

RCSLT Learning disabilities research priorities Current member research and quality improvement projects

Bronagh McAuley, Speech and Language Therapist

Project title: Service users' perspectives of their communication and literacy skills, in a community forensic and mental health learning disability service

Addressing research priorities:

#2 Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities.

#8 Selecting appropriate approaches to information gathering for individualised and holistic SLT assessment for people with learning disabilities.

Outline of project: A qualitative research project was conducted in an NHS Trust with service users who have a Learning Disability, Mental Health and Forensic needs. 11 individuals were interviewed about their perspectives of their communication and literacy, in relation to their perceived skills and challenges. Thematic analysis of the interview transcripts revealed 4 overarching themes:

1. Negative Feelings - firstly the participants experienced negative feelings when interacting with others, including reduced self-esteem and anger.
2. Perceived capability of communication and literacy skills - The participants noted that they had some strength in their ability to express themselves. They also were able to read small single words.
3. Challenges and difficulties with communication and literacy - A third theme discussed a range of challenges experienced with communication/literacy.
4. Adaptive strategies to overcome difficulties – Finally the participants discussed specific strategies which help to overcome their difficulties. The participants discussed having a support network available.

Implications for clinical practice: The findings of the research support the benefits of involving people with a learning disability in qualitative research, to explore their communication and literacy abilities. The findings highlight a need for staff to consider the opinions of service users in their assessments and interventions. It is necessary for staff to implement appropriate support strategies to overcome communication and literacy difficulties. It is vital for professionals to consider their own beliefs and attitudes when working with service users. This study has shown that these attitudes can impact upon interactions, in both a positive and negative way for service users.

Patient and Public Involvement: The research was discussed at a local service user forum. The forum meets within the NHS Trust where the service users were recruited from. Following the initial discussion with the members, the researcher discussed the easy read participant information sheets, consent forms and interview questions. Feedback was taken on board with the necessary amendments made.

Contact to find out more: BronaghE.mcauley@northerntrust.hscni.net

Emma Pagnamenta, Lecturer and Speech and Language Therapist

Project title: Evaluating an early social communication intervention for young children with Down syndrome (DS): a feasibility study

Addressing research priorities:

#4 Most appropriate ways of measuring long term personalised and holistic outcomes for a) people with learning disabilities and b) their parents/ carers

#5 Effectiveness of different service models of SLT input for people with learning disabilities to reach personalised and holistic outcomes.

#9 Level of SLT input (including timeliness, dosage, intensity and frequency) in achieving and maintaining long-term personalised holistic outcomes for people with learning disabilities

Outline of project: This NIHR-funded Research for Patient Benefit project aims to test the feasibility of a future randomised controlled trial of a parent-delivered joint attention intervention for young children with DS as delivered by NHS Speech and Language Therapy services. Parents of 25-30 children with DS (14-24 months) will be randomised to 10 weeks of parent-delivered shared attention intervention or treatment as usual across two NHS Trusts. Assessments of language, shared attention, parent-child interaction, well-being, quality of life and parental stress will be administered blind to group allocation before, immediately after and at 6 months post-intervention. The outcomes of this study will determine whether it will be viable to progress to a full RCT and whether adjustments need to be made to the procedures, data collection methods, delivery and intensity of the intervention.

Implications for clinical practice: This feasibility study is a first step in providing much-needed evidence for early intervention to improve language skills and school readiness for children with DS.

Patient and Public Involvement: PPI is central to every stage of this project, for example in developing the grant application, developing the therapy manual, and selection of the outcome measures.

Contact to find out more: e.pagnamenta@reading.ac.uk

Follow on twitter: @EmmaPagnamenta @StojanovikV @vjoffe @UniRdg_Psych

Anna Westaway and Sally Twigg, Senior Specialist Speech and Language Therapists

Project title: Promoting Makaton signing within Sheffield Children's Hospital Foundation Trust

Addressing research priorities:

#2 Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities

Outline of project: Through our clinical specialisms as well working within the Trust NHS Accessible Information Standard and NHS Learning Disability Improvement Standards working parties, we have been taking a lead in promoting use of Makaton signing as part of our work to encourage a Trust wide

approach to an inclusive communication environment. Examples of this have included:

- Working with Communications Team to include a link to the weekly Makaton sign of the week via www.wetalkmakaton.org
- Running a Makaton taster session during a staff 'Show and Tell' session, which was attended by nurses, physios, play workers, volunteers and members of the executive board
- Advising on use of Makaton signing during the production of accessible videos to provide procedure specific information
- Demonstrating how to sign 'Hello my name is...' to 400 members of staff at our annual staff 'Caring Together' Summit #hellomynameis
- Encouraging our executive team to introduce themselves at every staff induction training day for new starters by saying and signing in Makaton 'Hello my name is...'
- Aim for trust to achieve Makaton Friendly status as part of the Accessible Information Standard plan.

