International Specialised Skills Institute

VISUAL COMMUNICATION IN PAEDIATRIC HOSPITAL SETTINGS:

Improving participation and access for children with disability through the implementation of training and resources

An International Specialised Skills Institute Fellowship

KATHERINE LINGARD

Sponsored by The George Alexander Foundation

THE GEORGE ALEXANDER FOUNDATION

Table of contents

1. ACKNOWLEDGEMENTS

Awarding Body – International Specialised Skills Institute (ISS Institute)

The ISS Institute plays a pivotal role in creating value and opportunity, encouraging new thinking and early adoption of ideas and practice by investing in individuals.

The overarching aim of the ISS Institute is to support the development of a 'Better Skilled Australia'. The Institute does this via the provision of Fellowships that provide the opportunity for Australians to undertake international skills development and applied research that will have a positive impact on Australian industry and the broader community.

The International Specialised Skills Institute was founded 29 years ago, by a small group of innovators including Sir James Gobbo AC, CVO, QC, and former Governor of Victoria, who had a vision of building a community of industry specialists who would lead the up-skilling of the Australian workforce. The Fellowship program builds shared learning, leadership and innovation across the broad range of industry sectors worked with. Fellows are supported to disseminate learning's and ideas, facilitate change and advocate for best practice through the sharing of their Fellowship learnings with peers, colleagues, government, industry and community. Since its establishment, ISS Institute has supported over 450 Fellows to undertake skill and knowledge enhancement across a wide range of sectors which has led to positive change, the adoption of best practice approaches and new ways of working in Australia.

The Fellowship programs are led by our partners and designed in a manner which ensures that the needs and goals desired by the partners are achieved. ISS Institute works closely to develop a Fellowship program that meets key industry priorities, thus ensuring that the investment made will have lasting impact.

For further information on ISS Institute Fellows, refer to www.issinstitute.org.au

Governance and Management
Patron in Chief: Lady Primrose Potter AC
Patrons: Mr. Tony Schiavello AO and Mr. James MacKenzie
Founder/Board Member: Sir James Gobbo AC, CVO
Board Chair: Professor Amalia Di Iorio
Board Deputy Chair: Mark Kerr
Board Treasurer: Jack O'Connell AO
Board Secretary: Alisia Romanin
CEO: Wendy Draayers

Sponsor – The George Alexander Foundation

The Fellow sincerely thanks The George Alexander Foundation for providing funding support for the ISS Institute and for this Fellowship. In 1972, George Alexander AM (1910 - 2008) set up an independent philanthropic Foundation as a way of sharing his wealth and giving back to the community. Today, the main focus of The George Alexander Foundation is access to education for promising young people, particularly students with financial need and those from rural and remote areas.

The George Alexander Foundation (GAF) Scholarship and Fellowship Programs form the core of the foundation's work, operating in partnership with major tertiary institutions, while our Fellowships and other Education grants provide a variety of other unique and challenging educational experiences. George Alexander believed in the notion of 'planting seeds and hoping they grow into pretty big trees'. The programs supported by the Foundation endeavour to support this ideal and as GAF students graduate and go on to contribute to the community, George's legacy and spirit lives on through their achievements. George Alexander came to Australia as a child migrant, and went on to become a mechanic, an entrepreneur and a businessman and later, a generous philanthropist, who held that you do not own the possessions you have, 'you're just minding them'. This philosophy guided him to give during his lifetime and to hope that through his example, he might inspire others to do the same.

1. ACKNOWLEDGEMENTS

Personal:

The Fellow would like to acknowledge all those who supported and assisted her throughout the journey.

Specifically, the Fellow would like to thank Nick Johns and Wendy Draayers for their support and advice in planning the Fellowship as well as Ofelia Royo for her patient editing of the report.

Gratitude must be expressed to Colin Dobson, the most supportive principal, who provided understanding and generosity throughout the entire experience. Special thanks to Louise Marbina who inspired the Fellow to dream big, seize the opportunity, provided personal support and shared the joy and excitement of all the learnings.

To Catherine McAdams, thank you for joining the fun and helping to create a team to improve access for children with disability in our setting.

To those that lent the Fellow their spare rooms and lounge room floors, drove and fed the Fellow: Heather, Annie, Phil and Jo, Dan and Ali, thank you for your kind hospitality.

And finally, to the Fellow's family. To Glenda, Ian and Sarah who cheered me on, helped us move to a new house and believed we could do it- there aren't enough words to convey my appreciation. To Gill and Andy who let their house be my home. And to Adam: 'You believed in me and were my biggest cheerleader from the first interview to the submission of this report. I owe you one.'

Planning and preparation:

Thank you to the following professionals who advised and made recommendations based on their own research and experience in the field of AAC

» Dorothy Fraser
» Jane Remington
» Mary- Beth Happ
» Scope Australia
» Sarah Blackstone
» Meredith Allan
» Mercedes Wilkinson
» Michele Capurso
» Christopher Morris

Thank you to the ISS Institute and the generous donation by the George Alexander Fellowship who made the Fellowship possible.

Fellowship visitations:

Communication Matters Conference:

» Helen Paterson
» Chris Sherlock
» Tami Altschuler
» Catherine Harris
» Sara Dale and Euan Robertson (Ace Centre)
» Janice Murray: Manchester Metropolitan University:
» Lois Cameron Director, Talking Mats Ltd
» Manchester Children's Hospital
» Sarah Day: Assistant Head Teacher/SENC, Pip Kehoe and Janet Doherty (principal)

Boston:

Boston Children's Hospital:

» Rachel Santiago and Michelle Howard
» Integrated care team: Richard Antonelli and Casey Fee
» Kendal Temple

Toronto:

Holland Bloorview Kids Rehabilitation Hospital:

» Peter Rumney and Margaret Ettore

Bloorview School:
» Moira Kaminker, Linda Ward and Kathryn Marcus

Arrowsmith School:
» Tara Bonner

Sick Kids:
» Elizabeth N Kerr, Program Director The Epilepsy Classroom

» Stacie Carroll: Teacher - CTCC

Scotland:

» Call Scotland: Gillian McNeill, Joanna Courtney Alan

» KeycommAAC: Deborah Jans communication aid centre for Lothian Region

» Rachel's House, Kinross: Debbie and Linda

» Dundee AAC: Annalu Waller, Rolf Black and Kathleen Cummins

England

The Children's Trust:
» Dr Gemma Costello, Louise and Dr Lorna Wales

SHIPS:
» Sian Rees

Bristol Children's Hospital:
» Helen Cullimore

» Great Ormond St Hospital: Jayne Franklin and Jackie Goldsmith, Anthea and Kai.

2. EXECUTIVE SUMMARY

Background

There are more students now in hospitals with communication needs and disabilities than ever before (Gumm et al). Bartlett et al (2008) found that patients with impaired communication are three times more likely to experience a preventable adverse effec than those without. The number of students with significant communication needs in hospitals has increased due to increased skill in identifying children's need, the increased severity of illness and injuries survived and improved awareness of assistance available for such students. There is an increased need for Visual Communication tools in the hospital setting.

Patients who may be considered communication vulnerable include but are by no means limited to patients with depression or anxiety, those experiencing interference with sleep, trauma impacted patients, patients with an ABI, mechanically-ventilated patients, non-English speaking patients, non-verbal patients, patients with a language disorder, patients impacted by the ability to process information (confusion/ lack of comprehension/ misinterpretation/ increased fear).

Bronwyn Hemsley is one of numerous Australian speech therapists whose research has demonstrated that there is a significant gap in the literature around communication vulnerability and the numbers of patients entering hospital more frequently, for longer periods. Communication difficulties are known to impact on patient satisfaction, recovery and safety in hospital. Studies showed that neither community nor hospital allied health teams take an active role in enabling the child's access to communication or removing barriers to communication in the hospital environment. "We need to increase the communicative competence and confidence of hospital staff [and] increase their awareness of the broad range of communication needs among patients… There is an urgent need to conduct both intervention and observational research to explore what strategies work best and how they can best be implemented" (Hemsley and Balandin, 2014).

As a hospital teacher and Education Consultant with a master's in Special Education working at Monash Children's Hospital, the Fellow collaborated with nurses, doctors, teachers, allied health staff and volunteers and identified that staff are extremely aware of the needs of patients and want to better serve their patients but are lacking knowledge and tools to do so. The team at Monash Children's Hospital provide excellent care to all its patients including some initiatives around enhancing communication but collectively are hoping to learn how to better care for patients and include them in their health management.

Thus, the Fellowship aims, and objectives were to advance knowledge on how to use 'visual's in a meaningful and authentic way, expand the use of communication devices, assist children to access devices, and help train staff to communicate better with patients.

Fellowship learnings

For high quality holistic care, provision of human rights, improved diagnostic improvement, independence, autonomy and increased patient participation, communication is an essential priority that needs to be recognised sooner during an admission and appropriately managed.

Just one day in hospital, is too long without having a means to communicate and referrals should be made upon, if not before admission for supported communication care.

It is difficult but not impossible to introduce a new device or system of communication for a short term, or unknown length of stay to uphold basic human rights we MUST provide access to communication and the ability to understand within hours of admission

Personal, professional and sectoral impact

Exploring the world, and seeing new places always allows one to return home with fresh eyes and gratitude and put into practice new experiences. Having an opportunity to share the dream of communication access for all around the world with people passionately implementing the vision was a once in a lifetime opportunity. Being able to look closely at the Fellowship objectives but also immerse herself in hospital education around the globe and see how music, art, creativity, learning and medicine come together for holistic recovery and best life outcomes for a child and their family were spectacular.

Having seen the way children are being actively involved in their learning worldwide, Katherine find herself continually seeking to fin ways to incorporate them as active participants in their own learning and provide agency for them. Since the Fellowship, Katherine has been working to improve resources to make learning accessible to create rich and engaging teaching experiences.

While the Fellow was focusing specifically on communication, her understanding of how to support students at their most vulnerable time in hospital and then return them to school was also expanded. The Fellow certainly learnt beyond what she had hoped.

The Fellowship provided the Fellow with an opportunity to expand her networks, professionally and personally and enabled conversations which can continue with special educators in the hospital system for time to come. The sharing of resources and innovative ideas will improve hospital education for those with additional needs who often require the loudest advocacy and are often the most invisible to a busy system. Children with chronic illness are already often neglected in education, but those who require additional supports are often left from conversation. The Fellow was heartened to see groups of people working to include marginalised children better in society and help them participate in life in a happy and healthy, independent way during her Fellowship.

Monash Children's Hospital has already invested in incorporating Fellowship/Scholarship findings into their professional learning timetable for staff. A newly formed working party is meeting and planning how to further the findings into practical implications for a range of staff. The Fellow has been invited to present her findings from the Fellowship at a Grand Round, weekly seminars held for the hospital staff around education and training in healthcare. This is a thrilling opportunity of which the Fellow has been honoured to accept.

The Fellow intends to work collaboratively with medical and nursing teams to gather data and present findings on 'practice' improvements over time at a national level and will hopefully deliver multidisciplinary presentations to various organisations such as the H.E.L.P Alliance which will allow Katherine to disseminate learnings to teachers nationally as well as in New Zealand.

Considerations / recommendations

The Fellow observed best practice processes to implement positive change across hospitals. The Fellow noted best ways to increase awareness about the capacity of people who are communication vulnerable as well as increase engagement in treatment, practices in training staff and providing equipment. Best Practice looks like:

» creating a working party who represents different groups within the hospital and should be used to train, coach, and maintain use of visuals across the hospital

» designing of a toolkit that is generic and can support communication quickly should be accessible and usable on all wards

» provision of training; which should be focused less around skill development and more around awareness building and raising staff expectation about how people with communication vulnerabilities can interact. The Fellow has met with a Visual Communication Working party within Monash Health who are working on next steps of implementation following a presentation around the learnings from the Fellowship.

3. FELLOWSHIP BACKGROUND

Fellowship context

"Good communication is critical to good healthcare" (McDonald, 2016, pg. 6). Therefore, one must assume, in order to achieve outstanding healthcare, one must have access to outstanding communication.

Sadly, this is not the case for many people with communication difficulties, difficulty expressing themselves or understanding others, within hospital setting in Australia.

Internationally, Augmented and Assisted Communication (AAC) is an accepted model of best practice in assisting individuals with compromised communication. AAC is an integrated system of components including: continuum of communication supports, tools, techniques and strategies to assist communication. Unaided systems of communication enhancement include signing and gestures. Low tech aided communication enhancement tools include picture boards, whiteboards and high tech includes iPad or speech generating devices.

However, within Australia, the use of communication aids is not well implemented in paediatric hospitals. Furthermore, multidisciplinary approaches to assist children in hospitals connect with education is adhered to in theory but unfortunately not in practice, unlike in other areas of the world. Delivery of education services, particularly around literacy in hospitals is described as fragmented.

