



Provisional only - final version yet to be released.

**Provisional conference proceedings for the
ISAAC 2016 Research Symposium Biennial Conference Toronto Canada**

August 12-13, 2016

The Westin Harbour Castle Hotel

Chair of the Symposium: Associate Professor Bronwyn Hemsley, Ph.D.

STEP 1: Registration

To register, [click here](#).

The registration link is: <https://www.isaac-online.org/english/conference-2016/conference-registration/>

The option to register for the Research Symposium is included within the Conference 2016 Registration system.

STEP 2: Your preference for attendance

There are three 'streams' (options) for attendance at the Research Symposium, described in this document.

- Option A = Design and AAC (see pages 2-3); *or*
- Option B = AAC and Language (see pages 4-9); *or*
- Option C = Social Media and AAC (see pages 10-12) and Identifying Appropriate Symbol Communication Aids (pages 13-15).

Please read the materials in this document to help you decide on your preference for attending option A, B, or C in the research symposium.

After registration, please fill out the following survey to indicate your preferred option
https://www.surveymonkey.com/r/ISAAC16_Research_Symposium

Knowing preferences for options ahead of time will help us to plan for the symposium. At this stage, indicating a preference is not a commitment to attend that option nor a guarantee of a place in that option.

Associate Professor
Speech Pathology
The University of Newcastle, Australia
bronwyn.hemsley@newcastle.edu.au

@ISAACresearch #ISAACresearch
@bronwynhemsley

KEYNOTE SPEAKER

Professor Jeff Higginbotham on Design and AAC Innovation ISAAC 2016 Research Symposium

Professor Jeff Higginbotham is the Chair of the Department of Communicative Disorders and Sciences at the State University of New York, Buffalo.

In this presentation I will use the metaphors of "work" to introduce the notions of action and performance in Augmentative and Alternative Communication (AAC). Studying "how we work" is needed to be able to move both our research and commercial development to more directly address what and how people "do" in their everyday lives and interactions.



Professor Jeff Higginbotham

Since receiving his PhD in 1985 from the University of Wisconsin - Madison in Comparative Studies in Human Social Interaction, Jeff Higginbotham has used his skills in the video analysis of discourse and talk-in-interaction to research how people interact — in real time - to co-produce meaning, emotion and identity. He has applied this research toward the development of new communication technologies for individuals with complex communication needs, including persons with cerebral palsy, autism and neurodegenerative disorders. More recently, he has begun to apply his interests in human interaction and technology to explore alternative ways of engaging others through the use of recorded sound, music and visual modalities of expression. Currently, Jeff is professor and chair of the Department of Communicative Disorders and Sciences at the University at Buffalo. He is a fellow of the American Speech-Language and Hearing Association, a founding member of the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC, 1998 - 2013) and a Trinity College Long Room Hub Visiting Research Fellow (2015).

PROVISIONAL PROCEEDINGS

ISAAC 2016 Research Symposium

OPTION A (day 1 and day 2)

DESIGNING FOR EXPRESSION, IDENTITY and EXPLORATION in AAC (1.5 days)

Leader: Jeff Higginbotham

Co Presenters: Jeff Higginbotham, Rupal Patel, Graham Pullin, Jutta Treviranus

This stream brings together 4 researchers in the AAC area who have been exploring issues of designing for AT and AAC throughout most of their careers. Designing for communication represents more than ensuring access to words and utterances, and includes finding ways to enable individuals to “stay in the timestream,” to “be oneself,” and to have an original voice. The workshop will focus on examining contemporary issues and techniques in contemporary design and their application to designing technologies for augmentative communication. This stream will involve an introduction (Pullin & Higginbotham) plus sessions presented by different combinations of the group. At this time, here are our three sessions within the Research Symposia. Each address overlaps between our research interests and will be presented in the form of a dialogue, as well as including participants.

Voices and tones of voice

Rupal Patel & Graham Pullin

Voice—giving someone a voice, in the broadest sense—is fundamental to AAC. Device to device, it is now recognised that speech generating devices need a choice of voices, to allow a degree of individuality and also to represent someone’s identity. Wonderful progress has and is being made in voices that represent gender, age, accent, language and other aspects of cultural identity [e.g., VocaliD]. Utterance to utterance, advances in speech technology are opening up the possibility of high fidelity speech with more expressive intonation and prosody. Yet how a person using AAC might interact with nuanced tone of voice is still a frontier of AAC design and research [e.g., Tonetable]. What if these were two ends of a spectrum? Conversation to conversation, don’t we typically adopt *different voices* in different company, contexts and circumstances? [e.g., Speech Hedge] We will explore how taking a broad perspective of the role of the voice in conveying social identity and enabling social interaction might open up new research directions in AAC and beyond.

Inclusive design and research

Jutta Treviranus & Graham Pullin

Inclusive design is something the field of AAC signs up to in principle (“Nothing about us without us” of course). But what does it mean in practice? We will explore a landscape of different methodologies and methods, including co-design, participatory design, personas, design ethnography, experience prototyping and critical design [e.g., Finding My Words]. How does AAC fit into a broader context of inclusive design? Where is it

Provisional only - final version yet to be released.

unrepresented and why? Where is it pioneering practice that could be applied more widely in inclusive design and design in general?

