

Health at Warwick **update**

Finding out more about disabled children



Surprisingly little is known about some aspects of the population of disabled children, their circumstances and the role of social factors in producing and reducing childhood disability. As a result, policy makers and service providers often don't have the information they need.

Clare Blackburn, who leads the multidisciplinary Disability and Health Research Group at the University of Warwick, says: "Until recently, although we had rich information from qualitative studies on the experiences of disabled children and their households, there was a lack of up-to-date, reliable, quantitative data which could be used to inform policy and service delivery."

Clare says: "A range of bodies, such as local authorities, are obliged to provide services for children classed as disabled under a range of legislation, and it is therefore important to know how many such children there are, and their characteristics and circumstances." A study funded by the Economic and Social Research Council (ESRC), by Blackburn, together with colleagues Janet Read and Nick Spencer, looked at children defined as disabled under the Disability Discrimination Acts.

This study, published in 2010 in *BMC Paediatrics*, showed that more than 952,000 children (7.3 per cent) in the UK in 2004-2005 were reported as disabled, using the definition supplied by the Acts.

"This paper produced some key data on both the prevalence of childhood disability, and on the characteristics and circumstances of disabled children and their households," Clare says. "One important finding was that disabled children in the UK experience higher levels of poverty and personal and social disadvantage than other children."

In addition, the analysis showed:

- One-third of disabled children live in lone-parent households;
- Disabled children in the UK are more likely than non-disabled children to live in rented accommodation;
- Disabled children are more likely to live with disabled siblings and other disabled children than are non-disabled children; and
- The prevalence of parental disability was higher among disabled children than among non-disabled children.

Blackburn and her colleagues have provided advice and information to several Government departments, including HM Treasury and the Department for Education, and to primary care trusts and local authorities, on how they can

best estimate the numbers of disabled children, for planning and service delivery purposes. They also advised on the characteristics and circumstances of this group. Non-governmental organisations have also used prevalence estimates and information on the circumstances of disabled children provided by the paper in *BMC Paediatrics*.

Additional work by the group, commissioned by the Department for Children, Schools and Families, and carried out in collaboration with the National Centre for Social Research in London, and Bristol University, involved designing a national survey for families of disabled children, which local authorities used to measure improvement in service delivery for disabled children and their families, as part of the Government's initiative, *Aiming High for Disabled Children*.

The same collaboration is also responsible for the national evaluation of pilot programmes to improve day-care provision for disabled children and their families.

Some of the Warwick team were also involved in some of the research that fed into the Lamb Inquiry into special educational needs and disability. This inquiry reported in

Disabled children in the UK experience higher levels of poverty

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The advent of the digital poster



Last year, Davide Nicolini, Co-Director of the Institute of Health, had planned to attend a conference in Australia, but at the last minute he couldn't go. "Instead, I sent a poster and responded to questions over Skype," he says. "People loved it and said it was very different."

The experience gave him the idea of producing "digital" posters: posters that would be viewed on a large screen and which could incorporate sound, music, video and animation.

Davide says: "Many people will find that a digital poster is more accessible, and you can put it on your website or send it to someone via email. I wouldn't deny that producing a digital poster takes more time than producing a traditional print one, and it needs new skills, but I believe it is more effective."

Researchers sometimes include a massive 2000 words on a poster, he points out. But putting together a video or animation forces the author to focus on the key points, Davide says.

The Institute of Health road-tested the idea of digital posters at its networking event in April 2011. Held at The Digital Lab, a large, airy building on the University of Warwick campus, the event provided an opportunity to showcase health-related research across the university.

"We hold these events because there are plenty of people throughout the university who work on health, some of them in the most unexpected places," Davide explains. "There are a lot of people who are quite isolated, working by themselves, but who have tangential or overlapping interests and who need somewhere to meet. It's particularly important for young scholars."

The day included a series of short presentations by different research groups—each one just long enough to capture the interest of others and tell them where to find out more. To strengthen links with researchers at Coventry and Warwickshire NHS Trust, there was also an "outreach event", where a third of the posters went on display in the Clinical Sciences Building at Coventry Hospital.

