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Creators: Devecchi, C., Mintz, J. and March, C.

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SUPPORTING USER PARTICIPATION IN DEVELOPING MOBILE TECHNOLOGY TO HELP YOUNG PEOPLE'S WITH AUTISM: THE HANDS SMARTPHONE PROJECT

Dr Cristina Devecchi	Joseph Mintz	Caty March
Department of Education	Dept. of Education	Dept. of Education
London South Bank University	London South Bank University	London South Bank University
Rotary Street	Rotary Street	Rotary Street
London SE1	London SE1	London SE1
+44 (0)20 7815 5432	+44 (0)20 7815 5711	+44 (0)20 7815 5760
devecchm@lsbu.ac.uk	mintzjh@lsbu.ac.uk	marchc2@lsbu.ac.uk

Abstract

Located within the field of the development of mobile technology, the hands project aims to develop software to support the social and self-management skills of children with autism. As part of the HANDS project 10 young people were interviewed during the specification stage. This paper explores the methodological aspects of involving young people with autism spectrum disorders in research and argues that consulting children at the earlier stages of research can be a valid contribution to software development.

The HANDS project: developing a customizable mobile software solution for young people with autism

This paper examines methodological and practical questions related to consulting children with autism spectrum disorders (ASD) in the design and evaluation of technology developed to help them to be socially integrated. The consultation took place as part of the three-year HANDS (Helping Autism/ Diagnosed to Navigate and Develop Socially) project. Formulated as a European Commission (EC) Cordis research programme 'FP7.7.22d. Challenge 7: ICT for Independent Living and Inclusion' as part of the Accessible and Inclusive ICT section of the framework[1]. Based on the multidisciplinary integration of knowledge and research in Persuasive Design (Aalborg University, Denmark), cognitive psychology (ELTE University, Hungary) and pedagogical practice (London South Bank University, LSBU, UK), the new software mobile solution aims to help the children develop the social and self-management skills they need to cope and succeed in situations that they find problematic and difficult. The project development cycle includes the following phases:

1. Specification of Functionality for Prototype 1
2. Development of Prototype 1
3. Implementation and Evaluation of Prototype 1, feeding in to:
4. Specification of Functionality for Prototype 2
5. Development of Prototype 2
6. Implementation and Evaluation of Prototype 2
7. Review and Dissemination

The innovative HANDS toolset solution integrates already existing smartphone functionalities with six new ones, and they are:

1. *The Handy Interactive Persuasive Diary (HIPD).* An interactive calendar function with the usual calendar facilities, but also with configurable/programmable abilities and "knowledge" about situations, where the user is more likely to be persuaded to adopt a new behaviour or attitude. It is based on the concept of Kairos
2. *The Simple-Safe-Success Instructor (SSSI).* An instructor function, which gives precise and practical advice on how to solve a problem.
3. *The Personal Trainer (TT).* A training function that simulates a problematic situations
4. *The Individualiser (TIn).* An aesthetic customisation function
5. *The Sharing Point (SPo).* A facility that makes it possible for the teenagers with ASD to share their knowledge, experiences and interests with other users
6. *The Credibility-o-Meter (CoMe).* A facility to measure to what extent the HANDS toolset is experienced as being credible by the user. The measurement is mainly based on the electronic footprints left by the user on the mobile device during normal use.

Individually and together, the five functionalities allow for a customised response to the difficulties children with ASD might have. While the use of the technology is innovative, the devise of activities using the functionalities relies on existing pedagogical approaches such as TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children) and PECS (Picture Exchange Communication System).

Central to the project is the notion of Persuasive Design, or, according to Fogg (2003), the use of persuasion to develop computer software whose aim is that of changing behaviours or attitudes. When applied to technology, persuasive design aims to develop software for mobile technology that is interactive, responsive, meaningful and credible. The successful persuasive outcome depends on the level of customisation and individualisation of the software potential with what the child requires, needs or desires together with the use of microsuasion, suggestion, tunnelling, reduction, tailoring, self-monitoring, praise, virtual rewards, conditioning and surveillance.

