Disability and Mental Health in Ireland

Searching out good practice

GENIO

Forging alliances for
an inclusive society

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Genio's mission is to accelerate the availability of proven,
cost−effective, personalised supports and information, enabling
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social exclusion to lead full lives.

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1 Identify and promote good examples of cost−effective, personalised supports for
 people with disabilities and mental health difficulties

2 Provide the evidence required to accelerate the availability of these supports

3 Support the development of strategic self−advocacy

4 Facilitate and capacity−build cross−sector collaboration between key stakeholders
 (individuals at risk of social exclusion, statutory agencies, NGOs and
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5 Provide practical support in the form of expertise and funding

6 Offer independent research and evaluation

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DISABILITY AND MENTAL HEALTH IN IRELAND

SEARCHING OUT GOOD PRACTICE

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Many individuals and organisations were consulted over a period from 2006 to 2009 and took time to respond to requests for information, providing valuable comment and input, which informed the preparation of this report. These included people with disabilities and mental health difficulties, representative organisations, statutory agencies, non-governmental organisations (including advocacy groups and providers' federations), researchers and leaders of demonstration projects. Their contribution is gratefully acknowledged. A list of main contributors is in Appendix A.

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Executive Summary

There is a significant challenge facing the way in which services are provided to people with disabilities and mental health difficulties. The research evidence indicates that services and supports that encourage self-determination and provide opportunities for inclusion and participation, not only achieve good outcomes for the individual, but do this cost-effectively. National policy statements indicate that person-centred services that encourage inclusion should be available to people with disabilities and mental health difficulties. Most importantly, however, people with disabilities and mental health difficulties themselves have indicated very clearly that they want supports (and services when necessary) that do this in a real way. They want support to live in their own homes; to work in real jobs; and to be active, contributing citizens.

In spite of the research evidence, the policy statements and the desire of service users, many of the services for people with disabilities and mental health difficulties in Ireland do not work in this way. Many services still segregate people with disabilities and mental health difficulties, provide services to them in groups and work in a way that maintains this separateness. Many services do not encourage or enable the person to be self-determining or to participate in society in a meaningful way, on their own terms. This gap between what people with disabilities want and what is provided is captured in the words *'Thank you for everything that you've done ... for all the services that there are ... But what you have built, we don't want.'*[1]

The research reported here is part of a strategy designed to address this gap between the supports desired by people with disabilities and mental health difficulties and those currently provided in some parts of the country. This strategy aims to identify, develop and extend good practice, supported by advocacy and research, in order that they can be offered to more people with disabilities and mental health difficulties.

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[1] Rebecca Coakley, National Consortium on Leadership and Disability. Taken from Agosta, J. (2009) *Thinking through a next generation of services for people with intellectual and other disabilities.* NDA Conference, October 2009.

A number of services and initiatives for people with disabilities and mental health difficulties were identified in Ireland as pockets of 'good practice' in terms of being person-centred, encouraging self-determination and operating in a sustainable, cost-effective way. Twenty three such 'projects' were identified. Some of these are projects within larger organisations, others represent whole organisations. On the basis of wide-ranging consultation, a set of criteria was developed and used to assess these projects to determine, in a systematic way, the extent to which their practice was person-centred and cost-effective. Twenty-one projects participated in the assessment process. Examples of relevant practice were also identified from the international literature.

These findings are being used to inform the way in which person-centred sustainable supports and services can be evaluated, supported and extended to those who could benefit.

Quality cost-effective services for people with disabilities and mental health difficulties

1. Background

1.1 Developing a strategy to improve services

In 2005 The Atlantic Philanthropies commissioned an assessment of the disability and mental health sector with a view to identifying investment opportunities.[2] Information was drawn from a review of available documentation and interviews with fifty stakeholders including personnel from government departments, the Health Service Executive (HSE), people with disabilities and mental health difficulties, representatives of Non-Governmental Organisations (NGOs) including coalitions and alliances, researchers and academics. This assessment was based on a consideration of information available on people with disabilities and mental health difficulties and their needs; relevant legislation and policy; the provision, quality and funding of services; and the strength and coherency of advocacy. This assessment identified a clear consensus amongst stakeholders that services need to be 'person centred' (in line with government policy), cost effective and available to support people with disabilities and mental health difficulties to live as equal and valued citizens in the community. An investment strategy was proposed that would allow the Atlantic Philanthropies to make a contribution to help meet the challenges inherent in improving and extending services in a cost-effective, person-centred direction. The proposed strategy has three key inter-related strands; to identify and develop:

- **Effective supports and services for people with disabilities and mental health difficulties that represent value for money;**
- **Independent advocacy focused on the development and extension of such responses;**
- **Research and evaluation that ensures responses that reflect best practice internationally in both advocacy and services and supports.**

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[2] Clarke, M. (2006) Report on Disability and Mental Health, Republic of Ireland for the Atlantic Philanthropies (internal report).

In 2008 the Atlantic Philanthropies provided support to the *Person Centre* to develop an operational plan detailing how the strategy could be implemented. The *Person Centre* is a non-profit organisation established in 2008 to support self-determination, inclusion and equality for disadvantaged and vulnerable people including older people, people with disabilities, mental health difficulties and disadvantaged children. This report describes research undertaken between July 2008 and March 2009 to inform the development of an operational plan.

1.2 Objectives of the research

During the consultation process to develop the strategy, a number of characteristics of person-centred cost-effective services were suggested. These were used to draft possible criteria which could be used to define and identify good quality, cost-effective initiatives.

The objectives of the research were to:

1. Finalise criteria for identifying examples of person-centred initiatives that support inclusive opportunities for people with disabilities and mental health difficulties on the basis of consultation with key stakeholders;
2. Liaise with people with disabilities and mental health difficulties and with relevant personnel in the statutory, NGO and academic arenas to identify costing and delivery models that satisfy these criteria in Ireland;
3. Identify models in other countries that support person-centred, cost-efficient ways of meeting the needs of people with disabilities and mental health difficulties.

1.3 Policy and legislative context

The vision expressed in the current social partnership agreement is that 'Every person with a disability would, in conformity with their needs and abilities, have access to appropriate care, health, education, employment and training and social services' and includes, for example, the provision of 'person-centred supports for

adults with significant disabilities' and for 'long stay residents in psychiatric hospitals with a view to their movement back into community living' as priority actions.[3]

The National Disability Strategy included legislative commitments (Part 2 of the Disability Act, 2005 gives people with disabilities a right to individual needs assessment without regard to available resources), a promised multi-annual funding package to support new service development and a suite of plans from six key Government Departments.[4] The Health Information and Quality Authority has issued Standards for the Assessment of Need which state 'the assessment of need is person centred at all stages. The person is enabled to express what is important to him/her as a person. The assessment of need is built around the person, appreciates the person as an individual and focuses on outcomes important to him/her.'[5]

There is a particular and growing emphasis in national policy on a more individualised, 'person-centred' approach to meeting needs. The extent to which service users are satisfied that services fit their needs, rather than the reverse, is fast becoming the most important benchmark of quality. It is current policy to de-institutionalise people with intellectual disabilities, to close psychiatric hospitals in favour of 'providing accessible community-based, specialist services for people with mental illness' and the 'involvement of service users and their carers [in] every aspect of service development',[6] to educate children with special educational needs in an 'inclusive environment'[7] and to mainstream service *provision* within an overall lifecycle approach and tailored universalism[8] as opposed to pursuing a segregated

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[3] Department of the Taoiseach (2006) *Towards 2016: Ten-Year Framework Social Partnership Agreement 2006-2015.*

[4] Department of Communications, Marine and Natural Resources (2006**)** *Sectoral Plan 2000–2009 under the Disability Act, 2005.*
Department of Enterprise, Trade and Employment **(**2006) *Sectoral Plan under the Disability Act, 2005.*
Department of the Environment, Heritage and Local Government (2006) *Sectoral Plan under the Disability Act, 2005.*
Department of Health and Children (2006) *Disability Act 2005: Sectoral Plan for the Department of Health and Children and the Health Services.*
Department of Social and Family Affairs (2006) *Disability Sectoral Plan 2006.*
Department of Transport (2006) *Transport Access for All: Sectoral Plan for Accessible Transport under the Disability Act, 2005.*

[5] Interim Health Information Quality Authority (2007) *Standards for the Assessment of Need*

[6] Department of Health and Children (2006) *A Vision for Change: Report of the Expert Group on Mental Health Policy.*

[7] Government of Ireland (2004) *Education for Persons with Special Educational Needs Act.*

[8] National Economic and Social Council (2005) *The Developmental Welfare State.*

category or 'care group' model.[9] The principles of the current national health strategy include 'a people-centred service', 'quality of care' and 'equity and fairness'.[10]

The most recent recommendations of the National Economic and Social Forum relating to mental health and social inclusion call for 'person-centred and integrated services with appropriate inter-disciplinary input'.[11]

The principal functions of the Mental Health Commission are to 'promote, encourage and foster the establishment and maintenance of high standards and good practices in the delivery of mental health services and to take all reasonable steps to protect the interests of persons detained in approved centres'.[12] The Quality Framework: Mental Health Services in Ireland produced by the Mental Health Commission comprises eight themes including an 'empowering approach to service delivery' (indicating 'active involvement through information, choice, rights and informed consent') and 'family/chosen advocate involvement and support'.[13]

The National Disability Authority (NDA), established in 2000 to provide independent expert advice to Government on policy and practice, has a vision of an 'inclusive Irish society in which people with disabilities enjoy equal rights and opportunities to participate in the economic, social and cultural life of the nation' and regards human rights as a 'central value' ... 'The NDA respects the dignity and autonomy of all individuals as equal citizens.'[14]

The Office for Disability and Mental Health has been established to support the implementation of the Department of Health and Children Sectoral Plan under the Disability Act, 2005 and the implementation of recommendations of A Vision for Change[15] and Reach Out.[16] This is an important milestone development in the statutory disability and mental health institutional infrastructure as it has a broad brief including that of forging formal links with other Government Departments to 'oversee an integrated "whole of government" approach and implementation of joined up

[9] Department of Health and Children (2001) Primary Care: A New Direction.
[10] Department of Health and Children (2001) Quality and Fairness: A Health System for You.
[11] National Economic and Social Forum (2007) Mental Health and Social Inclusion.
[12] Mental Health Act 2001 Section 33 (1).
[13] Mental Health Commission, Quality Framework: Mental Health Services in Ireland.
[14] National Disability Strategic Plan 2007–2009.
[15] Department of Health and Children (2006) A Vision for Change: Report of the Expert Group on Mental Health Policy.
[16] Department of Health and Children (2005), Reach Out: National Strategy for Action on Suicide Prevention.

policy'.[17] Fostering collective responsibility across Departments is important given the traditional tendency to view the Department of Health and Children and the HSE as having almost exclusive responsibility in the areas of disability and mental health and the importance of taking a more rounded approach to identifying services, supports and opportunities necessary to promote participation. It is intended that this Office will monitor and evaluate the implementation of the multi-annual investment programme for people with disabilities.

National policy and legislation has moved towards a focus on the individual and his or her participation in identifying what he/she requires to benefit maximally from inclusion in the community. This is in keeping with developments in the international human rights context. The new Convention on the Rights of Persons with Disabilities adopted by the United Nations General Assembly in December 2006 includes the following general principle: 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.

1.4 Terminology

The term 'person-centred' is used throughout this report. Terms such as 'individualised' or 'personalised' are sometimes used interchangeably with 'person-centred'. There is increasing usage of the term 'person-centred' in the personal and social services sector and particularly in the area of intellectual disability. The term which most effectively captures the idea of person-centredness in mental health is 'recovery'. The term that is most often used in the area of physical disability to describe the kind of thinking encapsulated by 'person-centredness' is 'independent living'. These terms are described in more detail below as they are used throughout this report.

1.4.1 Person-centred

There are various definitions which generally focus on the importance of five characteristics:[18] dignity, choice, inclusion, relationships and competence. The term 'person-centred' was initially used to describe a way of working with people with intellectual disability that was the opposite of 'service-centred'. Service-centred

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[17] Department of Health and Children, Press Release, 30 January 2008, *Taoiseach and Minister for Health and Children announce the office for Disability and Mental Health and the Office for Older People.*
[18] O'Brien, J. and Lyle O'Brien, C. (1998) *A little book about person-centred planning.* Toronto: Inclusion Press.

approaches generally take as their starting point the available services. The focus tends to be on deficits and symptoms, and on services provided to groups of people with disabilities in segregated settings, with little or no choice or autonomy for the person with a disability: *'The pattern of service is largely pre-set. Thus the person is fit into the services that are available.'*[19] The adoption of a person-centred approach involves not simply a change in how services are planned and delivered, but crucially, a shift in power, from the service provider to the service user, so that the service user now determines the supports they want, when, where, how, or whether they want a 'service' at all. The person-centred approach recognises the person with a disability as a self-determining citizen.

1.4.2 Person-centred planning (PCP)

Person-centred planning is designed to assist the person to make plans for his or her future[20] and generally aims *'to expand the power people have to choose life conditions and experiences that make sense to them'*.[21]

The key characteristics of PCP can be summarised as:[22]

- placing the individual at the centre of the decision making process;
- involving family members and friends as partners, through creating circles of support;[23]
- focusing on the person's gifts, skills, capacities, strengths;
- listening to what is really important to the person, for example, what are his or her goals;
- Pursuing social inclusion and integration through inclusive means.

Although PCP was developed for use with people with intellectual disabilities, it has been advocated as a method of planning personalised support with other sections of

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[19] Kendrick, Michael J., Standardized Service Models; Innovation and The Life Potential Of People Who Receive Services, *TASH Connections,* January/February 2007, 21-23.

[20] Lyle O'Brien, C. and O'Brien, J. (2000) *The Origins of Person-Centred Planning: A Community of Practice Perspective.* Responsive Systems Associates, Inc. http://thechp.syr.edu/PCP_History.pdf

[21] O'Brien, J. and Lyle O'Brien, C. (1998) *A little book about person-centred planning.* Toronto: Inclusion Press.

[22] Sanderson, H. (2000) *Person-Centred Planning: Key Features and Approaches.* Rowntree Foundation.

[23] A circle of support refers to a group of people who come together to assist the individual in implementing his or her plan. There is an emphasis on family, friends and unpaid support, although paid staff can also be part of a circle of support.

society who find themselves disempowered by traditional methods of service delivery.[24]

The implications of taking a person-centred approach to providing services are described in the UK government strategy document *Valuing People*[25]: '*When we use the term "person centred", we mean activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society. Person centred planning discovers and acts on what is important to a person. Person centred approaches design and deliver services and supports based on what is important to a person. Hence person centred planning can promote person centred approaches.*' However, *Valuing People* cautions against using as '*an end in itself. ... There are serious risks in focussing on achieving plans rather than changing lives.*'

Kendrick also cautions against an over-reliance on PCP and notes that '*none of these methods can work if they are not undertaken by people who have cultivated in themselves the capacity to enable the person to remain at the centre of all thinking*'. [26]

1.4.3 Independent Living

'Independent Living' is the term used to describe a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. A descriptive definition notes '*Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and interests, and start families of our own.*'[27]

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[24] Thompson J., Kilbane J. and Sanderson H. (2008) *Person Centred Practice for Professionals*. Open University Press.

[25] Secretary of State for Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. The Stationery Office.

[26] Kendrick, M. (2004) Some Predictable Cautions Concerning the Overemphasis and Over-Reliance on Person-Centred Planning, *The Frontline of Learning Disability*, Issue 58, Dublin.

[27] http://www.independentliving.org/

The Independent Living movement is widely acknowledged to have its origins in the civil rights movement of the 1960s in the US. The first Centre for Independent Living was opened in California in 1972. These Centres were created to offer peer support and role modelling, and were run and controlled by persons with disabilities. This model is replicated today as more Centres for Independent Living (CILs) open around the world. The first Irish CIL opened in 1992 and there are now 26 throughout the island of Ireland.

1.4.4 Recovery

The term 'recovery' is now widely used in mental health and describes a concept that is similar to that of person-centred. Recovery in this context is defined as:

> *A deeply personal, unique process of changing one's attitudes, values, feelings, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of a new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness....* [28]

The provision of recovery-oriented mental health services is now a policy aim in several countries (for example, Ireland, the UK, the US and New Zealand). However, there is confusion over the term, largely because of the common understanding of the word recovery. It is argued that there are two overlapping conceptualisations of recovery.[29] Firstly, the common use of the word recovery referring to the return to a normal or healthy state, with no symptoms of illness. Although this is not the most common outcome for mental illness, in the case of at least 25% of people diagnosed with mental illness, recovery occurs.[30] For the 75% of those who do not 'recover' in this sense, mental illness is not a permanent condition for many people and the entirety of their lives is not affected.

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[28] Anthony, W.A. (1993) Recovery from mental illness: The guiding vision of the mental health system in the 1990s. *Psychosocial Rehabilitation Journal*, **16**, 11-23.

[29] Davidson, L. et al. (2009) *A Practical Guide to Recovery-Oriented Practice: Tools for Transforming Mental Health Care.* Oxford University Press, New York.

[30] Davidson, L. and Roe, D. (2007) Recovery from versus recovery in serious mental illness: One strategy for lessening confusion plaguing recovery. *Journal of Mental Health*, **16**, 459-470. This paper cites several rigorous, longitudinal studies of outcome in mental illness.

The second conceptualisation of recovery describes how a person can recover their life, without necessarily 'recovering from' their illness.[31] Mental illness is regarded as one aspect of an otherwise whole person. Emphasis is placed on the individual having power through taking control of his or her life and making choices, in essence being self-determined. The implication for service provision is that a 'whole person' perspective is taken, with an emphasis on collaboration and choice rather than coercion. This concept of recovery *'refers primarily to a person diagnosed with a serious mental illness reclaiming his or her right to a safe, dignified and personally meaningful and gratifying life in the community while continuing to have a mental illness. It emphasizes self-determination and such normative pursuits as education, employment, sexuality, friendship, spirituality'.*[32]

'Person-centred', 'independent living', 'recovery' all share common principles such as self-determination, inclusion and citizenship. Person-centred is used throughout this report to capture these principles which in essence describe the desire for an 'ordinary' life as a valued citizen.

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[31] Ibid p.460
[32] Davidson and Roe ibid. p464.

2. Refining criteria to identify person-centred cost-effective projects

The first objective of this research was to finalise criteria which had been drafted on the basis of consultation with key stakeholders (people with disabilities and mental health difficulties and representatives of relevant statutory, non-governmental and academic organisations) for identifying examples of person-centred, cost-effective initiatives. These examples are described as 'demonstration projects' throughout this report.

The criteria were also informed by the standards and guidelines that have been developed by the agencies that play a key role in the quality assurance of disability and other social services, and mental health services.

The HIQA has a statutory mandate to develop standards for health and social care services in Ireland (excluding mental health services). This agency is responsible for monitoring healthcare quality and inspecting residential services for people with disabilities. *National Quality Standards: Residential Services for People with Disabilities*[33] have been prepared by HIQA for use in their inspection of these services. These standards have been developed following extensive consultation with service users, their families, advocates and support groups, along with those who provide and deliver services. Nineteen standards are grouped into seven domains to reflect the dimensions of a person-centred, quality service: quality of life, staffing, protection, development and health, rights, the physical environment, and governance and management.

The National Disability Authority (NDA) has a statutory remit to develop standards and codes of practice and to monitor the implementation of standards and codes in programmes and services for people with disabilities. The NDA is working towards the establishment of enforceable standards for services for people with disabilities and a process to monitor the implementation.

The Mental Health Commission has a statutory mandate to develop standards for mental health services in Ireland, to put in place a system of inspection for mental health services, and to protect the rights of those involuntarily detained in psychiatric

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[33] Health Information and Quality Authority (2009) *National Quality Standards: Residential Services for People with Disabilities.* Dublin.

hospitals. *The Quality Framework for Mental Health Services in Ireland*[34] was developed following extensive consultation with stakeholders in the mental health sector, including service users and carers. Twenty four standards were developed for measuring quality in Irish mental health services. The Quality Framework details how these standards are to be measured in mental health services.

2.1 Methodology

The criteria in this research were refined on the basis of consultation with key informants in the physical disability, intellectual disability and mental health sectors and a review of relevant documentation concerning quality and standards. Consultation was undertaken to refine criteria with a wide range of relevant groups and individuals. This consultation took the form of small group meetings, one-to-one meetings and the circulation of successive drafts seeking suggestions for clarification and amendment. A stakeholders group was convened in order to finalise the criteria and to identify examples of innovative, person-centred, cost-effective initiatives.

The leaders of demonstration projects were also given an opportunity to comment on the criteria.

Those consulted in this process include:

- Groups representing service users and carers;
- Individual service users and carers;
- Voluntary organisations and other representative groups including the Disability Federation of Ireland; the National Federation of Voluntary Bodies; the Not-For-Profit Business Association; Inclusion Ireland; People with Disabilities in Ireland; National Parents and Siblings Alliance; the Mental Health Coalition; the Irish Advocacy Network;
- Department of Health and Children;
- Health Service Executive (HSE);
- National Disability Authority;
- Mental Health Commission;
- Academics;
- Service providers;

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[34] Mental Health Commission (2006) *The Quality Framework for Mental Health Services in Ireland*.

- Stakeholder group.

Responses were received concerning the content, structure and usefulness of the criteria. All feedback was considered and suggestions made were used to amend the criteria.

