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Perspectives of Neurodiverse Participants in Interactive Information Retrieval

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Perspectives of Neurodiverse Participants in Interactive Information Retrieval

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ABSTRACT

This monograph offers a survey of work to date to inform how interactions in information retrieval systems could afford inclusion of users who are neurodiverse. This existing work is positioned within a range of philosophies, frameworks and epistemologies which frame the importance of including neurodiverse users in all stages of research and development of Interactive Information Retrieval (IIR) systems. The monograph also offers examples and practical approaches to include neurodiverse users in IIR research, and explores the challenges ahead in the field.

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1

Introduction

This survey of work is presented to students, researchers and practitioners in the field of interactive information retrieval (IIR), with a view to provide both knowledge and inspiration towards more inclusive IIR approaches and systems. We introduce the survey by motivating the need for inclusive IIR to develop more broadly, and detail why assistive technologies are not sufficient to ensure inclusive access to information. We clarify the scope of the survey and situate its benefits specifically with regards to relevance to IIR. Finally, we present an overview of each of the sections to guide the reader to parts of the survey that may be most relevant to the work they are undertaking.

1.1 Motivations

This survey is motivated by the authors' desire to help transform IIR so that neurodiverse users can both inspire future research and benefit from innovation. While neighbouring fields such as Human Computer Interactions and Accessibility are engaging with users of all abilities and identifying technology's opportunities and barriers, neurodiverse users are seldom represented in IIR literature. We clarify why we believe that assistive technologies, while often used by neurodiverse users to engage

in information seeking tasks, should not be considered as an alternative to engaging with neurodiverse users in the design and development of IIR frameworks, algorithms and systems.

1.1.1 Neurodiversity

We chose to align the overall aim of this work, as well as our overarching statements, with the concept of neurodiversity, rather than with that of cognitive deficits or learning disabilities. We will develop the associated philosophies and terminology in Section 2. However, throughout the survey, we will, when appropriate, use the terminology used by the authors of the paper to which we refer.

Neurodiversity generally refers to autism spectrum disorders, developmental speech disorders, dyslexia, dyspraxia, dyscalculia, dysnomia, intellectual disability and Tourette syndrome, as well as schizophrenia. Estimates of prevalence vary, and many people do not receive a diagnosis, for a range of reasons. For example, estimates suggest that the prevalence of dyslexia is between 5 and 20 percent. However, this diagnosis has long focused only on people exhibiting difficulties with reading (Wagner *et al.*, 2020). Intellectual disability is estimated with a prevalence between 1 and 3 percent, however, definitions and thus diagnoses vary.

We also recognise that there is no agreed-upon definition of neurodiversity, and that neurodiverse individuals without learning disabilities sometimes feel that the expression has become too broad and no longer recognise themselves in it. It is likely that some neurodiverse individuals do not need to be supported to access IIR systems or to participate in IIR research, and we discuss this further in Section 1.2.2 with regards to the scope of this work. Furthermore, the concept of cognitive deficit also refers to temporary states, such as those caused by alcohol intoxication, illness or fatigue.

1.1.2 Recognising Diverse Abilities

Diversity, and particularly neurodiversity, exists on a spectrum. Recognising other ways of interacting with systems, which tend to be exacerbated when users are identified or identify with particular categories

of neurodiversity, can help design and imagine systems that will better respond to the needs and diverse ways of interacting of all users. A classical example is that of the television remote control that was initially created for users who could not move, and eventually found widespread adoption among the general population. We believe that the unique ways neurodiverse users may engage or wish to engage with IIR systems could similarly challenge IIR researchers and designers to think creatively and differently.

Conversely, if neurodiverse users are ignored during the development of new styles of interactions, the resulting technologies could impose rigid cognitive demands that do not match the abilities of neurodiverse users. This development could broaden the digital divide, and effectively exclude a part of the population from independently accessing information.

This survey hopes to provide all researchers in the field of Interactive Information Retrieval (IIR) knowledge, guidelines and tools to make sure their future research can best recognise the diverse abilities of users that their systems or designs intend to serve.

1.1.3 Representativity of Neurodiverse Users in IIR Research

While there exist several published studies of information behaviours of neurodiverse users, few have been presented to IIR audiences. Information behaviour studies particularly point to the barriers neurodiverse users encounter when seeking information online, often also in relation to web accessibility more broadly.

