# END USERS' PARTICIPATION IN THE DESIGN PROCESS AND PERCEPTIONS OF THE USABILITY OF THE AUTISM&UNI ONLINE TOOLKIT

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#### Abstract

Autism&Uni is a European-funded initiative with partners in five countries (UK, Finland, Poland, Netherlands and Spain). The project has involved end users at several stages of creating content, design and interactive features for an application intended to serve the needs of higher education (HE) students on the autism spectrum. We have learned about the process of working with individuals on the autism spectrum in co-design and evaluation, as well as their preferences and aspirations. This paper summarizes the feedback that was collected at each stage, and the approaches adopted in the course of the project to ensure that the students could participate effectively and comfortably.

Keywords: Autism spectrum, co-design, end user involvement, usability, evaluation.

## 1 INTRODUCTION

Individuals on the autism spectrum face a number of challenges that threaten their ability to continue past the early stages of their studies and to complete a degree in a higher education institution (HEI). These challenges include general lack of awareness and knowledge concerning autism spectrum conditions in HEI environment, lack of social networks to support them, and certain cognitive characteristics that can make managing studies and student life as a whole difficult, despite the fact that these students can exhibit remarkable skills and intense focus in a variety of fields.

The same challenges could prevent them from participating effectively in the development of support forms and tools that target the autism spectrum. In the Autism&Uni project, we thus faced the problem of creating conditions that would allow autistic participants to contribute to the content and design of the Online Toolkit, and to evaluate the final product, while ensuring that their needs were met at every stage. The main stages of collecting end user views and feedback were

- 1. an initial online survey, conducted in five partner countries;
- 2. a design workshop, conducted with autistic students in the UK, and
- 3. two evaluation workshops, conducted in the UK and in Finland.

These are described in sections 2-4 below. In addition, some valuable feedback was received through informal discussions with autistic students in partner countries.

## 2 ONLINE SURVEY

An important feature of the Autism&Uni Online Toolkit is the nature of its content. The online survey conducted in the early stages of the project was designed to collect information on the experiences and aspirations of students on the autism spectrum. The survey responses were analyzed and significant recurring themes were identified. These were then used in combination with research literature and survey responses from other stakeholder groups as the basis for scenarios, designed to allow end users to familiarize themselves with typical challenges, questions and possible solutions encountered by autistic students. Direct quotes and interviews were included to convey the students' first-hand experience in their own voices. This approach allowed the creation of content that is experience-based, grounded in the data, and reflects themes that the students are likely to find immediately relevant. This avoids the pitfalls of 'talking down' to the end users or making overgeneralizing assumptions concerning their needs, as can happen when content directed at people on the autism spectrum is based primarily on one of the numerous theoretical constructions concerning the core cognitive features of autism.

The launching of the online survey was accompanied by a brief period of informal end user feedback as the first respondents spotted faults and ambiguities in the questionnaires and suggested changes to wording and technical details, as well as certain features of the project website. Two problems stood out as significant obstacles to data collection. Some potential participants did not finish their responses because a multiple choice question did not offer an option that they agreed with, and the questionnaire did not allow them to proceed without selecting a 'false' option. Many participants wrote lengthy accounts of their experiences in boxes originally meant for brief comments, and were dismayed at the lack of space to express themselves, while they appeared to ignore (or failed to spot) the option of filling in a separate form specifically designed to allow them to tell their story in full.

The survey focused mainly on the challenges faced by autistic students and the associated services and adjustments, but to support the development of a usable and accessible online toolkit, HE applicants and those currently studying in HE were also asked about their preferences regarding information sources and website design.

The question concerning sources of information was worded as:

"When you want to find out about something, where do you usually get information from?"

To this, the most frequently selected response by far was "Internet search engines (like Google or Bing)". Wikipedia was another popular source of information.

The question concerning websites that the students preferred was optional:

"Do you have a website that you really like to use because it is well-designed? Please give us the name and if you remember it the address of the website. Describe what you like about it (optional, in less than 50 words) - this question is so that our website and the tool we create work well for you."

