### **Existing Evidence Resource**

#### Introduction

This is a list of useful evidence for DRILL. It contains summaries of some key evidence that exists already on DRILL's themes of participating in:

- the economy
- community and social life
- civic and public life and
- participating in anything!

The aim is to give everyone involved in DRILL a starting point for looking at existing evidence. We hope this will help you see what evidence there is to build on, for instance if you are developing new proposals for research studies or pilot projects.

This is not a complete list of evidence. We know there are gaps. We will add to this resource as DRILL develops. So do let us know if there is other evidence you think we should include. Do this by emailing <a href="mailto:sylviagordon@disabilityaction.org">sylviagordon@disabilityaction.org</a>. There are many thousands of articles and reports on these subjects. We encourage you also to look beyond this DRILL resource for evidence on the particular topic you want to research.

We have particularly included:

- Evidence and major agendas that have been developed by or with disabled people
- Evidence on 'what works' (not just what the challenges are that disabled people face)
- A few reports and articles that offer an overview of disabled people's lives and/or have been proposed as important evidence by our National Advisory Groups and Central Research Committee members.
- Academic articles that pull together a lot of evidence for instance, literature reviews. We found these articles by searching academic databases using specific search terms (see Appendix 1 'Search terms used for review articles' Page 72). We have included those that may be useful to DRILL. Some of these articles

don't ask the same questions disabled people would ask. Some are written in complicated language.

We have included UK-wide evidence, and evidence specific to devolved nations, and a few international examples. We have included some evidence on different groups of disabled people.

We hope you find this a useful starting point and welcome feedback and additions.

Some of the articles and reports are free to download – others are not. We plan in the course of the DRILL programme to explore how we can open up knowledge more widely.

## 1. Principles And Policy Agendas Developed By Or With Disabled People

### <u>The United Nations Convention on the Rights of Persons with</u> Disabilities

The Convention was developed with the involvement of disabled people from around the world. Its purpose is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'. It has been ratified (ie formally agreed) by over 150 countries. The UK ratified the Convention in 2009. Each right is set out in an 'Article' – including the right to live independently and be included in the community; the right to work; the right to participate in political and public life – and many more. By 'disabled people' the UN means those who have long-term physical, mental, intellectual or sensory impairments which - when they interact with various barriers – can hinder full participation in society on an equal basis with others.

http://www.un.org/disabilities/convention/conventionfull.shtml

### The 12 Pillars of Independent Living

The disability movement identified first 7 basic needs, and later 12 pillars, of independent living. Choice and control are key aspects of independent living. The International Summit Conference on Independent Living in 1999 adopted what is known as the Washington Declaration. This states that, '..... all human life has value and ....every human being should have meaningful options to make choices about issues that affect our lives'. 'Independent living' is therefore closely associated with the words 'choice and control' and is usually applied to both the environment in which someone lives and the assistance they might need in order to go about their daily lives.

#### The 12 are:

- Full access to our environment
- A fully accessible transport system
- Technical aids equipment
- Accessible/ adapted housing

- Personal assistance
- Inclusive education and training
- An adequate income
- Equal opportunities for employment
- Appropriate and accessible information
- Advocacy (towards self-advocacy)
- Counselling
- Appropriate and accessible health care provision

For the 12 needs or pillars see: <a href="http://spectrumcil.co.uk/wp-content/uploads/2015/04/SPECTRUM-12-Basic-Rights-2013.pdf">http://spectrumcil.co.uk/wp-content/uploads/2015/04/SPECTRUM-12-Basic-Rights-2013.pdf</a>

The earlier 7 needs were written up by Davis K (1990) The Emergence of the 'Seven Needs', Derbyshire Coalition of Disabled People.

A wider discussion of independent living is at:

http://disability-studies.leeds.ac.uk/files/library/morris-independent-living-scoping-paper-final-edit.pdf.pdf produced for DRC in 2003.

### Disability Rights Commission (2007) The Disability Agenda

The Disability Rights Commission engaged disabled people and a range of organisations – from the Crown Prosecution Service to social care agencies – to develop an agenda to put disability rights at the heart of public policy. Several booklets were published on different themes, from ending child poverty to increasing disabled people's skills and enabling active participation of disabled people in public life. The 10 recommendations with analysis are at:

http://webarchive.nationalarchives.gov.uk/20080530124139/http://equalityhumanrights.com/en/aboutus/history/disabilityagenda/recommendations/Pages/default.aspx

### Background papers and speeches are at:

http://webarchive.nationalarchives.gov.uk/20080530124139/http://www.celebratingthejourney.org/disability-agenda-launch.asp

### <u>Shakespeare T (2014) Disability Rights and Wrongs Revisited.</u> <u>London: Routledge</u>

This book, available for purchase, draws on wide-ranging evidence and theory to discuss ways forward on disability in areas including culture, genetic developments, sexuality and personal assistance. It argues that the field of disability studies has come from disabled people's activism; and that it now needs a stronger basis in theory and evidence.

### Priestley M, Waddington L and Bessozi C (2010) New priorities for disability research in Europe: Towards a user-led agenda

This paper presents findings from participatory action research with disabled people's organisations in European countries. The project sought to engage civil society organisations as agents of change in influencing future priorities for European disability research. Based on a consultation with 68 organisations in 25 countries it illustrates how the research priorities identified by representative organisations of disabled people were used to impact on European-level research funding. The findings show the potential to impact on the lives of disabled people, using social model and rights-based approaches. They also demonstrate how effective partnership between academics and activists adds to the relevance and impact of research.

http://www.sciencedirect.com/science/article/pii/S1875067210000751

## Beresford P and Croft S (2012) User Controlled Research: Scoping Review. NHS National Institute for Health Research (NIHR) School for Social Care Research, London School of Economics

The focus of this scoping review is user controlled research in social care. It aims to be accessible to lay and researcher readers. The review discusses the context of user-controlled research: its history and methods. It looks at the characteristics, strengths and limitations of such research, explores its theory and uses examples to illuminate its policy and practice. Social care is concerned with meeting the support needs of a wide range of people, including disabled people, mental health service users, older people and people with learning disabilities. Insights from user controlled research may improve our understanding of social care —

how it is offered and also how needs for social care support may be reduced.

sscr.nihr.ac.uk/PDF/SSCR-Scoping-Review 5 web.pdf

## Oliver M and Barnes C (2010) Disability studies, disabled people and the struggle for inclusion. British Journal of Sociology of Education Special Issue: The Sociology of Disability and Education

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This paper traces the relationship between disability studies and the struggle for meaningful inclusion for disabled people and particularly refers to the work of an important person in these developments, Len Barton. It argues that the links between disability activism and academic work were responsible for the emergence of disability studies and that this has influenced mainstream sociology and social and educational policy nationally and internationally. However, the impact of these developments has been only marginal, the need for meaningful inclusion is more urgent than ever and cannot be dependent on the work of a few key individuals for its success.

http://www.tandfonline.com/doi/full/10.1080/01425692.2010.500088

### **Disability Archive, University of Leeds**

The archive contains documents written by disability activists and allies, for those who wish to explore this historical literature further.

http://disability-studies.leeds.ac.uk/library/

## Swain J, French S, Barnes C and Thomas C (2013) Disabling barriers – enabling environments

An edited book, available for sale, containing chapters by different authors, covering issues including the role of user-led organisations in facilitating independent living

## Beresford P (2016) All Our Welfare: Towards participatory social policy, Bristol: Policy Press

This book, available for sale, argues that the welfare state is under attack and has also been undermined by accusations of paternalism and past failures to engage with the very people it is intended to help. It critiques the welfare state and draws on theory and the work of service user movements to argue for a new form of participatory and sustainable social policy. It is concerned with how we look after each other in future in society.

### **Evidence specific to Scotland, Wales, Northern Ireland or England**

Inclusion Scotland, Disability Action Northern Ireland, Disability Wales and Disability Rights UK often make proposals on a range of policy topics, developed by and with disabled people

www.inclusionscotland.org www.disabilityaction.org www.disabilitywales.org www.disabilityrightsuk.org

### **Disability Action Northern Ireland Charter of Rights**

Disability Action has created its own Charter of Rights: see:

http://www.disabilityaction.org/about/charter-of-rights/

### Welsh Government (2013) Framework for Action on Independent Living (2013)

The Framework for Action on Independent Living was developed following extensive engagement and consultation with disabled people across Wales. It examines the barriers to equality and inclusion faced by disabled people, and the action needed to address them. It has a government-wide and cross-generational focus. It supports the Welsh Government's wider Strategic Equality Plan and Objectives, with a detailed programme of action on its Objective 5 – To tackle barriers and support disabled people so that they can live independently and exercise choice and control in their daily lives.

http://gov.wales/topics/people-and-communities/equality-diversity/rightsequality/disability/framework-for-action/?lang=en

### Welsh Government Strategic Equality Objectives (2016-20)

http://gov.wales/topics/people-and-communities/equality-diversity/equality-objectives/?lang=en

http://gov.wales/topics/people-and-communities/equality-diversity/equality-objectives/?skip=1&lang=cy

### **Disability Wales (2016). Calls for Action**

Disability Wales delivered regional Manifesto workshops, across Wales. Disabled people said the lack of enforcement of rights together with the impact of UK Government welfare reforms and cuts in public services have led to a loss of independence, an increase in poverty and left many feeling isolated and fearful for the future. After gathering the range of views from the workshops, and from the response to a survey, the Disability Wales Disabled People's Manifesto was produced.

http://www.disabilitywales.org/calls-for-action/

### Disability Wales, 2011. Manifesto for Independent Living

The Manifesto identifies six priority areas to be addressed in a National Strategy on Independent Living. These priorities were agreed following a series of discussions with groups and individuals which took place during Disability Wales' Independent Living NOW! Campaign.

http://www.disabilitywales.org/wordpress/wp-content/uploads/Manifesto for IL E.pdf

### **Spectrum (2015) Disability Manifesto**

The 'Disability Manifesto' was produced by the South East Network of Disabled People's Organisations (SENDPO) – a coalition of over 30 Organisations run and controlled by Disabled People from across the South East of England. It sets out what we – as Disabled People, citizens and voters – believed to be the key issues in the 2015 General Election and what commitments we would like to see from our Political Parties. Disabled People have a valuable contribution to make, not only

to the democratic process, but also to the UK's social and economic well-being. Yet, far too often our voice is marginalised or ignored altogether. This is thoroughly undemocratic – and is simply not acceptable. There are more than 12 million Disabled People and people with long-term health conditions in the UK – a very sizeable part of the electorate. Disabled people are deeply affected by so many of the key issues at the heart of political debate

http://spectrumcil.co.uk/news/spectrum-launches-the-disability-manifesto-for-this-years-general-election/

### <u>Disability Action Northern Ireland (2015) Draft Report on the</u> <u>Implementation of the Convention on the Rights of Persons with</u> <u>Disabilities in Northern Ireland</u>

Disability Action engaged over 400 people with disabilities including their member organisations and other representative groups to develop this draft report documenting how the UN Convention is being implemented in Northern Ireland. They held a conference, a questionnaire, general call for information and wide-ranging discussions with people with disabilities in Northern Ireland. There is a full draft report and a summary report.

http://www.disabilityaction.org/centre-on-human-rights/shadowreport/

### Equality Commission for Northern Ireland (2012) Strengthening Protection for Disabled People – Proposals for Reform

This report recommends strengthening law to protect disabled people from discrimination.

https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1 &cad=rja&uact=8&ved=0ahUKEwiJvMOr9pDMAhUBmhQKHc9AC4MQF ggkMAA&url=http%3A%2F%2Fwww.equalityni.org%2FECNI%2Fmedia %2FECNI%2FPublications%2FDelivering%2520Equality%2FStrengthen ing protection for disabled people0312.pdf&usg=AFQjCNE2H4hgN51 gTApWmHdLL40Hmww48g

### 2. Evidence On Disabled People's Lives Overall

## Barnes C (1991) Disabled People in Britain and Discrimination: A case for anti-discrimination legislation

This ground-breaking book by disabled academic Colin Barnes documented the discrimination disabled people faced in areas of life such as housing, education, health and social care and political life. The book provided the evidence which disabled people and allies drew on to campaign for disability rights law (the Disability Discrimination Act 1995 and later improvements to it).

The book is available to purchase.

## Cabinet Office, DWP, Dept of Health and Office of the Deputy Prime Minister (2005) Improving the Life Chances of Disabled People

The report summarised evidence on life chances in areas including early years support and education, transition to adulthood and employment. It proposed that the Government should set an ambitious vision for improving the life chances of disabled people through practical measures: by helping disabled people to achieve independent living, by improving support for families with young disabled children, by facilitating a smooth transition into adulthood and by improving support and incentives for getting and staying in employment.

http://webarchive.nationalarchives.gov.uk/+/http://www.cabinetoffice.gov.uk/strategy/work areas/disability.aspx

## World Health Organisation and World Bank (2011) World Report on Disability

This report pulls together evidence showing that over a billion people world-wide live with some form of disability and that across the world disabled people have poorer health outcomes, lower educational achievements, less economic participation and higher rates of poverty than other citizens. This is partly due to barriers in accessing services including information, transport and education. The report makes

recommendations to enable disabled people to have their voices heard and to break down barriers to participation. The report is available in many languages and has summaries in British Sign Language.

http://www.who.int/disabilities/world\_report/2011/report/en/

## Office for Disability Issues (2013) Fulfilling Potential: Building a deeper understanding of disability in the UK today

This compilation of many sources of evidence covers how disability impacts on people across the life course; and understanding disabled people's lives. It covers a wide range of topics from independent living to poverty, from health to public attitudes, from education and employment to leisure opportunities; and brings together pre-existing evidence on these (and more) under the headings 'early intervention', 'choice and control' and 'inclusive communities'. It summarises the evidence by stating that disabled people are integral to the success of our society and economy - playing an active role in society, and making up a large consumer market; but inequalities persist and many face social exclusion. For example, disabled people are less likely than nondisabled people to go to university, more likely to live in poverty and more likely to be isolated. It covers how common the experience of disability is, and how changeable, and how disabled people identify themselves. It includes some breakdowns of data by impairment and by region and nation and contains links to openly available detailed data.

Whilst it mainly describes the position and lives of disabled people, it touches on evidence for what 'might help': for instance, evidence that flexible working and personalised support are key enablers of disabled people's employment; and that the 'individual placement with support' approach is effective for people with mental health problems.

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/320515/building-understanding-main-slide-deck.pdf

### **Equality and Human Rights Commission (2015) Is Britain Fairer?**

The EHRC is tracking progress in Great Britain (Scotland, Wales and England) towards a fairer society – collecting existing evidence to ask whether, over time, people experience more equality of opportunity, greater freedom from unlawful discrimination and harassment and better

protection of human rights. The 2015 publication looks at progress since 2010 in areas including life, health, education, standard of living, individual, family and social life and participation and voice. Each section covers the range of 'protected characteristics' under the Equality Act, from gender and transgender to faith and ethnicity. This includes disability (although not breakdowns of data by different impairment group). There are separate reports on 'Is Scotland Fairer?' and 'Is Wales fairer?' Amongst key findings are that material deprivation of disabled people has grown since 2010 and the gap between disabled and non-disabled people getting 5 good GCSEs also widened; and when in work, disabled people earn on average 90p per hour less than non-disabled people. More promisingly the gap between disabled and non-disabled young people being NEET (not in education, employment or training) narrowed.

