contrast, only four participants reported that their end users had more advanced information needs, merely referring to end users in the mild impairment category.

There were several explanations for why advanced information needs were not given attention. The most common reasons were impaired cognitive skills of the end users, lack of time among the caregivers and no awareness of this topic in the facility. Regarding the cognitive state of the end users, it was claimed by 16 participants that the end users did not have the cognitive capacity for having more advanced information needs exceeding everyday routines. For instance, one participant said: "*They don't have the skills for that*" (P02). Another caregiver working with severe to profound impairments stated: "*It is difficult to imagine what other types of information needs they might have*" (P13).

Time restrictions was one highly occurring explanation for not addressing information needs. For many caregivers, information needs were not regarded as basic needs within their work tasks, for instance: "*They have other basic needs that have to be covered, so they come first*" (P02). It was also emphasized that if the caregivers took one's time, the end users would communicate more advanced information needs: "*They talk a mile and minute when you have*

adjusted your time to understand. We have to focus on their lives, not dinner" (P08).

Another issue was that the caregivers had not really thought about information needs in this context, except for a need for information about their everyday lives, which was mostly related to communication. A total of seven participants mentioned specifically that information needs were something they had never thought about before. One participant said: "*No, that is not a focus. I just have to say that before you contacted me, I must admit that... it is not something that has been an issue, and I suddenly felt that... Oops! That was kind of lame! We have many focus, many things we try to address, this is not one of them*" (P16). This lack of awareness was also mentioned by another participant: "*We have never adapted for that. We haven't even thought about it! But I think we could have been better, but it will take time and adjustments. And the user needs to understand, and we will have to help so they can manage to ask or search for something. I am thinking that useful knowledge... I think that would be more difficult*" (P18). Similar attitudes were expressed by others, for instance: "*the information needs of the end users have never been discussed*" (P03).

4.3.2 How are Information Needs Expressed?

When asked about how the end users typically expressed their information needs, the answers varied according to user group. The caregivers who worked with people with well-developed verbal language reported that their users could clearly express information needs. This mainly applied to people with mild impairments, and a few people with moderate impairments (although the needs expressed by the latter group were mainly related to their everyday routines).

For the end users with severe or profound impairments the challenge was to understand when information needs occurred, since these people could typically not communicate their needs verbally. Participants working with this cohort focused on challenges with communication and discussed how sufficient effort was necessary from the caregivers' side to be able to solve the information needs of end users. For instance, one person mentioned that it took about six months to know the end users in her group home well enough to be able to communicate, and reflected upon this as follows: "*It is a frustration for many people in the health sector that you cannot teach; it is you that have to learn. I need this knowledge to be able to communicate, but many people do not manage or have the energy to do so*" (P08).

For participants working with multiple impairments, body language was especially important. For instance, one participant said: "*They probably have a need for information, and some express that more clearly than others. Then it is up to us to be awake. Do we see a question mark in the user's face? Is anyone waving with an arm? We have to fill in the blanks, tie up the loose ends in some way*" (P14).

Another participant elaborated on the role of the caregivers: "*If you are going to work here, you have to work with your heart because the users need you 100%. If you do not put your heart into it, you will not manage to give them the attention they need*" (P08). This participant provided an example of an end user who had been restless a whole day without the caregivers understanding what

was wrong. When P08 came to work, however, she remembered that the end user's neighbor was brought to the hospital the day before. When they explained that everything was all right with her friend she calmed down immediately. Consequently, the frustrations over not being able to communicate an information need might affect the end user both mentally and physically. The participant concluded: "*There are so many people who think they don't understand, but they do!*" (P08). The conception that communication was vital was supported by another user working with people with multiple impairments and severe intellectual impairments: "*Sometimes we do not always manage to solve it* (understand the information need), *it is like a mystery*" (P09).

A total of nine participants reported that end users displayed unrestrained behavior if they were not quickly provided with proper information (typically related to everyday life). One participant said: "*They react with a type of anger*" (P14). Another stated: "*We can understand it* [information need] *because they get angry, restless, out of control, there is something we don't manage to understand*" (P23).