2.2 Criteria to identify person-centred cost-effective projects

Twelve criteria emerged for use in identifying examples of effective, cost-efficient, person-centred supports and services. These criteria have been organised into five domains.

DOMAIN A: PERSON-CENTRED	
Criteria 1: Involvement in design, implementation and review The person (carer, family, advocate), is central to the design, delivery and review of supports and services he or she requires.	**Examples** Person (carer, family, advocate) is given the support he or she requires to be fully involved in the individual planning process; Staff receive support and training to enable the individual (carer, family, advocate) to be central in planning, delivery and review of the supports and services offered to him or her.
Criteria 2: Individualised supports and services Each individual receives integrated supports and services as appropriate which have been tailored to his or her individual needs and to providing opportunities that foster self-determination and inclusion. These are ideally delivered on an individual basis outside group settings.	**Examples** Person is supported to make informed choices about the kinds of services and opportunities he or she requires; Person has access to training and support to maximise their control over supports and services; Person is supported to engage in employment, training and leisure on the basis of his or her strengths and interests; Person has a personal network or circle of support maximising engagement of family, friends, neighbours and community.
Criteria 3: Dignity and respect The dignity and human rights of the person are clearly upheld. Relationships and contacts with	**Examples** Verbal and written communications with and about the individual are genuinely respectful and support self-

those providing supports and services are characterised by dignity and respect.	determination; Person has access to advocates who are acceptable to him or her; Supports and services respect the confidentiality and privacy of the person; Supports and services are compliant with all relevant legislation and with relevant regulations, standards and guidelines.

DOMAIN B: ENGAGEMENT	
Criteria 4: Collaboration The project exemplifies collaborative engagement with carer, family, advocate, other agencies, to enable the person to achieve desired outcomes.	**Examples** Engagement with carers/families/advocates is timely and acknowledges their pivotal role; There is close working with a wide range of organisations and agencies that is coordinated, proactive and focused on good outcomes for the person.
Criteria 5: Advocacy There is full support for a variety of advocacy initiatives within the project. Assistance for the person to self-advocate to the maximum extent possible is prioritised.	**Examples** Person is supported to exercise informed choice; Independent advocates are positively welcomed by the project and facilitated in their work; Initiatives to build advocacy capacity to achieve good outcomes for service-users are supported.
Criteria 6: Inclusion There is constructive and wide-ranging use of existing/mainstream and unpaid resources in the community to achieve the best outcomes for the person.	**Examples** There is a focus on building natural supports; Resources are devoted to engaging with the local community.

DOMAIN C: LEADERSHIP	
Criteria 7: Vision	**Examples**
Breadth of vision is encouraged and supported throughout the organisation.	Values-based training has taken place to achieve real adoption of the ethos of person-centred work; Guidelines and protocols are in place, which support staff in being flexible and imaginative regarding the possibilities for an individual, e.g. local health and safety guidelines support this way of working.
Criteria 8: Sharing the learning The project is open to learning and sharing as it develops.	**Examples** There is evidence of active transferring of learning internally and externally; Guidelines, processes, and learning tools have been developed for use by others.
Criteria 9: Evaluation and research The project has a commitment to evaluation, research and dissemination.	**Examples** Documented progress in developing project; Evidence-based decision-making is apparent; Evidence of impact on service users.

DOMAIN D: EFFICIENCY AND EFFECTIVENESS	
Criteria 10: Meeting needs There are processes in place to ensure that the priority needs identified by the person are met efficiently and effectively and in a way that is not more (and possibly less) expensive than current or more traditional methods. Services and supports should represent good use of public funds and demonstrate value for money.	**Example** Alternative ways of meeting needs and providing opportunities are actively considered, e.g. through developing circles of unpaid support, and/or by linking with other agencies.

Criteria 11: Flexibility	Examples
The organisation of resources allows flexibility in how they are currently allocated and used, or there are plans to move to a flexible model of resource allocation. This model demonstrates accountability and transparency in relation to the extent and use of funds.	'Money follows the person'; Funding is reconfigured according to changing needs of service users; Funding is allocated on the basis of prioritised needs.

DOMAIN E: GROWTH	
Criteria 12: Growing to scale/Reaching more people	Examples
The project has the capacity to grow to scale and could benefit a broader population of people with similar needs. Plans for growth include provisions to support sustainability.	Pilot work or early developments in the project have been further developed and have potential to be more widely applied to a broader population; Plans to extend person-centred cost-effective supports and services are developed.

2.2.1 Using the Criteria

Demonstration projects were assessed against the criteria using four levels of evidence; 1) no evidence; 2) some evidence; 3) good evidence; 4) strong evidence. A rating was made for each criterion on the basis of the information provided. If there was no evidence of a fit with a specific criterion, projects were requested to provide information as to why this was the case and what plans they had to address this deficit. Ratings of *some* to *strong* evidence are made on the basis of the numbers involved and breadth of the supports, services and work under each criterion as follows:

Strong evidence – examples fit very closely with the statement of the criterion, involve a good proportion of the service users (e.g. one third or more) and demonstrate a variety of ways in which there is a fit with the criteria;

Good evidence – examples are in keeping with the criterion but not as strong as they could be and/or, the examples apply to a smaller proportion of service users (e.g. one quarter or less) and/or show only one dimension in terms of the variety of ways in which the criterion is met;

Some evidence – examples are described as 'working towards', 'only begun' or are generally in the early stages of development, but are in keeping with the criterion, and/or involve a very small proportion of service users (e.g. less than 10%).

Information provided in the project summary, other documentary evidence and information from interviews were used in making a rating. An overall impression of the project was important in understanding the context and the depth of understanding of different concepts.

2.2.2 Criteria weighting

The criteria were weighted to ensure that projects which had the closest fidelity to the central elements of person-centredness, inclusiveness and cost-effectiveness could be determined. Thus, the rating for the following three criteria determined the summary rating for each relevant domain:

Domain A, Criterion 2 – Individualised supports and services (person-centredness)

Domain B, Criterion 6 – Inclusion (inclusiveness)

Domain D, Criterion 10 – Meeting needs (cost-effectiveness)

For example, in Domain A, Person-centred, if criteria 1 and 3 get strong ratings but criteria 2 gets a rating of 'good', the overall rating for that domain is 'good'.

3. Identifying demonstration projects

On the basis of consultation undertaken by the *Person Centre* prior to this research study, a number of suggestions were made regarding the range and type of initiatives that should be included in this initial search for demonstration projects. These suggestions were accepted as follows:

1. The demonstration of good practice should include funding and costing models as well as examples of cost-effective, person-centred service delivery.
2. In general, it would be best to nurture and amplify good practice already in existence and operating with statutory revenue costs in place.
3. The range of demonstration projects will not be an exhaustive number of person-centred, value- for-money projects but should include initiatives representing:
   - different types of disabilities and mental health difficulties;
   - different phases of the life cycle
   - a variety of locations, e.g. dispersed rural populations as well as urban settings;
   - those provided by statutory and non-governmental agencies;
   - Cross-departmental collaboration in the interests of people with disabilities and mental health difficulties.
4. An all-island approach should be taken to identifying good practice.

3.1 Methodology

3.1.1 Identifying potential demonstration projects

A 'key informant' approach was taken to identify projects in Ireland that might meet the criteria described in Section 2.2 above. Key informants from each of the three sectors were approached who were representative of, or had special knowledge of,

physical disability, intellectual disability and mental health respectively. Service users were also interviewed. Categories of stakeholders included:

- Advocacy groups representing service users and carers
- Individual service users and carers
- Non-governmental organisations
- The Department of Health and Children
- The Health Service Executive (HSE)
- Other relevant statutory agencies
- Academics
- Service providers

The responses of these key informants were compiled to identify projects which were mentioned most often as being good examples of the person-centred work as described by the criteria. Projects that were mentioned by three or more informants formed the list of potential demonstration projects.

3.1.2 Assessing demonstration projects

The lead person of each project was contacted and given information on the overall strategy for improving and extending good quality services and the draft criteria. They were invited to comment and provide suggestions for amendment of the draft criteria and the strategy. All those contacted were invited to be interviewed about their projects.

The purpose of the interview was twofold; firstly to obtain descriptive information about the project, its development, structure, the service users supported by the project and future plans; and secondly, to gain a more qualitative assessment of the services and supports provided by the project, such as how the person-centred approach was established and how their projects might meet the criteria.

An interview schedule was drawn up to guide the topics that would be covered in the interview (see Appendix B). This topic schedule was given to each interviewee beforehand. The interview topics included:

- origins and development of the project and how it changed;
- challenges and barriers faced in developing and/or changing the project;

- factors considered critical to success;
- leadership, management and organisation of the project;
- advocacy initiatives attached to the project;
- learning from the process of change and development to date;
- lessons for others in developing a similar project;
- future plans for developing the project.
- consideration of why this model of service is not more widely available.

It was open to interviewees to determine who was involved in interviews and in what way. In 50% of the project interviews more than one person was involved, usually the chief executive or equivalent and the person most closely involved in supervising or implementing person-centred work in the organisation. In several cases the management team or clinical team were included. The remaining 50% of the interviews were with one person, usually the chief executive officer or equivalent, or the person most closely involved in supervising or implementing person-centred work in the organisation. This methodology proved effective in capturing most, but not all, of the required information targeted by the interviews. There were variations in responses, with some organisations responding in greater levels of detail in different areas.

The overall strategy to improve and extend person-centred, cost effective services and the draft criteria were circulated to demonstration projects with an invitation to offer comments and suggestions for amendment.

In February 2009 a meeting of the demonstration projects was convened to explain the way in which the criteria would be used to assess their work within the context of this research study. All interested projects were asked to make an assessment against the criteria using a prepared form (see Appendix C). Each project was requested to provide actual examples of how their project met each criterion. These examples provided a verifiable way of assessing the extent to which projects met particular criteria. This process enabled the systematic collection of data from each project.

Relevant documentation (such as annual reports, strategic plans and other documents presented on websites) was used to complement information gleaned from both the interviews with project providers and the assessments against the criteria.

3.2 Results

3.2.1 Identifying potential demonstration projects

Twenty three potential demonstration projects were identified using the key informant approach. These represented examples of important characteristics suggested during the consultation, such as different types of disability, different phases of the life cycle, a variety of locations, a variety of providers and examples of inter-agency collaboration:

- Brothers of Charity, Clare, Adult Intellectual Disability Services
- Centre for Independent Living, Belfast – Direct Payments Service, Northern Ireland
- Cloonamahon Service, Sligo
- DETECT (Dublin and East Treatment and Early Care Team)
- Dublin City University, Service Improvement Leadership Programme
- Eastern Vocational Enterprises (EVE) Wicklow and Kildare
- Enable Ireland (national organisation)
- Headstrong, Ballymun Dublin, Kerry, Roscommon and Meath
- Mental Health Commission/Health Service Executive Collaborative project
- Microboards Association of Ireland, Tullamore Offaly
- MIDWAY (Meath Intellectual Disability Work Advocacy You)
- Project within Alzheimer Society of Ireland (national organisation)
- Project within Cheshire Ireland
- Project within Muiríosa Foundation (Sisters of Charity of Jesus and Mary), Midlands
- Project within The Irish Wheelchair Association (national organisation)
- Slí Eile, North Cork
- SOS Kilkenny
- St. Anne's Service, Roscrea, Tipperary
- Walkinstown Association, Dublin
- West Cork Mental Health Service
- West Dublin Mental Health Service
- West Limerick Centre for Independent Living
- Western Care Association, Mayo

Different types of disabilities: eight intellectual disability projects, eight mental health projects, four physical disability projects and three cross-disability projects
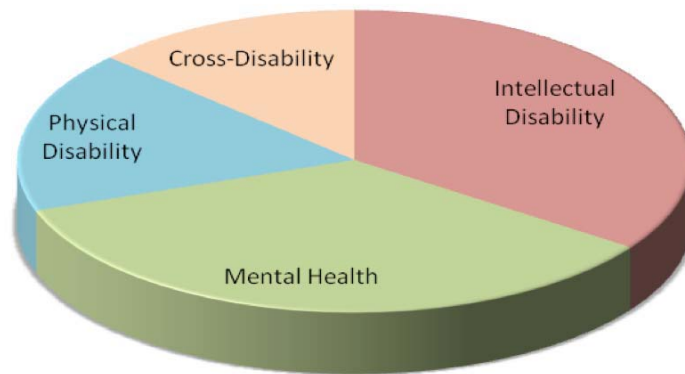
(Fig. 1).

Figure 1: Representation of disability sectors in the demonstration projects

Different phases of the life cycle: fifteen projects provide services and supports to adults, five to children and adults, two to young people (14–25 yrs), and one to older people (although many of the adult services include older people).

Variety of locations: nine projects are in a rural setting, five in an urban setting, three in a mixed rural and urban setting and six are national organisations (Fig. 2).

Figure 2: Map showing location of demonstration projects
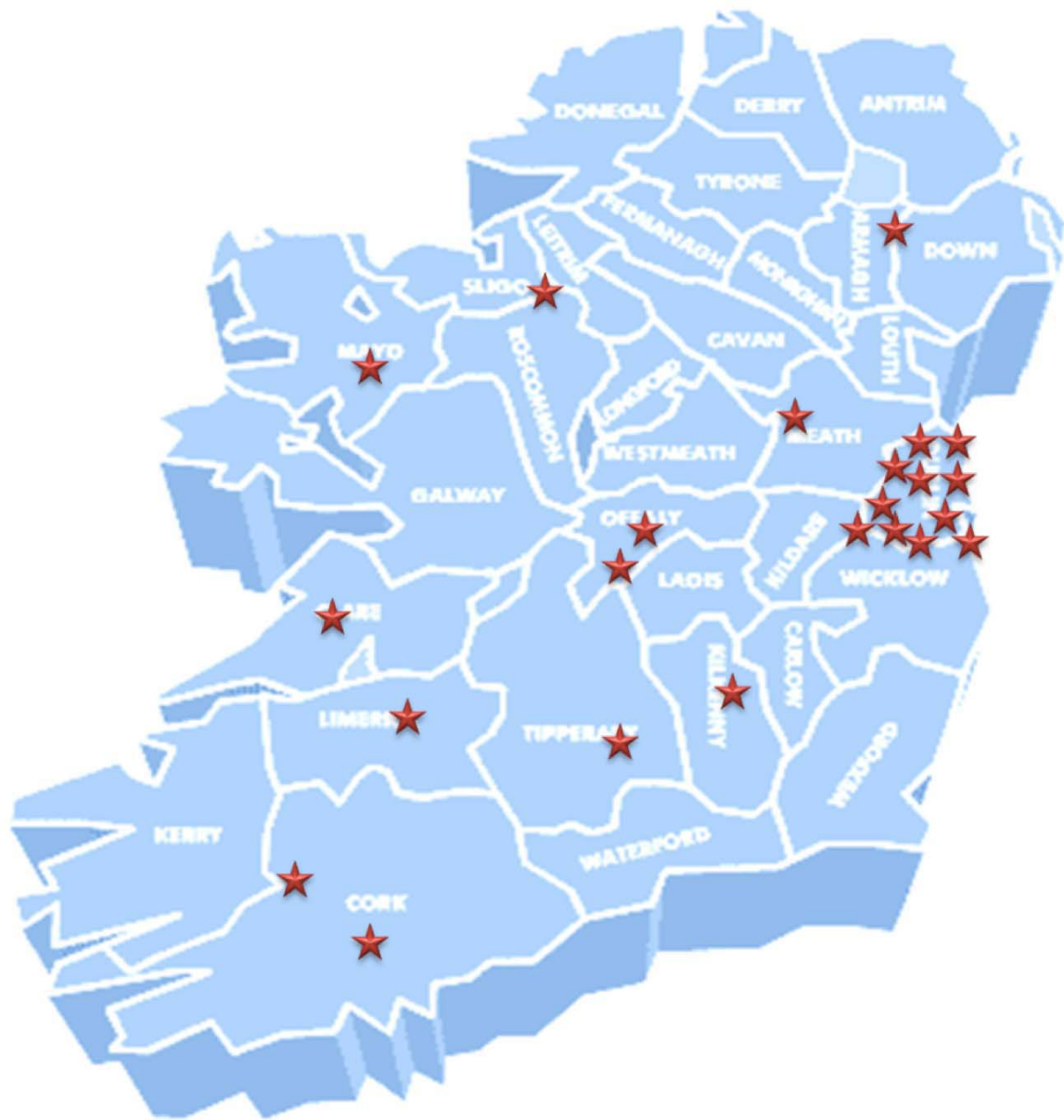
A variety of providers: fifteen projects are independent/not-for-profit organisations, three are directly provided by the HSE, two are subsidiary companies of the HSE and three are partnerships of the HSE and another organisation (Fig. 3).
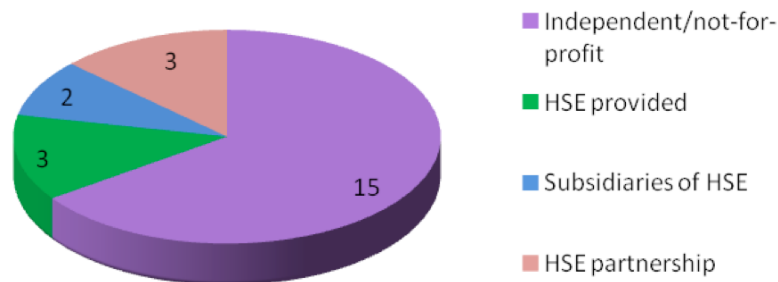
Figure 3: Categories of providers of demonstration projects

Instances of cross-departmental and cross-agency collaboration*:* three of the projects are examples of partnership/cross-agency collaboration. In addition, examples of cross-agency working in the provision of specific services and supports such as with housing, education and health are embedded within several projects.

It is important to remember that these demonstrations do not represent a comprehensive collection of person-centred work in Ireland and there may be others.

Some of these *projects are located within larger organisations*. In these cases, it is important to remember that the larger organisation is not suggested as demonstrating person-centred work as delineated by the criteria.

A summary description of each demonstration project was compiled from information supplied by the project providers (Appendix D).

Projects vary in relation to:

- Promoting inclusion and integration through the use of 'mainstream' community resources;
- Providing/supporting innovative housing options;
- Using creative techniques to elicit and record service users' views;
- Preparing guidelines and processes that support person-centred work;

- Developing models for service users, carers and service providers to work together;
- Training and support structures for staff;
- Developing advocacy initiatives;
- Using effective methods for working with behaviours that challenge;
- Working with communities to create supports.

3.2.2 Measuring projects against criteria

Twenty one of the twenty three projects completed the assessment form (See Appendix C).[35] The extent to which projects met the criteria was assessed using the methodology described in section 2.2.1. The ratings on the 12 criteria were aggregated into summary ratings for the five domains and these are listed for each project in Table 1. Projects are listed in rank order in terms of the number of ratings of 'strong evidence', 'good evidence' and 'some evidence' which each domain received.[36] There is at least one strong example from each of the four sectors: physical disability, intellectual disability, mental health and cross-disability. Only one project received a rating of strong for the Efficiency domain on the basis of information collected. It is difficult for projects to demonstrate cost-effectiveness in meeting needs, as more sophisticated data is required for such an analysis. Current funding allocation models are not perceived as facilitating most organisations to use funds in an individualised, flexible manner. However, several organisations have managed to deploy resources flexibly within this constraint and several can be judged to be good examples of cost-effectiveness within the limits of the available data. It is clear that some projects represent much more developed examples of cost-effective, person-centred work than others, although all displayed some evidence of meeting the criteria.

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[35] The Centre for Independent Living in Belfast was unable to complete the assessment at the time and St. Anne's Service in Roscrea has chosen not to take part in the context of the transition that is currently underway in the service.

[36] There are some differences in the ranking of projects between Tables 1 and 2 as the weightings of specific criteria affect the rating for the overall domain (as outlined in section 2.2.1).

Table 1: Summary domain ratings for 21 demonstration projects*

Project	Person-centred	Engagement	Leadership	Efficiency	Growth
PD	Strong	Strong	Strong	Good	Strong
MH	Good	Strong	Strong	Strong	Strong
ID	Strong	Strong	Good	Good	Strong
ID	Strong	Strong	Good	Good	Strong
ID	Strong	Strong	Good	Good	Strong
MH	Good	Strong	Strong	Good	Strong
CD	Strong	Good	Strong	Good	Strong
MH	Strong	Good	Strong	Some	Strong
PD	Strong	Strong	Good	Good	Good
ID	Strong	Strong	Good	Good	Good
ID	Strong	Good	Good	Good	Good
MH	Good	Good	Strong	Good	Good
ID	Strong	Good	Good	Good	Good
MH	Good	Some	Strong	Good	Good
MH	Strong	Good	Good	Good	Some
CD	Good	Good	Good	Good	Good
PD	Good	Good	Good	Some	Good
MH	Good	Good	Good	Some	Some
MH	Some	Some	Good	Good	Some
ID	Some	Some	Some	Some	Some
PD	Some	Some	Some	Some	Some

* St. Anne's Service, Roscrea and the Centre for Independent Living, Belfast, did not complete assessments.

The assessment process using the criteria worked well. It was easily understood and easily completed. Over 90% of projects invited to participate completed the assessment.

