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Nottingham City Council

LITERATURE SEARCH

JSNA Adult Physical and Sensory Impairment

Requested by:

Louise Noon
Insight Specialist – Public Health
Early Intervention

Search completed by:

Yvonne Finnigan
Resource Centre Officer
Yvonne.finnigan@nottinghamcity.nhs.uk

19/10/2015

LITERATURE SEARCH RESULTS

Search Results

Your results will be a mixture of key reports, journal articles and /or other publications. **Full-text journal articles** will be linked to the appropriate database. You will need to have logged in to the NICE Evidence website (click on journals and databases) with your Athens username and password before accessing the articles. Sometimes you may be prompted to enter your Athens username and password again. If you do not have an Athens account please register at OpenAthens.

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Knowledge Resources
The Resource Centre, Aspect House, Suite 6, 2nd Floor,
Aspect Business Park, Bennerley Road, Bulwell, Nottingham NG6 8WR
Tel: 0115-883 4205 Fax: 0115-883 4210
resource.centre@nottinghamcity.nhs.uk
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NICE Guidance (in date order – most recent first)

Home care: delivering personal care and practical support to older people living in their own homes
NICE guidelines [NG21], September 2015
This guideline covers the planning and delivery of person-centred care for older people living in their own homes (known as home care or domiciliary care). It aims to promote older people's independence and to ensure safe and consistently high quality home care services. The Care Quality Commission uses NICE guidelines as evidence to inform the inspection process. The social care sector guideline, which is also of relevance to CCGs and others who commission home care services, recommends that services support the aspirations, goals and priorities of each person, and that they and their carers are treated with empathy, courtesy and respect. Home care workers should make sure their support focuses on what people can or would like to do rather than a *"one size fits all"* service.

Older people in care homes
NICE advice [LGB25], February 2015
This briefing summarises NICE's key recommendations for local authorities and partner organisations on the health and care of older people in care homes. It also highlights relevant quality standards. It is particularly relevant to health and wellbeing boards, scrutiny panels, councillors and adult social care commissioners. The term 'care home' includes all residential and nursing homes registered with the Care Quality Commission where mainly older people live. Because some younger people may also live in these homes, parts of this briefing may also apply to them.

Multiple sclerosis: management of multiple sclerosis in primary and secondary care
NICE guidelines [CG186], October 2014
This guideline replaces NICE clinical guideline 8 (published November 2003). It offers evidence-based advice on the care and treatment of adults with multiple sclerosis. See also: CG186 Multiple sclerosis: costing statement.

Patient experience in adult NHS services: improving the experience of care for people using adult NHS services
NICE guidelines [CG138], February 2012
The Government signalled in its White Paper Equity and excellence: liberating the NHS (2010) that more emphasis needs to be placed on improving patients' experience of NHS care. This guidance is a direct referral from the Department of Health. It focuses on generic patient experiences and is relevant for all people who use adult NHS services in England and Wales. The aim of the guidance is to provide the NHS with clear guidance on the components of a good patient experience. This guidance provides the evidence and the direction for creating sustainable change that will result in an 'NHS cultural shift' towards a truly patient-centred service.

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Incidence and Prevalence

Documents

Adult health in Great Britain, 2013
Office for National Statistics, March 2015
Some of the key findings from this ONS Statistical Bulletin include:

- In 2013 more than one in three adults (36%) reported having a long-standing illness or disability (LSI) and one in five (20%) reported having a limiting LSI.
- The likelihood that someone reported having an LSI was closely associated with age. In 2013 69% of people aged 75 and over reported having an LSI. This compared with 15% of people aged 16 to 24.
- People living in Wales (27%) were more likely to report having a limiting LSI than those living in either England (19%) or Scotland (20%).
- Cigarette smokers (37%) were more likely to report an LSI than those who had never smoked cigarettes (32%).

Get all the tables for this Bulletin in the data section of this publication.

Annual Report of the Chief Medical Officer: Surveillance Volume, 2012: On the State of the Public's Health

Department of Health, March 2014

In this report, the Chief Medical Officer, Prof Dame Sally Davies, looks at some of the big issues she identified in her last (2011) surveillance report. She has invited experts to examine these issues in detail and explore them further. As well as presenting data and evidence, the CMO also comments on overarching trends. This year, information in the report suggests that we may need to rethink what is regarded as 'normal' in relation to our health and our society. For example, while some people drink more alcohol than is good for their health, many people drink very little or don't drink at all. While many people think that cycling is dangerous because we hear of deaths on the road, cycling is usually a safe and healthy thing to do but the benefits of cycling don't make the headlines. Highlights from the report include:

- Most adults in England are overweight or obese. As a society, we are in danger of 'normalising' being overweight, which is not good for our health. We should be striving to popularise healthy weight as 'normal'.
- There is very little good, national data on blindness and deafness, but it is important to have this because so many people are affected, and often live for many years with these conditions.
- Active travel (walking and cycling) is good for our health, and more should be done to make it even safer, which will encourage more people to travel this way.

Not enough information is collected for some health issues, for example sensory impairment such as blindness and deafness. Where this is the case, the experts have tried to come up with novel ways of getting more information out of existing systems. For example, in the **chapter on sensory impairment**, the author, Professor Adrian Davis, has looked at GP patient survey data to find out more about deafness and blindness.

The Bigger Picture: Understanding disability and care in England's Older Population

Strategic Society Centre; Independent Age, November 2014

This report explores disability and care at a national, regional and local authority level in England. It brings together data from the 2011 Census, the Department for Work and Pensions and Health and Social Care Information Centre administrative data, as well as from Wave 6 of the English Longitudinal Study of Ageing, to look at the prevalence of disability, need and care of different types, and to 'paint a picture' of the lives of different groups. The accompanying policy discussion paper uses the findings of the research to evaluate public policy in relation to the reach of publicly funded support, unmet need, consistency vs. variation, as well as to explore issues around the implementation of the Care Act in light of findings from the research.

Deafness and hearing loss: factsheet

World Health Organization (WHO), March 2015

This WHO factsheet includes the following data:

- 360 million people worldwide have disabling hearing loss.
- Hearing loss may result from genetic causes, complications at birth, certain infectious diseases, chronic ear infections, the use of particular drugs, exposure to excessive noise and ageing.
- Half of all cases of hearing loss are avoidable through primary prevention.
- People with hearing loss can benefit from hearing aids, cochlear implants and other assistive devices; captioning and sign language; and other forms of educational and social support.
- Current production of hearing aids meets less than 10% of global need.

Disability in the United Kingdom 2013

Papworth Trust, December 2013

This report gives an overview of the key facts and figures surrounding disability in the UK today. It covers areas such as employment, health, housing, transport and education.

Disability prevalence estimates 2011/12

Office for Disability Issues; Department for Work and Pensions, January 2014

These estimates, based on data from the Family Resources Survey, cover the number of people with a long-standing illness, disability or infirmity, and who have a significant difficulty with day-to-day activities.

The dynamics of ageing: evidence from the English Longitudinal Study of Ageing 2002-12 (Wave 6)

English Longitudinal Study of Ageing (ELSA), October 2014

The English Longitudinal Study of Ageing is a multidisciplinary study of a large representative sample of men and women aged 50 and over living in England. ELSA was designed to understand the dynamics of ageing as people move

through their later years and the relationships between demographic factors, economic circumstances, social and psychological factors, health, cognitive function and biology. The study began in 2002 and the sample is re-examined every two years. This report details the sixth wave of data collection, which was carried out in 2012–13.

Eye health data summary: a review of published data in England

UK Vision Strategy, February 2014

This report aims to provide a summary of published eye health data available in England. The report was commissioned by RNIB's Prevention of Avoidable Sight Loss programme in order to provide an update on the current picture in eye health data and to give indication of national level trends.

Health Profiles

Public Health England (PHE), updated August 2015

Health Profiles is a programme to improve availability and accessibility for health and health-related information in England. The profiles give a snapshot overview of health for each local authority in England. Health Profiles are produced annually. Search for a profile on Nottingham by using text search or select it using a clickable geographical map.

Health survey for England 2013

Health and Social Care Information Centre (HSCIC), December 2014

The Health Survey for England (HSE) is a series of annual surveys about the health of people living in England. The survey started in 1991 and has been carried out annually since then. The HSE includes a set of core questions, asked each year on general health and psycho-social indicators, smoking, alcohol, demographic and socio-economic indicators, questions about use of health services and prescribed medicines and measurements of height, weight and blood pressure. Each year, there is also a particular focus on a population group, disease or condition. Topics are repeated at appropriate intervals in order to monitor changes with time. As well as core topics, the focus for the 2013 survey was social care. Additional non-core modules of questions were also included; covering eye care, end of life care, medicines, shift work, obesity, fruit and vegetable consumption, and smoking.

Hearing loss and older people

Royal Voluntary Service, July 2015

There are more than 10 million people in the UK today who live with some degree of hearing loss. The vast majority of these individuals are older people – with 71% of people aged over 70 experiencing some degree of hearing loss, and 44% experiencing hearing loss that is moderate or worse. As society ages the number of people experiencing hearing loss is set to grow. Hearing loss has wide-ranging impacts. Improving the prevention, detection and treatment of hearing loss should, therefore, be a public health priority. The evidence, from our own recent survey and wider research, demonstrates that hearing loss is linked to: Loneliness and isolation; Reduced quality of life; Poor physical health – including an increased risk of cardiovascular disease; Dementia – with those with severe hearing at five times the risk of developing dementia; Depression and other mental health issues.

How do People Rate their General Health? An Analysis of General Health by Disability and Deprivation

Office for National Statistics, February 2014

Some of the key findings from this ONS Statistical Bulletin related to the 2011 census include:

- Across England and Wales one in 25 people (4.3% of the usual private household population; 2.4 million people) are in 'Good' health despite a disability.
- Among the disabled population, younger people are more likely to be in 'Good' health; more than half of all disabled children are in 'Good' health (55.3%) compared to a fifth (19.7%) of the disabled population aged 85 and over.
- Disabled males were generally more likely to be in 'Good' health compared to disabled females, regardless of the extent of their disability. The overall proportion of boys, aged 0 to 15, in 'Good' health despite a disability that limited them a lot (0.9%) was twice as high as it was for girls (0.4%) at this same age in England.
- Among the disabled population, people living in the least deprived areas were most likely to report 'Good' health; from the age of 35 the proportion of disabled people in 'Good' health in the least deprived areas was around twice the proportion in the most deprived areas.

- Because rates of disability increase with age, the overall proportion of people with 'Good' health despite a disability was higher among the elderly; at the oldest ages, 85 and over, around one in six people were in 'Good' health despite a disability, compared to around one in 50 children; ages 0 to 15.
- In England, Weymouth and Portland local authority had the highest overall proportions of people reporting both 'Good' health and a disability (5.7%). The lowest proportion was in the London Borough of Kensington and Chelsea (3.6%).

Life Opportunities Survey

Office for Disability Issues; Office for National Statistics; Department for Work and Pensions, updated September 2015

This is a collection of ssurvey results providing data on how disabled and non-disabled people participate in society. This was a major study, carried out for the Office for Disability Issues, part of the Department for Work and Pensions (DWP), by the Office for National Statistics (ONS). It ran from June 2009 to September 2014 and provides facts and figures comparing how disabled and non-disabled people participate in society in a number of areas. These areas include: work; education; social participation; transport and use of public services.

Living with sight loss: updating the national picture

Royal National Institute of Blind People (RNIB), June 2015

People with sight loss experience inequality across many areas of their lives. This report takes information from two national surveys, the Life Opportunities Survey and Understanding Society, to describe the extent of those inequalities for British adults in the period 2010 to 2013. The report updates the findings of the previous publication from NatCen Social Research and RNIB, Circumstances of People with Sight Loss (2012). Key findings

- Since the previous waves of Understanding Society and the Life Opportunities Survey, circumstances have worsened in some respects for blind and partially sighted people. 44 per cent reported feeling more than usually depressed, which was significantly higher than in the previous wave of the survey (38 per cent).
- The proportion of blind and partially sighted respondents who earn £500 or more a week is significantly lower, at nine per cent, than in the previous wave of the survey (13 per cent). However, the proportion earning less than £200 a week is also significantly lower than previously (48 per cent compared to 54 per cent).
- In other areas, such as accessing health and benefits services, respondents' circumstances have remained stable since the last wave.
- Key areas of inequality are employment, participation, and experience of hate crime. All three of these areas pose concern, as a much higher percentage of respondents with sight loss report difficulties than those without impairments.

The NHS Atlas of Variation in Healthcare 2015

Public Health England (PHE); NHS England; Right Care, September 2015

This is the ninth edition in the series of Atlases of Variation. This compendium Atlas is the largest yet, with 102 maps detailing widespread variation in the quality, cost, activity and health outcome of healthcare in the English NHS. Almost 25% of the indictors focus on children and young people services. The NHS Atlas of Variation in Healthcare 2015 identifies where opportunities to address 'unwarranted' variation exist – by revealing the possible over-use and under-use of different aspects of healthcare.

Onset of, and recovery from, visual impairment: analysis of causes and consequences using the English Longitudinal Study of Ageing

University of Manchester, August 2015

This report is independent research commissioned by Thomas Pocklington Trust. The report examines the relationship between socioeconomic risk factors and the development of visual impairment in later life and the impact of change in visual acuity (both deterioration and improvement) on older people's lives (social engagement, economic position and wellbeing). The analysis presented uses data provided by the English Longitudinal Study of Ageing (ELSA), a large multidisciplinary panel survey of a representative sample of people aged 50 and older in England that allows for an exploration of change in levels of visual acuity, factors related to such changes, and the social, personal and economic impacts of such change. A summary of the research can be found in Thomas Pocklington's Research Findings.

People Registered as Deaf or Hard of Hearing - England, Year ending 31 March 2010
Health and Social Care Information Centre (HSCIC), October 2010
This publication contains detailed statistics of persons registered as deaf and hard of hearing with Councils with Social Services Responsibilities (CSSRs) in England.

Personal Social Services: Expenditure and Unit Costs, England - 2013-14, Final release
Health and Social Care Information Centre (HSCIC), December 2014
This summary provides information about the money spent on adult social care by the social services departments of Councils with Adult Social Services Responsibilities (CASSRs) in England. It contains information taken from CASSR administrative systems used to record personal social services expenditure and income.

Registered blind and partially sighted people: year ending 31 March 2014, England
Health and Social Care Information Centre (HSCIC), September 2014
This publication contains detailed information on people registered with Councils that have Social Services Responsibilities (CSSRs) in England as being severely visually impaired (blind) or visually impaired (partially sighted). This data is collected every three years.

