Neurodiversity & HCI

N.S. Dalton
The Open University,
Walton Hall,
Milton Keynes,
UK
MK7 6AA
n.dalton@open.ac.uk

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Abstract
The objective of this paper is to introduce the an implicit notion of 'user' in the singular and has received criticism from Feminist HCI[5]. Neurodiversity suggests that even these approaches carry with them certain assumptions about the cognitive processing abilities of users which need to be challenged. This paper is concerned with the design and evaluation of interactive systems that are imbued with an awareness of the central commitments of Neurodiversity. The paper seeks to identify and promote neurodiversity under the banner of neurodiversity HCI. This paper introduces neurodiversity and then critically evaluates aspects of HCI from the perspective of neurodiversity.

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H.5.m. Information interfaces and presentation (e.g., HCI):

General Terms
Theory

Introduction
Historically, tool building was focused on the process of augmenting our physical selves. what makes computing

different is that these tools support the process of thought. Human Computer Interaction (HCI) is a subject concerned with the process of making tools which support the process of thinking, and it is this that in some way makes HCI unique compared to other tool making areas.

From its earliest inception, HCI has had the notion of 'the user' from 'user centered design' to 'user participation' there is the implicit notion of 'user' in the singular. This notion of 'user' in the singular has come under criticism from Feminist HCI[5]. Neurodiversity suggests that even these approaches carry with them certain assumptions about the cognitive processing abilities of users which need to be challenged. This paper is concerned with the design and evaluation of interactive systems that are imbued with an awareness of the central commitments of neurodiversity. The paper seeks to identify and promote neurodiversity to HCI under the banner of neurodiversity HCI. This paper will begin by introducing neurodiversity, then move on to critically evaluate aspects of HCI from the perspective of Neurodiversity.

Neurodiversity

The term neurodiversity was coined by Judy Singer a sociologist with Asperger syndrome and autistic rights advocate writing as part of a self advocacy movement[28]. The term has since spread to a number of support groups, blogs and books. It could be argued that this self advocacy rights movement formed partly due to the ability of members of the autistic community to come together on line and communicate with-out intermediaries as was the case with many of the previous organizations formed by parents and professionals. Singer's notion of neurodiversity was that autism and Asperger's were not an 'affliction' but another state of being[20] with equal rights to live and reproduce. The neurodiversity community uses the term 'neurotypical' to label the larger 'normal' society. Over time the neurodiversity community has grown to include conditions such as Dyslexia, Dyscalulia, Dyspraxia/DCD, Autistic Spectrum Disorder, Asperger's Syndrome, Tourette's Syndrome and Attention Deficit Hyperactivity Disorder (ADHD). This list should not be seen as definitive as many other conditions may be included. While other conditions many included there are for those such as Armstrong [2] three aspects which help define Neurodiversity: upsides, the social model of disability, and the spectrum of disorder.

1. Upsides

Neuroscientist Professor John Stein observes from an evolutionary point of view, "If conditions like dyslexia are wholly negative they would have evolved out" [15]. For neurodiversity, it is the positive aspects of the conditions that differentiate them from traditional 'disabilities'. People with autism and Asperger's are likely to do well at the embedded figures task, possess above average attention to detail, have strong visual-spatial skills, and are more likely to have perfect musical pitch. Those with Williams Syndrome are likely to be talented musically and have good interpersonal skills. Dyslexics tend to be highly creative and strong visual thinkers with the ability to develop a good overview of large complex problems. Those with attention deficit hyper activity disorder (ADHD) are likely to be highly creative and strong multi-taskers with the ability to operate in stressful high-input situations. Given the right triggers they are able to hyper-focus on tasks[2]. This list is highly incomplete. Generally, we only know about positive aspects if they

can be construed as negative, or if they have come about serendipitously from other research. One of the problems is that the medical community has the motivation and resources to explore these conditions but tends to 'medicalize' conditions [9][10] by focusing on the negative aspects. While this research has been highly useful in identifying differences in brain structure rather than 'laziness' or 'poor parenting' as causes, it does lead to the temptation to begin to cure these 'afflictions'.

