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FACULTY OF HEALTH & SOCIAL CARE

SOCIAL WORK PROGRAMME
SERVICE USER AND CARER INVOLVEMENT PROJECT

Resource list to support students and lecturers in learning and teaching. The list includes:

- Materials to support social work practice
- Materials to support learning and teaching about social work
- Materials written by service users and carers

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Introduction

This resource list is designed to increase students' awareness of literature written by service users and carers, and material generated to support users and carers. This is to both enable improvement in their understanding of theory and increase their knowledge for practice. It will enable students

- to begin to think about the wealth of literature on service user and carer issues
- to increase their knowledge and understanding of user and carer issues
- to increase their knowledge about user / carer led research
- to provide them with the resources to embed this literature and this perspective in the materials they produce

This resource contains the following categories:

- Involving service users and carers in health and social care education
- Involving service users, carers and public in research
- User led research
- User involvement in services
- Black Minority Ethnic involvement
- Children and Young People
- Older people
- People with Experience of Mental Ill-Health
- Disability awareness
- Carers
- Poverty and Social Exclusion

This is a living document that will be updated regularly on the internet. In no way does it claim to be representative of the wide amount of literature that is available on user and carer involvement. Students, service users and carers are invited to add to this resource. It is but a beginning! Please contact me on my email below with further additions to this resource.

Please email Joanna Fox with either your comments or further additions to this resource.

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Involving Service Users and Carers in Health and Social Care Education

Introduction

This section includes:

- some useful texts about service user and carer involvement in health and social care education;
- some useful policies and resources why service users and carers are involved in teaching health and social care students;
- different ways they can be involved;
- and the perspectives of both service users and carers of their experiences of being involved.

BOOKS

Doel M and Best L (2008) *Experiencing Social Work Learning: Learning From Service Users*. London: Sage

Stickley T and Bassett T (2007) *Teaching Mental Health*. London: John Wiley and Sons

Warren J (2007) *Service User and Carer Participation in Social Work*. Exeter: Learning Matters

This book is an excellent starter book for students.

POLICIES

Branfield F, Beresford P, and Levin E (2007) *SCIE Position paper 7: Common aims: a strategy to support service user involvement in social work education*. London: SCIE (Social Care Institute for Excellence)

www.scie.org.uk

Policy Guide

Levin E (2004) *Involving Service Users and Carers in Social Work Education*. Resource Guide no. 2. SCIE (Social Care Institute for Excellence). Bristol: Policy Press

www.scie.org.uk

Policy guide

REPORTS

Where's the Patient's Voice in Health Professional Education - Report of a conference held in Vancouver, Canada in November 2005

This report is now available on-line:

<http://www.health-disciplines.ubc.ca/DHCC/PtsVoiceReportBook.pdf>

This report discusses the active involvement of service users and carers in the education health and social care professional in North America, Europe and Australasia. It describes the ways they are involved and the outcomes of their involvement.

ARTICLES

Brown, K and Young, N. (2008) Building Capacity for Service User and Carer Involvement in Social Work Education, *Social Work Education*, 27(1), 84-96

This article describes a programme called Getting Involved designed by Skills For Care to encourage and support service users and carers to get involved in different aspects of the teaching and learning of students in the social work programmes. Opportunities and obstacles of such a programme are discussed.

Edwards C (2003) The Involvement of Service Users in the Assessment of Diploma in Social Work students on Practice Placement. *Social Work Education*. 24, (4)

Simons L, Tee S, Lathlean J, Burgess A, Herbert L, Gibson C, (2007)
A Socially Inclusive Approach to User Participation in Higher Education
Journal of Advanced Nursing, 58, (3), May 2007 , pp. 246-255

This paper reports on an evaluation of the development of an innovative Service User Academic post in mental health nursing. It evaluates the post in terms of effective student learning and good employment practice.

Vandrevala T, Hayward, M, Willis, J. and John, M. (2007) A Move Towards a Culture of Involvement: Involving Service Users and Carers in the Selection of Future Clinical Psychologists *Journal of Mental Health Training, Education and Practice*. 2(3), 34-43

Social Work Education (2006) Experts by Experience in Social Work Education: Our Lives, Our Contribution, Your Learning, 25 (4), June 2006

This issue focuses on user and carer involvement in education and contains a wide range of articles, including:

Robson P, Johns R , with Service Users & Carers & Staff from the University of East London

Strengthening Partnership, When is the best time to bring in the service users?