Many people will find that a digital poster is more accessible

As always at conferences, some of the most important interactions took place outside of the formal presentations, over coffee or lunch. "We wanted to bring people together, so that they can take notice of what others are doing—a place of 'creative abrasion,'" Davide says.

The digital posters provided one of the highlights of the day. Several large screens dotted around the poster area, with headphones, allowed those browsing the posters to look at the digital versions provided by 10 research groups.

Clicking on each title showed that different authors had interpreted the idea of a "digital poster" in different ways. Some had produced videos of members of their team talking about their work; others were more akin to PowerPoint presentations with music (or even PowerPoint without music!).

The Institute of Health had provided two free training sessions in February and March for people who wanted to find out how to produce digital posters. It also organised a vote for the best digital poster, with a cash prize of £100 for the one voted the best.

The winning poster—by a landslide vote—was that by Xiao Ma, a Ph.D. student at WMG (formerly Warwick Manufacturing Group), which is based at The Digital Lab, with Jay Bal (Xiao's supervisor), who together produced a digital poster on "Patient-Driven Healthcare".

Xiao says: "I think there are some difficulties in understanding what a digital poster is. It's a bit hard to define...there is a difference between a digital poster and a printed poster in digital format."

When he was first asked to produce a digital poster, he says, he did not know what to do. "I just made one as I thought it should be—it made me feel like an artist even though I am an engineer."

Xiao and Jay's digital poster incorporated a music soundtrack and lots of animation. Xiao says he has only scratched the surface, though, in terms of what might one day be possible.

"This was just a pilot. But I think that interactivity will be key to the success of digital posters. If you had touch-screen technology, that would help. And a lot of research is about the changes you observe, so you could use

animation to show people what these changes were over time, for example,” he adds.

In future, he predicts, digital posters will be multimedia in nature, including video, audio, and physical modalities. They could be interactive, using, say, a joystick or a glove to allow “real virtuality”. Already, audio gives important advantages: if you are describing the sound of an electric vehicle for your research on sound in healthcare environments, a digital poster would allow you to present this to the viewer as it sounds, rather than describing the sound in words on paper.

Christopher Golby, also a Ph.D. student in WMG at The Digital Lab, suggests that the digital posters of the future should allow you to click deeper and deeper into the topics that surround the work described. Touch-screen technology would be useful, he agrees; he predicts that, in a few years, it will be much more affordable.

Xiao adds: “Everything could be hyperlinked and described by subconcepts or superconcepts, and you could click on links to see what other work had been done in those areas, before skipping across to other disciplines, too.”

Another idea would be to form a Facebook group of people who attended the event, where users could access the digital posters and keep in touch with each other. Putting the posters up on YouTube would also help with making the information more generally available: Xiao predicts that, eventually, YouTube could be host to an entire education system, rather than mainly the preserve of music videos and DIY demonstrations.

The posters displayed at the April event had a button that viewers could click on, to allow them to email the author(s) and leave their feedback. It’s also possible, of course, to set up Skype so that viewers can call author(s) and ask them questions directly—but, on this occasion, the cost was too high to provide this facility.

Many people at the session seemed to enjoy viewing the digital posters. Christopher agrees with Davide that the format of a digital poster forces authors to boil down their ideas into digestible chunks—and watching a screen is something that many people naturally enjoy. “I’ve noticed that if you do a lecture with slides, people tend to drift off. But if you put on a video, people become more alert and watch it.”

Priya Tah, Research Associate at the Clinical Sciences Research Institute, Warwick Medical School, says the digital posters were very different to anything she had seen before. “I expected them to be more like presentations,” she says. “The music on some of the digital posters was very relaxing and helped to hold your attention.”

They were definitely a nice alternative to normal posters, she says, although authors need to strike a balance between too much information and not enough. Priya says, “I did find that, with one of the posters, there was too much information on the screen and too much narrative, to be able to take it all in, in the time available.”