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Journal Articles (in date order – most recent first)

Title: Prevalence of frailty and disability: findings from the English Longitudinal Study of Ageing.
Citation: Age & Ageing, 01 January 2015, vol./is. 44/1(162-165), 00020729
Author(s): Gale, Catharine R., Cooper, Cyrus, Aihie Sayer, A.
Language: English
Abstract: Objective: to examine the prevalence of frailty and disability in people aged 60 and over and the proportion of those with disabilities who receive help or use assistive devices. **Methods:** participants were 5,450 people aged 60 and over from the English Longitudinal Study of Ageing. Frailty was defined according to the Fried criteria. Participants were asked about difficulties with mobility or other everyday activities. Those with difficulties were asked whether they received help or used assistive devices. **Results:** the overall weighted prevalence of frailty was 14%. Prevalence rose with increasing age, from 6.5% in those aged 60–69 years to 65% in those aged 90 or over. Frailty occurred more frequently in women than in men (16 versus 12%). Mobility difficulties were very common: 93% of frail individuals had such difficulties versus 58% of the non-frail individuals. Among frail individuals, difficulties in performing activities or instrumental activities of daily living were reported by 57 or 64%, respectively, versus 13 or 15%, respectively, among the non-frail individuals. Among those with difficulties with mobility or other daily activities, 71% of frail individuals and 31% of non-frail individuals said that they received help. Of those with difficulties, 63% of frail individuals and 20% of non-frail individuals used a walking stick, but the use of other assistive devices was uncommon. **Conclusions:** frailty becomes increasingly common in older age groups and is associated with a sizeable burden as regards difficulties with mobility and other everyday activities.
Publication type: journal article
Source: CINAHL

Title: Prevalence, risk factors and disability associated with fall-related injury in older adults in low- and middle-income countries: Results from the WHO Study on global AGEing and adult health (SAGE)
Citation: BMC Medicine, June 2015, vol./is. 13/1, 1741-7015 (June 23, 2015)
Author(s): Stewart Williams J., Kowal P., Hestekin H., O'Driscoll T., Peltzer K., Yawson A., Biritwum R., Maximova T., Salinas Rodriguez A., Manrique Espinoza B., Wu F., Arokiasamy P., Chatterji S.
Language: English
Abstract: In 2010 falls were responsible for approximately 80 % of disability stemming from unintentional injuries excluding traffic accidents in adults 50 years and over. Falls are becoming a major public health problem in low- and middle-income countries (LMICs) where populations are ageing rapidly. Methods: Nationally representative standardized data collected from adults aged 50 years and over participating in the World Health Organization (WHO) Study on global AGEing and adult health (SAGE) Wave 1 in China, Ghana, India, Mexico, the Russian Federation and South Africa are analysed. The aims are to identify the prevalence of, and risk factors for, past-year fall-related injury and to assess associations between fall-related injury and disability. Regression methods are used to identify risk factors and association between fall-related injury and disability. Disability was measured using the WHO Disability Assessment Schedule Version 2.0 (WHODAS 2.0). Results: The prevalence of past-year fall-related

injuries ranged from 6.6 % in India to 1.0 % in South Africa and was 4.0 % across the pooled countries. The proportion of all past-year injuries that were fall-related ranged from 73.3 % in the Russian Federation to 44.4 % in Ghana. Across the six countries this was 65.7 %. In the multivariable logistic regression, the odds of past-year fall-related injury were significantly higher for: women (OR: 1.27; 95 % CI: 0.99,1.62); respondents who lived in rural areas (OR: 1.36; 95 % CI: 1.06,1.75); those with depression (OR: 1.43; 95 % CI: 1.01,2.02); respondents who reported severe or extreme problems sleeping (OR: 1.54; 95 % CI: 1.15,2.08); and those who reported two or more (compared with no) chronic conditions (OR: 2.15; 95 % CI: 1.45,3.19). Poor cognition was also a significant risk factor for fall-related injury. The association between fall-related injury and the WHODAS measure of disability was highly significant (P<0.0001) with some attenuation after adjusting for confounders. Reporting two or more chronic conditions (compared with none) was significantly associated with disability (P<0.0001). Conclusions: The findings provide a platform for improving understanding of risk factors for falls in older adults in this group of LMICs. Clinicians and public health professionals in these countries must be made aware of the extent of this problem and the need to implement policies to reduce the risk of falls in older adults.
Publication type: Journal: Article
Source: EMBASE
Full text: Available *BioMed Central* at BMC Medicine

Title: Understanding and reducing disability in older adults following critical illness.
Citation: Critical Care Medicine, 01 June 2015, vol. /is. 43/6(1265-1275), 00903493
Author(s): Brummel, Nathan E, Balas, Michele C, Morandi, Alessandro, Ferrante, Lauren E, Gill, Thomas M, Ely, E Wesley
Language: English
Abstract: OBJECTIVE: To review how disability can develop in older adults with critical illness and to explore ways to reduce long-term disability following critical illness. **DATA SOURCES:** We searched PubMed, CINAHL, Web of Science and Google Scholar for studies reporting disability outcomes (i.e., activities of daily living, instrumental activities of daily living, and mobility activities) and/or cognitive outcomes among patients treated in an ICU who were 65 years or older. We also reviewed the bibliographies of relevant citations to identify additional citations. **STUDY SELECTION:** We identified 19 studies evaluating disability outcomes in critically ill patients who were 65 years and older. DATA **EXTRACTION:** Descriptive epidemiologic data on disability after critical illness. **DATA SYNTHESIS:** Newly acquired disability in activities of daily living, instrumental activities of daily living, and mobility activities was commonplace among older adults who survived a critical illness. Incident dementia and less severe cognitive impairment were also highly prevalent. Factors related to the acute critical illness, ICU practices, such as heavy sedation, physical restraints, and immobility, as well as aging physiology, and coexisting geriatric conditions can combine to result in these poor outcomes. **CONCLUSIONS:** Older adults who survive critical illness have physical and cognitive declines resulting in disability at greater rates than hospitalized, noncritically ill and community dwelling older adults. Interventions derived from widely available geriatric care models in use outside of the ICU, which address modifiable risk factors including immobility and delirium, are associated with improved functional and cognitive outcomes and can be used to complement ICU-focused models such as the ABCDEs.
Publication type: journal article
Source: CINAHL

Title: Hearing in middle age: a population snapshot of 40- to 69-year olds in the United Kingdom.
Citation: Ear & Hearing (01960202), 01 May 2014, vol./is. 35/3(0-), 01960202
Author(s): Dawes, Piers, Fortnum, Heather, Moore, David R, Emsley, Richard, Norman, Paul, Cruickshanks, Karen, Davis, Adrian, Edmondson-Jones, Mark, McCormack, Abby, Lutman, Mark, Munro, Kevin
Language: English
Abstract: OBJECTIVES: To report population-based prevalence of hearing impairment based on speech recognition in noise testing in a large and inclusive sample of U.K. adults aged 40 to 69 years. The present study is the first to report such data. Prevalence of tinnitus and use of hearing aids is also reported. **DESIGN:** The research was conducted using the UK Biobank resource. The better-ear unaided speech reception threshold was measured adaptively using the Digit Triplet Test (n = 164,770). Self-report data on tinnitus, hearing aid use, noise exposure, as well as demographic variables were collected. **RESULTS:** Overall, 10.7% of adults (95% confidence interval [CI] 10.5-10.9%) had significant hearing impairment. Prevalence of tinnitus was 16.9% (95%CI 16.6-17.1%) and hearing aid use was 2.0% (95%CI 1.9-2.1%). Odds of hearing impairment increased with age, with a history of work- and music-related noise exposure, for lower socioeconomic background and for ethnic minority backgrounds. Males were at no higher risk of hearing impairment than females. **CONCLUSIONS:** Around 1 in 10 adults aged 40 to 69 years have substantial hearing

impairment. The reasons for excess risk of hearing impairment particularly for those from low socioeconomic and ethnic minority backgrounds require identification, as this represents a serious health inequality. The underuse of hearing aids has altered little since the 1980s, and is a major cause for concern.
Publication type: journal article
Source: CINAHL

Title: UK health performance: Findings of the Global Burden of Disease Study 2010
Citation: The Lancet, March 2013, vol./is. 381/9871(997-1020), 0140-6736;1474-547X (March 2013)
Author(s): Murray C.J.L., Richards M.A., Newton J.N., et al.
Language: English
Abstract: Background The UK has had universal free health care and public health programmes for more than six decades. Several policy initiatives and structural reforms of the health system have been undertaken. Health expenditure has increased substantially since 1990, albeit from relatively low levels compared with other countries. We used data from the Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010) to examine the patterns of health loss in the UK, the leading preventable risks that explain some of these patterns, and how UK outcomes compare with a set of comparable countries in the European Union and elsewhere in 1990 and 2010. **Methods** We used results of GBD 2010 for 1990 and 2010 for the UK and 18 other comparator nations (the original 15 members of the European Union, Australia, Canada, Norway, and the USA; henceforth EU15+). We present analyses of trends and relative performance for mortality, causes of death, years of life lost (YLLs), years lived with disability (YLDs), disability-adjusted life-years (DALYs), and healthy life expectancy (HALE). We present results for 259 diseases and injuries and for 67 risk factors or clusters of risk factors relevant to the UK. We assessed the UK's rank for age-standardised YLLs and DALYs for their leading causes compared with EU15+ in 1990 and 2010. We estimated 95% uncertainty intervals (UIs) for all measures. **Findings** For both mortality and disability, overall health has improved substantially in absolute terms in the UK from 1990 to 2010. Life expectancy in the UK increased by 4*2 years (95% UI 4*2-4*3) from 1990 to 2010. However, the UK performed significantly worse than the EU15+ for age-standardised death rates, age-standardised YLL rates, and life expectancy in 1990, and its relative position had worsened by 2010. Although in most age groups, there have been reductions in age-specific mortality, for men aged 30-34 years, mortality rates have hardly changed (reduction of 3*7%, 95% UI 2*7-4*9). In terms of premature mortality, worsening ranks are most notable for men and women aged 20-54 years. For all age groups, the contributions of Alzheimer's disease (increase of 137%, 16-277), cirrhosis (65%, -15 to 107), and drug use disorders (577%, 71-942) to premature mortality rose from 1990 to 2010. In 2010, compared with EU15+, the UK had significantly lower rates of age-standardised YLLs for road injury, diabetes, liver cancer, and chronic kidney disease, but significantly greater rates for ischaemic heart disease, chronic obstructive pulmonary disease, lower respiratory infections, breast cancer, other cardiovascular and circulatory disorders, oesophageal cancer, preterm birth complications, congenital anomalies, and aortic aneurysm. Because YLDs per person by age and sex have not changed substantially from 1990 to 2010 but age-specific mortality has been falling, the importance of chronic disability is rising. The major causes of YLDs in 2010 were mental and behavioural disorders (including substance abuse; 21*5% [95 UI 17*2-26*3] of YLDs), and musculoskeletal disorders (30*5% [25*5-35*7]). The leading risk factor in the UK was tobacco (11*8% [10*5-13*3] of DALYs), followed by increased blood pressure (9*0 % [7*5-10*5]), and high body-mass index (8*6% [7*4-9*8]). Diet and physical inactivity accounted for 14*3% (95% UI 12*8-15*9) of UK DALYs in 2010. Interpretation The performance of the UK in terms of premature mortality is persistently and significantly below the mean of EU15+ and requires additional concerted action. Further progress in premature mortality from several major causes, such as cardiovascular diseases and cancers, will probably require improved public health, prevention, early intervention, and treatment activities. The growing burden of disability, particularly from mental disorders, substance use, musculoskeletal disorders, and falls deserves an integrated and strategic response. Funding Bill & Melinda Gates Foundation.
Publication type: Journal: Article
Source: EMBASE
Full text: Available *Lancet, The* at Lancet, The
Full text: Available *Lancet, The* at The Resource Centre, Aspect House

Title: Ethnic variation in the prevalence of visual impairment in people attending diabetic retinopathy screening in the United Kingdom (DRIVE UK).
Citation: PloS one, Jan 2012, vol. 7, no. 6, p. e39608. (2012)
Author(s): Sivaprasad, Sobha, Gupta, Bhaskar, Gulliford, Martin C, Dodhia, Hiten, Mann, Samantha, Nagi, Dinesh, Evans, Jennifer

Abstract: To provide estimates of visual impairment in people with diabetes attending screening in a multi-ethnic population in England (United Kingdom). The Diabetic Retinopathy In Various Ethnic groups in UK (DRIVE UK) Study is a cross-sectional study on the ethnic variations of the prevalence of DR and visual impairment in two multi-racial cohorts in the UK. People on the diabetes register in West Yorkshire and South East London who were screened, treated or monitored between April 2008 to July 2009 (London) or August 2009 (West Yorkshire) were included in the study. Data on age, gender, ethnic group, visual acuity and diabetic retinopathy were collected. Ethnic group was defined according to the 2011 census classification. The two main ethnic minority groups represented here are Blacks ("Black/African/Caribbean/Black British") and South Asians ("Asians originating from the Indian subcontinent"). We examined the prevalence of visual impairment in the better eye using three cut-off points (a) loss of vision sufficient for driving (approximately <6/9) (b) visual impairment (<6/12) and (c) severe visual impairment (<6/60), standardising the prevalence of visual impairment in the minority ethnic groups to the age-structure of the white population. Data on visual acuity and were available on 50,331 individuals 3.4% of people diagnosed with diabetes and attending screening were visually impaired (95% confidence intervals (CI) 3.2% to 3.5%) and 0.39% severely visually impaired (0.33% to 0.44%). Blacks and South Asians had a higher prevalence of visual impairment (directly age standardised prevalence 4.6%, 95% CI 4.0% to 5.1% and 6.9%, 95% CI 5.8% to 8.0% respectively) compared to white people (3.3%, 95% CI 3.1% to 3.5%). Visual loss was also more prevalent with increasing age, type 1 diabetes and in people living in Yorkshire. Visual impairment remains an important public health problem in people with diabetes, and is more prevalent in the minority ethnic groups in the UK.
Source: Medline
Full text: Available *ProQuest* at PLoS ONE

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Policy and Commissioning

Documents

Accessible rail transport
Department for Transport; Disabled Persons Transport Advisory Committee, May 2015
This document explains what government is doing to providing an accessible rail system that offers disabled people the same opportunities to travel as other people.

Action plan on hearing loss
NHS England; Department of Health, March 2015
NHS England and DH have published 'Action plan on hearing loss' to support services for deaf people and those with diminishing hearing. The plan has been developed with a number of organisations including Public Health England, hearing loss charities and those whose hearing is directly affected. Aimed at commissioners, Clinical Commissioning Groups, GPs and healthcare providers, the report identifies multiple health and social issues associated with hearing loss. It recommends ways that services for children, young people, working age and older adults living with hearing loss can be improved.

