

<b>Institution: Manchester Metropolitan University</b>
<b>Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy</b>
<b>Title of case study: Enhancing the lives of people with severe and complex disabilities</b>
<p><b>1. Summary of the impact</b></p> <p>This case study describes the impact of 15 years of research on the health and well-being of people with severe and complex disabilities. Through collaboration with education and disability services, research-based guidance has been developed on communication intervention and safe eating and drinking, informing:</p> <ul style="list-style-type: none"> <li>• National Patient Safety Agency’s Guidance Paper on dysphagia.</li> <li>• Royal College of Speech &amp; Language Therapists’ (RCSLT) position paper on Adults with Learning Disabilities (2010).</li> <li>• RCSLT’s professional guidelines: Communicating Quality 3 (2006).</li> <li>• Department for Education’s training materials for teachers of learners with severe, profound and complex learning difficulties (<a href="http://www.education.gov.uk/complexneeds/">http://www.education.gov.uk/complexneeds/</a>).</li> <li>• Assessments for children and adults with profound intellectual impairments (Triple C; Routes for Learning).</li> <li>• Curriculum guidelines for children with severe learning difficulties across the UK.</li> <li>• Guidance for health service commissioners developed on behalf of the Royal College of Speech and Language Therapists and the campaigning charity Mencap.</li> </ul> <p>Outputs are also cited in many education, health and social care internet advice sources (see sections 4 and 5).</p> <p><b>2. Underpinning research</b> The underpinning research was conducted between 1997 and 2012 by Sue Caton, Darren Chadwick and Juliet Goldbart, in the context of a longstanding collaboration with the Manchester Learning Disability Partnership and specialist schools in the Manchester area. The research comprises two related strands which materially affect the lives of children and adults with severe and complex learning difficulties, their families and those who work with them; eating and drinking, and communication.</p> <p>Difficulties with eating and drinking (dysphagia) are a serious problem for some people with learning disabilities affecting individuals’ health and quality of life and, in serious instances, can lead to death. This research [1, 2, 3] examined the implementation of guidelines for eating and drinking developed by speech and language therapists in terms of carers’ knowledge of the guidelines, the accuracy with which they used them in practice, and the barriers to compliance. We found [1] that recommendations relating to concrete and routinely used management strategies are easier for carers to adhere to and remember than support-based strategies such as verbal prompting and pacing. Moreover, carers implemented management strategies significantly better than they could recall the details of the written management guidelines. This suggested a need for carers to re-familiarize themselves with management strategies and their rationales periodically following initial training.</p> <p>Furthermore [2, 3], whilst guidance relating to modification of the consistency of food and drink was generally adhered to by carers, other aspects, such as pacing correctly; facilitating people to adequately relax and concentrate; observing and prompting people to pace suitably and take safe amounts of food and drink in each mouthful, were not, thus increasing the risk of aspiration and asphyxiation [4].</p> <p>Over 80% of people with severe or profound learning difficulties have communication impairments which merit intervention (Bradshaw, 2007; RCSLT, CQ3, 2006). The findings reported in [5] offer a synthesis of theory and original research demonstrating how a detailed understanding of the cognitive and social roots of communication can be used to provide assessment and intervention approaches for children and adults with profound disabilities at a range of levels within developmental stages that typical infants would complete by the age of 15 months. The research demonstrates that reliable progression can be identified through these early developmental stages, identifying the importance of developing intentionality (the realisation that one can affect the environment) typically acquired around 6 months of age for avoiding learned helplessness and associated behavioural challenges.</p> <p>The utility of the Affective Communication Assessment is demonstrated and a sequence of intervention approaches leading to Joint Action Routines is mapped out. An assessment of early</p>

## Impact case study (REF3b)

pragmatic skills was also developed within the research. The synthesised information is incorporated into an Early Communication Assessment for which reliability data are provided.

### Key Researchers

Juliet Goldbart. Appointed L2 1/10/1980; SL 1/10/1988; Reader 1/10/2001; Professor 5/1/2009.  
Daren Chadwick. Appointed Research Fellow in Speech Pathology 1999 (joint post between MMU and Manchester Learning Disability Partnership), Senior Lecturer in Psychology (0.5) and Research Fellow in Intellectual Disability (0.5) 2001-9. 2009 - Marie Curie Research Fellowship, Trinity, Dublin. Sue Caton. Research Associate 1999- present.

