

Research Ethics in OutsideTheBox

Introduction

OutsideTheBox (OtB) aims to invite children with autism spectrum disorders (ASD) to co-design ubiquitous computing artefacts. The project will implement 6 different participatory design approaches over three years (2 in parallel each year) to demonstrate how this target group can be meaningfully included in the design of technology. By implementing these case studies we aim to substantiate a bigger argument about a necessary paradigm shift in the design of assistive technologies, away from designing for functional deficits towards a holistic design for experience, wellbeing and empowerment.

Thus, the design brief is deliberately kept open to enable the researchers and the children to explore new roles of technology that are meaningful in their lives rather than focusing on a specific intervention target or feature of the disability. The technologies we develop have to fulfil two basic requirements:

1. applications afford meaningful and positive experiences within the life-worlds of children with ASC and
2. they support children in sharing these experiences with their social environment.

Workplan

The work is organised in three, identical cycles, each lasting one year. Within each year, we will implement two different participatory design approaches, each with two to four children, i.e., we aim to involve four to eight children each year. Cycles start in July to allow for preparation work and initial recruitment to be done over the summer break. Actual recruitment of participants and contextual research will commence at the start of the school year in September with design work starting when appropriate relationships have been fostered.

For **contextual research** we will arrange meetings with parents, carers, teachers and the children for informal interviews and conduct observations in schools and use alternative methods such as probes and diaries to augment the data we collect.

We aim to meet children in intervals of one to two weeks for **design work** over a period of five months (depending on holidays, roughly 10 - 20 sessions). Each session will take place in the school, in a separate room with one child or a small group of children, a professional carer (mentor or teacher) and the researchers present. Sessions will last between up to one hour depending on the routine and attention spans of children. We will prepare appropriate materials and activities for each session which interpret one of the chosen participatory design approaches. Since we develop these activities as part of this research, it is impossible to provide details at this point in time. However, we will implement a rolling ethics monitoring mechanism (see below) that ensures that each planned activity is considered from an ethics perspective and is compatible with the overall research ethics we outline in this document and poses no risks to the participants.

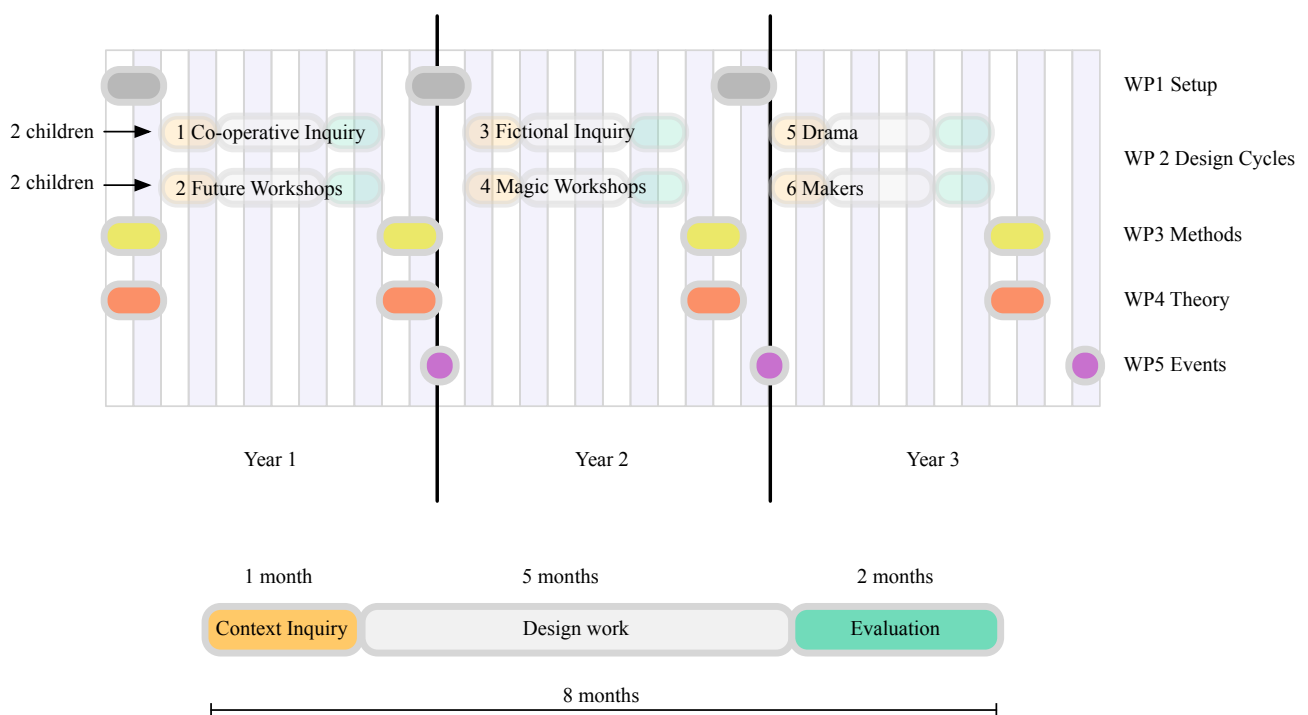
In some cases, we will try to arrange **excursions** with children, for example to visit a FabLab or the University. All excursions will be planned carefully in accordance with the children and the parents and at least one professional carer or one parent will accompany the group at all times.