Interaction design for social interaction

Jeff Higginbotham, Rupal Patel, Graham Pullin, and Jutta Treviranus

Interaction design involves more than the design of user interfaces. It is about our interactions with each other, through technology. We will explore the role of the design of AAC devices and how this influences social interactions: by encouraging co-creation, deferring to eye-to-eye contact and body language, alluding to ubiquitous consumer electronics (and so reducing differentiation and possibly stigma). How can we engage with the temporal dimension of interaction design (where interaction really comes into its own in relation to product design and graphic design)? How might we design for joint attention, communication repair, turn-taking, multi-modal communication? Presenters will discuss issues related to using social interaction as the basis for generating design goals and creating technologies to address interaction problems.

***Jeff Higginbotham, PhD** ([cgsjeff@buffalo.edu](mailto:cdsjeff@buffalo.edu)) is professor and chair of the Department of Communicative Disorders and Sciences at the University at Buffalo. He is a fellow of the American Speech-Language-Hearing Association, a founding member of the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC, 1998 - 2013) and a Trinity College Long Room Hub Visiting Research Fellow (2015). Jeff's research focuses on the video analysis of discourse and talk-in-interaction to research how people interact — in real time - to co-produce meaning, emotion and identity. He has applied this research toward the development of new communication technologies for individuals with complex communication needs, including persons with cerebral palsy, autism and neurodegenerative disorders. More recently, Jeff has begun to apply his interests in human interaction and technology to explore alternative ways of engaging others through the use of recorded sound, music and visual modalities of expression.*

***Rupal Patel, PhD** (rupal@vocalid.co) is a Speech Scientist and Technologist that is passionate about humanizing spoken communication interfaces. Dr. Patel is a tenured professor at Northeastern University with joint appointments in the Department of Communication Sciences and Disorders and the College of Computer and Information Science. She also holds numerous adjunct appointments including the Health Science and Technology program at Harvard /MIT, Haskins Laboratory at Yale University and the Department of Psychiatry at the University of Massachusetts. She is currently on leave from the University to launch VocaliD, a company she founded to personalize digital voices for speech interfaces.*

***Graham Pullin, PhD** (g.pullin@dundee.ac.uk) is a senior lecturer at DJCAD, the art college at the heart of the University of Dundee, Scotland, where he co-founded the Social Digital department combining Product, Interaction and Interior Design. He is the author of *Design meets disability* (MIT Press, 2009), a manifesto that argues for more art school-trained designers to be invited into disability-related design. His mid-career PhD entitled '17 ways to say yes' explored nuanced tone of voice in augmented communication, through the design collection *Six speaking chairs*. Previously, he was a senior designer and studio head at the design consultancy IDEO. He studied design at the Royal College of Art and engineering at Oxford University.*

***Jutta Treviranus, M.A.** (jtreviranus@ocadu.ca) is the Director of the Inclusive Design Research Centre (IDRC) and professor at OCAD University in Toronto. Jutta also heads the Inclusive Design Institute a multi-university regional centre of expertise on inclusive design and is the Co-Director of Raising the Floor International. She also established and directs an innovative graduate program in Inclusive Design. Dr. Treviranus has led many international multi-partner research networks that have created broadly implemented technical innovations that support inclusion and has played a leading role in developing accessibility legislation, standards and specifications internationally (including WAI ATAG, IMS AccessForAll, ISO 24751, and AODA Information and Communication).*

OPTION B (day 1 and day 2)

MULTICULTURAL AND WIDER SOCIAL CONTEXTS THAT FRAME AAC PARENT PERSPECTIVES: WHAT PROFESSIONALS NEED TO CONSIDER.

Leaders: Stephen von Tetzchner and Judith Oxley

A person with complex communication needs develops and lives within a family unit, a community, and a wider society. Despite commonalities in the human experience, there remain important differences arising from particular social circumstances. Numerous professionally-driven AAC research and training initiatives facilitate a deeper understanding of what it means to be a parent or caregiver to someone with complex communication needs and how this role is shaped by wider social and cultural beliefs and circumstances. While AAC is seen as important and primary by many stakeholders, including professionals, it is but one of many needs in the lives of families across the world. What is needed is a clearer understanding of the individual and family members' perspectives and priorities, and how issues beyond AAC itself shape them. Anthropological approaches are particularly well-suited to studying these issues and also the way clusters of issues interconnect and influence people at the level of society and the family. Without these insights, professionals may miss what is important to families, and fail to develop and deliver language assessment and training programs relevant to the local society. In the long run, the people with complex communication needs may lose the most when opportunities for communication are missed. Through this symposium, both senior and early career researchers will share different research techniques, with a focus on anthropological findings, to enrich the AAC research community and establish wider collaboration among all delegates. This 1.5 day symposium comprises presentations from nine AAC researchers, each delivering ethnographic considerations affecting AAC implementation and research globally. The facilitators Stephen von Tetzchner and Judith Oxley will moderate the presentations and discussions, to draw the several strands of meaning offered in the presentations together. Each of the presentations will include 30 minute discussions with delegates, so that by the end of the symposium important conclusions can be drawn into the overarching 'ethnographic research' theme, to guide future AAC research.

