Asperger's Syndrome, Autism, and Camouflaging: Reduced Empathy Revisited

William Hudson, Syntagm Ltd (

It's been nearly 10 years since I presented my short paper "Reduced Empathizing Skills Increase Challenges for User-Centred Design" at the CHI and British HCI conferences in 2009 [1]. The paper focused on the tendency of male IT workers who report their role as predominantly technical to have a reduced Empathy Quotient. This was measured using standardized questionnaires in the field of autism research. This result was less pronounced in female IT workers.

My original motivation for running the study was my longstanding observation that some technologists whom I had taught or worked with did not appreciate that users would struggle with complex interfaces. While their arguments varied, there was often an assumption that if users struggled with the interface they probably shouldn't be using it in the first place. This mindset was present even on projects whose target audience was the general public. The underlying cause appeared to be an assumption that users were no different from developers—something I referred to as *self as user* in my original paper. My view, confirmed in the study for men at least, is that low empathy has a significant part to play. People with low cognitive empathy find it hard to know what other people might be thinking and struggle to see a problem from another's perspective. While the arrival of the World Wide Web has modified technological cultures to a certain extent—Web developers are well aware that users will move on to another site if theirs is too complex—the self-as-user model certainly persists. I experience evidence of it regularly while teaching software engineering, Web technology, and computer science courses for the U.K.'s Open University.

Low Empathy, Autism, and Asperger's Syndrome

Low empathy is one of the defining characteristics of people on the autism spectrum. The spectrum includes, at one extreme, children with severe developmental and behavioral issues. The other extreme includes people with low empathy but without developmental issues. Until recently this extreme has been referred to as Asperger's syndrome, but this is changing for reasons I will describe below.

No matter where on the autism spectrum someone lies, they are likely to find social interaction challenging and lack the skills to understand what other people are thinking (referred to in autism literature as theory of mind).

Autism is by no means new—a Swiss psychologist is credited with coining the term in 1910 (from Greek *autos*—self). But it is only recently that we've come to understand more about how it affects those on the autism spectrum, particularly girls and women.

"Extreme Male Brain"

Hans Asperger described the autistic mind, in high-functioning autism (HFA) at least, as an extreme version of the male brain. This view has led many in the study of autism to suppose that it was

almost exclusively a male condition. In the case of Simon Baron-Cohen, head of the Autism Research Centre at the University of Cambridge, it led to his claim that the underlying mechanics of autism accounted for a significant difference between the male and female brains. This was a fairly controversial theory that further extended the idea that the autism spectrum was inhabited mostly by men and boys.

But since Asperger's syndrome was first added to the official U.S. manual of mental disorders in 1994, figures on the male-female split have changed dramatically. At that time, HFA was thought to be 12 times more prevalent in males, even higher in some assessments. But recent statistics from the Center for Disease Control (2016) show a boy-girl ratio of 4.5, or 1 in 42 boys, versus 1 in 189 girls (age 8, in the U.S.).

Explanations of this change in gender ratios vary from better familiarity with the condition and increased rates of diagnosis to the concept of camouflaging, discussed below. The latter is of particular interest to me in the empathy study since it might help to explain the enigmatic results for women in IT.

Empathizing and Systemizing Behaviors

The Autism Research Centre's model of autistic traits focuses on two distinct characteristics of autistic behavior: reduced empathy and interest in systems. This systemizing behavior might range from obsessions with structure and relationships between objects to innate ability to build and understand complex technologies.

In the neurotypical population there is very little connection between these two behaviors. But the autism spectrum is characterized by low Empathizing Quotients (EQ) and high Systemizing Quotients (SQ), as measured by standardized questionnaires. The empathizing-systemizing model and its prediction have recently been validated by an unprecedented study of over half a million participants [2].