Two further notions are pivotal in the development of persuasive technology. The first is the notion of Kairos, or the principle of presenting your message at the opportune moment. The second is the notion of intrinsic and extrinsic motivation. In either case, the development of persuasive technology requires the integration of expert academic knowledge, pedagogical practical knowledge, and the knowledge parents have of their children strength and difficulties. Most importantly, gaining an understanding of what motivates children requires rethinking the role of children from 'testers' of the product to consultants.

This paper focuses on the initial interviews for 'Specification of Functionality for Prototype 1' phase of software development, which were carried out by researchers at the London South Bank University during September and October 2008. The semi-structured interviews sought the views of five teachers, care support workers, ten parents and their children at a special

school for children with ASD in England. Particular attention was given to gaining the children's views on how the technology could have helped them and what would motivate them to use it. The paper argues that listening to the children has the potential of developing software that is meaningful to adults and children alike, but that it also offers the potential for the school to reflect on their practice and provision as a consequence of involving the children in the consultation. The paper concludes with reflection and lesson learned which might be applied to other similar situations

Mobile technology in the classroom: technology and children with ASD

London South Bank University contribution to the project is related to how the new technology would be applicable to the learning environment in relation to how it will fit into already existing practices, and also to how the use of the technology will improve children's wellbeing and the provision made available to support them. LSBU focus is located in the increased interest in the use of mobile technology - PDAs devices, laptops, notebooks, tablet PCs, and mobile phones- in the classroom. The rationale for developing mobile technology for children with ASD lies in a number of the technology positive features, such as its portability (Perry, 2003), mobility, connectivity and customization (van't Hooft, 2008), and social interactivity and context sensitivity (Naismith, et al, 2004).

The use of ICT and technology in the field of special and inclusive education has a relatively long history, but lacking a conclusive understanding of how best to apply the technology in the learning environment. If, as Florian (2004) suggests, ICT can be a tool for tutoring, exploration, assistance, communication, assessment, and data management, pedagogical decisions on how to use the technology are, however, informed by a number of other factors such as the degree of disability (Lewis and Norwich, 2005). Davis and Florian (2004) and subsequently Dee, Devecchi and Florian (2006), on the other hand, argue that teachers' decisions are the result of an informed combination of teaching strategies, previous experience and qualifications, personal and social attitudes towards disability, and an assessment of children's needs and potential.

Despite the increase in the number of children diagnosed with ASD, research on how technology can help them to become socially more integrated is still developing, while their involvement in research is still lagging behind. This is partly due to the fact that the atypical development of children with ASD is reflected in a triad of impairments in:
- Reciprocal social interactions and socialisation;
- Reciprocal communication (both verbal and non-verbal); and,
- Inflexible organisation of behaviour and interests (repetitive and stereotypic activities, restricted and stereotypic interest) (Wing and Gould, 1979).

All three impairments not only limit the quality of the child social inclusion, but they also create a set of methodological challenges in the process of consultation. Furthermore, while the triad of impairment is to some extent

common to all individuals with ASD, each individual varies greatly both in degree and kind of specific impairment. The use of technology, however, has been generally successful mainly because technology:

- Works in a consistent and predictable way;
- Provides a comfortable and rewarding environment;
- Raises less social demands;
- Allows the learner to control the pace of learning;
- Allows for mastery learning through repetition;
- Is a visually-based medium; and,
- Is culturally accepted (Gyori, et al, 2008)

The HANDS project, with its collaborative and user engagement features, is an innovative approach to the field of technology and autism. This is because research in this area has been generally directed at knowing more about the nature of autistic difficulties, and in developing therapeutic solutions. In the first case, research within psychology is undertaken in the hope that this will lead to greater understanding of what strategies will be effective, and in the further development of the three main theories. The three main explanatory theories being namely Theory of Mind (Baron-Cohen, 1995), theory of Weak Central Coherence (Frith and Happe, 1994), and the theory of executive functioning (Ozonoff, et al., 1991).

In the second instance, a helpful approach to map how technology has been used in relation to teaching and assisting children with ASD can be found in Gyori et al.'s (2008: 31) 'taxonomy for ICT tools in ASD intervention' (see figure below).

