

update

Understanding Diversity: Issues in Access to Health Care

This issue of Update draws attention to a key aim of the Institute of Health: to promote, support and develop research in health, medicine and social care. The research featured in the following pages exemplifies how multidisciplinary social science research at the University of Warwick is influencing policy and practice and linking health, medicine and social care research.

Ethnicity and Health Service Access

The ways in which people's ethnic backgrounds have an impact on their use of health services are innumerable. They may need interpreters to understand what their health care workers are saying to them; they may require special diets when in hospital; their ethnic group may put them in need of screening for particular diseases; or their cultural values may lead them to question their need for certain types of health care.

When the London Regional Office of the NHS Executive wanted to know how to tailor its planned services to ensure equitable access for the London population, including people from black and ethnic minorities, they commissioned the Centre for Health Services Studies (CHESS) at the Warwick Business School of the University of Warwick to help them find out.

The result was a weighty document, called *Systematic Review of Ethnicity and Health Service Access for London*, prepared by CHESS together with the Mary Seacole Research Centre at De Montfort University in Leicester, and the Centre for Research in Ethnic Relations (CRER), also at the University of Warwick.

Ala Szczepura, Professor of Health Services Research at CHESS, said:

"Our brief was very broad, to look across all specialties, to see what evidence there was on issues of access to health services by ethnic minorities. The London Regional Office wanted to be able to develop evidence-based policy and practice. This was an essential aim for them, because London has such a high proportion of people from ethnic minorities."

The main objectives of the study that Szczepura and her colleagues undertook were to carry out a wide-ranging literature review on ethnicity and health service access; to

provide relevant information on the demographic profile of London, and how this was predicted to change; and to identify gaps in the available research evidence and make recommendations for further research.

The Meaning of Ethnic Diversity

Undertaking such a project threw up important questions, Szczepura said. "For example, what does ethnicity mean? In what way is a population diverse? Are we talking about genetic diversity or cultural diversity? Some studies, for example, look at where people were born or what ethnic group they say they belong to, but they also need to look at what language people speak. Ethnicity does not always indicate someone's language needs."

Another difficulty was defining what was meant by "evidence". Szczepura said: "Evidence-based medicine has grown out of randomised controlled trials, and out of the assessment of new medical technologies. Clearly that is one form of evidence. The kind of evidence that social scientists produce is not necessarily of that kind, but it is equally pertinent to policy makers. While you might expect that much of the literature and research on areas like ethnicity and health would fall into the 'medical model', in fact much important evidence is qualitative research or not published in peer reviewed journals - it is what is known as 'grey literature'."

The report, which was launched by London Region Chief Executive, documents how London's ethnic minority population comprised nearly a quarter of the entire population of the area in 2001. Studies have suggested that over 300 languages are spoken in London's schools, and that perhaps 170,000 people in London have difficulties in speaking English.

In its conclusions, the report called for better ethnic monitoring data in London. Interventions designed to improve access to services by ethnic minorities should, it said, be routinely evaluated to establish their effectiveness and cost-effectiveness.

The report called for more and better-quality research. Fundamental research is needed, it said, to improve understanding of which dimensions of ethnicity should be studied. Long-term epidemiological studies, and coordinated projects, would be needed, as well as studies to find out which initiatives have had a positive impact on



Ala Szczepura

improving access to services, and why. Research findings need to be efficiently disseminated.

Researching evidence-based policy and practice

Since the publication of this review, the Economic and Social Research Council (ESRC) has funded a new body, the Centre for Evidence in Ethnicity, Health and Diversity (CEEHD). This centre is run jointly by CHES at Warwick, and by the Mary Seacole Research Centre at De Montfort University in Leicester. Its joint directors are Szczepura and Professor Mark Johnson, of De Montfort University.

CEEHD is one of seven centres that together comprise the ESRC's Network for Evidence Based Policy and Practice, with the Warwick-Leicester centre — as its name suggests — taking the lead on ethnicity, health and diversity.

The ESRC's pump-priming grant funds a half-time Senior Research Fellow, Dr Anil Gumber, and a Information Scientist in CHES, and a part-time Research Fellow at De Montfort. The main research interest of Dr Gumber, who qualified in Delhi, India, and Harvard, USA, is population diversity and public health.



Anil Gumber

A key aim of CEEHD, Szczepura said, is to understand what people's needs are, and to suggest ways of supplying services to meet those needs. One example is communication. To improve communication problems between health service providers and people from ethnic minorities, health authorities and trusts first of all need to know how many people speak certain languages.

