Enabling Health

Appendix 2: Data extraction tables



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ACCESS TO ECONOMIC RESOURCES — EMPLOYMENT

Population studied/ participants	Reference	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Systematic literature review – 14 papers	Blank et al. 2008	Literature review: why people with disability (episodic mental health) don't return to work.	Literature review	Studies had opposing results.	Further research is needed in this area.	• Systematic review. • Peer reviewed.
Cochrane Review	Crowther et al. 2010	Systematic review of vocational rehabilitation for people with severe mental illness.	Systematic review - Cochrane Review guidelines.	People in supported employment were significantly more likely to be in competitive employment than those who received prevocational training (at 12 months: 34% employed in supported employment compared with 12% in prevocational training).	Both prevocational and supported employment training improves outcomes for people with psychiatric disabilities. Supported employment is the most effective in terms of outcomes.	Systematic Cochrane Review.
People with intellectual disability, policy and legislative initiatives (Australia)	Dempsey & Ford 2009	Opinion/commentary, review of legislation, programs etc. related to employment of people with intellectual disability.	Review of demographics, outcomes etc. comparison to UK.	Placements under the department of employment and workplace very small – less than 6% made for people with disability. In 2003–4, 68 370 disabled supported in government-funded employment services. In 2003–4, government spent \$301 million on disability employment services. Most people in government-funded employment were permanent part time (43%). Supported employment had 39% full time. Most people with intellectual disability earned \$100 or less per week, compared to \$725 per week in 2003 for Australians without intellectual disability. In the UK in 2002, there were 969 government-supported projects on employment for people with disability and 399 focused on people with intellectual disability. Lack of cooperation among various agencies in the UK.	 Legislative and policy changes made positive impacts. Australian legislation increased employment for people with disabilities with more than 7000 government-funded employment services helping 68 000 people. However, this is still a small fraction of people with disabilities. Disability reform package and Disability Discrimination Act 1992 have reduced discrimination in employment. Lack of outcome-focused approach and measurable indicators of success or evaluation of employment services in meeting needs of people with intellectual disability. 	Comparison and commentary article – using secondary sources.

Population studied/ participants	Reference	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Interviews with 10 people with disabilities: eight current recipients of the Disability Support Pension (DSP), and two former recipients of the DSP (Melbourne)	Humpage 2007	Personal experiences of the DSP and the welfare system recorded, and used to inform commentary on mutual obligation and models of disability/welfare in Victoria.	Qualitative interviews and analysis of current welfare reforms and disability legislation compared to models for understanding disability.	Parallels between medical model of disability and current 'reforms' in disability section, especially regarding mutual obligation and the DSP. Contradictions in policy between welfare reform and disability legislation identified.	Mutual obligation reinforces medical model of disability – framing people with disabilities as conditional citizens, while ignoring entitlement to inclusion.	Small sample size informs commentary on reforms and models for understanding disability.
Physical disability. 3076 participants drawn from a national survey in the US.	Ipsen 2006	Employment for people with physical disabilities.	Quantitative. Stratified sampling. Binary regression model, data from the behavioural risk surveillance system used to explore relationship between employment and health behaviours. Discussion used extensive literature review to support tentative outcomes of quantitative results.	 Employment outcomes were better for younger, more educated and married people. Severity of disability impacted on employment. Physical exercise increased employment by 8.4%. Community health care and intervention programs improve wellbeing and health and quality of life for program participants. 	Targeted programming could reduce barriers and improve employment outcomes for people with physical disabilities, e.g. by proving transport assistance to participants, modified curricula, modified exercises and equipment. Access to health promotion programs begins the link between access and employment outcomes for people with disabilities.	Peer reviewed article. Used extensive literature review to support tentative outcomes of quantitative results. Used to support gaps in research section only.
People with intellectual disability in open or closed employment setting	Kober & Eggleton 2005	Assessment of quality of life compared to type of employment and functional capacity	117 people with intellectual disability in open or sheltered (closed) employment were interviewed. Quality of life assessed using QoL questionnaire. Functional work ability assessed using Functional Assessment Inventory.	People with intellectual disability with higher functional capacity experience a higher quality of life when in open employment. Caution to interpreting results: quality of life between open and closed settings could also be explained by income disparity.	Open employment – has two advantages: higher quality of life and higher wages.	Peer-reviewed article. High quality due to large sample size and use of validated tools.

Population studied/ participants	Reference	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with disability. Best practices (Georgia Department of Labour, US)	Smits 2004	Employment: disability policy and 'best practice' post-ADA 1990.	Quantitative and qualitative methods. Best practices reviewed national programmatic statistical data by the Rehabilitation Services administration. Interviews with 27 national experts from different service providers.	Progressive legislation has facilitated inclusion of people with disability in employment, e.g. American Disability Act requires employers to provide accommodation to qualified employees with disabilities. Summary of best practice, shared/pool expert in human service, coordinated services, accessible facilities, communication among multiple agencies, policymakers, service providers, consumers with disability, employers.	Government, NGOs, service delivery professional and persons: best practice occurs when: • service providers and people with disabilities have employment as a convergence priority • investments are made in public awareness to establish collaborative systems • employers get involved. Need for collaboration at local and national levels and cooperation if it is possible to increase employment for people with disability.	Peer reviewed, research article.
Adults with disability (Australia)	Stancliffe 2012	Inclusion of adults with disability via examination of different outcome areas: • community living • community participation and inclusive social roles such as open (competitive) employment • participation in university education • use of generic community services like public transport.	Analysis of legislation, and national survey of clients of disability services.	Different areas of results. This entry addresses only disability services – employment: little employment-related inclusion experienced for people with disability in Australia who are overwhelming employed in closed settings.	Closed employment settings provide low wages where people still need to rely on welfare support, and provide little employment-related inclusion opportunities.	 Analysis of secondary sources. Peer reviewed.
People with severe mental illness (Australia)	Waghorn et al. 2007	Evaluation of supported employment programs for people with severe mental illness.	Qualitative evaluation of seven sites where supported employment programs were implemented (or attempted).	Many challenges, including service integration difficulties and the need for greater partnerships between mental health and disability employment sectors. Need for more research into how to implement evidence based employment services.	 People with severe mental illness are marginalised socially and economically when they are unable to access employment. A lot more learning needed in the area of evidence-based employment services for people with severe mental illness in Australia. Integrating services, e.g. employment services with mental health and disability services, is one way forward. 	Peer reviewed. Descriptive rather than analytical.

Population studied/ participants	Reference	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
14 self-selected participants with physical impairments: eight women and four men.	Wilson- Kovacs et al. 2008	Employment for people with disability, opportunities (or lack of).	Qualitative (semistructured and in-depth interviews) and focus groups to understand the views of senior managers at work. Study guided by social model that disability is located within society, not the individual. Uses a feminist approach and rights-based approach.	Barriers to advancement at work: • lack of organisational support • lack of resources • lack of support. Participants want to be regarded as professionals – this is a major step to equality. Understanding disability and willingness to implement effective administration procedures necessary to overcome barriers.	Need to support people with disability in career advancement. Technological and physical resources required (wheelchair, ramps, lifts and specialised software). Need for informed human resources personnel. There is discrepancy between policy and practical implementation to support people with disability. Human resource departments, line managers and peers should understand and be willing to support people with disability and accommodate their needs.	Peer-reviewed article. International but transferable to Australian context.
Adults with ASD diagnosis (autism spectrum disorder)	Westbrook Nye & Fong, 2012	Adults with ASD diagnosis and effective employment programs for this population.	Systematic literature review.	Only two studies fit criteria and both were of low methodological quality. Additional research literature found elements of successful job placement: • costs for support • positive effect of employment on persons with ASD • providing effective support • identifying long-term support services for the employer and employee.	Gaps in research in this area. Need controlled studies with high methodological rigour.	

ACCESS TO ECONOMIC RESOURCES — EDUCATION Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Primary students with disability (Australia)	Boyle et al. 2011	Historical account of Australia's adoption of policies and practices regarding inclusive education.	Descriptive, commentary, e.g. accounts of legislation, inclusive settings, resourcing and barriers.	Differences exist throughout Australia re commitment to inclusive education. Many positive impacts identified.	Role of inclusive education. Key factors: Supportive legislation. Education department policies for inclusive education. Resourcing. Commitment across professions (health, disability, education). Collegial support for teachers.	Commentary article. Peer reviewed.
274 Pre-service teachers and community members	Campbell, Gilmore & Cuskelly 2003	Evaluation of structured fieldwork experience for preservice teachers in the area of inclusive education. Interviews of community members regarding attitudes towards inclusive education.	Evaluation of preservice experience and survey of attitudes.	Pre-service teachers benefited from structured fieldwork: • increased knowledge of Down Syndrome • higher opinion of inclusive education. Community members: • need to raise awareness of disability to change attitudes towards disability in general.	Exposure to intervention (structured fieldwork) – positive impact on future teachers.	 Primary intervention study. Peer reviewed.
Evaluation of National Assessment Program for Literacy and Numeracy (NAPLAN) Years 3, 5, 7, 9, Australia 2008.	Elliott, Davies, & Kettler 2012	Education curriculum improving accessibility for students with disabilities	Discussion of NAPLAN and accessibility for students with disability, in comparison to US experience.	Lesson from US. Strategies to increase access to the curriculum: • applying test accommodation, including changes to presentation (e.g. oral delivery, paraphrasing, Braille, sign language), timing (e.g. extended time, delivery of test on multiple days), environment (e.g. use separate room, elimination of distractions), mode of response (e.g. permit responses in booklet instead of answer sheet). • modifications of tests (e.g. reduce number of words (25–30%), refine or delete poor visuals, reduce alternative answer choice).	 Achievement of students with disability not accurately benchmarked, unlike in US. Australian legislation and educational policies espouse but not fully enacts inclusive assessments for all. Packages of modification result in high scores. Australia has no alternative assessment to identify student learning outcomes or offer modified achievement standards for people with IEP. Australia can learn from US innovative approaches. Modifications increase accessibility in US. 	Commentary article, no methodology section.

