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Using Design Thinking to engage autistic students in participatory design of an online toolkit to help with transition into higher education

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Structured abstract

Purpose of this paper: The paper reflects on engaging young autistic people in the participatory design of the Autism&Uni online toolkit. The purpose of the toolkit is to provide autistic students with information and strategies for dealing with the challenges they may encounter when entering higher education. The study adds to existing research on participatory design by considering the specific needs and contributions of autistic people who are of average or higher intelligence, academically competent and generally articulate, a group that has received limited attention hitherto.

Design/methodology/approach: The research used a 5-step Design Thinking approach and engaged multiple stakeholders at different points. The paper covers the whole process, paying particular attention to the final two steps of prototyping and testing. During three participatory design workshops, autistic people acted as codesigners and co-creators.

Findings: The workshops were effective in engaging participants in various design activities and rich discussions. Several assumptions about capabilities and preferences of autistic people were challenged. Design Thinking proved a suitable framework for involving this group in the creation of solutions that serve their needs.

Research limitations/implications: Because of the low number of workshop participants (11), research results may lack generalisability. Also, the workshop format with its focus on group activities may discourage some autistic people to take part. Further work is needed to explore this and to confirm the reported findings.

Practical implications: The paper offers practical advice regarding how to involve autistic people in co-design activities.

Social implications: The research contributes to a strength-based view of autism, rather than one that focuses on deficits.

Originality/value: The paper provides new perspectives on the strengths of autistic people in participatory design settings, with a focus on those autistic people who are of average or higher intelligence and able to communicate effectively.

Keywords

Autism, Participatory Design, Design Thinking, Creativity, Strengths, Higher Education

Introduction

Autism is a lifelong developmental condition that affects how a person communicates with and relates to other people, and to the world around them. It is estimated that around 1 in 100 people are autistic (Brugha et al., 2012). Autism is also a spectrum condition, which means that it affects different people in different ways. While some autistic people also have a learning disability (Fombonne et al., 2011), a substantial proportion is of average or advanced intellectual abilities, having been diagnosed with Asperger Syndrome or described as "high functioning".

Since Asperger Syndrome as a diagnostic category is likely to disappear entirely in the near future, and terms referring to "functioning" are both imprecise and offensive to many autistic people and other stakeholders, this article uses "autistic" to signify all individuals with autism spectrum conditions. In English-speaking countries, this agrees with the preferences of autistic adults as well as those of a considerable proportion of parents, family members and friends (cf. Kenny et al., 2015).

Autism can lead to ways of thinking and behaving that appear unnecessarily rigid or repetitive, difficulties in understanding social interactions, and to difficulties in concentrating and processing information in typical ways (American Psychiatric Association, 2013). On the other hand, many autistic people have specific strengths such as an ability to maintain intense focus, to think rationally and logically, to adopt unconventional angles in problem-solving or to spot errors that others may overlook (Grant and Davis, 2009, Lorenz and Heinitz, 2014). Recent research suggests that many autistic people possess strong cognitive and perceptual strengths, influenced by special interested (Meilleur et al., 2015) and aiding complex reasoning skills (Simard et al., 2015). The strengths of autistic people as professionals with a high work ethic are increasingly recognised by businesses world-wide e.g. in STEM (Science, Technology, Engineering and Maths) areas and also in the humanities and the arts (AHEAD, 2012; Alsop, 2016).

A higher education (HE) degree opens up many employment opportunities, as well as further postgraduate study. However, although autism is not a predictor for academic success, autistic people are generally under-represented in the HE student population and over-represented in those who drop out of university without finishing their degree (HESA, 2013; Ratcliffe, 2014). The transition from secondary to higher education presents particular challenges for this group of young people.

This paper reports on the participatory design process leading to the creation of an online toolkit, providing autistic HE students with strategies and advice for overcoming the challenges they typically encounter when applying to and settling in at university. The work is part of the European-funded multi-national Autism&Uni project which aims to widen access to HE for students on the autism spectrum. A wide range of stakeholders were engaged in the design process that involved surveys, interviews, ideation sessions and co-design workshops. The next section reviews the literature around common barriers to higher education for autistic students, before describing the participatory design process and reflecting on its suitability and outcomes.