In the light of the evidence, the EHRC suggests 8 priority areas for action (across the protected characteristics). These include improving living conditions in cohesive communities; raising standards and closing attainment gaps in education; and preventing abuse, neglect and ill-treatment in care and detention.

http://www.equalityhumanrights.com/sites/default/files/documents/triennial review/how fair is britain - comp+lete report.pdf

### Office for National Statistics (2015) Life Opportunities Survey

This is a study over time (a longitudinal survey) of the barriers disabled people face living in Great Britain (Scotland, Wales and England). It began in 2009. Amongst its findings reported in 2015 are that adults with impairments were less likely than non-disabled adults to have social contact than non-disabled people (ie more likely to be isolated); more likely to report barriers to leisure activities; less likely to be in work - and when in work less likely to work in higher, managerial and professional roles; and, when in work, more likely than non-disabled people also to have caring responsibilities.

http://www.ons.gov.uk/ons/rel/los/life-opportunities-survey/wave-three-final-report--october-2012-to-september-2014/index.html

## House of Lords (2016) The Equality Act 2010: the impact on disabled people

The House of Lords Select Committee investigated what difference the Equality Act 2010 had made for disabled people. It concluded that the Government is failing in its duty of care to disabled people. From taxi drivers refusing to take disabled people, to "disgraceful" accessibility at sports grounds, to pubs and clubs failing to provide disabled toilets, the report argues that much more needs to be done. It makes recommendations to strengthen and better enforce the legislation and improve access to justice for disabled people.

http://www.publications.parliament.uk/pa/ld201516/ldselect/ldeqact/117/117.pdf

## Young J (2014) Dignity and Opportunity for All: Securing the rights of disabled people in the austerity era. Just Fair

This report analyses the extent to which the UK government is meeting its international obligations to realise the rights of disabled people during a time of austerity. It examines the rights to independent living, work, social security, social protection and an adequate standard of living.

Combining legal analysis with testimony from individuals, the report concludes that government policies are compromising disabled people's enjoyment of these fundamental rights, causing significant hardship.

http://www.just-fair.co.uk/#!about1/c1ext

### **Evidence specific to Scotland, Wales, Northern Ireland or England**

### Scottish Government: information on disabled people in Scotland

The Scottish Government and its Agencies collect, analyse and publish equality evidence across a wide range of policy areas – including information on disabled people in Scotland. See:

http://www.gov.scot/Topics/People/Equality/Equalities/DataGrid/Disabilit

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This includes analysis of the 2010 census to show information relating to all the different protected characteristics under the Equality Act 2010 - including disabled people. See:

<u>Analysis of Equality Results from the 2011 Census</u>

Analysis of Equality Results from the 2011 Census - Part 2

### Spectrum (2014) Hampshire Cuts Campaign & Research

In 2013-2014 SPECTRUM started a campaign to raise awareness about the impact of the cuts to welfare benefits and services on Disabled People. Spectrum researched the issue – and wanted to challenge the often distorted and misleading portrayal in some parts of the media of Disabled People who claim benefits. Most importantly, Spectrum wanted to influence Government policy and try to secure a commitment from politicians to consider a full or partial reversal of the cuts as soon as economic circumstances allow.

http://spectrumcil.co.uk/get-involved/campaigns/past-campaigns/

### <u>Hughes C (2012) Report on CILNI Service User Survey. Centre for</u> Independent Living Northern Ireland and Queen's University Belfast

This survey of people using the Centre for Independent Living Northern Ireland shows high satisfaction and the importance of the service as people try to negotiate the bureaucracy that comes with taking on the assistance that allows them to live independent lives. The comments from respondents convey how CILNI's assistance, information and advice have been huge factors in their ability to live independently.

http://www.cilni.org/sites/default/files/PDFs/CILNI%20REPORT%2029% 2008%2012%20 final%20-%20for%20website.pdf

### 3. Participating In The Economy: What Works?

### Evidence led by disabled people

### Disability Rights UK (2014-15) Closing the Disability Skills Gap

Disability Rights UK (DR UK) commissioned a review of existing evidence on skills for employment for disabled people from Dr Gill O'Toole of the Institute for Policy Studies in Education (IPSE), London Metropolitan University. DR UK produced a summary document 'Closing the Disability Skills Gap' and a reflective report, based on round-table and working groups with a range of stakeholders, exploring approaches to reducing the skills gap through methods including peer support and different forms of incentives.

http://www.disabilityrightsuk.org/closing-disability-skills-gap

### **Disability Rights UK (2013) Taking Control of Employment Support**

Disability Rights UK conducted an open survey of disabled people. Over 500 disabled people responded. Findings suggested a strong appetite for more individualised employment support, knowing what resources were available and being able to decide how those resources should be spent to suit their particular circumstances and needs.

http://www.disabilityrightsuk.org/policy-campaigns/reports-and-research/taking-control-employment-support

### Radar (2010) Doing Seniority Differently

This first UK research into the experiences of disabled people succeeding in their careers identified a pool of high achievers, including people living with significant and long-term impairments. It found out from them what factors had enabled them to succeed. This included career long senior support and mentoring.

http://www.disabilityrightsuk.org/doing-seniority-differently-summary

## <u>Disability Rights UK and the Work Foundation (2016, forthcoming)</u> Peer support for employment

A pair of reports examine the research evidence on peer support to achieve employment outcomes; and practice examples, including in Disabled People's Organisations. The two reports suggest promising findings of positive outcomes from peer support, with a need for further testing.

### **Evidence from research and other organisations**

#### Scope (2015) Driving Down the Costs Disabled People Face

This report analyses the extra costs disabled people face. It proposes key sectors in which disabled people – together with businesses, regulators and others - could work to drive down costs. The key sectors were those most frequently mentioned by disabled people, those that have the greatest financial impact, and those where change appears possible. They are: energy, clothing and bedding, specialised disability equipment, taxis and private hire vehicles (PHVs) and insurance. The report calls on disabled people to be bold in exercising consumer power and on businesses, government and others to take action.

http://www.scope.org.uk/Get-Involved/Campaigns/Extra-costs/Extra-costs-commission/Full-Report#summary

## Contact a Family (2014) Counting the Costs 2014: research into the finances of more than 3,500 families with disabled children across the UK

This report is based on a survey and finds that cost for families with disabled children are high and growing, with impacts on families including sometimes going without food, taking out loans and more.

http://www.cafamily.org.uk/media/805120/counting\_the\_costs\_2014\_uk\_report.pdf

## Matsui A, Nagase Osamu, Sheldon A, Goodley D, Sawada Y and Kawashima S (2012) Creating a Society for All. Disability and Economy

This is a book, available for purchase. It explores the links between disability and the economy and how to create a more just global economy.

http://disability-studies.leeds.ac.uk/publications/creating-a-society-for-all-disability-and-economy/

### <u>Department for Business, Innovation and Skills (2012) Creating an</u> <u>Inclusive Apprenticeship Offer</u>

This report was commissioned by the Apprenticeships Unit, a cross department unit working across the Department for Education and Department of Business, Innovation and Skills.

This report aims to give an informed and up-to-date description and analysis of the issues related to the inclusion of people with learning difficulties and/or disabilities in Apprenticeship provision

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/387040/AU-CreatingAnInclusiveApprenticeshipOffer-Report-May2012.pdf

### Meager N and Higgins T (2011) Disability and Skills in a Changing Economy. UK Commission for Employment and Skills

This is a detailed analysis of the way that skills, the labour market and disability disadvantage intersect. It reflects on how in future disabled people could gain more and higher level skills and employment, given future economic projections.

http://webarchive.nationalarchives.gov.uk/20140108090250/http://www.ukces.org.uk/assets/bispartners/ukces/docs/publications/equality-disability.pdf

### **UKCES (2014) Careers of the Future**

This report and infographics provide useful background on which careers are growing in the UK (and in particular nations and regions of the UK) and how much people could earn in different types of job. This may be relevant to disabled people's future opportunities

https://www.gov.uk/government/publications/careers-of-the-future

### Watts R, Harflett N, Robinson C and Greig R (2014) The use of personal budgets for employment support. NDTI

This study found that social care personal budgets are not being used much for employment support. The report makes recommendations for change including increased awareness amongst personal budget holders and social services about how personal budgets could be used; and market development by commissioners, so there is more good quality employment support available.

http://www.ndti.org.uk/what-we-do/employment-and-paid-work/employment1/research-into-the-use-of-personal-budgets-for-employment-support/

## Roulstone A and Williams J (2014) Being disabled, being a manager: 'glass partitions' and conditional identities in the contemporary workplace

This article explores the working lives and views of disabled senior staff working in UK organisations. Through qualitative research with disabled managers it shows some people are not just working in peripheral roles. However barriers still exist to what disabled staff in senior positions can be seen to do and be organisationally. It is argued that these present limits to further promotion and workplace inclusion for some disabled managers.

http://www.tandfonline.com/doi/abs/10.1080/09687599.2013.764280

## <u>Disability Rights Commission (2007) Maintaining Standards.</u> <u>Promoting Equality</u>

This was a Formal Investigation into whether fitness standards in nursing, teaching and social work discriminate against disabled people. It found inconsistent standards and cultures in which disabled people were more likely to be asked 'what's wrong with you?' than 'what can

you contribute?' They made recommendations for significant change to ensure disabled people could contribute to public services.

http://www.equalityhumanrights.com/sites/default/files/documents/Education/maintaining standards summary report.pdf

#### JRF (2015 Disability: Monitoring Poverty and Social Exclusion

JRF monitors poverty and exclusion and how they impact on disabled people. See:

https://www.jrf.org.uk/mpse-2015/disability\_and

https://www.jrf.org.uk/people/disabled-people

## Riddell S, Edward S, Weedon E and Ahglren L (2010) Disability, Skills and Employment. Centre for Research in Education, Inclusion and Diversity, University of Edinburgh

This paper, commissioned by the Equality and Human Rights Commission, assesses both statistics and existing research. Its conclusions include the need for joined - up working between agencies to enable more disabled people to gain from skills, employment, welfare and health policies.

http://www.equalityhumanrights.com/sites/default/files/documents/resear ch/disability skills and employment.pdf

### Evidence relating to particular groups of disabled people

Burns T, Catty J, Becker T, Drake R E, Fioritte A, Knapp M, Lauber, C, Rossler W, Tomov T, Van Bussbach J, White S and Wiersma D (2007). Effectiveness of Supported Employment for People with Severe Mental Illness: A randomised control trial. The Lancet. 370, 9593, pp. 1146–1152

This randomised control trial confirmed that across European countries - including the UK - the 'individual placement with support' (IPS) approach is more effective in enabling people with mental health challenges to secure employment than traditional vocational services. IPS involves rapid job search, people seeking jobs they are interested in, with personalised support (where needed intensive, where needed long-term) for both the individual and employer. (Traditional vocational services are more likely to offer 'stepping stones' to employment). Those receiving

IPS support were significantly more likely to get employment, less likely to drop out and less likely to be re-admitted to hospital.

http://www.psych.ox.ac.uk/publications/176765

Similarly Hoffman and colleagues found, after following up people on IPS for 5 years that people receiving IPS were more likely to get competitive employment, with higher wages and lower hospitalisation rates, than people receiving traditional vocational services:

http://www.ncbi.nlm.nih.gov/pubmed/25124692

## Burns T, Yeeles K, Langford O, Vazquez Montes M, Burgess J and Anderson C (2015) A randomised controlled trial of time-limited individual placement with support: IPS-lite trial

This study found that a 'lite' version of IPS could be as effective as IPS, offering a shorter term and cost effective approach to using individual placement with support.

http://bjp.rcpsych.org/content/early/2015/06/09/bjp.bp.114.152082

## Greig R, Chapman P, Eley A, Watts R, Love B and Bourlet G (2014) Employment Support for Disabled People. National Development Team for Inclusion

This research found that only a third of money spent by commissioners on employment support for people with mental health problems or learning disabilities was going on approaches supported by the evidence of what works best: that is, individual placement with support (mental health) and supported employment (learning difficulties). These approaches involve supporting people to get and keep employment, with individualised support for them and the employer - intensive where needed (rather than stepping stones to employment as occurs in traditional vocational services).

 $\underline{\text{http://www.ndti.org.uk/major-projects/current/employment-support-for-}}\underline{\text{disabled-people1/}}$ 

Evidence specific to Scotland, Wales, Northern Ireland or England

### <u>Disability Wales and Bevan Foundation (2013). Cap in Hand? The Impact of Welfare Reform on Disabled People in Wales</u>

This report sets out an overview of the Welfare Reform Act 2012, the existing welfare benefits available to disabled people and changes that will be made to these. The changes are complex and involve a number of significant alterations to eligibility and entitlement to existing benefits in advance of them being replaced by a whole new benefits system, Universal Credit. The report concludes with a set of recommendations for both the UK and Welsh Governments and also public bodies such as local authorities, health boards and emergency services to mitigate the negative impact of these changes on disabled people in Wales.

http://www.bevanfoundation.org/publications/cap-in-hand-the-impact-of-welfare-reform-on-disabled-people-in-wales/

## Institute for Fiscal Studies (2014) The distributional effects of the UK government's tax and welfare reforms in Wales: an update, July 2014

This report is an updated analysis of the personal tax and benefit reforms implemented, or due to be implemented, by the UK's coalition government from when it was elected in May 2010 up to and including April 2015. This includes those measures that had been pre-announced by the previous Labour government which the new government chose to implement. Attention is restricted to personal tax and benefit reforms alone: it does not examine the impact of reforms to corporation tax and other taxes formally paid by businesses, nor the impact of changes to spending on public services. This is to ensure the analysis remains focused. Looking at reforms up to April 2015 means including almost all the major reforms currently in the pipeline. But with Universal Credit (UC), a combination of a long roll-out period and significant transitional provisions means that it will be a long time before UC is operating in a 'steady state'. Similarly, while new claimants in Wales have been required to claim Personal Independence Payments (PIPs) instead of Disability Living Allowance (DLA) since June 2013, existing working age claimants of DLA are being transferred slowly and most are not expected to be moved over until 2016 or 2017. For this reason, we analyse the reforms both including and excluding UC and PIPs

http://www.ifs.org.uk/uploads/publications/bns/bn150.pdf

## <u>Disability Wales (2014) Response to Communities, Equality and Local Government Committee; Inquiry into Poverty in Wales; Strand 1: Poverty and Inequality</u>

This response analyses poverty and inequality in Wales and makes recommendations.

http://www.senedd.assembly.wales/documents/s41203/PIW%2028%20 S1%20-%20Disability%20Wales.pdf

Co-operation and Co-operatives in the Development of Direct
Payment Schemes in Wales: A Report for Wales Co-operative
Centre and Disability Wales. nProfessor Alan Roulstone and Dr Se
Kwang Hwang, Northumbria University May 2013

http://www.disabilitywales.org/projects/current-projects/citizen-directed-co-operative-cymru-project/

### International examples

### Zero Project (2013) Report on Employment

The Zero Project developed indicators rooted in the UN Convention on Human Rights and identified many innovative policies and practices from different countries, including the UK, that met these indicators. Some of the projects include data on outcomes. Some are led by disabled people.

http://zeroproject.org/wp-content/uploads/2013/12/Zero-Report e - 2013.pd

#### Reviews of academic evidence

**Employers' Attitudes Towards Hiring and Retaining People with Disabilities: A Review of the Literature** 

This selective review provides an overview of salient research findings related to employers' attitudes towards disability and prospective influences on employers to improve employment outcomes of people with disabilities. Research studies included for review are mainly those which investigated employer attitudes towards disability as predispositions to hiring people with disability. Selected studies were classified into three categories including hiring and accommodating employees with disabilities, work performance, and affective reactions and behavioural intentions of employers. Excluded from the review were studies that investigated other factors influencing employer attitudes toward disability. Altogether 34 research studies from the period of 1987 until 2012 were included in the review. Primary databases for the review included ProQuest, Ebscohost, Lexus Nexus, ERICK Database and the Sage Sociology Collection. This review of the demand-side employment literature suggests employers hold relatively positive attitudes regarding individuals with disabilities. However, employer affective reactions and behavioural intentions of employers towards disability in the work setting were less positive and negatively impact hiring decisions, provision of accommodations and work performance appraisals. Employer attitudes represent an important demand-side factor impacting full participation in competitive employment for individuals with disabilities. While employers report generally positive attitudes toward disability, hiring practices may still be discriminatory.

http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8927848

## Factors that Promote or Hinder Young Disabled People in Work Participation: A Systematic Review

The aim of this systematic review was to study factors which promote or hinder young disabled people entering the labor market. The authors systematically searched PubMed (by means of MESH and text words), EMBASE, PsycINFO, Web of Science and CINAHL for studies regarding (1) disabled patients diagnosed before the age of 18 years and (2) factors of work participation.