Access to economic resources – Education (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Students with disability in VET system (Australia)	Griffin & Nechvoglod 2008	Literature review: considering four aspects of VET and disability: • participation • education outcomes • employment outcomes • costs and benefits of VET.	Data from NCVER's (National Centre for Vocational Education Research) national collection of student data from VET providers and literature review.	Many barriers faced by people with disability in accessing VET; however, numbers are increasing: Participation: barriers include lack of accessible information and lack of career guidance. Education outcomes: additional supports may improve outcomes – requires disclosure. Employment outcomes: most positive when VET organisation has positive relationships with employment agencies and employers. Costs and benefits not clearly understood or documented.	 Research in this area continues to be fragmented. Need to implement more transition planning (barrier to participation). Need to develop strategic collaborations within and across sectors (employment and education outcomes). Need further research to address costs v benefits. 	Occasional paper. Not peer reviewed.
Literature review on intellectual disability and inclusion in mainstream schools (Queensland)	Jackson 2008	To find out what the literature says about inclusion and segregation in schooling for children with an intellectual disability.	Literature review	Research – poorly controlled and mostly anecdotal; however, large volume located. Benefits – academic and social to mainstream schooling of students with disability.	Social impact of mainstream schooling for children with disability is 'consistently' positive. Impact on academic performance for children with disability in mainstream schooling is either neutral or positive.	• Represents academic literature review - not formally peer-reviewed, although findings said to be 'tested' by fellow academics.
Review of universal design within universities	Powell 2013	Description of how to implement universal design	Presentation of universal design principles for universities.	Promotion of universal design principles within universities will enable inclusive education for all.	Actively encouraging participation in universities can be achieved through affirmative action.	 Peer reviewed research article. Descriptive rather than analytical.

Access to economic resources – Education (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Data set of 603 pre-service teachers (Australia, Canada, Hong Kong, Singapore)	Sharma, Forlin, & Loreman 2008	Attitudes towards inclusion in education and disability in general	Quantitative. Data collected in universities across four countries during the first and last sessions of a unit of undergraduate teacher training. In Australia, participants were in their third or fourth year, participating in a mandatory 20-hour unit of study on special education.	 Attitudes towards disability and inclusive education changed over the course. Philosophy of inclusion needs to be taught. Teacher preparation programs are very important to future success of inclusive education. The content and pedagogy of a program are the most significant predictors of pre-service teachers: attitudes, sentiments and concerns about inclusion. 	More research required, for example, on impact of education and longitudinal studies. Pre-service training invaluable for success of inclusive education.	 Peer reviewed, primary study. Tools, reliable scales.
Adults with a disability (Australia)	Stancliffe 2012	Inclusion of adults with disability via examination of different outcome areas: • community living • community participation • inclusive social roles such as open (competitive) employment • participation in university education • use of generic community services such as public transport.	Analysis of legislation, and national survey of clients of disability services.	Different areas of results. This entry addresses only one - employment disability services. Little employment-related inclusion is experienced by people with disability in Australia who are overwhelming employed in closed settings.	University education provides excellent opportunities for inclusion and increases chances of open employment for people with disabilities. An increasing number of students with disability are attending university. Support programs exist to assist with transition and university life. More can be done.	 Analysis of secondary sources. Peer reviewed.

ACCESS TO ECONOMIC RESOURCES — HOUSING

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention/ article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Disability groups (cognitive, mobility impaired, persons with psychiatric disability and sensory loss and carers/family members (Darebin, Gippsland Melton and Brimbank, Victoria)	Beer & Faulkner 2009	Housing: the experiences ('careers') of housing for people with disability and for family members (carers) with 'significant care responsibilities'	Quantitative component: analysis of data on disability – Housing 21 Survey (part of national survey) Qualitative study in Victoria. Six focus groups, specialist survey of people with disabilities, questions to carers and in-depth interviews. Study examined issues and processes that shape housing careers of people with disability, including housing affordability, accessibility and suitability of housing stock and government assistance.	Housing careers of people with disability more restricted/limited than mainstream population. Lack of choice and constraints upon choice regarding housing and location. Households with a member with disability likely to report low income and experience home stress; more likely to be tenants and not home owners; had lower stock of assets; made housing decisions based on a member with a disability; and less likely to live in a household. Severity of disability affects career options. There is no coordination in housing service provision by governments, resulting in fragmentation hindering efficient and fair service delivery. Most public housing is physically inappropriate for people with disability because of design, distance from public transport, poor quality maintenance.	 Disability affects housing careers of all household members. Housing impacts wellbeing. Ageing population means the household has evolved from being a place of care for children (in the 20th century) to a place of care for adults. People with disability restricted/excluded from the private housing markets and rely on social housing. Cost of housing a significant barrier to movement, relocation and home ownership. People with disability vulnerable to discrimination from landlords or real estate agents. Policy issue: need for policy coordination between tiers of government – local, state and federal in service provision. Adoption of universal building codes increases accessibility to people with disability Government can use home lending agencies to support access to home ownership for people with disabilities, e.g. Keystart (WA), Homestart (SA), have specialist services for people with disability. In private housing, people with disability likely to face limited prospects due to lower than average income levels. 	Research paper Not peer reviewed

Access to economic resources – Housing (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention/ article	Design and methods	Outcome/results	Key learnings	Description of article/notes
30 middled-aged people aged 39-68 with intellectual disability in large institution. 15 had moderate level of intellectual disability, 7 severe, 3 not recorded (Melbourne)	Bigby 2008	Community connection and participation, networks	Sample of 24 randomly selected from a group of 55. Data collected before moving into community and one, three and five years after. Interviews with family members, survey and intensive case studies. Participant observation as residents interacted, use of space, personal autonomy/decision making and social networks. SPSS used and thematic analysis.	Most residents did not form new relationships after relocation. Number of clients in regular contact with families decreased, patterns of contact changed as they aged. 62% of residents had no one outside the service system who knew them or monitored their well being. Contact with friends: 82% identified staff member as friend, 50% had no friend other than staff. Informal networks: 16% had non-existent networks, no contact with family, 38% had an engaged family member.	 Physical integration does not equate with social integration or increased community participation. Service providers must play a more active role in the development of support relationships for people with intellectual disability, their families and the community. The community-based accommodation services paid little attention to development of informal relationships. High staff turnover affected families' ability to keep contact with residents. Need for strategies to nurture relationships for people with intellectual disability. Staff skills to foster friendship or advocacy critical. 	Peer reviewed primary study.

Access to economic resources – Housing (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention/ article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with intellectual disability (Victoria)	Bostock et al. 2001	Policy and program review around de-institutionalisation Housing futures for people with intellectual disability living in institutions at time of writing	Qualitative research. Review state/territory de-institutionalisation policies, reviews evidence, challenges faced, government policies and successful interventions. Methods: face-to-face interviews, telephone interviews Published as well as unpublished documentary.	Development of models of accommodation depends on primary policy drivers, either housing or disability. If aim is to meet individual housing needs, then support packages can be designed to meet housing requirements through modification, relocation assistance. If support services focus is economies of scale, aggregated support packages and group homes. In many states, housing model of group home means support services drive policies, but in Queensland housing is policy driver. Impact of deinstitutionalisation minimal because few people leave institutions and if they do relocations are closely managed within public housing or community housing sector. Social housing is the major provider of housing for people with disabilities, implies they cannot secure affordable and appropriate housing in the private market.	 Flexible housing provision/ tailored services (both in disability and housing agencies), services must be more responsive to client needs. Recognise housing needs and access, disabled people not homogeneous group. Need to address the inaccessibility of private housing market (address discrimination). Need for interagency co-operation to ensure success of public housing tenancies. Link between housing and disabilities services underlies successful housing solutions for de-institutionalised people (90% people with disabilities live in the communities). Need for information sharing between states, across sectors. Individualised/tailored approaches (e.g. funding that is tied to a particular individual and portable between service providers works). The cost of not providing adequate housing for people moving from institutions is the failure to secure citizenship rights for marginalised people. 	Research report – not peer reviewed. Information dated – over 10 years old, proposes housing options that have now been trialled/implemented.