Hemsley and Balandin (2014 p.337), two Australian Speech therapists asserted that "we need to increase the communicative competence and confidence of hospital staff-inc ease their awareness of the broad range of communication needs among patients". They advocated for interventions and evaluations to assess this and suggest 'there is an urgent need to conduct both intervention and observational research to explore what strategies work best and how they can best be implemented' (p.338). And yet they warn that strategies that clinicians recommend but which have not been evaluated or validated risk expenditure on resources that may or may not provide a material benefit to patient care, safety, or satisfaction. Thus, the need for further research and evaluation of implementation in Australia is essential for improved patient outcomes and care.

Research by the Royal Children's Hospital shows that best practice in educating children within hospitals is understood in theory but not in implementation. They describe its implementation, and the collaboration between medical staff and education teams as fragmented at best, uncoordinated and disorganised despite existing for 50 years (Shiu). When it comes to communication, this can be detrimental to the recovery and return to normal life of students with increased communication needs. While there is an abundance of research around the use or and need for visual communication training and improvement in Australia as well as passionate speech therapists advocating for the use of AAC, there are gaps in terms of training, implementation and a lack of consistent use of visuals to enhance communication for inpatients in children's hospitals. Furthermore, there are many missed opportunities with the implementation of visuals being limited, isolated and not being as accessible in Australia compared to other areas of the world.

Valentine and Payne assert that a positive outcome is more likely for patients when a partnership exists amongst education, health, student and family. Yet the practical implications of interdisciplinary modes of care are under researched

within Australia. Many of the children in hospitals experience "communication vulnerability" be that through airways, neurological conditions, impaired muscle function, strength and coordination issues, linguistic impairment, cognitive side effects from medication, anxiety, vision and hearing impairments, inability to produce speech, altered mental status etc. They often report being alone and fearful of the unknown.

Anything that provides comfort, not to eliminate procedures that must be administered but to help predict and prepare the patient are guaranteed to help their hospital experience (Wilson et al. 2010). With 30% of Australia children experiencing a medical / chronic health conditions it is important that all educators understand how to best cater for their specific needs. An article published in the Journal of Paediatric Rehabilitation Medicine found that, "Patients with communication problems are at an increased risk of experiencing preventable adverse events, and patients with limited English proficiency (in the U.S.) are more likely to experience adverse events than English speaking patients." The conclusion of their research was that children with limited communication abilities, including those with severe and multiple disabilities, benefit from using AAC approaches and, therefore, so does society. Research is conclusive and substantive that patients with complex communication needs have more frequent hospitalisations, longer admission periods, more health emergencies, inadequate pain medication, reliance on regular caregivers being present, be considered medically fragile, non-compliance, non-cooperation with routine and expectations, frustration and anxiety around not being heard or understood, restricted social interactions and refusal of treatment.

Recommendations from The Royal Children's Hospital suggest Australia needs research to inform the whole-hospital approach to children's learning. Other studies have indicated that all children in hospital want to be able to communicate yes / no, indicate 1-10 on a pain scale, communicate with nurses when parents aren't present, convey health related information and be actively included in social interactions on the wards. AAC enables patients to do this with ease where they previously have not been able to. The results of AAC being used hospital-wide by multiple stakeholders are shown to decrease frustration, confusion and anxiety, reduce fear, increase carer ability to provide appropriate comfort, create expectancy and preparedness for procedures, reduce behavioural problems, facilitate recovery and engaging in rehab, increased likelihood of a successful transition home, and improved sense of control.

Good communication in all patients leads to increased self-determination, patient and family satisfaction with care and improves patient safety. The need for further understanding in how to provide good communication for all families is imperative. Studies conclude that the better equipped children (who grow into adults with similar issues) are to communicate effectively and participate in discussions around their health, the more likely they are to remain healthy and get the care they need, when they need it.

Currently, Monash Children's Hospital School endeavours to provide tools for students to communicate whilst in hospital, but there is still a great need for, and an acknowledged amongst staff of a need for improvement. The leadership team within the School Council of Monash Children's Hospital School support a newly formed working party aimed at enhancing care for students with additional needs around communication. There was no doubt in the necessity of the Fellowship and its potential benefits for a large percentage of Australian children, their families, hospitals and teachers. Research that supports the care and provision of communication for these students is essential, and by experiencing positive implementations of AAC devices around the world, students within Australia would benefit

The potential for increased knowledge and implementation surrounding the use of AAC to benefit patients, families, health and medical teams and education support teams during inpatient admission and into the future is multifaceted and undeniable. For example, research out of the Central Coast Communication Foundation in Monterey is amongst many studies which highlight the importance

of having AAC practitioners who can share their knowledge across health care settings by educating more of their colleagues about the value of AAC approaches.

Increased training for the students/patients and building the number of communication partners would be a huge benefit to everyone. Statistics cite that normally developing 18-month-old children have been exposed to 4,380 hours of language orally at 8 hours a day since birth. Those who need AAC and receive speech/ language therapy for 2 times a week (for 20-30 minutes) will reach the same amount of language exposure in 84 years (Korsten) The Fellow truly believes as a professional that it is our responsibility to provide opportunities for using AAC so that this age is reduced, and children are able to access communication earlier.

Ultimately, the incorporation of AAC provides patients with a voice and the human right of communication. Furthermore, increased communication benefits many more people than the patient. For example, incorporating increased AAC to assist patient communication as well as training all stakeholders collaborating in their care could lead to equipping and empowering of medical/health staff who at times can feel guilt, lack of awareness and naivety about how to best cater for students with communication difficulties Often, people working with children with complex needs have shown (in research) to have low expectations of the child's ability to communicate. For example; nurses working with patients with high needs are frustrated, and guilty at not having adequate time to communicate with children who have high support needs (Hemsley, et al 2012). Parent outcomes would be increased as they trust in the medical and education systems and feel confident to leave their child with a communication partner who can advocate for and understand their child. Patient outcomes are highly increased, research demonstrates they experience, with good communication, enhanced patient care, quicker transition, a sense of control, increased compliance with treatment and rehabilitation, and recovery speed. It also reduces children's confusion and anxiety. In addition, effective communication with family, care staff, peers, teachers and friends are essential to recovery and a more seamless return to their 'normal' life.

The skill enhancement areas, knowledge and innovation of interest for this Fellowship were:

» to advance knowledge on how to use visuals in a meaningful and authentic way

» to continue to expand the use of visual communication devices throughout hospital settings to improve patient / student outcomes during their inpatient stay

» to assist children to develop life-long agency and advocacy over their learning and health through an increased understanding and ability to communicate with key stakeholders who are involved in their care

The initial focus is basic skill enhancement so that all levels of staff (multidisciplinary teachers, nurses, allied health, doctors etc.) have confidence in using visual communication systems. The trialing of some simple communication boards (meal choice, activity choice etc.) before looking at more comprehensive system implementation.

Outcomes desired include:

» to observe the practical use of visuals, as well as understand how hospitals train staff members inclusive of: doctors, nurses, allied health professionals, cleaners, cafe workers, entertainers, teachers etc. This would benefit local hospitals as they expand the use of visual communication to increase the hospital patient experience for children and families

» to witness innovative practice in how visuals are being made, used, taught, and rolled out around hospitals and ascertain how to best train staff

» to recommend through a variety of avenues to disseminate the learnings upon return. The benefits of this international research would be to focus on best practice with visual communication and see how multidisciplinary teams work together to improve patient outcomes which would then in turn benefit hospital schools

» to observe diffe ent hospital schools and their use of AAC to enable patients to participate in inpatient activities, communicate their needs and wants and be cared for. The Fellow would also gain a greater understanding of the impact of treatment which would allow her to lead the implementation of innovative and research-based practices within Australia. This does not currently operate to its full potential of allowing each child in hospital to adequately have a voice in their treatment, recovery and re-integration.

Fellowship methodology

» Literature review: the Fellow read over 60 articles to ascertain current practices within communication service providers, schools, hospital settings and pediatric wards. This reading enabled her to determine models of best practice, stakeholders, researchers and organisations invested in improving communicative practices for children in schools and hospital settings and combined settings

» Skype interviews with world leaders in communications best practice models: following the literature review, the Fellow contacted Australian and international speech therapists, school principals and researchers in the field and connected with an AAC Google group to build networks and seek referrals and introductions to centres.(Tami Altschuler, Mary-Beth Happ, Sarah Blackstone).

» Visits to hospital school settings:

Great Ormond St, Manchester Children's Hospital, The Hospital for Sick Kids, Bloorview School, Edinburgh Children's Hospital, Boston Children's Hospital

» Visits to organisations who provide support in communication provision:

Dundee AAC, Call Scotland, Key Comm, Ace Centre

» Attendance at two conferences:

Communication Matters, NAHE Conference

» Observership day at Boston Children's Hospital:
Appointments at centres involved tours, interviews, observing and shadowing onwards, attending a training day for teachers, observing an assessment for a child with speech needs, attending a university lecture for teachers as well as being shown numerous resources. Each visit had a distinctly different flavour and often resulted in provision and sharing of resources created by the organisation or a link to websites with free materials, connections within the organisation that led to extra interviews, or an opportunity for ongoing conversation as implementation commences at home.

» Reflective Journal: a summary of the Fellow's musings and observations were made available on a professional Facebook page, Katherine Lingard.

Fellowship period

This Fellowship was conducted in September/ October of 2019. Once connections were made, skype, zoom and facetime communication commenced to map out the priorities for visits. It was clear two conferences were relevant to the undertaking including the Communication Matters Conference in Leeds for speech therapists, AAC users, teachers, parents, hospital staff and interested community members. The NAHE conference was also scheduled for 6 weeks after that trip which was the National Association of Hospital Educators in the United Kingdom Conference day.

Boston Children's Hospital became the top priority to visit due to its world-renowned reputation. They approved a visit and gave a date so thus defined the itinerary. Report writing, synthesis of findings and dissemination then occurred in the following six-month period post trip.

Fellow biography

Katherine Lingard is currently employed as a teacher within the Victorian Department of Education and Training at the Monash Children's Hospital School which commenced in 2018. She is an Education Consultant for the Victorian Paediatric Rehabilitation Service and teaches in classrooms and on the wards within the hospital. She is a member of the Monash Children's Hospital School Council.

Prior to this teaching position, she spent 5 years teaching in specialist school settings; chiefly in a school for students diagnosed with intellectual disability. The Fellow obtained her master's in Special Education and graduated with distinction focusing on positive behaviour supports, wellbeing and learning interventions. She worked for one year in the Cape York Academy in Far North Queensland teaching indigenous students using the 'Direct Instruction' method. This involved rigorous assessment, weekly collection of data from student testing and implementing feedback from a team in the United States of America who analysed the results.

She was elected to run a sub-committee of the Health Educators Learners and Parents (HELP) Alliance. The role includes facilitating and increasing connectivity and resource sharing between teachers in hospital schools around Australia and New Zealand. She has an Arts/ Education degree majoring in Psychology and a master's in Special Education. Katherine Lingard is a member of Communication Matters Australian chapter, the AASE, HELP alliance and ISAAC.

She is working with a team at MCH to plan and implement learnings from the Fellowship as part of a Communication Accessibility working party which comprises a multidisciplinary team of speech therapist, paediatricians, allied health representative and school principal.

Abbreviations / Acronyms / Definitions

AAC:	Augmentative and Alternative Communication
AASE:	Australian Association of Special Educators
ABI:	Acquired Brain Injury
GOSH:	Great Ormond Street Hospital
HELP:	Health, Educators, Learners and Parents
ISAAC:	International Society for Augmentative and Alternative Communication
MCHS:	Monash Children's Hospital School
MCH:	Monash Children's Hospital
NAHE:	National Association of Hospital Educators
SHIPS:	Supporting Head Injured Pupils in School

AAC: augmentative and alternative communication (AAC) tools can enable communication vulnerable people to express themselves and understand others, supporting self-advocacy. Such tools can also support professionals in understanding clients and enabling a partnership. This paper uses the broad definition of AAC by Clarke and Bloch, which incorporates diffe ent forms of AAC: formal communication aid systems (e.g. voice output communication aids), conventional semiotic systems (e.g. handwriting), as well as unaided resources (e.g. gesture) and commonplace objects (e.g. maps or letters).

Access method: the various ways that a person using a communication device might control it. Access methods are dependent on physical abilities and needs and might include using eyes, hands, a switch, or their feet to access a device.

AGOSCI: an inclusive group interested in enhancing the participation of all people with complex communication needs. AGOSCI also aims to build the capacity of society to achieve their vision.

Allied Health: an umbrella term to represent the various trained health professionals, excluding doctors and nurses.

Boardmaker: an online program used to create print and interactive materials for special education needs. Their symbols are recognisable and used often in visual communication products.

Communication/ Patient Passports: profiles created around the additional needs of a patient which are often displayed in a hospital bedroom to guide carers around the specific needs of a child or person with a communication difficul . These are often coded red, yellow and green for the essential, helpful and desirable information to be read.