The smaller study reported in my 2009 paper was relatively straightforward; 441 participants (156 men and 285 women) were asked to complete online Empathizing and Systemizing questionnaires. They reported their results along with their gender and an indication of whether they worked at the people end of IT (technical writers, usability specialists, or similar), at the technical end (backend software developer, database specialist, and so on), or somewhere in between. This is indicated by the P-T index in the diagrams in Figure 1.
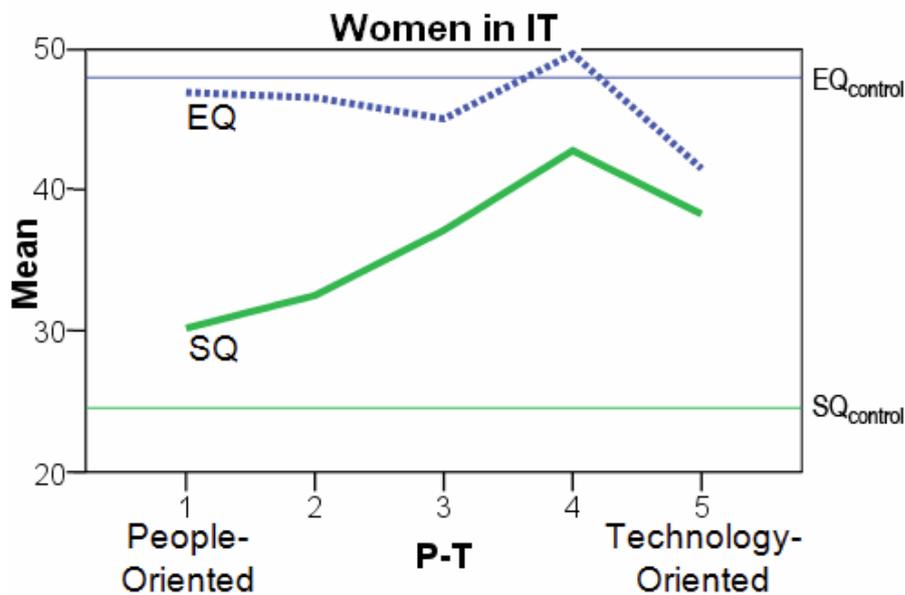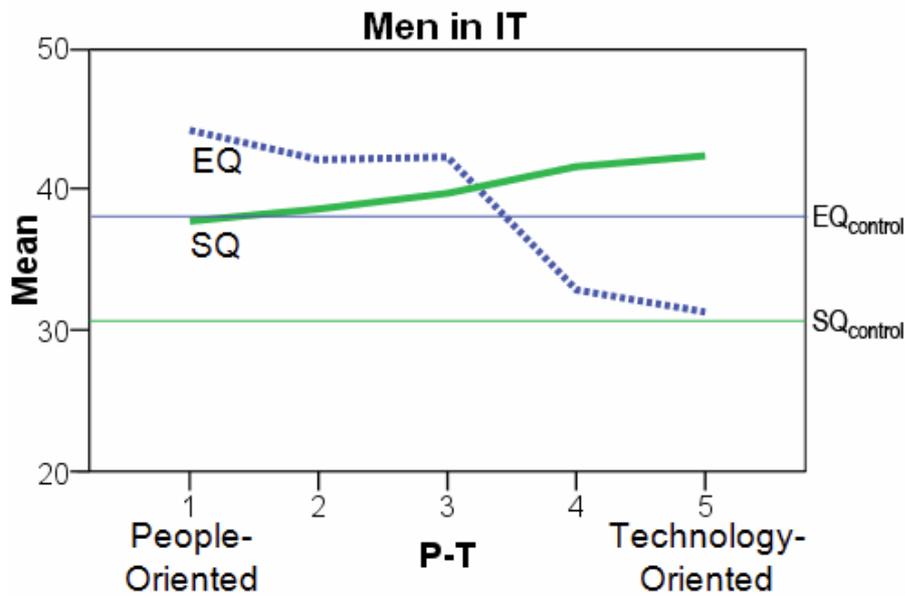
Figure 1. Empathizing and Systematizing Quotients for men and women in people-oriented versus technology-oriented IT jobs.