Adult social care outcomes framework 2015 to 2016
Department of Health, November 2014
The Framework measures how well care and support services achieve the outcomes that matter most to people. In addition, the Framework: supports councils to improve the quality of care and support services they provide; gives a national overview of adult social care outcomes in 2013 to 2014; and looks at how the framework will be developed in future. **Associated documentation:**

- Measures from the Adult Social Care Outcomes Framework, England 2014 to 2015
  Health and Social Care Information Centre (HSCI), October 2015
  This report provides the findings from the Adult Social Care Outcomes Framework (ASCOF) in England for the period 1 April 2014 to 31 March 2015.

Care and support for deafblind children and adults policy guidance
Department of Health, December 2014
This document explains how local authorities should act in relation to care and support for deafblind adults and children.
Commissioning better eye care: low vision

College of Optometrists; Royal College of Ophthalmologists, November 2013
This resource is to help those designing and commissioning eye care improve the value of their services. It is arranged in to the following sections: It is arranged in to the following sections: Summary and recommendations; Introduction: What is low vision? What are the causes of and scope of prevention for low vision? How many people have low vision? What are the best value diagnostic tests? What are the best value treatments? How can individuals and carers be best supported long term? Successful systems of care: pathways and service models; and How to compare services based on activity, quality and outcome

Confident commissioning: building relationships between local authorities and disabled people's user-led organisations
Disability Rights UK, June 2014
This report provides information and practical examples about why local is best, the benefits that disabled people's organisations (DPOs) bring to their community, how local authorities can successfully commission local services, and how DPOs can measure their own social value.

Disability, long term conditions and poverty
New Policy Institute (NPI), July 2014
This study shows the likely size of the levels of poverty among people with disabilities, and explores the difficulty in escaping poverty through paid work. It draws on: new data analyses using the Households Below Average Income (HBAI) data, supplemented by other surveys such as the Health Survey for England, and international data from the OECD and Eurostat; reviews of published literature on 'what works'; and a policy workshop organised by Disability Rights UK in October 2013. The report examines how poverty and disability are often inextricably linked due to the extra needs and the costs of disability and the lack of employment opportunities for disabled people. The report sets out a strategy for reducing disability poverty by reducing the extra costs of disability, through greater levels of suitable housing, greater enforcement of the 'reasonable adjustment' in public and private transport, end of discrimination in insurance and financial markets, greater accessibility to consumer devices and more efficient markets for assistive technologies. In addition, it identifies ways of reducing disability poverty by supporting paid work, through specialist programmes to help people return-to-work, early intervention to help people maintain work and stronger regulation supporting disabled people to assert their employment rights.

Disabled Facilities Grant funding via Better Care Funds: an opportunity to improve outcomes
Care and Repair England, April 2015
This briefing explains the changes to the provision of national government funding for home adaptations, clarifying the responsibilities for delivery and highlighting opportunities for integration. From 1 April 2015, instead of national government making a direct payment to each local housing authority to help them to meet the cost of providing Disabled Facilities Grants, the allocation will, for the first time, be paid through Better Care Funds. The briefing considers: the implications of this change; why help with home adaptations is particularly relevant to NHS, care and public health; the opportunities and risks associated with the inclusion of adaptations money in the Better Care Fund; and the scale of need for suitably adapted housing to enable healthy, independent living.

Distinctive, valued, personal: why social care matters: the next five years
Association of Directors of Adult Social Services (ADASS), March 2015
This document sets out the distinctive role and value of social care in the 21st century, when people are living longer, often with multiple health conditions that need a focus on the whole person and not just a single disease. The report considers why the care system needs to change, what the future will look like, including the role that individuals and communities must play and a joined-up care and health system, and how to get there. The report sets out a model for care and support, based on four key elements: good information and advice to enable people to look after themselves and each other, and get the right help at the right time as needs change; the recognition that people are interdependent and need to build supportive relationships and resilient communities; services that help people get back on track after illness or support disabled people to be independent; and services that are personalised, of good quality, that address mental, physical, and other forms of wellbeing and are much better joined-up around our individual needs and those of the carers.

Driving local change for effective and efficient eyecare services : sharing our learning from the Commissioning for Effectiveness and Efficiency (CEE) project

Royal National Institute of Blind People (RNIB), October 2014
This guidance brings together the learning from the CEE project and is accompanied by a suite of support tools to assist commissioners, local government partners, Local Eye Health Networks (LEHNs) and partnerships to plan and deliver eyecare services that maximise the best possible outcomes for their local communities.

Emerging practice in outcome-based commissioning for social care: discussion paper
Institute of Public Care, Oxford Brookes University, April 2015
This paper is a progress report exploring the lessons learnt from a variety of approaches taken by councils to outcome-based commissioning in adult social care (sometimes called 'payment by results'). It considers some of the opportunities and risks that arise from taking this approach. The paper puts the emerging practice in social care in a context with other developments within the public sector; explores current practices in social care from a small number of councils and looks at the advantages and risks in taking this approach. It suggests that this approach could deliver better outcomes for people at a lower cost if the transaction costs can be limited.

Ending the other care crisis : making the case for investment in preventative care and support for disabled adults
Scope; Mencap; National Autistic Society; Sense; Leonard Cheshire Disabilty, May 2013
This report demonstrates that spending money on social care for disabled people with moderate needs delivers improved quality of life and economic returns. See also: The other care crisis: making social care funding work for disabled adults in England (January 2013).

Evidence-based review: people of working age
RNIB, December 2014
This review looks in more detail at the experience of blind and partially sighted people of “working age”. It includes a profile of this group, the policies that govern their employment and economic circumstances, and a commentary on what the evidence tells us.

Evidence-based review: older people
RNIB, February 2014
This review looks in more detail at the experience of older blind and partially sighted people in the UK. It includes a profile of this group, the policies that govern their access to health, social care, and other services, and a commentary on what the evidence tells us. In this review “older people” is defined as 65 and over, unless otherwise stated.

Fit for purpose: transforming employment support for disabled people and those with health conditions
Centre for Economic and Social Inclusion, July 2014
This report sets out how the employment support system can be transformed to create a system that offers employment opportunity for all, including disabled people and those with health conditions – with the right support to prepare for and take up work. The report, which includes twenty case studies, describes the current and recent landscape of employment support for disabled people and those with health conditions, exploring both mainstream and specialist support with a primary focus on provision funded by DWP.

Fulfilling potential: making it happen
Office for Disability Issues; Department for Work and Pensions, July 2013
This report emphasises the need for innovative cross sector partnerships with disabled people and their organisations, and the promotion of new ways of working to deliver meaningful outcomes. It is supplemented by an action plan and framework, which provides a basis for the government to measure progress. Indicators within the framework cover six themes: education; employment; income; health and wellbeing; choice and control; and inclusive communities.

Home adaptations for disabled people: a detailed guide to related legislation, guidance and good practice
British Association and College of Occupational Therapists; Care and Repair England, October 2013
The purpose of this good practice guide is to provide local authorities and partner agencies with information about how to provide an excellent service to disabled people, their families and carers in enabling adaptations to their homes to help them live more independently. The guide is based on the social model of disability, in that it encourages authorities to start by understanding the experience of the disabled person and helping to identify an individualised solution rather than proposing standardised approaches.

Housing associations and the NHS: new thinking, new partnerships

Smith Institute, July 2014

The treatment and care of more people in their own communities and the provision of more support to allow them to stay in their own homes or in specially designed accommodation is vital if our society is to cope with an ageing population and the growing number of people with multiple long-term conditions. Furthermore, given the increase in demand and the consequential rise in healthcare costs, it is essential to secure efficiency savings and productivity improvements wherever possible. Much greater integration of health and housing is widely seen as one way of meeting these challenges, yet progress has been painfully slow and often unnecessarily bureaucratic. Although in theory there is everything to be gained from the health and housing worlds working closer together, all too often they operate in silos and are disconnected and detached from each other. This report, which captures the views of a range of healthcare and housing professionals and experts, explains why that is so and asks what can be done to remove the barriers to collaboration. That discussion is then followed by perspectives on what works and how new partnerships are reaping the benefits of better integration. In particular, the report breaks new ground by highlighting some excellent pioneering schemes and different types of innovation.

Implementing the NHS five year forward view: aligning policies with the plan

Kings's Fund, February 2015

The Five Year Forward View, published by NHS England and other national NHS bodies, sets out a shared view on how services need to change and what models of care will be required in the future. While the direction set by the Forward View has been broadly welcomed, it risks suffering the same fate as previous policy documents unless serious attention is given to the policy changes needed to support local leaders to make new care models a reality. The purpose of this paper is to outline some of the changes necessary to avoid reform being both slow and, in many cases, falling well short of the kind of future described by NHS England and its national partners.

Long term conditions compendium of information (3rd ed)

Department of Health, May 2012

The Department of Health has published the third edition of the Long Term Conditions Compendium of Information. It is aimed at commissioners as well as health and social care professionals, to provide the evidence for improving care and outcomes for people with long term conditions (LTCs). It updates the second edition of the compendium published in January 2008.

Making it real: personalisation in social care, a case study report

Voluntary Organisations Disability Group; National Care Forum; Sue Ryder, June 2014

The aim of this report is to highlight the usefulness of the Making it Real framework - developed by Think Local, Act Personal (TLAP) - in delivering high quality personalised services, especially for people with lifelong disabilities. Making it real enables social care professionals - providers, commissioners, policy experts and central and local government - to mark progress towards personalised, community-based support. It also allows people being supported and their families to judge how far an organisation puts them at the centre of the care. This case study report illustrates in practical terms and through true stories how the Making it Real initiative has the power to transform care for adults, touching on a range of areas, including risk enablement, community support, flexible integrated care, information and advice, personal budgets and self-funding, and personalisation.

Managing the care of people with long-term conditions: second report of session 2014-15

House of Commons Health Committee, July 2014

This report finds that 15 million NHS patients in England with long-term conditions such as diabetes, arthritis and asthma account for 70% of the annual expenditure of the NHS in England. It argues that demographic and cost pressures on the NHS from patients with long-term conditions is only likely to increase in the coming years, with one projection estimating that the bill for treatment of long-term conditions will require the NHS to find £4 billion more each year by 2016. See also: Managing the care of people with long-term conditions: Monitor's response to the Committee's second report of session 2014-15: third special report of session 2014-15 which was published September 2014.

Obesity and disability: adults

Public Health England (PHE), June 2013

This paper examines the evidence linking obesity and disability among adults. It looks in detail at the most prevalent disabling conditions in the UK as reported by the Department for Work and Pensions: arthritis, back pain, mental health disorders and learning disabilities. It also explores inequalities in relation to obesity and disability and highlights implications for health and social care. It discusses: the two-way relationship between obesity and disability in adults; issues around obesity, disability and inequalities; the implications for health and social care; and analysis of Health Survey for England data on obesity and long-term limiting illness or disability.

Our support, our lives: joining up the public services used by disabled people

Scope, March 2015

This report examines how health and social care integration can work better for working-age disabled people in the care system and applies key lessons and themes from integrated care and disabled people's definitions of independent living to a wider range of public services. It argues that while the drivers behind integration have mostly been considered in the context of the ageing population the evidence strongly indicates that disabled adults should become a priority group for integrated care, alongside older people. It suggests that existing integrated care initiatives are not going far enough and considers how the Better Care Fund, Integrated Care Pioneers and Integrated Personal Commissioning can do more to improve outcomes for disabled adults.

Population level commissioning for the future: implementing capitated budgets within long term conditions for people with complex needs

NHS Improving Quality, September 2014

This paper presents analysis of a Kent 'whole population' dataset, linking whole population demographics with activity and cost data for the population from acute, community, mental health and social care providers. The data helps commissioners to understand the impact of different selections methods for people with 'very complex' health and social care needs, particularly in relation to the development of a long term conditions year of care currency.

A practical guide to implementing the Care Act for deafblind people

Sense, December 2014

This guide is intended to support senior managers and policy makers involved in implementing the Care Act to enable them to understand the key aspects of the Act that have a bearing on care and support for deafblind people and people with complex needs. It will also be useful to anyone working in deafblind care and support to understand how the Care Act will impact on their work. It is not intended as a detailed guide to all the provisions of the Act, merely to draw out the key points in relation to deafblind people.

Reducing care utilisation through self-management interventions (RECURSIVE): a systematic review and meta-analysis

National Institute for Health Research (NIHR), December 2014

Many patients live with long-term conditions and the NHS needs to provide effective and patient-centred care to these patients. However, the NHS faces significant pressures on resources. One way of using NHS resources more effectively is to encourage people to engage in self-management, which refers to care taken by people to support their health and well-being, and can include adoption of a healthy lifestyle, actions taken to better manage long-term conditions, as well as meeting psychosocial needs. Encouraging self-management means that it may be possible for the NHS to use less of the expensive forms of care, such as hospital admissions. We reviewed the current international evidence to see what types of self-management could reduce patient use of NHS services, without causing difficulties in their quality of life (QoL). We found 184 studies that met our criteria, with most studies in patients with cardiovascular, respiratory and mental health problems. We also found many different types of self-management. Generally, self-management support was associated with small improvements in QoL. Some self-management interventions also reduced utilisation of health care, with the best evidence in respiratory and cardiovascular disorders. However, the effects were generally modest. Further research is needed to explore self-management in patients with more than one long-term condition, and to test how self-management can be better encouraged across the wider population of patients.

Research and development work relating to assistive technology: 2014-15

Department of Health, July 2015

A report on progress made in Government-funded research relating to equipment that might increase the range of activities and independence or well-being of disabled people, known as assistive technology. The report highlights developments in funding for assistive technology research and innovation, some particular areas of research activity, and the role of Academic Health Science Networks in supporting uptake and spread of assistive technology. The Annex provides a listing of Government-funded assistive technology research and development projects current in 2014/15.

See hear: a strategic framework for meeting the needs of people with a sensory impairment in Scotland
Scottish Government, April 2014
This strategic framework gives advice on providing high quality coordinated care and support for children and adults with hearing and sight loss. Its main focus is to bring local authority, health and third sector organisations together as partners to improve outcomes. The four main aims are to: provide seamless assessment, care and support; ensure people with sensory impairment have equal access to public services as everyone else; improve access to information and support; and to provide children and young people with appropriate and timely intervention. It highlights key points and principles that should guide the development of services and identifies factors that should be addressed when developing care pathways.