Communication vulnerable person: individuals who struggle to communicate; either experiencing difficultie in expressing their needs and/or in understanding information in an environment for several reasons including; medication, physical disorder, mental illness, cognition, environment, health literacy, English as an additional language.

Core word board: a visual symbolic or written representation of the most common words used in typical conversation. Ranges from 50-100 words and diffe ent amounts can be displayed on diffe ent boards.

Eye gaze: a way of accessing the computer or communication device using a mouse that can be controlled with eyes.

Partner assisted scanning: a method for communication “partners” to “assist” students by listing or “scanning” through possible choices.

PODD book: Pragmatic Organisation Dynamic Display (PODD) is normally a book or device that contains symbols and words to support communication between people with complex communication needs and their communication partners.

Scope: a registered NDIS provider specialising in provision of support in terms of therapy, resources and training around disability.

Talking mats: a communication symbols tool based on extensive research and designed by speech and language therapists. It uses unique, specially designed picture communication symbols that are attractive to all ages and communication abilities and is used by clinical practitioners, carers and support workers in a wide range of health, social work, residential and education settings.

4. FELLOWSHIP LEARNINGS

Summary of visits:

Day after day the Fellow was witness to amazing places and met inspiring individuals participating and developing innovative and inclusive practices and resources to ensure that those with disability are valued, respected and can participate fully in their communities. The Fellow was able to learn from every place and will apply them to her teaching and work across the hospital.

The fellow observed many organisations and settings delivering high quality care to patients and students in many ways. For the purpose of this report, the Fellow will highlight only those visits specifically relating to visual communication.

Firstly, the Fellow spent 3 days at the Communication Matters Conference in Leeds, UK and attended sessions specifically around the training of staff within organisations to be equipped and competent in using communication devices with customers and patients and clients.

1. Helen Paterson

Helen shared her brilliant work at the Royal Hospital for Neurodisability where she is undertaking a research project aiming to develop a care staff training program in AAC based on the views of AAC users and nursing staff in a long-term care setting. She used talking mats (visuals used on a board for discussion) with patients and nurses to collect information on the effectiveness of communication training for staff. Their training package involves practice, videoing, wall signs and therapist demos. Everything is research based and regularly evaluated to monitor effort and effectiveness of interventions and to develop a quality and meaningful program. Helen highlighted some of the well-intentioned innovations that are not used properly due to misunderstanding of their purpose, or lack of knowledge around them. For example, one response from staff when asked about communication passports, was that "'they help because when you bring the wheelchair out for cleaning you know who's it is". Provision of resources without knowledge and training to accompany and build understanding is useless. This message resonated with individuals worldwide and is a common problem experienced by practitioners and patients.

Helen shared the benefits for improving communication in hospital through nurse training such as patients are endangered by not having a method to communicate and use of AAC systems saves time and eases frustration. She used 'Talking Mats' to directly compare survey results from patients and nurses on evaluations of current communication training and ideas for future direction.

Talking Mats survey result: In an ideal world, what would communication aid training look like

When asked what they wanted, patients reported wanting a faster device to communicate and for staff to know how to use their device. Patients often also report feeling there is no use in these initiatives such as training of staff as they don't see if making a diffe ence. She is determined to keep trying! She had a valuable description of what they currently do provided in visual communication format to assist thinking about best practice models of training.

Taining at Royal Hospital for Neurodisability

2. Communication Access UK

The Fellow attended a presentation around the UK Communication Access symbol, Australia's recently created symbol being introduced by Scope Australia. Prior to the trip, the Fellow had met with Scope to ascertain whether their implementation package might be suitable for the hospital and has maintained a relationship with them for future discussions. One of the driving motives behind introducing a symbol for communication accessibility is that the wheelchair representing physical access is one of the top 10 most recognised symbols in the world. Yet, the communication access symbol is not commonly displayed, nor recognised or understood.Communication access means more than talking, but being able to be heard, understood and the understand messages.

Communication Access Symbol: UK

Communication access UK offers 1-hour training including one presenter with a severe communication difficulty. The Fellow heard AAC (augmentative and alternative communication) users speak of their experiences in shops, hairdressers and restaurants. One of the most frequently reported difficulties as reported by consumers is when people in the community such as shop owners, direct their questions to the carer or assistant. People with communication vulnerability want questions directed to them, rather than asking questions about them while they are there. Another common frustration is when people don't wait for a response if it takes a while and the communication partner feels they are either too slow or have nothing to say.

The communication access symbol is now used in pubs, funeral homes and shops around the UK during its soft launch. The problem across the world in countries starting to use this symbol is lack of awareness thus companies like Scope and Communication Access UK are hoping to increase the visibility and meaning around the symbol to assist participation in life for those with communication disability.

3. Tami Altschuler

In the lead up to travel the fellow connected with an amazing woman called Tami Altschuler from NYU Langone Health. Tami is a speech therapist who works with patients to cater for their communication needs and provide training to staff to be communication partners. The fellow shared Skype calls where Tami shared her experience in an ICU/ acute setting. Her passion to allow for greater and improved involvement, autonomy and participation in their decision making, socialising, wellbeing and recovery and her relentless advocacy and persistence in demanding better communication services for vulnerable patients is remarkable.

She outlined the risks of poor communication which helped frame the important need for change.

» Serious medical events

» Sentinel events (The joint commission, 2007)

» Increased diagnosis of psychopathology

» poor medication compliance

» leaving against medical advice

» fear, stress, sleep disturbance

» loss of ability to participate in own care

Tami shared heartening stories about the way she has enabled end of life decisions for patients including choosing specific ice cream flavours for what may be their last meal when before meeting her they were not able to participate in major life changing treatment options.

Her example in her brilliant talk was that two men, both facing end of life or permanent tracheotomy were given options using two fingers with only two choices. Through discussion they showed both men their options, one was to remove oxygen and let nature decide or tracheostomy and move permanently to care. After the men did not select a finger to show a choice, they called in next of kin who didn't want to make the choice for them, sensing they had capacity themselves. Tami was brought in after the patients did not respond to two finger options. She used numerous options to assist understanding and communication and used boards to offer another suggestion. One man used an alphabet board to spell 'What is a tracheotomy?' This highlighted that two choices aren't often enough, and we must always use a 3rd- either a question, don't know, or something different as in this case he did not understand the options despite explanations provided.

Man 1 chose to remove life giving procedures and Tami asked him what he wanted to eat for his last meal. He chose ice cream. She advocated that he should get to choose because ice creams is a personal thing, and thus he chose pistachio.

Man two was able to continue his life as an artist and Tami attended his art show recently. This showed the power of enabling choice making and providing more than just a yes or no.

While changing systems and causing positive disruption to the status quo, introducing new tools and shifting perspectives on capacity is never easy, Tami has inserted herself into the lives of patients and those in her care and because of that, is enabling people to have a voice. Her message started with the fact that, a communication breakdown is not one person's fault. All communication needs to involve two parties. We all need to learn how to listen, understand and speak so that both people are involved. A huge lesson for us all.

Eye Gaze lessons with Rachel Santiago

UNITED STATES OF AMERICA:

Boston Children's Hospital

When the Fellow started researching the use of visual communication tools to help give children in hospital a voice, all research and advice began with John Costello and his work at Boston Children's. The AAC program there became the goal for the Fellow's trip. After much documentation and contact, her application was approved to observe their work. Their research and presentations inspired the Fellow to think differently about her own work and getting to see that what they do is, in fact, what they speak about which was genuinely heartening.

The day with Rachel Santiago and Michelle Howard at Boston was a much-anticipated day of the trip and lived up to the Fellow's expectations despite nearly all the patients being asleep. The Fellow saw their All About Me stick on wall decals that are used to highlight basic important information about students in each hospital room, as well as their storage and hiring system used for their own AAC toolkits with instructions printed on the backs of each page.

This team is deeply valued and supported by the hospital and aid, support and contribute to patient outcomes, wellbeing and self-advocacy through ensuring that all patients have access to a call bell and a way to communication not only needs and requests, but social needs and conversations. The team has been around for many years, starting with the work of John Costello and has grown throughout the hospital.

When the Fellow was there, one of the chaplains approached the team with a referral. She had just met a family and realised their need for communication support and had asked the team to get involved. It was such great recognition, support and team work for families within this space.

Rachel and Michelle provided practical guidance such as, how to refer patients, pre admission preparation, creation of resources, access, storage, cleaning of resource, instructions, 'all about me'sheets, training programs, and worked through some practical challenges of developing systems within paediatric hospitals.

It was a unique privilege to see a world leading, innovative, caring, compassionate and inclusive team in action.

Boston Children's Hospital integrated care team

The Fellow attended a thoughtful and specialised, 'Bootcamp' around integrated care team planning at Boston Children's Hospital. The Integrated Care Program at Boston Children's Hospital creates and validates processes, tools and measures that improve the integration of patient care across the healthcare continuum. Their goal is to improve care integration within and across settings and disciplines-- especially for patients with complex and chronic conditions.

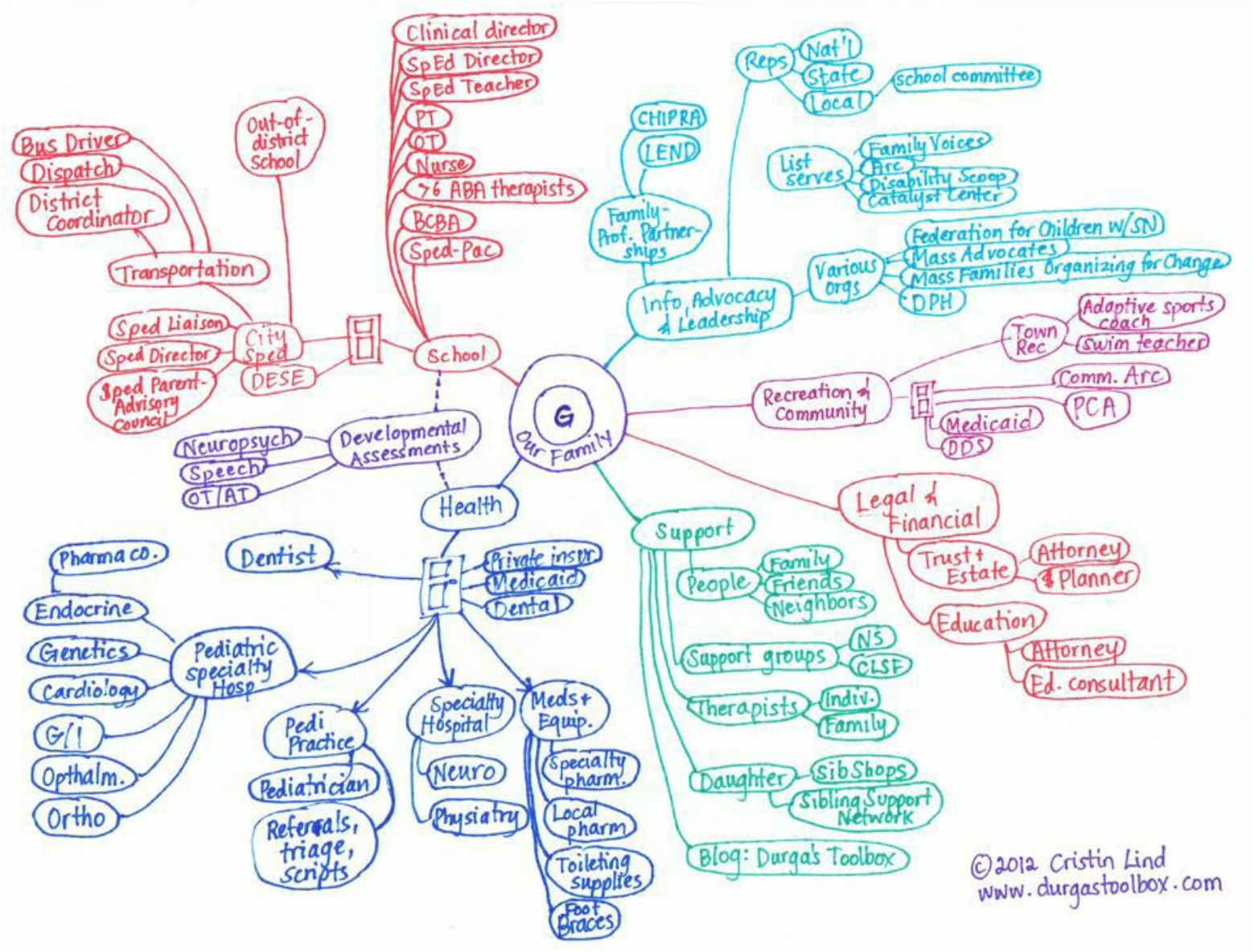
They measure success by impact on outcomes of quality and safety, patient and provider experience, and cost of care.

The Fellow had coordinated this visit with Cathy, so they could learn together about the tools that Casey Fee and her team are creating to help relieve the burden on families of coordinating care for their children. It was interesting to learn from them and reflect on how the tools could be used to measure implementation success of new programs.