That is only the first step. Szczepura said: "Even if I knew how many people had different language needs, actually translating that into services is problematic. Translating written material is not difficult, but physically getting interpreters to the general practitioner's surgery in time for the consultation requires a great deal of organisation. Then, what about in Accident and Emergency? People are not going to tell you in advance that they are going to turn up. Plus, we should not forget the impact language problems on services that rely on communication, such as speech and language therapy and talking therapies like psychotherapy."

The Department of Health has commissioned CEEHD to examine communication issues such as these in more detail.

Another project being carried out for CEEHD by Dr Gumber involves identifying NHS and other data sets on ethnic minorities. This study is being conducted in conjunction with the London Public Health Observatory which is taking the lead nationally on population diversity. Dr Gumber and colleagues are exploring data that has been collected locally for specific purposes or for other uses, such as patient satisfaction surveys within the NHS, which have asked people what ethnic group they belong to, and cancer registries.

Differential uptake of screening services

Szczepura is particularly concerned at the historic reluctance of health service providers to take account of attitudes of people from ethnic minorities when designing screening programmes. The evidence shows, she said, that women from ethnic minority groups are less likely to take part in the national

screening programmes to detect cervical cancer and breast cancer.

She was pleased, therefore, to be commissioned by the Department of Health to examine this issue during the piloting of a possible third national programme to screen for colorectal cancer, and will be undertaking quantitative and qualitative research alongside the pilot to examine the response of people from ethnic minorities.

CEEHD's formal aims are to provide first-class reviews of existing data and research evidence to inform policy and practice at national, regional and local levels; to develop ways of disseminating evidence to the people in the public, private and voluntary sectors who have an interest in this area; and to identify key gaps in research knowledge. In the long-term, the centre aims to develop a facility that can provide a national resource of research findings, including grey literature, in the area of ethnicity and health.

Szczepura sums it up more simply. "The centre is about raising the profile of ethnicity and health, and the need for a sound evidence base in this area. It is about ensuring that services are appropriate, and that they meet people's needs, including how services are organised and delivered locally. Finally, it is about demonstrating that those services are efficient and cost-effective."

Quality of life of disabled people



Janet Read

As for those from ethnic minorities, it can make an enormous difference to the quality of life of disabled people if they have access to appropriate support services and assistance. This can mean that they are able to have the sort of experiences that many non-disabled people take for granted. For Janet Read, Senior Lecturer in the School of Health and Social Studies at the University of Warwick, the idea that the quality of life of disabled children, disabled adults and those close to them should be markedly

different to those who are not living with disability or a role as informal carer should not be regarded as "exotic" at the beginning of the 21st century.

"If you accept this concept," she said, "then the next question is, what makes a difference? In many cases, the answer is to bring down the enormous barriers preventing their access to services — services that, if they were available, would enable them to have a quality of life that was comparable to the rest of the population.

This is, she said, the belief that underpins all her work, as stated in the Introduction to her recent book, *Disabled Children and the Law: Research and Good Practice*, co-authored with the lawyer Luke Clements (Jessica Kingsley, 2001).

Selected C in

Prof Paul Bywaters, (Coventry University) Ms Eileen McLeod (University of Warwick, University Hospitals Coventry and Warwickshire NHS Trust). **Social work in accident and emergency and older patients' health?** Funded by Accident and Emergency Programme, Department of Health.

Dr Matthew Cooke (University of Warwick and UCL), Eileen McLeod and Paul Walley (University of Warwick). **Systematic review to reduce waits in A&E.** Funded by NHS Service User Involvement Programme.

Ms Carol Davies (University of Warwick). **Evaluating the effectiveness of a children's home nursing intervention.** Funded by NHS Executive Research and Development.

Dr Hilary Hearnshaw (University of Warwick). **Introducing involvement instruments to improve governance in Europe.** Funded by European Commission.

Much of her research has demonstrated the verity of this belief, including that presented in a paper prepared jointly with Christine Harrison, also a lecturer in the School of Health and Social Studies at the University of Warwick, and currently in press in the *Journal of Social Work*. Its title is "Disabled children living away from home in the UK: recognising hazards and promoting good practice".

Read and Harrison conducted a review of literature on disabled children in the UK who are living away from home. They also examined research findings about the general population of children who live away from their families, highlighting areas of relevance for disabled children who likewise are separated from their families.

They found that disabled children have a substantially greater chance of being separated from their families of origin than non-disabled children. About 4 per cent of disabled children were being looked after by local authorities, about 10 times as many as for the population of children in general.

Read said: "If the child and his or her parents make a positive choice to, for example, allow the child to attend boarding school, that is one thing; but if it's Hobson's choice — because the family does not have the right sort of supports and services to enable them all to live together and have an ordinary family life of the kind which other people take for granted — then that is a worry."