We searched the ACM digital library for publications sponsored by SIGIR (which include SIGIR, JCDL, CIKM and CHIIR), as well as IIiX, in the last 20 years (between 2002 and 2021). Using the keywords *(disability OR disabilities OR dyslexia OR neurodiverse OR autism OR "down syndrome" OR ADHD OR dementia)* in the title or the abstract only returned 32 results. 26 of these were research papers (short or long). We manually inspected their abstracts to find that 23 are actually relevant to IIR. One addresses children with autism, nine address people with dyslexia, five focus on people with intellectual disability, two broadly address inclusive design and cognitive abilities,

three consider users with physical disability and two address users with visual disability.

Increasing the representation of neurodiverse users in the IIR literature, to which this survey contributes, is more likely to support interest in the study and design of inclusive IIR systems in the future.

1.1.4 From Assistive Technology to Inclusive IIR

Technology can present both challenges and opportunities for people with diverse abilities, and the domain of assistive technologies has embraced both of these. Assistive technologies provide a supportive layer between people and activities that they could not otherwise perform. For example, the television remote control enables a person with limited mobility to operate a TV without moving towards it. Screen readers allow people who cannot see documents on a screen to hear the text of these documents. However, neither the remote control nor the screen reader can operate if the TV, or the document, are not designed to support their operation. Consequently, to be accessible, technologies must be designed in a way that is compatible with assistive technologies, by following existing standards and/or accessibility guidelines.

Accessibility has long been seen as the domain of researchers and people defining standards for "interfaces", and of those creating tools to help people with diverse abilities get access to these systems. Screen readers are a good example, where standards for online document accessibility have been set so that every image has corresponding text, which in turn can be read by screen readers. However, documents that are designed without consideration for people using screen readers could end up with formats that have no logical coherence, or order, as they are relying on a model of their readers having visual abilities. In the domain of online documents, such as web pages, the developing diversity of devices, screen sizes, and now audio devices, has pushed web designers to consider diverse ways their content is accessed by a wide range of users. In turn, the community has embraced this diversity with new approaches. For example, voice search is receiving attention from both research and commercial communities, and is now enabled on all devices, and accessible either through web interfaces or native voice interfaces (such as Google talk© or Siri©).

Inclusive technology offers an alternative to the dynamic of creating new technology, building assistive technologies to access it, and establishing accessibility standards for these to work. Inclusive technologies attempt to recognise users' diverse abilities, or situations, as part of the interactions they offer. Inclusive technologies will enable more people to participate without the need for new assistive technologies. Like Universal Design (which we develop in Section 3.2), including everyone is an aspiring goal; researchers should continue to be attentive to individuals or communities to whom technology remain inaccessible, and design with them. This approach requires that accessibility and assistive technologies are no longer the domain of a few experts in the field, or even in a different subject area. Instead, an inclusive IIR field will require that everyone understands the perspectives of diverse users, and embraces their inclusion in ongoing development.

1.2 Scope

In this section, we delineate the scope of the work reviewed in this monograph. It is difficult to draw a clear line to determine which works we have deemed relevant, and which topics to cover. We delineate what we believe makes IIR a relevant scope for this work, with an emphasis on users and their ways on engaging with interactive systems. We begin to clarify our choice to focus on neurodiversity rather than a specific or a set of diagnoses or disabilities, and how diverse sets of abilities may be relevant to examine as part of IIR explorations. We finally clarify our methodological standpoint, with an emphasis on the participation of users in the research.

1.2.1 Interactive Information Retrieval

By 2023, it has become difficult to precisely define to what the terms 'information retrieval' and 'interactive information retrieval' refer. Information retrieval (IR) has become ubiquitous, often a component of a broader interactive system whose purpose may not be to access information or acquire knowledge. This means that while users and their values underpin current systems, users are often not considered or consulted.

Users at the Heart of IIR

IIR departs from IR in explicitly considering the users, concerning how and why they interact with IR systems. Users, as individuals, cohorts, or more broadly, bring to the interaction with IR systems their own contexts, interests (sometimes expressed as topics), values, abilities and knowledge.

Interests are important to address from the perspective of how collections of documents should be formed, what types of queries should be managed as a matter of priority, providing support for using the information. Lab-based IR evaluation drives a lot of research in IR, and encourages researchers to explore new algorithms or approaches that can in turn offer new types of interactions to users. However, they tend to be either inspired by users, or created from user-generated content emerging from platforms that are potentially inaccessible to neurodiverse users. As a result, they may ignore the interests and approaches of neurodiverse users. For example, queries collected from web-search engine logs are likely to under-represent neurodiverse users who may not be able to access the commercial system they are derived from. In turn, progress made towards adapting systems to diverse types of queries people are interested in, or to address the diversity of ways these queries are expressed, may not benefit neurodiverse users.