24 students responded to this question. Wikipedia was mentioned in six responses, making it the only site that came up in responses from all five countries. Themes that came up repeatedly, in connection with various websites, were clarity, simplicity, uncluttered design, general smooth functioning and the capacity to search and download content quickly and easily. Some mentioned the content or service on their favorite website being free of charge, or being able to personalize the look of the web page. The respondents clearly tended to appreciate ease and functionality over innovative or visually impressive design features. On the other hand, some mentioned popular social media websites such as Facebook or Youtube simply because they had become used to navigating the site or enjoyed the content.

#### 3 CO-DESIGN WORKSHOP

To evaluate prototype scenarios compiled by project partners and to collect ideas concerning design features, a human-centred, participatory design workshop was conducted with autistic students at Leeds Beckett University. This also served as a way to further tap into the students' expert knowledge about themselves and their condition, and give them ownership of the design process.

A search of research literature provided some recommendations on how best to design creative workshops and design activities with participants on the autism spectrum. These have been summarized in a project report [1]. The practical guidelines available in the literature were collated and grouped into sections:

- 1. Pre-event logistics how to prepare the environment and brief the participants
- 2. Designing artefacts and activities what to consider when planning activities
- 3. What to avoid common pitfalls and misconceptions
- 4. After the event how to debrief participants and how to interpret results

The location, structure, and content of the workshop were planned carefully to avoid participants feeling anxious about what to expect, how to behave and perform on the day. A pre-workshop questionnaire was prepared and sent to potential participants to find out about their individual needs and characteristics. The workshop 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.

Three students attended the workshop. All expressed satisfaction with the preparations, activities, and having a sense of their views being heard. The students made several suggestions that were used to

guide the development of the toolkit in later stages. A list of practical tips for running co-design activities with autistic students was compiled on the basis of the research literature, observations from the design workshop, and ideas from a separate workshop for professionals working with the autism spectrum and information technology [2].

In terms of preferences, it was apparent that the small group of participants had certain likes and dislikes similar to those commonly expressed in survey responses. They liked the idea of having easy access to large amounts of information. They did not wish to have visual elements, video or animations added just to improve the look of the website, but approved of visual content when it provided information that could not be easily conveyed in words, e.g. in connection with directions to a building on the campus. However, a comic strip featuring quotes from survey responses by autistic students was received positively. There were individual preferences regarding colours, fonts and the style in which the text was displayed (full page, broken into slides, or printable.) An important message was that the students did not wish to have certain choices made for them, as their preference might depend on content and context.

## 4 EVALUATION WORKSHOPS

To find out how successfully the end users' preferences were reflected in the Online Toolkit prototype, two evaluation workshops were run, one in the UK in December 2015 and the other in Finland in January 2016, utilizing the tips and guidelines from the design workshop described above. At this point, 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.

Four toolkit items and most of the text involved in the interface had been translated to create a smaller Finnish language version. However, it turned out that the architecture of the website did not agree with a language that was structurally very different from English, which led to some unexpected problems. The Finnish participants evaluated the design and functionality of the user interface by trying out the English version, and content by reading the items that had been translated.

The first evaluation workshop, conducted in Leeds and attended by five students from two universities, followed closely the outline developed for the design workshop. The schedule and activities were built around eight research questions:

- How do participants respond to the visual design of the toolkit?
- Which interactions lead to errors or confusion?
- How do users navigate to relevant information?
- How can related toolkit items be linked or grouped?
- How relevant is the content?
- How focused and detailed should a toolkit item be?
- Do users understand the narrative structure of a toolkit item?
- How specific to a country or institution do toolkit items need to be?

The System Usability Scale (SUS) [3] was employed to rate the overall usability of the toolkit. The scores suggested that its usability was above average even at the prototype stage. Again, students were happy with the experience, despite some initial anxiety, and came out with several useful suggestions to guide the further development of the Online Toolkit.

The second evaluation workshop was conducted in Helsinki, and attended by three students from three different HEIs, 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 person 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.

## 4.1 Interactive features

Some details of the toolkit were perceived in similar ways at both workshops. Effective and informed use of some of the interactive features depends on the user creating a profile and making choices regarding the level of automatic customization and level of privacy. This was explained in a section that had a prominent place among the main content categories on the front page. The explanations confused workshop participants in both countries. The Finnish students (to whom the content was available in two languages) questioned why the section was given so much space, why it was not simply part of a small "settings" menu in one corner of the front page, and how they were supposed to benefit from the presented options in the first place.