Fig.1: taxonomy for ICT tools in ASD intervention
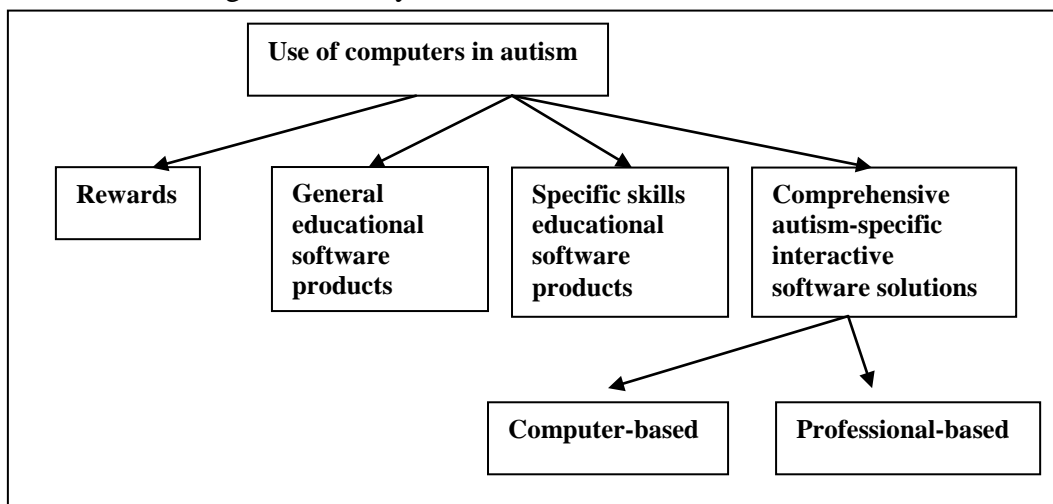
Because of the strong influence of the clinical psychology perspective, much of the research is based on randomised clinical trials (RCT), although questions have been raised about the need to involve practitioners in the research (Jordan, 1999), and there has been a call for more qualitative and naturalistic-based studies (Williams, 2006).

The HANDS project capitalizes on the mobile technology potential benefits of increasing motivation and facilitating communication and social interaction since these are some of the major obstacles to social inclusion for children with ASD. Mindful of the fact that the difference technology makes is closely related to how the use of the technology is planned and structured within the lesson; how teachers are trained and supported; and the technical support and resources available in the school (Higgins, 2008), the HANDS project has been framed as a collaborative effort. In this sense, the notion of 'user engagement' has been reformulated from one that entails consultation with the end-users of the technology at the evaluation stage, to one of participation in the development of the technological product. Moreover, the LSBU team were explicit that the notion of user in relation to a school-based project such as this must include the young people who will actually be using the software. In the end, teachers in four special schools in Denmark, Sweden, England and Hungary participated in the Specification and Functionalities Requirement phase. Parents, teaching assistants, and children were also interviewed in the school in England.

Consulting children with ASD: some key points

It is interesting to note, as Robertson (2009) suggests, that there is in the literature very little, if any, consideration the importance and challenges of consultation or student voice specifically in relation to children with autism. A review of the literature using the PsycInfo and Education Research Complete electronic indices indicated no direct references to articles on the topic from 1985 to the present. As such, this paper represents a useful contribution in that it reports on an actual example of consultation with children with autism in relation to a development directly related to learning and teaching.

Seeking the views of the children was pivotal for a number of reasons. First, because the children, being the ultimate users, are in the best position to give valuable ideas on the quality and usefulness of the educational provision they receive (Rudduck and McIntyre 2007, Bragg, 2007). Second, as Inman (2003) indicates, when consulting pupils is linked to a whole school approach, it can act as an effective democratic vehicle for valuing and responding to student voice. Third, consulting children with special educational needs is a statutory requirement as set out in the SEN Code of Practice (DfES, 2001).

To these we need to add that in the case of children with ASD their participation in the process of consultation can also be a way in which their social and communicative skills can be supported and developed. It is however important, as Fielding (2001) suggests, to avoid making their participation a tokenistic gesture. This implies the need to take what children say, and suggest seriously. In seeking their views we should also be mindful, as Arnot and Reay (2007) suggest, of the already existing power relations between adults and children and the way in which pedagogical discourse and classification of disability discourses shape the communicative and social interaction (Christensen and James, 2000; Corbett, 1996; Florian and McLaughlin, 2008).

