

Recognising and Protecting the Communication Rights of Autistic Children

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Recognising and Protecting the Communication Rights of Autistic Children

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- **Autistic children are at risk of having their communication rights violated. This risk is heightened for autistic children with communication disability, which can emerge from factors inherent autism, co-occurring language disorders and societal barriers. This risk is also unacceptably high for autistic children from minority groups.**
- **The autistic community, researchers, clinicians and policymakers must work together to promote the communication rights of all autistic children. In particular, Speech and Language Therapists (SLTs) can contribute valuable expertise to the development and implementation of impactful policies in this field.**
- **We propose three areas of policy action to better protect the communication rights of autistic children:**
 - **Area 1: Promoting more Inclusive Communication practices in our society;**
 - **Area 2: Enabling the co-creation of communication support services with autistic children and other relevant stakeholders;**
 - **Area 3: Increasing the visibility, access and inclusivity of specialist services.**

Introduction

Communication is core to our everyday life and an essential component of children's development. Children learn to communicate to express themselves, understand others, discover the world around them, and connect with others. Developing good communication skills during childhood is also linked to long-term benefits into adulthood, such as social

mobility, employment, and mental health. Therefore, supporting and protecting communication for all children is of critical importance.

The [United Nations Convention on the Rights of the Child](#) (UNCRC; UNICEF, 1989) sets out the fundamental rights to which *every* child should be entitled. Upon reading the UNCRC, one might expect to find rights directly related to children's communication, but there is no straightforward definition. Instead, communication rights are implied in various sections pertinent to children's rights to freedom, access to information, education, inclusivity and diversity. On the one hand, it is encouraging to see communication so pervasively considered in the UNCRC, reflecting its integral role in children's basic rights. On the other hand, the lack of clearly articulated protections for communication rights in the UNCRC may put children at risk of seeing their communication unsupported and unprotected. This is likely to be the case for children who communicate differently from what is considered to be the norm.

In this policy paper, we discuss some of the risks to communication rights for autistic children and make three suggestions for policy action. We elaborate the notion of communication rights through the rights of freedom (Article 13), disability (Article 23) and diversity (Article 30) of the UNCRC. This allows us to take a multi-perspectival approach to the communication rights of all autistic children, whilst also highlighting the specific risks for autistic children with communication disability and those from minority groups. We also highlight the promising role of Speech and Language Therapists (SLTs) to drive positive changes in this domain. SLTs are clinicians who support individuals in contexts of communication adversity, and so their expertise puts them at a strategic position to advocate for and actively support the communication rights of autistic children. Finally, and still largely based on SLTs' pivotal role, we set out a policy agenda to better protect the communication rights of autistic children.

Freedom of expression

'Every child must be free to express their thoughts and opinions and to access all kinds of information, as long as it is within the law' (Article 13, UNCRC, UNICEF, 1989)

Autism is a lifelong condition that affects the way that a person interacts with people and the world around them ([Autism UK Parliament Post, 2020](#)). The communication abilities of autistic individuals vary greatly, and they may prefer 'to express their thoughts and opinions' (Article 13, UNCRC) differently from socially established norms. For example, offering an autistic individual the option to avoid face-to-face interactions if they have a preference for text-based interactions can make a remarkable difference to their communication engagement and experience (Cummins, Pellicano, & Crane, 2020). However, the communication preferences of autistic individuals are not always accounted for. Moreover, evidence suggests that this lack of consideration can lead autistic children to experience high levels of anxiety and, eventually, avoid communication situations altogether. Therefore, without more inclusive communication practices, the right of freedom of expression is at stake for autistic children.

According to the Inclusive Communication statement by the Royal College of Speech and Language Therapists ([RCSLT](#)), 'all human beings use many ways of understanding and

expressing themselves’ and we should ‘encourage, support and enable people to use whatever ways of understanding and expressing themselves which they find easiest’. The positive impact of Inclusive Communication principles on the freedom of expression of autistic children has already been documented, e.g. in a study by Riach and Crompton investigating ‘How can we make hospitals more accessible for autistic children?’. In this survey, almost all parents (94%) reported that their autistic child found it difficult to express how they felt to healthcare professionals. However, when professionals adopted a more flexible approach to communication, it greatly supported them to express themselves during these medical encounters. For example, using of a combination of verbal and non-verbal communication and giving more time for the children to express themselves were considered very successful strategies. Another study by Wood (2018) showed similar advantages when autistic children’s preferred modes of expression were recognised and accounted for in schools. These are just a few examples illustrating how the principles of Inclusive Communication can effectively lead to more freedom of expression for autistic children and facilitate their communication.

