



# West Midlands Education Innovation and Notable Practice

**COMMUNICATION TOOLKIT: SUPPORTING CHILDREN, YOUNG  
PEOPLE AND FAMILIES WHERE THERE IS A LEARNING DISABILITY**

**2010 - 2011**



# COMMUNICATION TOOLKIT: SUPPORTING CHILDREN, YOUNG PEOPLE AND FAMILIES WHERE THERE IS A LEARNING DISABILITY

*KEELE UNIVERSITY AND BIRMINGHAM CHILDREN'S HOSPITAL*

<b>Overview:</b>	The collaborative development of a bespoke Toolkit that provides a dynamic communication resource to support healthcare professionals to provide palliative and end of life care for children, young people and families where there is a learning disability.
<b>Lead:</b>	Dr Sue Read & <sup>2</sup> Nicki Fitzmaurice, Reader in Learning Disability Nursing; CYP Lead, Connected <a href="mailto:s.c.read@nur.keele.ac.uk">s.c.read@nur.keele.ac.uk</a> - <a href="mailto:NICOLA.FITZMAURICE@bch.nhs.uk">NICOLA.FITZMAURICE@bch.nhs.uk</a>

A significant proportion of children and young people diagnosed with life-limiting conditions have some form of disability (DH, 2007), therefore training and education that addresses the specific communication needs of these children and young people is fundamental to effective palliative and end of life care and support.

This collaborative project materialised originally from a collaboration between Birmingham Children's Hospital NHS Foundation Trust, Birmingham CAMHS LD and Connected®, The National Communication Skills Training Programme, and funded by the Department of Health. It aimed to develop a communication Toolkit to help professionals to empower children, young people and their families where there is a learning disability, within the palliative and end of life care context. It brought together examples of existing good practice whilst simultaneously developing a range of additional tools to enhance the communication process.

Initially, we held a series of focus groups and interviews with a range of healthcare professionals and parents across the West Midlands to talk with them to explore exactly what they perceived to be the key issues and challenges around communication with children, young people and families where there is a learning disability. Such discussions became the foundations upon which the content of the Toolkit was developed.

The Toolkit has 26 components, incorporating a range of accessible information that can be easily accessed and updated, and therefore remains dynamic. It includes supportive leaflets; information sheets in a variety of different formats; and posters that can be displayed in prominent but not intrusive positions in clinical areas.

The interactive software (*picTTalk*®) provides a unique resource that can be downloaded and used to facilitate dialogues around sensitive topics using contemporary technology. Alternatively, the images found in the software (*picTTalk*®) are also provided as set of small credit card sized images (*Communication Cue Cards*®) that can be used in any location (playroom, bedroom, lounge, garden) and can be used in many different ways to help people to explore issues and make choices about their care.

The accompanying Resource Guide provides information regarding how to make the most out of these interactive resources. There is a DVD with a film entitled '*Listening to, hearing from, and involving people*' that has much flexibility of usage from an educational perspective and a film showing the full ballet performance entitled 'September 11<sup>th</sup> 2001', by children and young people with a learning disability. We have also included a PowerPoint presentation that provides a summary of the Toolkit and a range of information to inform the health care professional about learning disability and the importance of effective communication. The Toolkit has pictures and drawings by children and young people throughout all of its components.

This Toolkit was not developed to replace education and training around this sensitive area of care, but to complement existing opportunities and to encourage the further development of others. Similarly, whilst this resource may not provide a solution to every challenge, it is hoped that it will help palliative care professionals to realise their existing potential whilst encouraging them to explore other possibilities when communicating with children, young people and families where there is a learning disability.

The Toolkit was launched at Birmingham Children's Hospital on May 6th; in Worcester on May the 13th, and in Stoke on Trent on June 14th. To ensure its sustainability, the Toolkit can be purchased from an advocacy organization in Stoke on Trent (Reach) as part of a social enterprise scheme or can be and freely down loaded from: <http://tiny.cc/qpsxx>

#### References

DH (2007) *Palliative Care Services for Children and Young People in England* DH Publications, London.