Consulting children in general and consulting children with learning disabilities in particular is a challenging and complex activity. As Lewis and

Linsday (2000) warn the pursuit of collecting valid, reliable and authentic data requires us to keep at least two aspects into consideration. The first relates to the need of facilitating both understanding and communication while the second relates to establishing conditions that are neither harmful nor overpowering for the child (Alderson & Morrow, 2004).

Researchers at LSBU approached the task of consulting the children in four stages. Mindful of the difficulties children with ASD have in social and communication interaction, two researchers spent time familiarizing with the school and the children by conducting informal observations. These included classroom observations, but also joining the children during lunch, during break time activities, or by accompanying those who stayed at the residential unit during outings and shopping, or by simply being around in the school. Second, we gathered information from the teachers about each individual child's strengths and difficulties, likes and dislikes, and how best to speak to them. Third, we interviewed the parents so as to develop an understanding of what the child wanted to be able to achieve and how the smartphone technology could have helped them. In minimizing discomfort or anxiety, prior to the interview, which took place with their teachers present and after consent was obtained from both the parents and the children, we used visual means to explain to the children what the research project was about and we allowed the children time to ask questions and interact with the researcher. The interviews lasted around 30 minutes and took place in a room in the school the children felt comfortable in.

During the interview we sought to gain an understanding of the child's knowledge and ability of using technology (that is computers, games, mobile phones or the Internet), and of what the child deemed to be their strengths and difficulties. The main part of the interview focused on gaining from the child an understanding of what he[1] thought the use of the phone could have helped them with. At the basis of this idea was a person-centred approach to the planning of provision for children with learning difficulties and disabilities (Dee, 2006). Such an approach stresses the importance of considering how through supporting the child's agency and self-determination teachers, parents and other adult can help the child achieve what he views as important for him. This approach involves to enabling the child not only to see the difficulties in achieving the outcome, but also in presenting possible ways the group can help. Involving the children in this way enabled us to gather important data on what the children thought the phone could be useful for. The data collected were then used to write user stories that the software developers could use during the development stage.

How the children say mobile technology can help them

Content analysis was used to draw a map of what the young people saw as the main areas of difficulty and how they though the technology could help them. Analytical categories were drawn from the literature on social, communication and living skills and more specifically from cognitive psychological tests such as VINELAND, an Adaptive Behavior Profiles in Children with Autism and Moderate to Severe Developmental Delay, or SRS (Social Responsiveness Scale), or in teaching programmes and qualifications such as those provided

by ASDAN, an educational charity, whose purpose is to promote the personal and social development of learners through the achievement of ASDAN awards, so as to enhance their self-esteem, their aspirations and their contribution to their community. We also looked at what practices and skills were taught and encouraged in the school. We came to the conclusion that while the literature afforded an extensive array of possible categories to choose from, none was individually helpful. This was mainly due to the fact that while the literature focuses on specific skills as units of behaviour, the objective the children wanted to achieve involved a number of integrated social skills. We therefore took a bottom up approach and let the language of the children and of the teacher portray the nature of the activities and skills involved. In the final analysis we grouped the activities in a list that included:

- Managing money
- Preparing for difficult situations
- Understanding and managing time
- Emotions and appropriate reactions
- Organisation within and beyond school
- Health and hygiene
- Food preparation
- Travel
- Shopping

One significant case was chosen as exemplary for specification and functionalities purposes of each category. Below, we report the example from the 'shopping' category.