Intolerable patterns of care

Read and Harrison concluded that more research is needed to explore, for example, the relationship between disability, poverty and the risk of separation, and to identify the nature of the services which lead to the best outcomes, and reduce the risk of unnecessary separation. Much of the evidence, they reported, supported earlier conclusions, that disabled children experience patterns of care that society would never tolerate for non-disabled children.

During her quest to identify what services and support would make a difference to such families, Read realised that much of the key information she gleaned came from mothers of disabled children. "In talking to them, I felt

that their experience had been neglected and that many people had stereotyped them," she said. "So I set out to study the experience of mothers of disabled children, and ask what their experiences tell us about the lives that they and their children are leading."

The result was *Disability, the Family and Society: Listening to Mothers* (Open University Press, 2000). One of Read's main conclusions was that mothers had close, intimate relationships with their disabled sons and daughters. "This went well beyond what would be expected for a non-disabled child," she said, "but neither the mother nor the child had any choice because other things such as appropriate community care services that would have been life enhancing for the child and family were not in place, that would have allowed mothers to back off without feeling that their children would be in jeopardy."

Secondly, because others so often misunderstood their child's needs, they often found themselves in the role of mediator — particularly when it came to trying to obtain services. "These findings back up what was already known about disabled children — that if you are going to get anything in the way of services at all, you need a very active mother. I hope I also shot down a few stereotypes along the way about what mothers of disabled children do, and why they do what they do," Read added.

Internet access for carers

Together with her colleague Clare Blackburn, Read is also involved in an ongoing project, called Carers Online, which is examining how information and communication technology can help disabled people and their carers. Initiated by Carers UK, a national organisation that lobbies on behalf of carers and does research on people involved in informal caring, the project involves 75 carers in three local authorities.

Those taking part will have access at home to a computer, including internet access to national and local websites providing support and information, including, for example, rights on benefits.

Read said: "We want to know whether being online could help people who are involved in informal care, many of whom are very isolated and carrying huge workloads for no pay. It sounds like a good idea, but we don't know yet. Our team will be asking carers about how they use the technology, if they use it at all, and whether it helps."

A national survey of 2000 carers will follow, exploring their experience of using information and communication technology, and whether it helps them cope with their role.

Access to services is a recurring theme among many projects that focus on the provision of health services, whether to local populations or nationally. Health providers need to study the needs of many minority groups if they are to supply appropriate services, including ethnic minorities and disabled people, as current research at the University of Warwick shows.

Current Research at the University of Warwick in the Area of Access to Health Services

Dr John MacLeod and Dr Matthew Cooke (University of Warwick and Warwick NHS Trust [UHCW]).
Departments: a better deal for
and Emergency Modernisation

Ms Jo Higgins (University of Warwick), Dr S Wilson, Mrs P Bridge (University of Birmingham) and Dr Matthew Cooke (University of Warwick and UHCW).
Communication difficulties during 999 ambulance calls: observational study. Funded by Laerdal Foundation.

Professor Geoff Lindsay (University of Warwick). **Educational Provision for Children with Specific Speech and Language Difficulties in England and Wales.** Funded by Nuffield.

Professor John McKinlay (New England Research Institutes, Boston, USA), Professor Sara Arber (University of Surrey), Dr Ann Adams (University of Warwick) Dr Christopher Buckingham (Aston University), Dr David Armstrong and Dr Mark Ashworth (Guy's, King's and St. Thomas's Hospitals). **Clinical decisions with older patients: a US/UK comparison.** Funded by National Institutes of Health.

Professor Nick Spencer (University of Warwick), Professor Panos Vostanis (Leicester University), Ms Chris Coe (University of Warwick) and Mrs Lynne Laine (Coventry Primary Care Trust). **Services for pre-school children with behaviour problems in Coventry.** Funded by Coventry Health Authority.

UHCW), Professor Jeremy Dale, (University of Warwick), Sue Wilson and John Duffy
Review and study of innovations to
Primary Care Delivery Organisation.

Evaluation of the clinical and cost effectiveness of a new service in Warwickshire.
Coventry and West Midlands.