Stephen von Tetzchner is professor of developmental psychology at the Department of Psychology, University of Oslo, Norway. His research includes a wide range of issues related to typical and atypical development in general, and communication and language development in particular, including the development of individuals with intellectual disability, motor impairment, deafness, blindness, Rett syndrome, Tourette syndrome, and autism spectrum disorders. He has published textbooks on developmental psychology, language development, augmentative and alternative communication, rehabilitation, challenging behaviour and Asperger syndrome.

Judith Oxley is an assistant professor and Speech Language Pathologist in the Department of Communicative Disorders, University of Louisiana at Lafayette. Her research interests are in areas of augmentative and alternative communication, and speech acoustics. She has published papers and book chapters related to acoustics, memory issues in AAC, hearing impairment, and research design. Her clinical work is mainly with people who have developmental disabilities, including Down Syndrome, cerebral palsy, autism spectrum disorders, Rett Syndrome, CHARGE syndrome, but also includes ALS, and traumatic brain injury.

Partner training: addressing critical needs of individuals with CCN in low & middle-income countries.

Kathryn Drager and Nimisha Muttiah (United States)

With approximately 20% of the world's population having a disability, a significant number of individuals with disabilities live in low and middle-income (LAMI) countries. However, communication services for individuals with complex communication needs (CCN) are usually scarce in LAMI countries. We conducted a series of studies using multiple methods to investigate the services in Sri Lanka, a LAMI country including: (a) interviews with parents living in Sri Lanka, to find out their views regarding the special education system in the country; (b) an online focus group with AAC professionals who had extensive experience with providing instructional supports to professionals, family members, and individuals with CCN from LAMI countries; and (c) an AAC training study for special education teachers living in Sri Lanka. The parent interviews revealed that many children with communication needs were not receiving services, partially owing to a lack of qualified speech-language pathologists. Also, there was a need to know how best to train the partners of individuals with CCN. From the focus groups, four key practices were identified for training professionals in LAMI countries, and these practices informed a training program. Special education teachers were taught to provide evocative communication opportunities (opportunities that place the child in an active role) that consisted of: (a) asking an open ended question, commenting, or making a choice; (b) providing a means for the student to respond; and, (c) waiting five seconds for a response. The training study yielded positive finding for both the professional trainees and the children with CNN. We will discuss the methodologies and findings from all three of these studies to illustrate what can be accomplished, and the role played by mixed methods research in the field of AAC. Delegates will discuss directions for future research in Sri Lanka and other LAMI countries, particularly small-scale projects that when combined address important AAC issues.

Kathryn D. R. Drager, PhD, CCC-SLP, is a Professor of Communication Sciences and Disorders, and Associate Dean for Research and Graduate Education in the College of Health and Human Development, The Pennsylvania State University. Her research interests include augmentative and alternative communication (AAC) and applications for beginning communicators and individuals with severe disabilities, including effective interventions for individuals who require AAC and issues faced by the global community in AAC.

Parents' attitude and needs toward using AAC in China.

Xueyun Su (China)

Parents are the key communication partners of children with disabilities with little or no speech. Their attitudes and perspectives strongly impact the communication opportunities and participation level of children with complex communication needs (CCN). In mainland of China, research and practice on AAC are emerging, and the attitudes parents to AAC and their needs in practicing AAC are under-researched. Delegates will hear about some recent research on AAC in China. Questionnaires about AAC and its application in China were used to explore the perspective of parents (n=162) from six special schools and early intervention centres for children with disabilities. Results showed parents knew more about and used more low-tech than high-tech communication aids. According to the parents, more than 77 percent of the students had speech or communication difficulties. Seventy percent of the parents had heard about unaided AAC and 47 percent of parents had used this kind of communication. The general attitude toward AAC was positive among parents. Earlier experience with AAC affected the attitudes of parents positively. Mothers had more positive attitudes towards AAC than did fathers. Overall, parents expressed positive attitudes to AAC and willingness to learn about and practice AAC. They had more experience with manual signs and communication boards and books, and were somewhat concerned about the effectiveness of the high-tech devices. They wanted more policy

Provisional only - final version yet to be released.

and professional support, and more public education to create a positive environment for AAC users. In this presentation, delegates will be encouraged to discuss the role played by public attitudes toward people who use AAC, what could be done to shape these attitudes in China, and what research questions might be important in tracking impact of interventions as AAC emerges as a field in China.

***Xueyun Su** is a researcher in the field of early intervention, especially assessment and intervention for children with Autism Spectrum Disorders and Developmental Delays including using AAC to support the communication and learning of children in both special education and inclusive education settings. She also provides training for special education teachers and parents working with children using AAC. She works closely with children with special needs and their families in mainland of China to facilitate AAC emerging and development. She is PI for over 14 research projects, and has published over 30 peer-reviewed articles including SSCI and CSSCI journals, and over 5 books and chief editor of a series book on early intervention of children with ASD.*

Relocation for rehabilitation: the lived experiences of parents of children with complex communication needs.