Solutions from the frontline: recommendations for policymakers on supporting people with multiple needs
Making Every Adult Matter, June 2015
This report sets out how policy makers, local authorities, commissioners and frontline services can respond to the challenges faced by people experiencing multiple needs. The policy solutions it proposes have been developed directly with people experiencing multiple needs and those who support them. It marks the midway point of Voices from the Frontline, a two-year project working directly with people experiencing multiple needs and the practitioners who support them every day. The report sets out the specific ideas that people discussed, and makes recommendations for action nationally, locally and at the frontline, focusing on three main areas of action: listen to frontline voices and tackle stigma; deliver flexible and more joined-up services; and support people toward independent living.

Towards excellence in adult social care: progress with adult social care priorities England 2013-14
Local Government Association (LGA); Association of Directors of Adult Social Services (ADASS), February 2015
This report helps to inform and support improvement in adult social care. It also provides an overview of the progress of councils in England towards ensuring better care and support. Maintaining and improving the level of performance or perception (i.e. in terms of quality of life) of social care has taken place in the context of the 26 per cent savings that have been required over the last four years. The report attributes some of this as a result of the transformation of adult social care in terms of the increased personalisation of services.

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Health and Social Care

Documents

Accessible Britain Challenge: creating inclusive communities for disabled people
Department for Work and Pensions; Office for Disability Issues, September 2014
The site pulls together information on what organisations and individuals can do to help disabled people become full and active participants in their community. Disabled people face barriers in their everyday lives that prevent them from being full and active members of their community.

ADASS budget survey 2015: report
Association of Directors of Adult Social Services (ADASS), June 2015
The survey seeks to explore the views of Directors of Adult Social Services across English Local Authorities on how councils are reconciling the growing numbers of people, often with increasingly complex needs, requiring care and support with the significant and sustained reductions in the funding available. The survey data sets out the concerns of councils in making increasingly difficult choices, and the attempts to minimise impacts upon front line services. The report suggests that taking the growth in numbers of older and disabled people into account an additional £1.1 billion would be needed to provide the same level of service as last year.

Alcohol, other drugs and sight loss: a scoping study

Alcohol Research UK, December 2014

This is an exploratory study of the relationship between substance use, including alcohol and illicit and prescribed drugs, and sight loss. It focuses on the role substance use plays in the lives of people with sight loss and the experiences of professionals working with people who have sight loss and substance problems. It draws on a statistical exploration of existing large scale surveys, a comprehensive review of international research evidence and a survey of people living with sight loss and substance problems and professionals working with, and supporting, these people. The study shows that people with sight loss are more likely than their sighted peers to abstain from drinking alcohol. Analysis of two UK datasets showed that they are also more likely to drink fewer units of alcohol per week. For some people their substance use was a way of coping with the negative experiences of sight loss. Professionals felt that the number of people they worked with who had sight loss and substance problems was small but those who did posed considerable professional challenges. In general, professionals in sight loss and substance use services felt they were not adequately equipped with the knowledge, professional guidance or organisational policy frameworks, to help them to identify and respond confidently when working with someone with both sight loss and substance problems. They identified partnership working as key to providing support and to stopping people falling through the gap in services.

Changes in Vision in Older People: Causes and Impact

Thomas Pocklington Trust, August 2015

This briefing summarises wider findings from research commissioned by Thomas Pocklington Trust that uses the English Longitudinal Study of Ageing (ELSA) to look at the links between development of visual impairment and older peoples' social and economic position, and the impact of both deteriorating and improving sight on key aspects of their lives.

Eyes on Evidence: using information on quality to make decisions about services

NICE, July 2015

A systematic review reported that people with long-term conditions or disabilities and their families sought information on the quality of health and social care services from multiple sources, in particular social networks. These groups tended to use general or subjective information rather than formal quality indicators to make decisions about providers. Eyes on Evidence commentaries help contextualise important new evidence, highlighting areas that could signal a change in clinical practice. It does not constitute formal NICE guidance.

Facing blindness alone: what the government needs to do now to stop the isolation of blind people

Royal National Institute of Blind People (RNIB), September 2013

This report argues that within the next ten years, local support for blind and visually impaired people will be drastically reduced. The research shows that although care and support has declined for all adults with a physical disability (30%), people with sight loss have been the worst affected (43%).

Falls in older people with sight loss: a review of emerging research and key action points

Thomas Pocklington Trust, June 2013

This document draws on recent research to summarise what is known about falls and falls prevention amongst older people with sight loss. It explores the implications of research findings for action to address and reduce the risk of falls among older people with sight loss and suggests key issues for health and social care professionals to consider when working with older people, many of whom may have sight loss, and for sight loss specialists to consider when addressing individuals' risks of falls.

Inclusive integration: how whole person care can work for adults with disabilities

Institute for Public Policy Research (IPPR), December 2014

This report focusses on meeting the needs of working-age disabled adults as health and social care services are increasing integrated. It provides an empirical evidence base to demonstrate how whole person care (which is about making the connections between physical health, mental health and social care services) can be used to effectively meet these needs. The report also draws on the findings of a focus group with 12 disabled adults and carers on desired outcomes from the integration of health and social care services: Interviews with social care and voluntary sector professionals, commissioners and local authority policy to see if they are willing to include working-age disabled adults' needs in plans for future integration. The report looks at how working-age disabled adults have different needs and outcomes from older people and identifies the health inequalities they face in day-to-day life.

It all adds up: a guide for healthcare staff on supporting patients with a dual sensory loss

Sense, August 2015

The 'It All Adds Up' guide offers a variety of information for primary healthcare staff on identifying and supporting patients with dual sensory loss, including: Understanding dual sensory loss, its prevalence and its impact on your practice; Tips and ideas for making your services more accessible including environmental changes and good practice communication; Your legislative duties and information on organisations who can provide advice; and Where to refer patients for additional support.

Joining up: why people with hearing loss or deafness would benefit from an integrated response to long-term conditions

Action on Hearing Loss; Deafness Cognition and Language (DCAL) Research Centre, May 2013

This report looks at the issues around providing health and social care services to people who have hearing loss or who are deaf and also have other long-term conditions, including dementia, cardiovascular disease, stroke, diabetes, Parkinson's and sight loss. It shows how large cost savings and improvements to quality of life could be achieved from better provision of services. In particular, it reports evidence of a strong link between hearing loss and dementia, and show how at least £28 million could be saved in England by properly managing hearing loss in people with dementia.

NHS adult hearing services in England: exploring how choice is working for patients

Monitor, March 2015

This report presents the findings from Monitor's research and sets out how the NHS could ensure that choice works better for patients.

Occupational therapy in the prevention and management of falls in adults

College of Occupational Therapists, January 2015

This publication is an evidence-based resource to support occupational therapists working with adults in the prevention and management of falls. It provides a practice guideline with recommendations for those occupational therapists currently working in this speciality, as well as offering a useful reference document for students.

Person centred care 2020: calls and contributions from health and social care charities

National Voices, September 2014

The document advocates support proven, evidence based approaches which involve people in their health and care to improve care quality and lead to better outcomes. They include: genuine shared decisions about treatments, with routine use of patient decision aids and question prompts; supported self-management as a key component for people living with long term conditions and disabilities; access to personal records; personal budgets to hand people greater control over the way they maintain their health and wellbeing.

Personal Social Services: Expenditure and Unit Costs, England - 2014-15, Provisional release

Health and Social Care Information Centre (HSCIC), September 2015

This summary provides information about the money spent on adult social care by the social services departments of Councils with Adult Social Services Responsibilities (CASSRs) in England. Key facts include:

- Over the five year period from 2009-10, when the figure was £16.8 billion, expenditure has increased by one and a half per cent in cash terms; a decrease of eight per cent in real terms. Over the ten year period from 2004-05, when the figure was £13.5 billion, expenditure increased least 26 per cent in cash terms and half of one per cent in real terms.
- For people aged 65 and over, expenditure on long term support accounted for 40 per cent (£6.8 billion) of gross current expenditure; of which £4.4 billion was spent on physical support, £1.2 billion on support with memory and cognition,£540 million on learning disability support, £480 million on mental health support and £130 million on sensory support.

Promoting supportive relationships in housing with care

Joseph Rowntree Foundation (JRF), December 2012

Evidence has consistently shown that older people with high support needs, particularly those who have cognitive and sensory impairments, can be marginalised within housing with care schemes. This research looks at approaches to Housing with Care (HWC) in England and Wales, and how these communities are being made socially inclusive places to live, based on what older people with high support needs say they value and want. The report found that: communities are more likely to be inclusive when organisations have taken positive steps to promote a central ethos and culture of respect and tolerance of individuals; one of the ways of promoting respect and tolerance is by raising awareness of the experiences of people with conditions and impairments; organisations can take a number of steps to create an underlying environment that helps residents participate; and neighbourliness is key to supportive communities.

Secondary analysis of adult social care data: what can the data tell us about blind and partially sighted care users?

NatCen Social Research, May 2013

The RNIB asked NatCen to conduct a scoping project to identify what data are available from national administrative datasets in relation to local authority provided and paid for social care for blind and partially sighted people. The research used data from Referrals, Assessments and Packages of Care (RAP), Registered Blind and Partially Sighted (BPS), and Abuse of Vulnerable Adults (AVA), and secondary analysis of anonymised administrative data from the NASCIS portal (National Adult Social Care Intelligence Service). Also examined were survey data from the Health Survey for England and the English Longitudinal Study of Ageing (ELSA). The authors' analysis found that between 2005 and 2012 there was a 35% decline in the number of blind and partially sighted people receiving local authority social care compared with a decline of 16% for services users as a whole. In addition, the decline in the number of blind and partially sighted people receiving local authority provided social care services was greater for older than younger people. The exception to such decline in provision has been direct payments which increased between 2005 and 2012, reflecting growing personalisation in social care provision. However, the increase in direct payments has been less for BPS people than for other groups. Further possibilities for analysis and research are suggested.

Services for people with neurological conditions: progress review

National Audit Office (NAO), July 2015

This report sets out the findings of a review of progress against the recommendations that the Committee of Public Accounts made in its 2011 report on services for people with neurological conditions. Neurological conditions result from damage to the brain, spinal column or peripheral nerves. Some conditions are life-threatening with many severely affecting quality of life and causing lifelong disability. The most recent estimate indicates that there are 4.7 million neurological cases in England. People with neurological conditions may draw on a wide range of public services including health, social care, employment support and housing. The report shows that overall satisfaction with social care services for people with a physical disability has increased slightly in recent years, with 63 per cent of people stating they were either extremely or very satisfied with their care and support in 2013-14. However, the analysis highlighted that only one fifth of joint health and wellbeing strategies referred to neurology or a specific neurological condition, there were only occasional examples of health and social care joint commissioning and only a small proportion of people with a long-term neurological problem had a written care plan or had been offered one.

The state of health care and adult social care in England, 2014/15

Care Quality Commission, October 2015

This annual assessment report provides an analysis of the quality of health and adult social care in England. This is the first time such a national assessment has been possible following CQC's introduction of a tough, rigorous ratings system. Key findings include:

- Despite increasingly challenging circumstances, the majority of services across health and social care have been rated as good, with some rated outstanding.
- However, there is significant variation in quality - and safety continues to be the biggest concern across all the sectors that CQC regulates.
- Strong leadership and collaboration is emerging as more crucial than ever to delivering good care.
- Evidence increasingly shows that CQC's work is leading to improvements in care.

The number of services rated as either good or outstanding by CQC suggests most people are receiving safe, effective care. There is also a summary report and a response from NHS Providers.

Telehealth and Telecare

Houses of Parliament, Parliamentary Office of Science & Technology, February 2014

The UK's elderly population is growing and with it the number of people with long-term health problems. This is putting pressure on the health and social care systems. Increased use of technology such as telehealth and telecare may help to improve quality of care and reduce costs. This Post Note describes current UK telehealth and telecare initiatives and the role they may play in delivering future care.

Twenty-seven: 27 years of providing independent living support

Independent Living Fund (Nottingham), May 2015

As part of the closure of the Independent Living Fund (ILF), this report attempts to capture the learning, examining critically what the organisation has delivered and what policies, processes, attitudes and approaches have contributed to its achievements. The ILF has provided support to over 46,000 disabled people since it was established in 1988. Over this period of 27 years, the organisation has been able to develop a significant body of expertise and learning regarding the provision of high quality independent living support for disabled people. This report comprises 27 reflections - one learning piece for each of the ILF's years of existence - each penned by a different author with specific insight into the subject, as a permanent record of the work of the ILF. The closure of the organisation in June 2015 will see support for ILF users pass to local authorities in England and to new arrangements led by the devolved administrations in Scotland, Wales and Northern Ireland.

Unit costs of health and social care 2014

Personal Social Services Research Unit (PSSRU), January 2014

This publication provides unit costs for a wide range of health and social care services using a standardised methodology. The report is organised into five main sections. Section I covers services used by a particular client group, and includes services for older people, people with mental health problems, people who misuse drugs/alcohol, people with learning disabilities, younger adults with physical and sensory impairments, services for children and their families, hospitals, and care packages. Sections II, III and IV deal with the unit costs of professionals in community-based health care, community-based social care, and hospital-based health care. These include social care staff, health and social care teams, doctors, nurses, and other health professionals. Section V details the sources of information used.

Vision rehabilitation services: what is the evidence? Final report

Social Policy Research Unit, University of York, February 2015

This research examines the impact and cost effectiveness of local authority funded community-based vision rehabilitation services for people over the age of 18 years. It looks at how these services currently support people with visual impairment, what possible outcomes they might achieve and aims to identify gaps in the evidence base about current service arrangements. Information was collected using: a review of existing research, workshops with people with visual impairment and professionals delivering services, a national survey of local authority funded providers, and case studies of three models of vision rehabilitation services. The outcomes assessed in the study: activities of daily living; mental health and emotional well-being; quality of life; and service users and costs. The survey of local authorities found a wide variety of vision rehabilitation provision across England in relation to the type of providers (specialism within the teams, caseloads and waiting times); a quarter of services responding to the survey restricted access to services on the basis of Fair Access to Care Services (FACS); services mainly focused on mobility, independent living and aids and adaptations, rather than emotional support and counselling. Key features of 'good vision rehabilitation included: staff with specialist knowledge and skills; high quality assessment; personalised and user-led support; provision of a range of support, including emotional support, counselling and social activities. The report concludes that vision rehabilitation services have the potential to improve the quality of life and independence of people with visual impairment, which supports policy objectives to promote prevention and rehabilitation. However, further research is needed to identify what works, for whom and at what cost.

