

## Reading list of the Expertise Centre Independent Living

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### 1. Theoretical models

#### 1.1. Independent Living Movement

Barnes, C. (2007). 'Direct payments' for personal assistants for disabled people: a key to independent living? Unpublished document, Centre for Independent Living, Dublin, Conference 'Independent Living 2007', Croke Park Conference Centre, Dublin 3, Tuesday, June 5th 2007.

Brisenden, S. (1986). Independent living and the medical model of disability. *Disability, Handicap & Society*, 1(2), 173-178.

Opinion article by a peer counsellor. Accent on terminology and social model.

Independent Living Vlaanderen vzw (2000). *We zijn nog niet thuis! Twaalf jaar strijd voor een Persoonlijk Assistentiebudget in Vlaanderen*. Antwerpen: EPO drukkerij.

The long way ILV has covered. A bundle of texts by users.

#### 1.2. Social model

Burchardt, T. (2004). Capabilities and disability: the capabilities framework and the social model of disability. *Disability & Society*, 19(7), 735-751.

Comparison between the social model and the 'capabilities-frame. Consequences regarded from both paradigms..

#### 1.3. Disability rights discourse

Houston, S. (2004). The centrality of impairment in the empowerment of people with severe physical impairments. Independent living and the threat of incarceration: a human right. *Disability & Society*, 19(4), 307-321.

The right to live independently is regarded not only as empowerment, but as a fundamental human right.

Morris, J. (1997). Care or empowerment? A disability rights perspective. *Social Policy & Administration*, 31(1), 54-60.

Plea against 'care' which makes people dependent. Direct financing is seen as a means to reach civil rights.

#### 1.4. Quality of Life

Corbett, J. (1989). The quality of life in the 'independence' curriculum. *Disability, Handicap & Society*, 4(2), 145-163.

Effects experienced on youngsters after the transition from a life in institutions to an independent life, by means of training.

Kober, R. & Eggleton, I.R.C. (2005). The effect of different types of employment on quality of life. *Journal of Intellectual Disability Research*, 49(10), 756-760.

Effect of working on a regular job market compared to working in a sheltered working environment..

Quality of Life Research Group (2009). *Ecological Assessment Battery*. Unpublished research report, Quality of Life Research Group.

List of variables which are regarded predictors of a high or low Quality of Life..

Schalock, R. (1996). *Quality of Life volume I: conceptualization and measurement*. Washington: American Association on Mental Retardation.

Book on the conceptualization of the term 'Quality of Life', points of view of different authors.

Schalock, R. (1997). *Quality of Life volume II: application to persons with disabilities*. Washington: American Association on Mental Retardation.

Book on the possible applications of the concept 'Quality of Life' for people with a Disability.

Schalock, R. & Verdugo, M. (2002). *Handbook on Quality of Life for human service practitioners*. Washington: American Association on Mental Retardation.

Usage of Quality of Life within different contexts: education, health care, mental health care, mental disabilities, aging, and family..

Schalock, R. (2004). The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203-216.

Current situation regarding the concept and construct of Quality of Life.

Schalock, R., Gardner, J. & Bradley, V. (2007). *Quality of Life for persons with intellectual and other developmental disabilities: applications across individuals, organizations, communities, and systems*.

Washington: American Association on Intellectual and Developmental Disabilities.

Recent vision on Quality of Life for people with a mental disability. Accent on using the definition on a micro-, meso- and macrolevel..

van Loon, J., Van Hove, G., Schalock, R. & Claes, C. (2008). *Schaal voor persoonsgerichte ondersteuningsuitkomsten. Handleiding voor afname en standaardisering*. Onuitgegeven handleiding, Stichting Arduin – Universiteit Gent.

An instrument in order to scale the Quality of Life. Developed according the 8 domains by Schalock..