Background

Gobbo and Shmulsky (2014) asked academics to reflect on the strengths of autistic students. Positive traits were highlighted such as expertise and passion for the subject, a desire and commitment to be accurate, a drive to seek knowledge, and adherence to rules. In contrast, the perceived challenges or deficits were mostly connected to concerns around social behaviour, interpretation of learning material and anxiety.

Transition to higher education can be difficult. Typical challenges are group work, adjusting to independent living and the 'battle' to get appropriate support, difficulties with critical thinking, interpreting ambiguous instructions, inflexibility of thought and problems with switching perspectives (Beardon et al., 2009; Griswold et al., 2002; Fleischer et al., 2013). Autist students experience high levels of stress and anxiety at university (Liew et al., 2014; Gillott and Standen, 2007), particularly in response to change, anticipation and sensory issues. There may be no outward signs of distress (Glennon, 2001), making it difficult for others to recognise the signs of impending crisis.

A considerable number of autistic university students are reluctant to disclose their condition, unless there are clear benefits for them in doing so (Davidson and Henderson, 2010; Huws and Jones, 2008). This is a problem as a diagnosis and formal disclosure are requirement in most countries' HE systems to receiving autism-specific support. The traditional methods for supporting autistic students and disabled students generally involve 'reasonable adjustments' such as: more time during exams; study mentors; transcripts of lectures etc. These can alleviate concerns and reduce anxiety, but also separate students from their peers, increase social anxiety and exacerbate their sense of difference (Madriaga and Goodley, 2010). Yet the importance of receiving the right support early on has been pointed out repeatedly (Martin et al., 2008).

The development of self-determination and self-advocacy skills is recommended for all students with disabilities, in order for their needs to be fully met and their university study to be successful (Adams and Proctor, 2010). This may prove particularly difficult for students on the autistic spectrum, as their condition is often 'invisible' and as a result they have difficulties justifying their requirements. The social and communication difficulties common to autism can further complicate the situation (Adams and Proctor, 2010; Glennon, 2001).

Autistic students may also feel marginalised as transition support and the rhetoric around students with disabilities tend to focus on their deficits rather than their abilities. On the other hand, families of autistic students often express a desire for the student to be 'normal' and fit in (Bagatell, 2010). These conflicting perspectives can make it hard for autistic students to adopt a positive identity, and this can affect their ability to advocate for themselves. However, autistic students with higher levels of self-determination and better self-advocacy skills have been found to be more likely to complete their studies and to have positive experiences (Russo Jameson, 2007).

Designing with and for autistic people

The Autism&Uni project aimed to create an online toolkit that can help students navigate the transition to university successfully, primarily through providing information, increasing self-advocacy skills and reducing anxiety. However, the nature and content of this toolkit was not defined from the outset and the literature review, although providing useful pointers, did not provide a satisfactory set of user needs and conceptual requirements for the toolkit. The literature was limited in that it was biased towards the situation in the UK and the US as well as towards

research relating to younger children on the autism spectrum, often with learning difficulties and communication impairments (c.f. Aresti-Bartolome and Garcia-Zapirain, 2014). Young autistic adults with academic aspirations and competencies have hitherto received much less attention. Those studies that are available tend to be with limited generalisability or evidence base (e.g. Fleischer, 2012; Ness, 2013),

A deeper enquiry was called for regarding the challenges encountered by this group, the support offered, whether this support is actually effective, and what positive strategies autistic students developed whilst at university. Following a human-centred design approach with roots in the human-computer interaction tradition, multiple stakeholders were consulted. The next section elaborates on the methodological framework and outlines the research approach.

Participatory design

In technology development, human-centred design advocates the active involvement of users in the design process in order to gain a clear understanding of user and task requirements (Maguire, 2001). This may be in the form of interviews, focus group, prototype testing followed by system evaluation. While initially focusing on system end-users only, more recently this has been expanded to include multiple stakeholders with an interest or investment in the technology product. Participatory design differs from traditional, human-centred design approaches in that the user is not simply a source of information or evaluator of the final product, but an active contributor of design ideas and a decision-maker in the process, often referred to as "co-creator" or "co-designer" (Sanders and Stappers, 2008).