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Systematic Reviews (in date order – most recent first)

Title: Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation.
Citation: Cochrane Database of Systematic Reviews, 01 July 2015, vol./is. /7(0-), 1469493X
Author(s): Levack WM, Weatherall M, Hay-Smith EJ, Dean SG, McPherson K, Siegert RJ
Language: English

Abstract: Goal setting is considered a key component of rehabilitation for adults with acquired disability, yet there is little consensus regarding the best strategies for undertaking goal setting and in which clinical contexts. It has also been unclear what effect, if any, goal setting has on health outcomes after rehabilitation. To assess the effects of goal setting and strategies to enhance the pursuit of goals (i.e. how goals and progress towards goals are communicated, used, or shared) on improving health outcomes in adults with acquired disability participating in rehabilitation. We searched CENTRAL, MEDLINE, EMBASE, four other databases and three trials registers to December 2013, together with reference checking, citation searching and contact with study authors to identify additional studies. We did not impose any language or date restrictions: Randomised controlled trials (RCTs), cluster-RCTs and quasi-RCTs evaluating the effects of goal setting or strategies to enhance goal pursuit in the context of adult rehabilitation for acquired disability. Two authors independently reviewed search results for inclusion. Grey literature searches were conducted and reviewed by a single author. Two authors independently extracted data and assessed risk of bias for included studies. We contacted study authors for additional information. We included 39 studies (27 RCTs, 6 cluster-RCTs, and 6 quasi-RCTs) involving 2846 participants in total. Studies ranged widely regarding clinical context and participants' primary health conditions. The most common health conditions included musculoskeletal disorders, brain injury, chronic pain, mental health conditions, and cardiovascular disease. Eighteen studies compared goal setting, with or without strategies to enhance goal pursuit, to no goal setting. These studies provide very low quality evidence that including any type of goal setting in the practice of adult rehabilitation is better than no goal setting for health-related quality of life or self-reported emotional status (8 studies; 446 participants; standardised mean difference (SMD) 0.53, 95% confidence interval (CI) 0.17 to 0.88, indicative of a moderate effect size) and self-efficacy (3 studies; 108 participants; SMD 1.07, 95% CI 0.64 to 1.49, indicative of a moderate to large effect size). The evidence is inconclusive regarding whether goal setting results in improvements in social participation or activity levels, body structure or function, or levels of patient engagement in the rehabilitation process. Insufficient data are available to determine whether or not goal setting is associated with more or fewer adverse events compared to no goal setting. Fourteen studies compared structured goal setting approaches, with or without strategies to enhance goal pursuit, to 'usual care' that may have involved some goal setting but where no structured approach was followed. These studies provide very low quality evidence that more structured goal setting results in higher patient self-efficacy (2 studies; 134 participants; SMD 0.37, 95% CI 0.02 to 0.71, indicative of a small effect size) and low quality evidence for greater satisfaction with service delivery (5 studies; 309 participants; SMD 0.33, 95% CI 0.10 to 0.56, indicative of a small effect size). The evidence was inconclusive regarding whether more structured goal setting approaches result in higher health-related quality of life or self-reported emotional status, social participation, activity levels, or improvements in body structure or function. Three studies in this group reported on adverse events (death, re-hospitalisation, or worsening symptoms), but insufficient data are available to determine whether structured goal setting is associated with more or fewer adverse events than usual care. A moderate degree of heterogeneity was observed in outcomes across all studies, but an insufficient number of studies were available to permit subgroup analysis to explore the reasons for this heterogeneity. The review also considers studies which investigate the effects of different approaches to enhancing goal pursuit, and studies which investigate different structured goal setting approaches. It also reports on secondary outcomes including goal attainment and healthcare utilisation. There is some very low quality evidence that goal setting may improve some outcomes for adults receiving rehabilitation for acquired disability. The best of this evidence appears to favour positive effects for psychosocial outcomes (i.e. health-related quality of life, emotional status, and self-efficacy) rather than physical ones. Due to study limitations, there is considerable uncertainty regarding these effects however, and further research is highly likely to change reported estimates of effect.
Publication type: journal article
Source: CINAHL
Full text: Available *Wiley* at Cochrane Library, The

Title: Multidisciplinary rehabilitation after primary brain tumour treatment.
Citation: The Cochrane database of systematic reviews, Jan 2015, vol. 8, p. CD009509. (2015)
Author(s): Khan, Fary, Amatya, Bhasker, Ng, Louisa, Drummond, Kate, Galea, Mary
Abstract: Brain tumours can cause significant disability, which may be amenable to multidisciplinary rehabilitation. However, the evidence base for this is unclear. This review is an update of a previously published review in the Cochrane Database of Systematic Reviews [2013, Issue 1, Art. No. CD009509] on 'Multidisciplinary rehabilitation after primary brain tumour treatment': To assess the effectiveness of multidisciplinary rehabilitation in people after primary brain tumour treatment, especially the types of approaches that are effective (settings, intensity). For this update, we searched the Cochrane Central Register of Controlled Trials (CENTRAL, the Cochrane Library up to Issue 12 of 12, 2014), MEDLINE (1950 to January week 2, 2015), EMBASE (1980 to January week 2, 2015), PEDro (1985 to

January week 2 2015), and LILACS (1982 to January week 2, 2015). We checked the bibliographies of papers we identified and contacted the authors and known experts in the field to seek published and unpublished trials: Controlled clinical trials (randomised and non-randomised clinical trials) that compared multidisciplinary rehabilitation in primary brain tumour with either routinely available local services or lower levels of intervention, or studies that compared multidisciplinary rehabilitation in different settings or at different levels of intensity. Three review authors independently assessed study quality, extracted data, and performed a 'best evidence ' synthesis based on methodological quality. We did not identify any studies for inclusion in the previous version of this review. For this update, the literature search identified one low-quality controlled clinical trial involving 106 participants. The findings from this study suggest 'low-level' evidence to support high-intensity ambulatory (outpatient) multidisciplinary rehabilitation in reducing short- and long-term motor disability (continence, mobility and locomotion, cognition), when compared with standard outpatient care. We found improvement in some domains of disability (continence, communication) and psychosocial gains were maintained at six months follow-up. We found no evidence for improvement in overall participation (quality of life and societal relationship). No adverse events were reported as a result of multidisciplinary rehabilitation. We found no evidence for improvement in quality of life or cost-effectiveness of rehabilitation. It was also not possible to suggest best 'dose' of therapy. Since the last version of this review, one new study has been identified for inclusion. The best evidence to date comes from this CCT, which provides low quality evidence that higher intensity ambulatory (outpatient) multidisciplinary rehabilitation reduces short- and long-term disability in people with brain tumour compared with standard outpatient care. Our conclusions are tentative at best, given gaps in current research in this area. Although the strength of evidence has increased with the identification of a new controlled clinical trial in this updated review, further research is needed into appropriate and robust study designs; outcome measurement; caregiver needs; evaluation of optimal settings; type, intensity, duration of therapy; and cost-effectiveness of multidisciplinary rehabilitation in the brain tumour population.
Source: Medline

Title: Personalised care planning for adults with chronic or long-term health conditions.
Citation: Cochrane Database of Systematic Reviews, 01 March 2015, vol./is. /3(0-), 1469493X
Author(s): Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R
Language: English
Abstract: Personalised care planning is a collaborative process used in chronic condition management in which patients and clinicians identify and discuss problems caused by or related to the patient's condition, and develop a plan for tackling these. In essence it is a conversation, or series of conversations, in which they jointly agree goals and actions for managing the patient's condition. To assess the effects of personalised care planning for adults with long-term health conditions compared to usual care (i.e. forms of care in which active involvement of patients in treatment and management decisions is not explicitly attempted or achieved). We searched the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, EMBASE, PsycINFO, ProQuest, clinicaltrials.gov and WHO International Clinical Trials Registry Platform to July 2013. We included randomised controlled trials and cluster-randomised trials involving adults with long-term conditions where the intervention included collaborative (between individual patients and clinicians) goal setting and action planning. We excluded studies where there was little or no opportunity for the patient to have meaningful influence on goal selection, choice of treatment or support package, or both. Two of three review authors independently screened citations for inclusion, extracted data, and assessed risk of bias. The primary outcomes were effects on physical health, psychological health, subjective health status, and capabilities for self-management. Secondary outcomes included effects on health-related behaviours, resource use and costs, and type of intervention. A patient advisory group of people with experience of living with long-term conditions advised on various aspects of the review, including the protocol, selection of outcome measures and emerging findings. We included 19 studies involving a total of 10,856 participants. Twelve of these studies focused on diabetes, three on mental health, one on heart failure, one on end-stage renal disease, one on asthma, and one on various chronic conditions. All 19 studies included components that were intended to support behaviour change among patients, involving either face-to-face or telephone support. All but three of the personalised care planning interventions took place in primary care or community settings; the remaining three were located in hospital clinics. There was some concern about risk of bias for each of the included studies in respect of one or more criteria, usually due to inadequate or unclear descriptions of research methods. Physical health Nine studies measured glycated haemoglobin (HbA1c), giving a combined mean difference (MD) between intervention and control of -0.24% (95% confidence interval (CI) -0.35 to -0.14), a small positive effect in favour of personalised care planning compared to usual care (moderate quality evidence).Six studies measured systolic blood pressure, a combined mean difference of -2.64 mm/Hg (95% CI -4.47 to -0.82) favouring personalised care (moderate quality evidence). The pooled results

from four studies showed no significant effect on diastolic blood pressure, MD -0.71 mm/Hg (95% CI -2.26 to 0.84).We found no evidence of an effect on cholesterol (LDL-C), standardised mean difference (SMD) 0.01 (95% CI -0.09 to 0.11) (five studies) or body mass index, MD -0.11 (95% CI -0.35 to 0.13) (four studies).A single study of people with asthma reported that personalised care planning led to improvements in lung function and asthma control. Psychological health six studies measured depression. We were able to pool results from five of these, giving an SMD of -0.36 (95% CI -0.52 to -0.20), a small effect in favour of personalised care (moderate quality evidence). The remaining study found greater improvement in the control group than the intervention group. Four other studies used a variety of psychological measures that were conceptually different so could not be pooled. Of these, three found greater improvement for the personalised care group than the usual care group and one was too small to detect differences in outcomes. Subjective health status Ten studies used various patient-reported measures of health status (or health-related quality of life), including both generic health status measures and condition-specific ones. We were able to pool data from three studies that used the SF-36 or SF-12, but found no effect on the physical component summary score SMD 0.16 (95% CI -0.05 to 0.38) or the mental component summary score SMD 0.07 (95% CI -0.15 to 0.28) (moderate quality evidence). Of the three other studies that measured generic health status, two found improvements related to personalised care and one did not. Four studies measured condition-specific health status. The combined results showed no difference between the intervention and control groups, SMD -0.01 (95% CI -0.11 to 0.10) (moderate quality evidence). Self-management capabilities nine studies looked at the effect of personalised care on self-management capabilities using a variety of outcome measures, but they focused primarily on self-efficacy. We were able to pool results from five studies that measured self-efficacy, giving a small positive result in favour of personalised care planning: SMD 0.25 (95% CI 0.07 to 0.43) (moderate quality evidence).A further five studies measured other attributes that contribute to self-management capabilities. The results from these were mixed: two studies found evidence of an effect on patient activation, one found an effect on empowerment, and one found improvements in perceived interpersonal support. Other outcomes Pooled data from five studies on exercise levels showed no effect due to personalised care planning, but there was a positive effect on people's self-reported ability to carry out self-care activities: SMD 0.35 (95% CI 0.17 to 0.52).We found no evidence of adverse effects due to personalised care planning. The effects of personalised care planning were greater when more stages of the care planning cycle were completed, when contacts between patients and health professionals were more frequent, and when the patient's usual clinician was involved in the process: Personalised care planning leads to improvements in certain indicators of physical and psychological health status, and people's capability to self-manage their condition when compared to usual care. The effects are not large, but they appear greater when the intervention is more comprehensive, more intensive, and better integrated into routine care., [CINAHL Note: The Cochrane Collaboration systematic reviews contain interactive software that allows various calculations in the MetaView.]
Publication type: journal article
Source: CINAHL
Full text: Available *Wiley* at Cochrane Library, The

Title: Telerehabilitation for persons with multiple sclerosis.
Citation: Cochrane Database of Systematic Reviews, 01 April 2015, vol./is. /4(0-), 1469493X
Author(s): Khan F, Amatya B, Kesselring J, Galea M
Language: English
Abstract: Telerehabilitation, an emerging method, extends rehabilitative care beyond the hospital, and facilitates multifaceted, often psychotherapeutic approaches to modern management of patients using telecommunication technology at home or in the community. Although a wide range of telerehabilitation interventions are trialed in persons with multiple sclerosis (pwMS), evidence for their effectiveness is unclear. To investigate the effectiveness and safety of telerehabilitation intervention in pwMS for improved patient outcomes. Specifically, this review addresses the following questions: does telerehabilitation achieve better outcomes compared with traditional face-to-face intervention; and what types of telerehabilitation interventions are effective, in which setting and influence which specific outcomes (impairment, activity limitation and participation)? We performed a literature search using the Cochrane Multiple Sclerosis and Rare Diseases of the Central Nervous System Review Group Specialised Register(9 July, 2014.) We hand searched the relevant journals and screened the reference lists of identified studies, and contacted authors for additional data. Randomised controlled trials (RCTs) and controlled clinical trials (CCTs) that reported telerehabilitation intervention/s in pwMS and compared them with some form of control intervention (such as lower level or different types of intervention, minimal intervention, waiting-list controls or no treatment (or usual care); interventions given in different settings) in adults with MS. Two review authors independently selected studies and extracted data. Three review authors assessed the methodological quality of studies using the GRADEpro software (GRADEpro 2008) for best-evidence synthesis. A meta-analysis was not possible due to marked

methodological, clinical and statistical heterogeneity between included trials and between measurements tools used. Hence, we performed a best-evidence synthesis using a qualitative analysis. Nine RCTs, one with two reports, (N = 531 participants, 469 included in analyses) investigated a variety of telerehabilitation interventions in adults with MS. The mean age of participants varied from 41 to 52 years (mean 46.5 years) and mean years since diagnosis from 7.7 to 19.0 years (mean 12.3 years). The majority of the participants were women (proportion ranging from 56% to 87%, mean 74%) and with a relapsing-remitting course of MS. These interventions were complex, with more than one rehabilitation component and included physical activity, educational, behavioural and symptom management programmes. All studies scored 'low' on the methodological quality assessment. Overall, the review found 'low-level' evidence for telerehabilitation interventions in reducing short-term disability and symptoms such as fatigue. There was also 'low-level' evidence supporting telerehabilitation in the longer term for improved functional activities, impairments (such as fatigue, pain, insomnia); and participation measured by quality of life and psychological outcomes. There were limited data on process evaluation (participants'/therapists' satisfaction) and no data available for cost effectiveness. There were no adverse events reported as a result of telerehabilitation interventions. There is currently limited evidence on the efficacy of telerehabilitation in improving functional activities, fatigue and quality of life in adults with MS. A range of telerehabilitation interventions might be an alternative method of delivering services in MS populations. There is insufficient evidence to support on what types of telerehabilitation interventions are effective, and in which setting. More robust trials are needed to build evidence for the clinical and cost effectiveness of these interventions., [CINAHL Note: The Cochrane Collaboration systematic reviews contain interactive software that allows various calculations in the MetaView.]
Publication type: journal article
Source: CINAHL
Full text: Available *Wiley* at Cochrane Library, The