Underpinning their work is the idea that parents should not have to be 'case managers' for their children but should get to be 'mum' and 'dad', particularly during a vulnerable time.

They are working to create universal tools around handovers, referrals, tracking meetings, action grids, so that families present their story once, and then the care team work on managing care appropriate so families can care for their families and not worry another finances, advocating for what is best, medical information.

The team shared the complexity and role that parents take in organising care as shown in the care map attached created by one of their mothers outlining all the things she must coordinate. As you can see, caring for an unwell child is a full-time job.



Mind map of the areas of a family's life needing to be considered during a hospital stay/ chronic illness treatment program

CANADA:

Bloorview School, Toronto

The Fellow spent a marvellous morning at Bloorview School organised by principal Linda Ward and Kathryn Marcus. The butterfly is their emblem to represent the recovery, rehabilitation and transformation of children during their time. Their vision is to be an intersection of therapy and education and from observation and tours, seem to be achieving that dream in everyday practice. Their educators see the importance of health and education in one place, and provide space, time and room for therapy in that space. The medical team invite educators into meetings to add to the story and understanding of the child. The medical teams see education and wellbeing as valuable to recovery.

They have two strands of the school with different admission requirements so that students can arrive from home on the bus or attend from hospital, and not miss school due to high need for therapy. Being attached to the hospital students can come and go between school and therapy freely.

The school has a therapeutic model of education whereby therapists maximise their ability to see the student in real settings. They work with teachers in their classrooms as well as in therapy rooms.

(Bloorview school logo: The butterfly to symbolise the transformation of children during their rehabilitation program)

Holland Bloorview Rehabilitation Hospital, Toronto

The Fellow was incredibly inspired by the amazing hospital that is Holland Bloorview Rehabilitation Hospital.

They have a state of the art pool, amazing gym, sensational floor sensing visual TV so that students in wheelchairs can move around the mat and activate movement on the screen, fascinating research projects, integrated collaboration, a school for students to participate in rehabilitation therapy and school in a combined fashion, a Snoezelen sensory room, a highly interactive and accessible outdoor hospital space with wheelchair accessible painting, fi e pit and gardening activities on site. They have a kitchen where they teach children life skills, a dental service, and a rehab play therapy room where clinicians can observe their patients in a relaxed and natural environment to help their goals and

therapeutic work specific to their needs and give children opportunities to practice new skills and their progress in real life settings.

(Spiral Garden: accessible outdoor garden for children to play and explore nature through craft and activities)

This hospital together with the school was one of the best examples and is truly a leader in seamless integration of a multidisciplinary team, where health, education and all teams work together for the child's holistic wellbeing considering varied needs, timetables, therapies, recovery. It was sensational.

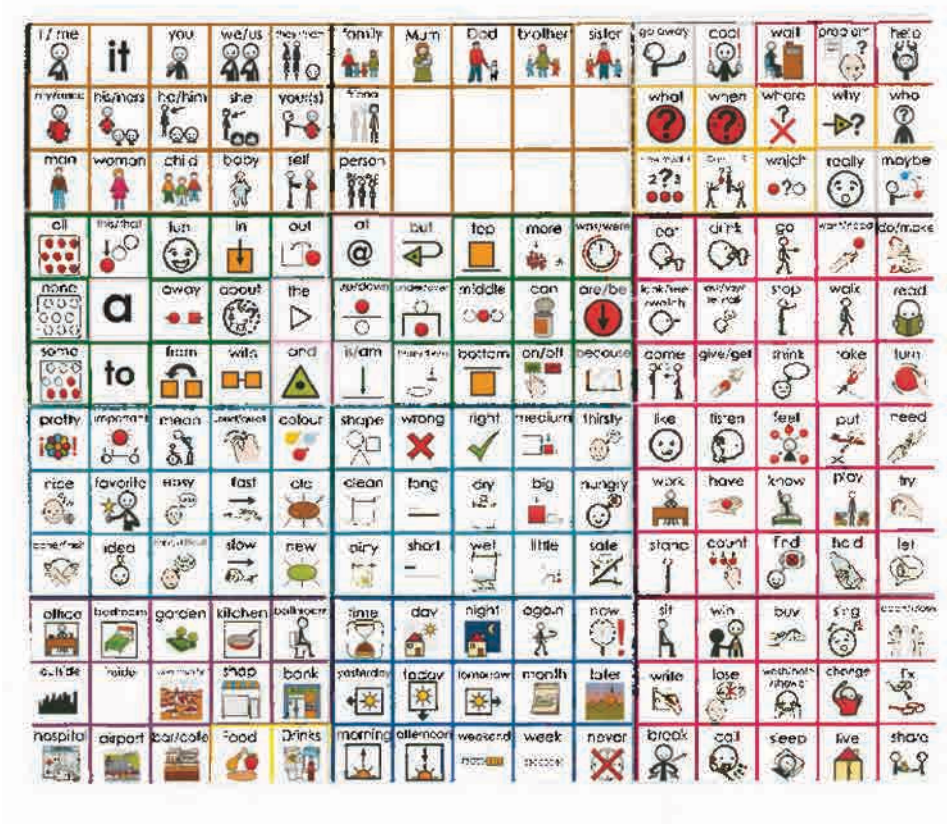
United Kingdom:

ACE Centre, Oldham, UK

The Fellow spent two days with the Ace Centre, a non-for-profit organisation funded by the government which does speech assessments. They are a group of teachers, occupational therapists and speech therapists who work out access, what the best system would be to last when conditions deteriorate, and, finall , provide switches, programs, devices, apps, and training for individuals with speech difficultie

The Fellow was lucky enough to attend a session where they were helping a young girl in a school with a degenerative condition and slowly losing speech and physical capacity to be fitted with a communication device. You could see the joy and spark in the young girl's face as she communicated through an iPad and app device and her family's delight as experiencing something they had been waiting for was happening there for them. Special thanks to Euan and Sam for allowing the Fellow to be present during such special moment.

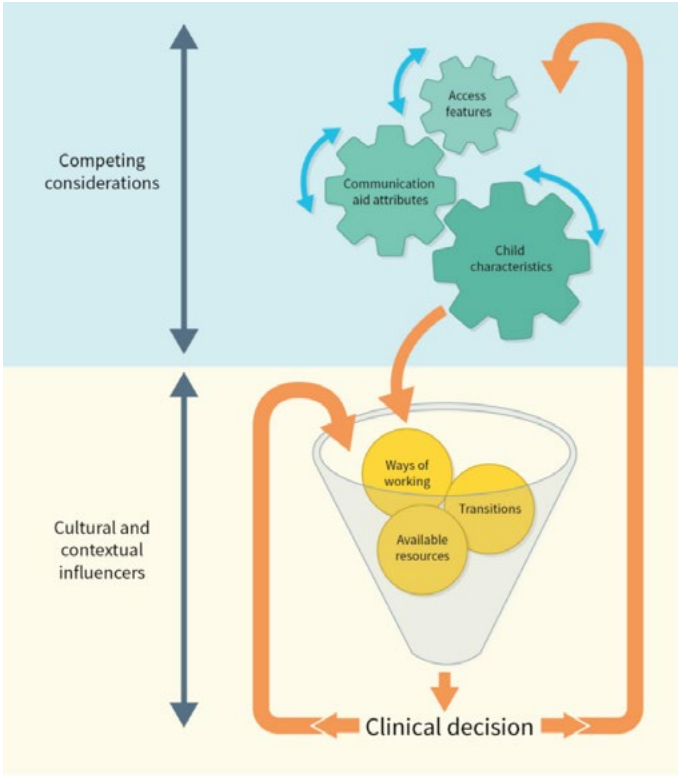
The Fellow also enjoyed time with Sara Dale, who has a background in teaching and is passionate about AAC requiring an inter/trans disciplinary approach. She demonstrated many resources and their alpha packs- which are generalised packs that they take on assessments which have a graded continuum of equipment to try and find the best fit. She explained to the Fellow the complexity of choosing a device, access, literacy levels, maturity, cognitive capacity, physical and sensory needs.



A pocket resource guide for nurses to use to identify children's visual communication needs

Manchester Metropol University

The Fellow met with a superstar at Manchester Metropolitan University, Janice Murray and was privileged to have some time with her. She guided the Fellow's ideas moving forward around how to evaluate and introduce communication devices for students, her interest and work has been in preparing students for new communication devices and preparing them for inpatient admissions. She is inspirational in her thinking. She shared some tools to help assist in deciding which tools might work best with diffe ent students from her joint research project I-ASC: Identifying Appropriate Symbol Communication.



The I-ASC Explanatory Model of AAC decision making

The I-ASC Explanatory model of AAC decision making used to assist organisation and individuals to select visual communication tools for individuals with communication needs

Reference for images: https://iasc.mmu.ac.uk/i-asc-explanatory-model-of-aac-decision-making/

Lois Cameron Talking Mats, UK

Janice and Sara suggested the Fellow attend a presentation by Lois Cameron at the Manchester Metropolitan University one evening on 'Inclusive Research Benefits Everyone'. Her research is focused around the fact that "people with disabilities face significant barriers to engagement and participation in research". They are often missing the opportunity to contribute to research and data collection about them despite many articles publishing that there is a lack of research around people with a disability. Through talking mats, she, and others like Helen Paterson are gaining invaluable data about people with additional needs, to contribute to research about them. It makes so much sense!

Great Ormond St, London

Great Ormond St Hospital and its School are rich with visual communication from their reception, survey feedback, signage to be inclusive and yet are seeking to improve their practice with their very own self formed Communication Team attempting to introduce training and packs within their setting. Jackie Goldsmith and Jayne Franklin of Great Ormond Street Hospital School kindly arranged for the Fellow to spend time with the Special Educational needs team who are pioneering the program exactly like the one the Fellow is hoping to implement in her own Children's Hospital. The Fellow met with Amy, a nurse for student with disabilities, Kai and Anthea who are special needs teachers within the school and are currently implementing a project called "Let's Talk communication" aimed at providing a resource kit for each ward, as well as training. Their belief is that before you enter the room and have a first encounter, you need to know so you make a positive impact from the start. We discussed the practical use of communication passports to aid positive interactions, and the training and visibility needed to make these documents relevant and useful.

The team shared the barriers they have faced in implementing communication into a hospital setting and that is around whose role it is. While in other settings communication might only be the responsibility of the speech therapist, often funding doesn't allow for speech therapists to spend time on communication. Thus, it isn't clearly defined as one person's job. Their perspective "It isn't one person's job, so it needs to be everybody's." Ownership of implementation falls across multiple teams given no one person or team has time or resources for it and yet it is involved in every interaction that every therapist. Their feeling is that this approach has made the teams and inter team communication tram strengthened. While there could have a whole team dedicated to it but it's not realistic in most hospital settings. In this way, communication referrals can be given to anyone in the team, wards or parents can contact speech and language about communication.

Great Ormond St Hospital

Let's Talk Communication kit

Ward training

This is implemented by the learning disability team, speech and language, OT, play, research personnel and school members.

Their training package includes one day of theory around Makaton and communication and then a full day simulation with actors from a theatre company with scenarios.

They have also implemented 'on the job' training, or 'ninja' training where by they work with small groups of nurses on an as needs basis in relation to specific tools or patients. The team show them how to use tools appropriately in spontaneous training systems which can be applied to patient needs immediately and have been effective in building nurse confidence.

Toolkit

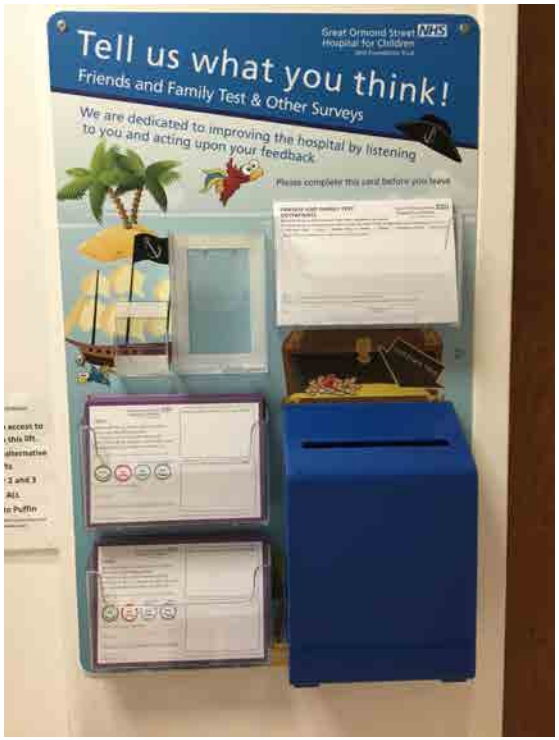
They have created a 'Let's Talk Communication' pack which will be provided to all the inpatient wards.

The child life team and Amy have been present on wards and demonstrating on the spot how to use it.

