Dear Families,

Thank you very much for your involvement in our research project about communication and conversation over the past two years. It wouldn't have been possible without the wonderful enthusiasm of all the families involved, and of course the hard work of your young people in completing our tasks. We are currently writing up the project for publication, and wanted to get in touch to let you know what we found out. Once published, details of papers can be found on our website (<https://www.psy.ox.ac.uk/research/oxford-study-of-children-s-communication-impairments>) and we are also very happy to forward you copies of publications of interest.

Our project was focused on children's language skills, specifically their understanding of spoken language. From an educational perspective, this is a really important area in children’s development. Spoken language feeds into literacy, is crucial for learning across the curriculum, and plays a vital role in the development of friendships.

As part of our project, we asked families to complete some questionnaires and take part in a telephone interview about their child’s communication skills. We asked children to complete a range of tasks focused on understanding of spoken language, and for many of the children, we also assessed their skills in conversation face-to-face.

We have now collated our results from all the families who kindly took part in the research, and we would like to share with you what we found.

In our study, we included 53 children with a sex chromosome trisomy (with about equal numbers of children with Klinefelter’s syndrome, Trisomy X and XYY). We also included a group of 62 children with an autism diagnosis. We did not expect the groups to be the same, but this allowed us to see the profile of language and communication skills and difficulties across the two groups.

1. As a group, young people with a sex chromosome trisomy often had some difficulties with language. By “language”, we mean difficulties with grammar or word meanings, or understanding sentences or longer sections of speech. However, there was a lot of variability in the group and it was rare to find children with very severe problems.
2. Also, some young people with a sex chromosome trisomy showed difficulties with social aspects of communication. A subset of children showed very similar difficulties to young people with autism. However, many other children showed no substantial difficulties or had advanced skills for their age. Among children who had some difficulties with social communication, this might include saying things out of the blue without giving context, pursuing their own interests in conversation, or having difficulty giving coherent accounts of events. It might also include having a quieter approach to conversation, perhaps giving brief contributions and finding it difficult to maintain conversation or ask questions. However, as noted above, these difficulties were not shared by all children. It is also interesting to note that these difficulties were not closely related to language problems, i.e. having problems with speech/understanding did not necessarily mean a child had social communication problems, and vice versa.
3. Many children screened as having some difficulties with anxiety, attention and/or challenging behaviour. Children in the general population also have a range of difficulties in these areas, and if these are a concern, it might be worth speaking to a professional, such as an educational or clinical psychologist.
4. Previous research has tended not to find any differences when comparing children with different trisomies (i.e. comparing children with Klinefelter’s syndrome, Trisomy X and XYY). Our research also did not find any differences by trisomy. What is striking in our results is the variability. Different children have different patterns of strengths and difficulties. We can’t predict what the child’s pattern might be based on their trisomy.
5. We looked at the level of special educational needs (SEN) provision received by children with a sex chromosome trisomy, compared to the group of children on the autism spectrum. Controlling for the level of difficulties experienced by the two groups, we found that children with a sex chromosome trisomy experienced less SEN support. It is possible that professionals are less familiar with sex chromosome trisomies, so children might be less likely to receive the support they might benefit from. Our advice to professionals and families is to focus on the actual difficulties the child has rather than the diagnosis. For instance, it is likely that a child with speech and language problems will benefit from a speech and language intervention whether or not they have a genetic diagnosis.

Thank you very much for reading this. We hope the feedback has been interesting and meaningful to you, and please let us know if you have any comments or questions. We'd like to extend our warmest thanks to everyone who helped make this research happen.

Best wishes,

Alex