Results: out of 1,268 retrieved studies and 28 extended studies from references and four from experts, ten articles were included. Promoting

factors are male gender, high educational level, age at survey, low depression scores, high dispositional optimism and high psychosocial functioning. Female and low educational level gives high odds of unemployment just like low IQ, inpatient treatment during follow up, epilepsy, motor impairment, wheelchair dependency, functional limitations, co-morbidity, physical disability and chronic health conditions combined with mental retardation. High dose cranial radiotherapy, type of cancer, and age of diagnosis also interfered with employment.

Conclusions: of the promoting factors, education appeared to be important, and several physical obstructions were found to be hindering factors. The last mentioned factors can be influenced in contrast to for instance age and gender. However, to optimize work participation of this group of young disabled it is important to know the promoting or hindering influence for employment.

http://dare.uva.nl/document/2/80969

## Participation in work: A source of wellness for people with psychiatric disability

Not enough is known about the relationship between work and health, particularly for people with psychiatric disability. A review of research investigating variables that predict success at work showed inconsistent and contradicting results. The voice of people with psychiatric disability was found to be largely missing from literature. A study was therefore undertaken to explore the influences that impacted on the work-lives of people with psychiatric disability. This paper elucidates the importance of participation in work as an essential ingredient in the promotion of occupational justice, in identity construction and in the process of recovery for persons with psychiatric disability.

Interpretive biography was utilised to explore the experiences of people with psychiatric disability in the Western Cape, South Africa. Seventeen participants were identified using maximum variation sampling. Life story narratives were elicited during an average of three individual interviews per participant. Processes of analysis and interpretation were informed by a combination of paradigmatic narrative analysis and narrative analysis strategies.

A complex interplay of influences that shaped the identities of participants in ways that can assist or hinder their participation in work was revealed. Participation in work was perceived to be a means of recovery and a source of wellness for participants. More conscious effort is needed to promote the use of work as source of support and resource for health for persons who live with psychiatric impairment

http://www.ncbi.nlm.nih.gov/pubmed/19478416

### <u>Factors Related to the Employment of Visually Impaired Persons: A</u> Systematic Literature Review

The aim of this systematic review of the literature is to increase understanding of the factors that influence the labor force participation of persons who are visually impaired. Labor force participation was associated with many factors, such as communication training and education. Future research should focus on high-quality studies of labor force participation and underemployment in more countries. (Contains 1 figure and 5 tables).

http://www.sciencedirect.com/science/article/pii/S1936657411000306

### Personal assistance services in the workplace: A literature review

Personal assistance services (PAS) can be valuable adjuncts to the complement of accommodations that support workers with disabilities. This literature review explored the professional literature on the use of PAS in the workplace.

Bibliographic sources were used to locate relevant research studies on the use of PAS in the workplace. The studies in this review used both qualitative and quantitative methods to identify current definitions of work-related and personal care—related PAS, agency-directed versus consumer-directed PAS, long-term and short-term funding issues, development of PAS policy, and barriers to successful implementation of PAS.

Results: the studies uncovered issues related to (a) recruiting, training, and retaining personal assistants, (b) employer concerns, (c) costs and benefits of workplace PAS, (d) wages and incentives for personal

assistants, and (e) sources for financing PAS as a workplace accommodation.

Conclusion: the findings reveal the value and benefits of effective PAS on the job. PAS can lead to successful employment of people with disabilities when other accommodations cannot provide adequate workplace support. Additionally, the evolution of workplace PAS is dependent on development of realistic PAS policy and funding options.

### **Review of International Evidence on the Cost of Disability**

Allowance programs are a conceptually appealing way to help people with disabilities and their families pay for goods and services that such individuals often need. The programs provide recipients with financial resources that they can use in a flexible and efficient manner to improve their standard of living. Current disability allowance programs in the United Kingdom have been strained by the sustained growth in the number of people obtaining benefits. This report examines how the international literature on the extra costs of disability could contribute to an assessment of the United Kingdom's Disability Living Allowance (DLA) and Attendance Allowance (AA) programs.

http://www.disabilitypolicyresearch.org/~/media/publications/pdfs/disability/international evidence cost.pdf

## <u>Is social capital in the workplace associated with work-related injury and disability? A systematic review of the epidemiologic literature</u>

Social capital is defined as resources embedded in social relationships. Social capital in the workplace may include social support, interpersonal trust, respect, and reciprocity; and may occur at both the worker and workplace level. The objective of this study was to determine if social capital in the workplace is associated with work-related injury or disability.

http://jech.bmj.com/content/65/Suppl 1/A168.1

### <u>Perspectives on workplace disability management: a review of the</u> literature

Work-related musculoskeletal injuries represent a major source of work disability. While many employers recognize the importance of workplace disability management approaches and are assuming greater responsibility for preventing and minimizing work-related disability, questions about the effectiveness of these interventions exist. The purposes of this article are to: 1) describe the essential components of workplace disability management programs related to musculoskeletal injuries; 2) review the literature on disability management practices based on research evidence by focussing on workplace-based interventions and the role of the workplace; and 3) provide recommendations for disability management in the prevention and reduction of disability, and the rehabilitation of injured workers with musculoskeletal work injuries. The literature suggests that employer participation, a supportive work climate and cooperation between labour and management are cruial factors in facilitating return to work. Given the complexity of the disability management process and the numbers of individuals involved, it is essential that all workplace parties work together to achieve the goal of safe and early return to work.

http://www.ncbi.nlm.nih.gov/pubmed/12454354

## <u>Workplace-Based Work Disability Prevention Interventions for Workers with Common Mental Health Conditions: A Review of the Literature</u>

The objective was to summarize evidence on workplace-based work disability prevention (WDP) interventions in workers with common mental health conditions (CMHCs). Primary outcomes of interest were work absence duration and work functioning; secondary outcomes were quality of life, and economic costs. The authors conducted a systematic literature search in 5 electronic databases (MEDLINE, EMBASE, CINAHL, PsychINFO, Web of Science) for studies published from 2007 to 2009. Two reviewers screened for studies: (1) Targeting workers with CMHCs absent from, or struggling at, work; (2) evaluating workplace-based WDP interventions; (3) assessing our primary outcome(s); and (4) with controlled trials. Quality assessment (using 29 criteria) was performed by two reviewers.

Results: the search yielded 671 abstracts: 8 eligible studies and of sufficient quality. We identified three main intervention elements: (a) Facilitation of access to clinical treatment; (b) Workplace-based highintensity psychological intervention; and (c) Facilitation of navigation through the disability management system. Moderate evidence was found that facilitation of treatment improved work functioning, quality of life and economic outcomes, with limited evidence for work absence duration. Moderate evidence was found that psychological interventions, primarily cognitive-behavioral therapy, improved work functioning, quality of life, and economic outcomes. Moderate evidence indicated that facilitation of navigation through the disability management system improved work absence duration. Conclusions Workplace-based interventions could improve work disability outcomes for workers with CMHCs. Facilitation of access to clinical treatment, and workplacebased high-intensity psychological intervention were most effective in improving work functioning and quality of life, and in reducing costs.

http://www.ncbi.nlm.nih.gov/pubmed/22038297

## Workplace Accommodations for People with Mental Illness: A Scoping Review

Disability discrimination legislation means that employees with a disability or mental illness are legally entitled to reasonable workplace accommodations that enable them to work effectively and safely. This scoping review aims to investigate the types of workplace accommodations provided for people with mental illness, and their costs and benefits.

A literature search was conducted using five electronic databases. Peer reviewed research articles published between 1993 and June 2013 were included in this scoping review and their quality was assessed. Opinion papers, reports, and case descriptions were excluded.

Results: nine studies explored workplace accommodations for people with mental illness. The most commonly reported work-related accommodations were flexible scheduling/reduced hours, modified training and supervision, and modified job duties/descriptions. The least common type of accommodation was physical modification to the workplace. For employees with persistent mental illness who were

accessing a supported employment agency, the majority of accommodations related to support from the job coach or employment specialist, such as facilitating communication with the employer during hiring or on the job. The quality of the studies varied considerably and the benefits of the accommodations are not yet well documented. There is limited evidence that a larger number of workplace accommodations are associated with longer job tenure.

Conclusions: Workplace accommodations appear to be important to support employees with mental illness, but more accessible information about how disability discrimination legislation applies to this population is needed. Future research should address the implementation and effectiveness of mental health-related workplace accommodations.

http://www.ncbi.nlm.nih.gov/pubmed/24841728

#### What work means to people with work disability: a scoping review

As paid work is the occupation that people spend the most amount of their time doing, it is an important provider of personal meaning in their lives. This meaning has been shown to vary from person to person and to be important to health and well being. When a person is unable to work due to a disabling condition, it is unclear whether this meaning remains or is replaced by other meanings. The purpose of this scoping review was to explore what was known in the existing literature on what work means to those with work disability. The review involved identifying and selecting relevant studies, charting the data and collating and summarizing the results. Fifty-two studies explored the meaning of work for those with cancer, mental illness, musculoskeletal disorders, brain injuries, paraplegia, and AIDS. The studies revealed that, for most, work continued to be meaningful and important. Common themes across all types of disability included work being a source of identity, feelings of normality, financial support, and socialization. These meanings were found to be both motivating for return to work and health promoting. Conversely, a small number of studies found that the meanings and values ascribed to work changed following disability. New meanings, found either at home or in modified work, replaced the old and contributed to new identities. The exploration of the meaning of work has been shown to provide important understanding of the experience of

work and disability. This understanding can guide rehabilitation professionals in their interventions with the work disabled.

http://www.ncbi.nlm.nih.gov/pubmed/23519737

### A critical evaluation of the contribution of trust to effective Technology Enhanced Learning in the workplace: A literature review

This paper offers a critical review of the literature that explores the building and development of trust in workplace learning, particularly in a virtual context and its implications for technology enhanced learning (TEL) in business. Trust is increasingly recognised as important in both business and education, and is the focus of increasing attention in relation to the virtual environment. It offers a range of potential benefits, but adoption levels remain low. However, there are indications that trust may be a significant factor in both low workplace participation in and its effectiveness as a learning medium. Although savings in both money and time are the main perceived advantages, this review highlights the

positive role of face-to-face contact in increasing take-up and

effectiveness, even though this diminishes cost savings. This paper highlights the scant level of research into TEL, particularly in work situations, and the extent to which trust has been overlooked in this context. In the light of this gap in knowledge, further investigations are suggested to contribute to understanding the issues affecting in the workplace.

http://onlinelibrary.wiley.com/doi/10.1111/bjet.12187/abstract

## <u>Untapped potential: Perspectives on the employment of people with intellectual disability</u>

While individuals with intellectual disabilities can make valuable contributions in community workplaces, they typically experience low rates of paid employment. The goal of this article is to explore the

reasons for the limited involvement of this population in competitive employment, provide a rationale for including individuals with intellectual disabilities as employees, and propose policy, structural and attitudinal changes that would be necessary to include them more meaningfully in the workforce. The authors conducted a review of the literature relevant to the key theoretical concepts of disability, employment, organizational management and inclusion. The analysis reveals a number of theoretical, philosophical, legal and business arguments for and against the inclusion of workers with intellectual disabilities as employees, and suggests a number of system level changes needed to mitigate challenges to recruiting, hiring and retaining these workers. Changes to the employment situation for workers with intellectual disabilities will require major shifts in government policy, workplace practices and vocational preparation of youth with intellectual disabilities. Continued research is necessary to identify best practices.

http://www.ncbi.nlm.nih.gov/pubmed/22495411

## Influence of poor health on exit from paid employment: a systematic review

The objective was to provide a systematic literature review on associations between poor health and exit from paid employment through disability pension, unemployment and early retirement, and to estimate the magnitude of these associations using meta-analyses. Medline and Embase databases were searched for longitudinal studies on the relationship between health measures and exit from paid employment. Random-effects models were used to estimate the pooled effects. In total, 29 studies were included. Self-perceived poor health was a risk factor for transition into disability pension (relative risk (RR) 3.61; 95% CI 2.44 to 5.35), unemployment (RR 1.44; 95% CI 1.26 to 1.65) and early retirement (RR 1.27; 95% CI 1.17 to 1.38). Workers with mental health problems had an increased likelihood for transition into disability pension (RR 1.80; 95% CI 1.41 to 2.31) or unemployment (RR 1.61; 95% CI 1.29 to 2.01). Chronic disease was a risk factor for transition into disability pension (RR 2.11; 95% CI 1.90 to 2.33) or unemployment (RR 1.31; 95% CI 1.14 to 1.50), but not for early retirement. This meta-analysis showed that poor health, particularly selfperceived health, is a risk factor for exit from paid employment through disability pension, unemployment and, to a lesser extent, early retirement. To increase sustained employability it should be considered to implement workplace interventions that promote good health

http://www.ncbi.nlm.nih.gov/pubmed/24169931

## Situating Disability within Comparative Education: A Review of the Literature

This paper is an inquiry into where the topic of disability falls within the vast field of comparative education research. It explores the extent to which disability is present in comparative education literature, and in what ways it is represented. A review of literature across the core comparative education peer-reviewed journals was conducted. Findings show that a limited number of studies in comparative education have examined students with disabilities, but numbers have increased in recent years. Additionally, two major themes emerged from the literature: (1) social interpretations of disability, and (2) global versus local. The findings are discussed in terms of implications for inclusive education and future research.

http://ger.mercy.edu/index.php/ger/article/download/6/9

### The Economic Costs of Childhood Disability

Childhood disabilities entail a range of immediate and long-term economic costs that have important implications for the well-being of the child, the family, and society but that are difficult to measure. In an extensive research review, Mark Stabile and Sara Allin examine evidence about three kinds of costs--direct, out-of-pocket costs incurred as a result of the child's disability; indirect costs incurred by the family as it decides how best to cope with the disability; and long-term costs associated with the child's future economic performance. Not surprisingly, the evidence points to high direct costs for families with children with disabilities, though estimates vary considerably within these families. Out-of-pocket expenditures, particularly those for medical

costs, for example, are higher among families with children with a special health care need. An important indirect cost for these families involves decisions about employment. Stabile and Allin examine several studies that, taken together, show that having a child with disabilities increases the likelihood that the mother (and less often the father) will either curtail hours of work or stop working altogether. Researchers also find that having a child with disabilities can affect a mother's own health and put substantial strains on the parents' relationship. In the longer term, disabilities also compromise a child's schooling and capacity to get and keep gainful employment as an adult, according to the studies Stabile and Allin review. Negative effects on future well-being appear to be much greater, on average, for children with mental health problems than for those with physical disabilities. Stabile and Allin calculate that the direct costs to families, indirect costs through reduced family labor supply, direct costs to disabled children as they age into the labor force, and the costs of safety net programs for children with disabilities average \$30,500 a year per family with a disabled child. They note that the cost estimates on which they base their calculation vary widely depending on the methodology, jurisdiction, and data used. Because their calculations do not include all costs, notably medical costs covered through health insurance, they represent a lower bound. On that basis, Stabile and Allin argue that many expensive interventions to prevent and reduce childhood disability might well be justified by a cost-benefit calculation.

http://www.ncbi.nlm.nih.gov/pubmed/22550686

### Employment of persons with disabilities in information technology jobs: literature review for "IT works"

This article reviews relevant literature as to the labor pool of qualified individuals with disabilities and employment in information technology (IT) sector jobs. First, the article reviews the empirical literature on barriers to employment in IT for persons with disabilities. The examination then is extended to studies of barriers to employment for individuals with disabilities in other employment sectors. Findings

illustrate the limited experiences that IT and non-IT companies have in

employing and accommodating employees with disabilities. Implications are discussed for enhancing the employment of qualified workers with disabilities in IT through research, education, training, and mentoring programs.

http://onlinelibrary.wiley.com/doi/10.1002/bsl.510/abstract

## <u>Trends in Employment for Individuals with Autism Spectrum</u> <u>Disorder: a Review of the Research Literature</u>

Employment is fundamental to the well-being of individuals including those with autism spectrum disorder (ASD). The purposes of this review are to provide an overview of employment-related research in individuals with ASD and increase our understanding of the factors that affect the employment situation of this population. Topics explored are employment outcomes revealed from adult outcome studies and national datasets as well as internal and external challenges that people with ASD may face in finding and maintaining employment. Social difficulties, comorbidity, education level, family support, employers' attitudes, access to services, and disability incentives have been implicated as factors that play an important role in predicting employment. Existing research evidence for specific employment training programs and strategies to successful employment are also introduced in regards to supported employment, transition services, assistive technology, and multidisciplinary collaboration. Finally, implications from both clinical practice and research perspective are provided.

http://link.springer.com/article/10.1007%2Fs40489-014-0041-6

### <u>Disability and Job Search Among Older Workers: A Narrative</u> Review

This article reviews published research on the effects of disability, age and gender on the job search process. Electronic databases (Medline [via Ovid], OT Seeker, CINAHL, AMED, and Proquest 5000) were used to identify studies focusing on job search and employment, disability, age, gender and other barriers to workforce participation. There has been extensive research on the effects of age and gender on the job search process, and the available evidence indicates that disability, age and gender play significant roles in shaping the job search processes of older workers. However, there has been little rigorous investigation of the role of disability and research specifically examining the relationships between disability, job search behaviours and employment outcomes was not identified. This is a significant gap in the literature on disability and participation in the labour market. Overall, this narrative review indicates that older workers with a disability face multiple disadvantages when seeking work, which impairs their ability to fully engage in the labour market.

http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814898

### **Epilepsy and employment: Literature review**

The aim of this review is to increase understanding of the factors that affect the regular employment positions of people with epilepsy by means of the World Health Organization International Classification of Functioning, Disability, and Health (ICF) model.