Monica Kaniamattam (India)

Parents of children with complex communication needs (CCNs) have multiple roles to play in the lives of their children; these roles extend well beyond typical parental responsibilities, and persist into their children's adulthood. Yet very little is known about the experiences of parents from developing countries - specifically, India. Delegates will hear about some recent research as a stimulus to discussion about AAC in India. In a recent study, a qualitative approach incorporated semi-structured interviews with 16 parents of 15 children with complex communication needs (CCN) aged from 3 to 27 years who were all obtaining services in a rehabilitation center in South India. Interpretative phenomenological analysis (IPA) of the transcribed interviews yielded initial themes related to the child, family and larger society. Subthemes included support systems and barriers regarding these social levels. At the interpretative level, the researchers further analyzed the data to determine what meaning parents derived from parenting. In this presentation, delegates will be asked to reflect upon the theme, 'relocation for rehabilitation' including its benefits to parents. Many of the parents in the study chose to relocate to live near the rehabilitation centre. Although they moved to obtain services, they remained in the area for other reasons. Parents identified barriers and challenges to AAC, which they attributed to beliefs and attitudes prevalent in their communities. Delegates will discuss: (a) What might family stressors mean in professional practice? (b) How might community groups facilitate resilience for families? (c) How might this practice promote self-selected social isolation of nuclear families? (e) What factors influence decisions to place child in inclusive vs segregated schools? (f) What underlies parents' experience that they themselves, not just their children, are disabled? and (g) How might these stressors be acknowledged by professionals? All of these questions will inform a future research agenda for AAC in India and potentially other countries developing AAC.

***Monica Kaniamattam** is currently pursuing a doctoral degree in the Department of Communicative Disorders at the University of Louisiana at Lafayette. She obtained her Masters in Audiology and Speech-Language Pathology from Manipal University. In India she has extensively worked with children with complex communication needs (including cerebral palsy, intellectual disability and autism) and their families. She has also organized various parent training workshops and community based rehabilitation (CBR) programs. Her research interests include multiculturalism, qualitative research methodologies, and AAC. She has conducted fieldwork in rural India, to understand the Lived experiences of parents and families of children with CCNs. She is currently collaborating with experts in the field and working towards developing family centered services for more than 500 families attending a rehabilitation center, in India. Her long term goal is to optimize the service delivery for children with CCNs by building effective parent-child-clinician collaboration in a culturally sensitive fashion.*

Experiences from a Norwegian support group for families of preschool children in the expressive AAC user group.

Kristine Stadskleiv (Norway)

Children develop language through interacting with more competent language users. Aided language users in the expressive group also need competent language models, but most of their parents will not have any prior experience with aided language. Research to date has addressed parents' roles and challenges in providing support. It is important to increase the aided language competence of parents, and support for this should be offered as early as possible. Oslo University Hospital has established a support group for parents of young aided language users in the expressive group, and five parents currently participate. The group meets 2-3 times per semester and each meeting lasts for 2 hours. At the meeting, a talk on AAC is provided either by the hospital staff or other professionals. The group is also a forum for the parents to share experiences of issues related to AAC, their children's situation, and the challenges the parents experience. Establishing the group increased the parents' aided language competence, and resulted in other benefits, including: (1) the parents created their own network and offer each other support and practical assistance; (2) parents have taken initiative for the children to meet, thereby providing the children with more diverse aided language experiences than the parents by themselves can provide; and (3) the group has increased the knowledge of AAC among other hospital staff.. Symposium participants will discuss and compare the experiences of these European parents with those of parents from other countries, to discuss: (a) What can be learned about the formation of parent groups? (b) In what ways can parents learn to support their children's aided communication? (c) How did the parents come to accept aided communication? and (d) What opportunities for AAC research exist in establishing and evaluating parent groups? Ethnographic approaches to exploring these questions in AAC research will also be considered.

Kristine Stadskleiv is a licensed clinical psychologist and licenced specialist in clinical neuropsychology. She is currently completing her doctorate at the University of Oslo. Her research is in areas of cognitive assessment of "hard-to-assess" populations; understanding the perspectives and needs of parents of children with CNN; parent training and support issues; play and peer support for children with CNN.

Brazilian parents' attitudes and use of augmentative and alternative communication systems.

Debora Deliberato (Brazil)

Collaborative work including the person with complex communication needs (CCN), a variety of professionals, school staff and family members in the use of Augmentative and Alternative Communication (AAC) systems is essential, and researchers have argued that parents and siblings of aided communicators are central figures in the lives of people who use AAC. A cross-cultural research on language development in aided communicators, led by Dr. Stephen von Tetzchner, University of Oslo, joined several countries and Institutions with the goal of using research instruments directed at aided communicators and their partners, including parents. The study used both qualitative and quantitative analysis of information obtained from their families. Findings from this wider study concerned the attitudes of Brazilian parents in the use of AAC systems of their children, and will be presented and discussed in this presentation. Ten families of Brazilian children and adolescent aided communicators participated in the research. The aided communicators receive services at a Rehabilitation Center in São Paulo State, Brazil. Data were collected through semi-structured interview, several checklists, and assessment scales. Data collection was conducted in rehabilitation centres and/or in the families' homes. The interviews yielded information about (a) the importance of aided communication for the children to be understood by different partners outside the school and family setting; (b) the need for its use in the school setting; (c) its importance for communication, language and learning; and (d) how limited communication had been prior to the introduction of aided communication. The checklist and assessment scales addressed parent

Provisional only - final version yet to be released.

perspectives about their children's needs and capacities to address different needs across contexts, and how home-school collaboration was accomplished. Delegates will be invited to discuss how parents come to adopt and prioritize aided communication in their children's development, and ways to capture and appreciate this through future AAC research.