In certain cases, the users displayed a clear change of behavior when they did not manage to express information needs or when the caregivers did not understand that they had an actual need. For instance, unrestrained behavior was sometimes misunderstood: "*For those who has the cognitive ability to express information needs, there is a lot of frustration if they don't manage, and then one can see self-injurious behavior, they bite, loud noises (...) and then there are a lot of the caregivers who think they are just a bit tired, and do not handle the actual need*" (P25).

This uneasiness was also found among the pupils at school. One of the teachers said about the end users without verbal language: "*Uneasiness can be a sign of an information need that is not covered. Then one needs to know the pupil better*" (P24). However, there was also a challenge with pupils who did manage to express themselves verbally: "*Even though they are capable of asking questions, they don't always do so anyway. So we have to be one step ahead as an educator*" (P24).

For the end users who did not manage to express any information needs, the caregivers typically tried to anticipate their needs, and often communicated the most vital information about their everyday lives on schedules, lists and activity boards, often using a combination of visual and tactile information (Figure 1).

Figure 1: Tactile and visual activity board, used with permission

All the seven participants who worked with multiple and severe to profound impairments discussed information needs in relation to providing the users with information before they for instance gave food or brushed their teeth, and related all the examples to basic care. In this context, lack of information about what was going to happen could, in worst case, cause an epileptic seizure. Among these caregivers, information needs were typically discussed in a quite different context from what is typically regarded as information needs in an IIR context, and seemed more related to general communication with the end users.

4.4 RQ₄: How are Information Needs Solved?

Some end users in the category mild impairment either solved the information needs themselves on tablets, smartphones or computers, or got help from the caregivers. Of the ten participants who reported that at least one of their end users sometimes retrieved information on their own, five mentioned spelling as the main obstacle for searching. All these participants emphasized the benefits of a high tolerance for errors and autocomplete functions, and reported that the users would probably not be able to search themselves without that functionality. For instance, one teacher said: "*Those who like searching are usually quite good at spelling, and manage to use Google. However, there are other search engines that are more strict, so that is something to make them aware of*" (P24). None of the users applied voice search.

Another barrier towards information searching was the results lists, containing long URL's and snippets from the Web pages. Consequently, some participants advocated the use of image search, and described how their end users applied the image search in Google as a way to retrieve relevant Web pages, although this strategy was not always successful.

Trustworthy information was mentioned by four participants, who described how the end users typically needed guidance. One participant said: "*I don't think there are many users that will manage much. They might be able to search for some information in Google, but not necessarily correct information, in which they can manage to sort. It is probably more coincidental. Evaluating sources is not something they relate to*" (P22). Another participant stated that the end users "*might solve their information needs themselves, but they do probably not retrieve the best and most correct answers. But there is the will to do it themselves and manage on their own*" (P18). One of the teachers said: "*There is a challenge for many users to find valid and high-quality results from a Google search*" (P24). Impatience was also mentioned: "*Some users are in a mode where everything should be done quickly, but is it the correct answer we have actually retrieved?*" (P24).

Only six participants searched together with the users, while 19 did not. One of the teachers expressed the importance of solving all types of information needs, although they might not always relate to the subject: "*It is harder to achieve learning when the head is filled with worries and questions, and not wonder related to the topic one is working with*" (P24).

For six participants, searching with the end users was not regarded as possible due to the severity of the impairments, while two said they were not allowed to use digital devices outside the office. Finally, two people emphasized that all the questions raised could typically be answered by the caregivers without online searching. Consequently, they saw no need to search with the users. Only two participants confirmed a clear role as mediator during search: "*The intermediary is alpha omega. Because of the cognitive impairment, none of these users will be able to search by themselves*" (P17). Another said: "*They are very dependent on the information we contribute with*" (P14).

Other reasons for not searching with the end users were lacking access to digital devices or no allocated time for such tasks: "*I haven't thought about that. We don't use digital devices here. We could have searched for information together with the users, but we haven't …. There are no work assignments related to that kind of thing*" (P12). Another participant related searching to a lack of resources, abilities and attitudes among the staff: "*When we discussed what you asked about, to retrieve information…. they might be capable of doing so, but they don't. I think that is due to a lack of focus from the service providers, and a lack of knowledge on maintaining skills! We are not good enough at that. We can blame a lack of resources… partly… But that is not the most important reason. Quite simply, I think it is about prioritizing other things. The system is not good enough!*" (P16).