Both genders showed higher SQs than the general population, which is to be expected since all were workers in IT. The notable difference between the two genders is the fall of EQ for people working at the technology end of IT (P-T of 4 or 5). For men this is very clear cut, but for women we have an unexpected rise before the fall. My explanation for this at the time was that very few women identified themselves as predominantly technology-oriented. This is where I now believe that *camouflaging* has a part to play. This is the name given to compensating behaviors in social interaction to allow those on the autism spectrum to better fit in. It has been known about for some

time, but the extent to which it has been employed has probably been underestimated in the past. Recent research suggests that some of the difference in diagnostic ratios between boys and girls is attributable to the use of camouflaging by girls. For women in IT, it may be that social expectations result in a people-leaning bias in their self-reported P-T scores.

Historical Context

The historical context of Asperger's syndrome has also received new attention recently. In 2018 two researchers concluded that Hans Asperger actively aided and supported the Nazi euthanasia program. Asperger was part of a commission that screened 200 children at a home for the mentally disabled. Of those, 35 were sent to the notorious Am Spiegelgrund children's clinic in Vienna and killed. A detailed account of the origins of AS can be found in Edith Sheffer's book *Asperger's Children* [3]. But of course it has led many involved in the field to question whether we should continue to honor the name Asperger in applying it to HFA. The complication is that the term has been adopted outside a purely clinical context—some describe themselves as *Aspies*. It isn't for others to dictate whether the term should be used by people with an HFA diagnosis, but perhaps when Hans Asperger's background becomes more widely understood, it will simply fall out of use.

Coincidentally, Asperger's syndrome (AS) was dropped from the U.S. official diagnostics manual (DSM-5) in 2013. It now falls under the umbrella term *autism spectrum disorder*. Aside from the issue of Hans Asperger's background, this decision may be painful for some since AS is often not seen as a disorder. What distinguishes it from other, more serious, forms of autism is the lack of developmental problems in childhood. However, the term *HFA* is approximately equivalent and addresses the issues of both the Asperger name and the new DSM categories.

Recruiting Autistic Staff

Attitudes toward autism have changed too. Increasingly, companies are mounting recruitment efforts to attract and retain staff on the autism spectrum. For example, Microsoft announced in a 2015 presentation at the United Nations its intention to recruit autistic staff. The program's aim was to increase diversity and take advantage of problem-solving and development skills that are often found in high-functioning people with autism. Similar schemes have been adopted by SAP, HP, and a range of non-technology companies. But their success hinges on a multifaceted approach. Those involved in recruitment need to be conversant in the differences they will see in the interviews of autistic candidates, while the candidates themselves need opportunities to demonstrate their skills and aptitudes outside conventional recruitment assessment. For these reasons, Microsoft adopted an academy or workshop model. SAP has a slightly older autism-hiring program (2013) and has collaborated with Microsoft in this area. SAP's approach also includes workshops but provides even more flexibility to autistic candidates by allowing them to decide what form the interviews take. That might range from a tour of the facility to one-on-one discussions or even group sessions. Successful candidates are assigned a volunteer mentor to help them acclimatize to their new environment and situation. (These approaches are not mandatory, but rather offered to candidates on the autism spectrum. Some may prefer the usual hiring process.)