It is natural then that computing & HCI have already followed previous modes of research by viewing these conditions under the larger banner of 'disability'. A meta-review was carried out for this paper by studying papers from both the ACM library including CHI and SIGACCESS proceedings for the years 1999- 2012 show that of 55 references to conditions of dyslexia or autism, no paper made any positive mention of any aspect of either of these conditions.

For many of the neurodiverse community it is these positive aspects which can be highly useful and principle components of their value and so identity. As Cooper says "I am not someone with dyslexia. I am dyslexic. Were I not dyslexic, I would not be me"[9]. It is the co-identification with the condition that produces what a neurotypical might think of as possibly perverse behaviors. For example medication exists to reduce the effects of ADHD. Yet this medication typically also reduces the positive aspects such as creativity as well. If a neurodiverse person in a creative job and considerably more creative than their neurotypical coworkers, it would be natural to expect them to be less than enthusiastic about taking a drug which might eliminate their unique advantage regardless of the negative aspects.

2. Social Model of Disability

So far we have seen that there has been an unintentional bias to medically label many of these cognitive conditions as illness. If there are upsides, this raises the question: are the neurodiverse truly disabled? One primary aspect of the 'difference' to 'affliction' debate is that of the social model of disability [16]. We live in a modern complex interconnected world far different from the environment in which humanity evolved. As society becomes more complex, we are required to meet many social norms in order to access society's basic resources.

As an example, consider conditions such as ADHD. In primitive hunter gatherer societies a hunter with the ability to multi-task between hunting, navigating, gathering all while avoiding numerous threats. With survival depending upon the ability to switching rapidly between stimuli suggests that those with ADHD would function well in a pre-civilized hunter gatherer society. Today the in-ability to work attentively in a class room or receptively on a production line makes those with ADHD poorly suited to earn income and so function in the modern world.

Alternatively, imagine a community consisting of purely Asperger's individuals the inability to use non verbal communication skills and limited empathy with their peers would no longer make them unable to function, they would be normal. It is being the lone Asperger's individual in the neurotypical world and not being able to meet general social norms that creates disability.

Gifted neurodiverse individuals

Einstein: Dyslexia,Autism.

Paul Dirac: Autism

Mozart: ADHD

Shakespeare: ADHD

Tracey Emin: Dyslexia

Ludwig van Beethoven:Autism

Michael Faraday: Dyslexia

Dr. Samuel Johnson: Tourettes

For example, a dyslexic in a pre-literate society would have little difficulty functioning and find the positive aspects of the condition useful. It is the switch to near universal literacy and society's dependence on high literacy which then denies a dyslexic access to the resources that creates dependence on external assistance which is the mark of disability. There is little doubt discrimination and disability exist. Examples of such discrimination for dyslexics are: education commensurate with IQ is refused [8] , employment opportunities may be restricted [6], in the US, their unemployment is twice as high compared to those without learning disabilities[11] wages may be less than their able and equally qualified counter parts[17][18], ability to rise to higher levels of management curtailed [21], some fear downgrading, career termination or dismissal if their difference is revealed [22]. It is for this and other reasons that Dyslexia is defined as a disability and employment protection legislation exists under the Americans with Disabilities Act[19] and the UK disability discrimination Act.

From these examples it should be clear that disability is more about the inability to function in a neurotypical society to a greater extent than being able to function in some absolute sense. As Finkelstein says "The central issue in our campaign is for a better life, therefore, we ought to be concerned with issues around emancipation and this requires struggles for social change rather than concentrating on individual experiences, 'rehabilitation', etc" [16].