There is a growing body of research concerned with involving people on the autism spectrum in the design of products for this group. Much of the participatory design literature in this field focuses on adequately representing the needs and requirements of people who have learning difficulties, communication impairments to the extent of being non-verbal, or difficulties imagining how they themselves or others might use the product (c.f. Millen et al., 2010; Coon and Watson, 2013). The target group for the Autism&Uni project, however, is different in that they are of average or advanced intelligence, academically capable and able to communicate effectively in most situations.

Design thinking

Design Thinking is a human-centred methodology that uses participation, co-design, co-creation and intuitive problem-solving techniques to match people's needs with what is technologically feasible and practically viable (Brown and Wyatt, 2010). It is typically applied to deal with difficult, multi-dimensional problems that lack recognisable requirements and solutions – traditionally referred to as "wicked problems" (Rittel and Webber, 1973).

Arguably the challenge of supporting autistic students on their journey into higher education is a wicked problem – characterised by a multitude of challenges for a heterogeneous target group. Design Thinking advocates argue that by combining empathy, creativity and analytical processes, true innovation can emerge in the process of solving such problems. There has been an increased uptake of Design Thinking in design, business, health, education and social innovation (Withell and Heigh, 2013).

A number of frameworks are available that help with the execution of a Design Thinking approach e.g. the IDEO (2015) HCD Field Guide with a 3-step process of Inspiration-Ideation-Implementation; the UK Design Council (2016) Double-Diamond with steps Discover-Define-Develop-Deliver; or the Stanford University d.school (2010) 5-step approach of Empathise-Define-Ideate-Prototype-Test. The names and number of stages may differ but the underlying ethos of all these approaches is remarkably similar.

The Autism&Uni project was guided by the well-established 5-step model promoted by Stanford University's d.school (2010). Table 1 outlines each step and how it was applied in the current context, effectively providing a high-level narrative of the entire project. Results from each step are reported in the next section.

Table 1: Design Thinking steps and how they were applied

Design Thinking step	How this step was applied in the project
Step 1: Empathise The main purpose of this first step is to understand what people do, what their needs are what affects their lives. One effective way of achieving this is to let people tell stories about real events, rather than speculate on possibilities.	An online survey with separate questionnaires for each of these stakeholder groups: 1. autistic student about to start university, 2. students who are currently at university 3. students who were previously at university 4. parents and carers of young autistic people, 5. secondary school teachers 6. HE academics and support staff 7. support staff and organisations outside of HE In addition, we conducted structured interviews with students to capture their personal stories in detail.
Step 2: Define During this step responses and observations are analysed and grouped, then patterns are identified. Rather than finding solutions just yet, the focus is on understanding people and their circumstances and needs.	During collaborative sessions that involved researchers, academics and autistic adults, we segmented the data, identified needs and summarised findings. In particular, we identified specific challenges typically encountered by students on the autism spectrum. Good practice and poor practice was also highlighted. For some of these sessions participants were co-located, for other sessions communication happened over email.
Ideation is essentially the generation of ideas. Taking the data from the previous step as a starting point, a large number of ideas about how to meet users' needs is generated. It is important that all project members have an opportunity to contribute and that the climate is non-judgemental. At the end of the step, the best ideas are selected to be taken forward for prototyping.	All project partners were asked to propose topics that relate to the challenges identified during the Define step. We asked for positive ideas based on the available evidence and meeting specific needs of autistic students. We provided a simple form template for making suggestions. Once all partners had contributed, we met, discussed the suggestions and clarified any questions or concerns. Three individuals closely involved with autistic communities and organisations in Finland, the UK and the Netherlands participated in the discussion. Following the meeting, partners voted on the topics they felt were most important to take forward into prototyping, based on the impact they were likely to have on the target audience.
Step 4: Prototype Build several prototypes to try and answer a number of key design questions. Start with the smallest, quickest, simplest, cheapest thing that will help you understand what users want. Prototyping and Testing (the next step) are part of an iterative process. Prototypes are refined (or discarded) as one goes through these iterations.	A prototype version of the online toolkit was created which covered a number of topics. There were variations in how the content could be explored e.g. in large scrollable sections or shorter sections with a previous/next navigation (often referred to as 'wizard-style'). The visual design of the toolkit prototype was minimal with very limited use of colour and simple, flat navigation. Some of the toolkit content was created not online but in the form of paper prototypes. A documentary filmmaker was commissioned to produce short clips about three toolkit topics, which were then presented with a video introduction.
Step 5: Test Test the prototypes with actual end users and identify improvements. Adapt your	To evaluate the prototype online toolkit and to collect ideas concerning design features, a series of participatory design workshops was conducted. The first workshop was conducted with autistic students in the UK in July