Personal Experience of HFA

Apart from repeated encounters with low empathy while working with or teaching development teams about user interface design, I have had more direct experience of the autism spectrum. While researching my original paper, I discovered that I was very bad at the Reading the Mind in the Eyes test from the Autism Research Centre at Cambridge. This is an alternative test of empathy skills. Participants are asked what emotion is represented by just an image of a person's eyes (Figure 2). Even though it's multiple choice, of the 36 images, I get only three or four right—the neurotypical average is around 25. And similarly, during the creation of an online video course on user-centered design I found that my empathizing quotient placed me in the high-functioning autism group.
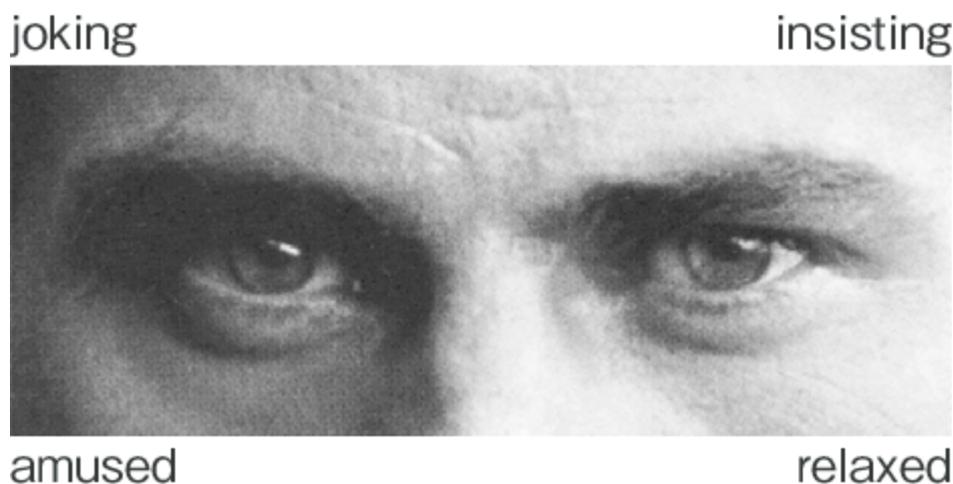
Figure 2. Image from the Reading the Mind in the Eyes test [4]. The answer for the image is "insisting."

These results don't particularly surprise me, as I've always felt somewhat awkward in social situations and recognize in myself some of the HFA-related behaviors regarding social interaction. But I've never felt the need for a formal diagnosis and seem to have improved my social skills—perhaps through many years of camouflaging and a progressive easing of autistic tendencies with age. (Being married and having a daughter also seem to help.)

My HFA story took another interesting turn recently. My grandfather was an amateur genealogist (mainly in the 1930s), so I have boxes of letters and family trees that I have been slowly unraveling. As DNA tests have become more useful in this area (Ancestry.com has tested more than 10 million people in the past few years), curiosity got the better of me and I submitted a saliva sample for analysis. The ancestry aspect of the results was something of an anticlimax; I'm half Eastern-European descent, one-quarter Welsh, and one-quarter American courtesy of the Virginia Colony. But I knew that from a headcount of my grandparents.

Having been underwhelmed by my ancestral DNA discoveries, I was interested to learn that the same DNA tests can also be applied to genetic predisposition for health purposes. Providers such as 23andme.com offer this as an expensive upgrade to their ancestry tests, but third-party analysis firms like promothease.com offer a similar service for quite a low fee ($12 at the time of writing).

This service is relatively instantaneous compared with sending saliva samples off for the initial analysis. I needed only to download my genetic data from Ancestry and upload it to Promothease. The results showed some hereditary conditions I was already aware of, but also an increased risk of autism and low empathy. The autism risk is associated with poor cell adhesion in neurons, and the low empathy is due to a variation in the oxytocin gene. Oxytocin is associated with social bonding. Various studies suggest it has a part to play in autism.

Of course, there are many concerns about the risk of abuse of genetic testing, particularly by health insurance companies and employers. But the upside is an awareness of potential issues that, in cases like childhood autism, benefit greatly from early treatment. Even for those diagnosed with HFA, but seemingly little affected on the surface, the mental health costs can be high. Particularly in girls, the efforts to mask low empathy through camouflaging can lead to anxiety and depression.

Beware that genetic testing is not for the faint-hearted. Among my various results are gene configurations that increase my risk of dementia and an almost equal number that reduce the risk. So I'm going to call that a draw. Bear in mind that the tests include around 700,000 chromosomes, and even at 99.9 percent accuracy, that means about 700 errors. You would certainly want professional medical advice and further tests before making any decisions with lasting consequences.