## **2. PAB in Flanders**

### **2.1. Description of users**

### **2.2. Assessment study**

Breda, J., Lombaert, G. & Schoenmaekers, D. (1999). *Experiment Persoonlijk Assistentiebudget. Eindverslag wetenschappelijke evaluatie*. Unpublished research report, UFSIA, Department Sociology and social policy. First study, looks at the effects of using a personal assistance budget after 1 year, draws conclusions and makes some policy suggestions..

Breda, J. & Schoenmaekers, D. (2001). *Experiment Persoonlijk Assistentiebudget. Eindverslag tweede wetenschappelijke evaluatie*. Unpublished research report, UFSIA, Department Sociology and social policy.

Second study. Regards the effects of using a personal assistance budget after 3 years and makes again some policy suggestions..

Breda, J., Van Landeghem, C., Claessens, D. & Vandervelden, M. (2004). *Drie jaar later: evaluatie van het PAB-gebruik. Eindrapport*. Unpublished research document, University of Antwerp, Department Sociology .

Final report on the experiment with the personal assistance budget (PAB). Includes a clear profile of users and assistants..

### **2.3. System**

### **2.4. Economic and social consequences**

## **3. PGB (Personal care Budget) in Flanders**

### **3.1. Description of users**

### **3.2. Assessment studies**

### **3.3. System**

### **3.4. Economic and social consequences**

### **3.5. Direct payments on the international level**

### **3.6. Inside Europe**

#### **3.6.1. Germany**

##### **3.6.1.1. Description of users**

##### **3.6.1.2. Assessment studies**

##### **3.6.1.3. System**

Bundesarbeitsgemeinschaft für Rehabilitation (2009). *The personal budget in Germany*. Consulted on 19.02.2009, [http://www.bar-frankfurt.de/upload/Vortragstext\\_Engl\\_641.pdf](http://www.bar-frankfurt.de/upload/Vortragstext_Engl_641.pdf)

#### **3.6.1.4. Economic and social consequences**

### **3.6.2. England**

#### **3.6.2.1. Description of users**

The NHS Information Centre, Social Care Statistics (2008). *Community care statistics 2007-08: referrals, assessments and packages of care for adults, England: national summary*. West Yorkshire: The NHS Information Centre.

#### **3.6.2.2. Assessment studies**

Carmicheal, A. & Brown, L. (2002). The future challenge for direct payments. *Disability & Society*, 17(7), 797-808.

Advantages and disadvantages of direct payment, seen from the users' perspective. Challenges for users and service suppliers.

Commission for Social Care Inspection (2004). *Direct payments: what are the barriers?* London: CSCI.

Concannon, L. (2006). Inclusion or control? Commissioning and contracting services for people with learning disabilities. *British Journal of Learning Disabilities*, 34(4), 200-205.

Accent on people with a mental disability. Problems with consumerism are touched upon, whereby direct payment is seen as a possible solution. Disadvantages and advantages of direct payment.

Blyth, C. & Gardner, A. (2007). 'We're not asking for anything special': direct payments and the carers of disabled children. *Disability & Society*, 22(3), 235-249.

Effect on direct payment on children with a disability and their family/Parents..

Glendinning, C., Halliwell, S., Jacobs, S, Rummery, K. & Tyrer, J. (2000). New kinds of care, new kinds of relationships: how purchasing services affects relationships in giving and receiving personal assistance. *Health and Social Care in the Community*, 8(3), 201-211.

Advantages and disadvantages of personal assistance, seen from the users' and assistants' perspective. Leece, D. & Leece, J. (2006). Direct payments: creating a two-tiered system in social care? *British Journal of Social Work*, 36, 1379-1393.

Are methods of direct payment more often used by the middle class, thus creating inequality within the social system? This research tells us this is not the case. .

Rabiee, P., Moran, N. & Glendinning, C. (2009). Individual budgets: lessons from early users' experiences. *British Journal of Social Work*, 39, 918-935.

Experiences and output from the first users of individual budgets.

Stainton, T. & Boyce, S. (2004). 'I have got my life back': users' experience of direct payments. *Disability & Society*, 19:5, 443-454.