It is this struggle with emancipation and social change that the neurodiversty movement seeks to foster. From an HCI perspective, optimizing the interaction with software with only one cognitive model is slowly eroding it's use by those with differing cognitive strengths and weaknesses. As designers and builders of tools with a particular cognitive perspective, we are potentially engaging in the further disenfranchisement of a number of groups and so creating more disability.

3. Spectrum of Disorder

The final aspect which makes neurodiversity stand out and makes its highly relevant for HCI is the spectrum observations from Dalton's[13] observations that most neurodiversity conditions are spectrum disorders ranging from normal to dysfunctional. One of the problems with conditions like dyslexia and Asperger's syndrome is that it is hard to give a definite diagnosis about who is or isn't afflicted with the condition. Figures on the prevalence of dyslexia for example range from 1-15% of the population due to the operational definition of how severe the condition is expected to be in order to be categorized as dyslexia. We must also consider that the negative and positive sides of a condition can impact an individual at different rates. This becomes clear when we consider the work of Baum[7], looking at the education of gifted and learning disabled individuals, Baum observes that the range of those with intellectual differences may be larger than those simply labeled 'learning disabled'. Baum suggests there are three categories of 'giftedness':

- Identified gifted students who have subtle learning disabilities- these are students who fall only slightly short of the vision of genius. They have some shortcomings but their gifts greatly outweigh any negatives, the overall result is still worthy of the label 'gifted'.

- Identified learning-disabled students who are also gifted- when the burden of learning disabilities outweighs the gifts, these individuals fall into the category of learning disabled students.

- Unidentified students- these are students who have a heavier burden of learning disabilities but also gifts, by using their talents to overcome their weaknesses they result in appearing only 'average' to their contemporaries. Their gifted qualities may go unnoticed. This adaptation mechanism can be so effective that individuals may not themselves be aware of having a condition and may only be identified much later in life. For example, some successful adults with ADHD are only identified when their children are diagnosed.

As such, we can see some aspects of high functioning abilities in relation to what is typically seen as disability. This situation can be more clearly explained in figure 1. Here we consider two axes. The first vertical axis is that of degree of ability. While degree of cognitive function is both subjective and, as we argued, also bound by socially enforced norms, the axis relates to our everyday notion of cognitive ability. The horizontal axis is the severity of condition. Again, this synthetically combines both positive and negative aspects of a particular condition. For example, we might begin on the left with Asperger's and the move to autism on the right. The curve consists of a number of individuals conceptually plotted along the scattergram. It begins in the middle with what would be regarded as neurotypical. As the cognitive condition (dyslexia, Asperger's, ADHD) increases minor problems occur but are outweighed by the benefits. At the peek this zone comprises people that Baum identifies as 'Identified gifted students who have subtle learning disabilities'. As the curve reaches its zenith, we enter the talented zone, and we see the people we would regard as truly gifted. Einstein is held up as an icon for dyslexics, but he was never tested during his life. As problems increase, we enter the zone where the negatives outweigh the positives. It in this zone close to the 'normal' line we find Baum's 'Unidentified students'. These are people who appear normal but have to devote a huge amount of their gifts to cope or manage the downsides. As mentioned many people who are so adept at coping and in doing so appear as unexceptional can discover a cognitive problem later in life are likely to appear in this area. Finally, when the negatives outweigh the positives, we get the severe end of any condition. Occasionally we see gifts as seen in savants for instance, the ability to multiply 20 digit numbers yet are unable to tie a shoelace.

So, we have seen that neurodiversity consists of three pillars. Upsides and the spectrum help to explain that these conditions are not one-off defects or aberrations but a reflection of the larger diversity of humanity.

Case studies of the Neurodiversity Perspective for HCI

The paper will now use the view of neurodiversity to reflect upon a number of case studies which will demonstrate how the neurodiversity perspective is relevant to HCI.