Understanding users' interests can also be an opportunity to build user's expertise in using IIR systems and learning their mental models, as they can motivate use even when cognitive demands are high. The ASK hypothesis (Belkin *et al.*, 1982) builds on users' knowledge by characterising information sought as filling in a gap in knowledge. However, in some scenarios, such as entertainment or retrieving details about a known topic, knowledge becomes a starting point for interacting with the system. Knowledge can also support understanding, as is obvious with expert vocabulary.

There can be a tendency from IR researchers focusing on systems and algorithms to make assumptions about user experiences, and a temptation to consider users' abilities from the perspective of multimodality. That is, a computerised view of users' abilities could form a mapping to interaction modalities, resulting in an assumption that

multi-modal systems would be sufficient to address any set of user's abilities. For example, systems that offer speech-to-text and text-to-speech (conversational voice assistants) are often presented as solutions to support people with actual or situational vision impairments. However, a text-to-speech system may only be usable under certain circumstances, and could limit the type of information a user could access. Regarding the previous example concerning images, even if they are captioned, they would typically not be included in interactions with conversational voice assistants. Instead, a deep understanding of users, their abilities, and their desires for accessing information, can contribute rich multi-modal designs that are inclusive.

The *Interactive* in IIR

As a research field, IIR can make explicit some of the implicit values encoded in IR models and systems, which are often assumed and/or modeled on the designer's own values. Some examples of this are information quality (which relates to trust), and time spent interacting with the system and information (which is sought to be minimized by optimal rankings). IIR can offer investigations and solutions that address parts of an IR system, or can offer entirely new models that embed this understanding. For example, economical models of search (Azzopardi, 2014) build on an understanding of how (most) users value time in order to derive ranking and Search Engine Results Pages (SERPs) models.

IIR also departs from the input/output modelling of several IR systems, and encompasses systems that rely on, learn from, and acknowledge continuous interaction with one or more users. IIR can also contribute with important input regarding search user interface design, by understanding the best way to support users before, during and after searching.

Interactive systems may present an information component, and this survey includes them if this component is reported in the research. For example, we will cover some research that pertains to multimedia information access, such as videos, and this can include how people learn from videos. However, we will not cover research that solely investigates video creation, or video sharing behaviours. We exclude from this survey

research that explores how people use and access libraries, and only focus on online information access through interactive systems.

1.2.2 Neurodiverse IIR Users

Neurodiversity is not a single trait, and people who may identify, or be identified by researchers, as neurodiverse, do not form a homogeneous group. In this work, we specifically consider neurodiverse individuals who share a perception or experience that commercial IIR systems as they are do not meet their ways of working, thinking or their needs to an extent that they are difficult to use. This does not assume that neurodiverse individuals who have developed strategies to engage with standard systems should not be considered in research, but it is possible that such individuals are not diagnosed, or that they are already taking part in IIR research amongst cohorts of participants. The paucity of research that investigates these strategies is also problematic but out of our scope.

All neurodiverse people have a universal right to access these systems with their existing abilities. With this in mind, we do not include in this work research involving people who may not be comfortable to experience systems or experimental settings because they do not have pre-requisite knowledge and experience. This would include people in developing regions, or people who do not master the language in use by the system/experimental framework. We acknowledge that more research is needed to address the needs of these users. These needs, however, can be seen as contextual and temporary.

This survey mainly presents concepts and work related to neurodiverse users who have dyslexia or intellectual disability, as this cohort is most represented in the work that specifically addresses neurodiversity in IIR (see Section 1.1.3). These neurodiverse ways of processing information and interacting cover a wide range of abilities and support requirements, and illustrate how to consider unique as well as patterned combinations of abilities and support requirements when including neurodiverse users. The approaches we will present can thus be applied to working with other patterned communities of neurodiverse users (users sharing similar ways of thinking and doing), such as people with aphasia,

people with dementia (sometimes referred to as cognitive decline), and people on the autism spectrum.

1.2.3 Research Methods

Most of the existing knowledge of how neurodiverse users engage with IIR systems, which we cover in Section 2.3.2, has been gathered through sets of interviews, log analysis or eye tracking. Interviews are typically conducted with users when they are able to engage in verbal conversations, and otherwise they are often conducted with people supporting neurodiverse users. Some interviews with neurodiverse users have been conducted as *contextual interviews*, where users can demonstrate how they engage with the technology as part of the interview. Log analysis or eye tracking have been used to establish the difficulties that neurodiverse users encounter with mainstream and commercially available systems, and to demonstrate the additional effort and time they have to invest to access information online.