Ratings for each criterion for each of the twenty one projects are presented in Table 2 below. The criteria with the lowest number of 'strong' ratings were those relating to *Meeting needs* and *Flexibility*, both of which relate to cost effectiveness. Further information is required to make a more definitive assessment regarding cost-effectiveness. Criterion 10 on meeting needs efficiently had one rating of 'strong' and

criterion 11 on flexibility received one rating of 'strong'. However, several projects received ratings of 'good' on both criteria.

It is clear from Table 2 that there is considerable variability across the projects, with some representing more strongly developed examples of person-centred working than others. Two projects received nine ratings of 'Strong' (on different criteria) and two projects received no rating of strong.

Overall these findings demonstrate that there are strong examples of person-centred work in Ireland and that it is possible to discriminate between strong and not-so-strong examples using the these criteria as an assessment tool. The criteria proved to be effective in differentiating between various projects on each of the five domains.

Table 2: Ratings on each criterion for each project. Projects are in descending order depending on the number of ratings of strong, good and some.

Criteria

PROJECT	Self-Determination	Individual	Dignity	Collaboration	Advocacy	Inclusion	Vision	Sharing learning	Evaluation and research	Meeting needs	Flexibility	Growth
1(PD)	Strong	Strong	Strong	Strong	Strong	Strong	Strong	Strong	Good	Good	Good	Strong
2(ID)	Strong	Strong	Strong	Strong	Strong	Strong	Strong	Good	Some	Good	Strong	Strong
3(MH)	Strong	Good	Good	Strong	Strong	Strong	Strong	Strong	Strong	Good*	Good*	Strong
4 (CD)	Strong	Strong	Strong	Good	Strong	Good	Strong	Good	Strong	Good*	Good*	Strong
5(ID)	Good	Strong	Strong	Strong	Strong	Strong	Strong	Good	Good	Good	Good	Strong
6(MH)	Good	Good	Strong	Strong	Good	Strong	Good	Strong	Strong	Strong	Some	Strong
7(ID)	Strong	Good	Strong	Strong	Strong	Strong	Strong	Good	Good	Good	Some	Strong
8(PD)	Strong	Strong	Strong	Strong	Strong	Strong	Good	Good	Good	Good	Good	Good
9(ID)	Strong	Strong	Strong	Strong	Strong	Good	Strong	Good	Good	Good	Some	Good
10(MH)	Good	Strong	Strong	Good	Good	Good	Strong	Strong	Strong	Some	Some	Strong
11(ID)	Strong	Strong	Strong	Good	Strong	Strong	Good	Good	Good	Good	Good	Good
12(ID)	Strong	Strong	Good	Strong	Good	Good	Strong	Good	Some	Good	Good	Good
13(MH)	Good	Good	Good	Good	Strong	Good	Good	Strong	Strong	Good	Some	Some
14(MH)	Strong	Strong	Strong	Good	Good	Good	Good	Good	Good	Good	Some	Some
15(MH)	Some	Good	Some	Strong	Strong	Good	Strong	Good	Good	Some	Some	Good
16 (CD)	Strong	Good	Good	Good	Good	Good	Strong	Good	Good	Good*	Good*	Good
17(MH)	Good	Good	Good	Some	Good	Some	Good	Strong	Strong	Good*	Some*	Good
18(MH)	Good	Some	Good	Good	Good	Some	Good	Good	Strong	Good	Good	Some
19(PD)	Good	Good	Good	Strong	Good	Good	Good	Some	Good	Some	Some	Good
20(ID)	Good	Some	Some	Some	Some	Some	Good	Some	Some	Some	Some	Some
21(PD)	Some	Some	Some	Some	Some	Some	Some	Some	Some	Some	Some	Some

*Assessing the cost effectiveness and flexibility in use of funding for 'capacity-building' projects focused on the cost-effectiveness of the overall projects and not the effectiveness of meeting individual needs as this was not the remit of the work of these projects.ID Intellectual Disability, MH Mental Health, PD Physical Disability, CD Cross-Disability

In order to illustrate the overall ratings in an accessible way, scores were assigned to the ratings of each project, with a score of 1 for 'some' evidence, 2 for 'good' evidence and 3 for 'strong' evidence. It is acknowledged that these scores are not 'interval scores', i.e. they are not measuring similar quantities. They do, however, give an overall sense of the spread of ratings across the different projects. The project's aggregate scores are illustrated in 4. (The maximum score attainable using this approach is 36).

Figure 4: Illustrative scores for the projects
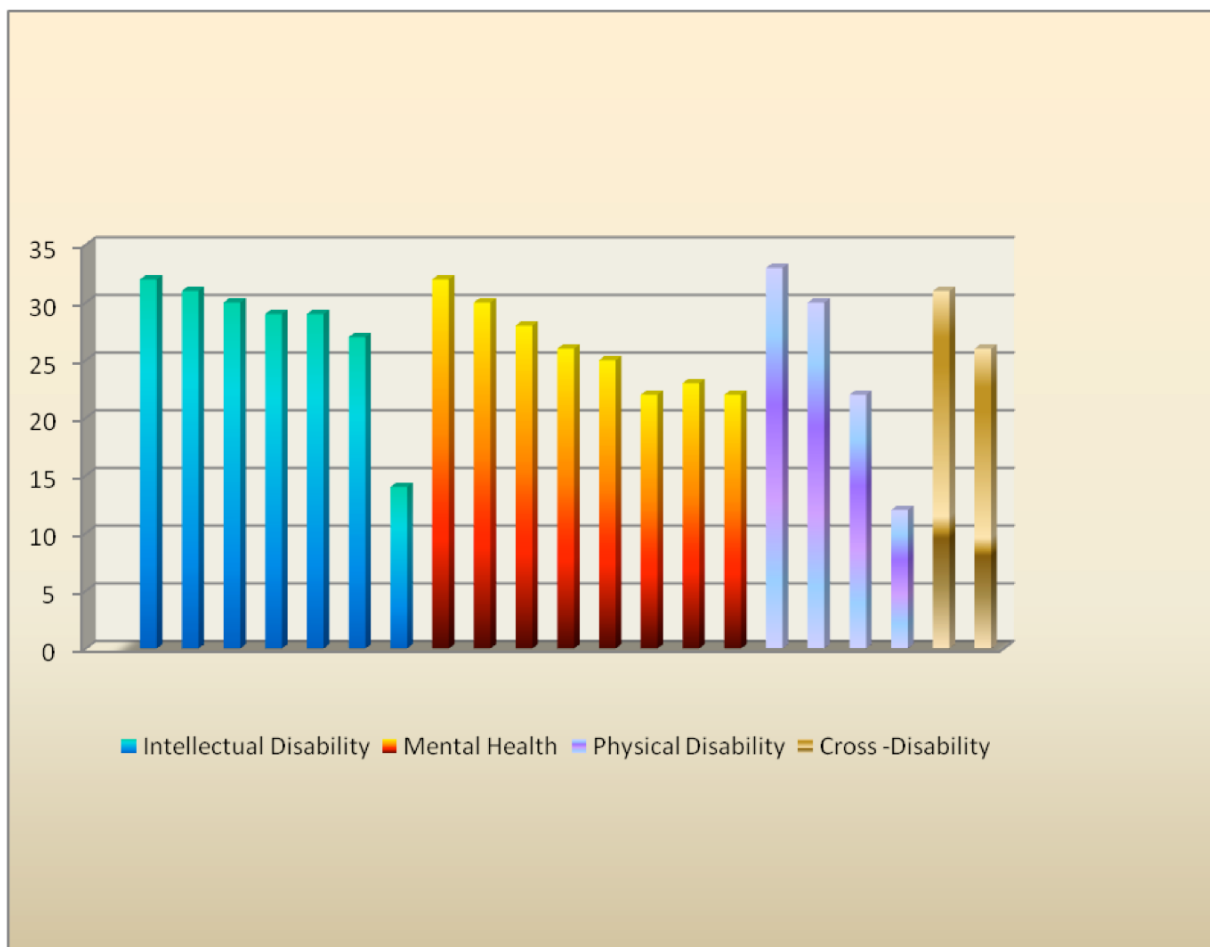
3.2.3 Comment on results from project identification and assessment against criteria

Given the extensive consultation undertaken across disability and mental health it is likely that most projects placing emphasis on working in a person-centred way as described by the criteria have been identified. However, there may well be other

projects working in this way around the country. The intention was to identify a representative number of projects across the disability and mental health sectors, in urban and rural settings, working with different age groups, operated by a mix of statutory and non-governmental agencies.

3.3 Examples of how projects are meeting the criteria

Examples of how various demonstration projects meet the criteria are drawn from information supplied by project providers. Some projects provided strong examples under several criteria. The inclusion of one project under one criterion does not mean that several other projects were not providing strong evidence of meeting that criterion. These examples demonstrate the diversity of activity across the projects and also specific strengths within each project.

Domain A: Person-centred

Criterion 1: Involvement in Design, Implementation and Review: The person (carer/family/advocate) is central to the design, delivery and review of supports and services he/she requires.

In the Slí Eile Housing Association, the tenants are central to how the service is planned and implemented. In the early stages of establishing the service, the tenants received considerable support in collaborative decision-making. Tenants meet every day with support workers to make decisions about all matters regarding the household and decisions about specific support an individual might need on that day (e.g. support in accessing a service in the community). These meetings provide a new opportunity for the tenants to make decisions and have control over their own environment.

The Microboards Association of Ireland (MAI) assists an individual to formulate their own person-centred plan and in all aspects of forming a Microboard. The person is a member of his/her Microboard and has direct input into the design of his/her plan and the implementation of the supports and services needed to make that plan a reality. In addition, MAI provides information and support around person-centred planning to ensure those on the board have an understanding of the philosophy and so can keep the focus person at the centre of all decision making.

> *Criterion 2: Individualised Supports and Services:* Each individual receives integrated supports and services as appropriate which have been tailored to his or her individual needs and to providing opportunities that foster self-determination and inclusion. These are ideally delivered on an individual basis outside group settings.

The MIDWAY Service in Meath has always encouraged service users to make choices for themselves. These choices usually related to training, leisure, employment and other opportunities, but were often confined to what was available within the service. MIDWAY has strengthened service user choice and extended it beyond the service through supporting the individual to develop his/her own 'circles of support'. In this way the service user has more control and also is supported to pursue goals that are outside of what is directly available within the service. Formal paid supports from Midway and unpaid supports are combined to address the identified needs of each individual. This has enabled service users to find and keep 'real' jobs in the community and to access a variety of social and leisure opportunities with community groups and organisations.

The possibilities of connecting people and families to lives beyond the confines of group based models of service is seen as increasingly important to the work of the Western Care Association in Mayo. In the last three years, the service has supported 17 people to move from Group Homes into more individualised living settings. These new support arrangements have been provided at a lower cost per person than the per capita rate used for the National Funding formula. The quality of lives experienced by those in these more individualised support arrangements has also improved. This experience has shown that circles of support; where power is shared with the person and family, staff and others, have been key to the success of this process for several individuals. Expectations are challenged and community resources are engaged more openly. Families and communities as well as staff have access to social capital that is more easily mobilised in this type of support arrangement.

When people are part of their community it is easier for them to build other 'natural supports'. For example, one woman who would have previously been considered very vulnerable moved out of a group home with a friend. She joined a women's group, was involved in all their activities and developed her friends in the group. She no longer relies exclusively on people who are paid to know her, and experiences relationships that cannot be provided by services. These social networks offer additional layers of safeguards and support that reduce the person's vulnerabilities. Working in this way enables the appropriate supports to be available to the person in their own community so they can access employment, leisure and other opportunities.

Criterion 3: Dignity and Respect: The dignity and human rights of the person are clearly upheld. Relationships and contacts with those providing supports and services are characterised by dignity and respect.

As a provider of Personal Assistance services to people in the Mid-West, the West Limerick Centre for Independent Living (CIL) has a very strong emphasis on quality. The CIL has a well developed 'customer charter' which gives a detailed description of what each service user should expect from their service in terms of courtesy and respect, fairness, clarity, accessibility, timeliness and responsiveness. The CIL has also worked to document policies in relation to service user safety, quality assurance, safety statements and others.

Walkinstown Association (WA) has established a Human Rights Committee comprising service user, staff, family and external representatives. This Committee reviews rights restrictions that may be imposed on any person using WA services with the aim of providing sufficient supports to remove these restrictions entirely. An example of a rights restriction could be that a person does not have a key to their own home and therefore their right of access to personal possessions is restricted.

To ensure that staff awareness of rights is embedded in the organisation's culture and ethos, staff induction includes a session dedicated to Human Rights Based

Approaches to service delivery and also an overview of the different committees, including the Human Rights Committee, that operate throughout the services. This training ensures staff learn how to identify and to bring possible 'rights restrictions' to the attention of the Human Rights Committee. 'Rights restrictions' may also be identified to the Human Rights Committee through the use of information gathered during the personal outcomes interview process, through incident reports and through complaints made by service users.

Criterion 4: Collaboration: The project exemplifies collaborative engagement with carer/family/advocate/other agencies, to enable the person to achieve desired outcomes.

Domain B: Engagement

Headstrong (The National Centre for Youth Mental Health) has designed and developed   an innovative model for systemic change called 'Jigsaw'. This collaborative model provides a framework in which young people, their families, service providers and community agencies work together to construct a system of intervention and support which meets the needs of young people. For example, in the north Dublin community of Ballymun, a Headstrong-led comprehensive needs and resource assessment, discovered that there were over 150 agencies and organisations providing one or more services in the community, but yet many young people were 'falling through the cracks' when they become distressed or were at high risk. Establishment of the role of wraparound facilitator (WAF) in Ballymun was a creative response to this need, utilising resources already embedded in the community. Headstrong facilitated systematic training and ongoing support to enhance the helping and support skills of a group of front-line providers from youth-serving organisations across the community. Wraparound facilitators work as a team in this community to provide an immediate and authentic response to young people in distress or at high risk, ensuring that someone listens to them, determines what they need and desire, supports them through the help-seeking process, problem solves with them, develops integrated and collaborative interventions, and links them to resources appropriate to their need.

The West Cork Mental Health Service collaborates with other community services in the West Cork area. Regular meetings and contacts take place to ensure safe practice and positive outcomes for service users. In order to facilitate wider collaboration and greater awareness of mental health issues, the service worked with others to develop the West Cork Mental Health Forum, which has a wide membership including service users, carers, and local community and social service groups.

Families are centrally involved in the service provided to children in Enable Ireland. A formal measure is used (Measure of Processes in Care – MPOC) to assess the parents' experience of family-centred services. Families also choose who attends person-centred planning meetings and they have the option of chairing these meetings. In addition, there is collaborative work with other agencies/services, such as schools and voluntary organisations. In adult services, circles of support and personal assistants are used to assist service users in accessing a wide range of supports and services in the community.

The Cloonamahon service has worked very closely with trades unions, staff representatives and management to bring about a significant change in service delivery aimed at improving the quality of life of service users. A partnership was formed between these three groups which has facilitated the moving of 30 service users from an institutional residence to houses in the local community. Plans are underway to move more service users out of the institution.

Criterion 5: Advocacy: There is full support for a variety of advocacy initiatives within the project. Assistance for the person to self-advocate to the maximum extent possible is prioritised.

The SOS service in Kilkenny has been involved in the development of a novel means of representing service users and hearing their contribution called Seasamh. Seasamh is an open forum, led by a peer-elected leadership team operating on a

parliamentary basis, and working to improve quality of life for persons who access intellectual disability services. The work involved in the establishment of Seasamh led to the development of a Certificate in Leadership and Advocacy, a third-level college course designed in direct consultation with people with intellectual disability. The course has college-accreditation in three institutes. From its inception Seasamh operated on a partnership basis involving forty-four voluntary and statutory organisations providing intellectual disability services. In addition, the SOS service uses a variety of techniques, including art and drama, to elicit and record the views of service users. Using these methods, service users are directly involved in the development of the strategic plan of the organisation and in other areas of management and planning.

In the West Dublin Mental Health Service work with advocates has been built into the service on three levels: members of the Irish Advocacy Network attend the inpatient and rehabilitation units on a daily basis to work with service users who request their assistance; a service user and carer advocate are members of the Planning Advisory Group for the service, and advocates meet regularly with the Senior Management Team of the service to discuss issues and concerns.

Criterion 6: Inclusion: There is constructive and wide-ranging use of existing/mainstream and unpaid resources in the community to achieve the best outcomes for the person.

The Irish Wheelchair Association (IWA) works to increase inclusion of its members in a variety of ways. The IWA Resource and Outreach Centres offer many activities such as educational and self-development programmes, information, and community links which individuals can choose to access. This work facilitates community participation and involvement at a group level. The increased implementation of Enhanced Person-Centred Planning means that inclusion on an individual basis is also supported. The IWA works on increasing the availability of natural supports through a volunteer network which is supported locally through the Resource and Outreach Centres.

The Brothers of Charity service in Clare has made a strategic decision that all new services are to be developed in community 'spaces' with other projects and organisations. For example, a partnership has been developed with the local VEC which has led to the location of the Rehabilitative Training Programme in an integrated training environment in the local Adult Education Centre. Previously this programme was located in a segregated building at the rear of a sheltered workshop. Service users now access a variety of training programmes, such as computer courses, in this integrated, inclusive environment. Natural supports are nurtured for each person. Families are encouraged to remain involved with the person and volunteers are recruited to support individuals with specific areas of their lives such as taking part in leisure, education and employment in mainstream settings. There is also a strong emphasis on developing relationships across the community in areas of mutual interest. Community development workers have been employed to focus on this work and to identify existing community resources for service users and establish links.

Domain C: Leadership

Criterion 7: Vision: Breadth of vision is encouraged and supported throughout the organisation.

The Muiríosa Foundation (Sisters of Charity of Jesus and Mary Services) in the midlands have committed to optimising the application of person-centred values and practice across all aspects of the service. There has been an extensive and sustained awareness-raising and values-formation process in place for the past three years. A more overt focus on training in person-centred practice has been promoted over the past two years. In addition to this general promotion of person-centred values, there has been a concentrated investment (a dedicated team of 7 full-time staff members) in an initiative which is pursuing a fully individualised approach with a cohort of 15 to 20 service users within a two-year timeframe.

The SOS service in Kilkenny describes itself as 'service user led' and works to be fully accountable to the service user. This has been achieved through the development of an information system which easily captures and tracks the progress of each person on their individual plan. There has been a significant emphasis on, and investment in values-based training for all staff, to ensure a full understanding of the person-centred philosophy and how it can be put in place for each individual service user.

Cheshire Ireland has used the strategic process to reorient the organisation towards more person-centred service provision. The organisation's Strategic Plan 2003–2006 Developing Quality – Promoting Choice describes six action areas which are aimed at the overall goal of the organisation to provide high-quality, person-centred services. The action areas are: listening and responding to people who use Cheshire services; providing quality accommodation and housing; developing the organisation to achieve standards and deliver value-for-money; positively influencing the external environment; developing and keeping a skilled and motivated workforce, and providing quality personal support and respite services. The organisation has been working to achieve these goals, and examples include the provision of training to staff in person-centred planning, the introduction of lifestyle planning with individuals who have expressed a desire to move to mainstream living from residential settings, the increasing offer of support to people in their own homes and the implementation of a quality system aimed at monitoring the implementation of person-centred planning and quality throughout the organisation.

Criterion 8: Sharing the Learning: The project is open to learning and sharing as it develops.

The Dublin and East Treatment and Early Care Team (DETECT) service regularly updates partner services through newsletter and direct presentations. Over 700 key professionals from community organisations, counseling services, Gardaı, university health staff, general practice staff and others have been informed about psychosis and how to access mental health services. Several publications have also been prepared documenting the activity of the service and addressing specific research

questions. A manual has been developed for upskilling General Practitioners (GPs) in conducting assessments and delivering interventions for this client group, and a CD containing Resources for setting up an Early Intervention Service in Ireland has been produced.

The Eastern Vocational Enterprises (EVE) adopts a very open approach to all their activities, and attempts to document learning so that it can be easily shared and disseminated. For example, 'Participant Representative Groups' were established in all the service centres to facilitate input from service users. A manual was developed for service users which explains the processes around participating in formal groups and this was circulated throughout the organisation. EVE has also developed the Recovery in Context Inventory (RCI). This is a tool which enables service users to measure and document their progress in their own recovery. This tool was developed in collaboration with service users and a wide range of experts. The tool itself will be widely shared once final testing is complete and papers documenting the development of the tool itself are also in preparation. A recent publication by EVE called Our Personal Stories of Recovery has brought together the narratives of service users and their experiences of Recovery to act as an inspiration to others that Recovery is possible.

> Criterion 9: Evaluation and Research: The project has a commitment to evaluation, research and dissemination.

The Mental Health Commission/HSE Collaborative project has a strong emphasis on evaluation. The Collaborative is being evaluated to assess the extent to which there has been a positive impact on outcomes for service users and their carers. In addition, the collaborative will be evaluated to determine what worked well in terms of implementing specific standards of the quality framework for mental health services, in order that this learning can be extended to other mental health services. Service users and carers are involved in the Steering and Advisory Groups overseeing the conduct of these evaluations and will have input into the design of the evaluations.

The Social Club within the Alzheimer Society of Ireland has been evaluated to establish the benefits for service users and their partners. The research report Social Space: Equal Place – The Social Club Model of Dementia Care has documented learning to date and has provided indicators for future policy and practice. This research also led to the development of practical guidelines for commencing a social club.