The idea is first going to the pack, then if a resource isn't there that is required, the team can be contacted for a referral to provide a more appropriate resource based on student need.

The toolkit includes:

- All about me
- Now and next
- Choosing boards
- Makaton signs
- Instructions



Great Ormond St consumer survey

SCOTLAND

Dundee AAC

In Dundee, the Fellow met Annalu Waller- Chair of Human Communication technologies at Dundee AAC. She is a professor whose determination to change the lives of people with disability, combined with her hilarious sense of humour and insight into disability intrigued the Fellow so much the Fellow returned unplanned to Dundee. The fellow wanted to hear her lecture on the topic of AAC for teachers so that she could soak up Annalu's stories and advice. Annalu has a background in engineering and has undertaken extensive research into the use of AAC and training around its implementation. Her ability to captivate disability, increased expectation towards those with disability and overcoming of fear and the unknown for people was so unique.

During her career, Annalu worked with Sue Baladin, an Australian Speech Therapist to investigate communication passports in acute and IC care. The more she analysed the use of communication passports, she realised the need was in the training around using the passports, rather than the technical creation side of the passports. Thus, she has spent years fighghting for education of professions at the undergrad level and lectures dentists, doctors, nurses, teachers about communication! Annalu provides training to dentists, teachers, medical professionals all in university training. She has fought for years to make this training a reality. Her main training goals are around reducing the unknown element of communication vulnerability and raising expectations that everyone can communicate just in different ways. She describes her main message as this; there is a person behind the disability, they have lives and can communicate. What a message!

Dundee AAC- goals of care and communication

During her talk, Annalu commented that, “Communication is what makes us human beings and differentiates us from other beings. Animals, and dogs can show us what they want. The ability to share more than needs and interact that is what makes us human. And everyone deserves that right.”

Annalu presented her strong feelings towards teachers taking ownership of communication for students with needs. Below are some of her main points:

» Assistive technology (can be considered as wheelchairs, iPads, devices, glasses) is about personal and medical care, mobility, environmental control, cognitive support but above all, communication. Communication is the essence of life

» Communication is affected when kids are hungry, upset, sleep deprived therefore, and thus all kids need help with communication at some point, and we all need to be able to provide that support

» Communication is fundamental to learning. Without language and communication, a child cannot learn to read or write. Annalu advocates that teachers need to be taking ownership to learning and communication provision as they simply cannot do their job without being able to talk to their students, or have their students communication with them. Instead of seeing communication as another angle, we need to see it as underpinning all we do.

» Teachers need to give the overpowering message to child that they will believe the child can do it even when t child doesn't believe it themselves. Or sometimes, we need to believe in the child even when the family cannot. We can believe on behalf of them.

» AAC commenced 40 years ago with teachers pioneering in special schools who couldn't get children to read and write so used pictures to support literacy. Teachers need to support the language development day to day. Speech therapists don't have the access to children all day like teachers do so it really should come under their banner. Teachers and healthcare workers should collaborate with a larger team of experts, such as speech therapists, to support implementation. Teamwork makes the dream work!

» Annalu believes that giving people the confidence that they can make a difference, rather than teaching them about resources is the key to change. She believes that by influencing attitude change, the switch will flick in people. People will start believing that if we treat everybody the way you want to be treated, as shent to be said "we could change the world and you can fly"

She provided an example that those with glasses don't count themselves as having a disability because it is so normalised, and yet, technically they do. Her aim is to even the playing field in perception of disability. Annalu's advice is so powerful because she herself too has a disability but talks of how she doesn't see herself as having a disability because there's nothing she finds that she can t do.

Annalu shared honestly and openly about her own experiences with communication. She said people after a year with her often comment, "Wow, your speech has improved so much" but actually she replies, "sadly not, it's your ability to listen."

Annalu spoke of a medical encounter she'd experienced when unwell and the sta couldn't understand her speech and thus were not including her in her care. She was able to communicate to friends and family who explained to the staff that she could understand what was happening but needed communication assistance. She was then treated differently and spoken to directly about her care decisions. Her recollection of the time, "I don't know what made me more upset, the way I'd been treated initially, or the fact that I was treated differently when they found out I'm a professor'. This happens all too regularly when staff are not trained or aware of the complexity of communication or how to assist someone who can communicate but needs resources to do so.

Therefore, perception and expectation are the key. In summary, if we treat people with the respect they deserve and expect communication, we will often have our expectations met if we try and communicate the way they know how to. If we however, expect little, they may never be a be able to communicate with us as we have both missed out, and left them frustrated and feeling undervalue

Key Comm

The Fellow met with Deborah Jans at Keycomm in Edinburgh. She is a speech and language therapist creating amazing and usable resources for children and families across Edinburgh and so generously shared her knowledge, experience and understanding of how to use communication tools to enhance the lfe of children with additional needs.

Two specifically relevant programs include:

The AAction Maker Program

The idea of the program is to have two nominated individuals from within a team to become AAC champions who are provided with training to help train their team, resources in the form of a low- and high-tech kit, a screening tool and ongoing support from Keycomm.

The Visual Support Program

This is a wonderful initiative in Edinburgh. Keycomm are overseeing it with the Department of Education and Speech. It is an initiative to improve visual communication use in all schools in a universal design model, believing that visuals will improve communication and understanding for all students.

The premise is that AAC is about being inclusive and accessible and that every child can benefit from having visual supports.

The steps involved are:

1. Principals sign up voluntarily to be involved
2. Training is provided by Julie Baxter
3. An entire pack of symbols cut and laminated is supplied
4. Implementation occurs over several years
5. Schools are evaluated and provided certificates of attainment based on evidence
6. Schools work through bronze, silver and gold.

Rachels House, Kinross

Rachel's House is a fabulous respite home for children with life affecting or life limiting illness. They have a visuals team implementing a training and visuals program to improve communication for students with communication difficulties The Fellow met with Linda, who is part of the working group called the Communication Champions. They applied for a grant and are going through the same process of determining how to improve communication practices for staff in their setting

Key Findings

Three of the groups that the Fellow met with are implementing projects that will formulate the basis of my key findings. These include

» Let's Talk Communication, project at GOSH

» Rachel House Kinross: Communication Champions project

» Key comm: AACtionmaker and Visual Support Programs

Their experiences and attempts at implementing training and tool kits and practical ideas and feedback helped to formulate a plan of implementation. Lectures observed by Tami Altschuler, Helen Paterson, Annalu Waller as well as conversations with Janice Murray and Rachel Santiago contributed to the key findings and ecommendations and suggestions sections.

Common Points of Agreement

To deliver high quality holistic care, provision of human rights, improved diagnostic improvement, independence, autonomy and increased patient participation, communication is essential as a priority that needs to be recognised sooner during an admission and appropriately managed

» In terms of communication goals within a referral, all agreed it is difficul but not impossible to introduce an entirely new device or system of communication for a short term, or unknown length of stay, and yet, as a team we need to rethink our perspective on it. The decision is that we must, to uphold basic human rights, provide access to communication and the ability to understand within hours of admission. It was generally agreed we should set ourselves a goal to deliver high quality care including communication.

Common Challenges and Barriers to Implementation:

Clinical priorities

» When working in a hospital, medicine often takes a priority and it was commonly discussed that funding, time and goals of stay govern who is involved in patient care as well as what care is provided. Communication doesn't fall under a clinical category in most cases of admission and thus isn't often managed as a priority. Being in hospital at your most vulnerable is the time you need to be able to ask for help, communicate pain and discuss treatment options

» Multidisciplinary approaches diffe ed amongst settings, but many struggled with education and health being separate services, with speech operating under the health banner.

Equipment

Many issues and questions arise around the provision of devices, both low and high tech in a hospital setting. These were common in every setting and are essential to manage when implementing a new system. Problems include:

» storage: where will it be kept, on what ward, in what sort of filing or cupboard system?

» cleaning procedures: infection control policies need to be adhered to and who will ensure these are thorough

» location for posters and displays and instructions; many hospital staff suffer from 'sign fatigue' and will not look at, nor do they have time to read mass amounts of information

» returning items

» lost items

» access to equipment: Limited by physical positioning issues and access in bed

» hiring system environment. There is so much medical equipment at the bed side it's had to add mode instructions and tools

» funding.

Pre-admission procedures

» tools are not often brought in for numerous reasons, parents don't know how to use them, are worried it will get lost, or parents presume no one in hospital can use it anyway sadly based on their past hospital and community experiences

» parents believe staff are not interested, not trained or time poor so feel burdened to stay in hospital with their child and then get burnt out, agitated, emotional and feel solely responsible to be the communication partner or voice for their child. If communication was raised by hospital staff as a safety issue, or important aspect of admission by staff, parents would feel more confident that they could leave their child to ease financial, family, emotional strain on families

» there is a common belief or oppositional argument to the provision of communication devices or tools within hospitals that AAC or communication devices and systems are created specifically for individuals based on their unique needs, and each child has such individualised needs that a generic model won't work yet, most the Fellow met hold the belief that that fact doesn't mean we shouldn't provide something. In response to concerns, teams recruit speech specialists who are able to determine what short term use visual care can look like.

Knowledge / experience around use of equipment

» resources that can be provided such as visual communication boards and adaptive call bells are useful but often staff are not equipped to use them or respond to them. Therefore, In response to concerns, teams recruit speech specialists who are able to determine what short term use visual care can look like. We need to train and educate with the provision of devices to the user and communicating partner

» too few staff are skilled, equipped, have an open-minded attitude or believe that children can communicate to be communication partners

» often elaborated or detailed documentation, such as a communication passport or instructions are not read or made available to the staff interacting most frequently with patients

» hospitals often have information displayed on their walls with instructions, warnings and procedures which are essential. They can lead to what some may call 'sign fatigue' so that staff and families may not see printed information on walls. Thus, training, conversation and face to face information delivery is best.

Staffing barriers to implementation

» staff turnover and redistribution to other areas

» untrained health professionals in visual and special ed

» time release from work

» mandatory training provided by hospitals takes time and staff hours, so it is difficult to get time allocated to this training

Staff attitude, expectation and emotion around disability

» fear of unknown e.g. AAC, disability

» embarrassment, lack of courage or confidence to speak and try visuals:

» therefore mini teams are used to build capacity.build capacity of nurses or staff and do the work together to get better results

» staff need to see impact and benefit and interact with patients with disability regularly to see purpose

» lack of experience with disability and thus low expectations of students with disability.

Practical di iculties in training

» engagement from staff in training

» access to staff for training

» new learnings not able to be used if low numbers of AAC users in at time of training

» forced participation in training leads to negative feedback and reduced attempts at using device

» training fatigue.

Role clarity

» huge problem exists in the world of communication over whose responsibility it is for assessment, referral and implementation of communication support. While speech therapists often want to be involved, and are the most skilled and trained for the need, they are often not allocated time for responding to communciation referrals.

» role of speech therapist in hospital: many acute speech therapists must prioritise swallowing and feeding and communication is not often referred during admission but only at discharge.

Sustainability

» ground swell from nurses and interest from those who have struggled to work with a patient with a communication difficulty is invaluable, but must be accompanied by leadership in order to secure funding for training and resources

» training needs to be updated regularly

» limited resources over time

» technology is moving so quickly which makes it hard to keep up and incorporate technology.

5. PERSONAL, PROFESSIONAL AND SECTORAL IMPACT

Personal

Having a chance to explore the world, and see new places always allows one to return home with fresh eyes and gratitude and put into practice new experiences. The Fellow's personal learning philosophy is for all children to be able to say what they want, when they want it, to whomever they want to say it and wherever they want to say it.

It was a truly amazing feeling to get to meet people who believed in the Fellow's dream for children and who are many steps ahead in the Fellow's own journey of special education. Sometimes the field of special education can feel quite small and frustrating but to get to share these frustrations and see positive examples of innovation reinforced the plans the Fellow has in place within her practice and renewed her own belief that we are able to make a difference to each other. Being able to use what the Fellow has seen to expand the educational experiences of each child she meets, would be a dream come true.

Professional

Within her team as an educator, Katherine Lingard is responsible for contributing to the establishment of the culture, and academic program of Monash Children's Hospital School. The Fellow read articles around hospital schooling and AAC about supporting students return to school and the opportunity to see best-practice in action and this is shaping and informing her own education philosophy and practice.

Having seen the way children are being actively involved in their learning worldwide, Katherine finds herself continually seeking to find ways to incorporate them as active participants in their own learning and provide agency for them as well as improve resources to make them accessible rich learning experiences.

The Fellowship not only enabled the Fellow to see visual communication in action, but also see other areas of her teaching, including support and training for students with Acquired Brain Injury as well as a range of Hospital School settings. While the Fellow was focusing specifically on one area, her understanding of how to support students at their most vulnerable time in hospital and then return them to school was also expanded. The Fellow certainly learnt beyond what she had hoped.