Research on the effect on users, i.e. the user him/herself and his/her family..

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Spandler, H. & Vick, N. (2006). Opportunities for independent living using direct payments in mental health. *Health and Social Care in the Community*, 14(2), 107-115.

Accent on people with psychic problems. Disadvantages and advantages of direct payment..

Ungerson, C. (1997). Give them the money: is cash a route to empowerment? *Social Policy & Administration*, 31 (1), 45-53.

Effect of direct payment on the position of the assistant and the market..

### **3.6.2.3. System**

### **3.6.2.4. Economic and social consequences**

Barnes, C., Jolly, D., Mercer, G., Pearson, C., Priestley, M. & Riddell, S. (2004). *Devolving direct payments: A Review of policy development in the UK*. Unpublished research report, presented on Disability Studies Conference 2004, University of Lancaster, 26-28 July 2004.

Commission for Social Care Inspection (2009). *The state of social care in England 2007-08. Executive summary*. London: CSCI.

Department of Health (2003). *Direct Payments Guidance. Community care, services for carers and children's services (direct payments) guidance England 2003*. London: Crown.

Department of Health (2006). *Our health, our care, our say: a new direction for community services*. London: The Stationery Office.

Spandler, H. (2004). Friend of foe? Towards a critical assessment of direct payments. *Critical Social Policy*, 24, 187-209.

'Direct payments' are situated within the political context. Advantages and disadvantages are enlisted, with the accent on market and society. Suggestions for improvement..

Prideaux, S., Roulstone, A., Harris, J. & Barnes, C. (2009). Disabled people and self-directed support schemes: reconceptualising work and welfare in the 21<sup>st</sup> century. *Disability & Society*, 24(5), 557-569. Description of the socio-economic position of direct payments. Accent on the role as an employer..

Prime Minister's Strategy Unit (2005). *Improving the life chances of disabled people. Final report*. London: The Strategy Unit.

Scourfield, P. (2007). Social care and the modern citizen: client, consumer, service user, manager and entrepreneur. *British Journal of Social Work*, 37, 107-122.

The modern civilian as an entrepreneur and manager within English politics. The public domain is transferred onto the individual. Consequences for users (strong focus on England).

The NHS Information Centre, Social Care Statistics (2009). *Personal social services expenditure and unit costs, 2007-08*. West Yorkshire: The NHS Information Centre.

West Sussex County Council (2009). *Indirect payments*. Geraadpleegd op 17 februari 2009 op <http://www.westsussex.gov.uk/CS/MIS/251005as11.pdf>

### 3.6.3. Finland

#### 3.6.3.1. Description of users

#### 3.6.3.2. Assessment studies

#### 3.6.3.3. System

Ministry of Social Affairs and Health (1999). *Independent Living- Challenge for disability policy*. Consulted on 23.12.2009, <http://pre20031103.stm.fi/english/pao/publicat/paocontents14.htm>

The Ministry of Justice (2003). *Guardianship Services*. Consulted on 23.12.2009, <http://www.om.fi/en/Etusivu/Julkaisut/Esitteet/Holhoustoimenpalvelut>

#### 3.6.3.4. Economic and social consequences

Kinnys Ry (2009). *General information*. Consulted on 28.01.2009, <http://www.kynnys.fi/kynnys/english.html>.

Ministry of Social Affairs and Health (2006). *Government Report on Disability Policy 2006*. Consulted on 23.12.2009, <http://www.stm.fi/Resource.phx/publishing/documents/7545/index.htx>

Risikko P.(2008), *The right of people with disabilities to personal assistance is a human rights issue*. Consulted on 23.12.2009, <http://www.stm.fi/en/pressreleases/pressrelease/view/1221713#en>

Urhonen, A. (2008). *Personal Assistant System in Finland*. Unpublished presentation, Kinnys Ry.