Impact of Low Empathy

Awareness of low empathy, whatever the cause, is important both for the individual and their personal contacts. I was fortunate enough to start my software-development career at a time when computing resources were scarce. That meant that I watched users struggling with my creations right from the start. Data-entry questions and teletype output (computer screens hadn't been invented yet) that made perfect sense to me often did not survive exposure to users. I quickly became aware of the importance of talking to and working with the intended audience.

But direct experience of users is far from normal practice, particularly since interactive technology has become ubiquitous. In the 1990s, when graphical user interfaces were just taking off in a big way, I recall running user-interface design courses inside companies and extolling the virtues of working directly with users. This advice was usually met with frustration, since the back-room nature of software development rendered speaking to users virtually impossible. This is still the case in many technology-focused organizations and teams today.

Low empathy means that many of the people involved in designing systems don't appreciate that they are gifted in having good systemizing skills at the same time as not being able to see the problems from a typical user's perspective. So while these are exactly the kind of people we need to build and run systems, we must make certain that our overall approach to development builds in users from the outset. I learned this the hard way, even though I have pretty low empathy—so empathy in itself need not be a hurdle.

Reduced Empathy in User-Centered Design

What impact might low empathy have on user-centered design? Very little if you follow the advice of most UCD practitioners and ISO standard 9241-210. Systems should be designed and developed with multi-disciplinary teams and should directly involve users. The main difficulties with UCD is that we don't teach it to developers, and many developers are wired to believe that it's not necessary. I have not taught a programming, software engineering, or Web technologies course yet that even mentions UCD—and that's across a range of institutions, some commercial and some academic. That's why I wrote my Guerrilla UCD courses, which can now be found under a variety of different guises at the Interaction Design Foundation.

Certainly in the academic courses that I currently teach for the Open University, usability does get a mention. But we need to revamp the way we teach developers about building interactive systems and not address usability as a seemingly trivial side issue.

Conclusion

The autism spectrum has an important role in technology fields. High systemizing skills are obviously very valuable in technological ventures, but the concomitant reduction in empathy raises real risks for interactive systems. We need to better understand and communicate these issues so that staff on the autism spectrum are more likely to be recruited and feel supported in their working environment. At the same time, we should recognize that higher adoption rates of user-centered methods are needed to ensure that users are involved throughout the development process: from early research through to regular usability evaluations.

Endnotes

1. Hudson, W. Reduced empathizing skills increase challenges for user-centered design. *Proc. of the SIGCHI Conference on Human Factors in Computing Systems.* ACM, New York, 2009; https://doi.org/10.1145/1518701.1518901 Also available at https://syntagm.co.uk/articles

2. Greenberg, D.M. et al. Testing the Empathizing-Systemising theory of sex differences and the Extreme Male Brain theory of autism in half a million people. *PNAS 115,* 48 (2018), 12152–12157; http://www.pnas.org/cgi/doi/10.1073/pnas.1811032115

3. Sheffer, E. *Asperger's Children: The Origins of Autism in Nazi Vienna*, W W Norton & Company, 2018.

4. Autism Research Centre. Eyes Test (Adult); https://www.autismresearchcentre.com/arc_tests

William Hudson has been active in HCI and user-centered design since the early 1990s. He has taught many courses in these fields in industry and at conferences. He currently teaches software engineering, computer science, and Web technology courses for the Open University in the U.K., develops video courses for the Interaction Design Foundation, and consults in industry on user experience and user-centered design. william.hudson@syntagm.co.uk

Insights

- Systemizing skills of people on the autism spectrum are important for software development, but reduced empathy is problematic for user-centered design.
- Women are more frequently on the autism spectrum than originally thought, but they are more difficult to assess because of camouflaging.
- Autism-focused recruitment efforts by Microsoft, SAP, and others show promise.