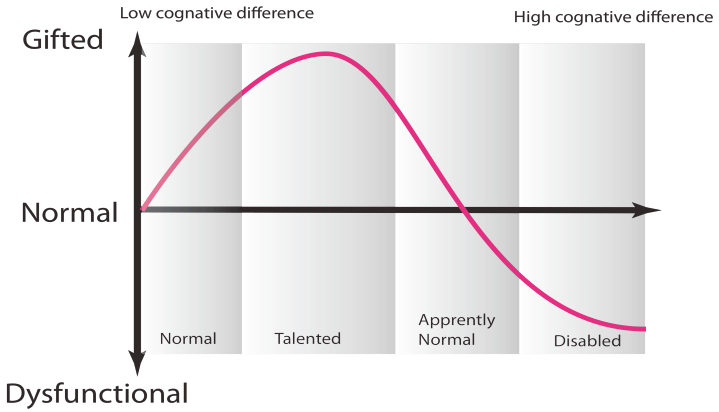

Figure 1: A conceptual curve of 'ability' against 'degree' of condition.

Users and spectrum

From an HCI perspective, researching and responding to neurodiversity should be seen not as an extension of e-inclusion [1] and disability but more as a fundamental and subtle response to the wider diverse user community. If the neurodiverse are part of a spectrum, then being inclusive to other cognitive modes suggests wider benefits. For example, Alan Dix [14] observes that supporting assistive materials and technologies for neurodiverse students has an effect of making the material more accessible for the wider student population. It seems natural to suggest that it would be reasonable to expect that technologies that support assorted gifts from the neurodiverse community might have an audience much larger than the neurotypical. If we can support the gifted in the more specialist neurodiverse community, then it is natural that we might expect wider benefits.

Giftedness

Baum's [7] work implies that we can consider the neurodiverse in relation to high functioning intellectual activity, and this is an area which has received little attention in the HCI literature. We need to see neurodiversity not only as approaching issues of the negative sides of the conditions but as a new opportunity to study the positive gifted and talented aspects of conditions traditionally viewed as disabilities. There have been many calls to explore HCI 2.0 aspects such as creativity, sociability, joy, and user temperament[26]. What makes these aspects intriguing in terms of neurodiversity HCI [12] is that they are areas were the neurodiverse are typically very strong. As[2] suggests, it is in supporting the positive aspects of neurodiversity that members of the neurodiverse community can find value in themselves. One example of this is Aspiritech[23] which uses Asperger's/autistic spectrum engineers to perform very high value testing of software. By doing so they are able to find more software defects than similar neurotypcially staffed companies. HCI is then challenged to facilitate new kinds of interfaces to support new kinds of value creation.

Neurodiversity within computing and HCI

It is obvious but regrettable that HCI does not reflect the wider user community, in terms of gender, culture, ethnicity and other aspects. Yet for HCI, awareness of neurodiversity does highlight a number of aspects within our own community. This part of the paper will highlight this aspect as it may have an impact in terms of how the HCI community reflects upon itself and its evolution.

In the book Microserfs author Douglas Coupland observes, "I think all tech people are slightly autistic.".

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Steve Silberman[27] reports on the high levels of autism and Asperger's syndrome in Silicon Valley suggesting a link between that and the high tech computing industry there. Silberman even identifies some of the qualities of famous IT professionals such as Bill Gates as being parallel to such conditions. Attwood[3] [4] also reported high numbers of people with Asperger's amongst IT professionals.

In terms of computation and interaction there are a higher proportion of dyslexics in the software community. [29] Reports Approximately 30% of dyslexic undergraduates study scientific, engineering or medical disciplines. Pure programming is a good example of an intellectual activity which currently fails to discriminate against dyslexics. Powell suggests that the positive aspects of dyslexia (good overview, visual thinking, creativity) can be of help. 'Programming is an arena where dyslexics can really flourish'[25].