VANE (2005). *Services and assistance for the disabled act*. Consulted on 02.02.2009, <http://www.vane.to/english.html>.

### 3.6.4. France

#### 3.6.4.1. Description of users

#### 3.6.4.2. Assessment studies

#### 3.6.4.3. System

BOURGEOIS A. , DUÉE M. (2008). *Les prestations de protection sociale en 2007*. Consulted on 20.01.2009, <http://www.sante-sports.gouv.fr/IMG/pdf/er665.pdf>

Espagnol, P. (2008). *L'allocation personnalisée d'autonomie et la prestation de compensation du handicap au decembre 2007*. Consulted on 20.01.2009, <http://www.sante.gouv.fr/drees/etuderesultat/er-pdf/er637.pdf>

Maison Départementale des personnes handicapées (2008). *Prestation de Compensation de Handicap Adulte*, Valence, France, La Drome.

Maison Départementale des personnes handicapées de la Seine Saint-Denis (n.d.). *La prestation de Compensation de Handicap*, Seine-Saint Denis, Place Handicap.

Pijl, M. in opdracht van VWS (2007). *Zelf zorg inkopen: hoe gaat dat in het buitenland. Persoonsgebonden budgetten in Frankrijk*. Consulted on 20.01.2009, <http://www.minvws.nl/rapporten/lz/2007/zelf-zorg-inkopen-hoe-gaat-dat-in-het-buitenland.asp>

#### **3.6.4.4. Economic and social consequences**

A.D.A.P.E.I. (n.d.) *La prestation de compensation à domicile*. Consulted on 14.01.2009, [http://www.adapei-04.fr/oidit\\_T003\\_4akirvolnhj7.html](http://www.adapei-04.fr/oidit_T003_4akirvolnhj7.html).

Association Handimat (2008). *La prestation de compensation : les aides humaines*. Consulted on 14.01.2009, <http://informations.handicap.fr/art-allocations-aides--1898.php>.

### **3.6.5. Ireland**

#### **3.6.5.1. Description of users**

#### **3.6.5.2. Assessment studies**

#### **3.6.5.3. System**

#### **3.6.5.4. Economic and social consequences**

Egan, D. (2008). *Draft. Issues concerning direct payments in the Republic of Ireland*. Unpublished research report, The Person Centre.

### **3.6.6. The Netherlands**

#### **3.6.6.1. Description of users**

Frans Oostrik (2008). *Als je het mij vraagt. Waarom mensen kiezen voor zelfbeschikking in de zorg*. Amsterdam: Modderman Drukwerk.

Extended research on the users of the Personal Budget in the Netherlands. The focus lies on the surroundings, motivations, personal backgrounds and characteristics of the users.

#### **3.6.6.2. Assessment studies**

#### **3.6.6.3. System**

#### **3.6.6.4. Economic and social consequences**

### **3.6.7. Norway**

#### **3.6.7.1. Description of users**

Askheim, O.P. (2005). Personal assistance – direct payments or alternative public services. Does it matter for the promotion of user control? *Disability and Society*, 20(3), 247-260.  
Comparison between models enabling personal assistance (USA, England, Sweden and Norway).

Askheim P. O. (2008). Personal Assistance in Sweden and Norway: From Divergence to Convergence? *Scandinavian Journal of Disability Research*, 10(3,) 179-190.

Askheim P. O. (2008), *Personal assistance service in Norway*, consulted on 10.02.2009, [http://www.apeirons.lv/down/PA/1\\_PA\\_service\\_in\\_Norway\\_OlePetterAskheim.pdf](http://www.apeirons.lv/down/PA/1_PA_service_in_Norway_OlePetterAskheim.pdf)

Uloba, *About Uloba*, consulted on 23.12.2009, <http://www.uloba.no/templates/Page.aspx?id=223>