Population studied/ participants	Reference	Focus of intervention/ article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Five middle aged men, aged 49-57, with severe intellectual disabilty, resident in a purposebuilt group home. Staff also participated (Victoria)	Clement & Bigby 2009	Community participation/social inclusion and autonomy	16 months evaluation of a program using a Community Inclusion Framework premised on beliefs about benefits of facilitating relationships with non-disabled people. Ethnographic and action research methods. Participant observation, interviews with five family members.	Service delivery based on community presence rather than community participation was noticed. Front-line staff had different notions of what community participation meant, whether it was achievable/realistic with their residents. They did not understand what inclusion meant. Some saw inclusion as community presence. There was little participation or social integration.	Front-line staff attitudes and practices influence the outcome of programs. The more time spent in segregated leisure activities, and group homes, the less likely the chance to change patterns to include community participation.	 Peer reviewed primary study. Small sample size.
Adults with intellectual disability living in a mix of supported housing models (UK)	Emerson 2004	Housing/community integration and wellbeing	Sample: 910 people drawn from 10 locations in northern England Statistical analysis/logistic regression.	Move from institutions to community housing associated with many positive outcomes, including increased: • satisfaction with living arrangements • choice on daily matters • participation in community activities • participation in domestic chores • support from care staff. Others argue de-institutionalisation has failed. Advocate for cluster housing which creates 'villages' or 'communities' found: • no evidence that cluster housing of people with intellectual disability provides a 'connected' community. • no difference in access to friendship activities between clusters and dispersed housing residents. • people in cluster housing were more likely to live in larger settings, supported by fewer staff, exposed to greater changes as homes were used for short-term care for others. • be exposed to more restrictive management practices including seclusion, sedation, physical restraint (polyphamarcy). • lead sedentary lifestyles, less and restricted leisure, social and friendship activities.	Cluster housing offers poorer quality of care and quality of life than dispersed housing schemes (disputes Cummins & Lau, 2003). Argues that dispersed offer a better quality of life for people with intellectual disability once differences in participant characteristics are taken into account. There is debate in literature about cluster housing/dispersed housing and community connectedness of people with intellectual disability. Normalisation through community-based housing has many advantages and should be promoted.	Peer reviewed, large-scale study UK based but applicable to Australia Intellectual disability focus

Access to economic resources – Housing (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention/ article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with disabilities who require access to 24-hour formal or informal support (Australia)	Fisher, Parker & Purcal 2009	Presents and applies a framework for analysing the effectiveness of new approaches to housing support using a rights perspective. Four domains: • client outcomes • administrative systems • service viability • coordination between formal and informal carers.	Six case studies – where framework was tested.	Foster independence while providing effective individualised, holistic housing support.		
Improving outcomes for people with disability and the ageing population through better housing design. Nine in-depth interviews with a range of key informants, and an assessment of Australian, and specifically NSW, policy and legislation.	Newman & Bridge 2011	Policy analysis, understanding of Australian context.	Literature review.	Australia needs to provide a socially sustainable housing stock via adoption of universal design features in mainstream residential development.	Too much diversity in terminology and design requirements across Australia means varied interpretations and applications. Current guidelines are voluntary. Traditional approaches mean people must relocate to specialised housing as they age. Attitudes towards future housing developments need to change – potential to create more equitable built environments.	

Population studied/ participants	Reference	Focus of intervention/ article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with disability (Australia)	Parker & Fisher 2010	Analysis of housing support policies and current housing support arrangements. Human rights framework applied.	Policy analysis	Four policy goals: • human rights • quality of life • independent living • cost effectiveness. Current supply of housing is inadequate and continues to include institutional support. Policy trend towards individualised and person-centred approaches offers pathway to achieving policy goals No one approach is sufficient.	Seven key facilitators and barriers to fulfilling the right to disability housing support: 1. legislation, agreements and regulations 2. funding and demand management 3. interagency coordination; 4. range, flexibility and choice of housing support 5. staffing quality 6. informal carers 7. discrimination.	
People with different kinds and degrees of disability (Victoria)	Saugeres 2010	Examination of the relationship between adequate housing and welfare provision for people with varying disabilities reinforces their marginalisation and dependency.	Qualitative research with people with disabilities and family carers in urban and regional Victoria	Lack of adequate housing and welfare provision reinforces the dependency of people with disability through low incomes, unsuitable housing design and poor housing conditions, restrictions in terms of location and place, and the lack of suitable care and assistance.		
People with intellectual disabilities and their family members (Australia)	Shaw, Cartwright & Craig 2011	Identify the housing and support preferences of people with intellectual disability and their carers – as they age.	Focus groups and individual interviews with 15 people with disability and 10 family members caring for adults with disability. Thematic analysis of data.	Four major themes: • Living arrangements • Housing preference • Ageing in place • Transition from informal to formal housing and support services.	Need for housing and supports which adapt to needs of people with disability – where people with disability maintain their social networks.	

Access to economic resources – Housing (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention/ article	Design and methods	Outcome/results	Key learnings	Description of article/notes
National data (Australia, England, USA)	Stancliffe 2002	Housing – international comparison	Quantitative data from Commonwealth data/ State Disability Agreement (CSDA) database 1995–1999. Different houses categories set-institutional/large residential of more than 20 beds; hostel; group home; attendant care; outreach support; alternative family arrangement; other accommodation.	People with intellectual disability or developmental delay make up 71.6% of CSDA funded housing/accommodation support services. In Australia, there is a decline in state provision of housing for people with intellectual disability in institutional/large residential housing.	Lower availability of government-funded residential/ housing services in Australia points to a lower level of service to people with intellectual disability. Australia lags behind UK and USA.	Peer reviewed research article. Uses secondary data, not primary sources.
People with intellectual disabilities (Victoria)	Weisel & Fincher 2009	Understand the concept of choice in housing for people with disability.	Case study of housing for people with intellectual disabilities in Victoria.	De-institutionalisation equals increased demand for community care, while resources to provide supported housing are inefficient.		
Young people with disabilities who currently live or previously lived in nursing homes	Winkler et al. 2011	Evaluation of national Young People in Residential Aged care program to reduce number of young people living in aged care.	Semi-structured telephone interviews with 20 service providers, 10 advocacy organisations, six public servants Australia-wide focus.	Only 139 people moved out of aged care in first four years of program. Those who did improved quality of life. Program unable to reduce number in the long term due lack of capacity within system.	 Systemic change still needed to reduce the numbers of new admissions. Accommodation options developed, almost at full capacity. Approximately 250 people under 50 likely to be admitted to aged care each year. 	

Population studied/ participants	Reference	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People experiencing transport disadvantage (Victoria)	Currie & Allen 2007, Section 3/7.	Victorian study of links between transport disadvantage, social exclusion and wellbeing.	Field survey Factor analysis	Review of transport disadvantage.	Transport disadvantage exists for/ compounded by people with disability due to economic disadvantage. • Uptake of public transport is less. • Inability to access transport decreases quality of life for people with a disability.	Not peer reviewed.
People experiencing transport disadvantage (Victoria)	Currie et al. 2010	Victorian study of links between transport disadvantage, social exclusion and wellbeing.	Field survey Factor analysis	Social exclusion, e.g. no car ownership, disengaged, lack participation and social support – links with transport disadvantage (transit, transport, vulnerability, reliance on others) – links to subjective wellbeing.	Experiences of transport disadvantage: • Lower quality of life. • Higher social exclusion.	Peer reviewed article. Original research article section of journal.
535 individuals from a household survey (Melbourne, Australia)	Delbosc & Currie 2011	Analysis of self-reported measures of transport disadvantage and how these relate to social exclusion and wellbeing.	Factor analysis of survey results.	Four factor groups identified: • transport disadvantage, e.g. geographical location prevents access to regular public transport • transit disadvantage, e.g. unable to access activities due to transport problems • vulnerable/impaired: physical access is an issue, feeling safe a priority, so often use private cars rather than public transport • rely on others.	Article did not discuss disability per se, but obvious inclusion in four factor groups identified.	Peer reviewed primary study.

Population studied/ participants	Reference	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with a disability (US)	Rimmer & Rowland 2008	How to deliver health promotion for people with disability.	A review – no methodology section to describe type of review undertaken.	 Priority for health promotion is to prevent secondary conditions. Health professionals should prioritise establishing disability-friendly environments that will reduce barriers (architectural, programmatic and attitudinal). This will enable people with a disability to be empowered to participate in health promotion practices. 	Different learnings for different sections of resource. For transport section: People with disability face many barriers to managing their own health – including a lack of accessible transportation – preventing them from participating in many health promotion programs which are based in mainstream community settings. Risk of inaccessible transport equals poorer health, loss of empowerment, risk of developing secondary and chronic conditions.	 Peer reviewed, but no methods section. Not a research article.
Adults with disability (Australia)	Stancliffe 2012	Inclusion of adults with disability via examination of different outcome areas: community living, community participation and inclusive social roles such as open (competitive) employment, participation in university education, as well as use of generic community services like public transport.	Analysis of legislation, and national survey of clients of disability services.	Different areas of results. This entry addresses only one: disability services – employment: little employment-related inclusion experienced for people with disability in Australia who are overwhelming employed in closed settings.	Key learnings for this section on employment: closed employment settings provide low wages where people still need to rely on welfare support, and provide little employment-related inclusion opportunities.	 Analysis of secondary sources. Peer reviewed. Quality journal.
People experiencing transport disadvantage (Victoria)	Stanley, Currie & Stanley 2007	Conclusion section of publication	Drawing conclusions from publication	Discussion around where results of publication lead. Lack of data overall around transport disadvantage in terms of interventions and trialled approaches.	Lack of data surrounding interventions and effective targeted approach for people with disability.	Not peer reviewed.