Thirty-four primary research articles describing factors associated with employment for people with epilepsy are reviewed.

Results: people with epilepsy may face a number of complex and interacting problems in finding and maintaining employment. Stigma, seizure severity, and psychosocial variables such as low self-esteem, passive coping style, and low self-efficacy have been implicated as factors that play an important role in predicting employment. Findings demonstrate the need for specific employment training programs.

Conclusion: the paper recommends specific training interventions that focus on increasing the self-efficacy and coping skills of people with

epilepsy so that these individuals will be able to accept their disorder and make personal and health-related choices that help them to achieve better employment positions in society.

http://www.ncbi.nlm.nih.gov/pubmed/17369102

# To what extent have relaxed eligibility requirements and increased generosity of disability benefits acted as disincentives for employment? A systematic review of evidence from countries with well-developed welfare systems

Reductions in the eligibility requirements and generosity of disability benefits have been introduced in several Organisation for Economic Cooperation and Development (OECD) countries in recent years, on the assumption that this will increase work incentives for people with chronic illness and disabilities. This paper systematically reviews the evidence for this assumption in the context of well-developed welfare systems.

http://www.ncbi.nlm.nih.gov/pubmed/20805199

### <u>Perspectives on Employment Integration, Mental Illness and Disability, and Workplace Health</u>

This paper reviews the literature on the interplay between employment integration and retention of individuals diagnosed with mental health and related disability (MHRD). Specifically, the paper addresses the importance of an integrative approach, utilizing a social epidemiological approach to assess various factors that are related to the employment integration of individuals diagnosed with severe mental illness. The approach to the review incorporates a research methodology that is multilayered, mixed, and contextual. The review examines the literature that aims to unpack employers' understanding of mental illness and their attitudes, beliefs, and practices about employing workers with mental illness. Additionally it offers a conceptual framework entrenched within the social determinants of the mental health (SDOMH) literature as a way to contextualize the review conclusions. This approach contributes to a holistic understanding of workplace mental health conceptually and methodologically particularly as practitioners and policy makers alike are grappling with better ways to integrate employees who are diagnosed with mental health and disabilities into to the workplace.

## A Conceptual Framework for Understanding Students' with Disabilities Transition to Community College

Students with disabilities are significantly underrepresented in the nation's community college population for multiple reasons. These include low expectations, poor high school preparation and transition planning, lack of communication or support services, and ineffective or poor support from school services personnel and faculty. This paper presents a literature synthesis. Its purpose is to inform an initial framework for building towards a conceptual framework for understanding the transition to community college by students with disabilities. The framework was developed from an earlier mixed methods study involving 100 college students with disabilities and 10 disability resource counsellors in eight universities and colleges, six of which were community colleges. The framework was examined by comparing six reviews from the What Works in Transition: Systematic Review Project (meta-analyses of previous studies) and five metasyntheses (rigorous evaluations). Based on these analyses, elements of the framework were confirmed and redefined to show what was needed for (a) high quality preparation in secondary education (self advocacy development and peer/teacher awareness and sensitivity to foster maximizing postsecondary options, focused training on self-advocacy, and college visits and orientation activities); (b) planning (ongoing communication between high school and postsecondary school); and (c) access and accommodations in community colleges (instructor awareness and sensitivity, financial aid opportunities in order to foster social support networks, mentoring support, and formulation of goals for future employment). Five recommendations are provided suggesting how community college leaders, policymakers, and practitioners could use the framework to enhance the transition to community college by students with disabilities.

http://www.tandfonline.com/doi/abs/10.1080/10668920802640079?journ alCode=ucjc20

#### 4. Participating In Community And Social Life: What Works?

#### **Evidence led by disabled people**

## <u>Disability Rights UK evidence review on Inclusive Communities</u> (2014)

Disability Rights UK undertook a review of existing research evidence on what makes a community inclusive and what the benefits can be – for whole communities, as well as for disabled people. It published this research review; and 5 messages from the review; and guidance for both disabled people's organisations and local authorities. See:

http://www.disabilityrightsuk.org/policy-campaigns/reports-and-research/inclusive-communities

#### Elder-Woodward J (2015) The Future without ILF

This paper reviews the achievements of the Independent Living Fund, arguably one of the most important achievements for the Independent Living Movement, now closed in parts of the UK. The paper makes the case for a new Trust to build on its achievements and guarantee the kind of portable national entitlement that disabled people require. It argues that such a Trust could be used to promote independent living through a different and more positive partnership with local government; and that this would be the kind of institution that would promote citizenship based on what people offer — so-called 'asset based citizenship'.

http://www.centreforwelfarereform.org/library/by-az/a-future-without-the-ilf.html

#### **Evidence from research and other organisations**

Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bognor, J., Rodrigues, E. (2008) What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation* 30,19, 1445-1460

This study sought to gain an insider perspective from people with disabilities on what participation means, how to characterize it, and the barriers and supports to participation. It involved people with different impairments who took part in focus groups in different areas. Participants thought of participation in terms including active and

meaningful engagement, choice and control, access and opportunity, personal and social responsibilities, having an impact and supporting others, and social connection, inclusion and membership. Participants wanted to be free to define and pursue participation on their own terms. Participation does not occur in a vacuum: the environment influences participation. This has implications for systems-level change to support participation.

https://enablemob.wustl.edu/OT572D-01/RequiredArticles/Hammel%20participation.pdf

#### Olsen R and Tyers H (2004) Supporting disabled adults as parents

This research focused on what would improve support for disabled parents. Conclusions included that professionals should 'think parent', recognising that disabled parents – like all parents – want to parent well and may need support to do so. Substantial support may be needed but low cost solutions can also be worked out with parents. Some authorities were using different legislation flexibly in the interests of the whole family.

https://www.jrf.org.uk/report/supporting-disabled-adults-parents

## Beckett A and Buckner L (2012) Promoting positive attitudes towards disabled people: definition of, rationale and prospects for anti-disablist education

This article explores the role of state primary schools in promoting positive attitudes towards disabled people. It presents data from a survey of schools and interviews with teachers. The article considers progress made by schools against particular aspects of the Disability Equality Duty 2006. The project was underpinned by a working model of anti-disablist education. It explores the rationale for a 'courageous' form of anti-disablist education, definition of this, schools' engagement in this type of practice and challenges to promoting such an ideal.

http://www.tandfonline.com/doi/abs/10.1080/01425692.2012.692046

Briant E, Watson N, Philo G and Inclusion London (2011) Bad News for Disabled People: How the newspapers are reporting disability.

### Glasgow University in association with Strathclyde Centre for Disability Research and Glasgow Media Unit

This study found an increase in print media coverage of disability from 2004-5 to 2009-10, an increase in negative, pejorative coverage, which is impacting on public attitudes and making disabled people feel threatened.

http://www.gla.ac.uk/media/media 214917 en.pdf

### Equality and Human Rights Commission (2011) Hidden in Plain Sight. Inquiry into disability related harassment

This is a formal inquiry (using the Commission's legal powers) into the problem of disability-related hostility and hate crime in Britain. It analyses data and individual examples and comes up with a manifesto to prevent and better address hostility, making 7 major recommendations. The EHRC's website has carried periodic updates on progress.

http://www.equalityhumanrights.com/publication/hidden-plain-sight-inquiry-disability-related-harassment

#### Baumberg B and Wood C (2015) Re-thinking incapacity. Demos

This report looks at how seven other countries assess incapacity and finds several lessons for the UK:

- Real-world assessment is possible even commonplace
- A standardised real-world test is possible
- We can separate real-world incapacity from unemployment
- Unemployment benefits must also be a 'safe place' for disabled people

http://www.demos.co.uk/project/rethinking-the-work-capability-assessment/

Burns, N, Watson, N, and Paterson, K. (2013) Risky bodies in risky spaces: disabled people's pursuit of outdoor leisure

Risk can be used to deny disabled people access to many parts of mainstream life. This study explores disabled people's views and experiences of outdoor recreation. Many people felt that the outdoors represented a risky environment. For some, risk was one of the main drivers for going out into the countryside; whilst for others, risk was a major cause of their reluctance to venture into the countryside. Engaging in risk can both disable and can challenge disablist views.

http://eprints.gla.ac.uk/73811/

# Agbakoba R, McGee-Lennon M, Bouamrane M-M, Watson, N and Mair F S (2016) Implementation factors affecting the large scale deployment of digital health and well-being technologies: a qualitative study of the initial phases of the 'Living-It-Up' programme

This qualitative study of the Living It Up programme in Scotland concluded that whilst Living-It-Up is ongoing, results to date suggest that – in order to be successful – the roll-out of digital health and well-being technologies at scale requires a delicate and pragmatic trade-off between co-design activities, innovative services and widespread marketing and recruitment initiatives

http://eprints.gla.ac.uk/108899/

#### Evidence relating to particular groups of disabled people

## Alliance for Inclusive Education, The Children's Society, the Council for Disabled Children and the National Children's Bureau Research Centre (2013) The Viper Project

VIPER stands for Voice, Inclusion, Participation, Empowerment, Research. This project explored disabled children and young people's participation in decision-making about services. A group of 16 young disabled people worked as joint researchers on this project. The project both researched participation — and was a participation project in its own right. The project works within the social model of disability, which recognises that people with impairments are disabled by barriers in society. The research found that young disabled people were often not given a chance to participate in decisions about their own services; and

that if they were they were often not told what happened next. The report makes recommendations for change.

http://viper.councilfordisabledchildren.org.uk/media/7834/hear-us-out.pdf

### Singh B (2005) Making change happen for black and minority ethnic disabled people

JRF supported 4 organisations to explore practical ways to improve lives of black and minority ethnic disabled people. Projects were most successful where they responded from the outset to the complexity of participants' identities, multiple support needs and experiences of multiple exclusion

https://www.jrf.org.uk/report/making-change-happen-black-and-minority-ethnic-disabled-people

## <u>Disability Rights Commission (2006) Closing the Gap: a Formal Investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems</u>

This was a Formal Investigation using the Commission's legal powers into health inequalities, including early deaths, of people with learning disabilities and/or mental health problems. Following analysis of 8 million primary care records and input from over 1000 disabled people, the investigation found that people with mental health problems were more likely to get common 'killer diseases', more likely to get them young, more likely once diagnosed to die from them quickly than other citizens. Both people with mental health problems and people with learning disabilities were less likely to get routine screening and treatments than others. It secured commitment from professional leaders and government to a series of recommendations.

http://collections.europarchive.org/tna/20060924151545/http://www.drc-gb.org/newsroom/health\_investigation.aspx#Finalreportsandsummaries

## Henden N and Pascali G (2002) Becoming Adult: Young disabled people speak

This study of 72 young adults who have grown up with disability compares the experiences of a group who achieved independent

households and jobs with groups of people who achieved one of these or neither. The study aimed to draw out the factors that enable and support disabled young people to move to independent adulthood. Findings included that getting work, running an independent household, achieving a social life and citizenship was difficult; and combining different aspects of adult status was especially difficult. Few had a job as well as an independent household, especially if they needed personal assistance. The young people wanted to work and contribute but need more support to do so.

https://www.jrf.org.uk/report/becoming-adult-young-disabled-people-speak

### Beckett A (2013) Non-disabled children's ideas about disability and disabled people

This article explores non-disabled children's ideas about disability, based on focus groups with children aged 6–7 and 10–11. The article explores how non-disabled children's enacted various cultural 'schemas' (patterns of thought) relating to disability and argues that although they are capable of questioning, even transforming, schemas, they are primarily engaged in enacting schemas that maintain their privileged position as non-disabled people. The article concludes by urging schools and educationalists to do more to encourage non-disabled children to think differently and positively about disabled people.

http://www.tandfonline.com/doi/abs/10.1080/01425692.2013.800444

#### Beresford B and Rhodes D (2008) Housing and disabled children

This report summarises what is known on this subject and finds that all disabled children and their families, not just children with physical impairments, are likely to experience housing difficulties – including overcrowding and difficulties with location. Housing improvements for these families can lead to increased independence, confidence and self-reliance amongst disabled children.

https://www.jrf.org.uk/report/housing-and-disabled-children

# Webber, M., Reidy, H., Ansari, D., Morris, D. (2016) Developing and Modeling Complex Social Interventions. Introducing the Connecting People Intervention. *Research on Social Work Practice*. 26,1,14-19

This article reports on a model of social work practice that supports people with mental health problems to enhance their social networks. It was developed through focus group discussions with service users and practitioners and involvement of relevant experts. The 'model' represents the process visually, which can assist practice and lead to improved outcomes for service users.

https://pure.york.ac.uk/portal/en/publications/developing-and-modeling-complex-social-interventions%2897a04de1-24b5-4df3-bb81-357b4c79b2f3%29.html

## Lundy H, Johnston A and Nisbet G (2015) Dementia friendly communities: supported learning and outreach with the deaf community

People with hearing loss are more likely to develop dementia and this programme was designed to raise awareness, reduce stigma. It made recommendations for further action

https://www.jrf.org.uk/report/dementia-friendly-communities-supported-learning-and-outreach-deaf-community

# Newlin, M., Webber, M., Morris, D., Howarth, S. (2015) Social Participation Interventions for Adults with Mental Health Problems: A Review and Narrative Synthesis. Social Work Research, 39,3, 167-180

People with mental health problems are socially excluded. Increasing their social participation—building trusting relationships and engaging in community activities—is an important role for mental health social workers. This article reviews evidence on which approaches are effective in enhancing people's participation in their wider communities (outside mental health services). A systematic review was done. Sixteen articles reporting 14 unique interventions were found. The review found

positive outcomes in asset-based approaches (ie building on people's strengths), social skills development, building trusting relationships between workers and service users, and finding resources to enhance community participation. Current evidence is however limited.

http://swr.oxfordjournals.org/content/39/3/167.abstract

# McConkey R, Keogh F, Bunting B, Garcia Irearte E and Watson SF (2016) Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalized arrangements and group home placements

Internationally the relocation of people with intellectual impairments from institutions has brought significant gains to their quality of life. This study contrasted three groups of people in Ireland who moved either to personalized arrangements or to community group homes with those who remained in congregated settings awaiting relocation. Persons moving to rented accommodation with personalized support tended to be younger and had fewer support needs than those in group homes. They had greater control and choice in their lives, more community engagement and increased personal relationships compared to residents in group homes but those remaining in congregated settings fared worse of all. However, average staff costs were significantly higher in the congregate settings.

http://jid.sagepub.com/content/early/2015/12/31/1744629515624639.abs tract

#### Emerson E and Robertson J (2008) SCIE Knowledge review 20: Commissioning person-centred, cost-effective, local support for people with learning disabilities

This knowledge review brings together knowledge from research and practice on commissioning person-centred, cost-effective, local support for people with learning disabilities who are labelled as having complex needs and/or challenging behaviour

http://www.scie.org.uk/publications/knowledgereviews/kr20.asp

## Thomas C and Milligan C (2015) How can and should UK society adjust to dementia? JRF

This paper aims to stimulate debate about new ways forward in understanding, and ways to meet the needs of the growing number of people living with dementia.

https://www.jrf.org.uk/report/how-can-and-should-uk-society-adjust-dementia

#### Sappey R and Bullmore P (2013) Listening to voice hearers

This article considers what the Hearing Voices Network can offer to mental health social work. It combines a literature review on voice hearing by Bob Sapey and the expertise by experience of Peter Bullimore who runs a peer support group for voice hearers. Listening to voice hearers offers positive alternatives to the current biomedical treatment of schizophrenia. This approach can be undertaken by experts by experience and mental health professionals. The authors argue that social workers can help voice hearers cope both with the content of their voices and the stigmatising responses to being diagnosed with schizophrenia.