Domain D: Efficiency and Effectiveness

Criterion 10: Meeting needs: There are processes in place to ensure that the priority needs identified by the person are met efficiently and effectively and in a way that is not more (and possibly less) expensive than current or more traditional methods. Services and supports should represent good use of public funds and demonstrate value for money.

The Irish Wheelchair Association Assisted Living Service (ALS) aims to meet the needs of each individual through the provision of a personal assistant service. Two different service packages are available under the ALS. The supported package offers the service user a personal assistant service and a service coordinator who take responsibility for some or all of the management, delivery and operation of the service.   With the self-directed package, the service user manages all aspects of the service, including recruiting his or her own personal assistants, rostering and organising holiday cover. The service coordinator is available for advice. The availability of a personal assistant enables service users to have maximum control over their lives. Support is provided in the person's own home and community, facilitating access to education, employment and full community participation. The Assisted Living Service represents an efficient way of meeting individual needs.

The DETECT service has a standardised assessment process in place to ensure the priority needs of the individual are identified effectively. Interventions and supports are put in place to address these needs. Early intervention services have been shown to be more effective than standard treatment, particularly in preventing the

development of hard-to-treat symptoms such as social withdrawal and avolition. Early data from the DETECT service support this conclusion. A formal cost-effectiveness study has commenced in collaboration with an Irish university.

Criterion 11: Flexibility: The organisation of resources allows flexibility in how they are currently allocated and used, or there are plans to move to a flexible model of resource allocation. This model demonstrates accountability and transparency in relation to the extent and use of funds.

Within the Brothers of Charity service in Clare, funds are ring-fenced for individuals. Funds are used flexibly and regularly re-focused to meet priority needs as they emerge. Staff are required to work flexibly to meet the changing needs of service users and are recruited with this capacity in mind.

The Belfast Centre for Independent Living (CIL) provides a support service for people with disabilities who wish to avail of direct payments (DPs) in Northern Ireland. Direct payments are essentially cash payments instead of services provided by health or social authorities. The individual uses the payment to arrange his or her own support. In other jurisdictions DPs have been shown to enhance the quality of life of the individual, empower the individual and offer good value for money in terms of the supports the individual receives. Direct payments are very flexible as the person determines how to use the payment to meet his or her own needs.

Domain E: Growth

Criterion 12: Growing to scale/Reaching more people: The project has the capacity to grow to scale and could benefit a broader population of people with similar needs. Plans for growth include provisions to support sustainability.

The Service Improvement Leadership Programme in Dublin City University (DCU) has expanded to six geographical areas since the first pilot programme in 2007/2008. Interest has been expressed from other areas and Northern Ireland. This

model also has potential to be adapted for other areas such as intellectual disability. Plans are underway to commence a programme addressing this sector.

The West Dublin Mental Health Service provides a community-based model of specialist mental health intervention in the largest mental health catchment area in the country, serving approximately 250,000 people. A pilot evidence-based programme serving 50,000 people was initially developed. Following an evaluation of this pilot, the model was eventually extended to the whole catchment area.

The Brothers of Charity service in Clare has adopted the 'one-person-at-a-time' approach, bringing incremental change to the organisation while moving service users from segregated settings to more independent, inclusive situations in the local community. This has resulted in a significant number of service users experiencing a wide range of person-centred supports.

3.4 Challenges and barriers

A thematic analysis was carried out on the qualitative information obtained from the interviews, combined with documentary information provided by the projects or from their websites. Themes are grouped under two headings: 'challenges and barriers' and 'critical success factors'.

3.4.1 Bringing about change

Most project providers reported the need to adopt a strategic approach to bringing about change which involves working with boards, management teams, staff and other stakeholders to reposition the organisation to provide individualised services and supports. Significant change is often required, necessitating partnership and engagement with staff to enable a more person-centred approach to be taken to service delivery. All of the projects have invested considerable resources to staff training. There was an appreciation by many that isolated training events are not sufficient to bring about real change in practice. Continuing support in everyday work

settings, developmental training and information provision are required to bring about the necessary change.

3.4.2 Adequate and flexible funding

Insufficient funding and a lack of flexibility in the way in which funds are allocated were both referred to as barriers. Even where funding is 'attached to an individual' (i.e. where a service receives a specified amount of funds for a named person) it was reported that there was little flexibility to change or modify the way in which those funds were used if the needs of the individual changed.

Many projects had moved to providing person-centred services and supports in spite of a very low resource base. Some acknowledged that a scarcity of resources can sometimes create conditions that are conducive to the type of re-orientation of services that is required. Some projects were less well resourced in comparison to other services meeting similar needs and reported that staff commitment and goodwill can be eroded by a continuous scarcity of resources. Frustration was expressed in response to a situation in which services that are aligned with policy are operating from a comparatively low funding base. Some projects in the physical disability sector expressed particular disappointment with the lack of resources which limited the provision of personal assistant hours to people with disabilities.

3.4.3 Industrial relations issues

A significant challenge to moving to a more person-centred approach is that of effecting the required changes in work practice, skill mix and overall service structure. For some of the projects involved in direct service provision, managing industrial relations issues proved to be an ongoing challenge. This necessitated regular engagement with trade unions and staff representative organisations. A partnership approach was cited as important in this process.

3.4.4 Working with families

For many services in the disability and mental health sectors there has not been a tradition of involving the family and service users. Some Individuals have lived in institutions for many years with little or no contact from family members. In some services staff have traditionally made decisions in which they are now endeavouring

to involve families. The availability of staff with the necessary competencies to sustain engagement with families was noted as a challenge for some projects. However, when services have focused on the involvement of families, they report this as being critical to success.

3.4.5 A different way of working

Many interviewees observed that person-centred working was challenging but staff who had experience in working this way were persuaded that it led to optimum outcomes for each individual. The importance of supporting the achievement of long-term improvements rather than focusing exclusively on short-term changes was emphasised.

Working in a person-centred way requires a different way of engaging and demands creativity and innovation. Most services and supports are provided in group settings (such as large day centres where everyone does the same activity at the same time or group homes which also have routines for all the residents). Staff and funding are currently linked to these settings and it can be difficult to move these resources around to facilitate a more person-centred approach.

3.4.6 Managing risk

Person-centred work can be seen as increasing risk for service users and staff (and consequently the organisation) as people with disabilities and mental health difficulties are involved in ordinary life in everyday settings in their local communities. However, several projects have addressed the issue of risk effectively. For example, one project addressed staff concerns in a practical way, obtaining clarification on insurance, liability and related issues. This information was incorporated into policies and communicated to all staff. Several organisations work on addressing risk in a very individualised way, working through any concerns that may arise for specific individuals.

3.4.7 Lack of understanding

Several interviewees observed that some other service providers in their field did not have a real appreciation of person-centredness – what it means for the individual and how services can be changed to support self-determination and real choice for service users. 'Person-centred' is a term that is widely used but not often reflected in how services operate.

3.5 Critical success factors

3.5.1 Staff

Staff were identified as being key to the successful implementation of a person-centred approach. Particularly valued and often mentioned qualities included: openness; commitment; dedication; flexibility; a high level of empathy; a real understanding of person-centredness; willingness to 'take risks' in a supportive environment; and creativity. Interviewees were clear that without staff with these qualities it would not have been possible to put a person-centred approach in place. Most projects began implementation with a core number of staff with the required strengths. A variety of training programmes were put in place to support other staff in moving to a person-centred way of working. Appropriate recruitment practices are important in ensuring that staff with these qualities and competencies were employed.

3.5.2 Leadership

Leadership was also identified as critical in moving towards a more person-centred approach. Positive leadership characteristics mentioned included: openness; being supportive; having a vision; being inclusive; and using a partnership approach. Some project leaders also acknowledged that strong leadership was required to steer a service through changes, particularly 'holding onto the vision' and being able to articulate what the person-centred approach means to the individual and how it can be achieved.

3.5.3 Flexibility and responsiveness

Many projects have demonstrated openness to the changing needs of their service users and have changed in response to input from service users and their families and carers. They have also changed their development and configuration of supports and services in response to research evidence of effectiveness.

3.5.4 Partnership approach

Adopting a partnership approach to management and to all the work of the project was mentioned by almost all interviewees as being critical to success. This approach is collaborative and inclusive and involves consulting in a meaningful way with those who use the service and valuing and using their input. Consultation with staff and other stakeholders was also identified as important.

3.5.5 Values

Almost all interviewees were very conscious of the importance of the values which underpin how they and the staff in their projects work. There was striking similarity in core values across all projects. Inclusiveness and openness were recognised as key values. An emphasis on 'the person at the centre', a respect for the person, for their integrity and their rights as citizens to be self-determining individuals were the predominant values.

3.5.6 Working with families

Real engagement with families was identified as a critical success factor by many projects, particularly in the intellectual disability sector. Staff realised that an in-depth involvement with families helps the whole person-centred approach work more smoothly and results in better outcomes for the service user. Projects in mental health and physical disability acknowledged the importance of involving families but the extent of involvement was determined by the person.

3.5.7 Origins of the project

Some projects were peer led initiatives or were originated by the family and friends of service users. These projects tended to have a stronger focus on the service user from the outset and to operate from a smaller funding base than projects originating within large institutional settings.

3.5.8 Community integration

Working to achieve community integration and inclusion was seen as critically important. Working in a true person-centred way inevitably leads to the need for greater engagement with the community and this is a process that has to be managed and directed. Services that have devoted resources to increasing inclusion and integration have seen significant benefits.

3.5.9 Team working

This was mentioned by a smaller number of projects as being critical to the success of their work. The flexible coordination of different inputs as required by a service user was important in achieving a good outcome.

3.6 Conditions likely to facilitate person-centred work

A consideration of the challenges, barriers and factors critical to the success of the 23 projects indicates a number of conditions likely to facilitate movement to individualised, person-centred supports. These can be summarised as follows:

- Non-institutional origins;
- Clear understanding of person-centred work;
- Clear articulation and understanding of organisational values that support person-centred work;
- Presence of a leader with a clear vision as to how the organisation can work in this way, an ability to articulate that vision and a facilitative, inclusive leadership style;
- Flexibility and responsiveness within organisations;
- Staff who understand person-centred work and have the competencies and qualities to work in this way;

- Understanding of change processes and an ability to engage staff and all stakeholders in changing an organisation;
- Adequate and flexible funding arrangements;
- Ability to engage with trade unions in a constructive way;
- Skills to engage with families in a supportive, sustainable way for the best outcomes for the person;
- Understanding of the importance of integrating with the wider community and the skills to do this effectively to achieve the best outcomes for the person;
- Good team working focused on achieving the best outcomes for the person.

3.7 Factors that hinder the spread of person-centred work

Results indicate the following inhibiting factors:

- Piecemeal implementation of person-centred approaches;
- Lack of understanding of what is involved in supporting people to live as equal and valued members of the community;
- Absence of detailed policy giving clear direction on implementing cost-effective, person- centred services and supports;
- Insufficient sharing of learning within and (particularly) across different types of disabilities and mental health areas and within the international context. A number of issues have been successfully managed by these demonstration projects to achieve:
  - Good outcomes in the context of industrial relations;
  - Successful management of risk, e.g. the development of guidelines and processes;
  - Recruitment policies that attract people with appropriate qualities for person-centred work;
  - Training approaches that have resulted in real change in how people work;
  - Organisational structures that support staff as they change their practice;
  - Inclusion in the community.

4. International models

The third objective of this research was to identify models that support person-centred, cost efficient ways of meeting the needs of people with disabilities and mental health difficulties in other countries. A combination of consultation and desk research resulted in identifying examples of person-centred services and supports and of funding models from different countries. These are presented under the headings: 'employment', 'inclusion and integration', 'housing' and 'funding'.

4.1 Employment

There are numerous challenges facing people with disabilities and mental health difficulties in accessing employment. Expectations tend to be low regarding employment success.[37] It is often assumed that people with disabilities or mental health difficulties do not want to work, yet studies have shown that most do want to work.[38,39] Even if work is considered, it tends to be in sheltered vocational settings or stereotypical employment options in an open employment setting.[40] The individual themselves and their families often have to negotiate a complex system working with schools, training centres, vocational employment services and others to ensure the desired outcomes of the individual are reached. Systemic barriers can also create difficulties, such as the 'poverty trap' that can be an issue when moving from social welfare benefits to a low paid job or the requirements of different legislation to maintain full-time work.[41]

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[37] Citron, T., Brooks-Lane, N., Crandell, D., Brady, K., Cooper, M. and Revell, G. (2008) A revolution in the employment process of individuals with disabilities: Customised employment as the catalyst for system change. *Journal of Vocation Rehabilitation*, 28, 169-179.

[38] McQuilken, M., Zahniser, J., Novak, J. et al. (2003) The Work Project Survey: Consumer perspectives on work. *Journal of Vocational Rehabilitation*, 18, 59-68.

[39] Meltzer, H., Gill, B., Petticrew, M. and Hinds, K. (1995) Economic activity and social functioning of adults with psychiatric disorders. London, HMSO.

[40] Citron, T. *et al.* op. cit. p. 170

[41] For example, The Workforce Investment Act (US Dept. of Labor, 1998), which provides the framework for a workforce preparation and employment system, requires people to maintain full-time employment.

4.1.1 Current models of supporting employment for people with disabilities and mental health difficulties

The Individual Placement and Support (IPS) model[42] is a set of principles and practices that have been shown to improve employment outcomes.[43] It has been developed generally for supporting people with long-term, severe mental illness in obtaining open employment.

The key features of the IPS model are:

- A goal of securing permanent, competitive employment in work settings integrated into a community's economy;
- Job development services that identify jobs based on each individual's goals, rather than securing positions set aside for people with disabilities;
- Starting the job search when a person expresses an interest, instead of using transitional employment and/or pre-employment training;
- Integrated employment and mental health services from one provider, with frequent service coordination meetings;
- Ongoing support once work begins, available with no time limits. [44,45]

Customised Employment (CE) emphasises getting the best fit between an individual and a job. This process of CE is based on an individualised assessment of the strengths, requirements and interests of a person and matching those to the needs of an employer. The methodologies of customising a job include:

- Job carving – creating a job from one or more but not all of the tasks of the original job;
- Job negotiation – creating a new job from various tasks from parts of several jobs;

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[42] The individual placement and support model of supported employment is one of six evidence-based practices identified in the *National Implementing Evidence Based Practices Project*, led by Dartmouth Psychiatric Research Centre and funded by the US Substance Abuse and Mental Health Services Administration (SAMHSA) and others.

[43] Becker, D.R., and Drake, R.E. (2003) *A working life for people with severe mental illness*. New York, Oxford Press.

[44] Evidence Based Practices Supported Employment Implementation Resource Kit (2003) Information for Public Mental Health Authorities. http://mentalhealth.samhsa.gov/cmhs/communitysupport/toolkits/employment/

[45] Promising Practices in Home and Community Based Services (2008) Maryland – Encouraging Evidence-Based Practices in Supported Employment. www.hcbs.org

- Job creation – creating a new job based on unmet workplace needs;

- Job sharing – two or more people sharing the same job;

- Self-employment – including use of a micro-enterprise. [46]

4.1.2 Individual placement and support (IPS)

There is considerable research evidence to show that supported employment is significantly more effective than traditional vocational services[47] in terms of obtaining and maintaining competitive employment.[48,49,50,51] One body of evidence in support of IPS is particularly useful as it examines the effectiveness of converting day vocational services to supported employment. Four studies, involving six different sites, have been reported.[52,53,54,55] Five of these sites closed day services completely and one curtailed its day services in favour of providing IPS. Comparisons were made between the new supported employment services and traditional day services. On average across the studies, the percentage of service users obtaining competitive jobs nearly tripled after conversion of day service to supported employment service.[56] These studies are of particular interest as they offer a compelling picture of how traditional services can be changed into more effective services, providing what service users want. A review of nine randomised controlled

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[46] Office of Disability Employment Policy (2003) *Fact sheet on customized employment.* Washington D.C.: US Dept. Of Labor. www.t-tap.org/factsheet

[47] Traditional vocational services were based on the assumptions that people with severe mental illness needed an extended period of time in vocational preparation and that rehabilitation services needed to be provided separately to mental health services. Both of these assumptions have been discarded because research has proven them to be unhelpful (Bond, 2004).

[48] Bond, G., Becker, D., Drake, D.R. et al. (2001) Implementing Supported Employment as an Evidence-Based Practice. *Psychiatric Services*, 52, 313-322.

[49] Bond, G. (2004) Supported Employment: Evidence for an Evidence-Based Practice. *Psychiatric Rehabilitation Journal,* 27, 345-359

[50] Becker, D.R., and Drake, R.E. (2003) *A working life for people with severe mental illness.* New York, Oxford Press.

[51] Cook, J. (2007) Executive summary of findings from the employment intervention demonstration programme www.psych.uic.edu/eidpfindings.htm

[52] Bailey, E., Ricketts, S., Becker, D.R., Xie, H. and Drake, R.E. (1998) Conversion of day treatment to supported employment: One-year outcomes. *Psychiatric Rehabilitation Journal,* 22, 24-29.

[53] Becker, D.R., Bond, G.R., McCarthy, D., Thompson, D., Xie, H., McHugo, G.J. and Drake, R.E. (2001) Converting day treatment centres to supported employment programs in Rhode Island. *Psychiatric Services,* 52, 351-357.

[54] Drake, R.E., Becker, D. R., Biesanz, J.C. et al. (1996) Day treatment vs. Supported Employment for persons with severe mental illness: A replication study. *Psychiatric Services,* 47, 1125-1127.

[55] Gold, M. and Marrone, J. (1998) Mass Bay Employment Services: A story of leadership, vision, and action resulting in employment for people with mental illnesses*, Roses and Thorns from the Grassroots* (Vol. Spring) Boston, MA: Institute for Community Inclusion.

[56] Bond, G. (2004) Supported Employment: Evidence for an Evidence-Based Practice. *Psychiatric Rehabilitation Journal,* 27, 345-359

trials[57] (RCTs)[58] concluded that 'all nine studies showed a pattern of substantially better employment outcomes for consumers receiving supported employment. The average competitive employment rate was 56% for consumers in supported employment, compared to 19% for controls'. Comparison services in several of these studies represented what was widely regarded as 'best practice' in vocational rehabilitation.

Two key policy changes in Maryland, U.S. have encouraged successful implementation of individual placement and support programmes.[59] Firstly, the Mental Hygiene Administration (MHA) and the Division of Rehabilitation Services (DORS) in the Maryland State Department of Education established a braided funding mechanism60 where a single provider offers mental health services and vocational rehabilitation services. Secondly, in 2001 MHA stopped providing funding for agency sponsored employment, where the participant works for the provider agency. This decision was important to encourage competitive employment. The Mental Health Systems Improvement Collaborative in the University of Maryland's School of Medicine was an important partner in helping agencies in Maryland to make the transition to IPS. The Collaborative provided trainers to train providers in implementing and using IPS most effectively. The results from this new approach to employment support in Maryland have been encouraging, with 62% of people receiving IPS in 2006 having a successful outcome.61 This compares to 37% having similar outcomes in other employment programmes.

The success of the IPS model has prompted other jurisdictions to conduct replication studies to determine if this model would be equally effective outside of the US. A UK study found that including a high fidelity IPS component in an early intervention service for young people with first-episode psychosis, increased the open employment rate from 10% to 28% in six months.62 A Canadian study also found very positive results, with 47% of those in the supported employment group obtaining

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[57] Ibid. p.347
[58] RCTs represent the highest level of research evidence in terms of evidence-based practice standards.
[59] This study was cited as a Centres for Medicare and Medicaid Services (CMS) *Promising Practice* in *Home and Community Based Services* (HCBS)
[60] A term widely used in the US to describe pulling multiple funding streams together for one purpose.
[61] Defined in this case as 90 consecutive days in competitive, integrated employment, at or above the minimum wage, with the person satisfied with his or her placement.
[62] Rinaldi, M., McNeil, K., Firn, M, et al. (2004) What are the benefits of evidence-based supported employment for patients with first-episode psychosis? Psychiatric Bulletin, 28, 281-284.

competitive employment compared to 18% of those receiving usual vocational services.63 A trial of the IPS model is currently underway in one of the demonstration projects reported in this research study.64

4.1.3 Customised employment (CE)

A key study in the US evaluated a customised employment programme and used its findings to suggest the system changes required to implement such programmes.[65] This seven year study focused on developing customised employment opportunities through a community rehabilitation programme (CRP). This programme provided supports to people with developmental disabilities, mental health difficulties and addictions in the State of Georgia. It was put together through a collaboration of a local community services board, a local 'one-stop' career centre, a local micro-enterprise centre and a variety of state agencies. Customised employment was defined in this study as 'individualising the relationship between job seekers and employers in ways that meet the needs of both'.

Three-quarters of the study participants achieved employment outcomes, with 73 participants obtaining open employment in jobs which had been negotiated as part of customised employment, 59 in self-employment and nine in open employment, using a supported employment approach. Six key organisational change factors were identified as key to the success of this approach:

1. Community partnerships and diversified funding: staff formed a collaborative partnership among 12 local business owners and used this to create further connections to business and social networks. This was key to helping find employment based on highly individualised profiles. 'Braided' funding packages were also created using funds from a variety of local, state, federal and novel (e.g. micro-loans) funding sources to support individuals in establishing their own business;

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[63] Latimer, E., Lecomte, T., Becker, D. et al. (2006) Generalisability of the individual placement and support model of supported employment: results of a Canadian randomised controlled trial, *British Journal of Psychiatry*, 189, 65-73.