This article describes University of London's first user / carer consultation day and the valuable material that came from that day – the beginning of greater things!

Beresford P, Branfield F, Taylor J, Brennan M, Sartori A, Lalani M , Wise G
Working Together for Better Social Work Education

This article looks at the development of user involvement in social work education at the national policy level. It is written by a group of service users who are involved in Shaping Our Lives, the national independent user controlled organisation and network.

Advocacy In Action with Staff & Students from the University of Nottingham
Making It Our Own Ball Game: Learning and Assessment in Social Work Education

This paper reflects on the different experiences of involving service users from Advocacy in Action in the social work degree at the University of Nottingham. It focuses particularly on their involvement in developing service user defined assessment tools.

Baldwin M and Sadd J

Allies with Attitude! Service Users, Academics and Social Service Agency Staff Learning How to Share Power in Running Social Work Education Courses

This article reflects on the alliance between The University of Bath and the Wiltshire and Swindon Users' Network of 12 years and the involvement in different aspects of the social work programmes.

Stevens S and Tanner D

Involving Service Users in the Teaching and Learning of Social Work Students: Reflections on Experience

This article reflects on the experience of one university develop service user involvement on the social work degree course. It includes the perspectives of a service user leading the project in partnership with a part time academic member of staff.

Advocacy In Action with Charles M , Clarke H ,and Evans H
Assessing Fitness to Practise and Managing Workbased Placement

This article describes the experience of Nottingham and Birmingham Universities in partnership with Advocacy In Action. It shows how service users and carers can be involved in assessing students' practice competencies.

Tyler G
Addressing Barriers to Participation: Service User Involvement in Social Work Training

This article describes the experience of user involvement in one university; and then goes on to focus how young people have been involved in the processes.

Basset T, Campbell P, Anderson J
Service User/Survivor Involvement in Mental Health Training and Education:
Overcoming the Barriers

This article identifies 10 barriers to involving service users in learning and teaching about mental health in higher education, and then discusses some solutions to each of these barriers.

Allain L , Cosis Brown H , Danso C , Dillon J, Finnegan P, Gadhoke S , Shamash M,
Whittaker F
User and Carer Involvement in Social Work Education, A University Case Study:
Manipulation or Citizen Control?

This paper describes how service users and carers have been involved in social work education. It asks the question: Is this a way of promoting active citizenship or is it manipulating powerless groups? It discusses this from the perspectives of service users, carers an social work tutors.

Glynn T and Ansell J
Survival and Abuse: What We Can Learn From It

This article is written by two people who have used mental health services. It describes how in situations of survival and abuse service users can both support and advocate for each other. They both use their experiences to contribute to social work education.

Involving Service Users, Carers and Public in Research

Introduction

This section draws together some on-line resources and website to help you involve service users, carers and public in research.

WEBSITES

INVOLVE
www.invo.org.uk

A national advisory Group, funded by the Department of Health, which aims to promote and support active public involvement in NHS, public health and social care research

PEPIN (Professional Education Public Involvement Network)
www.pepin-uk.net

Includes ideas about best practice involving service users and carers and public in different ways. This website is a useful resource for ideas and best practice. There is a discussion board you can join. It includes links to video diaries of people who experience different issues and disabilities; also other useful information.

A RESOURCE BOOK

Voluntary Action Westminster (2006) *Involving People: A practical guide*.
www.vawcvs.org/uploads/involving_people_a_practical_guide.pdf

User Led Research

Introduction

This section contains research that has been controlled and led by service users and carers. There are some examples of mental health user led research; research by deaf people; and research by people with disabilities.