#### **3.6.7.2. Assessment studies**

#### **3.6.7.3. System**

#### **3.6.7.4. Economic and social consequences**

### **3.6.8. Spain**

#### **3.6.8.1. Description of users**

Ripollés, A., Rodríguez-Picavea Matilla, A., Romañach Cabrero, J. (2006), *Asistencia personal para la vida independiente y la promoción de la autonomía de las personas con diversidad funcional en España*. Consulted on 23.12.2009, [http://www.minusval2000.com/relaciones/vidaIndependiente/asistencia\\_personal\\_vida\\_independiente\\_y\\_promocion/index.html](http://www.minusval2000.com/relaciones/vidaIndependiente/asistencia_personal_vida_independiente_y_promocion/index.html)

Arnau Ripollés, S.(n.d.), *Nace la primera oficina de la Vida Independiente de España, en la comunidad de Madrid*. Geraadpleegd op 23 december 2009 op [http://www.minusval2000.com/relaciones/vidaIndependiente/pdf/primera\\_oficina\\_vida\\_independiente.pdf](http://www.minusval2000.com/relaciones/vidaIndependiente/pdf/primera_oficina_vida_independiente.pdf)

Portal Mayores(n.d.), *Ley de promoción de la autonomía personal y atención a personas en situación de dependencia*. Geraadpleegd op 23 december 2009 op <http://www.imsersomayores.csic.es/landing-pages/ley-autonomia-personal.html>

#### **3.6.8.2. Assessment studies**

#### **3.6.8.3. System**

LEY 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.

#### **3.6.8.4. Economic and social consequences**

### **3.6.9. Sweden**

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### 3.6.9.1. Description of users

Blanck C., Scherman A., Sellin K. (2006), *Ten years with Personal Assistance*. Consulted on 23.12.2009, <http://www.jag.se/kunskap/10%20years.pdf> .

Askheim P. O. (2008). Personal Assistance in Sweden and Norway: From Divergence to Convergence? *Scandinavian Journal of Disability Research*, 10(3,) 179-190.

### 3.6.9.2. Assessment studies

### 3.6.9.3. System

Hayward R.(2007), Country Report Sweden. In: Beadle-Brown J., Kozma A., *Deinstitutionalization and community living – outcomes and costs: report of a European Study. Volume 3: Country Reports.(524-541)* Canterbury: Tizard Centre, University of Kent.

Pijl, M. in opdracht van VWS (2007). *Zelf zorg inkopen: hoe gaat dat in het buitenland. Persoonsgebonden budgetten in Zweden*. Consulted on 20.01.2009, <http://www.minvws.nl/rapporten/lz/2007/zelf-zorg-inkopen-hoe-gaat-dat-in-het-buitenland.asp>

### 3.6.9.4. Economic and social consequences

Berg S. (2003), *Personal Assistance in Sweden*. Geraadpleegd op 23 december 2009 op <http://www.independentliving.org/docs6/berg20030520.html>

Boeykens, J. (2007), *Persoonlijk assistentiebudget: een vergelijking van deze zorgvorm in Vlaanderen en in Zweden*. Licence thesis , department Orthopedagogy, University Ghent.

Egan, D. (2008). *Draft. Issues concerning direct payments in the Republic of Ireland*. Unpublished research report, The Person Centre.

Jeppsson Grassman, E., Whitaker, A., Taghizadeh Larsson, A. (2009) Family as failure. The role of informal helpgivers to disabled people in Sweden. *Scandinavian Journal of Disability Research*, 11 (1) 1-16.

Lewin B., Westin, L., Lewin L., Needs and ambitions in Swedish Disability Care'. *Scandinavian Journal of Disability Researc*, 10(4). 237-257.

Ratzka A.(2007), *Independent Living for people with disabilities: from patient to citizen and customer. Keynote at the conference in Barcelona*. Consulted on 23.12.2009, <http://www.independentliving.org/docs7/ratzka20071022.html>

Ratzka A.(2004), *The Swedish Personal assistance act of 1994*. Consulted on 23.12.2009, <http://www.independentliving.org/docs6/ratzka20040623.html>

### 3.7. Outside Europe

#### 3.7.1. United States of America

##### 3.7.1.1. Description of users

##### 3.7.1.2. Assessment studies

Carlson, B., Foster, L., Dale, S.B. & Brown, R. (2007). Effects of cash and counseling on personal care and well-being. *Health Services Research, 42(1)*, 467-487.