Interactivity will be key to the success of digital posters

Clearly, the medium of digital posters will carry on evolving in the coming years. Davide detects that some academics are so entrenched in their ways that they will simply ignore the screens. “Even when we offered them a reward of £100, not that many people chose to produce a digital poster,” he says.

No one would want to substitute conferences for events that take place purely online, using Skype and the like, he concludes. “We know there are enormous benefits from meeting other people in the flesh. But it is strange that, in an era where YouTube is one of the best-recognised brands, after Coca-Cola and Google, academics in 2011 still choose to communicate with each other via pieces of paper stuck on a wall. This is almost prehistoric—posters were invented by the Romans!”

Davide recognises that his kids automatically gravitate towards information on screens. And it will not be long before that generation includes up-and-coming researchers. Digital posters may be in their infancy today, but it won’t be long before they grow up!



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2009 and its recommendations eventually resulted in the Green Paper, *Support and aspiration: A new approach to special educational needs and disability*, which came out in March 2011.

While the work reported in the 2010 paper in *BMC Paediatrics* answered many questions about the prevalence of childhood disability in the UK, its findings also raised many new questions. The ESRC is now funding Clare Blackburn, Nick Spencer and Janet Read to conduct a new study that will explore the relationship between social disadvantage and the prevalence of childhood disability.

Clare says: "For example, using a longitudinal study, we are examining the extent to which disabled babies are born into disadvantaged households and the extent to which households get poorer once they have a disabled child. We want to find out whether social disadvantage precedes or follows childhood disability."

Likewise, she adds, the group wants to discover whether more disabled children are born to adults with a disability; or whether adults are more likely to become disabled while they are caring for a disabled child.

Janet says: "Our finding that disabled children are more likely to live with disabled parents, has already been very useful for practitioners and policy makers. Social care workers, whom we have worked with, are now more aware of this issue and its implications for service delivery for the whole family."

Does social disadvantage precede or follow childhood disability?

Other aspects of the new ESRC-funded study will include an analysis of anonymised data from the 1991 and 2001 censuses in order to identify trends in childhood disability and examine the associations between childhood disability, ethnicity, parental disability and lone parenthood, after adjusting for social disadvantage. There will also be a systematic review of the published literature on the association between disability in childhood and social disadvantage in high-income countries.

Further Reading

Blackburn C, Read J and Spencer N. (2010) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: Secondary analysis of the Family Resources Survey. *BMC Paediatrics*: **10**: 21.

Read J, Blackburn C and Spencer N. (2010) Disabled children in the UK: a quality assessment of quantitative data sources. *Child Care Health Development* **36**(1): 130-141.

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Blackburn C, Read J and Spencer N. (2007) Can we count them? Scoping data sources on disabled children and their households in the UK. *Child: Care, Health and Development* **33**(3): 291-295.

A new play about end-of-life care



Nearly 60 per cent of people will die in hospital even though, if asked, most people say they would prefer to die at home. Many people experience a disruptive transfer from their home or care home just before they die—a jolting ride in an ambulance followed by admission through the noisy and brightly lit accident and emergency

department, even though they have not had an accident and nor, one can argue, is it really an emergency.

Hospice care aside, the evidence suggests that almost every aspect of care for those who are dying could be better—communication between health care professionals and the person who is dying, their relatives or loved ones; the provision of palliative care; the attempts to provide last-

ditch treatments that, in the end, will probably do no good.

It is issues such as these that Claudette Bryanston, Associate Senior Fellow at the Institute of Health, and a freelance theatre maker and theatre director, has explored in a new production called *Passing On*. Collaborating with writer Mike Kenny and the theatre company Little Angel Theatre, she has put together a new play relating to death, and dying of old age in hospital.

Bryanston says: "Theatre is a very powerful medium, because it is so visual and emotive. As such, it provokes the opportunity for debate, which adds a further dimension to the dissemination of research."