### 3. References to the research

[1] Chadwick, D. D., Jolliffe, J., & Goldbart, J. (2002). Carer knowledge of dysphagia management strategies. *International Journal of Language and Communication Disorders*, 37(3), 345-358. DOI: 10.1080/13682820210137196 (10 citations)

[2] Chadwick, D. D., Jolliffe, J., & Goldbart, J. (2003). Adherence to eating and drinking guidelines for adults with intellectual disabilities and dysphagia. *American Journal on Mental Retardation*, 108(3), 202-211. DOI: 10.1352/0895-8017(2003)108<0202:ATEADG>2.0.CO;2 (21 citations)

[3] Chadwick, D. D., Jolliffe, J., Goldbart, J. & Burton, M. H. (2006). Barriers to caregiver compliance with eating and drinking recommendations for adults with intellectual disabilities and dysphagia. *Journal of Applied Research in Intellectual Disabilities*, 19(2), 153-163. DOI: 10.1111/j.1468-3148.2005.00250.x (7 citations)

[4] Samuels, R., Chadwick, D.D. (2006). Predictors of asphyxiation risk in adults with intellectual disabilities and dysphagia. *Journal of Intellectual Disability Research*, 50(5), 362-370. <http://www.ncbi.nlm.nih.gov/pubmed/16629929> (15 citations)

[5] Coupe-O'Kane, J. & Goldbart, J. (1998). *Communication Before Speech*, London: Fulton. Copy of this book, which includes empirical data, will be supplied on request.

[6] Goldbart, J and Caton, S (2010) "Communication and People with the Most Complex Needs: What works and why this is essential", Mencap, London. <http://www.mencap.org.uk/all-about-learning-disability/information-professionals/communication> - see Section 4 below.

### Quality Indicators:

Much of the research described in the above papers was funded through approximately £130,000 of Culyer funding gained by a joint bid between MMU and the Manchester Learning Disability Partnership to evaluate "cutting edge practice" in speech and language therapy for people with learning disabilities, from 1999 to 2007.

In addition, a small award of £5950 was gained for October 2009 – October 2010 through competitive tendering from Mencap and Department of Health Valuing People team.

### 4. Details of the impact

#### **Impacts On The Management Of Eating And Drinking Difficulties (Dysphagia)**

Research on adherence to dysphagia management strategies, and the barriers to adherence were of considerable interest to the National Patient Safety Agency who incorporated the findings into their Guidance Paper (ref 0500) which was designed to reduce the deaths and disease burden resulting from eating and drinking difficulties in people with learning difficulties. This Guidance Paper identifies best practice for healthcare organisations, such as a local policy on dysphagia care including systems for reporting patient safety incidents, provision of information on dysphagia management and recommendations for staff training. The risk assessment materials were devised for this report by authors of the research papers identified in 3 (above).

This research has informed practice in many Trusts, for example Guthrie's staff training at a medium secure unit (Calderstones Partnership Foundation Trust), after which increased risk awareness resulted in increased reporting of choking incidents but significant reductions in

severity. This work has been shortlisted for the National Patient Safety Award 2013, mental health category [A].

Research is extensively cited in Eating well: children and adults with learning disabilities, Nutritional and practical guidelines provided by The Caroline Walker Trust [B].

In addition, the research resulted in the establishment of an RCSLT Special Interest Group on Dysphagia which has disseminated research findings and resulting best practice guidance through regular meetings and seminars. The capacity-building role of this group is evidenced by members of this group who are now engaging in their own research (e.g. Manchester NHS PCT Small Grants Scheme: "Knowing when I'm sick and helping me stay healthy: Parents' insights into the impact of communication on the diagnosis, treatment and management of health; Department of Health Support For Science funded: "Training support staff to modify fluids to appropriate safe consistencies for adults with intellectual disabilities and dysphagia: an efficacy study."

### **UK And International Impacts On Communication Assessment And Intervention**

The approaches to communication assessment and intervention developed in "Communication before Speech" have informed the widely used Welsh government initiative for the education of children with profound disabilities, "Routes for Learning" [C]. One of its authors says *"the development group was unanimous in agreeing that it (Communication Before Speech) was unrivalled in the detail it provided in the very early stages of communication, and the clarity of the examples it provided. We felt that teachers could be referred to Communication Before Speech and would find practical guidance which was soundly based on evidence. It is worth noting that Routes for Learning is not only widely used in schools in the UK, but has also been translated into a number of European Languages. Consequently the influence of Communication Before Speech has also spread into these other countries."*

The book's research is extensively cited in Department for Education's (2010) Training materials for teachers of learners with severe, profound and complex learning difficulties [D], module 9 of Scope's curriculum Supporting Communication through AAC and the QCA guidance Planning, teaching and assessing the curriculum for pupils with learning difficulties (2009). It also provides the underpinning concepts for the Australian Triple C: Checklist of Communicative Competence, one of very few communication assessments designed specifically for adults with profound disabilities, and the only one with well-researched psychometric properties. According to its author [E] *"Communication before Speech" provided a framework for the Triple C... The Triple C used the terminology presented in "Communication Before Speech" for the 6 stages of communication – i) reflexive, ii) reactive, iii) proactive, iv) intentional informal, v) intentional formal and vi) intentional referential. Much of the descriptive information to accompany the stages was adapted from the work done by Coupe-O'Kane and Goldbart."*