Title: Use of quality information in decision-making about health and social care services - a systematic review.
Citation: Health & Social Care in the Community, 01 July 2015, vol./is. 23/4(349-361), 09660410
Author(s): Turnpenny, Agnes, Beadle-Brown, Julie
Language: English
Abstract: User choice and personalisation have been at the centre of health and social care policies in many countries. Exercising choice can be especially challenging for people with long-term conditions (LTC) or disabilities. Information about the quality, cost and availability of services is central to user choice. This study used systematic review methods to synthesise evidence in three main areas: (i) how people with LTC or disabilities and their family carers find and access information about the quality of services; (ii) how quality information is used in decision-making; and (iii) what type of quality information is most useful. Quality information was defined broadly and could include formal quality reports (e.g. inspection reports, report cards, etc.), information about the characteristics of a service or provider (e.g. number and qualifications of staff, facilities, etc.) and informal reports about quality (e.g. personal experience, etc.). Literature searches were carried out using electronic databases in January 2012. Thirteen papers reporting findings from empirical studies published between 2001 and 2012 were included in the review. The majority of papers (n = 9) had a qualitative design. The analysis highlighted the use of multiple sources of information in decision-making about services and in particular the importance of informal sources and extended social networks in accessing information. There is limited awareness and use of 'official' and online information sources. Service users or family carers place greater emphasis on general information and structural indicators. Clinical or quality-of-life outcomes are often difficult to interpret and apply. Trust emerged a key issue in relation to quality information. Experiential and subjective information is highly valued and trusted. Various barriers to the effective use of quality information in making choices about services are identified. Implications for policy and future research are discussed.
Publication type: journal article
Source: CINAHL

Title: The clinical effectiveness and cost-effectiveness of second-eye cataract surgery: a systematic review and economic evaluation.
Citation: Health Technology Assessment, 01 January 2014, vol./is. 18/68(1-206), 13665278
Author(s): Frampton, Geoff, Harris, Petra, Cooper, Keith, Lotery, Andrew, Shepherd, Jonathan
Language: English
Abstract: BACKGROUND: Elective cataract surgery is the most commonly performed surgical procedure in the NHS. In bilateral cataracts, the eye with greatest vision impairment from cataract is operated on first. First-eye surgery can improve vision and quality of life. However, it is unclear whether or not cataract surgery on the second eye provides

enough incremental benefit to be considered clinically effective and cost-effective. **OBJECTIVE:** To conduct a systematic review of clinical effectiveness and analysis of cost-effectiveness of second-eye cataract surgery in England and Wales, based on an economic model informed by systematic reviews of cost-effectiveness and quality of life. **DATA SOURCES:** Twelve electronic bibliographic databases, including MEDLINE, EMBASE, Web of Science, The Cochrane Library and the Centre for Reviews and Dissemination databases were searched from database inception to April 2013, with searches updated in July 2013. Reference lists of relevant publications were also checked and experts consulted. **REVIEW METHODS:** Two reviewers independently screened references, extracted and checked data from the included studies and appraised their risk of bias. Based on the review of cost-effectiveness, a de novo economic model was developed to estimate the cost-effectiveness of second-eye surgery in bilateral cataract patients. The model is based on changes in quality of life following second-eye surgery and includes post-surgical complications. **RESULTS:** Three randomised controlled trials (RCTs) of clinical effectiveness, three studies of cost-effectiveness and 10 studies of health-related quality of life (HRQoL) met the inclusion criteria for the systematic reviews and, where possible, were used to inform the economic analysis. Heterogeneity of studies precluded meta-analyses, and instead data were synthesised narratively. The RCTs assessed visual acuity, contrast sensitivity, stereopsis and several measures of HRQoL. Improvements in binocular visual acuity and contrast sensitivity were small and unlikely to be of clinical significance, but stereopsis was improved to a clinically meaningful extent following second-eye surgery. Studies did not provide evidence that second-eye surgery significantly affected HRQoL, apart from an improvement in the mental health component of HRQoL in one RCT. In the model, second-eye surgery generated 0.68 incremental quality-adjusted life-years with an incremental cost-effectiveness ratio of £1964. Model results were most sensitive to changes in the utility gain associated with second-eye surgery, but otherwise robust to changes in parameter values. The probability that second-eye surgery is cost-effective at willingness-to-pay thresholds of £10,000 and £20,000 is 100%. **LIMITATIONS:** Clinical effectiveness studies were all conducted more than 9 years ago. Patients had good vision pre surgery which may not represent all patients eligible for second-eye surgery. For some vision-related patient-reported outcomes and HRQoL measures, thresholds for determining important clinical effects are either unclear or have not been determined. **CONCLUSIONS:** Second-eye cataract surgery is generally cost-effective based on the best available data and under most assumptions. However, more up-to-date data are needed. A well-conducted RCT that reflects current populations and enables the estimation of health state utility values would be appropriate. Guidance is required on which vision-related, patient-reported outcomes are suitable for assessing effects of cataract surgery in the NHS and how these measures should be interpreted clinically. STUDY REGISTRATION: This project is registered as PROSPERO CRD42013004211. FUNDING: This project was funded by the National Institute for Health Research Health Technology Assessment programme.
Publication type: journal article
Source: CINAHL

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Journal Articles (in date order – most recent first)

Title: Care provision for poststroke visual impairment.
Citation: Journal of stroke and cerebrovascular diseases: the official journal of National Stroke Association, Jun 2015, vol. 24, no. 6, p. 1131-1144 (June 2015)
Author(s): Rowe, Fiona J, Walker, Marion, Rockliffe, Janet, Pollock, Alex, Noonan, Carmel, Howard, Claire, Glendinning, Richard, Feechan, Rachel, Currie, Jim
Abstract: We sought to explore the care provision for poststroke visual impairment and variations in this in the United Kingdom. Survey questions were developed and piloted with clinicians, academics, and users. Questions addressed types of visual problems; how these were identified, treated, and followed up; care pathways in use; links with other professions; and referral options. The survey was accessed via a Weblink, which was circulated through UK professional organizations to multiprofessional members of ophthalmic and stroke teams. A total of 548 completed electronic surveys were obtained. In all, 49.5% of respondents represented stroke teams, 42.5% eye teams, and 8% from other teams, for example, emergency care. Many respondents (41%) saw patients within 1 week of stroke. Nineteen percent did not personally test vision: 11% had a visiting clinician to test vision, and 22% used screening tools. Validated tests were used for the assessment of visual acuity (39.5%), visual field (57.5%), eye movement (48.5%), and visual function (58.5%). Visual problems suspected by family or professionals were high (88.5%). Typical overall follow-up period of vision care was less than 3 months. In all, 46% of respondents used designated care pathways for stroke survivors with visual problems; 33.5% of respondents did not provide visual information leaflets. Significant inequality exists in care for stroke survivors who experience visual problems. There is great variability in how vision screening is undertaken, which vision tests are used, methods of referral to eye care

services, how visual problems are managed, and what vision information is provided to stroke survivors/carers. Further work is required to ensure equality and effective care: Copyright © 2015 National Stroke Association.
Source: Medline

Title: Disabled people, choices and collective organisation: examining the potential of cooperatives in future social support.
Citation: Disability & Society, 01 July 2015, vol./is. 30/6(849-864), 09687599
Author(s): Roulstone, Alan, Hwang, Se Kwang
Abstract: Major shifts in funding, demography, personal expectations and the rise of a global disabled people's movement require new and creative solutions to the choices and rights agenda into the twenty-first century. Direct payments and the individual employment of personal assistants is one clear and recognised path to independent living. However, there have been some reservations about the nature, process and impact of the broader personalisation agenda more generally within which direct payments and personal budgets are located. Some commentators point to the loss of the collective impulse in personalised approaches – ideas that were central to the development of the independent living movement and its founding principles. Some countries have seen the rise of collective responses to direct payment developments. This is explicable in terms of a suspicion of individualist underpinnings of personalisation coupled with a collective vision of social life. This article is based on an exploratory study of collective approaches in the field of direct payments where choice and social solidarity are being combined. Drawing on developments in Sweden, England and Wales, the article aims to inform possible future debates about direct payments and cooperative approaches and argues that greater user-control is not inimical to enhanced collective action.
Publication type: journal article
Source: CINAHL

Title: Finding your own way around: experiences of health and social care provision for people with a visual impairment in the United Kingdom
Citation: British Journal of Visual Impairment, 33(3), 2015, pp.200-211
Author(s): Hodge Suzanne, et al
Abstract: The systems of support for people with a visual impairment in the United Kingdom are complex and can be difficult to access, involving input from a range of health and social care services. This article reports on qualitative findings from research looking at people's experiences of accessing health and social care services. These highlight the inconsistencies and variability in existing systems of support for people with a visual impairment, and show that access to services is largely dependent on the agency and initiative of individual service users in establishing networks of support for themselves. This means that those who are less able to do this may find themselves without the support necessary to maintain or improve their quality of life. It is argued that health and social care agencies need to be more proactive in addressing the support needs of people with a visual impairment beyond the point of initial diagnosis or registration.
Source: Social Care Online

Title: Hearing problems in the learning disability population: is anybody listening?
Citation: British Journal of Learning Disabilities 2015, vol. /is. 43/3(153-160), 13544187
Author(s): McClimens, Alex, Brennan, Siobhan, Hargreaves, Pauline
Abstract: People with learning disability tend to have more hearing problems than other people, often these hearing problems are not picked up by doctors, nurses, carers or even by the people themselves. Living with undetected hearing loss means people miss out on information, social opportunities and entertainment. Routine screening for hearing loss would improve the lives of many people with learning disability. We undertook this project because we believed that hearing loss experienced by the target population was greater than the referral figures suggested. Therefore, we set up a trial service initiative designed to examine the efficacy of different referral routes into audiology services for adults with learning disability. This retrospective analysis focuses on the generation of data on hearing loss on a small population sample (n = 136) gathered over a 6-month period in 2012. We suggest remedial action now to prevent more problems in the future.
Publication type: Academic Journal
Source: CINAHL

Title: Social and community participation following spinal cord injury: a critical review.
Citation: International Journal of Rehabilitation Research, 01 March 2015, vol./is. 38/1(1-19), 03425282

Author(s): Barclay, Linda, McDonald, Rachael, Lentin, Primrose
Language: English
Abstract: Evaluation of rehabilitation outcomes following acquired disability should include participation in social and community life. Evidence is needed to guide clinical practice to ensure that it is client-centered; therefore, findings from studies that report on social and community participation following spinal cord injury (SCI) need to be reviewed and synthesized. The objectives of this critical literature review are to examine the available evidence on social and community participation following SCI and to examine the factors that influence that participation. The barriers and facilitators will be identified and described in terms of the contextual factors – personal or environmental, as outlined by the International Classification of Functioning, Disability and Health. An additional objective is to appraise the quality of the evidence examined. A systematic literature search was completed in the databases OVID MEDLINE, AMED, CINAHL PLUS, PSYCHINFO, and hand searches were carried out. Quantitative, qualitative, and mixed methods studies were included. Twenty-three studies fulfilled the inclusion criteria: 17 quantitative, five qualitative, and one mixed methods. In general, studies were of low methodological quality, and no intervention studies were identified. The terms participation, social participation, and community participation were used interchangeably often without clarification of meaning. Adequate personal care assistance, appropriate social support, having adequate specialized equipment, and appropriate occupational therapy input were found to facilitate social and community participation, whereas problems with transport, inaccessibility of the natural and built environment, issues with healthcare services and rehabilitation providers, and pain were identified as barriers. In-depth investigation into what aspects of social and community participation are important to those living with SCI is needed so that client-focused solutions and interventions can be identified and developed, aimed at creating and promoting opportunities for social and community participation.
Publication type: journal article
Source: CINAHL

Title: Good practice in social care for disabled adults and older people with severe and complex needs: evidence from a scoping review.
Citation: Health & Social Care in the Community, 01 May 2014, vol./is. 22/3(234-248), 09660410
Author(s): Gridley, Kate, Brooks, Jenni, Glendinning, Caroline
Language: English
Abstract: This article reports findings from a scoping review of the literature on good practice in social care for disabled adults and older people with severe and complex needs. Scoping reviews differ from systematic reviews, in that they aim to rapidly map relevant literature across an area of interest. This review formed part of a larger study to identify social care service models with characteristics desired by people with severe and complex needs and scope the evidence of effectiveness. Systematic database searches were conducted for literature published between January 1997 and February 2011 on good practice in UK social care services for three exemplar groups: young adults with life-limiting conditions; adults who had suffered a brain injury or spinal injury and had severe or complex needs; and older people with dementia and complex needs. Five thousand and ninety-eight potentially relevant records were identified through electronic searching and 51 by hand. Eighty-six papers were selected for inclusion, from which 29 studies of specific services were identified. However, only four of these evaluated a service model against a comparison group and only six reported any evidence of costs. Thirty-five papers advocated person-centred support for people with complex needs, but no well-supported evaluation evidence was found in favour of any particular approach to delivering this. The strongest evaluation evidence indicated the effectiveness of a multidisciplinary specialist team for young adults; intensive case management for older people with advanced dementia; a specialist social worker with a budget for domiciliary care working with psycho-geriatric inpatients; and interprofessional training for community mental health professionals. The dearth of robust evaluation evidence identified through this review points to an urgent need for more rigorous evaluation of models of social care for disabled adults and older people with severe and complex needs.
Publication type: journal article
Source: CINAHL
Full text: Available *EBSCOhost* at Health & Social Care in the Community

Title: Improving access to optometry services for people at risk of preventable sight loss: a qualitative study in five UK locations.
Citation: Journal of Public Health, 01 December 2014, vol./is. 36/4(667-673), 17413842
Author(s): Leamon, S., Hayden, C., Lee, H., Trudinger, D., Appelbee, E., Hurrell, D.-L., Richardson, I.
Language: English