In the **evaluation phase**, the interval of meetings will be reduced to every two to four weeks. At these meetings we will conduct observational studies and interviews, and collect data from the artefacts. In between we will ask parents, carers, teachers and children to keep diaries or make notes of observations. We aim to minimise the work load by supporting each group with appropriate tools to collect such data.

By the end of the cycle, children and parents will be invited to participate in the creation of a small **exhibition**, however, taking part is voluntary. The goal of the exhibition is to showcase the resulting artefacts and tell the stories how they were created. We thereby hope to engage the general public and contribute to a wide social discourse about the relationships between technology, disabilities and society at large.

The exhibition will also mark the end of the formal working relationship with our participants. Since this will coincide with the end of term we anticipate that this will be perceived as a natural ending point for our participants. and As a token of gratitude, all artefacts will remain with the children after our collaboration ends. Time permitting, the research team will maintain these artefacts, if necessary, while the project is running, but we cannot guarantee any support afterwards.

The figure below presents a schematic representation of the workplan with the overall plan above and one design cycle in more detail below.



Participants

Our target group are children with ASD between six to eight years of age (i.e., primary school entry level). Two considerations have led to this decision:

1. Children should be able to participate in the likely workshop activities and thus have basic skills such as drawing, constructing with building blocks, imaginative play etc., depending on the PD approach.
2. Children should have an official diagnosis, but they should be as young as possible to be minimally primed by the existing technology landscape.

Autism is incredibly diverse and often additional disabilities or behavioural problems are present. The decision to involve a child in the project will be made on a case by case basis, carefully judging whether the child would be able to meaningfully participate in the planned activities. A decision will be made in collaboration with the parents, teachers and mentors who know the child well.

In the project, the social peers of the child are recognised as important stakeholders in the process and are therefore considered participants too. This includes parents, teachers, mentors or close friends and other carers. The scope of the relevant group around each child will be determined as part of the initial contextual inquiry.

Recruitment

Participants are recruited through two main paths:

- Through the “**Integrationsberatungsstelle des Stadtschulrates für Wien**” which is the central service provider in the regional education system for all children with special needs who attend school (special or mainstream). The service has agreed to facilitating access to schools, mentors and parents of suitable candidates who we can approach with information material and an invitation to participate.
- The “**Institut Keil**” is a special education unit with many children with more severe levels of ASD. It provides a kindergarden as well as primary and secondary schooling.