Debora Deliberato is an Associate Professor at the Special Education Department and Graduate Program in Education of Univ Estadual Paulista, Marília, SP, Brazil. Her qualifications include: a postdoctoral degree in Education (UERJ, 2013), Lecturer in the area of Alternative Communication at UNESP, Marília, SP, Brazil (2010), doctorate in Medical Sciences at the State University of Campinas (2000), Master in Language - Semiotics and General Linguistics at University of São Paulo (1993). Bachelor in Speech Language Pathology at Federal University of São Paulo - EPM (1985). She has experience in speech language therapy, with emphasis in Special Education, researching on the following topics: augmentative and alternative communication, special education, training of health and education professionals in the inclusive process of disabled students. She has several books and articles published in the area of Special Education, Augmentative and Alternative Communication. She is a CNPq fellow researcher.

Stopping the violence against people with disabilities: an international perspective.

Juan Bornman (South Africa)

Ensuring access to the criminal justice system for those who have little or no functional speech is a central concern in many countries. Parents live with the knowledge that their children with disabilities face danger and may experience violence at the hands of other people. And yet, little is known about how this impacts on the parents' approach to 'protection' or the impact of this upon the children (or adult children). International research and advocacy offer some promising practices and approaches that can reduce the risks of violence being experienced by children with disabilities, while providing intervention and access to justice for these children and their families. There is a pressing need for public awareness, knowledge and understanding of the violence, including rape and sexual abuse of people with disabilities, particularly those who have little or no functional speech. In this presentation, delegates will be asked to consider recent research, and discuss: (1) how the danger to children (and adult children) influences parents' willingness to promote greater independence for their children with disability and CCN, (2) how to give all stakeholders a voice in relation to 'risk' 'danger' and 'protection' from danger and abuse for children with disability and CCN, and (3) how the field of AAC research can further explore this area taking into account several legal and ethical concerns in the conduct of the research and dissemination of findings.

Juan Bornman is both the director of the CAAC, as well as a professor at UP. Her research focuses on AAC and severe disability. She has a special interest in the development of a functional approach towards disability and communication rehabilitation within a positivist, asset-based framework, particularly in the context of a developing country. Her research on the involvement of health care workers as part of the initial communication rehabilitation team has been adopted as an effective model by various developing countries. Her publications include books, various chapters in books, more than 25 ISI accredited papers and one special edition journal. She represents South Africa on the board of the International Society for Augmentative and Alternative Communication (ISAAC). She also acts as the AAC consultant for a number of local and international organizations. She is the recipient of several awards which have earned her national and international recognition.

Augmentative and alternative communication for children with developmental disabilities through parental training: a multidisciplinary approach.

P.A. Suresh (India)

At the Institute for Communicative and Cognitive Neurosciences (ICCONS), established in 1998 for the management and rehabilitation of cognitive and communicative disorders, we recognize family as the major source of support for children with complex communication needs. Families learning to implement AAC face multiple demands. To understand the diverse needs of their children, parents attend repeated interactive sessions that are objectively planned and implemented through the rehabilitation team. Parent training emphasizes knowledge on the use of aided and unaided systems and their effective implementation through in-home implementation, which can overcome the time limitation in therapy sessions. The presence of clearer communication can ease some of the burdens of caregiving. Delegates will discuss (a) how supporting parents' implementation of AAC in the home environment across the day can enhance the quality of family life, (b) how teams can collaborate to develop advanced situation-dependent AAC strategies to make it more effective (e.g. to enable children to communicate their physical states more precisely), and (c) how mixed methods research can yield data needed by policy makers to support the provision of effective, family-friendly services.

P.A. Suresh is the Founder Director of the Institute for Communicative and Cognitive Neurosciences (ICCONS), Trivandrum & Shoranur, Kerala, India. Established in 1998, ICCONS is among the few institutions in the field of Cognitive Neurosciences in Asian countries, and the first Neurocentre to obtain National Accreditation Board for Hospitals & Health Care Providers (NABH) accreditation in India. ICCONS has a broad perspective of research and development in the field of cognitive and communicative disorders. Dr. Suresh holds the following degrees: MBBS (Medical College, Kottayam, India); MD (General Medicine; Medical College, Alleppey, India); DM (Neurology; Sree Chitra Tirunal Institute for Medical Sciences and Technology (SCTIMST), Trivandrum, India); and an MBA (Health Administration; Sikkim Manipal University, India). Between 2000-2009 he served as Additional Professor SCTIMST, Trivandrum, Kerala; from 1998-2009 he held the position of Director ICCONS, Trivandrum & Shoranur, India; and since 2009 he has been the Executive Director there. He has research interests in neuroscience, neuroimaging, and genetics and published in numerous peer reviewed journals. He has received the Save India National award (2011) for contribution to Medical Sciences.

Provisional only - final version yet to be released.