Population studied/ participants	Reference	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People experiencing transport disadvantage (Victoria)	Stanley et al. 2010	Victorian study of links between transport disadvantage, social exclusion and wellbeing.	Field survey Factor analysis	 Review of transport disadvantage. Social policy impact of lack of social capital. Need to increase social capital for people experiencing transport disadvantage. 	Systemic changes needed to address transport disadvantage for example urban planning system. Social policy implications.	Peer reviewed article.
People with a disability (Melbourne)	VEOHRC 2010			Taxi reforms – continues to be a systemic issue. While reforms have been achieved – there is still some way to go.		
People with limited mobility (Victoria)	Wang & Winn 2010	Audit of a program to make public transport more accessible in Victoria.	Audit conducted by government department – reviewed for this paper. Case studies used to illustrate.	 Compliance: disability standards are being complied with for most part; however, have not measured how changes affect people with a disability. Effectiveness unclear as people with a disability not adequately consulted. 	Gaps – need further study in areas such as: • effectiveness of legislation and changes made to date • understanding of current and desired travel patterns of people with a disability – to help undertake a needs assessment.	Not peer reviewed.
People with a disability (UK)	Wilson 2003	Literature review on use and experiences and use of transport.	Literature review – focused on strategic (not technical) issues No attempt to cover breadth of literature – focus on key areas of interest to UK DRC only.	Recommendations included: need to place transport disadvantage within broader context of participation different disabilities and geographical location – impacts on transport needs and barriers faced disability awareness needs to increase regulations required – must be monitored disability organisations have role to play in advice to transport providers.	Systematic change needed to address transport disadvantage faced by people with a disability.	Not peer reviewed.

FREEDOM FROM DISCRIMINATION AND FREEDOM FROM VIOLENCE

Population studied/ participants	References	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Women with intellectual disability who are vulnerable to sexual assault	Barger et al. 2009	Sexual assault prevention programs.	Literature review of general sexual assault prevention research, applied to people with intellectual disability; then evaluate interventions published primarily in US. Evaluation of sexual assault prevention.	Recommendations for women with intellectual disability who are vulnerable to sexual assault.	Recommendations for women with intellectual disability. More work to be done in this space if we are to decrease the incidence of sexual violence against women with intellectual disability.	Literature review – drawing on both peer- reviewed and non-peer reviewed literature – with conclusions drawn re intellectual disability. Peer reviewed but uses non-reviewed articles.
Community members (Australia)	Blignault et al. 2010	People with mental illness and reactions to people with mental illness.	Intervention evaluation – primary study.	Culturally appropriate and innovative theatre productions portraying mental illness within an ethnic community – effective at reducing stigma and raising awareness.	Awareness raising in community: effective evaluation described.	Primary Australian study. Peer reviewed.

Population studied/ participants	References	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Evaluation of living safer sexual lives project for people with intellectual disability (Melbourne)	Frawley, Barrett & Dyson 2012	Prevention of violence with focus on safer sexual relationships. Peer-led program comprising 26 participants with intellectual disability plus 20 participants from the disability and social sectors as co-facilitators for workshops.	Evaluation aims: investigate program processes and outcomes from perspectives of key stakeholders in the service sector. develop a feedback loop with program team to enable identification and setting of benchmarks for good practice and continuous program improvement. understand processes employed in the establishment and delivery phases of the program, and ways in which these contribute to sustainability of program. identify and describe the adaptation of an international framework known as the 'ecological model' in the program.	 There was broad engagement to reach people with an intellectual disability to be peer educators, to run programs, and to develop skills in the disability and community sectors to work with people with an intellectual disability in violence and abuse prevention. The locally based approach was developed to address gaps in cross-sector responses to violence, abuse and disability and to establish relationships and processes necessary to sustain the program when the funded period ended. Cross-sector engagement with primary prevention programs is needed for people with an intellectual disability. 	Contributed factors for supporting and empowering people with a disability in preventing violence and abuse.	Not peer reviewed. Program evaluation only.

Population studied/ participants	References	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Women with disabilities (Victoria)	Healey et al. 2008.	Access to health services	Review of interventions and successful strategies. Provides profiles/examples of community based organisation providing services for women experiencing violence in Victoria, NSW, Queensland, UK, Canada and USA.	Successful interventions and positive development included four case studies of successful interventions in Victoria focusing on establishment of: • a disability unit: key features include affirmative access policies and a gendered approach, diversity in staff experiences, trained staff specialised in disability, collection of data on referrals, and supporting older women with disabilities. • cross-sector collaboration by service providers (Woorarra Women's Refuge), to develop protocols on domestic violence and mental health, domestic violence outreaches, engagement in local cross-sector staff training and workshops for mental health clinicians. • development of accessible communication/information, adopted a human rights approach, compiled stories of women who experienced domestic violence for a web guide for other women who experience domestic violence. • facilitated regional planning for violence policy development.	Positive developments occur as a result of: involvement of women with disabilities in policy development, service planning and delivery commitment of violence service providers inter-sector collaboration between disability and family violence services putting resources to supporting innovation in service development. Recommendations: government funding needed to increase support, cross-sector relationships access to information and communication, government supports and disseminates information about good practice developments local disability and family violence services to collaborate leadership at state, regional and local level support building of relationships, capacity and exchange of expertise between disability, family violence and other community sectors. Training of staff to improve knowledge in disability services.	Not peer reviewed. Program evaluation only.

Population studied/ participants	References	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Literature review - violence- related service, prevention and intervention programs for people with a disability	Lund 2011	Intervention and prevention programs	Literature review - focus on service programs and intervention and prevention programs - 16 articles (six on services, 10 on intervention and prevention).	Limited evidence for intervention and prevention programs. Recommendations include the need to bridge the 'disconnect' between violence services programs' perceived accessibility and perception of accessibility among people with a disability.	Need for empirical evaluation of intervention and prevention programs. Contributed factors for supporting and empowering people with a disability in preventing violence and abuse.	Peer reviewed. Literature review.
People with intellectual disabilities (accessing health care services) (UK)	Michael & Richardons 2008	UK based international review	Evaluated discrimination within healthcare systems for people with intellectual disability.	UK study into access to health care revealed consequences of failing to make reasonable adjustments included untreated ill health and an increased likelihood of avoidable deaths. Recommends coordinated approach from governments and health care systems.	Contributes to gaps in knowledge section: consequences of discrimination in health care. Australia would benefit from a similar enquiry. Recommends coordinated approach: • reasonable adjustments as part of core standard • proactive approach to health • partnerships formed between local providers and people with intellectual disability and their carers.	International review.

Population studied/ participants	References	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with a disability (Australia)	National People with Disabilities and Carer Council 2009	Housing, education, health care access, employment, transport, isolation from community.	Survey of experiences of people with disabilities. Case studies and life stories. Submissions to the National Disability Strategy.	Identified barriers to education, housing, employment, community participation, access to health, discrimination and lack of access to built environments and recreational centres. Improve service delivery, access and affordability of transport, education, access to built environment – ramps, wheelchair and lifts. Improved information dissemination and education of community to accept disabled people, dispel myths and taboos. Taxi drivers required to be incentivised.	 Systemic reforms required to increase social, economic and cultural participation of people with a disability. Introduce measures that address discrimination and human rights violations. Improve disability support services. Provide adequate financing over time. Need to provide a coordinated approach to enhance consistency at federal, state and local government. Provide funding to increase advocacy by non-government agencies. Improved information dissemination and education of community to accept disabled people, dispel myths and taboos. Teacher training to understand disability. 	Report based on consultation not research. Document used as a primary source in many other articles.

Population studied/ participants	References	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
305 disabled and deaf women, Texas, Oregon, Southwest Washington state. Mean age 50.75 years; white 56.7%, African American 30.5%.	Powers et al. 2009.	Freedom from violence and autonomy/accessible information.	Disabled and deaf women participated in a randomised control field test of the Safer and Stronger Program, specifically designed an accessible and anonymous method for women to self-screen for interpersonal violence, exposure and use of safety promoting behaviours. Baseline and follow data collected over 4 months. 2 groups: 172 in treatment group and 133 in comparison group. Completed audio computer-assisted self- interview Included 50 safety behaviour questions in eight categories: • learn about abuse • reach out to someone you trust • keep your money safe • know your legal options • plan for emergencies • build abuse safety skills • have good relationships • take charge of your support.	Source of information: 36% of women had information from magazines, books, radio TV; 33% from community (see pp. 1049–51 full responses) Participants in the sexual, physical and multiple abuse classes and those with controlling perpetrators were more likely to take action to learn about abuse than those in with minimal or no abuse. 80% of the 226 women reported they used support or assistance, had decided who provides their support (freedom/autonomy). However, only 46% had the skill to choose/supervise their assistants and only 405 had back-up available if assistant was abusive. Women who reported sexual, physical or multiple interpersonal violence and those with low-risk perpetrators were most likely to use personal assistance management safety behaviours.	Contributed factors for supporting and empowering people with disabilities in preventing violence and abuse. Safety promotion for disabled and deaf goes beyond planning in response to imminent threats and include behaviours that reduces women's vulnerability to violence (e.g. building social connections, safety skills, personal assistance management). These increase power and confidence in managing abusive relationships. Women need to be empowered with the information to recognise and enable them to respond to violence and abuse. There is need for greater support for women by providing accessible information and empowering abuse safety information and resources and providing back-up personal assistance.	Peer reviewed research article. Primary study.