MENTAL HEALTH USER LED RESEARCH

Beresford P (2000) Service users' Knowledges and Social Work Theory: Conflict or Collaboration? *British Journal of Social Work*, 30 (4) 489 - 503

Faulkner A (2004) *The Ethics of Survivor Research: Guidelines for the Ethical Conduct of Research Carried Out By Mental Health Service Users and Survivors*. Bristol: Joseph Rowntree Foundation

Fox, J R (2007) Experience of Mental Health Recovery and the Service User Researcher, *Journal of Ethics and Social Welfare*, 1 (2), p. 219 – 223

Lindow V and Morris J (1995) *Service User Involvement: Synthesis of Findings and Experience in the Field of Community Care*. York: Joseph Rowntree Foundation

The Mental Health Foundation (2003) *Surviving User-Led Research: Reflections on Supporting User-Led Research Projects*. London: The Mental Health Foundation

The Mental Health Foundation (2000) *Strategies For Living: A Report of User-Led Research into People's Strategies for Living with Mental Distress*. London: The Mental Health Foundation

Nicholls, V. (2001) *Doing Research Ourselves: A Report on the Strategies for Living Support Project*. London: The Mental Health Foundation. Strategies for Living. National Lottery Charity Board

Ramon, S. (2000) Participative Mental Health Research: Users and Professional Researchers Working Together. *Mental Health and Learning Disabilities Care* 3.(7). p. 224 – 228

Ramon, S. (ed) (2003) *Users Researching Health and Social Care: An Empowerment Agenda*, Venture Press, ISBN 1-86178-057-5

Turner M and Beresford P (2005) *User Controlled Research. Its Meanings and Potential.*
www.shapingourlives.org.uk

This website contains plenty of other resources on user controlled research.

Wallcraft, J, with Read J and Sweeney A (2003) *On Our Own Terms: Users and Survivors of Mental Health Services Working Together For Support and Change.* London: The Sainsbury Centre for Mental Health

RESEARCH LED BY DISABLED PEOPLE

Barnes C, Morgan H and Mercer G (2001) *Creating Independent Futures: An Evaluation of Services Led by Disabled People.* Stage 3 Report.
www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm

Further studies available on this site

British Deaf Association (1996) *Deaf People's Participation in Local Services.* London: Joseph Rowntree Foundation.
www.jrf.org.uk/knowledge/findings/socialcare/SC77.asp

Nolan M, Hanson E, Grant G, Keady J (2007) *User Participation in Health and Social Care Research: Voices, Values and Evaluation.* Maidenhead: Open University Press,

RESEARCH LED BY CARERS

Fisher M (2002) The Role of Carers in Problem Formulation and Technical Aspects of Social Research, *Social Work Education*. 21, (3)

User Involvement in Services

Introduction

This section contains some resources on developing user involvement in service planning and monitoring.

Community Care Needs Assessment Project (CCNAP) (2001) *'Asking the Experts', A Guide to Involving People in Shaping Health and Social Care Services.*

www.ccnap.org.uk

Robson P, Begum N, Locke M (2003) *Developing User Involvement: Working Towards User-Centered Practice in Voluntary Organizations.* Policy Press. (ISBN 1 86134 537 2)

Black and Minority Ethnic Involvement

Introduction

This section provides some resources on the experiences of Black and Minority Ethnic service users being involved in research and shaping services.

Atkinson A, Douglas C, Francis D, Laville M, Millin S, Pamfield J, Smith P, Smith R (2008) *Lifting Barriers: African and Caribbean People Tell Stories of Struggle, Strength, and Achieving Mental Health.*

www.safh.org.uk

THACMHO , c/o Social Action for Health, 192 Hanbury Street, London E1 5HU, tel: 020 7426 5389

www.thacmho.org.uk

Begum N (2006) *Doing It For Themselves: Participation and Black and Minority Ethnic Service Users.*

www.scie.org.uk/publications/reports/report14.pdf

Further documents available at this site.

Butt J and O'Neil A (2004) *'Let's Move On': Black and Minority Older People's Views on Research Findings.* York: Joseph Rowntree Association

Evans R and Banton m (2001) *Involving Black Disabled People In Shaping Services.* Joseph Rowntree Foundation.

<http://www.jrf.org.uk/bookshop/eBooks/185935114X.pdf>

Keating F (2002) *Breaking the Circles of Fear: A Review of the Relationship Between Mental Health Services and African and Caribbean Communities.* London: The Sainsbury Centre for Mental Health.