OPTION C (two topics)

SOCIAL MEDIA AND AAC: NEW RESEARCH IN ALL DIRECTIONS ONLINE (day 1)

Leader: Bronwyn Hemsley

Co-presenters: Bronwyn Hemsley, Amanda Hynan, Helen Paterson

In this symposium, three active researchers in the field of AAC and social media will stimulate discussions to drive AAC innovation across disciplines. The presenters have recently published their research in a special issue of 'Disability and Rehabilitation', and represent diverse interests in the inclusion and participation of children and adults who use AAC, and people with lifelong and acquired communication impairments, in online spaces. The overall aim of the symposium is to progress social media research in the field of AAC beyond 'views and experiences' or 'needs for support' and into 'surviving and thriving' with full participation and inclusion in online social media communities. Research into the use of social media by people who use AAC, or using social media data, is both simple and complex, and impacted by many fields of AAC research. At its core, however, are the social media spaces and communities, and the information communication technologies that form diverse platforms for social media interactions. The presentations in this symposium combine to stimulate audience discussion of under-researched areas in the field of AAC and social media, and methods that can be applied in relation to social media research with children and adults who use AAC and their supporters, families, and service providers. Audience members will be engaged as 'key stakeholders' in bringing their own knowledge, views, experiences, and curiosity about social media and AAC to discussion about future research in this field.

Publicity, Privacy, and Protection: Implications for Social Media Research in the field of AAC

Bronwyn Hemsley

To date, social media research in the field of AAC has primarily focused upon the views and experiences of people who use AAC in relation to social media use, and ways to support people who use AAC in learning to use social media. Very little AAC research has (a) explored what occurs in social media spaces and AAC communities online, (b) actively utilized public or private social media data in examining how people who use AAC use social media, or (c) used public social media data to explore other AAC research questions. Therefore, in AAC research to date there is an over-reliance on people's reporting of AAC and social media use, and an under-utilisation of evidence about that use which is available in the social media data. Public and private social media data provides useful insights on purposes of social media use and communities of AAC in online social media publics that could further growth in the relatively new area of AAC research, practice, and policy development. However, social media research is often complex in design and conduct for a range of methodological and ethical reasons. In this symposium, the audience will be engaged in considering aspects of 'publicity' and 'privacy' for people engaged in online interactions, that impact on the ethical conduct of research in social media in the field of AAC. The audience will consider a range of research questions, in the context of various data collection and analysis methodologies that might be applied in developing AAC research, and their legal and ethical implications.

Bronwyn Hemsley is a full time clinical researcher in the field of disability, augmentative and alternative communication, social media, dysphagia, and patient safety in relation to individuals with complex communication needs. She has for the past two years been leading a national research project on the use of social media by people with severe communication disabilities, including adults with cerebral palsy, motor neuron disease, and is currently supervising doctoral research in relation to the use of social media by people with traumatic brain injury. Bronwyn is a speech pathologist with 27 years clinical experience including working with

Provisional only - final version yet to be released.

children and adults with lifelong or acquired communication disabilities in a variety of hospital, community, and educational settings. She is a previous President-Elect of ISAAC and is currently an Associate Professor at the University of Newcastle, Australia. She leads three national research projects, is an Editor in the Cochrane Consumers and Communication Review Group, Associate Editor of the Augmentative and Alternative Communication Journal, and of the Journal of Intellectual & Developmental Disability. Bronwyn also co-administers the world's first Rotation Curation Twitter account connecting speech language professionals worldwide.

How are young people who use AAC navigating and conducting romantic relationships within social media environments?

Amanda Hynan

The diversity of social media platforms is having a profound effect on social interactions including romantic attachments. Forming intimate relationships is an area of interest for adolescents and young adults, yet also an area of societal concern regarding online privacy and safety. However, many young people are learning to negotiate a variety of social media platforms to manage their intimate relationships. Young people who use AAC may not have the same opportunities as their peers to initiate, maintain and terminate intimate relationships, either within offline or online environments. Their private relationships are often restricted by heightened parental concerns, the need for physical support, and educational or residential safeguarding obligations. The presenter will discuss excerpts of data within her doctoral research illustrating ways in which young adult AAC users were ready to discuss the importance of social media for supporting possible dating opportunities. Analysis of video data revealed a lack of vocabulary or ways to discuss dating and a possible 'blindness' on the part of the interviewers to recognize the communication strategies being employed to circumnavigate this challenge. The symposium audience will be invited to discuss aspects of the data, and explore how young people who use AAC negotiate romantic relationships within offline and online media environments, and the implications of this for future research exploring this under-researched area. The discussion will inform the development of future research questions, suggested methodologies, and ethical implications of exploring 'romantic' and 'intimate' relationships for young people who use AAC.

Amanda Hynan is a Speech and Language Therapist working as a Senior Lecturer at Leeds Beckett University, UK. She completed her PhD with Manchester Metropolitan University in 2013 under the directorship of Dr. Janice Murray. She has had two peer-reviewed papers published from her grounded theory doctoral research exploring the experiences of using the Internet and social media with young people who use Augmentative and Alternative Communication (AAC) and has a forthcoming book chapter. She has recently been approached to join the supervision team of an AAC related PhD project by Cardiff Metropolitan University and is currently supervising an AAC MRes project at Leeds Beckett.