SLTs have long-standing experience in raising awareness of Inclusive Communication. They even have a ‘leadership role to play in supporting the implementation of Inclusive Communication through increasing the awareness, skills and knowledge of others in the public, private and third sectors’ (RCSLT). Therefore, we must leverage SLTs’ expertise and resources to inform a coherent policy plan that will promote Inclusive Communication practices in our society and better protect the communication rights of autistic children. Concrete actions are detailed in our policy agenda below.

Children with a disability

‘A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families’ (Article 23, UNCRC, UNICEF, 1989)

Communication disability is a common experience for many autistic children that can emerge from factors inherent autism, co-occurring language disorders and societal barriers. Considering that communication (dis-)ability is an important predictor of quality of life in autistic adults, it is essential to support autistic children who experience communication disability as early as possible. This will help protect autistic children’s immediate and long-term right to ‘live a full and decent life with dignity’ (Article 23, UNCRC).

According to the World Health Organization (2001), communication disability is a complex phenomenon that can be influenced by both internal and external factors. On the one hand, internal factors represent the child’s own language and communication abilities. Research has shown that the language and communication abilities of autistic children can be extremely varied: some are verbally fluent whilst others present with significant language delays and disorders (e.g. 1 in 4 autistic children speak few or no words). These internal factors can therefore lead to varied levels of communication disability. On the other hand, external factors represent the contextual aspects that can help or hinder the children’s communication experience. For example, building the knowledge and skills of key individuals who interact

regularly with autistic children and raising public awareness of autism can contribute to a reduced experience of communication disability for autistic children.

Due to the multidimensional nature of communication disability, there is no ‘one-size-fits-all’ solution to supporting the communication disability of all autistic children. Rather, considering communication disability in a holistic fashion and tailoring services for each child and family will maximise benefits. SLTs have a high level of expertise in using such methods to support autistic children who experience communication disability (see [RCSLT’s guidance on autism](#)). For instance, SLTs can offer interventions to support the child’s own language and communication abilities (internal factors), such as scaffolding their vocabulary learning or facilitating their use of alternative modes of communication (see Picture Exchange Communication System). SLTs may also offer interventions to assist contextual elements (external factors), such as supporting the parents’ understanding of their child’s unique communication style (see [Paediatric Autism Communication Therapy](#)) or advocating for more inclusive communicative environments (see Total Communication approaches).

Overall, there is increasing evidence demonstrating the positive impact of communication interventions implemented by SLTs who support autistic children. However, SLT provision is not equitably offered at the national level, which means that many autistic children and families do not have access to these valuable services ([Bercow Report 2018: Ten Years On](#)). This poses a real threat to the communication rights of autistic children with communication disability throughout the UK.

Children from minority or indigenous groups

‘A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families’ (Article 30, UNCRC, UNICEF, 1989)

According to the Department for Education (2019), around 1 in 3 pupils in UK schools is from minority ethnic origins, and at least 1 in 4 speaks more than one language. Therefore, we must pay special attention to the ways in which linguistic and cultural diversity affects the communication rights of autistic children. This focus is particularly important because autistic children are not often offered the same opportunities to ‘learn and use the[ir] language[s], customs and religion[s]’ (Article 30, UNCRC) as other children growing up in multilingual and multicultural environments.

