

## Program & Table of contents

Time	Discussion	Presenter	Page
15:00 – 15:05	Welcome and introduction	Prof Shakila Dada	
15:05 – 15:45	Including children and adults with severe speech and motor impairments in research: From participants to researcher	Prof Janice Murray & Assistant Professor Yvonne Lynch	1
<b>15:45 – 16:00</b>	<b>Questions and Discussion</b>	<b>Participants</b>	
16:00 – 16:15	Models for co-development of materials	Ms Adele May & Prof Shakila Dada	3
16:15 – 16:30	Synthesis of findings from interviews with youth with communication disabilities	Dr Kirsty Bastable & Ms Contance Ntuli	4
16:30 – 16:45	Synthesis of findings from focus group discussions with professions	Prof Kerstin Tönsing	5
16:45 – 17:00	Synthesis of findings from interviews with caregivers of youth with disabilities	Dr Alecia Samuels	6
17:00 – 17:15	Presentation of draft materials	Dr Kirsty Bastable & Ms Maureen Casey	7
<b>17:15 – 17:25</b>	<b>Questions &amp; Discussions &amp; Feedback</b>	<b>All participants</b>	
17:25– 17:30	Conclusions and way forward	Prof Shakila Dada	

**\*3 CPD points for South Africans registered with HPCSA.**

**A link to multiple choice questions based on this workshop will be emailed to participants after the workshop to be completed by 28 October 2020.**

# Including children and adults with severe speech and motor impairments in research: From participant to researcher



**Prof Janice Murray**  
Professor in Speech-Language  
Manchester Metropolitan University, UK

Professor Janice Murray (Manchester Metropolitan University) is a speech-language therapist recognised internationally for her contribution to service developments, undergraduate and postgraduate education related to speech-language therapy and specifically augmentative and alternative communication (AAC); public involvement and translational research that informs, and supports evidence based practice. She is a Fellow of the Royal College of Speech & Language Therapists.



**Dr Yvonne Lynch**  
Assistant Professor in Speech-Language  
Trinity College, Dublin, Ireland

Dr Yvonne Lynch is a speech-language therapist and lecturer at Trinity College Dublin. She teaches at undergraduate and postgraduate level and her research interests include augmentative and alternative communication (AAC), language interventions and public involvement in research.

## Abstract



<https://iasc.mmu.ac.uk/>

This presentation comes in two halves: (i) an exploration of children and young people's views about their communication aids and the process they were involved in when choosing a communication aid that was best for them; and (ii) a summary of the approach to including people with lived experience of communication disability as part of a research team.

Children, young people and their family members are important contributors to any decision and recommendation process. Including their voices and perspectives is important but not always commonplace. We will describe how we did this and what these participants told us.

Public involvement and community engagement in the development, delivery and dissemination of research findings is regarded as good practice. Notably, including people with severe speech and motor impairment in these research processes is not easy and so their 'voices' are rarely heard. We will describe the I-ASC co-creation approach to research development, delivery and dissemination.

Lynch, Y., Murray, J., Moulam, L., Meredith, S., Goldbart, J., Smith, M., & Judge, S. (2019). Decision-making in communication aid recommendations in the UK: cultural and contextual influencers. *Augmentative and Alternative Communication*, 35(3), 180-192.

Murray, J., Lynch, Y., Meredith, S., Moulam, L., Goldbart, J., Smith, M., & Judge, S. (2019). Professionals' decision-making in recommending communication aids in the UK: competing considerations. *Augmentative and Alternative Communication*, 35(3), 167-179.

# Models on the co-development of materials



**Ms Adele May**  
PhD Candidate  
Centre for AAC

Ms Adele May is a registered speech and language therapist. She is completing her PhD at the Centre for AAC at the University of Pretoria. She has a special interest in developing interventions for children and adults with communication disability. Currently, her research focuses on AAC interventions for persons with dementia. Specifically those that are person-centered, evidence-based and participatory in design.



**Prof Shakila Dada**  
Director and Professor  
Centre for AAC

A speech-language therapist and has many years' experience in training and implementing AAC in the South African context as well as postgraduate training in AAC implementation. Her research concerns augmentative and alternative communication interventions with a particular focus on the role of graphic symbols in language learning and facilitating participation of persons with disabilities.