Social Media use by adults with acquired conditions who use AAC

Helen Paterson

Social media use can help to increase social participation, maintain social interaction between peers and families, increase social support, reduce social isolation, contribute to self-identity, and access information. However, adults with acquired communication impairments lack support and training from professionals and have problems with accessibility to social media sites when using alternative access methods. There is a need for a programmed plan of research relating to social media use by adults with acquired conditions, particularly stroke and progressive neurological conditions, as these adults may need support and assistance quickly before losing speech or movements needed for maintaining existing access to social media or beginning new social media efforts. In this session, the audience will be invited to reflect on research to date, and gaps in the research, to engage in discussion on issues particular to the field of AAC and social media for adults with acquired disorders, particularly how future research might be designed to inform: (a) ways to support AAC professionals to deliver timely and effective interventions that enable adults with acquired conditions affecting communication to use social media, (b) strategies to support adults with acquired conditions in safe and enjoyable social media experiences; (c) guidance for adults with acquired conditions and their families in managing social media profiles as their condition progresses and after death; and (d) innovative design by web and AAC software developers to enable easier access of people with acquired conditions to popular and commonly used social media sites. Symposium outcomes will inform development of suggested research pathways designed according to the nature of different acquired communication impairments.

Helen Paterson is a Speech and Language Therapist (SLT). She originally qualified as an adult nurse with a BSc (Hons) in Adults nursing (Edinburgh University), then after working on an acute neurological ward went on to study SLT (BSc Hons Birmingham City University). She worked as an SLT in the acute, community and rehabilitation settings with adults before specializing in AAC. For the past three years Helen has been the SLT on the Compass Assistive Technology service at Royal hospital for Neuro-disability in Putney, London which is a regional AAC specialist hub. In 2014 she completed my MSc in Assistive Technology (Coventry University) with the research dissertation topic of 'How do adults with severe acquired communication difficulties make decisions about, and experience, the communication methods they use?'. This was presented as a poster at ISAAC in 2014 and published in the 2015 special edition of Disability and Rehabilitation on Social Media and Communication. Helen is currently preparing an application for the NIHR clinical doctoral fellowship, to further pursue my research in the field of social media use and AAC. She was a founding member and is the chairman of the London AAC Clinical Excellence Network (CEN), which is committed to promoting education and collaboration between AAC users and SLTs working in this field in London.

OPTION C (two topics)

IDENTIFYING APPROPRIATE SYMBOL COMMUNICATION AIDS FOR CHILDREN: ENHANCING CLINICAL DECISION-MAKING (day 2)

Leader: Janice Murray

Co-presenters: Janice Murray, Yvonne Lynch, Liz Moulam, Martine Smith

Symbol communication aids are used by children with little or no intelligible speech; positive effects are well documented (Dada & Alant, 2009). However, Johnson et al. (2006) note there is a significant variation in provision and unacceptably high levels of abandonment; between 30-50%. The National Institute of Health Research (NIHR), UK, have funded an innovative 3 year study, involving the named investigators and Juliet Goldbart, investigating clinical decision making when prescribing symbol communication aids for children, the output to be evidence based best practice resources and decision making heuristic for professionals and families involved in future assessment and provision processes. The symposium has 4 parts:

1. Presentation of findings from 3 linked systematic reviews: (i) speech and language development (ii) communication aid attributes (iii) clinical decision making and prescription. Followed by audience discussion of studies that may not have been included.
2. Small group discussions of how this evidence relates to 4 research questions, shared back in plenary.
3. Small group discussion around methodologies for researchers working with children and adults who use AAC and their families, shared back in plenary.
4. Question and Answer session between the researchers and the audience on the project's expected outcomes.

Presenters from the research team include: Janice Murray (Chief Investigator), Liz Moulam (Co-Researcher), Yvonne Lynch (Research Fellow) and Martine Smith (Advisory Board member).

The symposium discussions will be used to ensure robustness of the systematic literature reviews, to triangulate findings and to ensure all appropriate methodologies are considered for the research to be undertaken with children and adults who use AAC and their families.

Presenter: Janice Murray

Symbol communication aids are used by children with little or no intelligible speech, the positive effects of use are well documented (e.g. Dada & Alant, 2009). Aids are provided following multi-professional assessment, yet Johnson et al. (2006) note significant variation in provision and unacceptably high levels of abandonment of between 30-50%. The challenge of making appropriate and long lasting clinical decisions about complex communication aid technologies for children with neurodisability who have significant communication disability has long been debated within the field of practice and existing research highlights multiple critical issues. The NIHR are funding three linked systematic reviews which will formally synthesize the current evidence relating to clinical decision making:

1. Speech, language and communication development with specific reference to children using symbol communication aids;

Provisional only - final version yet to be released.

2. The language and communication characteristics of both the child and the communication aids considered in decision making;
3. Clinical decision making related to aided communication in allied health professions.

These findings will inform the further work streams within the overall research project. Findings will be shared with the audience, who will be asked to consider their own knowledge and practice and share in plenary any studies they are aware of that have not been included so that a comprehensive global picture can be ascertained. In this context the word clinician is used to cover any professional who prescribes/assesses a child for a communication aid, including therapists, teachers, suppliers and others.