Implications for clinical practice: Demonstrating the need for SLTs to be involved with and commissioned to work through strategic planning to influence organisational policy, raise awareness, offer training and environmental input and guidance to improve accessibility and promote inclusive communication environments for children with learning disabilities. This will impact their experiences of healthcare encounters, enabling them to better understand what is happening and to communicate their needs and preferences using the methods that suit them best. This should lead to increased participation and decision making about their own lives and we also hope better health outcomes for children with learning disabilities.

Patient and Public Involvement: We will be organising a forum meeting with the local Parent Carer Forum to seek their views about the communication needs of children and families with learning disabilities. At previous events, we have invited speakers, eg. a young man with a learning disability and his mother to promote Makaton signing. This man has also been involved in making accessible videos that are shared on YouTube to explain medical procedures.

Follow on twitter: @anna_westaway @sallytwiggSLT

Anna Westaway and Sally Twigg, Senior Specialist Speech and Language Therapists

Project title: Membership of working party groups to implement the NHS Accessible Information Standard and the NHS Learning Disability Improvement Standards at Sheffield Children's NHS Foundation Trust.

Addressing research priorities:

#2 Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities

Outline of project: Working at a strategic level within Sheffield Children's NHS Foundation Trust within working party groups to implement the NHS Accessible Information Standard and the NHS Learning Disability Improvement Standards. This involves:

- Working alongside a wide range of clinical and non-clinical teams, including Communications, Patient Records, IT, Learning Disability Nurses, Consultants, Health Visitors and members of

the Trust Executive Board

- Contributing to development of Trust-wide plans for implementation
- Identifying training needs and advising how to meet these
- Contributing to raising staff awareness, eg through workshops, sharing Makaton signs via staff email, information stalls and trust-wide events
- Discussing the patient journey and identifying barriers to communication and to accessibility

Implications for clinical practice: Demonstrating the need for SLTs to be involved with and commissioned to work through strategic planning to influence organisational policy, raise awareness, offer training and environmental input and guidance to improve accessibility and promote inclusive communication environments for children with learning disabilities. This will impact their experiences of healthcare encounters, enabling them to better understand what is happening and to communicate their needs and preferences using the methods that suit them best. This should lead to increased participation and decision making about their own lives and we also hope better health outcomes for children with learning disabilities.

Patient and Public Involvement: We will be organising a forum meeting with the local Parent Carer Forum to seek their views about the communication needs of children and families with learning disabilities. At previous events, we have invited speakers, eg a young man with a learning disability and his mother to promote Makaton signing. This man has also been involved in making accessible videos that are shared on YouTube to explain medical procedures.

Follow on twitter: @anna_westaway @sallytwiggSLT

Michaela Steer, Senior Speech and Language Therapist and Sophie Howells, Speech and Language Therapist

Project title: Making choices about end of life care.

Addressing research priorities:

#10 The SLT role in end of life care for people with LD

Outline of project: We will be creating a resource pack to support people with LDs to understand the process of aging, dying, and making choices about their own end of life care. We will also be support individuals to understand and cope with the bereavement process involving loved ones and what this means.

Our resources will be suitable for people with a range of levels of understanding, and suitable for those who are also pre/non-verbal. We will be taking into account religion and cultural differences. Previously, research appears to focus on supporting people with 'mild' LD, whom are verbal. Initially we will be creating the resource pack and delivering staff training to determine staff confidence before and after, in regards to supporting individuals through bereavement and end of life choices. We are then hoping to obtain ethics approval to complete single case studies with PWS.

Implications for clinical practice: We are currently creating a bereavement and end of life choices pathway for the company we work for. We are hoping that by completing this research this will become best practice for all organisations supporting people with LDs.