### Sayce L (2003) Beyond Good Intentions: making anti-discrimination strategies work

This article provides a framework for challenging each aspect of discrimination faced by people living with mental health problems; analyses evidence for effective approaches; critiques counter-productive approaches, for instance those based on an 'illness like any other' message, which actually intensifies fear and prejudice; and sets out recommendations

http://www.tandfonline.com/doi/abs/10.1080/0968759032000097852

### Sayce L (2016) From Psychiatric Patient to Citizen Revisited. Palgrave Macmillan

This is a book, available for purchase. It reviews evidence on a range of approaches to tackling exclusion and discrimination of those of us living with mental health challenges - from legal rights to anti-stigma campaigns. It sets out an agenda, based on rights to participate, on which people might unify to make participation real.

#### **Time to Change**

This campaign to tackle stigma and discrimination faced by people living with mental health challenges is being evaluated and a number of evaluative articles have been published. These can be found through:

http://www.time-to-change.org.uk/about-us/our-impact

Thornicroft, G., Mehta, N., Clement, S., Lacko-Evans, S., Doherty, M., Rose, D., Koschorke, M., Shidhaye, R., O'Reilly, C., Henderson, C. (2016) Evidence for effective interventions to reduce mental-health-related stigma and discrimination. The Lancet 387,10023, 1123–1132

This article reviews what is known internationally about effective ways to reduce stigma and discrimination on mental health grounds. Some approaches are effective in the short-term but not always longer term. Given the huge challenges that result from stigma and discrimination they argue for strong research to provide evidence to support investment in approaches to tackling these challenges.

http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2815%2900298-6/abstract

#### Morris J and Wates M (2006) SCIE Knowledge review 11: Supporting disabled parents and parents with additional support needs

This knowledge review is about parents with physical and/or sensory impairments, learning difficulties, mental health problems, long-term illnesses such as HIV/AIDS, and drug or alcohol problems. Its main messages include that support needs of disabled parents need to be met better. Ways of doing that could be through local public service agreements, local strategic partnerships, local area agreements and individual budgets; practitioner networks to encourage good practice; and involvement of disabled parents in all activities relating to improving support to families

http://www.scie.org.uk/publications/knowledgereviews/kr11.asp

Richardson L, the Tizard Centre, University of Kent. Living in fear: the experiences of people with learning disabilities and autism

This detailed presentation analyses evidence of hate crime, with recommendations for change

https://www.kent.ac.uk/tizard/resources/db\_document.pdf

# Emerson E, Hatton C, Robertson J and Baines S (2014) Perceptions of neighbourhood quality, social and civic participation and the self-rated health of British adults with intellectual disability: cross sectional study

This analysis of data from the Understanding Society study found that people with intellectual impairments (learning difficulties) had lower levels of social and civic participation and less favourable perceptions of important characteristics of their neighbourhood – for instance, feeling safe after dark, employment, being able to access services when needed – than others. Positive perceptions and participation were positively linked with better self-rated health amongst people both with and without learning disabilities. The differences in participation and perceptions may partly explain health inequalities experienced by people with intellectual impairments.

http://www.research.lancs.ac.uk/portal/en/publications/perceptions-of-neighbourhood-quality-social-and-civic-participation-and-the-self-rated-health-of-british-adults-with-intellectual-disability%28e39fa7cd-8bcf-42c8-a2cf-f882b76cee81%29.html

## Robertson J, Hatton C, Emerson E and Baines S (2014) The impact of health checks for people with intellectual disabilities: an updated systematic review of evidence

This is a review summarising evidence from a range of countries on the impact of health checks on the health and well-being of people with intellectual disabilities. Health checks consistently led to detection of unmet health needs and targeted actions to address health needs. Health checks also had the potential to increase knowledge of the health needs of people with intellectual disabilities amongst health professionals and support staff, and to identify gaps in health services. Health checks are effective in identifying previously unrecognised health needs, including life threatening conditions. Future research should consider strategies for optimising the cost effectiveness or efficiency of health checks.

## Bowers H, Lockwood S, Eley A, Catley A, Runnicles D, Mordey M, Barker S, Thomas S, Jones C and Dalziel S (2013) Widening choices for older people with high support needs

This study explored different types of mutual and reciprocal support including

Shared Lives, Homeshare, cohousing, time banks, mutually supportive relationships, self-help/peer support networks, mutually supportive communities. These options work best when they are locally focused, personally delivered and connected to other services and networks. Significant change is needed in the way that services are commissioned and delivered so that current options for support are widened to include these models.

http://www.ndti.org.uk/uploads/files/older-people-support-choices-full.pdf

#### **Evidence specific to Scotland, Wales, Northern Ireland or England**

## Kelly B, McShane T, Davidson G and Pinkerton J (2014) A Review of Literature on Disabled Care Leavers and Care Leavers with Mental Health Needs. Queen's University Belfast

This is a review of evidence on the needs of disabled care leavers including those with mental health needs.

http://pure.qub.ac.uk/portal/en/publications/a-review-of-literature-on-disabled-care-leavers-and-care-leavers-with-mental-health-needs(c04cf0ae-7862-4d42-8bdd-adeab91e920a).html

## Welsh Government (2013) Building Resilient Communities: Taking Forward the Tackling Poverty Action Plan

This document sets out progress made to date by the Welsh Government against commitments made in Building Resilient Communities: Taking forward the Tackling Poverty Action Plan published in July 2013. It also includes new actions and commitments in respect of key areas identified in the recently published Child Poverty Strategy.

http://gov.wales/topics/people-and-communities/tackling-poverty/taking-forward-tackling-poverty-action-plan/?lang=en

### Welsh Government (2014) Tackling Hate Crimes and Incidents Framework for Action

This framework aims to tackle hate crimes and incidents against anyone with protected characteristics under the Equality Act 2010. These include: disability, race, religion, sexual orientation, gender identity and age. It covers cyber hate and bullying, far right hate and mate crime (befriending of people, who are perceived by perpetrators to be vulnerable, for the purposes of taking advantage of, exploiting and/or abusing them). The framework includes 3 objectives on prevention, supporting victims and improving the multi-agency response. It is supported by a delivery plan which will be updated on an annual basis

http://gov.wales/about/cabinet/cabinetstatements/2014/tacklinghatecrimes/?lang=en

### Welsh Government (2012) Working for Equality in Wales: Strategic Equality Plan and Objectives 2012-2016

The Strategic Equality Plan is based on eight key Equality Objectives which were developed following extensive engagement and based on available evidence. This helped to highlight the most pressing barriers to equality to be tackled by Government and by partner organisations.

http://gov.wales/topics/people-and-communities/equality-diversity/?lang=en

## Scottish Government (2010) A National Statistics Publication for Scotland: Registered Blind and Partially Sighted Persons

The purpose of this Statistics Release is to present national figures on visually impaired people registered with Local Authorities in Scotland. Registration with Local Authorities for blind and partially sighted persons is not compulsory. Research studies suggest that between a quarter and

a third of visually impaired people are in fact registered with Local Authorities

#### http://www.gov.scot/Publications/2010/10/26094945/0

#### **RNIB (2016) Scotland Reports**

#### A Vision for a Better Scotland

This is the RNIB Scotland manifesto for the 2016-21 Scottish Parliament, calling on all parties to back policies to help end the exclusion of blind and partially sighted people.

#### Vision Support Services

A report outlining the need for the emotional and practical support for local Vision Support Services to people newly diagnosed with sight loss.

#### Ayrshire & Arran Sensory Locality Plan 2014-24

This outlines the new approach to integrating sensory loss services across Ayrshire, in which RNIB Scotland was a key partner.

#### Scottish Vision Strategy (2013-18)

This outlines phase 2 of the cross-sectoral strategy for tackling preventable sight loss. Described as "the most concerted drive to safeguard eyesight ever undertaken in Scotland".

#### This is Working 3

Nine new case-studies of people with sight loss in Scotland who are employed in a range of jobs, including IT lecturer, civil engineer and secondary school teacher.

All can be downloaded in either pdf or word format from <a href="http://www.rnib.org.uk/scotland/reports-and-publications-rnib-scotland/">http://www.rnib.org.uk/scotland/reports-and-publications-rnib-scotland/</a>

#### **International examples**

#### **Zero Project (2014) Report on Accessibility**

The Zero Project drew up indicators rooted in the UN Convention on the Rights of Persons with Disabilities and identified numerous policies and practices from around the world that met those indicators. Some of the projects include evidence on outcomes.

http://zeroproject.org/wp-content/uploads/2013/12/ZERO-PROJECT-REPORT-2014.pdf

#### Zero Project (2016) Report on Education and ICT

The Zero Project drew up indicators rooted in the UN Convention on the Rights of Persons with Disabilities and identified numerous policies and practices from around the world that met those indicators. Some of the projects include evidence on outcomes.

http://zeroproject.org/wp-content/uploads/2016/02/ZeroProjectReport 2016 barrierfree.pdf

#### Reviews of academic evidence

### Out-of-school lives of physically disabled children and young people in the United Kingdom

Currently there appear to be few opportunities and little evidence of physically disabled children and young people (C&YP) participating in mainstream social activities. A qualitative review was undertaken to examine the factors affecting physically disabled C&YP (8-15 years) in the United Kingdom participating in out-of-school activities. Views and experiences were explored from the perspective of the service users and providers to assess current provision and to determine the need for future research into factors that may affect participation. Searches were conducted across eight databases, the references of the included studies were checked and the websites were searched. Studies that used a qualitative design that examined the views relating to out-ofschool activities were included. Nine papers were identified, which included three peer-reviewed papers and six pieces of grey literature and pertinent government documents to include views and experiences of out-of-school activity provision. The main themes emerging from the review were the need for social inclusion, out-of-school activities run by volunteers and accessibility, with threads throughout, which require further research including parental influence, provision, training and

attitudes. This review highlights the absence of the service user's voice and sheds light on the limited provision and barriers affecting participation in out-of-school activities.

http://www.ncbi.nlm.nih.gov/pubmed/23818148

## <u>Older people's perspectives on participation in physical activity: a</u> systematic review and thematic synthesis of qualitative literature

From 132 studies involving 5987 participants, this review identified six major themes: social influences (valuing interaction with peers, social awkwardness, encouragement from others, dependence on professional instruction); physical limitations (pain or discomfort, concerns about falling, comorbidities); competing priorities; access difficulties (environmental barriers, affordability); personal benefits of physical activity (strength, balance and flexibility, self-confidence, independence, improved health and mental well-being); and motivation and beliefs (apathy, irrelevance and inefficacy, maintaining habits).

Conclusions: some older people still believe that physical activity is unnecessary or even potentially harmful. Others recognise the benefits of physical activity, but report a range of barriers to physical activity participation. Strategies to enhance physical activity participation among older people should include (1) raising awareness of the benefits and minimise the perceived risks of physical activity and (2) improving the environmental and financial access to physical activity opportunities.

http://bjsm.bmj.com/content/early/2015/01/13/bjsports-2014-094015.short

### Barriers to and facilitators of sports participation for people with physical disabilities: a systematic review

Most people with physical disabilities do not participate in sports regularly, which could increase the chances of developing secondary health conditions. Therefore, knowledge about barriers to and facilitators

of sports participation is needed. Barriers and facilitators for people with physical disabilities other than amputation or spinal cord injuries (SCI) are unknown. The aim of this study was to provide an overview of the literature focusing on barriers to and facilitators of sports participation for all people with various physical disabilities. Four databases were searched using MeSH terms and free texts up to April 2012. The inclusion criteria were articles focusing on people with physical disabilities, sports and barriers and/or facilitators. The exclusion criteria were articles solely focusing on people with cognitive disabilities, sensory impairments or disabilities related to a recent organ transplant or similar condition. Fifty-two articles were included in this review, with 27 focusing on people with SCI. Personal barriers were disability and health; environmental barriers were lack of facilities, transport and difficulties with accessibility. Personal facilitators were fun and health, and the environmental facilitator was social contacts. Experiencing barriers to and facilitators of sports participation depends on age and type of disability and should be considered when advising people about sports. The extent of sports participation for people with physical disabilities also increases with the selection of the most appropriate sport.

http://onlinelibrary.wiley.com/doi/10.1111/sms.12218/abstract

## Quality-enhancing interventions for people with profound intellectual and multiple disabilities: a review of the empirical research literature

This study provides an overview of empirical research on the effectiveness of quality-enhancing interventions for people with profound intellectual and multiple disabilities (PIMD).

Through computerised searches of the PsycINFO and ERIC databases, and using several search criteria specifically relating to the target group and to the subject of this review, 16 studies were identified.

Results: the interventions described are targeted at the physical and material well-being, emotional well-being, social interactions, choices, and personal development of individuals with PIMD, but do not address

community participation and rights. The majority of the studies report positive effects of the interventions on staff and/or client behaviour. However these effects should be interpreted with caution because of methodological and other considerations.