Population studied/ participants	References	Focus of intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with disability and their carers (Australia)	Pricewaterhouse Coopers 2011	Evaluation of disability care and support – commissioned report	Extensive consultation and collaboration across Australia.	People with disability experience discrimination within current fragmented and inadequate service system.	 Institutional level of discrimination need resourcing (NDIS suggested) Systemic discrimination – focus on taking more responsibility for occurrence Strategies for awareness raising to disperse stigma associated with disability. 	
Health care students	Tracy & lacono 2008	People with intellectual disability and health care students	Program evaluation – primary study	Involving people with developmental disability in teaching medical students – as part of a communication skills session. An effective way to raise awareness and understanding of disability in preservice professionals.	Awareness raising among health professionals: effective intervention described.	Primary Australian study. Peer reviewed

SOCIAL CONNECTION AND COMMUNITY PARTICIPATION

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
30 middled-aged people, age 39-68, with intellectual disability, in large institution, then in community. Fifteen had moderate level of intellectual disability, seven severe, three not recorded (Melbourne)	Bigby 2008	Community connection and participation, networks	Sample of 24 randomly selected from a group of 55. Data collected before moving into community and one, three and five years after. Interviews with family members, survey and intensive case studies. Participants observed as residents interacted, use of space, personal autonomy/decision making and social networks. SPSS used and thematic analysis.	 Most residents did not form new relationships after relocation. The number of clients in regular contact with families decreased, patterns of contact changed as they aged. 62% of residents had no one outside the service system who knew them or monitored their wellbeing. Contact with friends: 82% identified staff member as friend, 50% had no friend other than staff. Informal networks: 16% had nonexistent networks, no contact with family, 38% had an engaged family member. 	 Physical integration does not equate with social integration or increased community participation. Service providers must play a more active role in the development of support relationships for people with intellectual disability, their families and the community. Community-based accommodation services paid little attention to development of informal relationships. High staff turnover affected families' ability to keep contact with residents. Need for strategies to nurture relationships for people with intellectual disability. Staff skills to foster friendship or advocacy critical. 	
Young people with intellectual disability	Burgen & Bigby 2007	Results of PhD thesis on friendships – qualitative approach, social and emotional development and relationships important to small group of young people (18–29) with mild to moderate intellectual disability.	Qualitative research – series of interviews	 Need individualised planning to include opportunities for friendships. Wellbeing and mental health may be seriously compromised by a lack of close friendships and positive peer relationships. Need for skills development post-transition from school. Need for case managers to advocate goals around friendships within individual plans and with clear strategies for staff and informal support. 	 Recognise need for staff to facilitated and enable friendships. Recognise value of friendships for people with intellectual disability – an area often overlooked in terms of active planning. 	Based on PhD thesis Small-scale, primary study

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Five middle aged men, aged 49-57, with severe intellectual disability, resident in a purpose-built group home. Staff also participated (Victoria)	Clement & Bigby 2009	Community participation/social inclusion and autonomy.	16 months evaluation of a program using a Community Inclusion Framework premised on beliefs about benefits of facilitating relationships with non-disabled people. Ethnographic and action research methods. Participant observation, interviews with five family members.	Service delivery based on community presence rather than community participation was noticed. Front-line staff had different notions of what community participation meant, whether it was achievable/ realistic with their residents. They did not understand what inclusion meant. Some saw inclusion as community presence. There was little participation or social integration.	Front-line staff attitudes and practices influence the outcome of programs. By spending time in segregated leisure activities, group homes, the less likely the chance to change patterns to include community participation.	 Peer reviewed primary study. Small number.
People with aphasia (communication disability)	Davidson et al. 2008	Social participation of people with aphasia – compared to people without this disability.	Naturalistic inquiry: two phases: • participant observation of 30 older people, 15 with aphasia, 15 without • collective case study stimulated recall of friendship conversations.	People with aphasia had fewer friends and smaller social networks. Acquiring disability has an impact on friendships.	Need to support communication of people with communication impairments – to enable/ facilitate communications with friends. Lack of research in this area – need for intervention program research.	Peer review Small-scale primary study
People with intellectual disability	Kozma, Mansell, & Beadle- Brown 2009	Systematic literature review based on original research only.	Systematic literature review. 68 articles included.	Community-based services were superior to congregate arrangements. Better outcomes facilitated for people with intellectual disability when more than a basic model of care is adopted.	Outcomes of community living post-deinstitutionalisation.	Systematic review
Adults with disability (Australia)	Stancliffe 2012	Inclusion of adults with disability via examination of different outcome areas: • community living • community participation and inclusive social roles such as open (competitive) employment • participation in university education • use of generic community services such as public transport.	Analysis of legislation, and national survey of clients of disability services.	Different areas of results. This entry addresses only one: disability services – employment. Little employment-related inclusion experienced for people with disability in Australia who are overwhelming employed in closed settings.		 Analysis of secondary sources Peer reviewed High quality journal

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with a disability and the influence of environmental factors influence on social participation.	Verdonschott et al. 2009	A systematic literature search for the period 1996–2006 in Pubmed, CINAHL and PSYCINFO. Out of 236 initial articles, nine quantitative studies and two qualitative studies met the selection criteria.	a predetermined search strategy that combined several terms for 'population' with a broad range of keywords related to 'outcome'. Aspects of community participation included were: domestic life; interpersonal interactions and relationships; major life areas; community, civic and social life. Environmental factors included were: • products and technology • natural environment and human-made changes to environment • support and relationship • attitudes • services, systems and policies.	Studies used various methods and only one study used a conceptual framework. None of the selected studies describes the impact of 'natural environments and humanmade changes' on community participation. Environmental factors positively affecting participation include: • opportunities to make choices • variety and stimulation of the environment of facilities • opportunities for resident involvement in policy making • small residential facilities • opportunities for autonomy • vocational services • social support • family involvement • assistive technology • positive staff attitudes. Environmental factors that negatively affected participation were: • lack of transport • not feeling accepted.	 There is limited or lack of studies on environmental factors affecting participation. Many studies do not clearly define the concept of community participation. Research on the impact of environmental factors on community participation not be based on or weakened by theoretical framework. Most studies focused on impact of services on community participation in general. Other factors important in community participation include legislation and policies (service and systems). In future, there is need for researchers to identify and reach agreement on the range of environmental factors relevant for community participation by people with intellectual disability. A general and valid theoretical framework for identifying environmental factors of influence on community participation by people with intellectual disability is needed. 	Peer reviewed Systematic review

HEALTH BEHAVIOURS

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Adults with developmental disabilities and obesity and staff from the health and medical department at a community agency serving people with developmental disabilities in Los Angeles.	Bazzano et al. 2009	Physical activity, Health Lifestyle Change Program (HLCP), self-efficacy.	A single group community-based demonstration project with pre-post test evaluation 2005–2006. No control group. Participants met for seven months, twice a week and aimed to increase knowledge, skills and self-efficacy on health, nutrition and fitness. Peer mentors selected, participant leaders and motivators, measured changes in MBI, abdominal girth, access to care, self-reported nutrition, physical activity and lifestyle satisfaction. HLCP was based on social cognitive theory of health behaviour change that environment and individual cognitive factors influence outcomes.	 Two-thirds maintained or lost weight. Mean weight loss of 2.6 pounds and median weight loss of seven pounds. Average MBI decreased by 0.5 kg/m². Abdominal girth decreased in 745 of participants. 61 participants reported increased physical activity. Mean exercise frequency increased from 3.2 times to 3.9 times per week. Improvements in nutritional habits and self-efficacy recorded. 59% improved life satisfaction. Health care access: a total of 206 referrals made for medical care. Participants had increased ability to access health care with 67% sure of making a GP appointment preprogram compared to 83% post-program. Program enabled peer mentors and participants to act as community advocates and partners in research (increased involvement). Videos showed across California and program well received by policy makers (they now include peer-led health programs as a funding priority for individuals with developmental disability). Social networks and friendships formed. 	 Improved lifestyles recorded and increased community participation. Community-based intervention program involving participation of people with disability in designing, implementing and making the decision. Programs with partner people with disability rather than research performed on them creates ownership of intervention by peer mentors. Accessible community-based programs increase community participation, self-efficacy if positive reinforcement and peer mentored are used. Program sustainability: trained peer mentors partner community care providers to continue the program in the community. HLCP led to development of community based organisation, e.g. a self-sustaining agency created Peer mentors employed as independent providers focusing on health coaching service providers specialising in health coaching. Limits: no control group used, selection bias possible. 	Trial. Primary research article. Peer reviewed