Fig.2: Example of User Story for Software Development Specifications
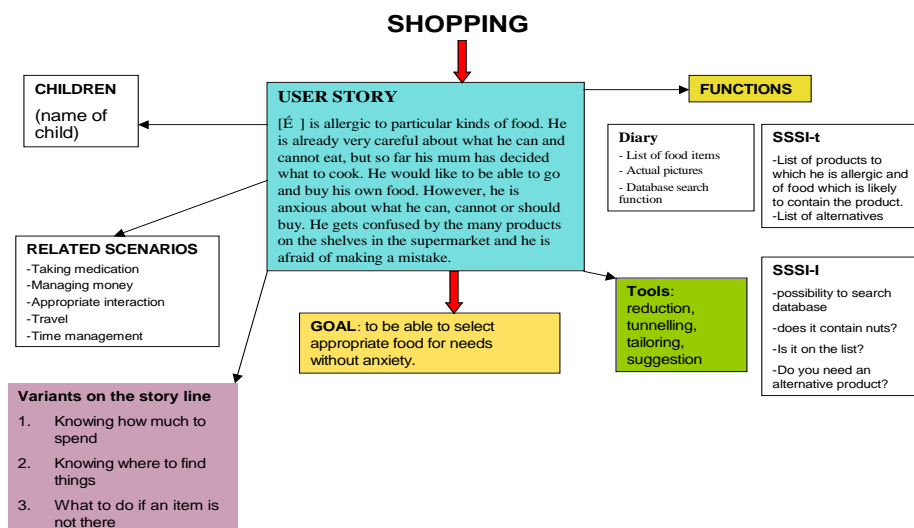
In writing the template or user story for each category we paid attention in remaining as close as possible to the child's intention. So the user story panel above reports what the child described as the activity he wanted to be able to do, what he found difficult or problematic or challenging. The goal section listed the skills and aims of the activity. These were drawn from a comparison between the teachers', the parents' and the children's interview responses and

formed a summative assessment of the child's needs. The sections on the right listed how each phone functionality could have helped the child to achieve the desired outcome, while the sections on the left showed how the activity, in this case shopping, was related to other activities and scenarios chosen by other children in the group.

Lessons learnt

The analysis of the interviews with the children, teachers and parents yielded a sizeable number of user stories. On average each child gave around two or three examples of how the phone could have helped. However, the main benefits of consulting the children were not limited to the range of stories we could have used to instruct the software developers. This final section reviews what we have learnt during the Specification of the phone functionalities phase of the research. We believe that such lessons are valuable examples of how productive involving children, and children with learning difficulties in research can be.

The paper started by arguing that much of the software and technology development available for pedagogical goals is still developed outside schools. This means that user engagement, that is the involvement of teachers and children, is at best left to the stage of evaluation. This then usually focuses on the impact of technology on learning by evaluating progress in terms of measurable learning outcomes, i.e. grades or scores on cognitive tests. While, other more formative and participatory approaches to evaluation are developing, the phase of software development is still detached from working closely with those who would benefit most from the technology. In addressing these limitations, the HANDS project team at London South Bank University took a more participatory approach from the very initial stages of software development. While we cannot at this stage comment on how the software solution will work, we can, however, reflect on the lessons learnt.

From a methodological point of view, consulting children on matters related to their wellbeing and learning – listening to the student voice, is a now accepted as a valuable and important part of decision making in education. In regard to consulting children with learning difficulties, there still remains a general skeptical attitude in their abilities to offer authentic, valid and reliable suggestions. In the case of children with autism, the triad of impairment with which the disorder is characterized still shape the perception of these children as being unable to hold a conversation, interact with others, and generally finding it difficult to make decisions. Yet, the research shows that to various degrees of interaction all the ten children were able and willing to interact, participate and forward valuable ideas and suggestions. Despite some initial concerns that the children would have suggested impossible activities or activities that were outside their abilities and reach, the children not only chose activities that were justifiable and achievable, but also showed the ability to reflect, examine and find possible solution to what they found difficult. They showed, to different degrees of complexity, sense of imagination and the ability to plan. While these might seem common sense and reasonable features of typical children, we need to consider them within the parameters by which children with autism are judged.

Conclusion

It needs to be pointed out that despite showing such positive features involving the children in the interviews required a great deal of care, understanding, and adaptation. This points to the fact that giving children a voice is not a straightforward matter. Rather it requires imagination, creativity, empathy and responsiveness on the part of the researchers. From the conceptual point of view, the task of analyzing the children's stories and examples, made us reflect on how social and living skills are classified, how they are ranked by adults and children, and how relevant they are to the practice of enabling children with autism to become included in society. From the point of view of pedagogical software development, we envisage that supporting children to achieve targets that they choose as relevant and meaningful will greatly benefit the research at the stage of implementation.

Footnote
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References
Alderson, P. & Morrow, V. (2004). *Ethics, social research and consulting with children and young people.* Ilford: Barnardo's.

Arnot, M. & Reay, D. (2007). A sociology of pedagogic voice: power, inequality and pupils consultation. *Discourse: Studies in the Cultural Politics of Education,* 28(3)**,** 311-325.