Conclusions: Current research gives only limited insight into the effectiveness of quality-enhancing interventions for people with PIMD. To foster evidence-based practice, further studies of larger groups and with more robust designs are warranted. The potential differential effects associated with client characteristics and the context of the implementation should also be considered.

http://www.multiplus.be/informatiedocs/quality%20enhancing%20interventions.pdf

## Participation in physical activity and the everyday life of people with physical disabilities: a review of the literature

This article questions how personal experiences from participating in physical activity may impact on participation in other contexts of everyday life for people with physical disabilities. Seven databases were searched to identify papers published between 1987 and 2009. Fourteen qualitative studies were included in the final sample. Six themes were identified: learning social rules; being disabled in an able-bodied society; perception of identity; being part of a community, empowerment, maintenance and independence; theoretical framework for discussion in critical psychology and social learning theory. Physical activity seems to exert some impact on disability management, and athletic identity seems to be more empowered than disability identity. Disabled athletes seem to feel part of a special valued community. It is not evident if these experienced benefits imply an extended participation in society in general. Participation in physical activity seems to imply a psychological empowerment in a sports context that might lead to an extended participation in other contexts of everyday life. Physical competence achieved through physical activity may serve to help persons to stay socially connected, establish an ability to participate in activities and stay independent. Further research is needed to elucidate the question of this study.

http://www.tandfonline.com/doi/abs/10.1080/15017419.2013.787369?journalCode=sjdr20

## Participation of Disabled Children and Young People in Decision Making Within Social Services Departments: A Survey of Current and Recent Activities in England

A survey of all social services departments in England was undertaken in order to identify and investigate current work concerning the participation of disabled children within decision making regarding their own care and in service development. Developing a culture of, and good practice in, children's participation is integral to government policy. Results demonstrate that disabled children are being involved in a range of decision-making areas; however, participation is not yet embedded or sustained across all social services departments, and the involvement of disabled children at a higher strategic level is still rare. The participation of disabled children needs further development including more evidence on which factors can support and promote disabled children's effective participation.

https://www.york.ac.uk/inst/spru/research/pdf/qualityprotects.pdf

## The state of the art in European research on reducing social exclusion and stigma related to mental health: A systematic mapping of the literature

Stigma and social exclusion related to mental health are of substantial public health importance for Europe. As part of ROAMER (ROAdmap for MEntalhealth Research in Europe), this study used systematic mapping techniques to describe the current state of research on stigma and social exclusion across Europe. Findings demonstrate growing interest in this field between 2007 and 2012. Most studies were descriptive (60%), focused on adults of working age (60%) and were performed in Northwest Europe—primarily in the UK (32%), Finland (8%), Sweden (8%) and Germany (7%). In terms of mental health characteristics, the largest proportion of studies investigated general mental health (20%), common mental disorders (16%), schizophrenia (16%) or depression (14%). There is a paucity of

research looking at mechanisms to reduce stigma and promote social inclusion, or at factors that might promote resilience or protect against stigma/social exclusion across the life course. Evidence is also limited in relation to evaluations of interventions. Increasing incentives for cross-country research collaborations, especially with new EU Member States and collaboration across European professional organizations and disciplines, could improve understanding of the range of underpinning social and cultural factors which promote inclusion or contribute toward lower levels of stigma, especially during times of hardship.

http://www.sciencedirect.com/science/article/pii/S0924933814000406

#### E-Mental Health: A Rapid Review of the Literature

The authors conducted a review of the literature on e-mental health, including its applications, strengths, limitations, and evidence base. The rapid review approach, an emerging type of knowledge synthesis, was used in response to a request for information from policy makers. MEDLINE was searched from 2005 to 2010 by using relevant terms. The search was supplemented with a general Internet search and a search focused on key authors. A total of 115 documents were reviewed: 94% were peer-reviewed articles, and 51% described primary research. Most of the research (76%) originated in the United States, Australia, or the Netherlands. The review identified e-mental health applications addressing four areas of mental health service delivery: information provision; screening, assessment, and monitoring; intervention; and social support. Currently, applications are most frequently aimed at adults with depression or anxiety disorders. Some interventions have demonstrated effectiveness in early trials. Many believe that e-mental health has enormous potential to address the gap between the identified need for services and the limited capacity and resources to provide conventional treatment. Strengths of e-mental health initiatives noted in the literature include improved accessibility, reduced costs (although start-up and research and development costs are necessary), flexibility in terms of standardization and personalization, interactivity, and consumer engagement. E-mental health applications are proliferating and hold promise to expand access to care. Further discussion and

research are needed on how to effectively incorporate e-mental health into service systems and to apply it to diverse populations.

http://www.ncbi.nlm.nih.gov/pubmed/24081188

## <u>User and carer involvement in the training and education</u> of health professionals: a review of the literature

Health policy requires consumer involvement in services, research and education but little is known about how consumers are being involved in healthcare education, the effect on learning and practice, nor how involvement initiatives are being evaluated. To describe methods of involving consumers in healthcare education, discuss ways in which initiatives have been evaluated, and identify areas for development in education, practice and research. All papers reporting specific initiatives involving consumers in health care worker training and education were included. Viewpoint articles and studies of consumers training consumers were excluded. Cinahl, Medline, Assia, PsycINFO, British Nursing Index, Social Science Citation Index, citations from reference lists, relevant websites and personal communication with key people known to be working in this area. A narrative approach was taken with categorisation of data to reflect objectives of selected studies; method of involvement; process issues and evaluation. Thirty-eight papers were included; most provide small-scale qualitative studies of mental health service users and focus on process rather than outcome. Various methods of involvement are described and consumers consistently prioritise the need for training in interpersonal skills over 'technical' skills. There is little research into organisational strategies and no studies investigate the effect of consumer involvement on practice. Two studies indicated that students exposed to consumer involvement demonstrate more empathic understanding and better communication skills. There is tentative evidence that consumer involvement in training enhances workers' skills in the manner prioritised by consumers. However, if consumer involvement in training and education is to facilitate services that reflect the priorities of the people using them, it must be developed in partnership with service providers; further research is needed to explore the impact of consumer involvement and to track the development of organisational consumer involvement strategies, also

systems for supporting consumers need to be established, including training for both consumers and staff.

http://www.ncbi.nlm.nih.gov/pubmed/16842793

## <u>Perceptions of barriers to physical health care for people with</u> serious mental illness: a review of the international literature

Premature death and poorer access to quality care for physical health concerns is common for people diagnosed with serious mental illness (SMI). However, there is lack of clarity regarding the nature of barriers encountered at different points in the physical health care process, and the level of consistency of these barriers both among countries, and between consumers with SMI and health care staff. The current narrative review integrates views of consumers and health care staff on barriers to physical health care. It involved a search of CINAHL. Proquest, and Web of Science, for peer-reviewed papers published between 2005 and June 2012, for studies of perceptions of barriers to physical health care, published in English. Despite variations in health care systems among countries, there is agreement between consumers and health care staff that division between physical and mental health care and stigma of mental illness act as barriers to all phases of the physical health care process. This uniformity is grounds for international policy development (in general public health and within mental health nursing) for reforms that improve the physical health care, quality of life, and longevity of people with serious mental illness

http://www.ncbi.nlm.nih.gov/pubmed/23146009

## Access to print literacy for children and young people with visual impairment: findings from a review of literature

This article presents a selection of findings from a literature review of best practice models and outcomes in the education of visually impaired children. The review suggested that a key focus of research in this area has been upon the concept of 'access', particularly with regards to barriers children with visual impairment face in accessing visual information. Given the broad scope of

the literature review, this paper focuses upon access to print literacy as an illustrative example. The potential impact of reduced access to the curriculum and the effectiveness of teaching approaches adopted to reduce these barriers are presented. The relative merits of two approaches to improve access are contrasted: providing children with accessible material in their preferred medium (e.g., large print), and teaching children 'access skills' (including the use of technology). There is evidence to show that both approaches are important, but teaching

children access skills has important longer-term benefits for visually

impaired children and young people. In spite of this evidence, it appears that this approach to teaching may often be neglected. Links are made with other areas of the curriculum to illustrate that this dual view of access is a helpful way of conceptualising the broader educational needs of visually impaired pupils.

#### http://eric.ed.gov/?id=EJ917902

# Secondary analysis of a scoping review of health promotion interventions for persons with disabilities: Do health promotion interventions for people with mobility impairments address secondary condition reduction and increased community participation?

Secondary conditions can have very serious outcomes for people with physical disabilities. Such consequences can range from immobility due to pressure sores to withdrawal and isolation due to depression, decreasing participation in the community.

To further investigate these assumptions, the authors conducted a review of the literature on health promotion interventions that include physical activity for adults with disabilities to determine whether they have a positive effect on the reduction of secondary conditions and increased community participation.

They conducted a secondary analysis of the results of a scoping review of health promotion programs containing physical activity for people with

mobility impairments (N = 5). This secondary analysis examined the relationship between health promotion containing physical activity and prevention of secondary conditions among people with various physical disabilities. They further examined evidence and effects of independent variables on the outcome of increased community participation for study participants.

Results: the outcomes from this investigation are varied, with 2 studies providing evidence of reducing secondary conditions while another shared anecdotal statements referencing a decrease in secondary conditions. Of the remaining 2 studies in this paper, 1 showed no intervention effect on reducing secondary conditions while the remaining study reported an increase in secondary conditions. Regarding increased participation in the community, 2 of 5 studies directly reported on these outcomes, while increased community participation was referenced in another 2 articles, but without any data presented. The final study did not report on any post intervention in the community.

Conclusions: this review demonstrates that research on health promotion interventions containing physical activity lack description about whether such interventions help reduce or prevent secondary conditions. Additionally, the review shows that further work is needed in terms of sustaining health program effects beyond the initial proximal activity gains, with attention given toward more distal outcomes of increased participant participation in the community.

http://www.ncbi.nlm.nih.gov/pubmed/21419376

## A systematic review of the impact of patient and public involvement on service users, researchers and communities

Patient and public involvement (PPI) in research has expanded nationally and internationally over the last decade, and recently there has been significant attention given to understanding its impact on research. Less attention has been given to the impact of PPI on the people involved, yet it has been shown that the success of PPI in research can be reliant on the processes of engagement between these individuals and communities. This paper therefore critically explores the impact of PPI on service users, researchers and communities involved in health and social care research.

Searches were undertaken from 1995 to April 2012 in the electronic databases MEDLINE, EMBASE, PsycINFO, Cochrane library, CINAHL, HMIC and HELMIS. Searches were undertaken for grey literature using the databases InvoNet and NHS Evidence. Studies were included if they included the impact of PPI on individual service users, researchers or communities under research. Studies were excluded if they were in a foreign language (unless they were deemed critical to the systematic review) or were in children and adolescent services.

Data were extracted using a narrative synthesis, and quality was assessed using the Critical Appraisal Skills Programme.

Main results: service users reported feeling empowered and valued, gaining confidence and life skills. Researchers developed a greater understanding and insight into their research area, gaining respect and a good rapport with the community. The community involved in research became more aware and knowledgeable about their condition. However, lack of preparation and training led some service users to feel unable to contribute to the research, while other service users and communities reported feeling overburdened with the work involved. Researchers reported difficulties in incorporating PPI in meaningful ways due to lack of money and time.

Conclusion: This is the first international systematic review to focus on the impact of PPI on the people involved in the process. The beneficial and challenging impacts reported highlight the importance of optimising the context and processes of involvement, so creating the potential for PPI to impact positively on the research itself.

http://www.ncbi.nlm.nih.gov/pubmed/25034612

Social inclusion and people with intellectual disability and challenging behaviour: a systematic review

Social inclusion is central to disability policies internationally. The high risk of social exclusion for people with intellectual disability is compounded for those with challenging behaviour.

A systematic literature review examined how social inclusion of people with intellectual disability and challenging behaviour has been researched and operationalised in the empirical literature, and aimed to determine what evidence exists about the extent of social inclusion by people with intellectual disability and challenging behaviour.

A thematic analysis of the 14 papers identified that social inclusion has been poorly defined and measured, and that the little research that has occurred in respect of people with challenging behaviour has demonstrated their potential to be socially included.

Clearer conceptualisation of inclusion, and greater understanding of practices that support social inclusion and system level mechanisms, which ensure goals around inclusion gain prominence in funding and support plans, may address the neglect of this critical quality-of-life domain for people with challenging behaviour.

http://www.ncbi.nlm.nih.gov/pubmed/23002899

## A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life

Themes included social functioning and quality of life (QoL). The paper concludes that informal support contributed to social participation, social functioning and QoL. Social skills instruction facilitated social functioning and participation. Supports for social participation and social functioning should be more available.

A systematic review of the literature was conducted to investigate what is currently known about support for social participation for adults with autism spectrum disorders (ASD). A computerized database search followed by hand searching was conducted to locate empirical studies published after 1995 in peer-reviewed journals that described social participation or social support for adults with ASD. 14 studies were identified, evaluated for strength of evidence, and organized into topical themes. These studies focused on support for social participation from two perspectives: social functioning and quality of life (QoL). Supporting

social functioning and social participation is important, as this is one route through which individuals with ASD may be able to form relationships and establish natural support networks, which can in turn contribute to QoL. In addition, working to improve social skills is of key importance as social functioning heavily impacts outcomes in a variety of areas. Social participation, social functioning, and QoL for adults with ASD appear to be facilitated through informal social support from social networks, participation in social skills groups, and membership in support groups

http://www.sciencedirect.com/science/article/pii/S1750946713002419

## <u>Student Participation in the College Classroom: An Extended</u> <u>Multidisciplinary Literature Review</u>

The trend towards inclusive education has led to an increase of studies focusing on peer attitudes. This review study presents an overview of studies describing attitudes of students, variables relating to students' attitudes, and the relationship between students' attitudes and the social participation of peers with disabilities. Based on a literature search the authors selected 20 studies that were conducted in seven different countries. Outcomes were described in terms of negative, neutral or positive according to three attitude components (cognitive, affective and behavioural). The results show that students generally hold neutral attitudes towards peers with disabilities. Several variables were found relating to their attitudes (i.e., gender, age, experience with and knowledge about disabilities, parental influence). Moreover, the results indicate that attitudes of peers relate to the social participation of students with disabilities. Implications of the findings are discussed in terms of promoting positive attitudes of peers.

http://www.csus.edu/indiv/s/stonerm/rocca-litrevengagingstudents.pdf

"I Hope He Goes First": Exploring Determinants of Engagement in Future Planning for Adults with a Learning Disability Living with Ageing Parents. What Are the Issues? A Literature Review

In 2001 the International Classification of Functioning (ICF) defined participation as 'someone's involvement in life situations'. Participation in leisure activities contributes to the development of children and their quality of life. Children with physical disabilities are known to be at risk for participation in fewer activities. The group of children with physical disabilities is highly heterogeneous consisting of children with different diagnosis and different ages. This systematic review aims to analyse the literature for the purpose of looking for variables involved in the frequency of participation in leisure activities for children and youth with different diagnoses and ages. Frequency of participation in leisure activities for children and youth with physical disabilities is associated with a variety of variables. Gross motor function, manual ability, cognitive ability, communicative skills, age and gender are the most important variables. The current evidence suggests that similar variables seem to apply to children with different diagnoses. Age is an important variable in participation of children and youth. However evidence about those variables associated with children at different ages is still lacking.

https://www.researchgate.net/publication/264406024 I hope he goes f irst' Exploring determinants of engagement in future planning for a dults with a learning disability living with ageing parents What are the issues A literature review

## <u>Autonomy in Relation to Health among People with Intellectual</u> Disability: A Literature Review

Background: Since the 1990s, individualisation, participation, normalisation and inclusion have been the main principles of care for people with intellectual disability (ID). Autonomy has become an important issue for these people. This review of the literature tried to answer the question: how do people with ID exercise autonomy in relation to health? Method: Searches in Cochrane, Medline and PsycINFO were based on the following aspects of autonomy: self-determination, independence, self-regulation and self-realisation. Results: Thirty-nine of 791 articles met our criteria, including 14 on self-determination, seven on independence, 15 on self-regulation and three on self-realisation. Conclusions: In spite of decades of promoting

autonomy, the exercise of autonomy in relation to health has so far rarely been an issue in the literature

http://www.ncbi.nlm.nih.gov/pubmed/19646099

## Benefits of the use of ICT in school activities by students with motor, speech, visual, and hearing impairment: a literature review

Information and communication technology (ICT) has the potential to enhance participation in educational activities for students with physical disabilities. Even though incorporating ICTs into teaching and learning in education has become an important issue, it is unclear what evidence research has provided. The aim of this study was to investigate types of ICT items and how ICT is being used by students with physical disabilities, and describe the benefits of ICT use in school activities.

A systematic literature search, covering the period 2000-May 2012, was performed in the databases AMED, CINAHL, Eric, OTseeker, Psych Info, PubMed, and Scopus. Data analysis entailed extracting, editing, grouping, and abstracting findings.