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Participants with spinal cord injury, multiple sclerosis and neurological impairment.	Block et al. 2010	Health behaviours: assessment of health promotion and capacity building, self- determination.	Qualitative (participatory intervention strategy) and quantitative. Participants completed self-efficacy measures at baseline and program completion and set health goals in 10 days over 5 months in 2002. Applied a disability framework, recognises role of environment, gender, race and social status in the experience of disability.	Increase in self-efficacy scores for intervention participants compared to non-participants. Self-efficacy denotes sense of accomplishment and personal wellbeing that comes from ability to overcome challenges or attain goals. Participants gained independent living skills and confidence in their abilities to achieve set goals in education, housing, transportation, accessing community resources, participation in sports and in health promotion. They increased knowledge in health living. Project adopted by the state department of health in collaboration with centres for independent living.	Participants increased quality of life, independence, community access and participation. Empowered participants to take control of their lives. Many were able to set goals for their lives. Programs should be culturally relevant and social support is important in overcoming barriers faced by people with disability. Participants identified these barriers as social and structural, lack of family support, transport, inaccessible environments, discrimination, physical and cognitive limitations, financial hardships and beliefs about personal capacity.	Primary study. Peer reviewed research article.
Systematic Cochrane review	Cleary et al. 2010	Literature review	Cochrane review	Systematic review of trials using psychosocial interventions for people with substance abuse problems and mental illness.	Contribution to gaps in learning More quality trials are needed in this area before conclusions can be drawn.	Systematic reviewCochrane review
Systematic Cochrane review	Dale et al. 2008	Literature review	Cochrane review	Systematic review of the impact of peer support telephone calls to improve health and health behaviours, suggested that peer support telephone calls may increase health screening activities, for example. However, randomised controlled studies are needed to clarify which elements of this intervention work best to improve health-related behaviours.	Contribution to gaps in learning.	Systematic review Cochrane Review

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Adults with intellectual disabilities.	Hamilton et al. 2007	Review of current evidence on effectiveness of interventions for obesity in adults with intellectual disabilities.	Review of electronic databases (Medline, PsychLit, Embase, Cinahl), the bibliography of journal articles and review articles, book chapters and hand searched for the journals American Journal on Mental Retardation, Journal of Intellectual Disability Research, Journal of Applied Research in Intellectual Disabilities, Mental Retardation and Journal of Intellectual and Developmental Disability, for 2000–2006.	 Obesity in adults with intellectual disability is a prevalent and under-researched phenomenon. There are unique barriers in access to weight-loss management strategies for adults with intellectual disability. Beyond the commonly recognised barriers associated with the physical environment of community residential settings, the additional communication needs, dependency on carers to identify and present health needs to services, and the lack of training of health professionals contribute to these access barriers. The associated health risks, combined with the vulnerability and specific needs of adults with intellectual disability, require the provision of effective interventions and accessible services. Interdisciplinary collaborations, in partnership with service users and carers, may contribute to the development of a robust understanding of the appropriate solutions. 	Interventions in following areas for adults with genetic syndromes (and intellectual disability): • behavioural interventions • weight loss interventions • physical activity interventions • carer involvement in interventions • health promotion interventions, including effectiveness of groupbased interventions.	• Systematic review
Systematic review	Harrison 2006	Literature review	A search of Medline and Cinahl databases for research on disability and health promotion was done. 23 articles were categorised into one of three areas: • the meaning of health and health promotion • factors that contribute to health and health promotion • health promotion • health promotion interventions.	Overall, health and health promotion were inductively defined concepts that emphasised function, relationships, and a positive mental attitude. Barriers to health promotion were frequently reported, fatigue being most common. Moreover, better health outcomes were reported when people with disability engaged in health-promoting behaviours. There were few interventions found, with only one being a randomised clinical trial. Health promotion should be studied as a macro (e.g. focus on societal change) as well as a micro (e.g. a focus on individual-level behavioural change) level tool for the improvement of health in people with disability.	Gaps in research: too few interventions found. Individual goal setting as part of health promotion. Facilitating access to community based services (i.e. mainstream access, not just disability services).	Only one RCT found, showing weak evidence from systematic review.

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Systematic review – described in text as a 'scoping review'	Heller et al. 2011	Examined health promotion interventions that focused on physical activity and nutrition among adults with intellectual disability. The review was organised using health promotion topics and considered the following questions: • What type of intervention is effective (with significant findings) on what outcomes, including physical and psychosocial outcomes? • What approaches (including protocols and curricula) were used? • What is the type of design (ranging from qualitative to quasiexperimental to randomised control trials? • What are promising approaches (e.g. ones that show some evidence but require further research)?	Literature review: Searches included Medline, Psycinfo, and Cinahl databases from 1986 to July 2006. The final number included 11 articles comprising 12 studies.	Overall, the studies reviewed show that health promotion interventions incorporating physical activity, better nutrition, and health behavior education can have some positive impacts on the health and function of adults with intellectual disabilities. However, the interventions need more rigorous testing because the evidence to date, while promising, lacks a strong empirically tested evidence base.	Evidence for interventions re health behaviours limited, with empirical evidence lacking.	Systematic review Peer reviewed

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Ninety-five people with disability aged 19-82 (cross-disability population). Participants recruited through independent living centres (Oregon, Washington, USA)	Horner- Johnson, Drum & Abdullah 2011	Healthy behaviours focusing on multiple effects of wellbeing (physical, social and emotional health). Framework of HL: an integrated approach and self-determination principles enable people to take control, choose and be accountable for lifestyle behaviours and actions; Salutogenic approach; social cognitive theory emphasising self-efficacy.	Healthy lifestyle workshop for people with disability grounded in social cognitive theory. Randomised trial of 95 participants randomly selected for a 2.5-day workshop followed by two-hour monthly follow-up. Health behaviours are measured through the Health-Promoting Lifestyle Profile 11 (HPLP), which measures health- promoting behaviours in health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations and stress management. Each item is scored on a 4-point score, four times at baseline, four months, seven months and 10 months. Analysis: chi squared tests, t-tests	 Intervention measure increased significantly. Health behaviour score increased significantly compared to the wait list participants who did not attend the workshop. Some overweight participants lost weight. High level of enthusiasm for the program and referred friends to program after it ended. Some participants received training to become peer trainers for healthy lifestyle programs. The success let to the development of train-the-trainer program implemented in nine states. Limits: sample white female and well educated. Randomised trial was not stratified based on demographic variables. 	Community participatory approach effective – people with disability designed, implemented and disseminated the results and promoted new health practices for the disability community. Health intervention programs help people with disability to increase healthy behaviours. Program provided knowledge, skill building and support and this enables participants to engage in healthy behaviours. Results support social cognitive theory in that an increase in skills in self-efficacy, in a supportive environment, results in positive health behaviours. Guidelines for success: • program should have a conceptual framework, e.g. social cognitive theory • implement process evaluation • collect data using disability appropriate measures • involve people with disability, care givers and families in design and implementation • consider the beliefs and values of target group and support people to work towards goals of their own choosing • program should be socially, behaviourally, programmatically and environmentally accessible and be affordable.	Peer reviewed.

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Fifteen women with physical disability, aged 34-71. (Houston, USA)	Hughes et al. 2003	Health behaviour, self-efficacy	Randomised short-term pilot study, (peer-facilitated, psycho educational programs to improve physical, psychological and social health of women). Two groups of women over seven-week sessions informed by social cognitive theory. Pretest and post-test. Measurements on self-efficacy, health status, social support, autonomy and coping.	Significant positive changes between pre-test and post-test scores on self-efficacy for dietary behaviour, medical decision making, social interaction, physical functioning. Social health improved as showed by pre- and post-tests. Program provided peer training and education. Program allowed opportunities to connect/social networks and stress management. Barriers confronted: structural, informational and attitudinal barriers in accessing health care.	Health promotion program that focuses on self-management, active coping skills, increased knowledge and awareness, empowerment and support important for people with disability. Key findings: well designed psychoeducational intervention and peer facilitated programs can improve scores on physical, psychological and social health status. Group intervention strategies are effective for improving health and wellbeing of people with chronic illnesses and physical disability.	Primary pilot study. Peer reviewed.
Systematic review - described in text as an 'integrated review method'	Jinks, Cotton & Rylance 2011	Review aimed to answer the following questions: • What is the effectiveness of non-surgical, non-pharmaceutical interventions designed to promote weight loss in people with learning disabilities? • How can qualitative evidence on peoples' experiences and motivations help understanding of quantitative research outcomes?	Papers published from 1998 to 2009 were identified through searches of the Cumulative Index for Nursing and Allied Health Literature, Proquest, Medline (PubMed), PSYCHINFO databases, and the Cochrane Library.	The evidence presented gives direction on how best to devise weight reduction interventions for people with learning disability. However, more work is required to develop user/carer-oriented and effective interventions. There are big gaps in knowledge about effective interventions, so future research agendas should include more qualitative studies of views and perceptions of clients and their carers, controlled trials to test the efficacy of the different treatment programs, studies of the cost and sustainability of the various interventions, and longitudinal studies examining whether weight loss can be maintained over time.	Raised more questions than it could answer. Gaps in knowledge contribution.	Systematic review