Widespread beliefs that multilingualism is detrimental (‘too much’ or ‘confusing’) for autistic children have led to practices of forced monolingualism. This is despite evidence showing that exposure to more than one language is not associated with any language delay or damage for autistic children ([Uljarević et al., 2016](#)). In fact, forced monolingualism may contribute to communication disability itself, as it can limit access to communication partners and to a full family and social life. Restricting language use may also provoke the loss of the customs, culture, emotional valence and religious heritage associated with the(se) language(s) and lead to decreasing family well-being (Howard, Katsos & Gibson, 2019). Importantly, there is also a stark lack of resources and confidence amongst service-providers to support the communication of autistic children with multilingual and multicultural backgrounds. For

example, SLTs have reported the lack of access to therapeutic tools in different languages, limited opportunities to collaborate with trained interpreters, the struggle to integrate more than one language during interventions, and uneven referral patterns for children from minority communities (Mennen & Stansfield, 2006). Sometimes, parents of autistic children are left with a very difficult choice to make between education for their child in a language for which there are therapeutic services and resources but which is not their home language, or education in their home language in the absence of such services and resources (Howard, Gibson & Katsos, 2020). The [RCSLT Clinical Guidelines on Bilingualism](#) provide useful guidance to inform more equitable SLT services for autistic children with diverse linguistic and cultural backgrounds.

Autistic children from minority groups are therefore at high risk of experiencing all aspects of their communication rights being violated: when they are not supported to ‘learn and use the[ir] language[s], customs and religion[s]’ (Article 30, UNCRC), it may impact their ability to ‘express their thoughts and opinions’ (Article 13, UNCRC) and reduce their chances to ‘live a full and decent life with dignity’ (Article 23, UNCRC). This risk is unacceptably high for autistic children with multilingual backgrounds.

A Policy Agenda to Promote the Communication Rights of Autistic Children

The [UK Government’s Joint Committee on Human Rights’ report](#) (2010) states that ‘the Government is fully committed to children’s rights and the continued implementation of the UNCRC to make the Convention a reality for all children and young people living in the UK’ (p.4). However, our analysis showed that communication rights are yet to become a reality for many autistic children. The autistic community, researchers, clinicians and policymakers need to work together to better protect the communication rights of autistic children. In particular, Speech and Language Therapists (SLTs) can contribute valuable expertise to the development and implementation of impactful policies in this field. Below, we propose a threefold policy agenda to do just that.

1. Moving towards widespread Inclusive Communication practices in society

Autistic children are likely to communicate differently from the prevailing societal norms. Regardless of whether these differences originate from preferences, disabilities, or multilingualism, communication should be fully inclusive so that all autistic children can achieve their full potential in life. As a society, we must recognise that communication is a multidimensional process, and empower everyone to facilitate communication. Given that SLTs have long-standing experience in raising awareness of Inclusive Communication ([RCSLT’s Position Paper](#)), we can leverage their expertise to inform most impactful actions. For direct benefits to autistic children, these actions can focus on organising a nation-wide Communication Awareness Day in schools, reforming teacher training and providing free Inclusive Communication resources for parents to use at home. To optimize impact, these efforts should be supported by authorities and stakeholders at both the local and national level, and coordinated by the RCSLT.

2. Co-Creating the Communication Services of Tomorrow

Many autistic children would benefit from specialist communication support, yet current services are not always accessible nor equitably delivered. Co-creating the communication support services of tomorrow with autistic children, their parents and all relevant stakeholders can effectively inform profoundly sustainable, equitable and impactful services ([Autistica](#)). These collaborations are already highlighted as key public health strategies to facilitate positive and impactful change (see [NHS England](#) and [NICE guidelines](#)). Furthermore, participatory approaches have already shown tremendous advantages in improving the quality of services for the autism community ([Fletcher-Watson et al., 2018](#)). During this process, the role of SLTs will be essential to ensure that the voices of autistic children with the most communication difficulties are also heard and included in the decision-making process. In collaboration with trained interpreters, it is also necessary to take this initiative further by representing our multilingual and multicultural society.

3. Focusing More on Diversity & Inclusion

Autistic children from minority groups are at high risk of seeing their communication rights unprotected. Promoting Inclusive Communication practices in society and co-creating services will benefit all autistic children, but we must also take specific actions to benefit autistic children with multilingual and multicultural backgrounds. By requiring services to complete audits on issues of diversity, we can identify the most impactful strategies to achieve more inclusive services in local contexts (e.g. developing resources in certain languages, increasing access to trained interpreters, or training practitioners on multilingual communication development). More powerful yet, these audits could be conducted as a collective endeavour between similar services so that joint actions can ensue, and benefits transferred across settings. For example, the authors of this paper are currently investigating the value of a collaborative learning programme for SLTs working in the UK and in India to exchange knowledge, resources and practices for the care of multilingual autistic children. Similar projects can challenge assumptions, inspire new practices and indeed, foster more inclusive services for our diverse population.

