

Research Update

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Involving Service Users in Research

There have been a number of recent developments highlighting the need for increased involvement of research participants in the research process. In 1996, the Consumers in NHS Research Group was set up to advise the NHS Central Research and Development Committee on how best to involve consumers in the research and development process. The Group is currently setting up a database containing examples of research projects in the field of health and social care that actively involve consumers in the research process. More details can be found on their website (<http://www.conres.co.uk>). Other initiatives occurring around this time were the formation of the Toronto Group (http://www.elsc.org.uk/bases_floor/toronto/torontoindex.htm), set up after a 1997 conference on empowerment in social care. The Toronto group works to promote research as an empowering process and to enhance the role of service users, carers and research participants in research. The Centre for Citizen Participation at Brunel University (<http://www.brunel.ac.uk/depts/social/Centrecitizen.htm>) was also established in 1997, working to support service user involvement in research and evaluation. More recently, the Department of Health's Research Governance Framework for Health and Social Care (2001) also stressed the importance of involving research participants in the research process wherever possible. This edition of Research Update looks at three pieces of research which have user involvement at their core.

What Service Users Want from Palliative Care Social Care Work

This project is being jointly led by the Centre for Citizen Participation and St John's Hospice, London. The project is funded by the Joseph Rowntree Foundation (<http://www.jrf.org.uk>) as part of its Social Care and Disability Promoting Voices and Choices programme. The researchers involved include Lesley Adshead, Suzy Croft, Vic Forrest and Peter Beresford. The project aims to inform social work practice and policy with people who are living with life threatening illnesses using the knowledge, ideas and experiences of service users. A series of in-depth-interviews, group interviews and discussions were used in the project

to gather user views about services. Qualitative methods enabled service users to offer their views fully. In addition to obtaining user views to inform practice, the research project itself has been participatory. Service users have been involved in the development and monitoring of the research process. The project is due for completion in September 2002. Newsletters providing updates on the projects progress are available on request from the Centre for Citizen Participation, Brunel University, 300 St Margaret's Road, Twickenham, Middlesex TW1 1PT, tel: 020 8891 8380 fax: 020 8891 8266, email: cit-participation@brunel.ac.uk. Details of the research are available on the Joseph Rowntree Foundation website (<http://www.jrf.org.uk>). The project has also been involved in producing a briefing paper 'Our lives, not our illness - User Involvement in Palliative Care' which can be purchased from the National Council for Hospice and Specialist Palliative Care Services, First Floor, 34-44 Britannia Street, London WC1X 9JG tel: 020 7520 8299 (<http://www.hospice-spc-council.org.uk>).

The Health Needs of Socially Excluded Young People

Another recent study involving service users in the research process is a joint project by De Montfort University (<http://www.dmu.ac.uk/>) and The Children's Society (<http://www.the-childrens-society.org.uk>). The project was funded by the Community Fund (<http://www.community-fund.org.uk>), previously the National Lotteries Charity Board, and looked at the health needs of socially excluded young people. The research proposal included a commitment to involve young people in all aspects of the process, including the project's planning, implementation and dissemination. The researchers decided on this approach in the belief that a participative approach would enhance the value of the results. Young people were involved in the project as designers, interviewers and research subjects. They were also involved in analysing and reporting the findings. In order for this approach to work, additional preparation was required and time was also spent training the young people to be involved in the project. However, the research also highlights the additional gains that can be made through a participatory approach, with a greater openness

and trust, resulting in improved and more relevant findings. The project also raised a number of methodological issues, ethical and practical concerns: can participatory research with young people work? How does participatory research affect the validity of findings? And what are the implications of additional demands on time, resources and expertise? Further details of the methodological questions raised during the project can be found in a recent article by Roger Smith, Maddy Monaghan and Bob Broad (2002) 'Involving young people as co-researchers: facing up to the methodological issues', *Qualitative Social Work*, 1(2), p.191-207. A detailed report on the research findings 'Improving the Health and Well-Being of Socially Excluded Young People' will be published by the Children's Society (date of publication yet to be confirmed). Further details about the work of the Children and Families Research Unit at De Montfort University can be found in their newsletter (pdf format) available at: http://www.dmu.ac.uk/Schools/Health_and_Community_Studies/Research/cfru_leaflet.pdf

Involving Parents in Research on Disabled Children and their Families

The last project to be featured in this edition of Research Update is from the Family Fund Trust. The Family Fund Trust (<http://www.familyfundtrust.org.uk>) is an independent charity supporting families with severely disabled children. In 1997, the Trust received funding from the National Lottery Charities Board's first Health, Disability and Care Programme for a research project. The Trust wanted to carry out a number of separate pieces of work which would be of particular relevance to families with disabled children. Keri Roberts and Dot Lawton,

researchers from the Social Policy Research Unit (SPRU) at the University of York (<http://www.york.ac.uk/inst/spru/index.htm>), worked in collaboration with families and staff from the Family Fund Trust to design and implement a programme of research, involving parents in decision making from the beginning of the project. Parents were active participants in choosing the topics to be researched and parents' groups were used to obtain parents' views and suggestions for research topics. In circumstances where it was not possible for parents to attend the groups, parents were also able to participate by post or telephone when necessary. Parents continued to be involved in the research throughout its duration, showing their commitment to the project. Many parents also later became involved in other research projects with SPRU, University of York. The continued enthusiasm of the research participants highlights the potential benefits for researchers who are able to engage and involve service users effectively. Work with the parents' group identified four main areas for research: access to the Disability Living Allowance by children; transport costs faced by families with severely disabled children; the need for greater recognition of the extra care parents provide for their disabled children and 'single point of access' information services. These areas of research have now been completed. For further details about the project or to purchase related publications visit the Social Policy Research Unit website (<http://www.york.ac.uk/inst/spru/research/summs/messages.htm>) or contact the SPRU's Information Office email: spruinfo@york.ac.uk.

Details of the work of the Family Fund Trust can be found at their website (<http://www.familyfundtrust.org.uk>) or email: info@familyfundtrust.org.uk.