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Systematic review	Johnson 2009	Systematic review of interventions	Three systematic reviews and 14 studies were reviewed. Strong evidence indicated that children and adolescents with developmental disabilities derive health benefits from participation in group exercise programs, or therapeutic riding or hydrotherapy. Lesser levels of evidence indicated that health benefits might be present for adapted skiing or aquatic programs. Documented benefits of physical activity include improvements in aerobic capacity, improved gross motor function, and high levels of participant/parent satisfaction.	Evidence exists that physical activity is beneficial for youth with developmental disabilities. However, further research studies of greater scientific rigour are needed, including larger sample sizes, control groups, and stringent, replicable methodology.	Contribution to gaps in knowledge section due to limitations identified (e.g. small sample sizes make it difficult to draw conclusions)	Systematic review Peer reviewed
Systematic review	Kerr et al. 2012	Literature review	Mixed method literature review aiming to assess feasibility, appropriateness, meaningfulness and effectiveness of interventions designed to address the use of tobacco and alcohol in people with mild to moderate intellectual disability.	 Limited evidence-based tobacco and/or alcohol-related health promotion interventions for people with intellectual disability has huge implications for practice. There is little guidance for health care and social professionals working with people with intellectual disability. Review identified need of clear and robust research methods. There is need to test the effectiveness of interventions in large-scale, well-designed trials and to ensure that outcome measures are developed or tailored appropriately for this client group. There are no 'one size fits all' solutions. 	Contributes to gaps in knowledge	Systematic review

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Adults with mild intellectual disability, care givers long-term assessment. RMIT university researchers collaborated with a community leisure centre, 2008 and 2009 (Melbourne)	Lante et al. 2011	Physical activity program (on sports, exercise and active recreation) named Creating a Sporting Chance over 2 years	Accelerometers used to collect data. Interviews with care givers and people with intellectual disability	Participants increased amount of physical activities. Psychosocial benefits included meeting new people, social integration and gaining social acknowledgements.	Long-term, sustainable and low-cost program reduces barriers to physical activities and increases health benefits. Psychosocial benefits can motivate people with intellectual disability to participate in physical activities.	Pilot. Peer reviewed primary study.
Young people(8-17) with vision impairment. (USA)	Lyndsey et al. 2010	Nutritional promotion for visually impaired, involving healthy eating, autonomy	Qualitative and quantitative research. Experimental group of 36 and control group of eight. One-week intervention program Tailored program excluded visual cues and substituted tactile methods. Applied social determination theory (individual motivation and social context criteria).	Investigated how health intervention affected acquisition of nutritional knowledge. Intervention was effective. Experimental group (visually impaired) increased its knowledge of nutrition compared to control group. Level of impairment and age did not influence acquisition of nutritional information.	There is need for information that is tailored to the needs of visually impaired people. The more the children knew about nutrition, the more choices they have and will have control over their lives. Education and provision of accessible information and support from staff are important.	Peer reviewed primary study.

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with intellectual disability recruited through community based organisation (South Carolina, USA)	Mann et al. 2006	Program emphasised benefits of weight loss, exercise, nutritional choice and stress reduction.	Eight-week health education program involving participatory and statistical analyses and linear regression. 192 overweight and obese adults with mental retardation. A Steps For Your Health curriculum was developed that emphasised exercise, nutritional choice and stress reduction. Eight classes of 90 minutes. Evaluation done in week 9.	Participation in the Steps For Your Health resulted in increased knowledge, healthier self-reported diet, more frequent physical activity and reduction in MBI immediately after program completed (reduction in body mass index by 2.3 kg for 26% of participants). Stress reduced. Increased knowledge about healthy diet and exercise were reasons for changes. However, weight loss was not significant.	Knowledge of healthy diet and lifestyle associated with BMI and weight loss. Exercise and healthy eating are important components of active treatment for people with a disability and should be a priority for service providers and families of people with intellectual disability.	Primary study Peer reviewed
246 people with mobility impairment. Community-based organisations recruited participants (US)	Ravesloot, Seekins & Cahill 2007	Evaluation of health promotion in eight states in the US through community bases centre	Randomised trial of 246 people with mobility impairment Participatory action research Logistic regression used in analysis. Design included a curriculum of 10 chapters on goal setting, problem solving, attribution training, depression, communication, information seeking, nutrition, physical activity, advocacy and maintenance. Data analysis SPSS.	There were reductions in three outcome variables. Participants reported fewer symptoms/limitations from secondary conditions, fewer unhealthy days and less health care utilisation. Program affected policy change, e.g. the Health Promotion and Prevention America Act of 2005 to promote funding for health promotion interventions for people with disability was based on part on the Living Well with Disability outcomes. Several organisation adopted program and training. In Iowa, disability program implemented and staff adopted living well concepts.	 Positive outcome because of approach in design and development of program. Trusting people with disability. Using participatory research methods to involve people with disability in the development and implementation of program and evaluation strategy; using health behaviour theories consistent with the values and experiences of target population. Training of group facilitators and mentoring of facilitators and sharing of information important. 	Intervention, research article. Peer reviewed. Strong methodology section.

Population studied/ participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Active living for people with physical disability in urban centres. Presence of supportive elements.	Spivock, Gauvin & Brodeur 2007	Environment/building access	Part of a larger project. Qualitative and quantitative. Observers recruited in 2003 and trained in field observations. They observed preestablished routes constructed around 10 randomly selected street segments and scored out of 10 on active living friendliness, safety and density of destinations.	Few neighbourhoods had environmental buoys to support active living for people with physical disabilities. Lower level of neighbourhood activity friendliness.	 Environmental buoys important for active living but many communities do not have them. Ability to manage stairs, curbs, slopes, obstacles and signs were important determinants of mobility among disabled. Modification to urban design and land-use policies is effective in increasing physical activity for general population, including people with disability. 	

ACCESS TO HEALTH SERVICES

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of Intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Systematic review Cochrane review	Balogh et al. 2009	Literature review	Systematic, Cochrane review of health care services for adults with intellectual disability.	Limited results found. Contributes to gaps in knowledge.	Further research is needed 'to determine the effects of different ways to organise (mainstream health) services for people with intellectual disability. Most studies focused on people who had intellectual disability and mental health problems but there were no studies on people who had intellectual disability and physical problems.	Systematic, Cochrane review.
Parents and support workers of adults with intellectual disability	Brolan et al. 2012	Interview to review understanding and experiences of advocacy.	Part of a larger randomised control trial – thematic analysis of qualitative research interviews.	 Number of concerns raised, including access to quality health care. Recommendation: policy and practice obligations under the CRPD support advocacy efforts in this area, for people with intellectual disability. 	Employing health advocacy, using the United National Convention on the Rights of Persons with Disabilities (CRPD) where necessary, to promote the health rights of people with a disability, and the obligations of governments to meet the needs of people with a disability in this area.	Review article.
Fifty people aged 20- 79 with intellectual disability, over one year (Glasgow, Scotland)	Cooper et al. 2006	Access to treatment and health system	Fifty people with intellectual disability matched with 50 without (control participants). Assessment after one year via semi structured interviews.	Health checks useful in identifying health needs. Health need detection was more than twice for intervention group compared to control participants. The level of health promotion needs was greater. More monitoring needs were met.	There are sustained benefits in health outcomes from clinical interventions for adults with intellectual disability compared to standard treatment alone. These positive outcomes could be achieved with few staff, minimal training, equipment and additional costs.	Peer reviewed. Peer reviewed.
First year health care students	lacono et al. 2011	To analyse the use of DVD stories about people with a disability with allied health students.	 DVD intervention showing woman with developmental disability and complex health needs. Quantitative attitude scales pre- and post-testing. Qualitative interviews post-intervention. 	 Quantitative data did not show significant differences in attitudes pre- and post-intervention. Qualitative data showed shift in assumptions, perceptions and understandings of disability shown on DVDs. 	Providing training to pre-service allied health professionals increases knowledge, confidence and ability to communicate.	 Primary study. Peer reviewed. Differences between qualitative and quantitative needs to be further evidenced.

Access to health services (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of Intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
Systematic literature review - focus on: people with intellectual disability	Krahn, Hammond & Turner 2006	Reviews intervention and promising practices from perspective of people living with intellectual disabilities, providers of care and services Recommendations for future from a policy perspective.	Comprehensive literature search of MEDILINE, PsychINFO and Canahi databases	 Medication for psychiatric issues – common. Disparities in access to health care identified, across early intervention, reduction of secondary conditions, empowering caregivers to meet health needs, and health promotion across the lifespan. Health promotion required to ensure equitable access to health care – reduce the barriers/disparities currently identified. There is need to improve training of healthcare staff and providers, service coordination and systemic changes. In summary, intervention must be at multiple levels and address multiple issues. 	Access to health services for people with disability: number of ways to overcome disparity in access identified.	 Comprehensive systematic review. Peer reviewed.
Adults with intellectual disability living in supported accommodation setting (Australia) GPs and carers also considered as participants	Lennox et al. 2007	Access and treatment in the health system. Provision of information to enhance interactions between people with intellectual disability, carers and GPs.	Cluster randomised trial. GP clinical records. CHAP tool (booklet with sections for carer and GP). Intervention group comprised 17 clusters with 134 people with intellectual disability, control group 17 clusters with 219 adults. 118 residential staff and 120 GPs participated.	 Increased health promotion, disease control increased in intervention group. There was six times increase in detection of visual impairment, a 30-fold increase in hearing testing, an increase in immunisation testing and improvement in women's health screening. The intervention increased detection of new diseases six times. Two Australian states have implemented the tool based on particular population needs. 	Healthcare intervention was acceptable to people involved. Comprehensive program increased GPs focus in health needs of people with intellectual disability. CHAP process reduced barriers in health care, made information accessible and improved communication between people with ID, carers and GPs and enabled GPs to focus on core health issues for this group. Helpful where there is high turnover of care staff (health history is recorded and transferred).	 Randomised trial. Primary study, peer reviewed.