Young People

Introduction

This section contains resources and information about involving children and young people in your practice, in decision-making and in other ways.

Children Now (2006) *The Participation Charter*.
www.childrennow.co.uk/charter

Children's Rights Alliance for England (CRAE) (2005) *Ready Steady Change Participation Training Materials*. London: CRAE

Children's Society (2006) *Young People's Key Skill Development Training Manual*.
www.childrenssociety.org.uk

Other resources on this website

Children and Young People's Unit (CYPU) (2001) *Learning to Listen – Core principles for the Involvement of Children and Young People*. London: Dept for Education and Employment

Cutler D (2003) *Standard! Organisational Standards and Young People's Participation in Public Decision-Making*. London: Carnegie Young People's Initiative.
www.carnegieuktrust.org.uk

Danso C, Greaves H, Howell S, Ryan M, Sinclair R, and Tunnard J (2003) *The Involvement of Children and Young People in Promoting Change and Enhancing the Quality of Services*.

A research report for SCIE from the National Children's Bureau. London: National Children's Bureau

Franklin A and Sloper P (2004) *Participation of Disabled People and Young People in Decision-Making within Social Services Departments. A Survey of Current and Recent Activities in Social Services in England*.

www.york.ac.uk/inst/spru

Older People

Introduction

This list is a resource list of services that support older people and their carers, and research to support and promote the older person.

RESOURCES TO SUPPORT AND PROMOTE SERVICES FOR OLDER PEOPLE

Action on Elder Abuse

www.elderabuse.org.uk

An organization working to prevent the abuse of older adults.

Age Concern

www.ageconcern.org.uk

Help the Aged

www.helptheaged.org.uk

INVOLVING OLDER PEOPLE

Cordingley L, Hughes J and Challis D (2001) *Unmet Need and Older People: Towards a Synthesis of User and Provider Views*. York: Joseph Rowntree Foundation

DEMENTIA INFORMATION

Alzheimer's Society

www.alzheimers.org.uk

The Dementia Services Development Centre University of Stirling

<http://www.dsdac.stir.ac.uk/>

This resource website contains research and resources on older people and dementia.

People with Experience of Mental Ill-Health

Introduction

This resource list contains information and websites resources on mental health;

- information about recovery
- anti-discriminatory practices in mental health
- and much more besides.

WEBSITE RESOURCES

The bi polar organization

www.mdf.org.uk

Mind (National Association for mental health)

www.mind.org.uk

Moving People

<http://www.movingpeople.org.uk/>

Website in development on anti discrimination in mental health (07.08)

Rethink website

www.rethink.org.uk

For people and their carers with severe mental health needs.

Roberts A (2006) *Mental Health History Timeline*.

www.mdx.ac.uk/www/study/mhhtim.htm

Scottish recovery network

www.scottishrecovery.net

Good website on recovery and rehabilitation

The Virtual Ward

<http://www.nimhe.csip.org.uk/virtualward/>

A place to share good practice between staff and people who use mental health services. The site is designed for all to access information about positive and innovative practice, to read supporting policy and to utilise training examples and materials.

BLACK AND MINORITY ISSUES AND MENTAL HEALTH

Atkinson A, Douglas C, Francis D, Laville M, Millin S, Pamfield J, Smith P, Smith R (2008) *Lifting Barriers: African and Caribbean People Tell Stories of Struggle, Strength, and Achieving Mental Health.*

www.safh.org.uk

THACMHO , c/o Social Action for Health, 192 Hanbury Street, London E1 5HU, tel: 020 7426 5389

www.thacmho.org.uk

Sainsbury Centre for Mental Health (SCMH) (2002) *Breaking the Circles of Fear. A Review of the Relationship Between Mental Health Services and African and Caribbean Communities.* London: Sainsbury Centre for Mental Health

USER AND CARER INVOLVEMENT IN RESEARCH

Rose D, Fleischman P, Tonkiss F, Campbell P and Wykes T (2003) *User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature.* Report to the National Co-ordinating Centre for NHS Delivery and Organisation Research and Development. (NCCSDO)

www.sdo.lshtm.ac.uk/files/project/17-final-report.pdf

THE SERVICE USER MOVEMENT IN MENTAL HEALTH

Campbell P (2005) From Little Acorns. The Mental Health Service User Movement. In Bell A and Lindley P (eds) *Beyond the Water Towers. The Unfinished Revolution in Mental Health Services (1985 – 2005)* London: The Sainsbury Centre for Mental Health.