All autistic children should see their communication rights protected with respect of linguistic and neuro(-)diversity to live a [long, happy and healthy life](#) ([Autistica](#)). This is of critical importance in regular times and an ultimate priority in coronavirus times, as we see the inequality gap widening at an alarming rate. Researchers, clinicians and policymakers have a duty to make this happen – will you?

Further reading

Cummins, Clare, Elizabeth Pellicano and Laura Crane. 2020. 'Autistic Adults' Views of their Communication Skills and Needs', *International Journal of Language and Communication Disorders*: 1–12. <https://doi.org/10.1111/1460-6984.12552>

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UNICEF. 1989. *The United Nations Convention on the Rights of the Child*.

Uljarević, Mirko, Napoleon Katsos, Kristelle Hudry and Jenny L. Gibson. 2016. 'Practitioner Review: Multilingualism and Neurodevelopmental Disorders – an Overview of Recent Research and Discussion of Clinical Implications', *Journal of Child Psychology and Psychiatry*, 57(11): 1205–1217. <https://doi.org/10.1111/jcpp.12596>

Wood, Rebecca. 2018. 'The Wrong Kind of Noise: Understanding and Valuing the Communication of Autistic Children in Schools', *Educational Review*, 72(1): 111–130. <https://doi.org/10.1080/00131911.2018.1483895>

World Health Organization. 2001. *ICF: International Classification of Functioning, Disability and Health*. Geneva: W.H.O.

Resources

Autistica (UK national charity for autism research): <https://www.autistica.org.uk/what-is-autism/what-is-autism>

Bilingualism (RCSLT): <https://www.rcslt.org/speech-and-language-therapy/clinical-information/bilingualism>

Inclusive Communication strategies (RCSLT): <https://www.rcslt.org/speech-and-language-therapy/inclusive-communication-overview#section-1>

Human rights for people with autism (Professor Baron-Cohen's keynote speech at the UN Convention on the rights of people with disabilities): <https://www.cam.ac.uk/research/news/human-rights-of-people-with-autism-not-being-met-leading-expert-tells-united-nations>

UNICEF's statement on children's communication rights:

https://www.unicef.org/cwc/cwc_58613.html

About the authors

Mélanie Gréaux

Mélanie (mg696@cam.ac.uk) is a PhD candidate at the Faculty of Education, University of Cambridge. She is co-supervised by Dr Jenny Gibson and Dr Napoleon Katsos, and funded by the ESRC-DTP Cambridge in partnership with Autistica. Her doctoral research is looking at the potential of collaborative and cross-cultural professional learning opportunities to foster inclusive healthcare services for autistic communities. Alongside her academic research, Mélanie is also involved in public engagement projects aimed at supporting children with Speech, Language and Communication disorders (RADLD) and multilingual families (CBN).

Napoleon Katsos

Napoleon brings to the project expertise in language acquisition research, especially in how typically- and atypically-developing children learn two languages (or two dialects) simultaneously. His current projects in this area focus on exploring bilingualism in autism and/or ADHD through clinical and sub-clinical population studies and systematic reviews. He is also studying the differences between bilingual and bi-dialectal development. A better understanding of the process of bilingualism is of paramount importance to families, professionals and the society at large. Together with colleagues in Cambridge, Napoleon co-founded the Cambridge Bilingualism Network which aims to increase awareness about the benefits and challenges of raising bilingual children by disseminating state-of-heart research findings and by fostering partnerships between researchers, teachers, clinicians and parents of bilingual children.

Jenny Gibson

Jenny brings to the project her research and clinical expertise in autism and developmental language disorders. As a qualified Speech and Language Therapist, working in a London Borough where over 70% of referrals involve children from bilingual/multilingual families, she has direct experience of the issues faced by speakers of community/minoritised languages who also have communication disabilities. Jenny is a steering group member of the East Anglian Regional Hub of the Royal College of Speech and Language Therapists which provides a valuable link for recruitment and dissemination activities. She is also an early career researcher specialising in the cognitive and social aspects of developmental disorders of language and social communication, and has received ESRC and MRC funding to investigate how pragmatic language difficulties impact on children's relationships within their social worlds.

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