prototypes based on user feedback and show them the improved version.	2015. This also served as a way to further tap into the students' expert knowledge about themselves and their condition, and share ownership of the design process.
	In December 2015, a second participatory design workshop was conducted in the UK. The prototype used in this workshop was an improved version, taking into account findings and suggestion from the first workshop. Visual design had been added, the number of toolkit items had grown, and there had been some attempts to link the items together to provide logical sequences the reader could follow.
	In January 2016, a third participatory design workshop was conducted in Finland, using the same prototype as in the second workshop. The Finnish participants evaluated the design and functionality of the user interface by trying out the English version, and the content by reading four items that had been translated.

To illustrate the variety of tasks and the underlying rationale, table 2 summarises three of the activities set for the first participatory design workshop.

Table 2: Selected workshop activities

Activity	Description	Nature of tasks
1. The benefits of disclosure	The purpose of this activity was to get feedback on the best way of presenting long text-based content with complementary information. The scenario was based on a narrative that explained the background, consequences and possible actions related to disclosure of autism. The content was written by a researcher with autism, and based on the analysis of survey and literature review.	 Discussion about experiences of telling the university about autism diagnosis Engagement with the online content, followed by a discussion about the layout and narrative of the mainly textual information Relating back to self, considerations of whether the information would have been helpful to the participants in their HE journey
2. Managing expectations	We prepared a number of "Myths and Truths" pairs which were meant to clarify some of the common misconceptions about university. These were presented as two 1-minute animated motion graphic sequences. We wanted to find out whether video was a suitable way of conveying this information, and whether participants could imagine other ways.	 View the motion graphic and discuss content and effectiveness Draw paper prototypes of how else the information could be conveyed via a website
3. Find out about the Study Needs Assessment	We produced a number of wireframes* that illustrate how the scenario content could be displayed, and how users could interact with it. The purpose was two-fold: capture responses to wireframes as tools to simulate a website, and suitability of the video.	 Manual walkthrough of the wireframes on paper, followed by a projection of a video about the assessment (around 2 minutes long) Discussion of wireframe content and navigation Discussion about the format and purpose of wireframes

Results

The following sections summarise the results from each step of the Design Thinking process, with a focus on the nature and effectiveness of stakeholder participation.

Step 1: Empathise

The online survey ran for 4 months in the second half of 2014 and attracted 300 responses in 5 countries, illustrated in table 2. 20 responses were later discarded because they were not related to HE studies. In addition to responses to the 7 structured surveys, detailed personal stories from 10 autistic students were captured, alongside 6 additional personal stories told by a parent or supporting professional, rather than the students themselves.

Table 3: Overview of survey response rates

	English	Dutch	Finnish	Polish	Spanish	TOTAL
Survey 1: Students not yet at university	3	0	6	9	12	30
Survey 2: Students currently at university	17	2	16	0	12	47
Survey 3: Students previously at university	23	3	18	0	10	54
Survey 4: Parents & Carers	10	0	8	4	26	48
Survey 5: Teachers	4	1	1	10	10	26
Survey 6: HE academics and support staff	10	2	3	2	10	27
Survey 7: Support staff external to HE	6	1	3	2	20	33
First person story	2	0	5	0	3	10
Third person story	0	0	1	0	5	6
TOTAL	75	9	61	27	108	280

It should be noted that with 141 responses (surveys 1-3 and first person stories), the voices of autistic students accounted for over 50% of the data. High-level results from the surveys are summarised in the next step.

Step 2: Define

An analysis of responses revealed a number of recurring patterns in the challenges encountered by autistic students on their journey from secondary education into higher education. Some of these had to do with the higher education system and the organisation of disabled student support, or with the social and physical environment at university. Others related to the characteristics of autism and how they affected academic and social life at university.