A simple interactive feature that appealed to participants in both countries was the option of viewing longer text either as a single page or divided into smaller sections, with quick links at the top of the toolkit item.

# 4.2 Visual design

All students liked the clear and simple visual image, but some visual details were still in need of fine tuning. For example, Finnish students would have preferred a front page that showed main topic categories without scrolling, and criticised the presence a large field at the top of the page that prevented this. The UK students tended to ignore a box placed in the same field, meant to be informative but giving the impression of an unimportant error message. However, a narrow timetable/alarm bar at the top of the page, showing the next lecture the student should attend, was appreciated in both countries, and sparked suggestions to develop this type of feature further, incorporating a calendar, maps or directions.

## 4.3 Use of images

While most students appeared to like text, a suggestion also came up in the Finnish workshop to add visual content that would utilize the capacity for visual analysis exhibited by some autistic individuals. Also, the longest item was criticized for being too long and difficult to read. As the number of autistic students involved in design and evaluation has been fairly small, there might be minorities within the spectrum that have not been adequately heard at this point, and should be given careful consideration in any future work on the Toolkit.

#### 4.4 Text and tone

In terms of content, there appeared to be universal agreement that most of the items in the prototype were interesting and relevant, and the inclusion of first-hand experience in the form of interviews and quotes received general approval. The students paid close attention to the tone in which autism was portrayed, being critical of both overly negative depictions and 'glossing over' challenges. Some called for more concrete advice on how to proceed in solving a problem, rather than the general thoughts and questions to ponder offered in some of the toolkit items.

## 4.5 Connecting content

The preference for having large amounts of information at their disposal, apparent at earlier stages of the project, was further confirmed by the evaluation workshop participants. Various suggestions were made about topics that should be added, but at the same time there was a sense of concern about keeping the toolkit navigable. This was expressed in the UK workshop as a wish to have the toolkit items linked or grouped, making connections more visible, and in the Finnish workshop as a request for a search field on the front page, as well as the option of customizing the toolkit to only show selected items on the basis of the student's location and the current stage of their study career.

## 5 DISCUSSION

Numerous students encountered in the course of this project were keen to share their experiences of HE and their views on suitable support. There appears to be an abundance of general potential for individuals on the autism spectrum to support each other by sharing information, if only structures and channels are made available to facilitate this.

The enthusiasm for sharing is in contrast to the anxiety and inertia when faced with questionnaires or unfamiliar situations such as evaluation workshops. 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 our survey that the approach to data collection needs some careful consideration when autistic participants are involved, and our methods would have benefitted from some fine tuning, had the project time frame allowed it.

In future research, involving several autistic individuals in questionnaire design, starting from the earliest stages and investing time in repeated testing, might solve such problems to some degree. Another solution might be to conduct face to face interviews and use audio recording to collect personal stories.

Overall, the Autism&Uni project has shown that the idea of an online toolkit is acceptable and even appealing to many HE students on the autism spectrum. This is reflected in the relatively large number of survey responses, a total of 141 from autistic individuals, and the type of feedback received through both informal discussions and the design and evaluation workshops. The students involved in the project signalled a certain level of trust in this particular approach as they allowed us to use their personal experiences to benefit others in similar situations, or suggested ways to improve and expand the prototype Online Toolkit. They did not reject the idea of this type of online application or suggest that something entirely different should be developed; rather, they appeared to think that this was a sound concept with some room for improvement. This leads us to believe that it would probably be easy to find students to participate in further development of local toolkit versions in HEIs across Europe.

While the number of students involved in design and evaluation was small, we received in many respects very similar feedback from students in two different countries, representing several different academic disciplines and currently at different stages in their studies. They showed preferences that agreed with many responses from the online surveys, which covered five countries and an even broader range of disciplines. It appears likely that a considerable proportion of autistic students from diverse backgrounds share similar preferences with regard to certain 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.

The students' experience of the more advanced features, such as detecting the users' preferences and automatically adjusting to display visual or verbal information first, could not be evaluated within the time constraints of the project. Some students found the idea interesting, but they had trouble comprehending the associated choices concerning privacy and storage of data on the basis of the information offered in the Toolkit prototype. Therefore, determining the effect of such features on the usability of the Online Toolkit remains a task for future research projects to tackle.

#### 6 DISCLAIMER

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