The Fellowship provided the Fellow with an opportunity to expand her networks, professionally and personally, while traveling which she can already see will be hugely beneficial

Sectoral

Monash Children's Hospital School is invested in incorporating Fellowship/Scholarship findings into their professional learning timetable for all staff. For example, the Fellow presented to the Monash Children's Hospital School Council, which is comprised of the following members: Nurse Unit Manager from the Cancer Centre, the General Manager of the Children's Hospital, Head Paediatrician for Monash Children's Hospital, Manager of Allied Health, Parent Advocates and Department of Education staff. The Fellow presented on the need for increased

visual communication within our hospital which was warmly received. They are exploring avenues for a newly formed working party to train junior medical staff, nursing staff and Allied Health teams within the Monash Children's Hospital – Clayton campus with the ongoing intention to then expand this training.

Designing specific visuals, such as a menu ordering system, waste management could be managed by parents and families when ordering and eating the foods they want with a genuine understanding. The impact of meal selection and its positive benefits for children ordering what they want to eat as a basic human right could be measured and monitored by dietitians in a collaborative process for the hospital.

After running a brief training session with the Melbourne Starlight Captain Team, who entertain our children, they have indicated that they as an organisations are interested in expanding training nationally to both their Captain Teams and Head Office staff to promote inclusion of students with diverse needs.

The Fellow intends to work collaboratively with medical and nursing teams to gather data and present findings on 'practice' improvements in the form of poster presentations at a local and national level and will hopefully deliver multidisciplinary presentations to various organisations. Furthermore, opportunities will be created in my role as a leader of the sub-committee for the H.E.L.P Alliance which will allow Katherine to disseminate learnings to teachers nationally as well as in New Zealand.

6. RECOMMENDATIONS AND CONSIDERATIONS

Language Choices

Language was seen to be important in developing a working party and project. Language choices that are easy to understand are crucial to increase buy in from staff

For example, patients with a communication difficult were referred to as communication vulnerable, AAC user, alternative communicator, and non-verbal.

AAC could be referred to as visual communication, aid, device, tool, communication support, inclusion tools.

Language choice is about increasing the ability of people with communication difficultie to participate and the terms should be appropriate, inclusive and represent a wide and diverse range of users and the tools they need to increase participation.

The following is a list of considerations and recommendations that has been drawn from the learnings and the experience. They outline the steps involved in successfully setting up a Visual Communication working party, a training package and toolkit.

1. Formation of a Visual Communication Working Party

The first step identified in implementing a hospital wide change in process is to formulate a working party. I currently sit on an ABI working party so understand the process in terms of agenda, action plans and ensuring accurate representation and input across the hospital.

It is recommended that for a Visual Communication Working Party to reflect the needs and opinions of staff members should be from Allied health, school, doctors, reception or administration staff, nursing and a consumer.

The team at Great Ormond St Hospital, said, “communication is not one person’s job, so it must therefore be everybody’s.” This was one of the most powerful lessons the Fellow learnt. It doesn’t come specifically under any one person’s job description within a hospital because everyone must communicate to do their job. Thus, we must work together to share the job of making communication accessible for all.

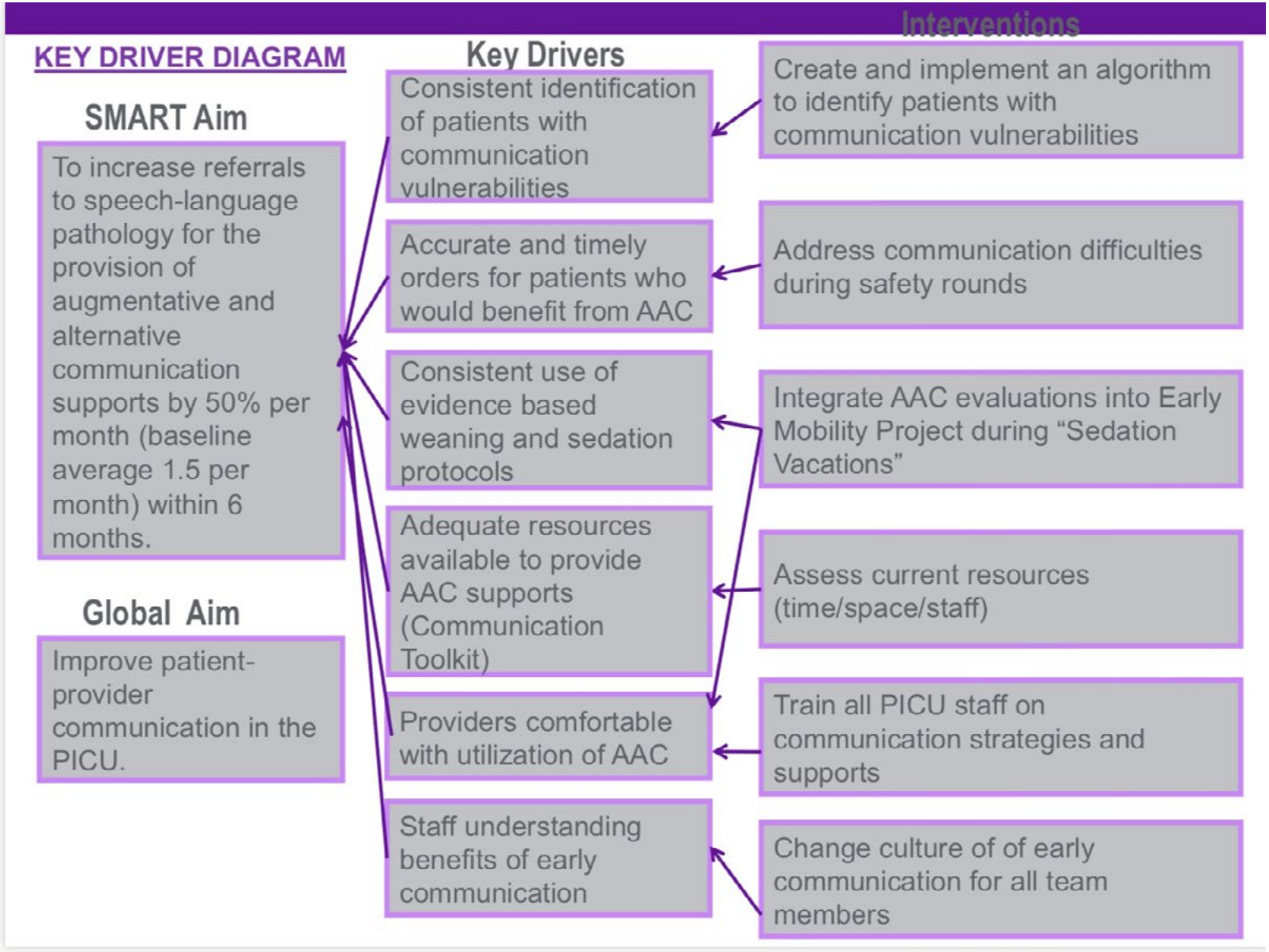
The role of the working party should not be about the training, resource development or be on the ground working with staff necessarily, but rather be about advising on the process of obtaining funding, research to formalise the process of implementation, accurate representation and abiding by hospital policy.

» A main aim for the working party is to determine agreed language around the project and communication. Feedback from Janice Murray was that the term AAC can sometimes be divisive in diffe ent settings, or at the least, unknown and foreign and so might alienate people from participation from the outset. Rather, she suggested a term that is less threatening to people such as ‘tools that help us communicate’

» When Tami Altshuler was commencing implementation, she created the Key Driver Diagram below. This helps to formalise the nature and purpose of the project and would be useful to be created in consultation with the Working Party whose interest is in Quality control, hospital Improvement, patient safety, and consumer practice.

Current Progress: A small working party of 4 members existed before the Fellowship which has grown.

The expanded team has meetings set to determine the future progress of the project, funding, staff allocation, resource purchasing, training, implementation for the survey.



Tami Altshuler, NYU Visual Communication program; Key Driver Diagram

2. Data Collection

In order to decide upon training, resource / toolkit creation and implementation across the wards, it is important to accurately collect data to inform practice. While the Fellow saw beautiful models of communication, it will be important to make sure the program is tailored for our staff, and children and their families. Possible information gathering tools include:

» Helen Paterson's interview model using Talking Mats. She collected data from consumer patients as well as nurses using talking mats for both groups so that she could compare the data directly.

» Focus groups of students / users from the hospital and parents to gain their insights, experiences of communication in the hospital. This could be done by going out to a Special School in the area that we work with closely and collecting information on their experiences in a focus group setting.

» Online survey: using an online survey mechanism, data can be collected and compared for pre-and post with ease. Qual Trix and Red cap were both suggested by Tami Altschuler.

Current Progress: Before the Fellowship tour, the Fellow had identified capturing data as crucial for potential research reports/ posters of my project. Katherine created a survey and asked Monash Health employees to view then asked some of the people she met for feedback. The survey draft is attached in the appendix.

3. Obtain Funding

» Some of the groups that the Fellow met with had no funding to formulate their project which made resource buying such as apps, iPad, and the laminators, Velcro, colour printing difficult and costly to groups within the hospital.

» some had grants from location organisations to assist with funding the toolkit and staff time towards the project.

» Suggestions for funding obtainment include approaching organisations such as the hospital foundation to see if groups would sponsor aspects of the project.

4. Training and Formation of Communication Champions team

The next step will be to determine a team who will be live 'on the ground', an expert user group in a 'train the trainer' typed model who will be able to assist wards and teams to implement visual communication as necessary.

This team will not be setting up a new communication system for a patient that is complex such as eye gaze, or a new high-tech device. Even a speech therapist may struggle to do that during a short stay due to time restrictions. The aim of this group is to provide a support system so that the child may request help, order meals, request activities or changes such as, turning on the light, and have social contact with members in their team.

Again, language choice for the group is important and some ideas for names of this team include:

» communication care team

» communication support team

» enhanced care coordinators

» communication champions

» participation enabling team

» communication access team

This should be a small team on each ward, or area of the hospital who are passionate and interested, possibly willing to give up their own time to pursue the project.

It is essential that participation in this team should be voluntary to equip and gain members who work regularly or are passionate about students with communication difficulties who naturally be inclined to better serve such patients and support staff.

Each team would ideally have one-two communication champions for ongoing maintenance of the program to offer sustainability. These 'champions' revealed themselves organically in most settings. This team would also involve speech therapists who would play a key role in more complex cases and respond to communication referrals.

Their role would be to upskill, provide support and training to their own teams working with children with specific communication needs. They would refer or answer questions about patients and provide direct training, modelling of tools at the time of need. Their goal would be to act as a lead communication key contact who can provide information around the dislikes, likes, yes/ no response, pain response and cognition / understanding of the patient.

Care for patients within hospitals is clustered around a specific team. In education sessions there is a term 'team around the learner' and involves all key stakeholders inputting into the child and families' life. In this model, you would have a 'a team around the patient' who would involve a key communication advocate for that child to help upskill their team in communication to increase engagement in therapy and health management for their team.

5. Referrals to Communication Support Team

The referral process to a communication team comes with a range of problems to be solved. Funding and role position descriptions is a main part of the hurdles to be overcome by a communication team.

In some settings, they had petitioned for paid employees and departments whose sole purpose was around responding to referrals and ensuring adequate communication systems were in place, and staff knew how to use them adequately.

Other places had advocated for one day a week of a speech therapists' role to be around inpatient communication support.

Either way, there needs to be a referral set up in place, usually using an electronic online medical system. Word of mouth, and 'hallway' or 'stair' referrals are commonplace in hospitals for many services and happen on the go during the day.

A member of the communication support team would be contacted and conduct an assessment which will be outlined below. Children with certain diagnosis or procedures known by the admission team should be flagged as getting instant communication assessments who will need support. These might include tracheostomies, English and a second language, or non-verbal patients.

A challenge during the introduction phase of a new team and referral system is the promotion of the referrals, getting hospital staff to firstly understand, then promote the role of a communication support team, and identify patients who need it and then actively refer to communication speech referrals all needs to be considered during implementation and training.

The process for the communication referral changes depending on whether the admission is planned, whereby the referral could be made pre-admission, or unplanned, whereby a referral would be made upon admission.

Pre admission

» Letter could be sent home that ask for communication items to be brought in.

» Some teams are made available to families in waiting rooms, at clinics and have a pre admission chat about communication to prepare staff for patient arrival.

» To help prepare a patient, a Video to explain what hospital will be like and what to expect is provided to families before admission.

» If possible, a video of a child using their device with a familiar communication partner is used to provide the team with visual evidence/ example of the child at their best interaction level to aim for. This could be stored on a device such as an iPad at the bedside for staff to watch befo e interactions.

Admission

Ideally, referrals would be made to the communication support team during first 3 hours of meeting patient. They would determine:

» can the patient access the call bell without a parent?

» can they then ask for the help they need without a parent?

» can the patient access the entertainment screen without a parent?

» can the patient use the entertainment screen to order meals or do they need assistance either to touch the device or read the information?