Results: A total of 32 articles were included, 16 of which were intervention studies. More than half of the studies concerned students with motor impairments. Type of ICT used differed among impairment groups, and ICT seemed to be especially beneficial for writing, spelling, and communication.

Conclusions: Even though the review found heterogeneity across the studies students seemed to benefit from ICT use regardless of the type. For future research it is important to highlight intervention studies, especially for students with visual, hearing, and communication impairments.

http://www.ncbi.nlm.nih.gov/pubmed/24506197

## Community Participation of People with an Intellectual Disability: A Review of Empirical Findings

The objective was to investigate community participation of persons with an intellectual disability (ID) as reported in empirical research studies.

A systematic literature search was conducted for the period of 1996-2006 on PubMed, CINAHL and PSYCINFO. Search terms were derived from the International Classification of Functioning, Disability and Health. Three investigators assessed the relevance of the initially identified studies using predefined content and methodological selection criteria. Included domains of community participation were: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, civic and social life.

Results: Of 2936 initial hits, 23 quantitative studies eventually met the selection criteria and were included in the study. Only two studies are based on a theoretical framework. Research instruments were various and were most often "ad hoc" and not validated. The average number of persons in the social network of people with ID appears to be 3.1, one of them usually being a professional service staff member. People with ID are 3-4 times less employed than non-disabled peers; they are less likely to be employed competitively and are more likely to work in sheltered workshops or in segregated settings than those with other disabilities. People with ID are less likely to be involved in community groups, and leisure activities are mostly solitary and passive in nature. Most of the people with ID had been accompanied in an activity by training/therapeutic staff.

Conclusion: It can be concluded that on the basis of empirical evidence, within the time frame of this literature search, little is known about community participation of people with ID. Many researchers did not clearly define community participation and were concerned with limited areas of community participation; research is seldom based on a theoretical framework. Most studies focus on people with mild ID, and there are few reports of the subjects' sample. However, one conclusion can consistently be drawn from the review: people with ID living in community settings participate more than people living in a segregated setting, but their participation level is still much lower than non-disabled and other disability groups

http://www.ncbi.nlm.nih.gov/pubmed/19087215

A critical review of the literature on social and leisure activity and wellbeing in later life

An engaged lifestyle is seen as an important component of successful ageing. Many older adults with high participation in social and leisure activities report positive wellbeing, a fact that fuelled the original activity theory and that continues to influence researchers, theorists and practitioners. This study's purpose is to review the conceptualisation and measurement of activity among older adults and the associations reported in the gerontological literature between specific dimensions of activity and wellbeing. We searched published studies that focused on social and leisure activity and wellbeing, and found 42 studies in 44 articles published between 1995 and 2009. They reported from one to 13 activity domains, the majority reporting two or three, such as informal , formal and solitary , or productive versus leisure . Domains associated with subjective wellbeing, health or survival included social, leisure, productive, physical, intellectual, service and solitary activities. Informal social activity has accumulated the most evidence of an influence on wellbeing. Individual descriptors such as gender or physical functioning sometimes moderate these associations, while contextual variables such as choice, meaning or perceived quality play intervening roles. Differences in definitions and measurement make it difficult to draw inferences about this body of evidence on the associations between activity and wellbeing. Activity theory serves as shorthand for these associations, but gerontology must better integrate developmental and psychological constructs into a refined, comprehensive activity theory.

 $\frac{http://journals.cambridge.org/action/displayAbstract?fromPage=online\&aid=8235361\&fileId=S0144686X10001091$ 

## Staff training in intellectual disability services: a review of the literature and implications for mental health services provided to individuals with intellectual disability

The Department of Health (2001, 2009) policy shift from specialist intellectual disability (ID) services towards mainstream mental health service provision has implications for staff. Research suggests that mainstream mental health service staff perceive inadequate training and a consequent knowledge deficit in relation to individuals with ID. Consequently, the implementation of appropriate staff training packages

seems imperative to ensure high quality mental health care to this population.

http://www.tandfonline.com/doi/abs/10.1179/2047387711Y.000000005

## Ethnic Factors in Mental Health Service Utilisation among People with Intellectual Disability in High-Income Countries: Systematic Review

An emerging literature suggests that ethnic and cultural factors influence service utilisation among people with intellectual disability (ID), but this has not previously been reviewed. The aim was to investigate possible ethnic variation in uptake of mental health services in children, adolescents and adults with ID in high-income countries.

A systematic review was undertaken using main databases of studies that consider ethnic influences on mental health utilisation of people with ID. Methodological quality of studies was assessed.

Results: Nine studies that reached selection criteria were identified. Six studies that compared two or more ethnic groups found a variation in levels of mental health service utilisation. The most consistent finding was that South Asian children, adolescents and adults with ID in the UK had lower use of mental health services than White British comparison groups.

Conclusion: Ethnic influences on mental health service utilisation were identified. Understanding their significance and potential negative consequences requires further investigation. (Contains 1 figure and 4 tables.)

http://www.ncbi.nlm.nih.gov/pubmed/21883599

<u>Public Awareness, Attitudes and Beliefs regarding Intellectual</u> Disability: A Systematic Review

The general public's responses to people with intellectual disabilities influence the likely success or failure of policies aimed at increasing their social inclusion. The present paper provides a review of general population based research into awareness, attitudes and beliefs regarding intellectual disability published in English between 1990 and mid-2011. An electronic search using PsycINFO and Web of Science plus a hand search of the literature was completed. Most of the 75 studies identified consisted of descriptive surveys of attitudes. They tend to conclude that age, educational attainment and prior contact with someone with an intellectual disability predict attitudes, while the effect of gender is inconsistent. Eight studies examined lay knowledge about intellectual disability and beliefs about its causation in a range of cultural contexts. The impact of interventions designed to improve attitudes or awareness was examined by 12 studies. The evidence is limited by the fact that it is mostly based on relatively small unrepresentative samples and cross-sectional designs. It is concluded that overall, high quality research into general population attitudes to intellectual disability is limited. Public knowledge of intellectual disability and causal beliefs are particularly under-researched areas. There is a notable absence of well designed evaluations of efforts to reduce misconceptions about intellectual disability and tackle negative attitudes. Areas for future research are noted, including the need for well designed studies that consider awareness, attitudes and beliefs in relation to stigma theory. (Contains 1 table.)

http://www.ncbi.nlm.nih.gov/pubmed/21798712

## The Impact of Learning Disabilities on Adulthood: A Review of the Evidenced-Based Literature for Research and Practice in Adult Education

It is now well established that learning disabilities (LD) persist into the adult years, yet despite a developing literature base in this area, there is a paucity of evidence-based research to guide research and practice. Consistent with the demands of the adult stage of development, autonomy and self-determination are crucial to quality-of-life issues to adults in general, and specifically to adults with LD. There are many areas of functioning in which adults need to adapt successfully, such as

employment, family, social and emotional, daily living routines, community, and recreation and leisure. In essence, there are a myriad of challenges and outcomes as adults navigate the trials and tribulations of LD as it manifests itself into adulthood. This review of the extant evidence-based literature seeks to discover relevant knowledge that can be shared with practitioners who serve adults with LD in a variety of professional and volunteer roles, particularly in adult education settings. (Contains 1 table.)

http://www.ncbi.nlm.nih.gov/pubmed/22064950

## Bullying Perpetration and Victimization in Special Education: A Review of the Literature

Bullying perpetration and victimization have become pervasive problems in American schools. Recent research suggests a causal association between prolonged periods of victimization and overt acts of school violence. These findings are germane to students with disabilities in light of evidence suggesting these students are victimized more often than typically developing peers. The purpose of this review is to provide special educators with an overview of definitions and issues related to bullying perpetration and victimization and to synthesize research on this topic as it pertains to students with disabilities by disability type, personal characteristics, and educational placement. It was concluded that additional research is needed on prevalence and types of bullying, factors related to perpetration or victimization, and appropriate school-based interventions for special needs populations.

http://ir.lib.uwo.ca/cgi/viewcontent.cgi?article=1037&context=eei

## 5. Participating In Civic And Public Life: What Works? Evidence led by disabled people

#### Radar Leadership Programme

Radar (2011), now Disability Rights UK, evaluated a leadership programme run by and for disabled people. Over 500 people took part in the programme, which involved programme days focusing on leadership style, influencing, presentation and other aspects of leading. It also involved individual coaching. Over 80% said they were more likely to pursue their leadership ambitions as a result of the programme and people went on to a range of roles – a local Mayor, setting up BSL-signed services in a Mosque, campaigning for improved transport, being Trustees, taking on public appointments. This programme was recognised as an international good practice by the Zero Project.

http://zeroproject.org/wp-content/uploads/2013/12/Zero-Report e - 2013.pd

#### **Evidence from research and other organisations**

### EHRC (2015) Smoothing the Pathway to Politics for Disabled People

This paper analyses data on inequalities in securing leadership roles and makes recommendations for change

http://www.equalityhumanrights.com/sites/default/files/uploads/document s/Smoothing%20the%20Pathway%20to%20Politics%20for%20Disabled %20People.pdf

#### The Speaker's Conference 2010

Speaker's Conferences are very rare: there can be a gap of decades between Conferences. This Speaker's Conference focused on access to parliamentary elected office for people from under-represented groups including disabled people. It made hard-hitting points about under-representation and a series of recommendations for change.

https://www.parliament.uk/business/committees/committees-a-z/other-committees/speakers-conference-on-parliamentary-representation/news/final-report-published/

#### Evidence relating to particular groups of disabled people

## Shah S (2005) Career Success of Disabled High Fliers. Jessica Kingsley

This is a book available for purchase. It interviews people with physical impairments in senior roles to learn from their experiences.

#### **International examples**

## Zero Project (2015) Report on independent living and political participation

The Zero Project drew up indicators rooted in the UN Convention on the Rights of Persons with Disabilities and identified numerous policies and practices from around the world on independent living and political participation that met the indicators. Some of the policies and practices report on outcomes

http://zeroproject.org/wp-content/uploads/2015/03/ZP-Report Barrierfree.pdf

**Evidence specific to Scotland, Wales, Northern Ireland or England** 

#### Reviews of academic evidence

### The paradox of diversity in leadership and leadership for diversity

The paradox of diversity is that successful diversity interventions require leadership support when diversity in leadership positions is so evidently lacking. In order to explore this paradox in the UK, we examine progress towards demographic diversity in leadership roles in the higher education sector, a sector in which there is much espoused support for diversity. Through a critical and comprehensive review of the literature, we illustrate the persistent nature of inequalities that hinder diversity and inclusion in leadership. We examine studies on salient forms of

inequality in higher education leadership including research on gender, ethnicity, class, sexual orientation and disability. We show that leadership diversity remains a significant challenge for the higher education sector. Drawing on the example of this sector, we demonstrate that leadership occupies a contradictory space in terms of demographic diversity, both as the focus of criticism due to its homogeneous profile and counter-intuitively as an essential force for progress towards greater equality. We investigate the paradox of the relative homogeneity of higher education leadership set against its role for championing and promoting equality and identify ways in which demographic diversity as well as the progressive potential of higher education leadership may be fostered.

https://www.erudit.org/revue/mi/2013/v17/nmi0591/1015808ar.pdf

## <u>Disability, Health, Independent Living, and Rehabilitation Research</u> <u>Leaders from Traditionally Underrepresented Racial and Ethnic</u> <u>Populations: Career Development and Success Factor</u>

This article provides a comprehensive overview of select research skill and leadership building opportunities and research infrastructure systems that contribute to research leaders from traditionally underrepresented racial and ethnic populations and communities (i.e., African Americans, Native Americans, Latinos, and Asians) in the field of disability, health, independent living, and rehabilitation career development and success. After a short presentation of the Social Change Model of Leadership (SCML) and issues relative to the current insufficient supply of such research leaders, the article shifts focus to a detailed synthesis of the available peer review and grey literature and policy on research career development and success factors. Critical contemporary issues affecting these target groups are discussed. Recommendations for advancing the current state-of-the-science for improving the research and leadership skills and career development outcomes for investigators from these populations, especially those with disabilities, are presented.

https://www.questia.com/library/journal/1G1-409548738/disability-health-independent-living-and-rehabilitation

#### Patient participation in public elections: a literature review

Healthcare organisations and nurse leaders have an important role in promoting patients' right to vote, through the development of policy guidelines, integrated networking and innovative practice. Patients' mental capacity to vote is usually assessed by nurses, who must therefore be aware of clients' voting rights and if the right resources are in place to help them do so. Patients' rights, as citizens, are recognised in law and in professional guidelines, but more needs to be done to protect their voting rights. There should also be better access to transport and family support, and more flexible electoral procedures. This article reviews the literature on promoting patients' participation in local and general elections and suggests that their voting rights should be endorsed by organisations and nurse leaders through policy guidelines and a flexible and proactive nursing approach to participation.

http://www.ncbi.nlm.nih.gov/pubmed/21485910

#### 6. Participating In Anything: What Works?

### Evidence led by disabled people

### National Centre for Independent Living (2008) Peer Support and Personalisation

This review of evidence on peer support by the National Centre for Independent Living (now Disability Rights UK) draws particularly on evidence from Centres for Independent Living and other Disabled People's Organisations. It includes both research references and examples from practice.

http://www.disabilityrightsuk.org/sites/default/files/word/Peersupportandpersonalisation.doc

## Rose D, MacDonald D, Wilson A, Crawford M, Barnes M and Omeni E (2016) Service user-led organisations in mental health today. Journal of Mental Health

This review, led by Diana Rose, Professor of User-led Research at Kings College London, aims to explore mental health service user-led organisations (ULOs) in England, as they interact with decision-makers to bring about change desired by them. There is a focus on institutional norms behaviour and specialised knowledge impacting service users' relationships with services

Since 1990, health policy in England has stressed the importance of user involvement in shaping and delivering services.

An ethnography of five ULOs in two provider organisations (NHS Trusts) including observing their meetings and interactions with decision-makers, conducting in-depth interviews and collecting reflective diaries kept by two members of each group.

Results: During the study, one group ceased to operate. This was a group which refused to adopt the institutional rules and norms of managerial discourse. The other four groups survived by navigating the changing environment which existed at the time of the study, although often at some cost. Themes of autonomy and leadership were also identified.