[64] DETECT project, personal correspondence.

[65] Citron, T., Brooks-Lane, N., Crandell, D., Brady, K., Cooper, M and Revell, G. (2008) A revolution in the employment process of individuals with disabilities: Customised employment as the catalyst for system change. *Journal of Vocation Rehabilitation*, 28, 169-179.

2. Staff development: innovative approaches, such as book club discussions on the best practice books on supported employment, and e-learning professional courses, were used to enable the acquisition of new skill sets for staff;

3. Sustainability: two important forms of sustainability were identified in this study – provider and individual. Provider sustainability is achieved when the providing agency finds, secures and uses new funding sources to support its work. Sustainability of jobs for individuals needs to focus on the provision of customised efforts and continuous tailored supports. These are best provided by the customised employment team, made up of friends, family, provider staff and funding personnel;

4. Shift in managerial approaches and supervision: concurrent with the activities in staff training and development, staff were offered opportunities to assume different support roles based on their interests and skills. This approach used the same customised employment values of building on strengths rather than deficits. Attention to specific management factors was essential to the success of the system change undertaken. These management factors included: gathering support for the leadership and change; empowering direct support staff to 'get out of the building' and into the community with individual customers; focusing on strengths, assuring quality, and customised outcomes.

5. Human resource processes: in keeping with the emphasis on systems change, the agency wanted to find new staff from new sources. In the past people came from other 'disability agencies' and had many years' experience working with people with disabilities but lacked the creativity and enthusiasm for systems change and the commitment to rights and social justice that the new system required. To obtain workers with these qualities the agency changed how they advertised job vacancies, developed an interview tool (the Values-Based Interview Questionnaire) and developed an improved selection process.

6. Expanding customised employment to diverse populations: described as 'a very important by-product' of the success of this customised employment

process, was 'the opportunity to incorporate the methodology into other areas of service'. Thus, the lessons learned from customised employment and this process of systems change were transferred to adolescent services, prison and jail outreach services and recipients of temporary aid to needy families (TANF). The principle is that customised employment can be used with virtually any population of people who suffer from chronic unemployment and the stigmatizing forces of poverty (p. 176).[66]

This study concluded that the methodology of customising a job is applicable to any employment situation and that it is possible to transfer learning to all as required:

> Simply put, it is human resource management at its best and most effective. It is not a process driven by disability. Customizing employment ensures a good job match for the individual since it begins with the focus person's passion. When an individual is engaged in economic pursuits of their interests, there is assurance that both the employee and employer benefit.[67]

4.1.4 Discussion

Customised employment can be viewed as a further development of IPS. The principles underlying both are the same but CE takes the process further by customising jobs to fit specific individuals and working closely with employers. These studies demonstrate that supported employment approaches are effective in achieving real employment for people with disabilities and mental health difficulties. They also illustrate that current service models which provide support to people on a group basis can be much more productively replaced by supported employment models. The organisational changes that are required to implement and sustain these approaches are also usefully described.

4.2   Inclusion and integration

Inclusion is one of the central characteristics of person-centredness.[68] The goal of person-centred planning is to support an individual in becoming integrated with his or

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[66] Ibid. p. 176

[67] Citron, T., Brooks-Lane, N., Crandell, D., Brady, K., Cooper, M and Revell, G. (2008) A revolution in the employment process of individuals with disabilities: Customised employment as the catalyst for system change. *Journal of Vocation Rehabilitation*, 28, 169-179.

[68] O'Brien, J. and Lyle O'Brien, C. (1998) *A little book about person-centred planning.* Toronto: Inclusion Press.

her community, accessing whatever services and supports are required in 'mainstream' settings. This level of inclusion for people who have been traditionally excluded and segregated, requires work on both sides; support for both the individual and for the community, which often takes the form of community development. Much of the literature on community development adopts another central principle of person-centredness, i.e. building on strengths rather than deficits. This is particularly emphasised in the 'asset-based' community development approach.[69]

An important characteristic of involvement in a community is mutual aid, 'one of the basic building blocks of community'.[70] In supporting vulnerable people to live in the wider community this expression of mutual aid is often missing. This denies these individuals the opportunity to experience the benefits of this type of engagement:

> From the engagement in the mutual exchange of community involvement comes a sense of belonging, of safety, of importance and entitlement. And, if people are to take part in this process of mutual exchange, then we have to have an approach which starts from the position of identifying what people can contribute.[71]

4.2.1 Supported Living Networks

Innovative programmes such as KeyRing Supported Living Networks[72] in England and Neighbourhood Networks in Scotland, both emphasise mutual aid as a key feature. KeyRing works by providing assured tenancies to local authority housing to ten people in a network in a small neighbourhood. Nine flats or houses belong to 'vulnerable or excluded people'. The tenth property is occupied by KeyRing's Community Living Volunteer (CLV) who supports the network members on a flexible basis. This volunteer is supported by a KeyRing Supported Living Manager who also gives direct support to network members around more complex issues. This arrangement enables KeyRing to build layers of support around the network

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[69] Kretzmann, J.P. and McKnight, J. L. (1993) *Building communities from the inside out: A path toward finding and mobilizing a community's assets.* Evanston, IL: Institute for Policy Research.
[70] Young, M. and Lemos, G. (1997) *The Communities We Have Lost and Can Regain*, London.
[71] Poll, C. http://valuingpeople.gov.uk/dynamic/valuingpeople69.jsp
[72] www.keyring.org *KeyRing* is a charity which works with health, social and housing services. The organisation has enabled over 600 people to lead independent lives in the community in various locations in England.

members in 'natural' community settings. The living support network model provides many benefits, particularly in releasing other resources, such as members' own skills. Members provide a mutual support network and their individual skills are available to each other and shared. The Community Living Volunteer supports network members to build healthy links with neighbours, community organisations and agencies such as the police and the Citizens Advice Bureau. Local authorities and other housing providers note many benefits for them as providers and the communities they serve, such as bringing a safe and stable presence to estates and providing exemplar long-term reliable tenancies.

An independent review of the work of KeyRing in 2002 found that most KeyRing members had strong connections in the neighbourhood and make much use of community resources.[73] The KeyRing model was seen to be particularly effective in minimising dependency on health and social care workers and encouraging the use of ordinary community facilities. The review also noted a high level of cooperation, with network members being both givers and receivers of help. Network members wanted to be more involved in the selection of Community Living Volunteers and other network members. The maintenance of standards was also seen as a challenge as the organisation expanded.

4.2.2   Community Integration Projects

Valuing People, the UK government strategy on learning disability,[74] has a very clear view on the importance of inclusion:

> Being part of the mainstream is something most of us take for granted. We go to work, look after families, visit our GPs, use transport, and go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.

As part of the implementation of Valuing People a series of resources and details of demonstration projects were made available. One such demonstration project[75] is

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[73] www.keyring.org/site/keyring_links.php
[74] Department of Health (2001) *Valuing People. A New Strategy for Learning Disability for the 21st Century*. A White Paper. CM5086, London.

the Grapevine[76] Community Connections project in Coventry, England, which supports people with intellectual disability to access community facilities, activities and social networks to reduce dependency on services and enjoy a network of friends and associates in their neighbourhoods.[77] Grapevine have described a simple four step process which involves: collecting information about people, groups and activities in the local community; getting to know the needs and wishes of the person using a person-centred planning tool called identity mapping; connecting them to their local community (with the help of a support worker), and providing support for that connection to grow.

This process is similar to that described by Rans and Green[78] who collected and evaluated accounts of four community integration projects in Canada and the US. Three common characteristics of these projects were identified:

- They all centre on identifying the gifts and dreams of each individual isolated person – they do not centre on their 'needs';

- 'Citizen Space' is important where connections and associations are made. These are everyday social settings outside health and social care settings;

- 'Connectors' are key to this process. These are 'local people who know lots of people' and are good at connecting people in the course of everyday life.

Lessons from the project indicated that there should be clear boundaries for agencies that are involved in both service provision and developing community connections. These are very different ways of working, and 'it is very difficult to mix the two efforts without undermining the connection work'. The four projects were all citizen-led efforts and this was identified as a critical factor for both the success and sustainability of the work. Experience emerging from this project suggests that 'connectors' and local leaders should be asked how they can help, and advises against 'bringing in experts' too much, as the provider-client thinking can limit the

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[75] Grapevine Community Connection Project Coventry (2004). http://valuingpeople.gov.uk/dynamic/valuingpeople69.jsp
[76] Grapevine is a charity 'run in partnership with people with learning disabilities' which provides support to people with learning disabilities to connect with their local community and have valued social roles. www.grapevinecovandwarks.org/
[77] Recognised in the Care Services Improvement Partnership *Positive Practice Awards*.
[78] Rans, S. and Green, M.(2005) *Hidden Treasures: Building Community Connections by Engaging the Gifts of people on welfare, people with disabilities, people with mental illness, older adults, young people. A Community Building Workbook.* Asset-based Community Development Institute: Evanston Il.

possibilities of seeing the dreams and potentials that can be contributed by others. What the authors advised as: 'Protecting the connectors from the influence of helping systems allows the connection project to remain in citizen space'. Useful assistance from 'friendly institutions' included: funding; a staff person; some resources; and advocacy and support for citizens making their own decisions and choosing their own action. A 'toolbox' of resources was developed to help others build inclusive communities.[79]

4.2.3 Discussion

There is extensive literature on community integration and inclusion. Most approaches to person-centred planning are focused on achieving greater inclusion for people with disabilities.[80] Inclusion is also a fundamental premise of the recovery and independent living approaches for people with mental health difficulties and people with physical disabilities. Much of the work in this area is not formalised in a way that makes it readily available to others. Establishing 'best practice' in this area is challenging because approaches need to be highly individualised and formulating 'models' of inclusion will not necessarily lead to programmes which generalise effectively to other settings.

The approach of the Grapevine in England, and the Ran and Green study in Canada and the US, provide useful 'pointers' and simple methods which can be incorporated into local inclusion and integration projects. The KeyRing model is a promising approach to housing and supported living which has inclusion and integration as a central aim.

4.3   Housing

Housing has for many years been the central focus of service provision for people with disabilities and mental health difficulties. Institutions provided a place to live where medical and support services could be provided to large groups of people in a seemingly 'cost-effective' way. Policies of deinstitutionalisation have been widely adopted as institutional care has become increasingly seen as providing a poor

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[79] http://www.sesp.northwestern.edu/images/hiddentreasuretoolbox.pdf

[80] O'Brien, J. and Lyle O'Brien, C. (1998) *A little book about person-centred planning.* Toronto: Inclusion Press.

quality of life for individuals.[81] However, the move away from institutions has had variable success and the 'community residential care' model which replaced institutions in many cases, has also been criticised as having many limitations.[82]

Deinstitutionalisation[83] has been widely and rigorously studied. However, the possibilities for novel alternatives and approaches can be limited by the perspective and thinking underlying research studies. For example, a large scale review of board and care[84] housing for people with mental health difficulties in the US (Transforming Housing for People with Psychiatric Disabilities)[85] formulated a series of recommendations on how to improve the provision of this form of housing to this vulnerable group. However, the approach adopted was largely based on improving the current system through greater regulation, needs assessment and outcome measurement. In contrast, a large scale European study of deinstitutionalisation[86] took a human rights perspective: 'Supporting disabled people to live in the community as equal citizens is an issue of human rights. The segregation of disabled people in institutions is a human rights violation in itself. Furthermore, research has shown that institutional care is often of an unacceptably poor quality and represents serious breaches of internationally accepted human rights standards.' The recommendations of this study are described below.

4.3.1 Deinstitutionalisation studies

Individual studies and reviews of studies in the area of deinstitutionalisation have concluded that 'where institutions are replaced by community-based services the results have generally been favourable'[87] and that smaller, less institutional settings are associated with greater choice and self- determination, greater participation in community-based activities and participation in wider social networks.[88] However,

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[81] World Health Organization (2003) *Mental Health Legislation and Human Rights.* WHO, Geneva.
[82] Joseph Rowntree Foundation (1997) *The Early Years of Supported Living.* Social Care Research Findings. Joseph Rowntree Foundation, York.
[83] The practice of moving residents from large, long-stay institutions to small community-based settings.
[84] Akin to residential care homes, Board and Care is a term used in the US to describe living arrangements that provide shelter, food, and 24-hour supervision and personal care services to residents.
[85] US Department of Health and Human Services (2006) *Transforming Housing for People with Psychiatric Disabilities.* Substance Abuse and Mental Health Services Administration Centre for Mental Health Services.
[86] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study.* Canterbury: Tizard Centre, University of Kent.
[87] Ibid.
[88] National Disability Authority (2007) *Supported Accommodation Services for People with Intellectual Disabilities: A review of models and instruments used to measure quality of life in institutional settings.* Dublin: NDA.

there is also evidence that simply shifting services to a community setting does not guarantee better outcomes as these settings can become 'mini-institutions' in the community.[89,90,91] Similarly, the relationship between costs and outcomes is not a simple one, and the provision of good quality supports and services in the community is not necessarily less costly than an institutional alternative.[92]

A large scale study (28 European countries) examined the costs and outcomes of deinstitutionalisation.[93] This study did not recommend specific models but that; 'a long-term, comprehensive perspective is required and creativity in developing solutions to the many implementation problems as deinstitutionalisation proceeds'. The many recommendations of this study were summarised into four suggested actions that governments, with others, need to undertake:

1.   Strengthen the vision of new possibilities in the community – such as developing policies in favour of inclusion, strengthening the voice of people with disabilities, their families and advocates;

2.   Sustain public dissatisfaction with current arrangements;

3.   Create some practical demonstrations of how things can be better;

4.   Reduce resistance to change by managing incentives for the different actors in the process.

These broad actions and principles are a useful guide to further developments in the provision of housing for people with disabilities and mental health difficulties.

4.3.2 Supported living

Policy and service provision is moving increasingly in the direction of 'supported living' or 'independent living' for people with disabilities and mental health difficulties. The goal of services for these individuals is not the provision of a building or

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[89] NDA Op. cit.
[90] Tedstone-Doherty, D., Walsh, D. and Moran, R. (2007) *Happy Living Here: A survey and evaluation of community residential mental health services in Ireland.* The Mental Health Commission and the Health Research Board Dublin.
[91] Joseph Rowntree Foundation (1997) *The Early Years of Supported Living.* Social Care Research Findings. Joseph Rowntree Foundation, York.
[92] The issue of costs is discussed in more detail in section 4.4 below.
[93] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study.* Canterbury: Tizard Centre, University of Kent.

'residential care', but the provision of a flexible range of supports and services, that are tailored to the needs of the individual, and which enable them to live in their own home and to fulfil their goals in life with the support and protection they need. 'These services support people to live as full citizens rather than expecting people to fit into standardised models and structures.'[94] The European deinstitutionalisation study and others who have studied supported living have described the fundamental principles that determine the success of supported living as:[95,96,97]

- The separation of buildings and support – level of support should not be determined by the type of building a person lives in but by their needs and choices. Support should follow the person;

- Access to the same options as everyone else – as equal citizens, people with disabilities and mental health difficulties should have access to the same housing options as everyone else;

- Zero Rejection – nobody should be seen as 'too disabled' to live in their own home;

- Choice and control for the disabled person and their representative – supports are organised on the principle that the person should have, and be supported to have, as much control over supports as possible;

- Focusing on individuals – by moving away from the model of group home and using detailed person-centred planning to provide services that are genuinely individualised;

- Focusing on relationships – People's links (their families, friends and community) are the starting point in designing supports, not an afterthought. Through the use of 'support tenants' (who share the home with the disabled person and can provide assistance if necessary) and circles of support, people's relationships are kept at the forefront.

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[94] Ibid.
[95] ibid.
[96] Joseph Rowntree Foundation (1997) *The Early Years of Supported Living.* Social Care Research Findings. Joseph Rowntree Foundation, York.
[97] Klein, J. (1994) *Supported Living: Not just another rung on the continuum,* TASH newsletter, 20, 16-18.

These characteristics represent a useful framework for the evaluation of housing 'models' and supported living arrangements. There are many social housing organisations in most western countries that work through a variety of funding schemes and partnerships to provide housing for vulnerable people (which includes people with disabilities and mental health difficulties). These models and funding mechanisms tend to be localised and must be tailored to fit other jurisdictions. However, one simple model that has had positive results is KeyRing.[98] This model is described in detail in section 4.2 on community integration (above) as housing provision and support for community living and community integration are closely tied together in this model.

A number of models have been summarised in an Australian Government Discussion Paper[99] that may also have wider relevance. This paper was part of an exercise focused on finding solutions to the housing and tenancy needs of people with disabilities through new public, community or private arrangements. Housing initiatives that were suggested by government agencies and community groups included:

- Co-tenanting in public and community housing – this is an arrangement where a person with a disability accessing public or community housing chooses to share his or her home with a non-disabled person (described above as 'support tenants'). This model is used in several states in Australia and has been in place for 15 years in some states. There is evidence of the success of this arrangement, which has been shown to mirror similar arrangements in society. This model is also used to a limited extent in some services in Ireland;

- Responsive Landlord – this model provides tenancy support for people with disabilities who are in public housing but require support that is additional to property management. It consists of an inter-agency arrangement between the housing provider, the support provider (provides non-tenancy support) and the 'responsive landlord' (an agency which provides specific tenancy support such as budget management, paying rent, maintenance);

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[98] *KeyRing* www.keyring.org/site/keyring_links.php
[99] Department of Disability, Housing and Community Services (2006) *Minister's Housing Advisory Forum. Housing for People with a Disability: Discussion Paper. www.dhcs.act.gov.au/__data/assets/word_doc*

- Housing cooperatives – a Canadian model is cited as a good example of this arrangement,[100] where a cooperative was formed to run a government housing development. Six people with disabilities were included in this cooperative which had 105 units. These individuals receive the mutual support of the cooperative and are residents with full rights in running the cooperative.

4.3.3 Discussion

As with inclusion and integration, where supports are highly individualised, there can be as many models of supported living as there are individuals involved. However, the principles of supported living provide a useful guide as to how this arrangement may be provided. The recommendations from the European deinstitutionalisation study[101] provide broader guidance as to how systemic changes can be made to increase the availability of supported living for people with disabilities and mental health difficulties.

4.4   Funding individualised services and supports

The provision of services and supports in a truly individualised way, as epitomised by a person-centred approach, requires flexible, individualised funding. In some jurisdictions people with disabilities and people with mental health difficulties are given the opportunity to be directly responsible for, and in control of, funding to buy services. This model of funding has different terms in different countries, the most widely used term in Europe being 'direct payments' (DPs). In the US the term 'consumer-directed services' usually means services and funding under the control of the service user. Funding systems are strong determinants of the type of services and supports that are available to people with disabilities and mental health difficulties. Funding systems can also represent strong barriers to change and can be a disincentive to change to alternative, individualised systems of support.[102]

An overview of direct payments is given below, followed by descriptions of various models of direct payments from England and Northern Ireland, Sweden, and the US.

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[100] Deohaeko Support Network www.smartcarefoundation.com/docs/pdf/Deohaeko%20Support%20Network.pdf

[101] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study.* Canterbury: Tizard Centre, University of Kent.
[102] Ibid.

The development of an alternative model of resource allocation is described. One of the main bodies of literature concerning costs and funding of disability in general, centres on deinstitutionalisation. A recent, large scale EU study of the costs and outcomes associated with deinstitutionalisation is described in section 4.3 on housing above, and the findings in relation to costs are detailed here.[103]

4.4.1 Direct payments

The issue of 'Direct Payments' has been recently considered by David Egan from the perspective of people with disability, service providers and funders.[104] Direct payments are cash payments to individuals to enable them to employ, either directly or indirectly, individuals to assist them with their everyday tasks. Direct payments operate in a number of EU countries including Britain, Sweden, Austria, Finland, Belgium, Holland and Germany.

4.4.1a Direct payments in England and Northern Ireland

In the UK, the introduction of the Independent Living Fund (ILF) represented the first large scale opportunity for people with disabilities to use direct payments to address their support needs. The establishment of the ILF resulted in two distinct funding bodies for direct payments: local authorities and the ILF. Direct payments legislation was enacted in 1997 in England, and in Northern Ireland following the Personal Social Services (Direct Payments) (NI) Order 1996 (April 1997). The Carers and Direct Payments Act (Northern Ireland) 2002 extended the provision of direct payments. Persons eligible for direct payments are those assessed by the Health Trusts as needing personal social services, who are over 16 years and are 'willing and able' to manage Direct Payments alone or with support. Direct payments can be used for any personal social service (except for permanent residential care) and are also available to disabled people, older people who get services from a Health Trust, disabled parents, parents of disabled children and other carers. Direct payments are essentially cash payments instead of Trust services. The individual uses the payment to arrange their own support. Over 1,100 people in Northern Ireland currently receive direct payments. The direct payments system in Northern Ireland is

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[103] ibid.
[104] Egan, D. (2008) *Issues concerning direct payments in the Republic of Ireland: A report for the Person-Centre.* The Person Centre, Mullingar.

administered by the Centre for Independent Living (CIL) in Belfast, which also provides support to individuals receiving direct payments through Independent Living Advisors. Funding for the Belfast CIL is provided by the trusts.