According to the Learning and Skills Excellence Gateway [F] *"Written by two specialists in the field, Coupe-O'Kane and Goldbart is a key text on early communication. Through an extensive review of the literature it provides a very comprehensive and clear understanding of pre-intentional and intentional communication. It also provides methods of teaching early meanings to children and adults with severe communication delay. One of the most practical aspects of this book is the two detailed assessment schedules with extensive notes about their use. It is an invaluable resource for anyone working with people with profound and complex learning difficulties. The revisions to Milestones 1-3 of the Pre Entry Curriculum Framework drew extensively on the Early Communication Assessment (ECA) described in this book."*

The research contained in the book has been incorporated into a wide diversity of training materials, such as RNIB's Effective Practice Guide: Becoming a Sensitive Communication partner, Scope's Supporting Communication through AAC Module 9: Children and Adults with Profound and Multiple Learning Difficulties.

The pervasive impact of this research enabled Goldbart and Caton to tender successfully to Mencap and Department of Health's Valuing People team for a project aimed at providing clear information for commissioners of services, service providers and carers and family members of people with severe and complex disabilities (proxy consumers of services) on what communication intervention approaches were evidence-based (using Sackett et al's triarchic concept of EBP). This

document [6 above] was published in 2010 by Mencap. In addition to the review of existing evidence, interview and focus group data were collected from parents of children and adults with complex communication needs as well as from researchers and expert practitioners. Thus, this report constitutes both underpinning research and impact. *"The new guide will be a valuable tool for families and professionals,"* said Beverley Dawkins OBE, chair of the PMLD Network and national officer for PMLD at Mencap. *"Communication is a human right that many of us take for granted. It allows people to interact with others, express their feelings and be involved in the decisions that affect their everyday lives."* [G]

The report has been uploaded to the websites of a wide range of education, health and social care providers and is cited by the Social Care Institute for Excellence' Social Care Online [H], NHS Evidence in Health & Social Care, Values Into Action Scotland, NHS Education Scotland, Public Health England's Child and Maternal Health Intelligence Network, the Government of Western Australia's Disability Services Commission, inter alia.

According to the chief executive of one agency *"As part of [our] staff induction programme, we do sessions on non-verbal communication. Reference [6] is central to this training. Staff are given a copy of this publication and also referred to [5] as essential reading. Additionally, we recommend [6] to professionals from other voluntary organisations and health and social care staff working with people with profound and multiple learning disabilities."* [I] It also forms the basis for Mencap's 2013 "How to" guidance on communication for people with PMLD [J].

### 5. Sources to corroborate the impact

[A] Link to 2013 award announcement corroborating the success of MMU MSc student Guthrie, whose research and service developments draw heavily on refs [1-4].

<http://www.hsj.co.uk/Journals/2013/07/18/v/d/f/PSCI Awards 2013 Brochure ToUse Jul9.pdf> p.16.

[B] Link corroborating the impact of Chadwick and Goldbart's research on evidence-based national guidance on safe eating and drinking for children and adults with learning disabilities.

<http://www.cwt.org.uk/pdfs/EWLDGuidelines.pdf>

[C] Written testimonial on file from co-author of the widely used Welsh government initiative for the education of children with profound disabilities, Routes for Learning, corroborating the impact of *Communication Before Speech* on current assessment approaches for children with profound and multiple learning difficulties (PMLD).

[D] Department for Education's (2010) Training materials for teachers of learners with severe, profound and complex learning difficulties, <http://www.complexneeds.org.uk/>. Reference to *Communication Before Speech* is made in many of the modules in this training package, corroborating the impact of the research within the book on the education of children with PMLD.

[E] Extract from written testimonial on file from lead author of The Triple C: Checklist of Communication Competencies, the major communication assessment for adults with PMLD.

[F] The Learning and Skills Improvement Service's Excellence Gateway appraisal of *Communication Before Speech* can be found at

<http://repository.excellencegateway.org.uk/fedora/objects/import-pdf:9879/datastreams/PDF/content>

Specific references can be found at

<http://www.excellencegateway.org.uk/searchresults?qq=Goldbart&submit.x=-1404&submit.y=-70>

[G] Statement by Beverley Dawkins OBE corroborating the impact of the research contained in Goldbart and Caton [6]. [http://www.mencap.org.uk/sites/default/files/documents/2011-01/viewpoint\\_janfeb11.pdf](http://www.mencap.org.uk/sites/default/files/documents/2011-01/viewpoint_janfeb11.pdf)

[H] <http://www.scie-socialcareonline.org.uk/profile.asp?guid=d0864a1f-87bf-4aab-812f-a48343a4ee71>

[I] Written testimonial on file from Chief Executive of PAMIS, Scotland's major campaigning and research charity supporting people with PMLD, their family and carers and professionals.

[J] <http://www.mencap.org.uk/node/6008> corroborates the impact of [5 and 6] on current approaches to communication with people with PMLD.