Several respondents recounted positive experiences and provided valuable insights into how these individuals managed to succeed in their studies. This is an important element in the Design Thinking process: to identify the so-called "positive deviants" which are individuals who cope better than others, even when they appear to start out from the same situation. For a full overview of challenges and examples of best practice, the reader is referred to the Autism&Uni Best Practice Guides (Autism&Uni, 2016)

The step was effective in that findings from the literature were confirmed and extended through students' first person accounts and the experiences of professionals working in autism support, lending greater authenticity to the available data. It also allowed proceeding to the next step with greater confidence.

Step 3: Ideate

During the Ideate step, ideas for toolkit topics were generated by all partners simultaneously, akin to a brainstorming session. The inspiration was the data from the previous step, in fact each topic had to be justified with a reference to one or more of the challenges identified to ensure ideas are grounded in evidence. However, the topics were not necessarily direct responses to the challenges, but creative ideas for helping and supporting students.

The project partners proposed 19 different topics overall and, following short listing, these were reduced down to 6 topics to be taken forward to prototyping. Topics were shortlisted based on the impact they were likely to have on the student audience. At this stage none of the project partners knew what the online toolkit would look like or how it would function, and they initially felt they did not know enough to a) make suggestions for topics and b) make decisions about which topics should be shortlisted.

This is not uncommon in a Design Thinking process, and in fact an element of uncertainty and speculation is deliberately introduced to free the ideation step from being driven by technical or ideological constraints and encourage divergent thinking (Brown and Wyatt, 2010). It is during the prototyping step when criteria such as viability, practicality, usefulness and usability come to the fore, and as a consequence some prototypes are discarded and others change in an evolutionary fashion.

In the event, partners overcame their initial hesitancy and effectively followed the ideation process. Table 4 lists the final shortlist of topics that partners decided on.

	Table 4: Toolkit to	pics to take for	orward to	prototyping
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Topic title	Rationale / Comment
Why declare a disability	Many autistic students do not declare their autism before starting university,
	which prevents access to support at the start of the study when it matters most.
What is the Study Needs	To reduce anxiety about being interviewed and discussing uncomfortable issues.
Assessment?	(Study Needs Assessment is a UK term, similar processes exist in other countries)
Managing expectations	Many autistic students (and their parents) have expectations that do not match
	the real situation at university. The surveys provided many accounts and quotes
	to support this.
Help with getting to	Students reported getting repeatedly lost on campus and not remembering items
campus locations	on their timetable. And when they are late there is a reluctance to enter the
	room.
Typical study situations	Advice on what to do in certain unfamiliar situations, e.g. during a lecture, when
	working with other students in a team, in a tutorial, etc.
Managing difficult	It is important for students to advocate for themselves. Parents and teachers
situations	were very vocal about this, and a number of typical situations were identified
	(e.g. talking about one's autism, complaining about something, when and how to
	arrange a meeting with a tutor)

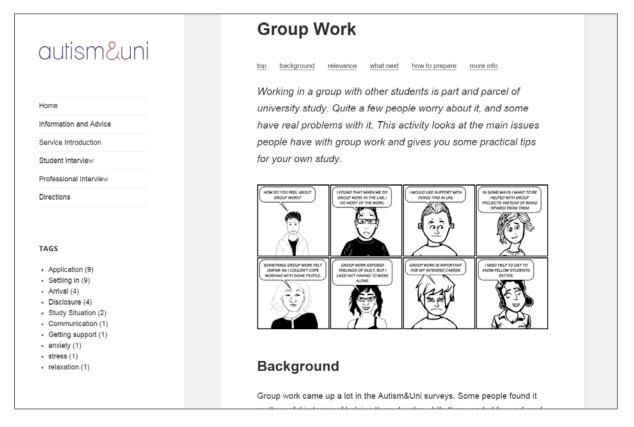
Steps 4+5: Prototype and Test

Workshop 1

The first workshop was conducted in the UK. It took a total of four and a half hours, and included an introduction, five structured half-hour activities separated by breaks (including lunch), and a final debriefing session. 3 students took part: a 24 year old female graduate now working as a graphic designer, an 18 year old male due to start a Creative Technology degree course (accompanied by his mother), and an 18 year old male with an interest in Finance and Accounting who has not yet applied to university.

The layout and visual design of the prototype toolkit was chosen to be deliberately minimal (see figure 1), in line with research findings from the initial survey regarding interface preferences of the target audience.