Disability Awareness

Introduction

This section contains websites on:

- deaf awareness..
- disability awareness;
- the disabled people movement,
- and learning disabilities;

DEAF AWARENESS

British deaf association

www.bda.org.uk

DISABILITY AWARENESS

British Council of Disabled People

www.bcodp.org.uk

Directgov disabled people and carers

<http://www.direct.gov.uk/en/DisabledPeople/index.htm>

A specific section within UK Government's Directgov website that provides comprehensive information for disabled people and regarding financial support, home and housing, employment, rights, independent living and much more. The section also contains links to hundreds of national charities and other disability-related organisations.

Disability archive

<http://www.disability-archive.leeds.ac.uk>

Some articles of interest from this website:

Disability Awareness in action (2007)

www.daa.org.uk

Follow the link from resources to reading list.

This includes resources from advocacy / self advocacy – HIV / AIDS issues for people with disabilities, - disability studies / theories.

Evans J (1996) *Campaign for Civil Rights Legislation*
www.independentliving.org

DISABLED PEOPLES MOVEMENT

Barnes C (1997) CHAPTER 1 'A Legacy of Oppression: A History of Disability in Western Culture' in Barton L and Oliver M (eds) (1997) *Disability Studies: Past Present and Future*, Leeds: The Disability Press, (pp. 3 – 24).

<http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/chap1.pdf>

Finkelstein V (Leeds University Centre for Disability Studies) *A Personal Journey into Disability Politics*

<http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/presentn.pdf>

[Accessed online 07.08]

Priestley M and Jolly D *A Postcode Lottery? Explaining the uneven implementation of direct payments in the UK*

Centre for Disability Studies University of Leeds

<http://www.leeds.ac.uk/disability-studies/archiveuk/Priestley/direct%20payments%20conference%20paper%202.pdf>

[Accessed online 07.08]

LEARNING DIFFICULTIES

Brookes M (2005) *Promoting Advocacy with People with Learning Difficulties from Black and Minority Ethnic Communities*.

Can be ordered from values into action website.

www.viauk.org.uk

Values into action UK

www.viauk.org.uk

Publication list of resources on learning disabilities and related issues

Carers

Introduction

This section contains information and resources for support when working with carers.

GENERIC CARERS

Banks, P, Cheeseman C, Maggs, S (1998) *The Carers Compass: Directions for Improving Support to Carers*. London: Kings Fund

Carers UK

www.carersuk.org.uk

Website with plenty of information and resources about / for unpaid carers.

The Princess Royal Trust for Carers

www.carers.org

www.youngcarers.net

The Princess Royal Trust for Carers supports a national network of carers centres where unpaid carers can obtain advice, information and support. Useful website with resources

MENTAL HEALTH CARERS

Meriden family centre programme

<http://www.meridenfamilyprogramme.com/>

Website on support and education to mental health carers. Also on website: Mental Health Carers Support Curriculum - a '*Scoping Exercise To Inform the Development of a National Mental Health Carer Support Curriculum*' by City University

Poverty and Social Exclusion

Introduction

This section contains some resources about poverty and social exclusion and user involvement.

Bennett, F. with Roberts, M. (2004) *From Input to Influence: Participatory Approaches to Research and Inquiry into Poverty*, York: Joseph Rowntree Foundation

Beresford, P. (Ed.) (1999) *Poverty First Hand: Poor People Speak For Themselves*, London: Child Poverty Action Group

Joseph Rowntree Foundation
www.jrf.org.uk

Ridge, T. (2002) *Childhood Poverty and Social Exclusion: From a Child's Perspective*
Bristol: Policy Press

World Bank 'Voices of the Poor' project
<http://go.worldbank.org/H1N8746X10>