## Abstract

The co-development of interventions, materials and projects in health related fields has been recommended as a mechanism to improve patient or user engagement, adherence and ownership of the services.

Various frameworks have been suggested which illustrate the mechanisms of co-development. All of the frameworks represent the researcher- user relationship and encourage the involvement of users across all phases of the process.

Two models of co-development will be highlighted. The first which provides theoretical foundations for co-development of materials, and the second which provides a functional tool for the evaluation of co-development within any process.

Park, S. (2020). Beyond patient-centred care: a conceptual framework of co-production mechanisms with vulnerable groups in health and social service settings. *Public Management Review*, 22(3), 452-474. <https://doi.org/10.1080/14719037.2019.1601241>

Smits, D. W., van Meeteren, K., Klem, M., Alsem, M., & Ketelaar, M. (2020). Designing a tool to support patient and public involvement in research projects: the Involvement Matrix. *Research involvement and engagement*, 6(1), 1-7. <https://doi.org/10.1186/s40900-020-00188-4>

# Synthesis of findings from interviews with youth with communication disabilities



**Dr Kirsty Bastable**  
Postdoctoral Fellow  
Centre for AAC

A registered Speech-Language therapist and audiologist, currently working as a post-doctoral fellow at the Centre for Augmentative and Alternative Communication at the University of Pretoria. Her research has primarily been on the participation and engagement of children with disabilities.



**Ms Constance Ntuli**  
Disability Advocate  
Centre for AAC

An Administrative Assistant at the Centre for Augmentative and Alternative Communication, University of Pretoria, who uses AAC. She is a disability advocate as well as a mentor to young adults who use AAC.

## Abstract

The needs of youth in health care settings have long been neglected. Youth from a relatively early age are legally required to consent to various health care interventions yet the materials available to them are written for adults. In particular, youth with disabilities face vulnerability in this regard due to challenges they may experience in learning and communication. This project sought to develop health education materials for youth with disabilities in South Africa. 14 Youth who have disabilities were interviewed regarding the barriers they face with regards to healthcare information.

The youth participants reported on the barriers faced, in general as well as specifically around the COVID-19 epidemic. The findings highlighted a lack of training and methods for their inclusion in the decision making regarding the management and procedures relating to their health care. The youth participants indicated interest in gaining knowledge around their own health, keeping healthy, preventing diseases such as cancer and diabetes, and mental health support.

Further input was provided on the mechanisms for the sharing of health information, with input being provided on the symbols which should be used, as well as the format of health education materials, e.g. videos.

Hawkins, J., Madden, K., Fletcher, A., Midgley, L., Grant, A., Cox, G., ... & White, J. (2017). Development of a framework for the co-production and prototyping of public health interventions. *BMC Public Health*, 17(1), 689. <https://doi.org/10.1186/s12889-017-4695-8>

Nightingale, R., McHugh, G., Kirk, S., & Swallow, V. (2019). Supporting children and young people to assume responsibility from their parents for the self-management of their long-term condition: An integrative review. *Child: care, health and development*, 45(2), 175-188. <https://doi.org/10.1111/cch.12645>

# Synthesis of findings from focus group discussions with professions



**Prof Kerstin Tönsing**  
Associate Professor  
Centre for AAC

Prof Kerstin Tönsing (PhD) is a speech-language therapist and audiologist with extensive experience in the field of augmentative and alternative communication. Her research interest is AAC, with special focus on language development supported by AAC, language representation using aided AAC, and AAC implementation in multilingual contexts, including classroom implementation.

## Abstract

Two online focus groups were held with 15 professionals working with persons with communication disabilities. Participants identified a number of challenges experienced by youth with disabilities in accessing health information, similar to those reported in the literature (Geiger et al. 2010).

Amongst others, these related to the format, language, and modality in which information was provided, but also to beliefs and expectations of health care professionals. Participants had used a number of methods to make health information more accessible, including using multiple modalities such as pictures, video and audio information, and concretizing information through role-play, real objects and in-situ experiences.

The participants suggested that health education on COVID should not only cover physical health and knowledge about procedures such as testing and hospitalization, but also mental health issues related to social isolation, fear of infection and death, coping with boredom and appropriate help-seeking practices.

