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Neurodiversity HCI

Dr N.S Dalton n.dalton@open.ac.uk

Dr Nick Sheep Dalton studied Engineering Design and Appropriate Technology at Warwick University. His PhD was in Virtual Environments at UCL where he also founded the MSc in Virtual Environments at the Bartlett School of Architecture. He now is a Lecturer and HCI researcher in ubiquitous computing at the Open University.

Introduction

Doug Englebart said *“a computer is a device for thinking with”*. This ability to assist the process of thought separates computing from most other technologies. Historically human computer interaction focused on the use of technology in the work place and could speak about the ‘user’ in the singular. This singular user assumed a near uniform style of cognitive processing and, if software conformed to this cognitive style, its use could be simplified. As technology increasingly permeates the fabric of life, HCI needs to respond to the diversity of the wider, global population. As part of this diversification I want to introduce a previously under-reported population discussed under the banner of Neurodiversity. First, I will explain what the Neurodiversity movement is, then the three basic issues defining it and finally suggest its potential impact on HCI.

Neurodiversity

The term, ‘Neurodiversity’ was coined by Aspergers and Autistic Rights activist, Judy Singer, from Autistic Rights, to describe a bottom-up, self-advocacy movement. Neurodiversity has since expanded to include a group of non-related, cognitive disabilities such as Dyslexia, Dyscalculia, Dyspraxia/DCD, Autistic Spectrum Disorder, Aspergers Syndrome, Tourettes Syndrome and Attention Deficit Hyperactivity Disorder (ADHD). Those affected by these conditions are referred to as ‘the neurodiverse’. Rather

satirically, the neurodiverse movement uses the term ‘neurotypical’ to describe the non-neurodiverse individuals constituting wider society.

According to Armstrong¹, with the exception of occasional co-morbidity, three things tie the apparently disassociated conditions together: the notion of cognitive ‘upsides’, the spectrum of conditions, and the social model of disability.

1. Upsides

For Armstrong, what makes Neurodiversity different from other disabilities, is that these conditions have upsides. For example, those with ADHD can be strong multi-taskers with the ability to operate well in stressful, high-input situations. Those with ADHD are also more likely to be highly creative and, with the right stimulus, able to ‘hyper-focus’. Those with Autism and Asperger’s are more likely to have perfect musical pitch, do better than average at the embedded figures task, have above-average attention to detail and strong visual-spatial skills. Those with Williams Syndrome are likely to have high musical ability and may have good interpersonal strengths. Dyslexics are thought to be creative, highly visual thinkers with an ability to easily form an overview of large, complex problems. The list goes on, but given the current lack of coherent research into the positive dimension of many cognitive conditions, it would be incomplete. The positive aspects we do understand tend to be the serendipitous outcome of research into negative qualities therefore neither comprehensive nor complete.

The neuroscientist Professor John Stein offers an explanation for neurodiversities, *“If conditions like dyslexia are wholly negative they would have evolved out”*. It is the positive aspects of these conditions that might explain their continued presence in the population. It is these positive aspects that unite the diverse cognitive conditions under the banner of Neurodiversity.

According to an educationalist, Professor John Cooper, while medical research has been useful in showing that these conditions exist due to permanent differences in brain structures rather than previous theories of poor parenting or laziness, it has medicalised them as afflictions which need to be ‘cured’ or eradicated. This creates blindness to the

positive aspects of these cognitive differences. For those with the conditions, the positive sides can be highly valuable. As such, the positive elements are a strong source of their uniqueness and identity. As Cooper says *"I am not someone with dyslexia. I am dyslexic. Were I not dyslexic, I would not be me"*². The integration of self-definition with conditions has led individuals to exhibit apparently curious behaviors such as the rejection of possible 'cures'. ADHD medication, for example, can reduce the creative upsides that someone with ADHD might find vital to their identity and uniqueness.

For Cooper, Neurodiversity redefines dyslexia as another way of being: a cognitive style. It is the medicalised language of the neurotypical that speaks of a 'cure' or support; this language dominates societies' approach and has an implicit effect on interaction design.