Abstract: Background: Reducing preventable sight loss is an increasing priority for public health and health care providers. We examined the factors affecting people's use of optometry services in population groups at increased risk of sight loss. **Methods** This is a qualitative study in five UK locations. In England, participants were from the Pakistani and Black Caribbean communities; in Scotland from the Pakistani community; and in Northern Ireland and Wales from white socio-economically deprived communities. Thirty-four focus groups were conducted (*n* = 289). The study included people who attend optometry services and people not engaged with services. **Results:** Barriers to access included limited awareness of eye health and eye disease, concern about the cost of spectacles and the appropriateness of optometry in a commercial setting. Attendance at the optometrist was primarily symptom led. A positive previous experience or continuing relationship with the optometrist helped to alleviate the barriers and promote attendance. **Conclusion** Addressing the disparity between the broader messages about eye health and the current perception of the function of optometry could help improve access to services. Uptake may be improved through the co-production of interventions that better resonate with local communities. Non-retail service delivery options should be explored.
Publication type: journal article
Source: CINAHL
Full text: Available *Oxford University Press* at Journal of Public Health

Title: Service use and costs for people with long-term neurological conditions in the first year following discharge from in-patient neuro-rehabilitation: a longitudinal cohort study.
Citation: PloS one, Jan 2014, vol. 9, no. 11, p. e113056. (2014)
Author(s): Jackson, Diana, McCrone, Paul, Mosweu, Iris, Siegert, Richard, Turner-Stokes, Lynne
Abstract: Knowledge of the configuration and costs of community rehabilitation and support for people with long-term neurological conditions (LTNCs) is needed to inform future service development and resource allocation. In a multicentre prospective cohort study evaluating community service delivery during the year post-discharge from in-patient neuro-rehabilitation, a key objective was to determine service use, costs, and predictors of these costs. Patients consecutively admitted over one year to all nine London specialised (Level 1) in-patient neuro-rehabilitation units were recruited on discharge. They or their carers completed postal/web-based questionnaires at discharge and six and twelve months later, providing demographic data and measures of impairment, disability, service needs and provision. This paper describes health and social care service use, informal care and associated costs. Regression models using non-parametric boot-strapping identified predictors of costs over time. Overall, 152 patients provided consistent data. Mean formal service costs fell significantly from £13,290 (sd £19,369) during the first six months to £9,335 (sd £19,036) from six-twelve months, (t = 2.35, P<0.05), mainly due to declining health service use. At six months, informal care was received on average for 8.2 hours/day, mean cost £14,615 (sd 23,305), comprising 52% of overall care costs. By twelve months, it had increased to 8.8 hours per day, mean cost £15,468 (sd £25,534), accounting for 62% of overall care costs. Being younger and more disabled predicted higher formal care costs, explaining 32% and 30% of the variation in costs respectively at six and twelve months. Community services for people with LTNCs carry substantial costs that shift from health to social care over time, increasing the burden on families. Prioritising rehabilitation services towards those in greatest need could limit access to others needing on-going support to promote their independence and reduce their reliance on families. This argues for greater investment in future rehabilitation services.
Source: Medline
Full text: Available *ProQuest* at PLoS ONE

Title: Social prescription and the role of participatory arts programmes for older people with sensory impairments.
Citation: Journal of Integrated Care, 2014, vol./is. 22/2(39-50), 1476-9018
Author(s): Vogelpoel, Nicholas, Jarrold, Kara
Language: English
Abstract: PURPOSE: The purpose of this paper is to describe the benefits of a social prescribing service for older people with sensory impairments experiencing social isolation. The paper draws on the findings from a 12-week programme run by Sense, a voluntary sector organisation, and illustrates how integrated services, combining arts-based participation and voluntary sector support, can create positive health and wellbeing outcomes for older people. **DESIGN/METHODOLOGY/APPROACH:** The research took a mixed-methodological approach, conducting and analysing data from interviews and dynamic observation proformas with facilitators and quantitative psychological wellbeing scores with participants throughout the course of the programme. Observations and case study data were also collected to complement and contextualise the data sets. **FINDINGS:** The research found that participatory arts programmes can help combat social isolation amongst older people with sensory impairments and can offer an

important alliance for social care providers who are required to reach more people under increasing pecuniary pressures. The research also highlights other benefits for health and wellbeing in the group including increased self-confidence, new friendships, increased mental wellbeing and reduced social isolation. **RESEARCH LIMITATIONS/IMPLICATIONS:** The research was based on a sample size of 12 people with sensory impairments and therefore may lack generalisability. However, similar outcomes for people engaging in participatory arts through social prescription are documented elsewhere in the literature. **PRACTICAL IMPLICATIONS:** The paper includes implications for existing health and social care services and argues that delivering more integrated services that combine health and social care pathways with arts provision have the potential to create social and medical health benefits without being care/support resource heavy. **ORIGINALITY/VALUE:** This paper fulfils a need to understand and develop services that are beneficial to older people who become sensory impaired in later life. This cohort is growing and, at present, there are very few services for this community at high risk of social isolation. [Abstract]
Source: HMIC
Full text: Available *ProQuest* at Journal of Integrated Care

Title: Assistive technologies in caring for the oldest old: A review of current practice and future directions
Citation: Aging Health, August 2013, vol./is. 9/4(365-375), 1745-509X;1745-5103 (August 2013)
Author(s): Robinson L., Gibson G., Kingston A., Newton L., Pritchard G., Finch T., Brittain K.
Language: English
Abstract: Our aging populations have led to concern as to whether existing care provision will cope with the predicted future demand. The oldest old (those over 85 years) are a particular challenge; they are the fastest growing sector of our population and have high rates of comorbidity and cognitive impairment. Assistive technologies provide one possible solution to promote independence for older individuals, but are often underutilized in routine care. In this perspective, we consider how assistive technology can support the future care of the oldest old. First, we summarize the evidence on the health of the oldest old and their current use of assistive technology with a review on the evidence to date on the effectiveness, and potential benefits, of assistive technology. We then discuss the ethical issues associated with the use of assistive technology in this population and, finally, identify key directions for future research and service development in this field.
Publication type: Journal: Review
Source: EMBASE
Full text: Available *ProQuest* at Aging Health

Title: Emotional support and counselling for people with visual impairment: Quantitative findings from a mixed methods pilot study.
Citation: Counselling & Psychotherapy Research, 01 December 2012, vol./is. 12/4(294-302), 14733145
Author(s): Barr, Wally, Hodge, Suzanne, Leeven, Martina, Bowen, Louise, Knox, Paul
Language: English
Abstract: Aims: This paper reports on mainly quantitative findings from a mixed methods evaluation of a new model of emotional support and counselling for people with moderate visual impairment. **Method:** The CORE Outcome Measure was completed with service users at baseline and post-intervention to assess the impact of the new service on psychological wellbeing and social functioning. Their perceived needs and expectations of the service were also explored. **Results:** Of the 35 individuals providing data at each assessment time, mean item scores on the CORE fell significantly ($p<.001$), taking the sample from within a clinical population before therapy, to a mean score below this following therapy. A more positive outlook accompanied this improvement in functioning. **Discussion:** Findings from the study augment the growing evidence that emotional support and counselling services can play an important role alongside and within related vision services. Implications for practice: The study indicates that therapeutic input for the visually impaired client group may need to target both wellbeing (feelings about oneself and the future) and problems (depression, anxiety, physical health, and trauma). **Conclusions:** Our findings suggest that a dual model of emotional support and counselling offers considerable benefit for people with visual impairment.
Publication type: journal article
Source: CINAHL
Full text: Available *EBSCOhost* at Counselling & Psychotherapy Research

Title: Improving healthcare access for people with visual impairment and blindness.
Citation: BMJ, 2012, vol./is. 344/7842(42-46), 0959-8154
Author(s): Cupples, M., Hart, P., Johnston, A.

Language: English
Abstract: Visual impairment can have adverse consequences for health and wellbeing, and its prevalence is increasing, especially among older people. People with visual impairment are likely to have limited access to information and healthcare facilities, and to receive sub-optimal treatment because staff are unaware of specific needs related to vision. Being aware that people may have problems with vision is an important pre-requisite for good healthcare. Taking time to communicate effectively about access, facilities, diagnosis, and management plans is necessary; communications, in visual or audio format, should be tailored to individuals' needs. Checking that personal resources are in place to facilitate compliance with treatment plans is essential for good clinical care. [Summary]
Source: HMIC
Full text: Available *Highwire Press* at The BMJ

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User Experience and Quality of Life

Documents

As life goes on - a closer look at how support services respond to the changing needs of people with sight loss
Thomas Pocklington Trust, March 2013
Previous Pocklington-funded research had shown that the support needs of people with sight loss increase over time but that the support available is failing to keep pace. A more detailed follow-up study confirms that the changing needs of people with sight loss are still not being met.

Audiology services and hearing technologies : the experiences of deafblind individuals
Sense; Ear Foundation, January 2014
The views of 37 deafblind adults were collected using questionnaires and interviews. Participants varied in communication preferences, age, and gender, and geographical location, type/severity of deafblindness and use of hearing technology. Recommendations based on the results of this study have been produced relating to: technology self-efficacy, access to information and service provision. It is essential that services and clinicians are aware of these recommendations in order to meet the needs of this ever increasing population.

Better living, higher standards: improving the lives of disabled people by 2020
Scope, April 2014
This report focuses on three areas that need immediate action nationally to improve disabled people's living standards: extra costs faced by disabled people, poor access to the labour market and inadequate social care. Disabled adults spend on average £550 per month specifically on costs related to their disability while they are almost twice as likely to be unemployed as non-disabled people. The evidence shows that too many working age disabled people cannot afford the care and support they need to live independently and take part in community life. The report makes a number of recommendations, including protecting the value of DLA, Personal Independence Payment (PIP) and Attendance Allowance (AA), working with disabled people to develop more personalised, targeted employment support for disabled people to find, stay in and progress in work, and providing the financial resources to allow those eligible for social care to receive all the support they need to live independently in the community.

Disability and minimum living standards: the additional costs of living for people who are sight impaired and people who are Deaf
Loughborough University, Centre for Research in Social Policy, January 2015
This report presents key findings of research into the additional amount that it costs people who are sight impaired and people who are Deaf to reach a minimum acceptable standard of living. The study asked three groups of people who were sight impaired and three groups of people who were Deaf, each to reflect on the additional things that households with impairments similar to their own would require in order to reach a minimum standard of living. Needs were specified for an imaginary 'case study' person, of working age, living alone with a particular type of disability. The main categories incurring extra costs included: technological equipment; domestic help; additional travel costs; additional costs of socialising and going on holiday; additional costs of household goods (eg lighting, type of flooring); additional health care costs; electricity; and interpretation. Overall, additional costs for a person who is sight impaired added £50.49 came on a £198.60 minimum household budget for a single person, with a

quarter of the additions coming from technology, a quarter from domestic help, and the rest spread across the other categories. Additional costs for a single person with a hearing impairment came to £163.03, with over three quarters of the additions coming from interpreters and most of the remainder from social activities. The study demonstrates how living with a disability can bring additional costs, but these can vary depending on the personal assistance or services that someone requires. It also demonstrates the scope for doing similar research with people who have different types of impairment or disability.

Associated documentation:

- Additional costs of living for people who are deaf: research findings
- Additional costs of living for people who are sight impaired: research findings

Fluctuating needs: the Care Act 2014 (Video)

Social Care Institute for Excellence (SCIE), 2015

Under the Care Act 2014, assessments should reflect more accurately a comprehensive picture of people's needs - including how they change over time. In this film two people, one with mental health needs, the other with a physical disability, talk about their conditions, assessment, how their needs can fluctuate and the impact this has on the level of care and support they need: Running time: 6 minutes 56 seconds.

Housing and independent living: four scoping studies

Thomas Pocklington Trust, March 2015

This scoping research into the housing circumstances, experiences and aspirations of younger adults with sight loss (aged 16-44) consisted of four studies. The findings from the interviews and focus groups highlight the views of participants on the aspects of their homes which influence independence and wellbeing, as well as the obstacles encountered in trying to achieve the right housing and support. The four studies are listed below:

- Research Report 1 - Housing and independent living: views and experiences of younger adults (aged 16-44) with sight loss
- Research Report 2 - Housing and independent living: needs and aspirations of younger adults (aged 16-44) with sight loss
- Research Report 3 - Housing and independent living: understanding the policy and funding climate
- Research Report 4 - Housing and independent living: reviewing housing advice and information resources

The research also looked at the policy context, the variety of advice and information available and the potential to create and develop an improved range of housing opportunities.

Myth buster: independent living

European Network on Independent Living, December 2014

This document addresses some of the most common misconceptions about disabled people, independent living and personal assistance. They have been selected by staff and members of the European Network on Independent Living, based on their lived experience, and have been inspired by the organisation's work with policy and decision makers at the European, national and local level. This publication is intended to contribute to a better understanding of the right to live independently in the community, as set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities. Key themes include: being self-sufficient, the role of institutions, access to and quality of support, isolation and loneliness, financial implications of independent living, and personal assistants.

Personal Health Budget Holders and Family Carers: the POET Surveys 2015

In Control; Lancaster University; Think Local Act Personal, September 2015

The purpose of the Personal Outcomes Evaluation Tool (POET) survey 2015 for Personal Health Budget Holders and Family Carers is to provide insight into the experiences of personal health budget holders and their families. The survey also shows the impact having control over the budget has on their lives. The findings of POET can be used by NHS and local authorities to assess the effectiveness of their delivery methods and to identify priorities for improving the process. Altogether, 302 personal health budget holders from 31 different areas across the country and 247 carers from 37 different areas completed the survey.

Personal Social Services Adult Social Care Survey, England - 2014-15

Health and Social Care Information Centre (HSCIC), October 2015

The Personal Social Services Adult Social Care Survey (ASCS) is an annual survey for England that took place for the fifth time in 2014-15. The survey covers all service users aged 18 and over in receipt, at the point that data are extracted, of long-term support services funded or managed by the social services following a full assessment of need. It seeks to learn more about how effectively services are helping service users to live safely and independently in their own homes, and the impact that these services have on their quality of life. Service users were sent questionnaires, issued by Councils with Adult Social Services Responsibilities (CASSRs), in the period January to March 2015. Further information about the survey, including the methodology, can be found here.

Physical activity among older people with sight loss: a qualitative research study to inform policy and practice

University of Loughborough, June 2014

This is a report of a research study aimed at increasing the knowledge and understanding of physical activity among older people with sight loss. The report explores individual experiences of physical activity among older people (60+ years of age) who have acquired sight loss later in life; identifies the ways in which visually impaired older people's participation in physical activity can be facilitated and/or prevented; provides an evidence base with examples of good practice, which can be used to inform policy and practice regarding the promotion of physical activity among older people with sight loss; examines the value of novel and imaginative qualitative research methods to understand these issues in more complete and nuanced ways; and establishes areas for future research that will develop knowledge and improve commercial enterprise and service delivery in this area.