Protection was brought up by five participants. For instance, one participant said the following about information retrieved online: "*many users are negatively influenced*" (P02). Moreover, it was reflected upon how the users sometimes ended up with information that was not optimal: "*Sometimes the information they retrieve is not always so desirable, but they read a lot of strange things online, they really do. They are capable of figuring out quite a lot of things, but it is probably not the things they really need to cope in their everyday lives they search for the most*" (P11). Another participant (P08) talked about how many users were overprotected by the parents, among others in relation to their own diagnosis and deaths among other end users. The same need for protection was commented on by P02, although this participant also questioned whether the caregivers sometimes overprotected the users, as well.

Loss of abilities was addressed by four participants. This issue was especially related to communication skills that were necessary for expressing information needs. For instance, one teacher said: "*I experience that the pupils gain skills at school, and when they graduate and move into group homes, there is not enough expertise or knowledge to follow up upon that. Then the skills don't develop further, and in worst case they disappear*" (P24).

5 Discussion

RQ₁ addressed access to information. The findings revealed a very limited access to information sources, except for at school. Most users relied on intermediaries. *RQ₂* looked into the technological skills among caregivers. This study suggests that few of the end users had access to digital devices and that the technological skills of the intermediaries played a vital role. Limited access to technology might be stigmatizing, and a digital divide was found both among elderly and younger end users. The former were not introduced to technology, while the latter had skills that were not followed up by the caregivers. This divide could be reduced by

providing post-qualifying education to the caregivers and to encourage the use of technology in group homes, activity centers and sheltered workshops. This topic should be explored further in future research.

RQ_3 investigated attitudes towards and awareness of information needs among intermediaries. Findings from this study indicate that the information needs of many adults with intellectual impairments are not properly attended to, either in group homes, sheltered workplaces or activity centers. This finding is worrying. Information needs can be considered a basic human need [1, 29], and this cohort has information needs similar to other users [5, 6]. It may affect the quality of life if such needs are unsolved [1].

There were noteworthy differences in attitudes and awareness of information needs among the participants. All the intermediaries were very engaged in their work and expressed much compassion for their end users. For many participants, however, information needs were not discussed or paid attention to in their profession, and was consequently not included in their routines. Nevertheless, the participants became quickly aware of the potential importance of addressing information needs during the interviews and expressed a will to pay more attention to this topic.

RQ_4 investigated how information needs are solved. In this study, most of the end users could assumedly not search for (trustworthy) information by themselves. Consequently, intermediaries seem especially important for this group. The user-intermediary interaction between end users and caregivers should be studied in a variety of contexts and settings in future research, among others including observational studies of users and intermediaries. It might also be purposeful to look at user-intermediary interaction in other contexts and settings, to better understand how to support caregivers in their role as mediators, taking into account that this interaction may be particularly demanding due to communication challenges. The caregivers must also have an awareness of information needs and understand the importance of their roles as intermediaries.

Information needs must be interpreted and understood correctly to achieve successful user-intermediary interaction. The quality of communication in this interaction has been emphasized in the research literature [25-27]. The model presented by Saracevic et al. [26] seems to be applicable for user-intermediary interaction with this cohort, with an emphasis on user question and experiences of the intermediary. Based on this study, communication of needs might be a potential barrier for this cohort, among others due to reduced language capacity. Consequently, it seems purposeful that caregivers act as intermediaries rather than, or in cooperation with, information professionals, such as librarians. However, there might be a need for increased information literacy to enable the caregivers to adequately fulfil their role in this interaction. Some collaboration with a local library may be therefore be purposeful.

Successful information searching also entails digital literacy. Therefore, intermediaries should have well developed technological skills. This study indicate that a lack of such skills probably represents one of the most severe barriers towards user-intermediary interaction. This finding is coherent with Chiner et al. [21], who reported that caregivers can be important facilitators in the use of technology among this cohort.