Janice Murray is Reader in Community Rehabilitation and former Head of Speech and Language Therapy at Manchester Metropolitan University. A speech-language therapist by profession, she began her career in AAC in 1987. Her PhD studies explored working memory skills in preschool children with cerebral palsy/limited speech intelligibility compared with their typically developing peers. She has continued with her interest in this area through national and international research collaborations, with significant publications in several AAC related topics. She has led funded research, for example, PI on the An AAC Evidence Base Project, funded by BIG Lottery, commissioned by Communication Matters; £468,000, July 2010-Mar 2013. She is Chief Investigator NIHR: HS&DR Project: 14/70/153: Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision making. £837,560, Jan 2016-Dec2018. She was formerly ISAAC Bulletin Editor, Chair of ISAAC-UK and Currently Chair-ISAAC Council.

Presenter: Yvonne Lynch

The NIHR funded study, which has both Manchester Metropolitan University and English National Health ethics approval, focuses on 4 key research questions aimed at improving outcomes for children using symbol communication aids. There are several separate but interlinked studies, as part of the bigger project, around these questions, with work to be undertaken with clinicians (professionals), families and those of all ages who use AAC. The symposium participants will be asked to work in small discussion groups to discuss the evidence presented in the first session in relation to the research questions:

1. What characteristics related to the child, their context and generic communication aids, do clinicians consider important in making decisions about the process of provision of a communication aid?
2. What other factors influence or inform the final decision?
3. What characteristics are considered important by other participants (e.g. the child and family) and how do these impact on communication aid use in the short, medium and long term?
4. What decision support guidance and resources are needed to enhance the quality, accountability and comparability of decision-making?

Each group will summarise their findings and share in a plenary session with the other participants. The input at this stage to assess the robustness of the initial findings and help triangulate the evidence gathered in the remainder of the project.

Yvonne Lynch is a Research Fellow at Manchester Metropolitan University working on the NIHR funded Identifying Appropriate Symbol Communication project. Yvonne is a speech-language therapist by profession and has a long-standing passion for the field of AAC. She has over fifteen years' experience working with children and adults who use AAC and has managed a national AAC service at the Central Remedial Clinic (CRC, Ireland). She has recently completed her PhD at Trinity College Dublin exploring intervention methods in AAC with a particular focus on graphic symbol knowledge, which she presented at ISAAC Pittsburgh (2012) and ISAAC Lisbon (2014).

Provisional only - final version yet to be released.

Presenter: Liz Moulam

The project team includes researchers from 2 universities and a National Health Trust, as well as 2 co-researchers; one a person who uses AAC and one a family member of a young adult who uses AAC. The research aims to seek the views of children who already use AAC, adults who are communication aid users and their families. Those who will be invited to participate may also have learning difficulties, and/or be on the autistic spectrum, and/or be cognitively able. The project team has ideas on methodologies that may be successful, and will be adopting a mixed methods approach, to elicit participant's views at various stages of the project. We wish to invite the symposium delegates to discuss their experiences of undertaking qualitative and quantitative research with children and adults who use AAC and their family members, specifically what has worked well previously, any pitfalls to avoid and how they would approach future similar studies. Following a short presentation of proposed methodologies, this session will break into small working groups, with each group being chaired by one of the research team. The findings will be summarized and shared with the whole audience. The outcomes from this session will be used to inform the research practice, and will raise awareness of the need to include those who use AAC and their families in key decision making processes that will affect their long term futures.

Liz Moulam, BSc(Hons) Psychology, Post Graduate Diploma in Social Sciences, Post Graduate Advanced Diploma Child Development,) is a Co-Researcher Manchester Metropolitan University, UK. She is a parent of young adult using AAC, and has a long involvement in leadership in the field of AAC. Liz is a previous President of ISAAC UK and ISAAC Council Member, and Previous Trustee for One Voice Communicating Together. Liz was Research Lead (2008-2009) for Communication Matters - Research Matters: 'Shining a Light' (Pre-award and establishing research team £468,000) and is currently a Patient Participation Involvement Co-Researcher (2015-2019): MMU "Investigating Appropriate Symbol Communication Aids (£837,560).

Presenter: Martine Smith

The overall project over 3 years involves researchers with depth and breadth of experience that has not previously (to our knowledge) been seen for a single AAC research project. The panel of researchers will be happy to answer questions from the audience on:

- How they put together their funding bid
- The oversight of the project including advisory, steering boards and general management
- What co-researchers bring to the project
- What we expect the final outputs to look like and how this might inform clinical practice
- What benefits this should bring for people who use AAC and their families longer term
- How the findings are expected to inform future research as well as research and development of communication aids
- How the findings are planned to be disseminated both during and at the end of the project

Martine Smith is Associate Professor of Speech Language Pathology and Head of the School of Linguistic Speech & Communication Sciences at Trinity College. A speech-language therapist by profession, she has worked in the area of AAC for most of her professional career. Her MSc and PhD studies both focused on language and literacy challenges for children using aided communication. She has continued her research in these areas and has published extensively on these topics, including a textbook on Literacy in AAC. She has supervised MSc and PhD students researching in the area of AAC and has developed international collaborations with leading researchers nationally and internationally. She was Chair of the Scientific Program of the ISAAC Biennial Conference in Dublin in 1998 and is currently the Editor of the AAC journal.