Baron-Cohen, S. (1995). *Mindblindness: An essay on autism and theory of Mind.* Cambridge, MA: MIT Press.

Bragg, S. (2007). "It's not abut systems, it's about relationships": Building a listening culture in primary school. In. D. Thiessen and A. Cook-Sather (Eds.) *International handbook of student experience in elementary and secondary school* (pp. 659–680). Netherlands: Springer.

Christensen, P. and James, A**.** (Eds.) (2000). *Research with children. Perspectives and practice.* London: Falmer Press.

Corbett, J. (1996). *Bad-mouthing. The language of special education.* London: The Falmer Press.

Davis, P. & Florian, L. (2004). *Teaching strategies and approaches for pupils with special educational needs: A scoping study.* London: DfES.

Dee, L. (2006). *Person-centred approaches and adults with learning difficulties.* Leicester: NIACE.

Dee, L., Devecchi, C. and Florian, L. (2006). *Being, having and doing. Theories of learning and adults with learning difficulties.* London: Learning and Skills Council.

Department for Education and Skills (DfES) (2001). *Special educational needs code of practice.* London: DfES.

Fielding, M. (2001). Beyond the rhetoric of student voice: New departures or new constraints in the transformation of 21st century schooling?. *Forum for Promoting 3-19 Comprehensive Education,* 43(2)**,** 100-109.

Florian, L. (2004). The use of technology that supports pupils with special educational needs. In L. Florian and J. Hegarty (Eds.) *ICT and special educational needs: A tool for inclusion.* London: McGraw-Hill International.

Florian, L. and McLaughlin, M. (Eds.) (2008). *Disability classification in education: Issues and perspectives.* Thousand Oaks, CA: Corwin Press.

Fogg, B. J. (2003) *Persuasive technology. Using computers to change what we think and do.* San Francisco, CA: Morgan Kaufman Publishers.

Frith, U. and Happé, F. G. E. (1994). Autism: beyond 'theory of mind'. *Cognition*, 50, 115-132.

Gyori, M., Stefanik, K., Kanizsai-Nagy, I., Öszi, P., Vigh, K., Balazs, A. and Stefanics, G. (2008). D2.1.1. Report on Test Methodology and Research Protocols, from http://hands-project.eu/index.php?page=downloads-2

Higgins, S. (2008). *Does ICT improve learning and teaching in schools?.* Edinburgh: BERA.

Inman, S. (2003). School councils and pupils' personal and social development. In M. Buck M. S. Inman and M. Tandy (Eds.) *Enhancing personal, social and health education challenging practice, changing worlds*. London: Routledge.

Jordan, R. (1999). Evaluating practice: Problems and possibilities. *Autism,* 3(4)**,** 411-434.

Lewis, A. and Linsday, G. (Eds.) (2000). R*esearching Children's Perspectives*. Buckingham: Open University Press.

Lewis, A. & Norwich, B. (Eds.) (2005). *Special teaching for special children? Pedagogies for inclusion.* Buckingham: Open University Press.

Naismith, L., Lonsdale, P., Vavoula, G. and Mike, S. (2004). *Literature review in mobile technology and learning. Report 11.* Bristol: NESTA FutureLab.

Ozonoff, S., Pennington, B., F., and Rogers, S. J., (1991). Executive function deficits in high-functioning autistic individuals: Relationship to theory of mind. *Journals of Child Psychology and Psychiatry,* 32(7)**,** 1081-1105.

Perry, D. (2003). *Handheld computers (PDAs) in schools.* Coventry: BECTA.

Robertson, J. W. (2009). Informing the public? UK newspaper reporting of autism and Asperger's syndrome. *Journal of Research in Special Educational Needs*, 9(1), 12-26.

Rudduck, J and McIntyre, D. (2007). *Improving learning through consulting pupils.* London: Routledge.

Van't Hooft, M. (2008). Mobile, wireless, connected information clouds and Learning. In BECTA (Ed.) *Emerging technologies for learning volume 3.* Coventry: Becta.

Williams, K. R. (2006). The Son-Rise program® intervention for autism. Prerequisites for evaluation. *Autism,* 10(1)**,** 86–102.

Wing, L. and Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Childhood Schizophrenia*, 9, 11–29.

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