Effect of cash and counseling on users.

##### 3.7.1.3. System

##### 3.7.1.4. Economic and social consequences

Moseley, R.C. (2005). Individual budgeting in state-financed developmental disabilities services in the United States. *Journal of Intellectual & Developmental Disability, 30(3)*, 165-170.

research on 'individual budgeting' in the USA. Concludes there exists a great variety..

#### 3.7.2. Australia

##### 3.7.2.1. Description of users

##### 3.7.2.2. Assessment studies

Ottman, G., Laragy, C. & Haddon, M. (2009). Experiences of disability consumer-directed care users in Australia: results from a longitudinal qualitative study. *Health and Social Care in the Community, 17(5)*, 466-475.

Longitudinal research on consumer-directed care. Impact on families supporting a person with a disability.

Brown, C. & Ringma, D. (1989). New disability services: the critical role of staff in a consumer-directed empowerment model of service for physically disabled people. *Disability, Handicap & Society, 4(3)*, 241-257.

critical remarks on supporters/personal assistants. How can empowerment be enabled?

##### 3.7.2.3. System

##### 3.7.2.4. Economic and social consequences

### 4. Research methodology

#### 4.1. Peer counselors in research

Beresford, P. (2000). Service users' knowledges and social work theory: conflict or collaboration? *British Journal of Social Work, 30*, 498-503.

Plea for inclusive research and formation of theories.

Beresford, P. & Branfield, F. (2006). Developing inclusive partnerships: user-defined outcomes, networking and knowledge – a case study. *Health and Social Care in the Community*, 14(5), 436-444. Plea for gathering outcome-directed evaluations and involving users.

Beresford, P. (2007). User involvement, research and health inequalities: developing new directions. *Health and Social Care in the Community*, 15(4), 306-312.

The role of having users involved in the research. Accent on advantages, disadvantages, ideology and forms of expression, but also on contribution to research.

Glasby, J. & Beresford, P. (2006). Commentary and issues: Who knows best? Evidence-based practice and the service user contribution. *Critical Social Policy*, 26, 268-284.

Critical remarks on evidence-based working methods. Proposal for knowledge-based working with peer counselors. Examples are discussed..

Lindow, V. (1999). Evaluation of the national user involvement project. *Joseph Rowntree Foundation Report*.

Conclusions drawn from a project concerning having users involved in research and practice.

#### **4.2. Research tools**

Maes, B., Bossaert, G., Kuppens, S. & Buntinx, W. (2008). *Inschaling van bijzondere doelgroepen met de Supports Intensity Scale (SIS-NL1.0): besluit en beleidsaanbevelingen*. Unpublished research report, K.U.Leuven, Faculty Psychology and Pedagogic Sciences.

Research on the usability of the SIS expanded to people other than those with a mental disability..

### **5. Texts written by Expertise Centre Independent Living**

#### **5.1. Direct payments in Europe**

Expertise Centre Independent Living (2009a). *Summary Germany*. Unpublished text.

Expertise Centre Independent Living (2009b). *Directe financiering in Engeland*. Unpublished text.

Expertise Centre Independent Living (2009c). *Summary England*. Unpublished text.

Expertise Centre Independent Living (2009d). *Report Finland*. Unpublished text.

Expertise Centre Independent Living (2009e). *Summary Finland*. Unpublished text.

Expertise Centre Independent Living (2009f). *Report bis direct financing France*. Unpublished text.

Expertise Centre Independent Living (2009g). *Summary France*. . Unpublished text.

Expertise Centre Independent Living (2009h). *Information brochure Ireland*. Unpublished text.