» do they have a communication device?

» are they confident in using it to talk/ listen

» are their family competent in using their device?

» how do they say yes/ no

» what is their expressive/ receptive language ability

» where will the communication device be stored?

» is there a communication passport?

- if not, who could make one? Who knows their communication best?

» can they access the call ball without a parent?

Process

1. Priority is to get the patient's device as quickly as possible, or provide them with a generic one for the interim.
2. Ensure staff working with patient have been briefed on the device being used.
3. Ensure device is stored in a location.
4. Remember even with a device -they may not be competent with it, have different experiences and use it in isolated locations.
5. Check in with the child if using a generic device to ensure they can use it to call for help, say yes/no/ something else and establish that eye symbols means the same to child and communication partner.
6. Add communication information to safety section/ safety handover.

Patient handover

A communication team member, or nurse in charge, should attend and give information about the patient with a communication difficult each day so each new team is aware of their needs.

They should advise on visuals in room, call bells, signs in the room and demo use of tools. This information should be provided to therapists working with the patient as well as nursing staff

In many settings, the communication team had advocated for safety rounds and paper work to include communication as a section.

Training package

Rather, training is to ensure staff feel confident to use low- tech devices to help students with basic needs ,yes/ no , activity selection or help seeking.

Aims of training

The number one priority of training for teams the Fellow met, was to impress upon people to speak directly to the patient not about the patient to others.

Other main aims of training include:

1.staff should know what team to contact for communication need

2.staff should know how to contact the communication tea

3.staff should, know who their human resources are E.g., communication consultant

4.staff should know where to find tool

5.staff should know benefits of using devices

6.staff should know when and who to use them for or at least when to make a referral

7.Training should be around changing perception, increase expectation and perspective on patients with a disability and helping staff to realise the capacity of patients.

When interviewed by Helen Paterson, the most common identified sadness from communication users was their feelings of sadness when people didn't think they could answer because they took so long or when people walked thinking they weren't answering.

In her training of doctors, teachers and medical staff, Annalu Waller suggests learning how to use a resource or systems isn't as important as assisting people to want to use them by changing their expectations and attitudes towards disability. Her goal in training is to raise expectations that everyone can communicate just in different ways. Her main message is that

"there is a person behind the disability, they have lives and can communicate".

Many people haven't interacted in their life with someone with a disability, so sta often have a hesitation towards the unknown. The team's work should remove fear and have confidence to try whilst emoving a fear of diffe ence.

» in Boston, all ome models for training:nursing graduates have a one-hour training session and a 10-15 min e-learning module at the ACE Centre, they have staff role-play using eye gaze.

» teach basic communication partner skills in general training and me specific ones for specific patient

» video themselves using ten tools and self-reflect on your performance

» remind staff it will feel awkward to be talking and not have verbal talking back.

» remind staff it will take time to get used to being in a communication interaction where you are verbal and the other person is not.

» train with each other, practice together to reduce fear, embarrassment, lack of confidence

» online modules.

Many training packages used video for training that included:

» testimonial, have parents talk about difficulties in hospital and requests

» show length of time required to type a message

» nurse testimonial about how naïve they felt before using AAC

» nurse testimonial about how AAC changed their delivery and experience

7. The Toolkit

The aim is to develop a generic kit where general staff with the help of a communication champion, could select the best tools for the patient. Where a generic tool could not be used, a speech therapist referral would need to be involved.

In deciding the best elements for a continuum-based support toolkit, the main advice was that less is more, it needs to be available and usable, as well as hospital infection control grade to be cleaned if being reused. Instructions should be written on the back of each device so staff can pick up a tool and use it with a prompt they don't need to find separately.

The toolkit should include:

if literate:

» Writing page

» Magnet board

» Velcro board

» Pain scale

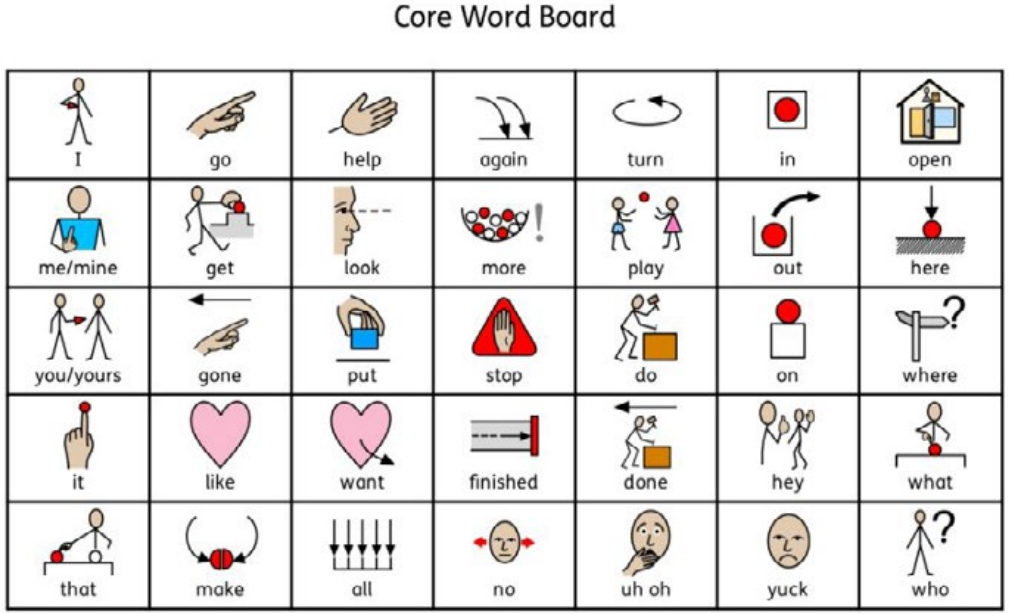
If they cannot read and write:

» symbols

» yes/ no response

Examples of various alphabet boards

Visual yes/ no response



Letter boards: whole and chunked

- Core word boards in range of colours and cell amounts per page.
- Core word boards
- Generic PODD book.

Communication specific iPad

» Recommended 3 sizes- mini/ medium/ large to cater for fine motor and visual needs

iPad should contain:

» demonstration/ instructional videos using different tools on it

» videos of hospital events and procedures to help prepare children who cannot understand verbal instructions

» visual stories to explain hospital procedures

» Apps such as Proloquo2go, Our Story, Predictable

iPad and iPad accessible case

Nurse picture resources

Nurse lanyard of commonly needed vocabulary in visual form

» Yes / no lanyard

» Pocket key ring

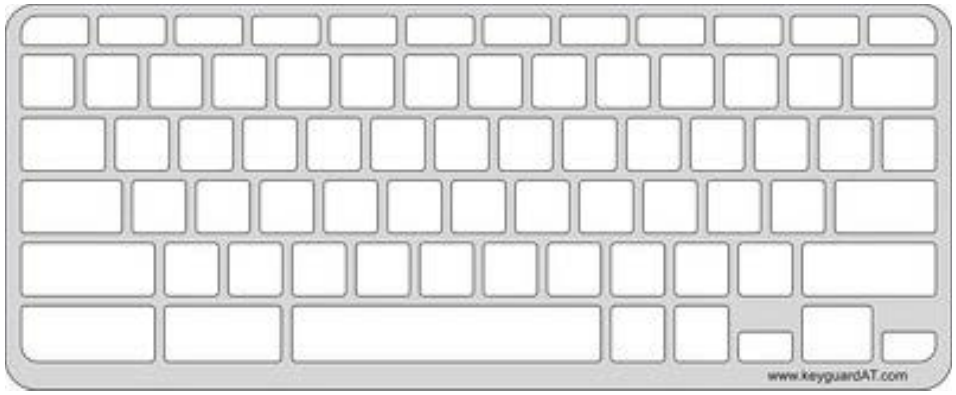
Other accessories:

» Switch Mount

» range of switches for accessing toys, devices

» Keyguard: used to prevent accidental hits or tremor

Switch devices



Keyguard for keyboards to improve accessibility

Resource development

In order to create low-tech, re-usable, or one time use resources, teams suggested partnering with local speech therapist trainees, volunteers and high school students to assist with creation of low-tech resources. This could be a working bee styled project, or donation of time from local school communities.

Identifying what resource to use

Throughout the Fellowship the Fellow realised that selection of a tool to use is complicated.

Many groups used a decision making tool to help staff, but most often, complex cases relied on the communication referral team to make decisions around what tool to use, then assist other staff to use them properly.

Figure 1: throughout the Fellowship the Fellow learnt how complex the decision making is around how to appropriately choose a communication tool for a child with a communication need. Many factors must be considered.

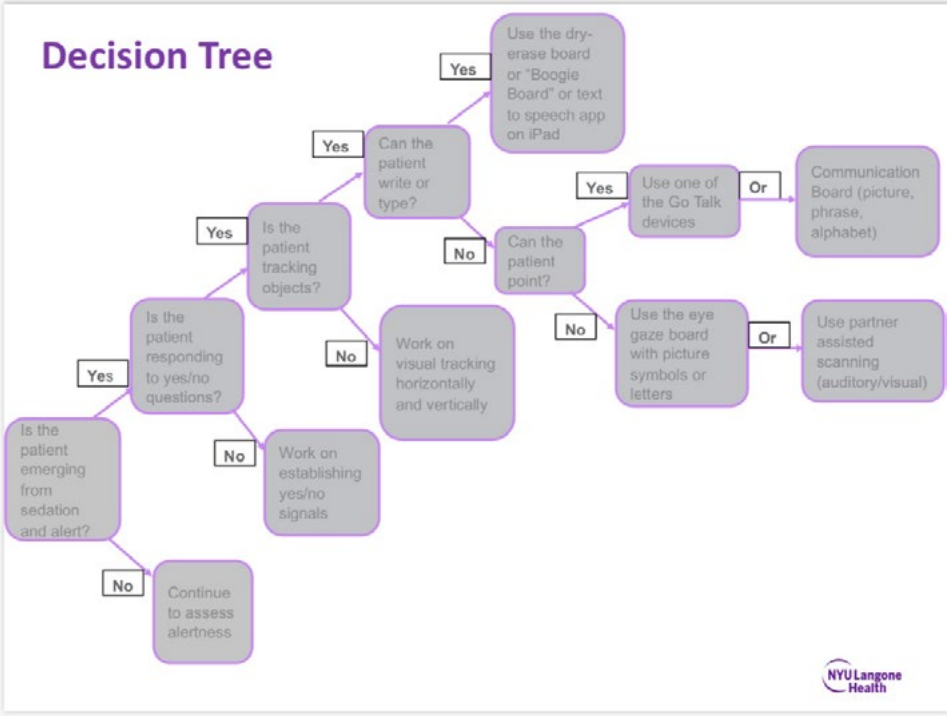
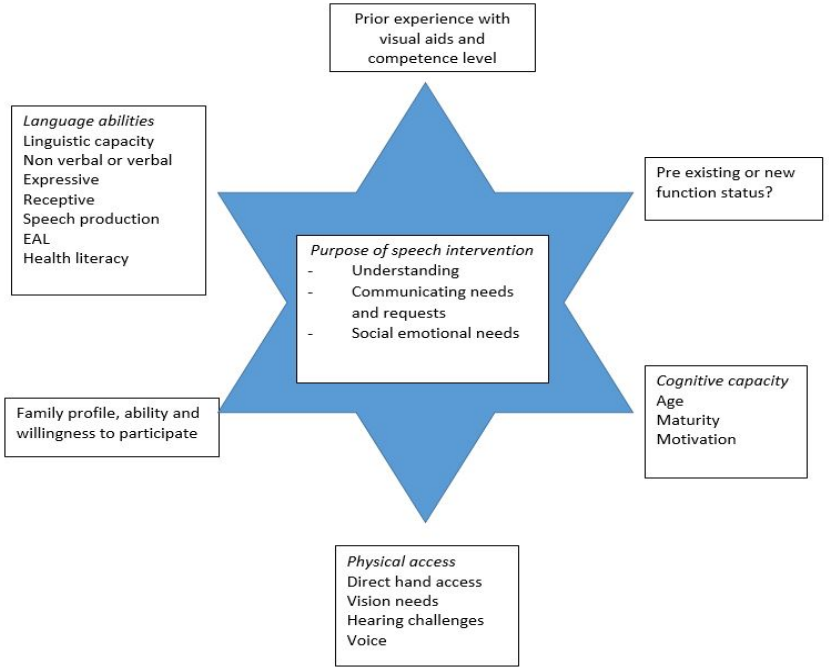


Figure 2 A diagram the Fellow created outlining the multi-factored decision-making process involve in selecting a device, and the many interacting factors that must be considered in selecting a tool.