2. Spectrum

The notion of cognitive upsides explains why many conditions exist and the second aspect, spectrum, explains how these conditions fit into the population. Most Neurodiverse conditions exist in a spectrum of disorders ranging from 'normal' to dysfunctional. This spectrum makes it hard to define the exact numbers of people with a particular condition as it depends on its severity. This spectrum widens if we consider the suggestion of Susan Baum looking at the education of gifted and learning disabled individuals, who 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.**

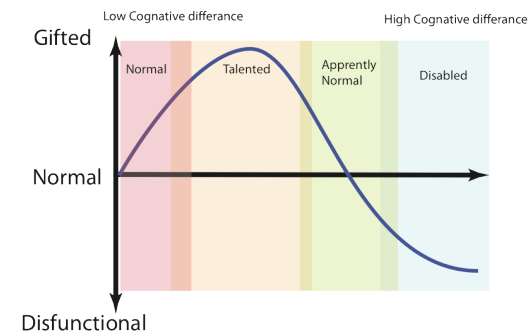
Students who fall only slightly short of the vision of genius. They have some shortcomings but their gifts greatly outweigh any negatives, the overall result is still worthy of the label 'gifted'.

- **Identified learning-disabled students who are also gifted.**

When the burden of learning disabilities outweighs the gifts, these individuals fall into the 'normal' category of learning disabled students.

- **Unidentified students.**

These are students who have a heavier burden of learning disabilities but use their talents to overcome their weaknesses, resulting in appearing only 'average' to their contemporaries and their gifted qualities may go unnoticed. This adaption mechanism can be so effective that individuals may not notice it themselves and only be identified much later in life. For example, some successful adults with ADHD are only identified when their children are diagnosed.



The spectrum argument introduces the notion of a hockey-stick effect on cognitive performance. Starting from a baseline of 'normal', increasing the degree of a condition leads to an increase in cognitive performance (in mathematics, logic, multi-tasking, creativity etc.). As the performance rises, so do the negatives, until they peak. A decline follows, until the mix of giftedness and negatives appears as simply 'normal'. The decline continues, falling below normal, passing through the 'idiot-savant' and then into 'low functioning' or dysfunctional.

From this spectrum perspective there is less clarity discussing separate categories of the cognitively disabled in need of assistive technology and the normal population. For HCI, this suggests that any gains from catering for differing cognitive styles may also be reaped by others than those labeled with a particular cognitive style. This view is echoed in Alan Dix's observations that assistive technologies for neurodiverse students have the effect of making the material more accessible to the wider student population. Catering for outliers in a population reaps rewards further afield, not just for those with 'impairments'. For HCI this means that supporting differing cognitive styles should be something all software does rather than be limited to assistive ghettos. This also promises benefit, to a wider range of users, from research into Neurodiversity interaction design.

3. The Social model of disability

The final pillar of Neurodiversity is the 'social model of disability' indicating that the general term, disability, is applied not because of an inability to function but an innate inability to operate by modern society's standards. The 'social model of disability' suggests that disability is more a matter of an inability to comply with social norms and use society's resources than a fundamental lack of cognitive ability. For example in a pre-literate society, someone with Dyslexia would have no problem functioning and would not be considered disabled. In a pre-urban society, an individual with autism, toiling long hours over the same task in a field, may stand out less nor be in need of 'care'.

From this point of view, the combination of society plus a neurological condition makes a difference, a disadvantage and so a disability. Vygotsky, called this idea, disontogenesis: disability compounded by society. As Finkelstein says³ *"The central issue in our campaigns for a better life, therefore, ought to be concerned with issues around emancipation and this requires struggles for social change rather than concentrating on individual experiences, 'rehabilitation', etc."*

As digital technologies tend to fix certain cognitive assumptions into the environment. For example creating a detailed, highly textual and verbose airline booking system might create new barriers for dyslexics, requiring them to seek assistance and hence 'disabling' them. HCI needs to be aware of how it is creating social disability when it locks assumptions into software. It is in this light we must consider Neurodiversity HCI.

Neurodiversity HCI

One of the objectives of Neurodiversity HCI would be to expand the broader aims of social justice of the Neurodiversity movement. Neurodiversity is about rejecting the idiom of impairment. It tries to promote an understanding of alternative cognitive styles, their negative and positive sides. Significant social discrimination and injustices against the neurodiverse come from inaccurate perceptions of the limitations and abilities of those concerned.