The intention of this survey is in part to provide readers with a way forward in making their own research endeavours more inclusive of neurodiverse participants. As a result, the approaches addressed in this work will both investigate how existing approaches could include a broader diversity of users, as well as how specific approaches can be elaborated. In this context, this work will not expand on the often traditional distinction between qualitative and quantitative research, which are equally valid, but rather offer avenues to expand on both types of research approaches, which can otherwise equally perpetuate ableist principles and perspectives (Williams and Gilbert, 2019).

The core methodological concept which this survey is hoping to convey is participation. That is, allowing neurodiverse participants to take part in mainstream IIR research through inclusive and adapted research methods, as well as exploring opportunities for participatory design. The field of Human Computer Interaction already has rich perspectives on methods, approaches and philosophies that are effective to invite, support and ensure participation of neurodiverse users. Yet, these are seldom employed to imagine new approaches and create innovative IIR systems. This survey will introduce what we believe can be translated to IIR for more inclusive futures.

1.3 Overview

This monograph aims to present a variety of foundations for researchers to transform their approaches and make their research and that of new entrants to the field more inclusive. We believe that the pillars for this transformation include a better understanding of who are neurodiverse users, design approaches that can guide a rethinking of IIR systems or research methods, examples of IIR systems designed to address neurodiveristy, practical tools/ideas to make IIR research more inclusive, and perspectives for future work towards inclusive/neurodiverse IIR research.

Section 2 intends to accompany the reader on a journey to understand how neurodiverse users are, or should be, positioned within IIR studies. We first develop some of the philosophies, models and terminology that are relevant to engaging with neurodiverse users, and particularly the shift from the medical to the social model (Section 2.1.1). We clarify how neurodiversity can be expected to interfere with inclusive and accessible interactions with IIR systems, and present the literature that investigates the experiences of neurodiverse users with existing IIR systems. Moreover, neurodiversity is presented as a natural variation in human cognition rather than a group which diverges from the majority population. Further, the value of including a broad spectrum of abilities in studies, and how they can contribute with more usable systems for everyone is discussed. Through the lens of the concept of interdependence, we finally develop the shift from considering individual users as sole participants in interactions with IIR systems to considering their interactions as part of a network of interdependent relationships.

Section 3 offers some insights into how the field of interaction design has already established fundamental principles for inclusive interactive systems, and frameworks to ensure that people of all abilities are involved in shaping the systems that they are entitled to use. The section opens with clarifications on how interactions are distinct from interfaces. It then offers foundations to rethink the approaches to conceptualise IIR systems through the lenses of Universal Design, Ability Based Design, and Competency Based design, and places these approaches in the broader field of participatory design.

Section 4 surveys the nascent applications of these design frameworks into some of the innovative and inclusive systems that have so far emerged from the field of information retrieval. After presenting the range of systems that have so far been explored, we compile the various design guidelines which have emerged from their evaluation with neurodiverse users. We also include in this compilation design guidelines that have emerged from evaluating non-inclusive systems.

Inclusive and neurodiverse IIR should not remain an isolated field of expertise, and we recognise that design approaches may not always be applicable to the ongoing studies or operational systems. Thus, Section 5 offers an overview of practical approaches to include neurodiverse users into a broader range of existing IIR methodologies and studies. The section starts with ways to design the user study inclusively in order to enable traditional approaches to suit the needs of neurodiverse users. We then look more specifically into how systems involved in the studies can be adapted to create the conditions for participation of neurodiverse people. We conclude more formally with the ethical considerations necessary to respectfully approach and involve neurodiverse study participants.

The concluding Section 6 presents some avenues for emerging issues in IIR to be considered inclusively. We propose that as models are becoming more and more aware of issues around fairness and bias, the opportunity to consider neurodiverse voices in this agenda is not to be missed. Neurodiverse users are often the most vulnerable to misinformation, and sometimes intentionally targeted by scams as a result. We also highlight how collaborative approaches can not only be part of solutions regarding misinformation, but more broadly considered from the perspective of ensuring autonomy in models of supported access to information. We consider how conversational systems, as they are becoming more and more multimodal, and embedded in embodied technologies such as social robots, present an opportunity to develop inclusively, and also to better meet the needs of neurodiverse users. Finally, we suggest a new category of intent for information seeking, one that recognises the communicative and social dimensions of information and information sharing.

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