Removing barriers, raising disabled people's living standards

Office for Public Management; Ipsos Mori, May 2014

This report presents the findings from research which aimed to understand disabled people's priority for change. The research involved in-depth qualitative research (including 10 focus groups and 30 one-to-one interviews with disabled people) and quantitative surveys (including an online survey of 1,674 disabled people and a face-to-face survey with 371 disabled people). The survey highlights different experiences and perceptions, both amongst the disabled population as a whole and amongst specific groups. The research findings are discussed in the following areas: attitudes in health and social care; financial wellbeing; employment and education; leisure, social connections and living independently, and public attitudes.

Review of adult social care complaints 2013

Local Government Ombudsman Social Care, May 2014

This report covers the adult social care complaints that we have considered during the 2013 calendar year. What constitutes adult social care is often the subject of debate, especially as the boundaries with healthcare become less defined. This report focuses upon complaints about services provided for adults who need extra support. This includes: older people; people with learning disabilities; people with a physical disability; people with a sensory impairment; people with mental ill health; and carers. The report considers complaints about all types of registered social care providers regardless of whether care is delivered by a local authority, commissioned by a council or privately funded.

Satisfaction with social care services among black and ethnic minority populations: exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people

National Centre for Social Research, December 2014

This study aimed to understand why people from black and minority ethnic groups consistently reported lower levels of satisfaction with social care provision than white British people (as reported in the Adult Social Care Surveys).

Additional links:

- Cognitive interviewing phase report
- Appendices to Cognitive interviewing phase report
- Literature review

A systematic review and metaethnography to identify how effective, cost-effective, accessible and acceptable self-management support interventions are for men with long-term conditions (SELF-MAN)

National Institute for Health Research (NIHR), August 2015

The number of people living with a long-term condition (LTC), such as diabetes, heart failure or arthritis, is set to grow rapidly over the coming years. There are a number of different types of support that can help individuals to 'self-manage' their LTC better and live a better quality of life. However, men appear to underuse health-care services, and we currently do not know what types of self-management support are most effective and appealing to

men living with LTCs. This project reviewed the current research evidence to see if certain types of self-management support are more appealing to, and work better in, men with LTCs. 40 studies of self-management support across varied LTCs were examined to see how effective different types of support service were in men compared with women. In addition, 38 studies of men's experiences of self-management support were also examined to see if there were any key themes or common patterns in the evidence. There were no consistent findings that certain types of self-management support work better or worse in men than in women, but this review found that support that involved physical activity, education or peer support may work well at improving men's quality of life. The paper concludes that men may find self-management support more appealing if it has a clear purpose, involves activity and offers practical strategies that can be integrated into daily life. Further research is needed to identify the important factors that make self-management support services effective and attractive to men with LTCs.

Taking on and taking over: choice and control for physically disabled young adults
NIHR School for Social Care Research, 2015
This document summarises the findings of a study on approaches to supporting physically disabled young adults to achieve their preferred levels of control over care and support arrangements. The study took place between July 2012 and January 2014 and involved semi-structured interviews with young adults, parents and social care professionals. It examined physically disabled young adults experiences of managing their care and support arrangements and explored how they can be better supported. Key findings and practice implications are included. A video about the research findings is also available.

Vital signs: taking the temperature of health and care services for people living with long term conditions
Richmond Group of Charities, March 2015
The report brings together the data the Richmond Group of Charities individually hold about how their beneficiaries, the 15 million people in England with long term conditions, experience their use of the NHS. It focuses on five themes: coordinated care; patients engaged in decisions about their care; supported self-management; prevention, early diagnosis and intervention; and emotional, psychological and practical support. It shows that there are some significant gaps in the provision of care which lead to many preventable problems.

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Journal Articles (in date order – most recent first)

Title: Preventing sight loss in older people: a qualitative study exploring barriers to the uptake of regular sight tests of older people living in socially deprived communities in South Wales.
Citation: Public Health, 2015, vol./is. 129/2(110-116), 0033-3506
Author(s): Biddyr, S., Jones, A.
Language: English
Abstract: OBJECTIVES: This paper describes research findings that try to understand some of the reasons that prevent older people in deprived communities in South Wales from accessing NHS funded sight tests and leads to a discussion of suitable interventions that seek to improve access to primary eye care services and prevent avoidable sight loss. **STUDY DESIGN**: Data were collected from eight focus groups (n = 63) of mixed gender and ages (60-80+ years), of white origin living in deprived communities in South Wales. Individuals were recruited for the focus groups by extensively publicizing the project, with a range of health and older people's community services and groups such as sheltered housing complexes, stroke support groups and coffee morning groups. The study included people who attended optometry services and people not engaged with services. A purposive sampling technique summarizes the sampling approach taken, an approach which the team utilized to recruit 'information rich' cases, namely individuals, groups and organizations that provided the greatest insight into the research question. **METHODS:** Focus groups were recorded and transcribed verbatim. Data underwent thematic content analysis and subsequent interpretations were corroborated by expert advisors and a project steering group. **RESULTS:** Cost was perceived as a significant barrier to accessing sight tests, particularly in relation to purchasing glasses. Other barriers included the perceived pressure to buy glasses associated with visits to the optometrists; poor understanding of the purpose of a sight test in a health prevention context and acceptance of deteriorating sight loss due to the ageing process. **CONCLUSION:** Areas of improvement for the delivery of preventative eye health services to older people are identified, as are areas for reflection on the part of those who work within the eye health industry. [Abstract]
Source: HMIC
Title: What outcomes are important to people with long-term neurological conditions using integrated health and social care?

Citation: Health & social care in the community, Sep 2015, vol. 23, no. 5, p. 559-568 (September 2015)
Author(s): Spiers, Gemma, Aspinal, Fiona, Bernard, Sylvia, Parker, Gillian
Abstract: Measuring the outcomes that are meaningful to people with long-term neurological conditions (LTNCs) using integrated health and social care services may help to assess the effectiveness of integration. Conventional outcomes tend not to be derived from service user experiences, nor are they able to demonstrate the impact of integrated working. This paper reports findings about outcomes identified as being important to people with LTNCs using integrated services. We undertook qualitative work with five community neuro-rehabilitation teams that were integrated in different ways and to different degrees. In-depth, semi-structured interviews were conducted with 35 people with LTNCs using these teams. Data were collected between 2010 and 2011 and analysed using an adapted version of the Framework approach. We identified 20 outcomes across three domains: personal comfort outcomes, social and economic participation outcomes, and autonomy outcomes. Inter-relationships between outcomes, both within and across domains, were evident. The outcomes, and the inter-relationships between them, have implications for how individuals are assessed in practice. © 2014 John Wiley & Sons Ltd.
Source: Medline

Title: How do adults with physical disability experience primary care? A nationwide cross-sectional survey of access among patients in England.
Citation: BMJ open, Jan 2014, vol. 4, no. 8, p. e004714. (2014)
Author(s): Popplewell, Nicola T A, Rechel, Boika P D, Abel, Gary A
Abstract: Almost a quarter of adults in England report a longstanding condition limiting physical activities. However, recent overseas evidence suggests poorer access to healthcare for disabled people. This study aimed to compare patient-reported access to English primary care for adults with and without physical disability. Secondary analysis of the 2010/11 General Practice Patient Survey (response rate 35.9%) using logistic regression. 1,780,977 patients, from 8384 English general practices, who provided information on longstanding conditions limiting basic physical activity. 41,389 of these patients reported unmet need to see a doctor in the previous 6 months: difficulty getting to the general practitioner (GP) surgery as a reason for unmet need to see a doctor in the preceding 6 months; difficulty getting into the surgery building. Estimated prevalence of physical disability was 17.2% (95% CI 17.0% to 17.3%). 17.9% (95% CI 17.4% to 18.4%) of patients with an unmet need to see a doctor were estimated to experience this due to difficulty getting to the surgery, and 2.2% (95% CI 2.2% to 2.3%) of all patients registered with a GP were estimated to experience difficulty getting into surgery buildings. Adjusting for gender, age, health status and employment, difficulty getting to the surgery explaining unmet need was more likely for patients with physical disability than for those without. Similarly, difficulty getting into surgery buildings was more likely among physically disabled patients. Both associations were stronger among patients aged 65-84 years. Adults in England with physical disability experience worse physical access into primary care buildings than those without. Physical disability is also associated with increased unmet healthcare need due to difficulty getting to GP premises, compared with the experience of adults without physical disability. Increasing age further exacerbates these problems. Access to primary care in England for patients with physical disability needs improving.
Source: Medline
Full text: Available *Highwire Press* at BMJ Open

Title: Older people's views on what they need to successfully adjust to life with a hearing aid.
Citation: Health and Social Care in the Community,, 2013, vol./is. 21/, 0966-0410 (May 2013)
Author(s): Kelly, Timothy B.
Language: English
Abstract: This article reports a study exploring what older people believe would enable them to adjust to and gain maximum benefit from wearing a hearing aid. A mixed methods approach was employed during 2006 involving interviews with key stakeholders, a survey across three Scottish health board areas and focus groups. Nine key stakeholders from six national and local organisations were interviewed about the needs of older people being fitted with hearing aids. In total, 240 older people belonging to three different types of hearing impaired older people were surveyed: long-term users of hearing aids, new hearing aid users, and those on a waiting list from urban and rural areas (response rate = 24%). A series of eight follow-up focus groups with 31 audiology patients was held. Health professionals appeared to neglect appropriate provision of information and overly rely on technological interventions. Of 154 older people already fitted with hearing aids, only 52% of hearing aid users reported receiving enough practical help post fitting and only 41% reported receiving enough support. Approximately 40% reported not feeling confident in the use of their aids or their controls. Older people wanted more information than they received both before and after hearing aid fitting. Information provision and attention to the psychosocial aspects of care are

key to enabling older people to adjust and optimise hearing aid benefit.
Publication type: Article
Source: HMIC
Full text: Available *EBSCOhost* at Health & Social Care in the Community

Title: Emotional well-being and adjustment to vision loss in later life: a meta-synthesis.
Citation: Disability and Rehabilitation,, 2012, vol./is. 34/12, 0963-8288 (2012)
Author(s): Nyman, Samuel Robert.
Language: English
Abstract: The purpose of the study was to review perceived emotional wellbeing in older people with visual impairment and perceived factors that inhibit/facilitate psychosocial adjustment to vision loss. The databases of MEDLINE, EMBASE, PsycINFO and CINAHL were searched for studies published from January 1980 to December 2010, which recruited older people with irreversible vision loss, and used qualitative methods for both data collection and analysis. Results sections of the papers were synthesised using a thematic-style analysis to identify the emergent and dominant themes. The results were, 17 qualitative papers were included in the review, and five main themes emerged from the synthesis: 1) the trauma of an ophthalmic diagnosis, 2) impact of vision loss on daily life, 3) negative impact of visual impairment on psychosocial wellbeing, 4) factors that inhibit social well-being, 5) factors that facilitate psychological wellbeing. The authors found the response shift model useful for explaining their synthesis. The conclusions were, acquired visual impairment can have a significant impact on older people's wellbeing and make psychosocial adjustment to the condition a major challenge. Acceptance of the condition and a positive attitude facilitate successful psychosocial adjustment to vision loss as well as social support from family, friends and peers who have successfully adjusted to the condition. [Journal abstract]
Publication type: Article
Source: HMIC

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|Knowledge Resources|

Nottingham City Council

Literature Search Enquiry Form

Name: Louise Noon

Organisation: Early Intervention Directorate, Nottingham City Council

Date requested: 25/06/2015
Date Completed: 19/10/2015

Time taken: 22 hours

Information needed by:

Details of Enquiry: **JSNA Adult Physical and Sensory Impairment**

MeSH Headings Thesaurus terms used in Medline, CINAHL, BNI, HMIC , EMBASE	**Keywords** Keywords used in Medline, CINAHL, BNI, HMIC, EMBASE
DISABLED PERSONS DISABILITIES ENGLAND UNITED KINGDOM GREAT BRITAIN ADULT ADULTS HEALTH SERVICES PREVALENCE HEALTH POLICY PHYSICAL DISABILITIES SENSORY IMPAIRMENT CHRONIC DISEASE AND/OR CHRONIC ILLNESS CHRONIC DISEASE LONG TERM CARE DEAF-BLIND DISORDERS BLINDNESS HEARING DISORDERS SYSTEMATIC REVIEW COSTS AND COST ANALYSIS SELF CARE SOCIAL WORK REHABILITATION QUALITY OF LIFE	"visual impairment" "physical disabili*" "social care*" "long-term conditions" ("social care" AND "physical disability") "sensory impairment*" Deafblindness ("hearing problems" AND disability) (prevalence AND disability) "acquired disability*" "independent living*"

Resources

Databases	Searched
Medline	✓
CINAHL	✓
EMBASE	✓
PsycINFO	
HMIC	✓
Health Business Elite	
AMED	
BNI	✓
Core Websites	
NICE Evidence Services	✓
Cochrane Library	✓
Local Government Association	✓
Department of Health	✓
Department for Education	
Department for Communities and Local Government	✓
Primary Care Commissioning	
Kings Fund	✓
Nuffield Trust	✓
Joseph Rowntree Foundation	
Social Care Online	✓
Institute of Public Care (IPC) Oxford Brookes University	✓
Royal Society for Public Health (RSPH)	✓
PubMed	✓
National Institute for Health Research (NIHR)	✓
NHS Improving Quality	✓
NHS England	✓
CRD – Centre for Reviews and Dissemination	✓
Public Health England	✓
Health and Social Care Information Centre (HSCIC)	✓
National Child and Maternal Health Intelligence Network	
Quality and Outcomes of Person-Centred Care Policy Research Unit (QORU)	✓
House of Commons Research Briefings	✓
Other Websites	
PEDro – Physiotherapy Evidence Database	
Office for National Statistics	✓
Mental Health Foundation	
Centre for Mental Health	
NHS Confederation	✓
Mental Health Network NHS Confederation	
Royal College of Psychiatrists	
Google	✓
Rethink Mental Illness	
The Health Foundation	✓
Think Local, Act Personal	✓
National Audit Office	✓
National Voices	✓
Right Care	
Policy Innovation Research Unit	✓

UK Health Forum	✓
Understanding Society: UK Household Longtitudinal Study	
Centre for Social Justice	✓
Action on Hearing Loss	✓
Scope	✓
Sense	✓
Royal National Institute of Blind People (RNIB)	✓
Thomas Pocklington Trust	✓
English Longitudinal Study of Ageing (ELSA)	✓