By using design to support cognitive strengths rather than weaknesses we can enable the neurodiverse to have a position in the market place – some surveys in Europe suggest 62% of those with Autism have never had employment and are therefore denied the confidence that being in the workplace can bring. A positive example is Specialisterne, a company that employed autistic spectrum software testers and was able to achieve higher rates of bug discovery over neurotypically staffed competitors. By using design to support diverse cognitive strengths we can offer new opportunities.

The spectrum aspect suggests that we should not distinguish the neurodiverse and neurotypical. The notion that responding to impairment can be relegated to the role of specialist software user ghetto rather than reconsidering mainstream software fails to understand the benefits to the wider population that considerably designed software can bring.

To the HCI research community the notion of examining and designing for 'exceptional ability' creates a new set of under-explored challenges. By working with individuals with exceptional ability, neurodiversity HCI can help create new and original approaches to many current active research areas.

Neurodiversity HCI can also be seen as a new research and design agenda:

- We need to draw together knowledge about the positive aspects of differing cognitive styles. By understanding the aspects relating to the interaction design domain we might build a clear picture of how Neurodiversity HCI might add to HCI design practice;
- We need to create resources and educational materials to help interaction designers be informed about the many differing cognitive styles in the user population;
- As part of this process, we need to understand the impact of Neurodiverse conditions on our own constituent disciplines. For example, Dyslexia is known to have a high occurrence in many top art and design schools. There are many perceptions in Computing about autistic spectrum individuals but we have no clear data on this. This lack of self-knowledge needs to be remedied.

Knowledge is needed about how far the design community is from the actual user population and how this frames approaches and problems;

- Human centered design methods and protocols need to be studied to identify ones that need to be questioned, revised or remodeled;
- We need to start developing Neurodiverse design protocols and methods – for example for participatory design, requirements elicitation, as well as adapting existing ones maintained by a strong process of empirical work and theoretical reflection;
- We need to form collaborations with the Neurodiverse not just their carers, charities or other forms of support. By reaching out to this group we can engage in participatory user centered design;
- We need to work with Neurodiverse designers and listen to them. Interaction is dominated by the neurotypical. By creating an explicit presence for Neurodiverse designers we can reduce the gap between the design team and target user groups. We need to encourage Neurodiverse designers and realize their value beyond inclusive design. For example, when designing for the 799 Million illiterate adults worldwide, openly dyslexic designers can contribute a unique critical perspective for the design team;
- It seems that there are strong overlaps between other more developed types of enquiry. Neurodiversity is similar to Feminist HCI in its approach. With Central tenets of ‘commitment to agency, fulfillment, identity, equality, empowerment, and social justice’ could well define the Neurodiversity approach. These overlaps need to be explored and collaborations with these other approaches to interaction need to be made to generate a better picture of what interaction is and could be;
- Traditional accessibility design is quite clear what has to be achieved – normality. What is currently unclear is the limits to place when designing to exploit cognitive advantages;
- Trickle down: If techniques for design for high functioning can be developed we need to understand if the design

artifacts can be re-appropriated by the neurotypical population. Are tools designed to support hyper-focus or extreme creativity useful for a wider population?

Conclusion

The Neurodiversity literature is awash with the names of gifted individuals who also seem to have experienced many cognitive hindrances, Paul Dirac for Autism and Asperger’s, Mozart and Shakespeare for ADHD, Einstein for dyslexia. These are some who have found a way of exploiting their gifts rather than being satisfied with just overcoming their deficiencies. Neurodiversity HCI should seek an exploitation of gifts for the neurodiverse population and doing so provide benefits to the wider population.

Neurodiversity is still a relatively young and evolving movement and is likely to evolve over the next twenty years as much as it has over the last twenty. A new voice is being found and we have a duty to listen. Neurodiversity isn’t and has never been, a new form of political correctness. It is not a new polite term to cover a collection of cognitive impairments. It is a mutiny of the disabled, sometimes striking at the very charities that exist for them. As designers of ‘tools for thinking with’, Neurodiversity HCI should exist as part of this cognitive insurgency.

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[2246 words]

¹ Armstrong, T. 2010. Neurodiversity: Discovering the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences

² Cooper, R. 2009. Dyslexia. Neurodiversity in higher education: Positive responses to specific learning differences. D. Pollak, ed. Wiley-Blackwell

³ Finkelstein, V. 2002. The social model of disability repossessed. Coalition: the Magazine of the Greater Coalition of Disabled People. (2002), 10–16.