4.4.1b Direct payments in Sweden

The system is Sweden is seen as the 'gold standard' on direct payments since the introduction of the Personal Assistant Act in 1994.[105] Sweden is the only EU country which confers a right in law to a personal assistant without regard to cost. This Act allows for PA cover for all assessed needs, is not means tested and includes a payment to cover the administrative costs associated with direct payments. There is one centralised source of funding for all PAs – the National Social Insurance Fund. Approximately 14,000 people are entitled to PAs currently. Most users (55%) buy their services from local government (municipalities) who traditionally provide a home-help type service, 11% manage their service through cooperatives while another 30% used commercial companies to provide their PA service. Only 4% of the 14,000 act as direct employers to their personal assistants.

A cost analysis[106] of different forms of services and supports to people with extensive functional impairments was carried out by The JAG Association.[107] The aim of the study was to provide an economic analysis of the impact of the legislative reform of personal assistance. The study was prompted by concerns with the continued increase in both the number of people eligible for assistance and the average number of hours of assistance granted, since the inception of the scheme in 1994. A parliamentary inquiry (the Assistance Inquiry) was established in 2004 to review the personal assistance service. The Swedish National Audit Office proposed that the target group for personal assistance should be limited on the basis that

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[105] Egan, D. Op.cit. p. 6

[106] Blanck, C., Scherman, A. and Sellin, K. (2006) *The price of freedom of choice, self-determination and integrity: A report from the Knowledge Project. A cost analysis of different forms of support and service to people with extensive functional impairments.* JAG, Stockholm.

[107] The JAG Association is a user co-operative and is one of the largest private providers of personal assistant services in Sweden. Members of the co-operative have major functional impairments, including physical and intellectual disabilities.

people with reduced autonomy should be living in group homes. This was based on the belief that group homes were less expensive than personal assistance.[108]

The costs of personal assistance and group homes were compared very carefully for people with major functional impairments in JAG and four group homes. This cost analysis highlighted instances of inefficiencies that can occur in inflexible settings where, for example, three employees spent six hours of one afternoon per week with no service users in the house as they all were in activities on that day.

The results of the study showed that supporting a person with extensive functional impairments in a group home is often more expensive than the cost of personal assistance. The provision of personal assistance leads to additional benefits such as greater flexibility and freedom of choice for the person, thus leading the authors to conclude that personal assistance was more cost-effective. There was a marked difference in the quality of support: 'The staffing of the group homes is not tailored to provide continuous individual support, but is instead based on the users either managing independently for some of the time, or being able to "wait their turn" if everyone on the staff is busy' (p. 18, 2006).[109]

The separate issue of the increase in the number of people using personal assistance and the increase in the number of hours was also examined. It was concluded that the assistance reform was more expensive than anticipated as both the number of people and their needs was underestimated. This was largely due to the fact that little account had been taken of the support provided by relatives for little or no remuneration, which decreased after the reform of the personal assistance legislation and that the costs associated with the reform are 'the price we pay for increased equality for women who previously represented the lion share [sic] of the care provided to close relatives with functional impairments' (p. 3).[110] It was also found that the increase in the number of people receiving personal assistance was part of a general increase of people with functional impairments receiving supports. Increased costs could be partially explained by increasing needs (for example with

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[108] National Audit Office (2004) *Personal Assistance for people with functional impairments.* Riksrevisionen, Sweden.
[109] Blanck, C., Scherman, A. and Sellin, K. (2006) *The price of freedom of choice, self-determination and integrity: A report from the Knowledge Project. A cost analysis of different forms of support and service to people with extensive functional impairments.* JAG, Stockholm.
[110] Ibid. p. 3

people ageing) but they are also due to an increased awareness that 'people with functional impairments should be offered support and service in a manner enabling them to enjoy freedom of choice, self-determination and integrity' (p. 32).[111]

4.4.2 Self-directed support in the UK

Current resource allocation systems (which are prevalent in Ireland, UK and other countries) rely, in general, on a system which involves an assessment by a health professional and the preparation of a care plan, with the costs of the paid care in the plan being determined by the service provider. It is argued that this type of system is disempowering, as it does not allow for the possibility of the individual assessing his or her own needs, does not control costs well, limits or discourages family and community support solutions, does not result in a good alignment between individual levels of needs and level of service, and generally is a costly and inefficient process.[112,113]

To address these deficiencies, In Control[114] has been developing a model of Self-Directed Support (SDS) which uses a Resource Allocation System (RAS) to let the person know how much money they might reasonably expect to have in their individual budget. Certain parameters were decided at the outset. The RAS needed to fit within existing statutory guidance and the existence of other systems (for example the Independent Living Fund), should have the lowest feasible transaction costs, be economically and practically feasible for a local authority to deliver and use definitions of need that are clear and make self-assessment possible.

In Control has taken an evolutionary, shared learning approach to developing the RAS. Each version of the RAS has been developed by working closely with local authorities that were committed to the principles of self-directed support (SDS) and to sharing their learning with others. Each version has been used by these local authorities and their experience of the RAS has informed the next version. Versions 2 and 3 were released during the period from 2003 to 2005 and version 5 was published in 2007. Useful insights were gained during this process of development

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[111] Ibid. p. 32
[112] Duffy, S. And Waters, J. (2005) *Resource allocation. In Control*. www.in-control.org.uk
[113] Waters, J. (2007) *Resource Allocation System Discussion Paper*. www.in-control.org.uk
[114] *In Control* is a social enterprise company which has been working since 2003 on helping to transform the present social care system into a system of Self-Directed Support (SDS). They are currently on version 5 of their resource allocation model designed to support SDS.

and refinement with local authorities. When the self-assessment of need was used, one local authority found a poor correlation between need and the current cost of support. Some individuals receiving little support had relatively high needs while others with lower levels of need were receiving support at a relatively high cost.[115]

Work on early versions of the RAS focused on people with learning disabilities but the work has broadened to include all adult social care groups. A self assessment tool has also been developed for older adults. The self assessment questionnaire provides a framework against which people with disabilities can describe their needs under a number of headings, such as personal care needs, aspects of daily living, making decisions etc.

4.4.2a How the RAS works

The person completes the self-assessment questionnaire. Each area of need is scored according to the level of support required to address that need. Each area is also weighted and has associated outcomes so that it is clear what will result from funding allocated. Completing the whole questionnaire gives an individual profile of needs and an individual points total. It is this points total that is used to offer an indicative budget allocation. The allocation system has been further refined. Now that the RAS has been in use in some areas for some time, it is possible to use real data relating to individual budget allocations made to disabled people (previous versions used pricing information drawn from the existing social care system). This provides a range of allocation levels linked to points from the individual's self-assessment questionnaire. The result is a table of actual monetary amounts for total points from the needs assessment (e.g. 8 points receives £1,500, 52 points receives £24,644).

This RAS seeks to define the process and rules governing the allocation of funds to different people in a clear and transparent manner. In Control recommends that the monetary amount that results from this process is seen as 'an indication of what is fair and reasonable, a guide for planning purposes'. There will be circumstances where it is not possible for the person to develop a plan based on the allocation, and equally it may be possible to develop a plan at a lower cost than indicated by the

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[115] Waters, J. Op.cit.

RAS. In these circumstances it is up to the funder and the person with a disability to work out what is reasonable. However, early indications have shown that money under the control of disabled people held in individual budgets appears to often achieve far more than money that is managed using traditional care management.[116]

There are several challenges to the use of this model. A significant challenge is to prevent the RAS from being viewed as a rationing or cost-cutting tool. There is also a need to incentivise input of families and other non-paid support. Past systems have tended to 'penalise' disabled people who had a good support network, creating a disincentive for families and others to get involved in support. However, it is equally important not to create a system that places an over-reliance on families and non-paid support. It is also important that the RAS is developed in partnership and not imposed on disabled people and local communities. The current version of the RAS is being used in several local authorities around England, and learning will be used to develop the next version.[107]

This RAS represents a transparent, objective means of allocating individual budgets to disabled people. It has significant potential for translation to other care systems and countries.

4.4.3 Consumer-Directed Services in the United States

A national review of the implementation of consumer-directed services (CDS) for people with intellectual or developmental disabilities in the United States provides the most recent and comprehensive picture of this area.[117] The study examined the extent to which states have implemented both individual budgets and consumer control over services for Medicaid Home and Community Based Services (HCBS) recipients with intellectual or developmental disabilities (IDD). Consumer control was defined as encompassing services that involve both individual budgets and decision-making authority over the budget. This study found that CDS have been implemented to a variable extent across the states. Thirteen states had state-wide availability of individual budgets and consumer control for at least some HCBS recipients with IDD. A further eleven states had a consumer-directed option available

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[116] Waters, J. Op. cit.
[117] Policy Research Brief (2009) *Implementation of Consumer-Directed Services for Persons with Intellectual or Developmental Disabilities: A National Study.* Research and Training Centre on Community Living. University of Minnesota.

as a pilot to a limited number of people or available within a limited geographic area. Eight states were in the final stages of development of a consumer-directed option and 18 states had not established individual budgets and consumer control and did not anticipate doing so. The number of CDS participants ranged from 15 individuals in a small pilot in Oklahoma to 4,000 individuals enrolled in the consumer-directed option in Oregon.

The two most significant factors that promoted CDS initiatives were: previous participation in Robert Wood Johnson Foundation's (RWJF)[118] self-determination projects, and political and legal factors. In 1991, RWJF funded a self-determination project in New Hampshire.[119] Based in part on the success of this project, eighteen additional states were awarded grants to promote self-determination. This initial funding has had a significant impact as these nineteen states feature prominently in the states currently providing CDS across the US. Significantly, the lessons learned from implementing the RWJF grants have influenced states as they developed strategies to establish consumer-directed models of support.[120,121] Political factors were cited as a facilitating factor in some states and a hindrance in others. A small number of states have enacted legislation that promotes individualised supports in general or, more specifically, consumer-directed supports. In some states the move towards more consumer control was prompted, in part, by lawsuits, usually regarding the waiting list to access services.

Although many states have not yet formally evaluated the impact of CDS, these options were reported to be highly successful and satisfactory to those who use them. Findings on cost are variable, with some states reporting significant savings, others reporting cost neutral and others reporting CDS as being more expensive. These are initial findings and formal cost-effectiveness studies are required. It is recommended that costs are assessed within the service system as a whole to assess impacts on other cost areas (e.g. possible decreases) and that wider benefits

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[118] The Robert Wood Johnson Foundation is a large philanthropy in the US with an exclusive focus on health and health care. www.rwjf.org

[119] Monadnock Developmental Services (1996) *Whatever it takes: Stories of self-determination from the Monadnock Region.* University of New Hampshire, Institute on Disability. Durham, NH.

[120] Bradley, V., Agosta, J., Smith, G., et al. (2001) *The Robert Wood Johnson Foundation: Self-Determination Initiative: Final impact assessment report.* The Human Services Research Institute, Cambridge, MA.

[121] Sunderland, A. (2007) *Self-determination for people with developmental disabilities: Grant results.* Robert Wood Johnson Foundation, Princeton, NJ.

also need to be taken into account.[122] This review also recommended that adequate information, training and support 'needs' be provided to the individual and their family, and that a separate broker role should be formulated to assist families in administering the payments. Different levels of assistance are also recommended so that some individuals can choose to completely administer their budget while a variety of supports are available to others depending on their needs. Significant changes need to be made to information technology systems to support this different way of allocating funds. Much more complexity is involved in making 100 separate payments to different individuals compared to one contract payment to provide a service to 100 individuals. Monitoring and quality assurance systems also need to be modified for the same reasons, as do the systems ensuring accountability and equity. Finally, many states reported a loss of flexibility when they moved from pilot level to state-wide consumer control options. The administration and monitoring systems described above need to become more formal when this increase in scale is achieved.

4.4.4 Deinstitutionalisation costs and outcomes

The already-mentioned study on deinstitutionalisation carried out in twenty eight European countries is described as the most wide-ranging of its kind ever undertaken.[123] Three countries were chosen for in-depth study of the deinstitutionalisation process: England, Germany and Italy. The overall aim of this project was 'to provide scientific evidence to inform and stimulate policy development in the reallocation of financial resources to best meet the needs of people with disabilities, through a transition from large institutions to a system of community-based services and independent living' (p. 20). [117]

Findings in England and Germany illustrated the importance of involving people with disabilities in the process of service development, with a particular emphasis on listening and responding to their views and wishes. Service-led reform in these countries resulted in simply redesigning existing service structures – replacing institutions with group homes, for example. However, once people with disabilities

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[122] Policy Research Brief (2009) *Implementation of Consumer-Directed Services for Persons with Intellectual or Developmental Disabilities: A National Study.* Research and Training Centre on Community Living. University of Minnesota.
[123] Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study.* Canterbury: Tizard Centre, University of Kent.

were involved, they identified and pursued the considerably more ambitious goal of independent or supported living, organised as 'self-directed services' using individual budgets. This highlighted how service-providing agencies on their own are likely to be constrained by their past and present ways of thinking and working; the new models of service require a partnership between people with disabilities (and those who help and represent them) and agencies planning and providing services.

This research indicates that a complex relationship exists between costs and quality that must be factored into comparisons between community and institutional care. The assumption that community services will be of lower cost than institutional care is too simple. Essentially, in a good quality care system, the costs of supporting people with substantial disabilities are usually high, wherever those people live and low-cost institutional services are almost always delivering low-quality care.[124] The findings of this study in terms of costs, outcomes and effectiveness are summarised in Table 3 which showed that the quality of service/support for the person with a disability was the same or higher after transfer to the community, regardless of level of disability. Costs were generally the same or lower and even where costs were higher, cost effectiveness was the same or better because the outcome for the person was better.

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[124] Ibid.

Table 3: Table showing the effect on costs and quality of the transfer of 'good services' to the community (p. 98). From Mansell et. al. (2007) Deinstitutionalisation and Community Living: Costs and Outcomes.

	After transition to services in the community		
	Costs	Quality	Cost-effectiveness
Less expensive institution			
Less disabled person	Same or lower	Same or higher	Same or better
More disabled person	Higher	Higher	Same or better
More expensive institution			
Less disabled person	Lower	Same or higher	Better
More disabled person	Same or lower	Higher	Better

Among the many recommendations of this study was the need for a central role for vision and leadership by government, working in partnership with users or their representatives and their families, and adopting policies that support inclusion. One of the recommendations suggested the creation of practical demonstrations of how things could be better. This included suggested actions such as funding the development of independent living in the community using ordinary housing and ensuring demonstration projects reflect best practice in how they are set up and run.

4.4.5 Person-centred planning (PCP) costs and outcomes

The most significant study examining the costs and impact of PCP was conducted in four locations in the UK, and examined a comprehensive range of costs and outcomes that included almost 100 people with a wide range of intellectual disabilities.[125] The two central aims of the study were to evaluate costs and outcomes of PCP and to identify personal, contextual and organisational factors that facilitate/hinder the introduction of PCP. In terms of costs and outcomes, the main

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[125] Robertson, J., Emerson, E., Hatton, C. et al. (2005) *The Impact of Person-Centred Planning*. Institute for Health Research, Lancaster University.

findings of the study were that implementing PCP was largely cost neutral (i.e. did not cost significantly more than had previously been spent on each individual) and it was effective in improving the life experiences of people with intellectual disability. PCP was associated with measurable benefits in the area of community involvement, contact with friends, contact with family and choice. However, the study found that there were areas of life in which there were no apparent benefits, such as employment, physical activity and medication.

The findings of the study in the area of outcomes and contextual factors highlight the complex relationship between individual characteristics, organisational features, implementation, and fidelity to the model of PCP. For example, the existence in an organisation of person-centred ways of working prior to the formal adoption of PCP was associated with increased chances for individuals in getting PCP. Having a care manager was associated with benefits in the area of choice, the number of community-based activities and contact with family, but decreased benefits in the area of contact with friends. Results also showed that individuals with mental health or emotional or behavioural problems were less likely to receive a plan and less likely to benefit in several areas if they did receive a plan.

4.4.6 Discussion

The study of the feasibility of direct funding mechanisms and resource allocation models is a priority if person-centred approaches are to be made more widely available to people with disabilities and mental health difficulties. There is a growing body of evidence that direct funding results in the provision of supports that are, at least, cost-neutral when compared to alternatives, and may well be more cost effective.

5.   Conclusion

The research described in this report is one part of a strategy that aims to extend sustainable person-centred supports and services to more people with disabilities and mental health difficulties. On the basis of wide-ranging consultation, a set of criteria was developed to identify such services. These criteria were used as a basis to assess services and supports.

The consultation process also led to the identification of twenty-three projects which provide person-centred services and supports to people with intellectual disabilities, mental health difficulties and physical disabilities. A range of providers in urban and rural settings, operate services and supports across the life span and provide examples of cross-agency and cross-departmental collaboration.

Twenty-one projects were assessed using the criteria. Overall the findings demonstrate that there is considerable variability across the projects, with some representing more strongly developed examples of person-centred working than others. Initial indicators of cost indicate that many of these examples are working in a cost-effective way. Each project demonstrated particular strengths and innovations, pointing to significant potential for transferring learning to other services which are trying to move to a more person-centred way of working.

Factors that facilitate and hinder the development of person-centred work were identified. Strong leadership, a clear understanding of the person-centred approach, committed staff with the necessary competencies, adequate and flexible funding and an ability to work positively with families and others were some of the factors which facilitate person-centred working. A piecemeal implementation of person-centred approaches, along with a lack of understanding of this approach and inadequate and inflexible funding were cited as factors which hinder this work.

International examples of person-centred, cost-effective services and supports were also identified; including models of employment, housing, supported living, community integration and different funding arrangements. Innovative aspects of

these models could be adapted for services in Ireland to increase the range and quality of supports available to people with disabilities and mental health difficulties.

This research has begun the process of identifying effective person-centred services and supports in Ireland. Impressive examples of good practice have been described, with evidence of significant improvement in people's lives. The learning from these examples and international models can inform the development of solutions to the challenge of making person-centred services and supports more widely available in Ireland.

Appendix A   List of main contributors

People with Disabilities and Representative Groups

Nigel Brander, People with Disabilities Ireland

Eugene Callan, Centre for Independent Living, Dublin

Deirdre Carroll, Inclusion Ireland

David Egan, Director, Dublin Bus

Tricia Kelly, STEER, Northern Ireland

Olan McGowan, Presenter of 'Outside the Box', RTE Radio 1

Paddy McGowan, Lecturer, Dublin City University

Caroline McGrath, Irish Mental Health Coalition

Martin Naughton, Disability Federation of Ireland

Betty O'Leary, member of the National Disability Authority

John Redican, National Service User Executive

Michael Ringrose, People with Disabilities in Ireland

John Saunders, Shine

Donal Toolan, Forum for People with Disabilities

Colm Wooley Spinal Injuries Action Association

Statutory Agencies

Aidan Browne, Health Service Executive

Pat Dolan, Health Service Executive

Governance Group, Disability, Health Service Executive

Governance Group, Mental Health, Health Service Executive

Hugh Kane, Health Service Executive

Leo Kinsella, Health Service Executive

Seamus Mannion, Health Service Executive

Seamus McNulty, Health Service Executive

Anne Melly, Health Service Executive

Marion Meany, Health Service Executive

Yvonne O'Neill, Health Service Executive

Martin Rogan, Health Service Executive

Bairbre Nic Aongusa, Office for Disability and Mental Health

James O'Grady, Office for Disability and Mental Health

Sylda Langford, Office for the Minister for Children

Frances Fletcher, Department of Health and Children

Fergal Lynch, Department of Health and Children

Mary Doyle, Department of the Taoiseach

John Shaw, Department of the Taoiseach.

Kevin Byrne, Department of Justice, Equality and Family Affairs

Philip Cox, Department of Social and Family Affairs

Theresa Donohue, Social Inclusion Housing, Department of Environment, Heritage and Local Government

Leo Sheedy, Department of Enterprise, Trade and Employment

Mary Tully, Department of Environment, Heritage and Local Government

Siobhan Barron, National Disability Authority

Larry Bond, Equality Authority

Brid Clarke, Mental Health Commission

Eileen Fitzgerald, Citizens Information Board

Angela Kerins, National Disability Authority

Helen La Hert, Citizens Information Board

Leonie Lunny, Citizens Information Board

Interviewees for demonstration projects

Tony Bates, Headstrong

Mark Blake-Knox and Niall Turner, Cheshire Ireland

Pat Bracken and Tracey Griffiths, West Cork Mental Health Service

Brendan Broderick, Muirıosa Foundation (Sisters of Charity of Jesus and Mary), Midlands

Francis Coughlan, SOS Kilkenny

Ian Daly, Colum Bracken and Antoinette Barry, West Dublin Mental Health Service

Patricia Gilheaney and David Drohan, Mental Health Commission/Health Service Executive Collaborative project

Joan Hamilton and Harry Gijbels, Slı Eile, North Cork

Siobhan Hayden and Tony Corry, Microboards Association of Ireland, Tullamore, Offaly

David Kieran, St. Anne's Service, Roscrea, Tipperary

Mary Kealy, Brothers of Charity, Clare, Adult Intellectual Disability Services

Catherine Keogh, Alzheimer Society of Ireland

Catherine Lynch, Cloonamahon Service, Sligo

Philomena McCrory, Centre for Independent Living, Belfast

John McEvoy, MIDWAY (Meath Intellectual Disability Work Advocacy You)

Trish McEvoy and John O'Sullivan, Enable Ireland

Liam McGabhann and Paddy McGowan, Dublin City University, Service Improvement Leadership Programme

Kathleen McLoughlin, Irish Wheelchair Association

Eadbhard O'Callaghan, DETECT (Dublin and East Treatment and Early Care Team)

Gerard O'Connor, West Limerick Centre for Independent Living

John O'Dea, Tom Hughes and Bernard O'Regan, Western Care Association, Mayo

Margaret Webb, Eastern Vocational Enterprises (EVE), Wicklow and Kildare

Sandra Whelan and Gale Gilbert, Walkinstown Association, Dublin

NGOs, Providers and Coalitions

Gerard Byrne, National Council for the Blind of Ireland

Geraldine Clare, Aware

Breda Crehan Roche, Galway Association

John Dolan, Chief Executive, Disability Federation of Ireland

Frank Flannery, Rehab Group

Brother Alfred Hassett, Brothers of Charity

Paul Henry, Irish Society for Autism

Brian Howard, Mental Health Association of Ireland

Christy Lynch, KARE

Clodagh O'Brien, Not for Profit Association

Patsy O'Brien, Mental Health Association Ireland (Limerick Office)

John O'Dea, National Federation of Voluntary Bodies

Brian O'Donnell, National Federation of Voluntary Bodies

Jenny O'Reilly, Bodywhys

Sr. Catherine Prendergast, Daughters of Charity

Tim Sheehy, Daughters of Charity.