The production is a play for anyone, she says. "One thing we all share is our mortality. However, it will be particularly interesting for health care professionals and students

in training, such as doctors and social work students. We want to invite anyone who is involved in working with people at the end of life—doctors, nurses, social workers, care home and nursing home staff, bereavement counsellors and relatives.”

A study of the care provided to people who died within 48 hours of admission to a Midlands hospital formed the starting point for the project. This research, funded by the Burdett Nursing Trust, and conducted by Ann Jackson, Judith Purkis, Elizabeth Burnham, Gillian Lewando Hundt and Loraine Blaxter was published in *Emergency Nurse* in 2010. Transcripts of 40 interviews with staff and bereaved relatives were also available from this study.

“The accounts were incredibly articulate,” Bryanston says. “I read through all this material and we then held six Saturday workshops.” The aim was to take the written material and explore some of the issues and findings “from the inside” with those working in end-of-life care, and then to transpose their experience using drama techniques.

“We explored all kinds of things in these workshops, which were really interesting and exciting,” Bryanston recalls. “For example, some nurses described some of the rituals that they would perform when they carried out ‘last offices’, which includes the washing and preparation of the body. But they also mentioned such things as opening a window, ‘to let the soul fly out’, and the importance of being able to do this for patients who had become well known to nursing staff.”

Some of the discussions focussed on the tensions that can develop when formal policies clash with traditional practices. For example, one family found it very traumatic that they were not allowed to help wash the body of the deceased, because of the potential dangers of hospital infection.

“These kinds of things are rituals that offer people catharsis,” Bryanston observes. “But they are not always allowed to do them.”

The workshops helped the theatre team to distil out several key themes, which feature in each of the scenes of the production. These themes include communication and mis-communication, the difficulty of mentioning death, the problem of unwelcome medical interventions, and the

consequences of moving patients at the end of life.

Bryanston decided to use a life-sized puppet to play the person who was dying. “Someone who is dying is always being handled either by health professionals or by members of the family. I wanted to take that imagery of the puppet being handled, and at the same time manipulated, in order to come to life, to provide a realistic vision of what was happening. The actor puppeteers enabled the puppet to ‘breathe’. As a result, the puppet can actually die, in a way that no actor can—as soon as the puppet ceases to be handled and the actor puppeteer moves away, the puppet is dead. It provides a very powerful image,” Bryanston explains.

One clear message from the transcripts, which the production focuses on, is that there comes a point at the end of life, when carers need to stop providing treatment to cure and just provide appropriate palliative care. “People said that it was important to be able to recognise the signs of death, to know that the body is shutting down, and to allow it to shut down as peacefully as possible,” says Bryanston.

Another theme homes in on the need for better communication. One transcript, Bryanston found, was “almost Pinteresque in its inability to get to the point”. She says: “It seems that, in 2011, we struggle to talk about death. It becomes the ‘elephant in the room’. In Victorian times, people would talk about death with almost too much enthusiasm, but could never talk about sex. In this age, it seems to be the other way round.”

She hopes that *Passing On* will provide health care professionals with a stimulus to help them discuss some of these difficult issues and bring them into the open.

There will be a performed reading of the production on 7 June 2011 at the studio at Warwick Arts Centre. The production has also been invited to participate in the Suspense Festival—an international festival of adult puppetry—which will take place in London between 28 October and 6 November 2011.

Further Reading

Jackson A, Purkis J, Burnham E, Lewando Hundt G, Blaxter L. (2010) Views of relatives, carers and staff on end of life care pathways. *Emergency Nurse* **17**: 22-26.

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PASSING ON

Date: 7th June 2011

Performances at 2.30pm and 7.30pm

The Studio, Warwick Arts Centre

University of Warwick

Coventry CV4 7AL

The play explores issues and dilemmas confronting relatives and health professionals during End of Life Care by juxtaposing powerful testimony with puppetry and physical theatre. The post-show discussion panel will include social scientists, health professionals and theatre artists.

By Mike Kenny in collaboration with The Little Angel Theatre

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Directed by Claudette Bryanston

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<http://www.warwick.ac.uk/go/passingon/>

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