A majority of the participants reported that many end users only had everyday life information needs, and they were typically related to practical information. These information needs correspond with the concept everyday life information seeking (ELIS) by Savolainen [30]. ELIS comprises informational elements people employ in their everyday lives to, among others, orient themselves in daily life. Savolainen's model includes cognitive capital and current situation such as health, both elements that seem relevant in the context of people with intellectual impairments.

Several barriers towards information seeking and successful user-intermediary interaction were identified in this study (Table 2). A comparison with the findings by Hanson-Baldauf [9] shows correspondence with certain intrapersonal barriers in the categories cognitive barriers (literacy skills, cognitive skills and limited perception of need), communication (language challenges) and psychosocial barriers (difficulty regulation emotion, anxiety and naivety). Regarding physical barriers, a limited access to information sources was also consistent with Hanson-Baldauf [9].

Category	Barrier
Intrapersonal barriers	*Cognitive*: Reduced literacy skills, impaired cognitive skills, limited perception of need, loss of acquired skills *Communication*: Language challenges *Psychosocial*: Challenges with regulation emotion, anxiety, naivety, personal interests
Physical barriers	Limited access to information sources, limited access to technology, inaccessible search user interfaces
Societal barriers	Unawareness of needs, lowered expectations of abilities, lack of properly trained staff, digital illiteracy among staff, overprotection

Table 2: Barriers identified in this study

In the context of societal barriers, there were several common findings, such as unawareness of needs, lowered expectations of ability and lack of properly trained staff. No economic or institutional barriers were found. However, this study addressed the perspectives provided by the caregivers, while Hanson-Baldauf [9] interviewed four end users. Moreover, the study was conducted within a Norwegian context, where the social system is quite different from the U.S., possibly affecting personal economy and the organization health care and facilities for working and living.

A few additional barriers were identified in this study, namely personal interests among the users, inaccessible user interfaces, limited access to information sources in general, lacking technological skills and communication skills among the caregivers in addition to overprotection.

Several of the barriers correspond with previous user studies, for instance challenges with spelling, formulating queries and

assessment of results [17, 18, 20]. The overprotection of users reported by Salmerón et al. [18] and Williams [3] was also found in this study, both when using the Web and communicating information about diagnoses or bad news in general. The lowered expectations of abilities corresponds with Sitbon et al. [10], who emphasized that many users with intellectual impairments have sufficient skills for information searching, but do not retrieve information due to a lack of confidence. It seems probable that the behavior of caregivers and family members may play a vital role in this context.

Bilal [7] found that family members did not have knowledge of the search skills of their children and conducted all information searching on their behalf. This finding corresponds with attitudes among participants in this study, stating that the end users would not manage to search. Such attitudes are likely to affect trust in own skills. Moreover, it seems important that the staff have proper knowledge on how to maintain previously acquired skills.

Functional level seems to affect the user-intermediary interaction. The findings in this study suggest that impairment category has an impact on what type of interaction the end user needs. For people with mild impairments, a thorough and adapted literacy training might be sufficient, while others may need help with spelling or assessing results. In contrast, other end users need technological support and are dependent on intermediaries to interpret needs and conduct the actual searching.

This study did not include end users. It is therefore not possible to conclude on how severe an impairment has to be before it is difficult for intermediaries to interpret and solve information needs. However, it seems likely that this happens somewhere in the severe category, maybe slightly earlier. That does not entail that users in the severe and profound categories do not have information needs. On the contrary, it is possible that this group needs even more attention since more effort is required to understand their needs.

It has been argued that researchers should address one impairment type at a time, because people with similar impairments typically share a common set of characteristics [24]. However, for intellectual impairments it seems more purposeful to apply level of impairment [4], at least in certain contexts. The participants consequently addressed end users based on functional levels, particularly related to communication [14, 15]. Consequently, it seems purposeful to study the end users based on the ICD classification scheme [4]. One advantage of using the ICD scheme is that all the end users are classified based on a common set of tests and procedures, allowing for a clear allocation of people to each category.