Kevin Stanley, Irish Deaf Society

Researchers and Human Rights Experts

Jerome Connolly, Human Rights Consultant

Pauline Conroy, Rahaleen

Fiona Crowley, Amnesty International

Eithne Fitzgerald, National Disability Authority

Kieran McKeown, Social and Economic Researcher

Brian Nolan, Economic and Social Research Institute (subsequently moved to UCD)

Patricia O'Brien, National Institute for Intellectual Disability, Trinity College Dublin

Gerard Quinn, Disability Law and Policy Research Unit, NUI Galway

Patricia Noonan Walsh, Centre for Disability Studies, University College Dublin

Politicians

Frank Fahey, Minister of State at the Department of Justice, Equality and Law Reform

Kathleen Lynch, Labour Party Spokesperson on Disability

David Stanton, Fine Gael Party Spokesperson on Disability

Other Funders

Mathew Hamilton, One Foundation

Declan Ryan, One Foundation

Deirdre Mortell, One Foundation

Interview schedule

Persons to be interviewed include the person(s)/team with lead responsibility for the service/programme and a service user representative if relevant/available

Topics to be covered include:

- The 'story' of the service – how it developed and how it changed
- The challenges and barriers faced in developing and/or changing the service
- A description of critical success factors
- A description of the leadership, management and organisation of the programme/service
- A description of any advocacy initiatives attached to your service/programme
- What has been learned from the process of change and development so far?
- Why isn't this model of service more widely available?
- Lessons for others in developing a similar programme
- Future plans for developing the service/programme
- The service user will be asked about their experience of the service and how it meets their needs, how their life has been changed or not by using this service.

If necessary, follow-up calls and e-mails can be made for further information or clarification of information.

Documents

A request will be made to the service director/manager for the following documentary information:
- Most recent Annual Report
- Documents providing background to service development
- Service activity data –

Number of service users

Profile of service users

Activity of service components

- Staff numbers and skills

- A resource map of services provided (setting, locations, support groups etc)

- Usual referral pathway for service users

- Details of information given to service users and carers

- Details of initiatives to involve service users and carers

- Details and reports from any research carried out in the service

- Details of feedback/outcome information for service users

- Details of costs and funding

NOTE: Please do not undertake fresh data collection exercises. Whatever existing data is readily to hand will be sufficient (for example 2007 year end returns or most recent annual report). The data will only be used to give an overall profile of the service/programme and to locate it in the overall scope of provision.

How to complete the form

For ease of completion, an electronic version of this form will be e-mailed to each project. It can be completed directly into the Word file and e-mailed back.

There are three parts to the form:

Part 1:   Information about the organisation.

Part 2:   Examples of fit with each criterion.

Part 3:   A summary of the overall work of the project and the extent of fit with the criteria and the aims of the proposal.

Part 1

This is to record whether your entire service/organisation is to be included as a project, or whether it is a specific part of the organisation. If only one part of the organisation is being considered as the project this needs to be described. Information on finance and staffing is also required for all projects.

Is your whole organisation being included as a project?   _____ Yes   _____ No

If Yes, please complete the following information for the whole organisation:
(Information from the complete year 2008 if possible)
Total number of service users supported by the organisation: _____

Total budget of the organisation: _____

Total staff of the organisation: _____
(Please use WTE (Whole Time Equivalent) for all staff numbers)

        Number of WTE professionally qualified staff: _____

        Number of WTE other staff: _____

        Number of management, administrative staff: _____

        Ratio of pay to non-pay costs   _____

If No, please define and describe below the part of the organisation that will be the project. This should include:

Its place in the overall organisation

How it is separate from/integrated with the overall organisation

How the learning from the project will transfer to the overall organisation

If part of the organisation is to be included, please complete the following information for the part of the organisation that is being defined as the project (information from the complete year 2008 if possible):

Total number of service users supported by this part of the organisation: _____

Total budget of this part of the organisation: _____

Total staff of this part of the organisation: _____
(Please use WTE (Whole Time Equivalent) for all staff numbers)

Number of WTE professionally qualified staff: _____

Number of WTE other staff: _____

Number of management, administrative staff: _____

Ratio of pay to non-pay costs _____

Part 2

There is a statement of each criterion and some examples of how this criterion might be met. For each criterion please give two relevant examples as to how your project fits this criterion.

This should include numbers (e.g. of staff who have been trained and what proportion this is of the workforce, or service users involved and what proportion they are of the all service users in your project), the extent of the fit with the criterion and other relevant information.

If there is No evidence of a fit with a specific criterion, an indication should be given as to why this is the case and what needs to be done to address this, i.e. barriers that prevent a fit with this criterion and plans, if any, the project has to address this if possible.

The 12 criteria are listed below, one per page, for examples to be inserted.

Statement of Criterion	Fit with criterion
Domain A: Person-centred	
1.Involvement in Design, Implementation and Review	*Examples:*
The person (carer/family/advocate) is central to the design, delivery and review of supports and services he/she requires.	Please give the two most relevant examples here as to how the project fits this criterion.
	These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	
• Person (carer/family/advocate) is given the support he/she requires to be fully involved in the individual planning process;	
• Staff receives support and training to enable the individual (carer/family/advocate) to be central in planning, delivery and review of the supports and services offered to him/her.	

Statement of Criterion	Fit with criterion
Domain A: Person-centred	Examples:
2. Individualised Supports and Services	Please give the two most relevant examples here as to how the project fits this criterion.
Each individual receives integrated supports and services as appropriate which have been tailored to his/her individual needs and to providing opportunities that foster self-determination and inclusion. These are ideally delivered on an individual basis outside group settings.	These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	

- Person is supported to make informed choices about the kinds of services and opportunities he/she requires;
- Person has access to training and support to maximise their control over supports and services;
- Person is supported to engage in employment, training and leisure on the basis of his/her strengths and interests;
- Person has a personal network or circle of support maximising engagement of family, friends, neighbours and community.

Statement of Criterion	Fit with criterion
Domain A: Person-centred	Examples:
	Please give the two most relevant examples here as to how the project fits this criterion.
3. Dignity and Respect	These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
The dignity and human rights of the person are clearly upheld. Relationships and contacts with those providing supports and services are characterised by dignity and respect.	
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	
• Verbal and written communications with and about the individual are genuinely respectful and support self-determination;	
• Person has access to advocates who are acceptable to him/her;	
• Supports and services respect the confidentiality and privacy of the person;	
• Supports and services are compliant with all relevant legislation and with relevant regulations, standards and guidelines.	

Statement of Criterion	Fit with criterion
Domain B: Engagement	
4. Collaboration	Examples:
The project exemplifies collaborative engagement with the carer/family/advocate/other agencies, to enable the person to achieve desired outcomes.	Please give the two most relevant examples here as to how the project fits this criterion. These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	
• Engagement with carers/families/advocates is timely and acknowledges their pivotal role;	
• There is close working with a wide range of organisations and agencies that is coordinated, proactive and focused on good outcomes for the person.	

Statement of Criterion	Fit with criterion
Domain B: Engagement 5. Advocacy There is full support for a variety of advocacy initiatives within the project. Assistance for the person to self-advocate to the maximum extent possible is prioritised. Examples: The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation. • Person is supported to exercise informed choice; • Independent advocates are positively welcomed by the project and facilitated in their work; • Initiatives to build advocacy capacity to achieve good outcomes for service-users are supported.	Examples: Please give the two most relevant examples here as to how the project fits this criterion. These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.

Statement of Criterion	Fit with criterion
Domain B: Engagement	Examples:
6. Inclusion	Please give the two most relevant examples here as to how the project fits this criterion.
There is constructive and wide-ranging use of existing/mainstream and unpaid resources in the community to achieve the best outcomes for the person.	These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	
• There is a focus on building natural supports;	
• Resources are devoted to engaging with the local community.	

Statement of Criterion	Fit with criterion
Domain C: Leadership 7. Vision Breadth of vision is encouraged and supported throughout the organisation. Examples: The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation. • Values-based training has taken place to achieve real adoption of the ethos of person-centred work; • Guidelines and protocols are in place, which support staff in being flexible and imaginative regarding the possibilities for an individual, e.g. local health and safety guidelines support this way of working.	Examples: Please give the two most relevant examples here as to how the project fits this criterion. These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.

Statement of Criterion	Fit with criterion
Domain C: Leadership 8. Sharing the Learning The project is open to learning and sharing as it develops. Examples: The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation. • There is evidence of active transferring of learning internally and externally; • Guidelines, processes, and learning tools have been developed for use by others.	Examples: Please give the two most relevant examples here as to how the project fits this criterion. These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.

Statement of Criterion	Fit with criterion
Domain C: Leadership 9. Evaluation and Research The project has a commitment to evaluation, research and dissemination Examples: The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation. • Documented progress in developing project; • Evidence-based decision-making is apparent; • Evidence of impact on service users.	Examples: Please give the two most relevant examples here as to how the project fits this criterion. These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.

Statement of Criterion	Fit with criterion
Domain D: Efficiency and effectiveness	**Examples:**
10. Meeting needs	Please give the two most relevant examples here as to how the project fits this criterion.
There are processes in place to ensure that the priority needs identified by the person are met efficiently and effectively and in a way that is not more (and possibly less) expensive than current or more traditional methods. Services and supports should represent good use of public funds and demonstrate value for money.	These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	
• Alternative ways of meeting needs and providing opportunities are actively considered, e.g. through developing circles of unpaid support, and/or by linking with other agencies.	

Statement of Criterion	Fit with criterion
Domain D: Efficiency and effectiveness	
11. Flexibility	
The organisation of resources allows flexibility in how they are currently allocated and used, or there are plans to move to a flexible model of resource allocation. This model demonstrates accountability and transparency in relation to the extent and use of funds.	Examples:
	Please give the two most relevant examples here as to how the project fits this criterion.
	These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	
• 'Money follows the person';	
• Funding is reconfigured according to changing needs of service users;	
• Funding is allocated on the basis of prioritised needs.	

Statement of Criterion	Fit with criterion
Domain E: Growth	**Examples:**
12. Growth	Please give the two most relevant examples here as to how the project fits this criterion.
The project has the capacity to grow to scale and could benefit a broader population of people with similar needs. Plans for growth include provisions to support sustainability.	These examples should specify numbers of service users involved (if relevant) and the extent of fit with this criterion.
Examples:	
The following are just some examples as to how a project might fit this criterion. Other examples may be more relevant to your organisation.	
• Pilot work or early developments in the project have been further developed and have potential to be more widely applied to a broader population;	
• Plans to extend person-centred cost-effective supports and services are developed.	

Part 3

A summary of the work of the project can be included (max. 2 pages) as it may not be possible to give a full flavour of the work being undertaken by simply giving examples for each criterion. This is a space to convey the overall work of the organisation, the stage it is at (it may be at a very early stage or more developed) and plans within the organisation to continue, extend and develop the work.

Appendix D   Summary description of 21 projects

Brothers of Charity, Clare, Adult intellectual disability services

The Brothers of Charity is a large organisation with services mainly in the West of the country. The demonstration project identified is a service for adults with intellectual disability in Clare.

The individuals being supported

Services and supports are provided to adults with a wide range of intellectual disabilities in Clare. Over 200 adults are supported by the organisation, including ninety nine adults who have a residential service.

Background and development

The Brothers of Charity have provided services in Clare since 1983, when the workshop opened in the Gort Rd Industrial Estate. A number of community group homes were also opened at this time. Until 1999 the services in Clare remained under the auspices of the Brothers of Charity in Limerick. In 1999, Clare became a region in its own right and a Director of Services was employed. The Brothers of Charity, Clare initially used Personal Outcomes Measures (POMS)[126] to create more individualised services. It was found that using POMS did not necessarily result in fully individualised services and supports. In the last five years the emphasis and focus of the Brothers of Charity Services in Clare has been to transform the service from supporting people with intellectual disability in segregated group models, to one where individuals are supported to access opportunities, services and supports which enable each individual to live a 'real life in a real place'. To facilitate this, initially two staff members were trained on the Optimal Individualised Service Design (OISD)[127] course and the service began to develop real person-centred supports.

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[126] Personal Outcomes Measures (POMS) is a measure developed by the Council for Quality and Leadership (CQL www.thecouncil.org). It is a 21 item tool which measures various life domains for an individual. It is used to facilitate person-centred planning and review.

[127] Optimal Individualised Service Design (OISD) is a course focused on designing and delivering person-by-person, individualised lifestyle arrangements. It is a practical way of implementing person-centred planning.

The organisation is moving forward to provide individualised supports for those remaining in traditional parts of the service. There is a continuing focus on providing a range of residential options for people and the service believes further development of the Banner Housing Association will be important in this regard. There is also a continual emphasis on building partnerships with local and community organisations.

Nature and organisation of services and supports

The organisation has committed not to build special day centres, group homes, training centres, respite facilities or other segregated settings. Resources are used to create opportunities for service users to build, create and maintain lifestyles of their choosing in the community. All changes have taken place using the 'one person at a time' approach. Over half of the 200 service users are currently supported in a full person-centred way, experiencing individualised, person-centred planning. The remainder have plans developed using the Personal Outcomes Measures (POMS) methodology. The organisation is working towards person-centred planning for all service users.

Day supports: A large sheltered workshop which supported 110 people in Ennis has been closed down. A number of administrative staff have offices in the centre at present. The individuals who used and were employed in the workshop in the past, are based in the community, some in their own homes, accessing employment, education and volunteering opportunities from their own home.

Respite supports: Traditionally when a family/person needed respite, a place was offered in a house with other people with disabilities. The experience within the service was that in some cases the person did not want this option, although it was the only option available. A new approach to respite was developed within the service, *Homeshare Clare*, where ordinary families have a person to stay for a week. The person and family are matched. Sixteen people with intellectual disability have been matched and placed with families to date. Nineteen families that have been assessed and a further six are currently being assessed. *Homeshare Clare* works well, as the service is provided by families in their own home as opposed to residential respite group

homes. This in turn leads to a more individualised person-centred approach. The family takes a child or adult with a learning disability into their own home for a short period of time. The child/adult will enjoy a break or a holiday in a homely atmosphere and their parents and siblings will have a break from their full time caring role.

Residential supports: In response to requests from service users for different living arrangements, service users are being moved from group homes[128] on a 'one person at a time' basis. Several service users now have their own home, others are supported to live at home or in accommodation with siblings, and others are sharing with a flatmate or friend in rented accommodation. Some service users are still in group homes, although plans are in place to move these individuals into their preferred accommodation option. The Banner Housing Association was formed in 2002 as a Social Housing Provider and a sister company of the Brothers of Charity Services Clare Ltd. The Banner Housing Association provides people with an intellectual disability the opportunity to establish their own home.

Community links: Strong links with the community have been built which have enabled a wide range of opportunities and supports to be made available to service users. The Clare service has also demonstrated an innovative approach to the recruitment of support staff (with service users and families interviewing their own support staff) and employing a much wider skill mix than is traditionally the case in service provision in intellectual disability. The service has also decided (from 2006) that all adults referred to the service will not be brought into segregated settings but will be supported by their families, friends and natural supports to live a life of their choosing in the community.

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[128] Group homes are houses in community settings which accommodate a number of people with disabilities. Generally, the residents do not have a choice of who they live with, nor where their 'home' is located.

Research

A research group was formed in partnership with the National Institute of Intellectual Disability (NIDD) in Trinity College Dublin: the "No Longer Research About Us Without Us" project. Two research projects were carried out by service users and staff with advice from the NIDD, describing a coffee shop and a garden project.[129]

Advocacy

The *Clare Independent Advocacy Service* is a collaboration between the Clare Citizen Information Service (CIS) and the Brothers of Charity in Clare. An independent advocate is employed by the Clare Citizen Information Service and managed by the local CIS Manager. The independent advocate is available to people within the Brothers of Charity Services, Clare. In addition, self advocacy is encouraged in the organisation and service users now participate in interview panels for new staff. An inclusive research group has been formed to support people to undertake research and make presentations on issues that are important to them. Currently, twelve people benefit from this approach and it is intended to include others in the near future.

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[129] *The Garden Story* and *Brian and Joe's Coffee Shop* – No Longer Research About Us Without Us Research Group. National Institute for Intellectual Disability.

Centre for Independent Living (CIL) Belfast – Direct Payments Service

The Belfast Centre for Independent Living (CIL) is an organisation run by disabled people for disabled people. The Belfast CIL as a whole has been identified as a demonstration project.

Direct payments (DPs) are essentially cash payments instead of services provided by health or social authorities. The individual uses the payment to arrange his or her own support. In other jurisdictions DPs have been shown to enhance the quality of life of the individual, empower the individual and give good value for money in terms of the supports the individual receives.

Direct payments came in to place in Northern Ireland following the Personal Social Services (Direct Payments) (NI) Order 1996 (April 1997). The Carers and Direct Payments Act (Northern Ireland) 2002 extended the provision of direct payments. Persons eligible for direct payments are those assessed by the Health Trusts[130] as needing personal social services, who are over 16 years and are 'willing and able' to manage direct payments alone or with support. Direct payments can be used for any personal social service (except for permanent residential care) and are also available to disabled older people who receive services from a Health Trust, disabled parents, parents of disabled children and other carers.

Background and development

The philosophy of the Belfast CIL, in common with CILs everywhere, is to promote and pursue independent living for people with disabilities. The introduction of DPs in Northern Ireland (NI) in the 1990s provided the impetus for the development of the CIL. The primary purpose of the Belfast CIL is to support users and potential users of direct payments (direct payments are described in more detail below). The initial DP legislation was introduced in 1996. However, there was no support in place for people with disabilities to avail of direct payments and initial uptake was low. A review of the DP service recommended the provision of supports to increase uptake. In 2001 Belfast CIL was funded by the Eastern Health and Social Services Board (EHSSB) to provide this support service. The work of the CIL was independently evaluated after three years. The results were positive and led to the CIL receiving

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[130] The term for health authorities in Northern Ireland.

recurrent funding from EHSSB. In 2004 the Belfast CIL began a direct payments support service for the Southern Board area and was subsequently awarded the contract to set up a similar service for the Western Board Area in 2007 and the Northern Board Area in 2008.

There is a low uptake of direct payments for people with mental health difficulties. The Belfast CIL plans to have more outreach and awareness activities to help increase uptake of direct payments generally but particularly in mental health.

Nature and organisation of services and supports

The Belfast CIL is the head office for the organisation and supports the service for the Eastern Area. There is a small office in each of the other three areas, with one Independent Living Advisor (ILA) and part time administrative support.

CIL Belfast provides a Direct Payment service to all four health trust areas in Northern Ireland. Over 1,100 people currently receive direct payments (DHSSPS, June 2008). The Independent Living Advisors employed by the CIL provide advice and support to people before assessment, direct training and assistance to those who want to use direct payments, assistance with setting up support arrangements, advice on recruitment and training of staff and ongoing support.

The CIL provides a payroll service to those who prefer not to manage the administration of payment (currently provided for approximately 450 people). The payroll service carries out the administrative work associated with direct payments for a small fee. The provision of a payroll is important as there are many who could not take up direct payments without this in place.

The CIL engages in awareness raising and training activities concerning DPs among the eligible population, health and social care professionals and voluntary groups. The *Direct Payments Development Group* is in place to support the further development of direct payments and to consider associated issues.

Advocacy

Direct payments enable the person with a disability to self advocate as they allow the person to decide what services and supports he/she needs and in what way these should be provided. This enables the person to take part in work and other activities.

Cloonamahon Service

The Cloonamahon Service is a HSE service for people with intellectual disability in the Sligo area. The whole of the Cloonamahon service is a demonstration project.