In [24] O'Keefe suggests that dyslexia was called the 'MIT disease' because both Nicolas Negroponte and many of the researchers at the Media Lab were themselves dyslexic. Many dyslexics move into intellectual domains that can take advantage of high visual ability and strong creative passion which is typical of the visual arts. [30] Reports that 5.59% of UK Creative Arts and Design where dyslexic compared to 1.9% for all UK undergraduates and 4-10% for the general population. One study reported by Armstrong[2] identified 75% of fine art students at one of the top art schools in the UK as being dyslexic. This suggests that those in the area of interaction design may have a higher tendency for dyslexia.

If this rate is reflected in interaction design, it is more surprising that neurodiversity has not emerged as an issue already. From this we might conclude while neurodiversity is an invisible disability, it also forms 'an invisible community' or at least a self-unaware community with in the HCI community. This part of the vision of neurodiversity HCI is to recognize and research the effects that Neurodiversity has potentially had already. Does creating a neurodiversity framework create a new kind of ontology about HCI and change the way we reflect upon our selves and our methods of practice? We believe that using neurodiversity as a banner under which this kind of work can be articulated will provide fresh insights into the practice of HCI.

Challenges for HCI research practice

As digital technologies become a greater part of our every day lives, they become vital aspects of our ability to both exploit society's resources to live and importantly deliver value and employment in the larger economy. So on the one hand, interaction technology has the potential to further disenfranchise and further marginalize the neurodiverse. On the other hand, we have seen that there are a large number of untapped gifts which the neurodiverse possess. By creating technologies to help exploit these gifts HCI has the opportunity to develop new wealth creating potential in the neurodiverse and for the betterment of all.

Further, if research is undertaken which can exploit aspects of giftedness in the neurodiverse, we can see from the spectrum argument that there are many in the neurotypical community that may be able to find advantage from this research. HCI research is a discipline which is strongly tied to and highly influential on the development of new interaction technologies. Therefore, it is natural for the neurodiverse to be able to raise its voice in this community. It is this voice which neurodiversity HCI tries to articulate. As

mentioned above, it seems natural that there are many within the neurodiverse community in the field of computing and interaction design already and it seems natural to begin to expect them to speak up.

To understand why this has not yet happened we must begin to ask about the barriers that the academic study of HCI research introduces. By its very nature human computer interaction is hardly attractive to those with poor social skills. Yet the academic setting also demands high literacy skills as a barrier to entry to the high table of influencing the larger research agenda. These and other aspects all cumulate to exclude many from the neurodiverse community as active participants in top level research.

Neurodiversity at its heart has the agenda that differing cognitive styles are respected as different rather than seen as 'able' and 'defective'. As such, the broader social aims of neurodiversity can be seen as a fight to raise awareness of differing cognitive styles. For example only 5% of people with Tourette's swear, but they are much more likely to be musically gifted. It also seeks changes in the wider society to discourage focusing on individual problems toward a wider social emancipation. In the field of academic HCI we must start the conversation as to what aspects of our own procedures, customs, and protocols inhibit those in the neurodiverse community having access to the top academic events. The alt.chi English review is a good example of a positive step forward that can be made in this respect. Can we honestly declare an adherence to the ambition to publish archival work of the 'highest academic quality' while having unwitting processes that exclude all but neurotypical perspectives?

Conclusion

The primary contribution to knowledge of this paper is to make the HCI aware of a new and growing social movement which provides a critical perspective from which to view the process and practices of HCI. The core demand of neurodiversity is mutual respect for different ways of being. For interaction designers and researchers this is partly an expectation not to reinforce the social exclusion already widely experienced. Partly this is about pushing research on making users access to resources vary to acknowledge differing points of view and experiences.

Secondly, Neurodiversity introduces the notion of seeing the neurodiverse as a spectrum of intellectual riches which can be utilized both in practice and research.

Thirdly, we must conduct research in a way which is aware, responsive, and critical of what's considered 'normal'.

Finally, we must acknowledge, employ and listen to neurodiverse designers. Design is dominated by neurotypical thinking. An increase in presence of neurodiverse designers who can understand and appreciate neurodiverse experiences can narrow the gap between users and the design team.

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