Access to health services (continued)

Enabling Health – Appendix 2

Population studied/ participants	Reference	Focus of Intervention/article	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with a disability (US)	Rimmer & Rowland 2008	How to deliver health promotion for people with disability.	A review – no methodology section to describe type of review undertaken.	 Priority for health promotion is to prevent secondary conditions. Health professionals should prioritise establishing disability-friendly environments that will reduce barriers (architectural, programmatic and attitudinal). This will enable people with a disability to be empowered to participate in health promotion practices. 	Different learnings for different sections of resource. For health access: Need to provide both an enabling environment and an empowerment model for individuals.	 Peer reviewed, but no methods section. Not a research article.
Undergraduate medical students	Tracy & lacono 2008	Communication skills session conducted as an intervention. Tutors in session had a disability that involved communication impairment.	Attitude scale completed pre- and post-intervention.	Significant change in attitudes post- intervention, with students identifying a greater level of understanding and insight into the communication issues faced by people with disability. Found valuing people as individuals also improved as a result of the intervention.	The value of training pre-service workers – in order to provide good quality health care in the future.	 Primary intervention research study. Peer reviewed.
Adults with intellectual disability; also GPs who regularly provided services to people with intellectual disability and health advocates (including family, caregivers etc.)	Ziviani et al. 2004	Evaluate the experiences of communication within the GP/primary health care setting with people with intellectual disability.	 Program evaluation: communication with GPs. Qualitative research: interviews and observations. 	Conceptual model proposed – with attention to training, access, adequate preparation for the appointment, and shared information.	Ways to overcome disparity in access to primary health care, including: • preparing for appointment • establishing relationships with regular GP • role of support worker in monitoring adequate records • GPs learning alternative communication methods for patients who are non-verbal.	Primary study.Peer reviewed.

SELF-DETERMINATION

Enabling Health – Appendix 2

Population studied / participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Systematic Cochrane Review	Duncan, Best & Hagen 2010	Shared decision making interventions for people with mental health conditions.	Systematic Cochrane Review.	Unable to make firm conclusions, no evidence of harm, but no established or proven intervention either.	Contributes to gaps in knowledge – need for further research.	Systematic review. Cochrane Review.
Proposal for National Disability Insurance Scheme (NDIS) (Australia)	Foster et al. 2012	Discussion article	Discussion of Productivity Commissions' proposal for an National Disability Insurance Scheme (NDIS). Case studies used as illustrations, draw on international experience to inform Australia.	 Many conceptual tensions exist in current proposal. Personalisation and entitlement are key concerns of NDIS. Need to recognise the complex policy domain this involves. 	Providing individualised funding to people with disability is a way of promoting self-determination. This is a key element of the NDIS – such a scheme should be allocated according to need on basis of entitlement.	Peer reviewed.
Disability support workers working with people with intellectual and developmental disabilities	lacono 2010	Opinions and perspectives	Discussion of issues	Need for support and supervision to facilitate positive outcomes. Risk associated with neglecting needs of staff – unengaged, poorly trained. Meaningful changes are required.	Challenge in Australia: current lack of skill within disability support system, particularly with staff.	Opinions and perspectives article only. Not a research article.
Systematic review	Kozma, Mansell & Beadle- Brown 2009	Review of outcomes in different residential settings for people with intellectual disability.	Systematic review: 68 articles included.	Community based services are 'superior' to segregated, congregate services Basic model of care underlying all services is important in determining outcomes.	The role of community-based services in ensuring self-determination for people with intellectual disability – role of accommodation services in facilitating self-determination.	Systematic review. Peer reviewed.

Self-determination (continued)

Enabling Health – Appendix 2

Population studied / participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
182 adults (92 men and 90 women), with intellectual disability, living in community settings (Canada, US, Ireland, Belgium, France)	Lachapelle et al. 2005	Evaluate the relationship between self-determination and quality of life.	Evaluation of relationship between self-determination and quality of life. Self-determination measured by the Arc's self-determination scale – a 72-item scale which measures autonomy, self-regulation, psychological empowerment, self-realisation. Also used quality of life questionnaire – a 40-item rating scale designed to measure quality of life for people with intellectual disability.	Results show that self-determination improves quality of life (discriminant function analysis/self-determination and quality of life correlated). Self-determination defined as acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference.	Self-determination enhances quality of life. Gaps in knowledge: while a link between self-determination and quality of life has been confirmed, more research is required in this area.	Primary study Peer reviewed Limited relevance to Australia where QOL measures established for Australian context
Detailed study and analysis of ten initiatives (US, Canada, Australia)	Lord & Hutchinson 2003	Analysis of current individualised support initiatives to establish capacity-building and inclusion.	Identified several successful individual support arrangements – thematic analysis.	Individualised support can build capacity if embedded in new paradigm of disability and community. Consumer-driven supports must be individualised and based on self-determination	Contributes to understanding of how NDIS may contribute to self-determination for people with disabilities in Australia.	Research article Peer reviewed
Focus on people with disability	Rimmer & Rowland 2008	How to deliver health promotion for people with disability.	A narrative review – no methodology section to describe the type of review undertaken.	Priority for health promotion is to prevent secondary conditions. Health professionals need to give greater priority to establishing disability-friendly environments that will reduce barriers (architectural, programmatic and attitudinal). This will enable people with a disability to be empowered to participate in health promotion practices.	Policy and legislative reforms can promote disability-friendly environments that will reduce architectural, programmatic and attitudinal barriers that make it difficult for people with disability to engage in self-initiated health promotion activities.	 Peer reviewed. No methods section. Not a research article.

Self-determination (continued)

Enabling Health – Appendix 2

Population studied / participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
People with intellectual and developmental disabilities attending a rural educational residential program (Victoria)	Sheppard & Unsworth 2011	Autonomy and self- determination	Quasi experimental program with 31 participants over 18 months to assess a short-term educational residential program. Structured design to assess self-determination, life management, recreational leisure and social/vocational skills. Pre and post testing. No control group used.	 Participants increased skills in self and family care. Life management improves significantly at three months post-intervention phase. However, skills for social/vocational didn't improve significantly but participant self-rated scores on self-determination improved with small effect size at post program. Teacher ratings of capacity for self-determination behaviours increased significantly. Students' own ratings improved between baseline and post-program and follow-up. 	Interventions to improve performance in daily activities related to autonomous functioning can also improve self-determination. As participants improved skills in daily activities, they were given greater autonomy and independence.	Research article. Peer reviewed.
Examines Australian legislation	Stancliffe 2012	Review of inclusion for people with disability in Australia.	Reviews Australian legislation, national survey of disability services, inclusion of service provision, to draw conclusions about people with disability.	Ongoing heavy reliance on segregated services. Evaluation of inclusion is not possible due to data not being available.	Practising self-determination will include: • enabling people to live more independently • facilitating the delivery of more individualised services where choice-making can be routinely provided • providing opportunities for people with disability to receive higher education and to transition to genuine work opportunities • incorporating instruction in self-determination and problem solving skills within school curriculum.	Research article. Peer reviewed.

Self-determination (continued)

Enabling Health – Appendix 2

Population studied / participants	Reference	Focus of intervention	Design and methods	Outcome/results	Key learnings	Description of article/notes
Adolescents with disabilities attending special education services under the category areas of 'mental retardation or learning disabilities' (i.e. intellectual or developmental disabilities).	Wehmeyer et al. 2013	To establish a causal relationship between efforts to promote self-determination and the enhancement of self-determination in group of adolescents with disabilities.	Randomised control trial. Students in intervention group received instruction program in self-determination. Students in intervention group over three years showed significantly greater improvement in self-determination.	In brief, self-determination program linked to improvements for intervention group showed significantly greater growth in self-determination over three year period than placebo group.	A number of key elements contribute to successful self-determination programs for people with disability, including: • integrating with transition services • teaching autonomous behaviours • assessing preferences • promoting self-awareness and self-knowledge.	Research article. Peer reviewed.
Systematic review. People with intellectual disability	Wullink et al. 2009	Review explored published studies to find information on the way in which people with intellectual disability exercise autonomy in relation to health. Focus was on everyday activities, such as making an appointment with a physician, discussing visits to the doctor with a support worker, being interviewed during research studies or taking part in a program to give up smoking.	Searches in Cochrane, Medline and PsycINFO, with 39 out of 791 articles included: 14 of these on self- determination (7 on independence, 15 on self-regulation, 3 on self-realisation).	 Good communication is a prerequisite of autonomy and health workers have opportunities to improve their own skills and to stimulate the communication skills of people with intellectual disability. Technology and skills training are important as is setting of goals for improving skills of people with intellectual disability. Many studies have made recommendations about how to increase the autonomy of people with intellectual disability but putting recommendations into practice is difficult. Self-determination and autonomy can be taught. Training for people with intellectual disability in autonomy and self-determinant is a must but improving autonomy in relation to health is not easy to achieve. Policy and practice recommendations include: tailored prevention programs about cigarettes, alcohol and illicit drugs teaching health workers, parents and people with intellectual disability the skills to ensure that they can exercise autonomy (e.g. menstrual management). 	Gaps: In spite of decades of promoting autonomy, the exercise of autonomy in relation to health has so far rarely been an issue in the literature.	Systematic review