For more information:

My Facebook page:

» https://www.facebook.com/katherinelingardeducationpage/?modal=admin_todo_tour

ACE Centre
ACE Centre are resourcing families and schools with the skills and tools they need to improve quality of life for individuals.

https://acecentre.org.uk/resources/

Call Scotland
Call Scotland's website is a treasure trove of resources for teachers, families and individuals working with students. Wonderfully innovative resources that are being used and recognised around the world.

https://www.callscotland.org.uk/blog/tag/?tag=resources

Talking mats
https://www.talkingmats.com/about-talking-mats/

Key Comm
Key Comm have brilliant models in place actively improving communication in their area of influence in Scotland. Lucky me to get to hear about such a fabulous model.

https://keycommaac.wordpress.com/aactionmakers/

Visual Schools Project:
A fabulous resource helping schools to be 'Communication friendly' with a checklist of standards for auditing how you are tracking.

https://www.rcslt.org/…/…/RCSLT/5-good-standards-a4-2019.pdf

Janice Murray:
This is part of her work and this website is a fabulous resource with lots of great links for teachers and health care professionals.

https://iasc.mmu.ac.uk/i-asc-explanatory-model-of-aac-deci…/

7. REFERENCES

1. Ali, M (2017) Communication skills 1: benefits of effective com nication for patients. Nursing Times (online) 113:12,18-19

2. Altschuler, T (2019) Meeting the complex Communication needs of patients in acute care. Communication Matters Conference

3. Altschuler, T & Happ, MB (2019) Partnering with speech language pathologist to facilitate patient decision making during serious illness. Geriatric Nursing Jun;40(3):333-335

4. Avis, M & Reardon, R (2008) Understanding the Views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study. Journal of Child Health Care Vol 12 (1) 7-17

5. Bardach, L, Blackstone S, Beuklmann, D. & Costello, J., (2016). Providing Communication access across medical settings: A fundamental role for AAC.

6. Bartlett, G., Blais, R., Tamblyn, R., Clermont, R.J., & MacGibbon, B. (2008) Impact of patient communication problems on the risk of preventable adverse events in acute care settings. Canadian Medical Association Journal. 178 (2)

7. Blackstone, Sarah. (2010). Communication Access for Children: The Role of Augmentative and Alternative Communication Technologies and Strategies in Pediatric Rehabilitation. Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach, 3, 247-250

8. Blackstone, S., & Pressman, H (2011) “Communication Enhancement in Children’s Hospitals: Practical Tools to Support Communication Vulnerable Patients,”. BrainChild 12 (1)

9. Blackstone, S., & Pressman, H (2016) Patient Communication in Health Care Settings: new Opportunities for Augmentative and Alternative Communication, Augmentative and Alternative Communication, 32:1, 69-79

10. Blackstone S., & Pressman H. (2011) Effective Communication in Child en’s Hospitals: A Handbook of Resources for Parents, Patients, and Practitioners. 2Central Coast Children’s Foundation Augmentative Communication Inc. Rehabilitation Engineering Research Center on Communication Enhancement. California.

11. Burkhardt, L. (2014) Practical Strategies for Implementing Aided Language Stimulation. [PowerPoint Presentation.]

12. Beukelman, D. & Ray, P. (2010). Communication Supports in Pediatric Rehabilitation. Journal of Pediatric Rehabilitation Medicine, 3, 279–288

13. Beukelman, D. & Ray, P. (2010). Communication Supports in Pediatric Rehabilitation. Journal of Pediatric Rehabilitation Medicine, 3, 279–288

14. Costello, J.M (2000) AAC intervention in the intensive care unit: The Children's Hospital Boston Model. Augmentative and Alternative Communication. Vol. 16. 137-153

15. Costello, J.M., Patak, L., & Pritchard, J. (2010). Communication Vulnerable Patients in the Pediatric ICU: Enhancing Care through Augmentative and Alternative Communication. Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach, 3.

16. Costello, J.M (2016) augmentative communication in the paediatric/ ICU/ Acute Care. [PowerPoint Presentation]. ISAAC 2016, Toronto Conference

17. DeBeule, K (2001) The use of communication aids with children in health care and the outcomes for the child's functioning based on the ICF-CY: A systematic literature review. SCHOOL OF EDUCATION AND COMMUNICATION

18. Fager, S., & Spellman, C. (2010). Augmentative and alternative communication intervention in children with traumatic brain injury and spinal cord injury. Journal of Pediatric Rehabilitation Medicine, 3, 269–277

19. Fraser, D () Growing AAC: supporting Parallel Strategies in Education and Healthcare through International Collaboration. Central Coast Children's Foundation Inc. available at: bhttp://www.patientprovidercommunication.org/files/Dot_fraser_serbia_ppc_powerpoint.pd

20. Fried-Oken, M., Mooney, A., & Peters, B. (2015). Supporting communication for patients with neurodegenerative disease. NeuroRehabilitation, 37(1), 69–87. doi:10.3233/NRE-151241

21. Ganz, J., Rispoli, M., Mason, R & Hong, E. (2014) Moderation of effects of AAC based on setting and types of aided AAC on outc me variables: An aggregate study of single-case research with individuals with ASD, Developmental Neurorehabilitation, 17:3, 184-192

22. Ganz, J., Rispoli, M., Mason, R & Hong, E. (2014) Moderation of effects of AAC based on setting and types of aided AAC on outc me variables: An aggregate study of single-case research with individuals with ASD, Developmental Neurorehabilitation, 17:3, 184-192

23. Gumm R, Thomas E, Lloyd C, et al. (2017) Improving communication between staff and disabled child en in hospital wards: testing the feasibility of a training intervention developed through intervention mapping. BMJ Paediatrics Open

24. Hawkins, H. & Clayton, C. (2011). Using visual cues to improve classroom instruction for young children with developmental delays. Atlanta, GA: Assistive Technology Dept. Fulton County Schools

25. Hemsley, B., & Balandin, S. (2014). A Metasynthesis of Patient-provider Communication in Hospital for Patients with Severe Communication Disabilities: informing new translational research. Augmentative and Alternative Communication, 30, 329–343

26. Hemsley, B, Kuek, M, Bastock, K, Scarinci N & Davidson, B. (2013) Parents and children with cerebral palsy discuss communication needs in hospital, Developmental Neurorehabilitation, 16:6, 363-374

27. Hemsley, B., Lee, S., Munro, K., Seeda, N., Bastock, K., & Davidson, B. (2014). Supporting communication for children with cerebral palsy in hospital: Views of community and hospital staff. Developmental Neu orehabilitation, 17, 156–166

28. Hurtig, Richard & Alper, Rebecca & Berkowitz, Benjamin. (2018). The Cost of Not Addressing the Communication Barriers Faced by Hospitalized Patients. Perspectives of the ASHA Special Interest Groups. 3. 99. 10.1044/persp3.SIG12.99

29. Lambert V, Glacken M, McCarron M. (2011) Communication between children and health professionals in a child hospital setting: A Child Transitional Communication Model. Journal of Advanced Nursing 67(3), 569–582

30. Light, J. & Drager, K. (2007) AAC technologies for young children with complex communication needs: State of the science and future directions. Augmentative and Alternative Communication, 2007 VOL. 23 (3), pp. 204-216

31. McDonald A (2016) A Long and Winding Road: Improving communication with patients in the NHS

32. Miller, S, & Donnelly, J, () Symbolising the Environment: Symbolising the Environment: A Whole School Approach A Whole School Approach How we did it! How we did it. FACCT

33. Millar, S. V.; Scott, J. (1998). “Chapter 1: What is Augmentative and Alternative communication?”. In Wilson, Allan (ed.). Augmentative Communication in Practice: An Introduction. University of Edinburgh. ISBN 978-1-898042-15-0

34. Mcroy, A. & McCarthy, J (2015). Pediatric Nurses' Perceptions and Experiences with AAC. University of Tennessee Health Science Center, Knoxville

35. Morris, C (2018) Training for ward stuff to imp ove communications. Pencru. University of Exeter Medical Crew

36. Murray, Lynch, Moulam, Meredith, Goldbart, Whittle, Judge, Randall, Webb, Meads & Hess, 2019 Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision making (HS&DR number: 14/70/153) available at: https://iasc.mmu.ac.uk/i-asc-explanatory-model-of-aac-decision-making/

37. National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC), (2015) Communication Bill of Rights www.asha.org/njc

38. Paterson, H (2019) Nurse training and AAC: What can nurses and AAC users teach us?' Research into a new training intervention. Communication Matters Conference, Leeds

39. Porter, G. (2007). Pragmatic organisation dynamic display communication books. Melbourne: Cerebral Palsy Education Centre.

40. Teaching Strategies - Modelling in Everyday Activities October 2010 Supporting Communication Device Use 6.2© Rocky Bay 2010 Positive AACtion Information Kit for AAC Teams

41. Santiago, R (unknown) AAC considerations in Advance of a child's upcoming hospital admission: Preparing early to enhance Care. [PowerPoint Presentation], Boston Children's Hospital

42. Santiago, R. & Costello, J. (2018) AAC in Pediatric ICU and Acute Care Settings: A Requirement for Best Patient Care, (Presentation handout from ASHA 2018), Boston Children's Hospital

43. Scope and CDDHV (2008) Because Mental Health matters. The Bridging Project. Submission to the Victorian department of human services

44. Sharkey, S., et al (2015) Communication with disabled children when inpatients: barriers and facilitators identified by pa ents and professionals in a qualitative study. Sherlock, C (2006) A survey of AAC need in a Children's Hospital. Birmingham Children's hospital

45. Tainsh, H. (2018) 'Pragmatic Dynamic Display Communication Books.' [PowerPoint presentation] One Day Overview: Nepean School

46. The Communication Trust; Supporting children and young people who have no speech or whose speech is diffi lt to understand. Other ways of speaking. Communication Matters

47. Thunberg G, Buchholz M, Nilsson S.(2015) Strategies that assist children with communicative disability during hospital stay: Parents' perceptions and ideas. J Child Health Care. 2016 Jun;20(2):224-33. doi: 10.1177/1367493514568298

48. Trotta, R., Hermann, R., Polomano & Happ, M, (2019) Improving Nonvocal Critical Care Patients' Ease of Communication Using a Modified SPEACS-2 P ogram.

49. The Journal for Healthcare Quality: January 03, 2019 - Volume Publish Ahead of Print - Issue - p

50. Vantaa Benjaminsson, Merja & Thunberg, Gunilla & Nilsson, Stefan. (2015). Using Picture and Text Schedules to Inform Children: Effects on Dist ess and Pain during Needle-Related Procedures in Nitrous Oxide Sedation. Pain Research and Treatment. 2015. 1-6. 10.1155/2015/478503.

51. Williams. A 'Meeting Patient Communication Needs with Evidence-Based Practice.' [PowerPoint presentation] The Vidatak EZ Board. PPT presentation-presentation transcript. Available at: https://slideplayer.com/slide/232548/. Accessed 1/05/2019

52. Wilson M, Megel M, Enenbach L, Carlson K. (2010) The voices of children: stories about hospitalization. J Paediatr Health Care. Mar-Apr;24(2):95-102. doi: 10.1016/j.pedhc.2009.02.008.

8. APPENDIX

Appendix 1:

Communication aids questionnaire

Communication Aids for patients with communication difficulties
- utilisation, access and understanding Questionnaire
Prior to Training

Department/ Ward		Discipline (if relevant)	
Years employed at Monash Children's Hospital		Gender	

The following questions relate to your patients who use communication aids (charts, PODD (pragmatic organisation dynamic display) books, visuals, switches, devices (low and high tech) which enable them to communicate with you. For example:

(0 not at all - 5 very confident) OR (0= not at all important 5 extremely important)	0	1	2	3	4	5
I have used communication aid/ devices in my practice within the hospital						
I am familiar with communication aids that currently exist and are used within the hospital						
I am familiar with different types of communication aids that children may require to communicate						
I know where to locate or access a communication aid if a child required one within the hospital						
How confident do you feel working with children who have communication difficulties or are non-verbal?						
I am aware of how I could use communication aids in my area of the hospital						
I am able to find information about how a child communicates when I am caring for them						
I feel confident that I know the cognitive ability and understanding of children in my car						
How important would you rate using a patient's communication aid						

with them when they need to talk to you?						

- How often do you care for a child who has difficulty communicating?

_____
_____
_____

- Where would you find out information about how to communicate with a specific child?

_____
_____
_____

- What communication method do you typically use when a child is non-verbal?

_____
_____
_____

- What would be the most important question/ conversation you need to communicate with a patient that you have had difficulty with in the past?

_____
_____
_____

- State one word to describe interactions with a patient who is unable to speak.

_____

Do you have any suggestions or things that have worked in the past you could share?

_____
_____
_____
_____
_____

If you are interested in becoming a Communication Champion who is able to help support needs of students in your care please email Katherine Lingard.

International Specialised Skills Institute

ISS Institute
Level 1, 189 Faraday Street
Carlton VIC 3053

T 03 9347 4583
E info@issinstitute.org.au
W www.issinstitute.org.au

Published by International Specialised Skills Institute, Melbourne | www.issinstitute.org.au