Patient and Public Involvement: there is staff involvement PWS involvement.

Contact to find out more: Michaela.Steer@hesleygroup.co.uk and Sophie.Howells@hesleygroup.co.uk

Follow on twitter: @SLTMichaela @SophieGraceSLT

Kunden Patel, Principal Speech and Language Therapist

Project title: Dysphagia in people with learning disabilities

Addressing research priorities:

#3 Impact of a multidisciplinary approach to dysphagia management for people with learning disabilities

#7 Presentation of eating and drinking difficulties for people with learning disabilities across the lifespan and their associations with dysphagia (including aspiration, choking, safety, nutrition and hydration and enjoyment).

Outline of project: An annual dysphagia review aimed to indicate how many service user's dysphagia needs required a reassessment and may not have received one, if Speech and Language Therapy (SLT) had not initiated a triage. This annual review was completed as a pilot from Jan 16, in response to LeDeR. An annual telephone triage (ATT) was completed primarily by Therapy Assistants and SLT students with supervision from qualified and dysphagia competent SLT's. The ATT was completed with either with a key family member (if living at home) or with a manager of a care home.

Implications for clinical practice:

1. To update a dysphagia database of people with learning disabilities known to have dysphagia.
2. For therapy assistants and students to conduct an annual telephone dysphagia triage (ATT) to establish any change or areas of concern regarding dysphagia.
3. To provide direct assessment as determined by the telephone dysphagia triage.
4. To monitor hospital admissions related to dysphagia
5. To support the continuing healthcare review process by having recent reports.
6. To alert carers of existing guidelines in the light of frequent staff changes

Contact to find out more: kundenpatel@nhs.net

Alix Lewer, Director of Include.org and Specialist SLT

Project title: The Include Choir

Addressing research priorities:

#2 Inclusive communication environments and staff's skills in supporting speech, language and communication needs of people with learning disabilities

With links to **#3 #5** and **#9**

Outline of project: Following research into the long-term barriers of maintaining inclusive communication environments following indirect intervention (Bulletin 2009 / Lewer & Harding 2013a / Patel et al 2019), the Include Choir was established. It is an inclusive communication choir for people

with cognitive communication difficulties, support staff, family members and other local community members.

As well as inclusive social & musical activity for people with learning disabilities, The Include Choir provides:

- An environment modelling a range of inclusive communication techniques (e.g. Makaton signing/ visual supports / visual timetables / iPad apps / accessible information / Talking Mats / Objects of reference /sensory interaction)
- Opportunities for care staff to practice & gain confidence in inclusive communication
- Promotion of inclusive communication & its use within the Mental Capacity Act to audiences within and beyond health and social care (through writing & performing songs)
- Empowerment opportunities for people with learning disabilities.

Implications for clinical practice: Looking at ways which NHS therapists can link in with third sector organisations like Include.org to help continue to provide inclusive communication modelling & practice opportunities for people with learning disabilities / support staff / families, after a period of intervention. Or to signpost people while waiting for initial assessment / reassessment, and also opportunities for social prescribing services.

Patient and Public Involvement: Our Choir members (with and without learning disabilities) and family members are involved in current evaluation. When we reach the stage of designing a more formal research question and gathering research evidence, they will certainly be involved in all stages of the research project

Contact to find out more: alix.lewer@include.org

Follow on twitter: @includeorg

Laura Douglas, Speech and Language Therapist

Outline of project: Blossom House Pimlico is a new provision for pupils with severe language difficulties and moderate learning difficulties where a functional curriculum is delivered through real-life experiences. We are using the MAPP assessment of lateral progress tool <https://equals.co.uk/mapp2-mapping-and-assessing-personal-progress/> to assess the progress of pupils following this new curriculum. We are baselining pupils and recording pupil progress as a MDT (SLT, OT and teaching staff) and the targets are then carried out across the day by all the therapy and teaching staff. The targets cover all areas e.g. shopping, toileting, communicating within the community, use of public transport and cooking skills. The pupils have made steps of progress across the areas of independence, fluency, maintenance and generalisation of skills.

Addressing research priorities:

#5 Effectiveness of different service models of SLT input for people with learning disabilities to reach personalised and holistic outcomes.