

## Steering Group 6 Summary: 17<sup>th</sup> and 18<sup>th</sup> June 2026

### Update

Ahead of the this month's steering group meetings, members were sent a video providing an update on Wave 3 progress, alongside information about the sibling engagement project (starting August 2026), the verbal autistic sample comparison project (ongoing), and Wave 4 data collection plans (starting October 2026).

Members were asked to provide feedback on the following areas:

1. Dissemination feedback
2. Caregiver interview topics
3. Sibling engagement project
4. Future funding plans

### Dissemination Feedback

- **Written and Video Summaries:** The one-page summaries and animations of study findings were viewed as clear, easy to digest, and provided enough information without requiring people to read the full reports. However, some technical terminology was identified as potentially difficult for non-specialist audiences to understand.
  - **Outcome:** We are going to create a glossary of key terms and acronyms to add to the Publications page of the website.
- **Sharing research:** Members highlighted the importance of ensuring findings reach both families and professionals with a direct interest in the research and its implications, including school staff, speech and language therapists, advisory teaching services, and AAC providers. One member shared previous written and video summaries with their child's school, which received positive feedback and generated interest in potential future involvement in the study.
  - **Outcome:** We are going to develop a more formal dissemination strategy to ensure our findings reach a wider audience.
- **Online presence:** Members noted that many people look for information online and through social media. It was suggested that creating a Project ISLaND LinkedIn profile/page could increase visibility among clinicians, educators, researchers and other professionals. LinkedIn was seen as a useful platform because posts can be followed, shared and recommended to relevant audiences.
  - **Outcome:** We are going to review examples of LinkedIn pages used by other research groups and explore creating a page for Project ISLaND.

## Caregiver Interview Topics

- **Emotional Regulation (ER) and Communication:** Members strongly agreed that ER is an important topic for future caregiver interviews. Discussion highlighted the close relationship between communication and regulation, with many noting that communication difficulties can contribute to frustration, misunderstandings, and dysregulation.
  - Members suggested exploring the role of trust, safety, co-regulation and communication repair strategies in facilitating successful de-escalation. Other topics included; the impact of ER on family life, the role of sensory processing in ER, and how caregivers regulate themselves.
  - **Outcome:** We are going to refine the ER section of the interview schedule to include questions about these topics.
- **Special Interests and Communication:** Members discussed the important role that special interests can play in supporting communication, language learning, motivation, and AAC use.
  - Examples included using interests to introduce new vocabulary, facilitate interaction, and support discussions about emotions and social situations.
  - There was also interest in understanding the role of screen-based interests, such as television programmes and online content, in communication development.
  - **Outcome:** We are going to consider how we can incorporate questions into the interview schedule that will allow us to explore the role of special interests in communication development.
- **Interview Question Wording:** Members expressed concerns about the question asking caregivers what one thing they would change about their child's communication, as it could feel overly sensitive or emotive.
  - **Outcome:** We are not going to include this question in future interviews. Instead, we will focus on writing up our findings relating to caregivers' experiences of speech and language therapy, including recommendations for improving support and service accessibility.
- **Other Potential Topics:** Members identified several additional topics that would benefit from further research, including Gestalt Language Processing (GLP), how families access information and support, and how language development changes during puberty and adolescence.
  - **Outcome:** These topics will be considered as potential areas for future interview questions and research projects.

## Sibling Engagement Project

Members welcomed the proposed sibling project and agreed that understanding the experiences and support needs of siblings is an important area for future research.

### Things to consider:

- **Potential areas of focus:** Suggested topics included siblings' wellbeing, identity, advocacy roles, experiences of stigma and judgement, restrictions on family life, hypervigilance, compassion, how schools support siblings, and the accessibility of SEND activities for whole families.
  - Members also highlighted the role siblings can play in supporting communication, language development, AAC use, and intervention strategies.
  - There was particular interest in ensuring the project also captures strengths and positives, rather than focusing solely on difficulties.
- **Inclusion and participation:** Members emphasised the importance of ensuring that siblings of different ages and abilities can contribute to the project.
  - Suggestions included keeping the age range broad, offering different participation methods (e.g., interviews, questionnaires, drawing activities, recorded conversations with parents, Talking Mats, or live online message responses), and considering the needs of siblings who may also have additional support needs.
  - Members also highlighted the importance of making participation a positive and rewarding experience for siblings, for example through certificates of involvement and opportunities to contribute meaningfully to the project.
  - However, it was recognised that not all siblings may wish to participate, with some preferring to maintain a separate identity and focus on their own interests and experiences.
- **Support and safeguarding:** Members discussed the sensitive nature of some topics and the importance of appropriate safeguarding and support procedures. It was noted that, for some siblings, this may be the first time they have been asked about their experiences.
  - Members also suggested that peer-led approaches may encourage more open discussion, particularly amongst older siblings.

**Outcome:** We are going to use these suggestions to inform the development of the sibling project and will consider how best to capture the experiences of siblings across different ages, abilities, and family circumstances. We will also explore opportunities to develop practical resources and guidance based on the findings.

## Future Research Plans

Members were enthusiastic about potential future research directions and discussed several areas where they felt there are important evidence gaps.

- **AAC:** Members expressed strong interest in research relating to AAC, including barriers and facilitators to use, differences between AAC systems and apps, support and training needs for families and professionals, and how AAC is implemented across home and school environments.
  - There was discussion about the need for better information and guidance to support families in accessing and using AAC effectively, alongside training for healthcare/education professionals.
- **Language Learning and Screen-Based Media:** Members highlighted the value of television programmes, online media, and special interests in supporting language development, communication, learning, and emotional regulation.
  - There was particular interest in non-social language learning and understanding how children learn and use language from media, such as television programmes and online content.
  - This was also linked to the role of special interests, and the timeliness of debate around screen time for children with SEND.
- **Technology and Innovative Research Methods:** Members were interested in the potential use of eye-tracking, video-based approaches, and AI-assisted methods to better understand communication and language development.
  - However, they also highlighted the importance of considering practical challenges, child engagement and attention, accessibility, ethics, data security, and family preferences when developing technology-based research.
- **Additional Research Priorities:** Other topics identified as important areas for future research included hearing loss and sensory processing, childhood apraxia of speech (CAS) in autistic children, Gestalt Language Processing (GLP), vocabulary development and word choice in AAC systems, and communication development in children with complex communication needs more broadly.

**Outcome:** These ideas will be incorporated into a funding application to be submitted in Autumn 2026, with activities planned to commence following completion of Wave 4. We will provide an update at the next Steering Group meeting regarding the outcome of the application for a three-year extension of the project.