The recruitment process in each project cycle will be as follows:

1. Definition of a minimum skill set that is required for children to be involved in the planned activities.
2. Based on this skill set, the Integrationsberatungsstelle and its mentors will compile a list of potential list of suitable participants.
3. The project team establishes contact with the schools, mentors and parents of this list, sending out an invitation letter and tailored information material for each group (see appendix).
4. We arrange a meeting with parents, teachers and the child to provide further information and to get to know each other in person.
5. We ensure all information has been provided to enable parents to make an informed decision about participating in the project (informed consent, see below).
6. Start of contextual research.

Consent

Informed consent to take part is central to the ethical procedure we implement in the project and we will ask all participants, including children, parents, mentors, teachers and others, to formally agree to being involved. Sample consent forms are available in the appendix, but they share the following qualities:

- Forms are written in accessible, age-appropriate language and provide unambiguous ways for participants to agree or disagree with aspects of their involvement.
- Participants are fully informed about the purpose and the goals of the project as well as their intended role in it.
- The forms provide information about what participants can expect from taking part, both in terms of likely activities, required investment of time as well as potential outcomes and ownerships.
- Participants are free to terminate their involvement at any time and without providing any reason.
- Participants are encouraged to ask any questions as they arise.
- Specific attention is paid to the legal implications of collecting data from the work such as personal information, pictures or video. Participants can choose between different levels of anonymity in the publication of their data (see below).

Collaboration will only commence if all participants have provided consent.

Risks and benefits to stakeholders

Children

The physical, psychological and emotional wellbeing and safety of the children involved is centrally important to us. If any of the researchers or participants observes any signs of the work having negative impacts on the children, or any other involved stakeholders the collaboration will be immediately paused and only continued once all participants have agreed that it is safe to do so (see conflict resolution below).

We are aware of the following **potential risks** to the children and will act to minimise the risk of their occurrence (potential counter strategies in parenthesis).

- Anxiety and stress during workshop sessions (flexibly adapting tasks during the workshop, taking breaks, aborting the session, seeking the help of professional carers).
- Behaviour meltdowns including actions intended to cause physical harm or self-harm (being vigilant for early signs and immediately seeking the help of the professional care team)
- Injuries during workshop activities (materials for activities have to be chosen to minimise the risk of any injury, the use of materials will be discussed with teachers and mentors considering each particular child. e.g., regarding DIY materials like glue, scissors etc., activities must be designed to ensure physical safety)

There are also various **potential benefits** to participants that the project aims to realise:

- Enjoyable and novel activities for children during the design process.
- Empowerment of children and other stakeholders by demonstrating how they can take charge of the design of technology they interact with in their lives.
- Scaffolding a novel interaction channel between the child and her social peers that potentially leads to positive behaviour change.

Parents

Potential risks to parents include:

- Parents might have unwarranted expectations about the benefits of the projects for their child (the information for parents will state expected benefits, but also be very clear that this project is not an intervention, and as such does not promise any cognitive or behavioural improvements or gains).
- Additional time effort might be required by parents due to the direct involvement in the research as well as by the involvement of their children (the project team aims to minimise these disruptions and will work with the parents to ensure they are not overcommitted).

The work has the following **potential benefits** for parents:

- Novel and shared activities with the child

Teachers and mentors

Teachers and mentors play a key role in the collaboration we aim to establish. **Potential risks** to them include:

- Additional time effort (the project team seeks to minimise disruptions in schools and is sensitive to the work load of teachers and mentors)
- Mismatch between activities in the project and the curriculum in class (the team tries to design activities considering the current curriculum and thereby work in accordance to educational goals)

The work has the following **potential benefits** for teachers and mentors:

- Novel activities to engage the child and supporting mentors and teachers in their daily work.