Figure 1: Visual design and navigation of the first toolkit prototype



All participants enjoyed the activities, commenting on their interactive nature. They also emphasised how good it felt to be listened to, not just in accordance with the principles of community-based participatory research (McDonald and Stack, 2016) but in comparison with their daily lives as young autistic people.

The most valuable parts of the day involved discussion of issues faced and strategies for coping in various situations. This indicates what is lost when autistic participants are merely treated as 'test users', presented with products and services to test and use to help with their presumed deficits.

Some stereotypes were challenged, like the assumption that all autistic people think visually and prefer visual information, which is in accordance with the findings of Erdödi et al. (2013) that autistic people find verbal learning tasks easier than visual alternatives. Participants strongly preferred well-structured text information to infographics or video. Participants only wanted visual information when it specifically added something that text alone could not achieve, such as

- showing landmarks and turnings in directions to reduce ambiguity
- images of the people they would be meeting
- images of the buildings and exact rooms they would be using

Participants developed clear preferences for how headings, quotations and other non-paragraph text should be presented and which fonts and colours did not work well for them. They told us that they wanted to be able to choose how they looked at information, whether it was all in one long document or broken up into chunks or in a printable format. Participants challenged 'negative' wording that made assumptions that they would find things difficult, preferring a more neutral tone that provided information without judgement.

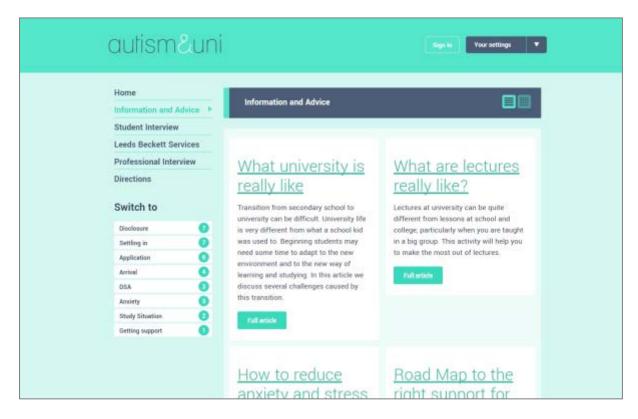
Figure 2: Paper prototypes created by workshop participants



Workshop 2

The second workshop, also conducted in the UK, followed closely the outline developed for the first workshop. It was attended by three undergraduate and two postgraduate students, all from local universities. Again, participants were happy with the experience, despite some initial anxiety, and shared several useful suggestions to guide the further development of the Online Toolkit. Issues explored during the workshop activities related to the new visual design of the toolkit, navigation across a number of related toolkit items, and the way toolkit appearance and behaviour could be customised.

Figure 3: Interface design of the improved toolkit



At the end of the workshop participants completed a short questionnaire about the usability of the prototype, using the well-established System Usability Scale by Brooke (1996). The score of 71% suggested that its usability was above average (considered to be at 68%) even at this prototype

stage. Participants also told us that they felt comfortable to share their experiences and that their opinions were valued on the day.





Workshop 3

The third workshop was conducted in Finland and attended by three students from three different HEIs, one female Arts student and two males studying technology and IT, along with one parent of an HE graduate contemplating postgraduate studies. Both recruiting and the workshop itself followed a more streamlined approach than their UK counterparts, largely because the participants were contacted through an association for autistic adults.

In Finland, universities do not systematically collect data that would allow them to help in recruiting autistic students, and finding young students to participate would have taken too long. Hence, the participants were in the later stages of their study careers, assertive and adept at expressing any discomfort, and had met each other before; they were not in need of cautious approaches to minimize anxiety in unfamiliar surroundings or group situations.

The evaluation workshop lasted three hours and was divided into two main sections covering the design and interface aspects (in English) and the content of four toolkit items (in Finnish). The list of research questions developed for the UK workshop was followed, but the students were invited to approach them through free exploration of the toolkit and spontaneous discussion rather than structured activities. The facilitator running the workshop felt that a highly structured setting would have caused anxiety for this particular group rather than diminish it, while younger students would have been likely to benefit from more precisely defined activities.