A fundamental question addressed by several researchers is whether information need is a basic need all people have. The participants expressed various opinions about information needs. Some people regarded such needs as very important, while others commented that information needs were not basic needs or a part of their work tasks. Nevertheless, the reports about end users who became aggressive and, in some cases, harmed themselves or others due to frustration of unsolved information needs, suggest that such needs are important for this cohort, as well. Consequently, it seems necessary to direct attention towards information needs both in the facilities and in the education of caregivers. Moreover, information needs and user-intermediary interaction should be incorporated in daily routines of caregivers and teachers.

6 Conclusion

In this study, several barriers were identified that hindered successful information seeking and user-intermediary interaction. Several of these barriers must be considered when designing search user interfaces, to facilitate both intermediaries and end users. Cognitive level and verbal skills may affect the ability to communicate information needs and search for information. Consequently, it may be purposeful to look further into how to assist end users in query input. For some end users, speech input might be purposeful. However, many people with intellectual impairments have unclear speech, and especially for small language groups such as Norwegian, the technology is not robust enough yet. Moreover, it seems purposeful to include more images in result lists, to reduce the demands for reading.

It is not possible to alter the cognitive functional level of people. However, several barriers were related to the intermediaries or the search systems. Providing post-qualifying education of caregivers and modifying search user interfaces are both achievable tasks. Consequently, there is potential for both increasing the quality of the user-intermediary interaction and to encourage more end users to search themselves by providing proper support.

Overall, there are several measures that may be considered by caregivers and policymakers to ensure that the information needs of the end users are adequately met, such as:

- Ensure sufficient digital literacy among caregivers to act as intermediaries
- Increase the awareness among caregivers of the importance of information needs
- Incorporate information needs (and solving these) in daily routines
- Avoid overprotection of end users
- Provide end users and mediators with better access to technological devices and information sources
- Provide end users with digital literacy when possible
- Counteract loss of acquired skills among end users

This study addressed intermediaries and their role in the user-intermediary interaction. More research is needed on this interaction. All the participants except for two in this study had formal education and many years of experience. This is a profession with a high frequency of caregivers without formal training, especially among the people working night shifts and weekends. It might be purposeful to conduct a similar study with these caregivers.

REFERENCES

[1] D.G. Dorner, G.E. Gorman, and P.J. Calvert. 2014. *Information needs analysis: Principles and practice in information organizations.* Facet, London, UK.

[2] M.O. Bertelli, K. Munir, J. Harris and L. Salvador-Carulla. 2016. "Intellectual developmental disorders": Reflections on the international consensus document for redefining "mental retardation-intellectual disability" in ICD-11. *Advances in Mental Health and Intellectual Disabilities, 10*(1), 36-58.

[3] P. Williams. 2019. 'It all sounds very interesting, but we're just too busy!': Exploring why 'gatekeepers' decline access to potential research participants with learning disabilities. *European Journal of Special Needs Education, Early view,*1-16.

[4] World Health Organization. 2019. *ICD-11 Browser.* Available from: https://icd.who.int/browse11.

[5] I. Tuffrey-Wijne, J. Bernal, A. Jones, G. Butler and S. Hollins. 2006. People with intellectual disabilities and their need for cancer information. *European Journal of Oncology Nursing, 10*(2), 106-116.

[6] L.L. Clark and M.S. O'Toole. 2007. Intellectual impairment and sexual health: information needs. *British Journal of Nursing, 16*(3), 154-156.

[7] D. Bilal. 2010. The mediated information needs of children on the Autism Spectrum Disorder (ASD). In *Proceedings of The 31st ACM SIGIR Workshop on Accessible Search Systems.* ACM, Geneva, Switzerland, 42-49.

[8] T. Rocha, D. Carvalho, M. Bessa, S. Reis and L. Magalhães. 2017. Usability evaluation of navigation tasks by people with intellectual disabilities: a Google and SAPO comparative study regarding different interaction modalities. *Universal Access in the Information Society, 16*(3), 581-592.

[9] D. Hanson-Baldauf. 2013. *Exploring the everyday life information needs, practices, and challenges of emerging adults with intellectual disabilities.* University of North Carolina, Chapel Hill, USA.

[10] L. Sitbon, A. Bayor, F. Bircanin, S. Koplick and M. Brereton. 2018. An exploration of how people with intellectual disability engage with online information retrieval. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems.* ACM, Montreal QC, Canada, 1-6.