Conclusion: The current environment is one of organisational complexity and change and the place of ULOs is an ambiguous one as they strive to maintain autonomy whilst at the same time being an acceptable voice to managers.

https://kclpure.kcl.ac.uk/portal/en/publications/service-user-ledorganisations-in-mental-health-today%28815344ad-2745-4d55-8e1adc7044e38ae0%29.html

## <u>Beresford, P. (2013), Beyond the Usual Suspects: Towards inclusive User Involvement – Research Report, London, Shaping Our Lives.</u>

The focus of this report is to make it possible for everyone who wants to, to be more involved in and have more say over their lives and the services they use to live them. The report draws on findings from a three-year national research and development project supported by the Department of Health, which aimed to find out how inclusive user involvement could be achieved. This user controlled project was particularly interested in looking at why certain groups of 'seldom-heard' service users experience barriers to involvement and how these barriers can be overcome.

http://www.shapingourlives.org.uk/documents/BTUSReport.pdf

### **Evidence from research and other organisations**

Social Policy Research Unit, University of York with other European partners (study in progress, 2013-16) Making persons with disabilities full citizens: new knowledge for an inclusive and sustainable European social model

This research covers topics including active citizenship and social inequalities, labour market participation, community living, using new technologies and political participation. Updates and presentations are at:

http://php.york.ac.uk/inst/spru/research/summs/discit.php

#### NESTA (2012) People Powered Health Co-production Catalogue

This report contains examples from practice of how co-production has been used to improve services – particularly in health and social care. It includes examples from the UK and internationally.

http://www.nesta.org.uk/publications/co-production-catalogue

## Community Care. Direct payments, personal budgets and individual budgets

This article summarises knowledge on personal budgets and direct payments: what they are, how much they are used, by whom – and more.

http://www.communitycare.co.uk/2007/01/05/direct-payments-personal-budgets-and-individual-budgets/

## <u>Shakespeare T, Stockl A and Porter T (ongoing) Personal</u> <u>Assistance Relationships; ethics, power and emotions</u>

This is an ongoing study which aims to understand the relationships of power, ethics and emotions which underlie the Personal Assistance model, by gathering and analysing qualitative data

http://www.wecil.co.uk/uploads/attachments/304/tom\_porter\_wecil\_slide s\_mar15.pdf

http://parelationships.blogspot.co.uk/

## Beresford, P. Fleming, J. Glynn, M. Bewley, C. Croft, S. Branfield, F. and Postle, K. (2011), Supporting people: Towards a person-centred approach, Bristol, Policy Press

This book, available for purchase, explores with service users, practitioners, carers and managers what person-centred support means to them, what barriers stand in the way and how these can be overcome. It offers both theoretical insights and practical guidance and highlights the importance of a participatory approach. Based on the largest independent UK study of person-centred support and written by a team that includes service users, practitioners and researchers, it

demonstrates how change can be made now, and what strategic changes are needed for needed for person-centred support to have a sustainable future

## Carr S and Robbins D (2009) The implementation of individual budget schemes in adult social care

This report reviews evidence on individual budgets, in the UK and more widely. It concludes that people using individual budgets are generally positive about them and identifies the importance of support and brokerage

http://www.scie.org.uk/publications/briefings/briefing20/

## Jones K, Forder J, Caiels J, Welch E, Glendinning C and Windle K. (2013) Personalization in the health care system: do personal health budgets impact on outcomes and cost?

This evaluation of personal health budgets found that use of personal health budgets was associated with significant improvement in care-related quality of life and psychological wellbeing at 12 months. Personal health budgets did not appear to have an impact on health status, mortality rates, health-related quality of life or costs over the same period. With net benefits measured in terms of care-related quality of life, personal health budgets were cost-effective: that is, budget holders experienced greater benefits than people receiving conventional services, and the budgets were worth the cost.

http://php.york.ac.uk/inst/spru/pubs/2623/

## Social Care Institute for Excellence (2013) Co-production: what is it and how to do it

SCIE has produced a guide to co-production – what it is and how to do it – involving disabled people in its development. The guide includes video material and a version of the guide in Easyread

http://www.scie.org.uk/publications/guides/guide51/what-is-coproduction/index.asp

## Series L (2015). Relationships, autonomy and legal capacity: Mental capacity and support paradigms

This article looks at concepts of 'mental capacity'; and 'legal capacity', which covers support to enable universal legal capacity for all. It argues that the 'legal capacity' approach, in line with the UN Convention on the Rights of Persons with Disabilities, is refreshing in its emphasis on relationships of support; but that all approaches contain challenges in terms of how others can know our autonomous, authentic selves

http://orca.cf.ac.uk/73420/

## Meddings S, McGregor J, Roeg W and Shepherd G, (2015) Recovery colleges: quality and outcomes, Mental Health and Social Inclusion, Vol. 19 Iss: 4, pp.212 - 221

The purpose of this paper is to review the available evidence regarding the effectiveness and cost effectiveness of Recovery Colleges. It involved a selective review of relevant published studies, including reports in the "grey" literature.

Findings: despite methodological limitations, it has been consistently found that attendance at Recovery Colleges is perceived to be useful and to help people progress towards their recovery goals. There is some evidence of reductions in service use (and therefore costs). In addition, there is evidence of beneficial effects for peer trainers and possible positive impact on staff attitudes.

Research limitations/implications: the existing research highlights the need for further robust studies, using both qualitative and quantitative methods, to understand better the overall impact of Recovery Colleges and the underlying mechanisms of change.

Practical implications: There is a need for further studies of the relationship between the "key defining features" and outcomes. This means the collection and pooling of systematic, "practice-based" evidence.

Social implications: The introduction of an explicitly recovery educational ("learning") model into mainstream mental health services seems to have a profound effect on reducing the power differences inherent in traditional professional/patient relationships. If this can be replicated across organisations it could facilitate the kind of fundamental cultural

change necessary to give back recovery to the people who have always owned it.

http://www.emeraldinsight.com/doi/abs/10.1108/MHSI-08-2015-0035

#### Cooper H (ongoing) Rights-based rehabilitation

This is an ongoing, qualitative research project co-produced with disabled people. It is a PhD project funded by the NIHR's Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England. It is being undertaken at the University of East Anglia by Harriet Cooper, under the supervision of Tom Shakespeare, Fiona Poland and Swati Kale. The project is funded within the CLAHRC's Public and Patient Involvement Theme, which means that members of the public (in this case disabled people with an experience of rehabilitation) will have an advisory role in the project

## <u>University of East Anglia/Bezmez (ongoing) The role of the family in rehabilitation</u>

This is a 1 year EU project on the role of family in in-patient rehabilitation

## Burchardt T, Evans M and Holde H (2013) Public policy and inequalities of choice and autonomy

This article explores the conceptualisation of choice as autonomy using three components – self-reflection, active decision-making, and quality and range of options - and investigates inequalities in autonomy, using newly-collected data for the UK. The empirical findings indicate that disabled people are most likely to experience constrained autonomy in all respects, while being from a low socio-economic group and/or lacking educational qualifications is a risk factor across several components. This points to the importance of taking into account underlying inequalities when developing choice-based policies. The conclusions include that improving the 'choice' agenda for policy requires removal of barriers to active decision-making through effective support and advocacy, especially for disabled people.

http://sticerd.lse.ac.uk/case/ new/publications/abstract.asp?index=4256

### Townsley R, Marriott A and Ward L (2009) Access to Independent Advocacy: An Evidence Review. Office for Disability Issues

This report reviews evidence – and evidence gaps – on independent advocacy to support disabled people in different circumstances, including during transition to adulthood; when the children of disabled parents are subject to safeguarding procedures; when entry to residential care is a possibility; and when disabled people are victims or alleged perpetrators of anti-social behaviour

http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/iar-full.pdf

## Burd H, Hallsworth M, the Behavioural Insights Team (2016) Making the change: Behavioural factors in person- and communitycentred approaches for health and wellbeing

This report highlights that a multi-faceted approach is needed to enable effective self-care. It identifies five enabling factors:

- 1. growth mindset, self-efficacy and 'grit'
- 2. removing friction costs (i.e. removing increases in effort required to perform a behaviour)
- 3. social connections
- 4. intrinsic motivation
- 5. goal setting and feedback.

It provides a framework for understanding the drivers of behaviour and includes examples and case studies to illustrate how the theories work in practice. It explores the behavioural science theories that suggest new ways of enabling people and communities to take a more active role in managing their own health. This report provides an accessible introduction to the theories of change behind a series of action-focused guides that will be published as part of the <a href="Realising the Value">Realising the Value</a> programme in autumn 2016. It is aimed at policymakers, commissioners, service designers and organisations working to promote more personand community-centered approaches for health and wellbeing.

http://www.nesta.org.uk/publications/making-change-behavioural-factors-person-and-community-centred-approaches-health-and-wellbeing

## Wood S, Finnis A, Khan H and Ejbe J (2016) At the heart of health: Realising the value of people and communities

This report seeks to bring together in one place a wide range of personand community-centred approaches for health and wellbeing. It provides an overview of the existing evidence base with a particular focus on the potential benefits of adopting person- and community-centred approaches. It also describes where there are gaps in the evidence and where we need to know more.

The report is intended to be a practical resource to support the work of commissioners, providers, communities and others seeking to find ways to empower individuals and communities in their health and care. In addition, they hope that it will help commissioners, policymakers and practitioners to understand the range of approaches available, some of the key components and their potential to improve health and wellbeing outcomes, NHS sustainability and social value.

Alongside the main report, there are two annexes produced by the Institute of Health & Society, Newcastle University: a scoping review of the evidence base and evidence summaries for five shortlisted approaches.

http://www.nesta.org.uk/publications/heart-health-realising-value-people-and-communities

### <u>Personal Social Services Research Unit (PSSRU) and University of</u> Manchester, University of Kent and London School of Economics

The PSSRU publishes widely on the impact of health and social care services, with a particular emphasis on needs, resources and outcomes. This includes whether particular approaches are effective and/or cost effective, from behavioural support in schools, to digital engagement or GP support for South Asian older people with memory problems (and more).

http://www.pssru.ac.uk/

Evidence relating to particular groups of disabled people

## Beresford, P. Perring, R. Nettle, M. (2010), From Mental Illness To A Social Model Of Madness And Distress, London, Shaping Our Lives and National Survivor User Network

This national study explores with mental health service users what models they feel underpin current thinking in mental health policy and practice. It asks what effects these models may have, and looks at what models service users think might be helpful. It found that most service users believe that a medical model based on deficit and pathology still dominates public and professional understanding of mental health issues, shaping attitudes and policy. The idea of a social model of madness and distress, following the format of the social model of disability, met mixed views.

The labelling and stigma following from a medical model of mental illness are major barriers for mental health service users. Service users see social approaches to mental health issues as much more helpful

http://www.shapingourlives.org.uk/wp-content/uploads/2016/02/mental-health-service-models-full.pdf

# Byrne B and Tobin J (Forthcoming), Article 23 of the United Nations Convention on the Rights of the Child: Children with Disabilities, in P. Alston and J. Tobin (eds) A Commentary on the United Nations Convention on the Rights of the Child, Oxford University Press

This chapter in a book, available for sale, discusses current issues relating to the rights of disabled children

## Mitchell, W, Brooks J, Beresford B, Moran N, and Glendinning C (2015) Taking On and Taking Over: Choice and control for physically disabled young adults

This study looked at ways of supporting physically disabled young adults to achieve their preferred levels of control over care and support arrangements. It asked questions including: What are physically disabled young adults' experiences of managing their care and support arrangements? How can they be better supported? Key findings and practice implications are included. A video about the research findings is also available and a poster showing the challenges and solutions for supporting young physically disabled people.

## Gridley K, Brooks J and Glendinning, C (2014) Good practice in social care: the views of people with severe and complex needs and those who support them

The study involved qualitative research with adults with disability and older people with severe and complex needs, family carers and members of specialist organisations (n = 67), focusing on the features of social care services they considered to be good practice.

http://php.york.ac.uk/inst/spru/pubs/2714/

## Williams V (2016) Being a researcher with intellectual disabilities: The hallmarks of inclusive research in action. Chapter in book, available to purchase

This chapter aims to showcase different voices in research, and to show how we can learn more about what constitutes inclusive research by analysing the fine detail of the interactions that take place during the conduct of research studies.

http://research-information.bristol.ac.uk/en/publications/being-a-researcher-with-intellectual-disabilities%28d9d12be6-b052-4348-ac07-5f43cc4aefa5%29.html

## Williams V and Porter S (2015) The Meaning of 'choice and control' for People with Intellectual Disabilities who are Planning their Social Care and Support

This research found that identity, other people and personal budget processes were all important for choice and control. People needed to build confidence in themselves as decision-makers, both through peer support and through joint decisions with trusted others. Practitioners need to take into account the spectrum of ways in which people may make decisions. Action needs to be taken both at the micro level of support interactions and at the macro level, with a clearer articulation of

independent living in policy and strategy for people with intellectual disabilities.

http://research-information.bristol.ac.uk/en/publications/the-meaning-of-choice-and-control-for-people-with-intellectual-disabilities-who-are-planning-their-social-care-and-support%28b3812638-cfc6-4d9a-beba-f65f10ce163f%29.html

# Webber, M., Treacy, S., Carr, S., Clark, M., Parker, G. (2014) The effectiveness of personal budgets for people with mental health problems: a systematic review. Journal of Mental Health, 23,3,146-155

This article systematically reviews evidence for the effectiveness of personal budgets for people with mental health problems across diverse outcomes.

The review was informed by guidelines for conducting a systematic review by the Social Care Institute for Excellence.

Results: Fifteen studies were included in the review which found mostly positive outcomes in terms of choice and control, quality of life, service use and cost-effectiveness. However, there are limitations to research. Further high quality studies are required to inform policy and practice for mental health service users, which lags behind other adult social care groups in the use of personal budgets.

### http://www.ncbi.nlm.nih.gov/pubmed/24803221

Further evidence on personal budgets for people living with mental healht challenges can be found in Hitchen, S., Williamson, G., Watkinson, M. (2015) Personal budgets for all? Implementing self-directed support in mental health services. Action Research, 13,4,372-391

### Repper J and Perkins R (2003) Social Inclusion and Recovery. Bailliere Tindall

This book, available for sale, takes as its starting point the lived experience of recovery which is the process whereby individuals can be

helped to understand and come to terms with their illness. The role and actions of mental health professionals is explored as part of the process of recovery. The major part of the book will focus on ways in which direct care staff can assist people with mental health problems, reflecting the accounts of the nature and type of assistance which have been valuable, and the ways in which such help can best be offered. It addresses two key components of recovery access and inclusion to life opportunities and acceptance.

## Repper J and Carter T (2011) A review of the literature on peer support in mental health services. Journal of Mental Health

This article aims to review the literature on Peer Support Workers (PSWs) employed in mental health services to provide a description of the development, impact and challenges presented by the employment of

PSWs and to inform implementation in the UK. A literature search was undertaken.

Results: the literature shows that PSWs can lead to a reduction in admissions among those with whom they work. Additionally, associated improvements have been reported on numerous issues that can impact on the lives of people with mental health problems, including hope and empowerment.

Conclusion: PSWs have the potential to drive through recovery-focused changes in services. However, many challenges are involved in the development of peer support.

http://www.peerzone.info/sites/default/files/resource materials/Peer%20 Support%20Literature%20Review%20Repper 1.pdf

### **Evidence specific to Scotland, Wales, Northern Ireland or England**

## Kelly B (2013) Don't Box Me In. Disability Identity and Transitions to Adulthood. Barnardos Northern Ireland

This is a follow-up study of young people with learning disabilities in Northern Ireland, exploring transition to adulthood. It contains 7 key

messages for policy, on subjects including transition, participation and advocacy.

http://www.barnardos.org.uk/don t box me in - final report.pdf

# Larson J, Tew J, Hamilton S, Manthorpe J, Pinfold V (2015) Outcomes from personal budgets in mental health: service users' experiences in three English local authorities. Journal of Mental Health, 24,4,219-224

In England, personal budgets are offered to eligible people with severe mental health problems to enable them to purchase what is helpful for their quality of life or recovery. This study aimed to investigate people's own reporting of outcomes from using personal budgets in relation to social care needs arising from severe mental health problems.

A sample of 47 individuals receiving personal budgets was recruited from three English local authorities. In-depth semi-structured interviews were analysed.

Results: Most participants identified positive outcomes across areas of life. Mental health and wellbeing, social participation and relationships, and confidence and skills were most commonly reported. Some needed more support than others to identify goals and make use of the personal budget to take a more active part in society.

Conclusions: Personal budgets can enable people to achieve outcomes that are relevant to them in the context of their lives, particularly through enhancing their wellbeing and social participation. Consideration should be given to distinguishing those individuals potentially requiring more support for engagement from those who can engage more independently to identify and pursue their goals.

http://www.tandfonline.com/doi/abs/10.3109/09638237.2015.1036971

**International examples** 

Appendix: Search Terms used for review articles

#### Operational search terms for disability:

Disability/Disabled persons/hearing impaired persons/sensory/mental health/visually impaired persons/activities of daily living/health condition/Developmental disabilities/Mobility limitation/chronic disease

#### Operational search terms for social participation:

Participation/social activity/community/volunteering/services/coproduction/public attitudes

#### Operational search terms for economic participation:

Extra costs/workplace/education/employment/careers

#### Operational search terms for public life:

Leadership/office holders/ organisational leader/media portrayal/voting

#### General:

Independent living/peer support/wellbeing