Discussion

The Design Thinking process provided an effective framework for involving intellectually able autistic adults in the creation of solutions that serve their needs. In the Autism&Uni project, end user participation took place in a systematic manner in three of the five stages: Step 1 (Empathise), Step 4 (Prototype) and Step 5 (Test). While end user involvement was not specifically invited in Steps 2 and 3 (Define and Ideate), there is nothing to suggest that the workshop approach could not be extended to these, creating an uninterrupted continuum of user involvement throughout the design process.

In hindsight, the 'Empathise' stage could have been enriched by adopting methods such as focus group interviews, 'day in the life of...' diaries and co-research activities (cf. IDEO, 2015). Throughout the project, research participants showed enthusiasm for sharing experiences which stood in contrast to some anxiety and inertia when faced with questionnaires. On several occasions, students would spontaneously and eloquently recount experiences in informal discussions, only to fail to type them into an online form, even when they wished to do so. It is clear from the early stages of the survey that the approach to data collection needs some careful consideration when autistic participants are involved.

The approach of running workshops that combine the 'Prototype' and 'Test' stages appeared to work well with the eleven workshop participants. The approach proved robust in the sense that it could be simplified for a group and situation that did not require careful structuring, while still generating useful feedback that was very similar in content to the more structured workshops. As autistic individuals are part of a spectrum with varying genetic, biological and cognitive characteristics, the participants at any such event will differ from each other in terms of needs and preferences.

One of the most ubiquitous oversimplifications concerning autistic people is that they are predominantly 'visual thinkers', combined with the conclusion that they benefit from, or are likely to prefer, images rather than text to convey information. The results of this research suggest the opposite is true for the Autism&Uni participants. While many may share perceptual strengths, they consistently preferred text with a minimum of visual distractions.

Other common assumptions concerning the autism spectrum might discourage people from adopting approaches like Design Thinking, as autistic people can be considered to lack creativity or to have little desire to share their ideas and observations. Such views are commonly repeated in professional literature, yet over the past few years various researchers have pointed out ways in which autistic imagination can present itself, and suggested suitable methods to study it (Lyons and Fitzgerald, 2013; Best et al, 2015). Observations from the Autism&Uni workshops agree with this research in that the participants demonstrated their ability to contribute to the design process — both creatively and imaginatively — in environments and situations where their well-being and comfort was ensured.

Concerning the validity of this research, one of the aspects of HE study that came up as a common challenge in the survey responses was group work. A participatory design workshop is arguably a group work situation. The prospect of unfamiliar surroundings, facilitators and participants may be stressful enough to prevent some autistic individuals from attending. As a whole, the approach may favour the participation of the more confident, sociable and articulate among autistic students.

Another obstacle is the limited number of participants (eleven). It is not clear how representative these were of the autism spectrum in general, or some reasonably large proportion of it. It is

encouraging, however, that very similar feedback was received from workshop participants in the two countries, representing several different academic disciplines and currently at different stages in their studies. It appears likely that a considerable proportion of autistic students from diverse backgrounds share similar preferences with regard to the toolkit's design features, particularly a clean and minimal overall look, architecture that allows easy navigation of large amounts of data, and the opportunity to adjust the amount of information displayed on the screen. Further, the uniformity of the feedback suggests that the participants were able to express their views effectively in the workshops, and were thus contributing to the design in a meaningful way.

There is some discomfort among autistic adults and their parents with projects that offer brief, one-off encounters in consulting roles (cf. Pellicano et al, 2014). Arguably that is what Autism&Uni did, by first consulting students as part of the online survey and interviews, and later as participants during the workshops. The role of autistic people as experts in that context needs to be carefully considered – are they really experts in the sense that they take part in the professional discourse concerning results and findings? Are they being asked what the research questions for the next project should be? More often than not their role is limited to being experts in their own experiences and circumstances, which they are asked to share and expose. This tradition tends to firmly separate the discourses of the academic community and the autistic community, where they should perhaps be integrated.

In the Autism&Uni project, autistic people were involved right from the start as part of the project team so arguably there was a continuous connection with the autism community (albeit a weak one) since the team members had the opportunity to shape the research and discuss its results. This link was perhaps less immediate with the workshop student participants who influenced the discourse around the toolkit design and content through their helpful suggestions, but did not directly take part in it. There is some effort, however, at continuing involvement up to and past the end of the Autism&Uni project in that project outcomes, publications and the toolkit itself are shared freely with the autism community.

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