[11] R. Hu and J.H. Feng. 2015. Investigating information search by people with cognitive disabilities. *ACM Transactions on Accessible Computing*, 7(1), 1-30.

[12] R. Nour. 2015. Web searching by individuals with cognitive disabilities. SIGACCESS Accessibility and Computing, (111), 19-25.

[13] L. Dowse. 2009. 'It's like being in a zoo.' Researching with people with intellectual disability. *Journal of Research in Special Educational Needs, 9*(3), 141-153.

[14] G. Laws and D.V.M. Bishop. 2004. Verbal deficits in Down's syndrome and specific language impairment: a comparison. *International Journal of Language & Communication Disorders, 39*(4), 423-451.

[15] C. Basil and S. Reyes. 2003. Acquisition of literacy skills by children with severe disability. *Child Language Teaching and Therapy, 19*(1), 27-48.

[16] P. Williams. 2019. A tangled web?: How people with learning disabilities negotiate the world wide web: The accumulating evidence. *International Journal of Computer Science and Mobile Computing, 8*(4), 317-324.

[17] B. Harrysson, A. Svensk and G.I. Johansson. 2004. How people with developmental disabilities navigate the Internet. *British Journal of Special Education, 31*(3), 138-142.

[18] L. Salmerón, I. Fajardo and M. Gómez-Puerta. 2019. Selection and evaluation of Internet information by adults with intellectual disabilities. *European Journal of Special Needs Education, 34*(3), 272-284.

[19] L. Kumin, J. Lazar, H. F. Jinjuan, B. Wentz and N. Ekedebe. 2012. A usability evaluation of workplace-related tasks on a multi-touch tablet computer by adults with Down syndrome. *Journal of Usability Studies*, 7(4), 118-142.

[20] P. Williams and C. Hennig. 2015. Effect of web page menu orientation on retrieving information by people with learning disabilities. *Journal of the Association for Information Science and Technology, 66*(4), 674-683.

[21] E. Chiner, M. Gómez-Puerta, and M. Cardona-Moltó. 2017. Internet and people with intellectual disability: An approach to caregivers' concerns, prevention strategies and training needs. *Journal of New Approaches in Educational Research, 6*(2), 153-158.

[22] E. Chiner, M. Gómez-Puerta and M.C. Cardona-Moltó. 2017. Internet use, risks and online behaviour: The view of internet users with intellectual disabilities and their caregivers. *British Journal of Learning Disabilities, 45*(3), 190-197.

[23] P.R. Bohman and S. Anderson. 2005. A conceptual framework for accessibility tools to benefit users with cognitive disabilities. In *Proceedings of the 2005 International Cross-Disciplinary Workshop on Web Accessibility (W4A).* ACM: New York, NY, USA, 85-89.

[24] G. Berget and A. MacFarlane. 2019. What is known about the impact of impairments on information seeking and searching? *Journal of the Association for Information Science and Technology, Early view,* 1-16.

[25] D. Ellis, T. D. Wilson, N. Ford, A. Foster, H. M. Lam, R. Burton and A. Spink. 2002. Information seeking and mediated searching. Part 5. User–intermediary interaction. *Journal of the American Society for Information Science and Technology, 53*(11), 883-893.

[26] T. Saracevic, H. Mokros and L. Su. 1990. Nature of interaction between users and intermediaries in online searching: A qualitative analysis. In *Proceedings of th 53rd Annual Meeting of the American Society for Information Science, November 4-8 1990 Toronto, Canada.* ASIS, 47-54.

[27] N.J. Belkin. 1984. Cognitive models and information transfer. *Social Science Information Studies, 4*(2), 111-129.

[28] SSB. 2019. *Helse og sosialpersonell* [Health care personnel]. Retrieved from https://www.ssb.no/arbeid-og-lonn/statistikker/hesospers.

[29] T.D. Wilson. 2006. On user studies and information needs. *Journal of Documentation, 62*(6), 658-670.

[30] R. Savolainen. 1995 Everyday life information seeking: Approaching information seeking in the context of "way of life". *Library & Information Science Research, 17*(3), 259-294.