A number of possible formats and strategies were suggested, amongst others the use of short informative videos in different South African languages to make information easily accessible, shareable, and understandable. Findings underline the importance that resources in multiple languages and modalities play in ensuring equitable health services for all (Blackstone & Pressman, 2016).

Blackstone, S. W., & Pressman, H. (2016). Patient communication in health care settings: new opportunities for augmentative and alternative communication. *AAC: Augmentative and Alternative Communication*, 32(1), 69–79. <https://doi.org/10.3109/07434618.2015.1125947>

Geiger, B. F., O'Neal, M. R., Firsing, S. L., Smith, K. H., Chandan, P., Schmidt, A., & Jackson, J. B. (2010). HealthyME HealthyU: A collaborative project to enhance access to health information and services for individuals with disabilities. *Journal of Health Communication*, 15(SUPPL. 3), 46–59. <https://doi.org/10.1080/10810730.2010.525295>

# Synthesis of findings from interviews with caregivers of youth with Disabilities



**Dr Alecia Samuels**  
Senior Lecturer  
Centre for AAC

A speech-language therapist and audiologist with a special interest in the field of early childhood intervention. Her current research is focused on the participation and engagement of vulnerable children in the family, community and education environments. Having worked at the Centre for AAC for almost 15 years, she has gained extensive experience in the assessment and implementation of AAC.

## Abstract

Caregivers play a key role in ensuring that the rights of their children with disabilities are met. This includes the right to healthcare of a good quality, as well as the right to “full an effective participation” (United Nations, 2006, p.6) in all aspects of their lives. Furthermore, it is caregivers who are most likely to identify areas in which their child’s rights are not being met. Hence it was important to also consult with caregivers of youth with disabilities in order to obtain their perspectives on their children’s health education needs. (Einfeld et al., 2012; World Health Organisation, 2007).

Six caregivers have been consulted thus far. The caregivers highlighted, both personal and environmental challenges with regards to the healthcare of their children. In addition, the caregivers reported on mechanisms which they felt would assist their children in the comprehension of health education materials, and benefit them in the healthcare settings. The caregivers also provided feedback on the specific themes that they would like to see addressed.

Einfeld, S. L., Stancliffe, R. J., Gray, K. M., Sofronoff, K., Rice, L., Emerson, E., & Yasamy, M. T. (2012). Interventions Provided by Parents for Children with Intellectual Disabilities in Low and Middle Income Countries. *Journal of Applied Research in Intellectual Disabilities*, 25, 135–142. <https://doi.org/10.1111/j.1468-3148.2011.00678.x>

United Nations. (2006). *Convention on the Rights of Persons with Disabilities* (p. 37). p. 37. Geneva, Switzerland.

World Health Organisation. (2007). *International Classification of functioning, disability and health - Child and Youth Version (ICF-CY)*. Geneva: World Health Press.



# Presentation of draft materials



**Ms Maureen Casey**  
Educational Consultant

An educational consultant in the field of AAC who has extensive experience in training educators, therapists and caregivers in AAC, as well as extensive experience in implementing AAC in various educational settings.

## Abstract

Based on the feedback of the youth with disabilities, caregivers and professionals, health education materials were developed. In order to ensure the validity and social utility of these materials, six of the youth with disabilities from the first phase of the project were consulted for their feedback. Input was sought regarding the appropriateness of the language used, the iconicity of the symbols, and the preferred formats for health communication and education materials.

The youth provided feedback with regards to preferences, for example colour symbols rather than black and white, but also with regards to differences in comprehension of symbols, and the appropriacy of symbols for use. The provision of health educational materials in video format, available in different languages was also highlighted.

Hariman, R., & Lucaites, J. L. (2018). Icons, Appropriations, and the Co-production of Meaning. In *Rhetorical Audience Studies and Reception of Rhetoric* (pp. 285-308). Palgrave Macmillan, Cham.

Park, S. (2020). Beyond patient-centred care: a conceptual framework of co-production mechanisms with vulnerable groups in health and social service settings. *Public Management Review*, 22(3), 452-474. <https://doi.org/10.1080/14719037.2019.1601241>

Park, J., & Zuniga, J. (2016). Effectiveness of using picture-based health education for people with low health literacy: An integrative review. *Cogent Medicine*, 3(1264679), 1–14. <https://doi.org/10.1080/2331205X.2016.1264679>