Researchers

The project recognises the roles of researchers involved as stakeholders in the work and is committed to provide an equally safe and enjoyable working process for them. Below, we have identified **potential risks** and possible counter-strategies:

- Emotional and psychological stress. Working with children with disabilities can be strenuous and may affect researchers on an emotional and psychological level. (researchers are encouraged to seek advice from the academic peer group at the institute, particular from Prof Geraldine Fitzpatrick who acts as a mentor and advisor)

for the project. Psychological support structures are also in place at TU Wien which the researchers can contact).

- Pressures related to academic work (as with potential emotional stress related to working with children with disabilities we encourage team members to make use of psychological support if needed. Additionally, we aim to find an external mentor for each team member who can advise regarding academic work, e.g., secondary PhD supervisor, career coach)
- Injuries during workshop activities (as for children, we aim to design activities with health and safety for all participants in mind)

It is the hope that researchers also benefit from their involvement on different levels, ranging from conducting enjoyable workshop activities to the academic achievements and rewards.

Data Collection & Protection

During the work we will collect data in the form of personal information, photos, videos, drawings or artefacts. For example, we will describe habits, video tape workshops, photograph artefacts built during the workshops, audio record interviews, keep research diaries detailing our experiences or collect drawings made by children (or parents). Most raw data will be digitised and stored electronically on the project server. Access to the raw data is restricted to the members of the project and appropriate measures are taken to protect the data on the server and the backup (encryption, access control).

We will ask participants as part of seeking their consent whether they are comfortable with us collecting data in this form and under which circumstances they would prefer us to not collect any data. We will also stress that participants can always ask for us to stop recording or delete any previous recording without providing any reason.

In the project, the raw data will be analysed and processed as part of our research. We will provide participants with a range of options regarding the potential use of this processed data. The levels of use are:

1. Data can be used in scientific publications if fully anonymised (all personal data removed)
2. Video and pictures can be used in scientific publications if faces and other significant personal features are distorted.
3. Video and pictures can be used in scientific publications unaltered if no other personal information is provided.
4. Data can be used in clear and for any kind of publication (e.g., webpage, news papers) after seeking consent from the parents for each individual case.

The use of data that allows the identification of children is strictly an exception and will generally be minimised, even when consent has been given. Unintentional consequences like stigmatisation in peer groups can never be fully avoided and parents might not always be aware of such implications. The project team has a general responsibility to make judgements in the best interest of the child.

Rolling Ethics Monitoring

The nature of our work requires us to remain open for change and flexible with regards of developing our methods. Consequently, the way we interact with participants and involve them in our research might change. We therefore need a mechanism to continuously assess our research ethics. To this end, we introduce the following rolling ethics monitoring into our research process:

1. Before each coherent series of workshops with participants, the project team will hold a designated meeting to assess the ethical implications of the specific activities that are planned. The assessment will be guided by a check list developed from this document and the recommendations of the ESRC Research Ethics Framework¹.

¹ http://www.esrc.ac.uk/images/framework-for-research-ethics-09-12_tcm8-4586.pdf

2. After each cycle, there will be an annual, comprehensive research ethics review on the basis of the experiences made in the work. The project team will adapt its ethics procedures accordingly and will document any change in subsequent version of this document. If any substantial changes are planned, the project team will call on a panel of experts within the Institute to collect feedback.

Conflict Resolution

In case of any conflicts arising during the work, we have two mechanisms to resolve them:

1. If any conflicts involve the work with children, we will pause the collaboration immediately and call a meeting with all participants around this child (parents, teachers, mentors, carers) or the group of children. If no resolution can be found that is supported by all, the collaboration will be ended. Naturally, the parents of the children always have the last word in determining the kind of collaboration they want them and their child to be involved in.
2. If conflicts arise within the research team, we seek the advice from our academic peer group at the institute, particularly from Prof. Geraldine Fitzpatrick who has agreed to act as an advisor and mentor for the project and its members. Any member of the team is encouraged to contact her directly if she does not want to voice the issue within the group or if the issue is confidential.