Implementation of patient centred general practice care for older people

Continuing Professional Studies: Short Courses (no academic award)

2 - 3 September	An Introduction to Bioinformatics: a practical approach
9 - 12 December	Techniques & Applications of Molecular Biology

Postgraduate Professional Courses

(typically 4 – 5 day courses which can earn 15 – 25 credits at 'Masters' level: some form part of full Certificate, Diploma and Masters programmes – please ask for details)

September 2002	Advanced Leaders Course
September 2002	Certificate in Diabetes Care – On-site
September 2002	Certificate in Diabetes Care – IDEAL
16 - 20 September	Principles of Diabetes Care
20 September, 10, 11, 31 October & 1 November	Research in Primary Health Care
23 - 27 September	Models of Emergency Care
24 - 26 September	PGA in Medical Education
30 September - 4 October	Epidemiology, Statistics and Research Methods in Community Child Health
7 - 11 October	The Essentials of Community Gynaecology
7 - 11 October	Research Methods in Health Information Science
8 - 9 October & 4 - 6 February 2003	Learning in Practice
14 - 16 October & 20 - 21 March 2003	Management of the Menopausal Years
16 - 18 October	PGA in Medical Education
21 - 25 October	Palliative Care: Care of the Dying
21 - 25 October	Communicable Diseases and Immunisation
22 - 25 October	Counselling Skills for Health Care Professionals in Diabetes
4 - 8 November	The Menopause and Beyond
4 - 8 November	Diploma in Occupational Health (2)
4 - 8 November	Medical Statistics and Epidemiology in HIS (1)
11 - 15 November	Public Health and Women's Health
11 - 15 November	Clinical Governance in the NHS
18 - 22 November	Diploma in Occupational Health (3)
18 - 22 November	Diabetes and the Older Person
18 - 22 November	Health Protection, Promotion and Prevention
25 - 27 November	PGA in Medical Education
December 2002	Certificate in Diabetes Care – On-site
2 - 5 December	Patient and Public Involvement
2 - 6 December	Medical Statistics and Epidemiology in HIS (2)
9 - 13 December	Diploma in Occupational Health (2)
9 - 13 December	Child Health Services: Management, Organisation and Data Systems

For further details please contact:

Institute of Health

John Moorhouse, CPD Manager, phone 024 7652 4483
or visit: www.healthatwarwick.warwick.ac.uk
Email: enquiries@healthatwarwick.warwick.ac.uk

Occupational Health: a popular choice for professional studies

One of the major successes of the Centre for Primary Health Care's expanding CPD Programme this year has been the new Diploma in Occupational Health led by Cynthia Atwell. A flexible modular course, the Diploma consists of lectures, seminars, visits, skill acquisition in the workplace and tutorials. The first group of practitioners have now completed the course and, as places are already filled for the next two courses both starting in November, there is already a waiting list.

For further details, please contact Carmel Parrott on 024 7652 4625

Forthcoming Events

Centre for Primary Health Care Studies, University of Warwick

Quality of Life When Living with Diabetes

13 September 2002, British Association Festival of Science,
Bennett Lecture Theatre 1, University of Leicester

For further details please contact Kate Webb:

Tel: 024 7657 4096 Fax: 024 7657 3959 Email: Kate.Webb@warwick.ac.uk

Centre for Primary Health Care Studies, University of Warwick

The Patient Contribution: today and tomorrow, a one-day conference for people who live with diabetes

14 September 2002, Clarendon Suite, Birmingham

For further details please contact Kate Webb:

Tel: 024 7657 4096 Fax: 024 7657 3959 Email: Kate.Webb@warwick.ac.uk

Institute of Health and the Association for Education and Ageing

Towards Healthy and Productive Ageing: Making a Difference. Issues for policy, research and practice

17 September 2002, 10:30 – 5:00, University of Warwick

For further details please contact Nihid Iqbal:

Tel: 024 7657 4098 Fax: 024 7657 4101 Email: Nihid.Iqbal@warwick.ac.uk

University of Warwick in association with Coventry University

Working Together to Make Research Count

23 September 2002, 9:45 – 1:15, Techno Centre, Coventry University

For further details please contact Sylvia Moore:

Tel: 024 7657 4136 Fax: 024 7652 4415 Email: Sylvia.Moore@warwick.ac.uk

Centre for Primary Health Care Studies, University of Warwick

Models of Emergency Care

Thursday 26 September 2002, University of Warwick

For further details please contact Claire Runaghan:

Tel: 024 7657 2905 Fax: 024 7652 8375

Email: Claire.Runaghan@warwick.ac.uk

School of Postgraduate Medical Education Guest Lecture

Martin Vessey CBE, FRS (Emeritus Professor of Public Health,
Unit of Health Care, University of Oxford)

Mortality in the Oxford - FPA study with regard to Pill Use and Smoking

24th October 2002, 5.30, Leicester Warwick Medical School,
Gibbet Hill Campus, University of Warwick

For further details please contact Kerry Drakeley:

Tel: 024 7652 3913 Fax: 024 7652 4311 Email: K.J.Drakeley@warwick.ac.uk

School of Law, University of Warwick

UnHealthy Housing: Promoting Good Health

19 – 21 March 2003, University of Warwick

For further details please contact David Ormandy:

Tel: 024 7652 4936 Email: david.ormandy@warwick.ac.uk

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