Background and development

The Cloonamahon service is a residential service which originally opened to house former residents of the mental health services, when units in St. Columba's Hospital in Sligo were de-designated.[131] The residence in Collooney (about 20 miles from Sligo town), is a three-storey former seminary built in the 1950s, and was adapted for people with physical disability when the service commenced in 1976. Fifty people were moved into the residence in Collooney in 1976. More people were transferred from mental health services at different times and over 130 people resided there at one time. In 2000 a decision was made to move residents to community living. A partnership was formed between the four trades unions representing staff, management and representatives of all staff, to plan how this process might take place. Research was also undertaken to determine which model might work best for the residents and staff. A person was appointed to lead the process and 20 residents were identified as the first to move. All had a psychological assessment and a POMS[132] assessment and data from both were used to develop a person-centred plan for each individual. Discussions were also held with families to involve them in the process and take their views into account. Two houses were identified and acquired (with four places each). Extensive mediation between staff and management was required to finally move eight residents into these places. Further places in houses in the community have been developed.

The individuals being supported

There are currently 98 persons in the service, with a wide range of disabilities, from moderate to profound intellectual disability. Many have co-occurring problems such

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[131] A process of 'de-designation' of units in (generally old) psychiatric hospitals took place in the late 1970s and early 1980s, where patients who did not have a primary diagnosis of mental illness (mostly elderly people and persons with intellectual disability who had been resident in the hospital for some time), were moved into units which were not designated as part of the mental health service (although these units often remained in the grounds of psychiatric hospitals).

[132] Personal Outcomes Measures (POMS) is a measure developed by the Council for Quality and Leadership (CQL www.thecouncil.org). It is a 21 item tool which measures various life domains for an individual. It is used to facilitate person-centred planning and review.

as physical disability and/or mental health difficulties. A small number of residents have solely physical disabilities (e.g. cerebral palsy, epilepsy). Overall, approximately one third of service users have physical disabilities.

Nature and organisation of services and supports

There are now seven houses in the Collooney/Sligo area, providing 30 places for former residents of Cloonamahon. Two small day services have been developed to provide activities for those living in these houses. Several links have also been made with the community so that social and recreational activities are undertaken away from these day centres (e.g. golf and swimming). There are approximately 67 people still in the main institution (20 of whom are in houses in the grounds). Two further houses in the community with an associated day service will be opening shortly for ten service users with multiple needs.

Advocacy

An advocate is available to the users of the Cloonamahon service. This advocate is employed by a partnership group consisting of most of the intellectual disability providers in Sligo, and is hosted by the local Citizens Information Service office in Sligo. This advocate focuses on four groups, including three residential services, all for people with intellectual disabilities.

DETECT (Dublin and East Treatment and Early Care Team)

DETECT is an early intervention service (EIS) aiming to maximise recovery from psychotic illnesses through early identification. The service is based in Dublin South (including parts of the city centre and South County) and Wicklow. The DETECT service as a whole has been identified as a demonstration project.

The individuals being supported

The target population are those aged between 17 to 65 years in the HSE Dublin Mid-Leinster Region (approximately 375,000 people). Once referred, individuals are given rapid, holistic assessment. Individuals with confirmed symptoms of psychosis are offered an individualised programme. Over 186 cases of psychosis have been identified since the service began in 2004/05.

Background and development

There is strong research evidence that a long period between the first appearance of symptoms of psychosis and the commencement of effective treatment leads to poorer outcomes for individuals. This period is known as the duration of untreated psychosis (DUP). It is particularly important as it often occurs at a time when the person is involved in transitions from second-level to third level education or onto employment (i.e. late adolescence/early adulthood). Disruptions at this time can have long-term negative effects. Evidence from other early intervention services shows that reducing the DUP has significant benefits for the individual. Intervention at this time has also been shown to be particularly cost effective.

The HSE and St. John of God Hospitaller services came together in 2005 to fund a pilot early intervention service. A small team works with GPs to increase the recognition of symptoms of psychosis and the importance of early referral. DETECT then is available to work with local mental health teams to conduct rapid, specialist assessment and offer an individualised, effective treatment package. DETECT now assesses three suspected cases of psychosis per week, all within 72 hours. This service was shown to be effective and has been extended.

The priorities for the developing service are to:

- Secure funding to maintain and if possible expand service delivery;

- Address the poor mental health literacy among the Irish population with a multi-media advertising campaign;

- Complete a comprehensive cost-benefit analysis of the DETECT model;

- Publicise the benefits of the DETECT model of early intervention nationally and internationally.

Nature and organisation of services and supports

DETECT focuses on reducing the time delay at two periods: firstly, the period from when symptoms of psychosis first appear, to when help is sought, and secondly, the period between when help is sought and receiving effective treatment. A reduction in the first delay depends on people recognising symptoms and seeking help. This requires large scale and ongoing public education programmes. A variety of approaches has been used to raise awareness. For example, DETECT worked with RTE in creating a story line in a popular Irish 'soap' which was helpful in highlighting this issue with the general public.

A considerable amount of work has been undertaken to reduce the period between initial contact with health services and the provision of effective treatment. A reduction of 66% in unnecessary delays has resulted. This has been achieved through a comprehensive educational programme with GPs and other key professionals from community organisations.

A detailed assessment is carried out within 72 hours of referral. An individualised plan is prepared on the basis of this assessment. A specialised treatment package is offered which includes evidence-based psychological, occupational and family interventions. In addition, service users remain closely linked in with their local community mental health team to ensure continuity of care.

Advocacy

The service continually seeks and uses service user input in refining service delivery. DETECT has close links with a service user research group within the local adult mental health service called SOURCE (Source of User Research Collaboration and Expertise). The members of this group have been trained in research techniques and have conducted some research for the local mental health service. Members of the

group also participate on the research advisory committees of DETECT and the local mental health service. DETECT has also consulted with the Irish Advocacy Network[133] with a view to developing increased access to advocacy services for people who use the DETECT service.

Research

This service has a very strong research ethos and all work is evaluated. There have been several publications on the work of the service to date.[134]

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[133] The Irish Advocacy Network is a national, mental health, peer advocacy organisation.
[134] Jackson et al (2008) Is the duration of untreated psychosis temporally stable? *European Psychiatry*, 97-99. Renwick, L. et al. (2008) Early intervention service for psychosis: view from primary care. *Early intervention in Psychiatry*, 285-290. Turner, N. et al (2007) What influences Purpose in Life in First Episode Psychosis? *British Journal of Occupational Therapy*, 401-406.

Dublin City University (DCU) Service Improvement Leadership Programme

The Service Improvement Leadership Course is a ten credit, level 8 (degree level) course taken over two semesters at Dublin City University (DCU). The DCU Leadership Programme has been identified as a demonstration project.

Background and development

This educational programme has been developed around the concept of 'trialogue'[135] – where three groups with different perspectives – service users, carers and mental health professionals – are brought together in a cooperative learning environment. Research evidence has demonstrated that educational programmes that harnessed this tri-partnership approach (service user, carer and mental health professional), and that used an 'Open Dialogue'[136] approach could have measurable outcomes for service improvements.

Several mental health services, the National Office for Mental Health Services, the Irish Advocacy Network and the National Service User Executive came together as a steering group to explore how such a course could be put in place. The steering group approached the School of Nursing at DCU with their initial ideas for the educational programme. This approach was successful and a larger steering group was convened to develop the course. The first course was delivered in 2007/2008.

The educational programme

Teams of three join with other teams where they engage in a specifically designed process of open dialogue and participatory inquiry. These teams create mutually agreeable solutions to service improvements, and implement these initiatives within their own service as an outcome of the course. Through team leadership and participatory action, all relevant stakeholders are part of service improvements. In the first year of the course (2007/2008) there were 15 participants; five teams of three from mental health services in Donegal, Mayo, West Cork, South Dublin and

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[135] Trialogue - an interchange and discussion of ideas among three groups having different origins, philosophies and principles. Amering et al. 2002 has used this concept in mental health settings to create constructive dialogue between three groups – service users, carers and mental health professionals.

[136] Open dialogue is a process that ensures all participants' perceptions and understanding of health, illness and ways to improve services, are heard and understood.

West Dublin. In 2008/2009 six teams of three are participating in the course. Each sponsoring mental health service identifies a senior manager in the service who is a mentor to the team to aid their progress in jointly implementing a service improvement project, this project being a requirement of the course. It is intended that this support and the direct link into the management of the service will lead to the implementation of real change – change that has been agreed by service users, carers and professionals as a team.

The individuals taking part in the course have the direct benefits of the learning and team experiences, and receive credits towards a higher qualification. Other individual outcomes have been identified, including an increased awareness of the role of carers for all participants, embedding service user and carer involvement in decision making and identifying different needs and a process to address them.

Advocacy

The learning process within the project itself provides individuals with much of the knowledge and skills necessary to advocate on behalf of themselves and others. The overall project embodies the principles of citizen and community advocacy, where each individual and group exercise informed choice on how to improve services. The project work which each team must complete is often about increasing the potential for personal and group advocacy for people accessing mental health services.

A 'Community and Citizen Advocacy' practice development programme is in preparation. Individuals, organisations and communities involved in specific advocacy initiatives can access this programme to harness their knowledge and practical skills, and avail of the educational credits towards further learning if they wish.

Eastern Vocational Enterprises (EVE) Ltd.

EVE is a subsidiary of the HSE, providing a range of person-centred community services in Dublin, Wicklow and Kildare. The services of EVE as a whole have been identified as a demonstration project.

The individuals being supported

EVE currently provides services in twenty three locations in Dublin, Kildare and Wicklow. Over one thousand service users access these services. Most service users have mental health difficulties, with a small number of people with intellectual disability and physical disability.

Background and development

The initial focus of EVE was to provide traditional vocational services[137] and training opportunities for people with long-term mental health difficulties. New models of service provision have been developed by the organisation, and the ethos of EVE has changed significantly. Recovery is the central principle that informs the delivery of all services in EVE. A strong emphasis is placed on the participation of service users in designing and planning services. The core values expressed in their strategic plans are partnership, quality services for improved quality of life and community integration.

Nature and organisation of services and supports

EVE provides a range of supports and services including:

> *Clubhouse:* Clubhouse[138] is one of the few peer provided/peer led mental health services in Ireland. There are currently four Clubhouses provided by EVE in Blanchardstown, Coolock, Clondalkin and Newbridge. Clubhouses focus on social activities and work programmes. Members (service users) work alongside staff in three main ways: a work-ordered day (the work of the clubhouse is done by everyone); an out-of-hours social programme, and a

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[137] This refers mainly to sheltered workshops, where people with mental health difficulties worked on routine tasks.

[138] Clubhouse originated in 1948 in New York when former patients of a psychiatric hospital began to meet together informally. It was organised to be a support system for people living with mental illness, rather than a service or treatment programme. Today there are over 400 Clubhouses worldwide that have modelled themselves on this premise.

transitional employment programme (TEP). In the TEP, members can work in paid part-time employment. Each individual chooses the type and level of support he/she wants from the Clubhouse. A Clubhouse Forum has been established within EVE to further develop the Clubhouses (with an emphasis on quality) and to promote and raise awareness of a Clubhouse approach.

Training: In the context of their strategic objective '*Creating recovery-oriented competencies'*, EVE has developed an accredited mental health training programme to up-skill frontline staff (care assistants, etc.) in mental health skills in partnership with a number of organisations. This programme contains a module on recovery and advocacy. The training programme has been evaluated and will be delivered by VECs. EVE is the lead partner responsible for the design, delivery and evaluation of a national Wellness Recovery Action Plan (WRAP) training programme.

Occupational programmes: EVE also provides a range of occupational/rehabilitation programmes and training centres. Work is ongoing to promote a more person-centred/individualised ethos in these centres, and throughout the whole organisation.

Tuiscint: Tuiscint[139] was established in 1999 by EVE in an initiative with ASPIRE, the Asperger Syndrome Association of Ireland. The aim of Tuiscint is to provide social and vocational training for adults with Asperger Syndrome.

Research

One of the ways in which EVE is working to achieve their strategic objective of *Creating evaluation tools to capture recovery-oriented processes and outcomes*, is through a research project called *Understanding Recovery in Context.* This project is developing an innovative tool called the Recovery Context Inventory (RCI). Service users and carers have been centrally involved in its development, complemented by input from an international advisory committee. The RCI enables a structured engagement with the individual in a responsive, person-centred manner and acknowledges the contexts that help or potentially hinder recovery. This facilitates

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[139] Tuiscint is the Irish word for 'understanding'.

work in which the person can set personally meaningful, recovery-promoting goals. EVE is also exploring ways in which the RCI can be adapted to provide a set of recovery-oriented benchmarks for use in mental health services.

Advocacy

The Irish Advocacy Network facilitated service users in a consultation exercise to ensure maximum input into the organisations strategic plan entitled *EVE-Creating Contexts for Recovery*. EVE also prepared *Speak Up: Start-up Guidelines for Representative Committees,* a booklet designed to help all EVE service users understand how a representative committee can empower each individual. Eve is completing the process of having representative committees in every part of the organisation and ensuring that service users have the skills to participate. Some representative committees are already established. EVE received funding from the CIB for a dedicated advocacy programme with *Tuiscint* (the programme within EVE for people with Asperger Syndrome). The work of this advocate is to be expanded through the provision of interview skills training with all service users. This will enable service users to participate on interview boards for new staff.

Enable Ireland

Enable Ireland provides a range of services and supports for children and adults with physical disabilities, and their families. The Enable Ireland organisation is included as a demonstration project.

Background and development

Enable Ireland was founded in 1948 as Cerebral Palsy Ireland. The National Association of Cerebral Palsy was established in 1951 and worked in partnership with the State (through County Councils, Regional Health Boards and the Department of Education) to provide a range of services for children with physical disabilities and their families. Enable Ireland has evolved from a strong volunteer base. During the 1980s, parents, friends and families of children requiring services established a branch network throughout Ireland to meet the need for local assessment and treatment. Enable Ireland has a strong emphasis on the social model of disability[140] and aims to provide person-centred services and supports through inter-disciplinary teams.

The individuals being supported

Services are provided for 3,500 children and adults with primarily a physical disability, in 14 service centres nationally. The majority of the service users in Enable Ireland are children.

Nature and organisation of services and supports

Enable Ireland has begun to implement person-centred planning to provide individualised services to all service users and families. The European Foundation for Quality Management (EFQM)[141] is used to quality assure services.

Children receive an assessment and access to specialist skills support and training. There is a team based approach to service delivery. A variety of services and supports is available depending on individual needs, including; Family Support,

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[140] This means the focus is on the person and not the impairment. The social model of disability also emphasises access, inclusion and equality as basic rights for all people, with or without a disability.
[141] EFQM is a not-for-profit membership foundation. It focuses on mutual assessment to enable organisations to implement their strategies. It has a number of tools and strategies available to member organisations.

Personal Assistants, Speech and Language Therapy, Physiotherapy, Occupational Therapy, Independent Living, Life Skills, Training and Assistive Technology.

Personal Assistants[142] are used to enable adult service users to access mainstream services. Approximately one third of adult service users are supported in a person-centred planning process. Individual service users identify their personal goals with the support of a trained facilitator, the person's own circle of support[143] or a personal assistant. Key staff in the organisation have been trained in person-centred planning and Optimal Individualised Service Design.[144]

Advocacy

Work is undertaken with parents and families of children who use Enable Ireland services to empower families through specific training and provision of information and advice. Centre-based services have local advocacy forums where service users can utilise internal and external supports and advice. A number of services have access to an independent person to assist in self advocacy through Citizens Information Board advocacy initiatives. There is a national service users' council in place within the organisation to promote advocacy for all service users.

Research

The National Disability Authority undertook a research project with Enable Ireland North-East to evaluate the Individual Family Service Planning Process. The findings of this project have been fed-back to the organisation and the project will be implemented throughout the North-East. Research has also been conducted on the needs of adult service users for supported living opportunities.

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[142] Personal assistance services involve the provision of a paid assistant for a number of hours per week to help the person with a disability in their daily activities.

[143] A 'circle of support' refers to the people who come together to assist the individual in implementing their plan. There is an emphasis on family, friends and unpaid support, although paid staff can also be part of a circle of support.

[144] Optimal Individualised Service Design (OISD) is a course focused on designing and delivering person-by-person, individualised lifestyle arrangements. It is a practical way of implementing person-centred planning.

Headstrong, The National Centre for Youth Mental Health

Headstrong is a relatively new not-for-profit organisation working with communities in Ireland to support the mental health and wellbeing of young people. The whole of Headstrong is included as a demonstration project.

Background and development

Headstrong does not provide mental health services directly to young people but works with those concerned with youth mental health, such as youth and health service providers, community leaders, NGOs and young people themselves. Headstrong has three key objectives:

- To coordinate and integrate existing services and support systems and ensure that they work for young people;

- To improve mental health outcomes for young people;

- To build greater community awareness regarding the needs and challenges facing young people.

Headstrong works in three main areas to achieve these objectives: service development, advocacy and research.

Service development

Headstrong's primary service development activity is a model for an enhanced youth mental health support system called *Jigsaw*. *Jigsaw* is a community-based system of care that supports young people, aged 12–25, to achieve better mental health and wellbeing. The *Jigsaw* programme works with identified communities to enhance and develop services and supports for young people with emerging mental health problems. The first step in creating a Jigsaw programme involves a detailed planning process in which the whole community and all local groups and organisations are encouraged to take part. This identifies all relevant resources in the community that can support young people's mental health.

The next step is to integrate supports and services that already work for young people and provide access to them in ways that are acceptable to young people. At the end of the process within each site, a comprehensive and integrated set of

interventions is designed, with the focus on engaging with young people in accessible settings where they feel respected and safe, and where they can access high quality, evidence-based mental health services and supports. The components of each community's response depend on local needs and resources, but all involve prevention, intervention, and capacity-building components. Galway has formally launched its *Jigsaw* programme and it is already responding to significant numbers of young people. Four additional demonstration sites are in various stages of development: Ballymun, and Counties Kerry, Roscommon and Meath. Many other communities in Ireland have expressed an interest in developing a *Jigsaw* model and Headstrong is keen to support more demonstration as resources become available.

Advocacy

Headstrong's advocacy is focused on shaping government attitudes and public policy on youth mental health. A Youth Advisory Panel has been established which informs all aspects of Headstrong's planning and development and also provides input to external advocacy activities. Members of the Youth Advisory Panel and staff of the organisation make representations at community, public and political meetings. The *Jigsaw* model of service development ensures a significant input from young people in designing and delivering services for them in their communities.

Research

Headstrong has conducted a nationwide validation study of a national youth mental health survey called My World with over 1,000 young people, and has plans to expand this to encompass a much larger sample (e.g. 10,000) to provide a periodic and in-depth snapshot of the mental health of young people in Ireland.

Headstrong conducts local research in each of its *Jigsaw* sites to map needs and resources in specific communities. It also conducts multiple focus groups with young people and key providers in local communities. An analysis of this information is reported to the local *Jigsaw* planning team to assist them in adapting *Jigsaw* to their community's unique requirements and resources. This process ensures that local *Jigsaw* teams are driven by a needs-based approach centred on the voice of young people.

Headstrong aims to evaluate the impact of its *Jigsaw* programme on young people, services and local communities. Initial evaluation of the Galway *Jigsaw* programme has commenced and has shown a high number of 'drop-ins' (young people seeking help directly themselves), substantial male engagement, significant collaboration on interventions with other community agencies, and extensive outreach and prevention activity. These early data demonstrate the accessibility and 'youth friendliness' of the model. Further evaluation will provide important information on the strengths and weaknesses of the model and enable it to be refined and improved on an ongoing basis.

Mental Health Commission/Health Service Executive Collaborative

The National Mental Health Services Collaborative (NMHSC) is a joint initiative between the Mental Health Commission (MHC) and the Health Service Executive (HSE), with the support of the Department of Health and Children. The MHC/HSE Collaborative has been identified as a demonstration project.

Background and development

This initiative arose following the findings of the Inspectorate of Mental Health Services in 2007, that compliance with the standards and regulations required of approved centres,[145] particularly with regard to the use of individual care plans, was very low. There were also concerns over the implementation of the Quality Framework[146] and how this could be supported in a practical way to achieve the high standards that are required in mental health services.

Breakthrough Collaboratives were developed in the US by the Institute for Healthcare Improvement with the aim of providing *a real structure for learning and action that would engage organisations in making real, system-level changes that would lead to dramatic improvements in care* (IHI, 2003, p. 2).[147] Collaboratives work by combining experts in a specific subject with experts in implementation who work together with organisations for a specified period of time. Learning materials are provided and participants are required to return to their organisations between meetings and implement and test the changes. In this way learning periods are interspersed with action periods. On-going support is available from the experts through teleconferences, on-line conversations and on-site mentoring visits. There is good evidence of the effectiveness of this approach in bringing about sustainable change in mental health services.

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[145] *Approved centres* is the term used to describe inpatient psychiatric hospitals and units under the Mental Health Act 2001. These hospitals and units are required to register and become approved centres for the admission of psychiatric patients.

[146] Mental Health Commission (2006) *Quality Framework for Mental Health Services.* Dublin. See page 8 for details.

[147] IHI (2003) *The breakthrough series: IHI's collaborative model for achieving breakthrough improvement.* Cambridge, MA.

The National Mental Health Services Collaborative (NMHSC)

The NMHSC has been established to progress the implementation of the Quality Framework. The evidence suggests that choosing one specific, well defined clinical or administrative topic is a critical success factor for collaboratives. Individualised care plans have been identified as key to the outcomes of service users and can help plan the supports needed for recovery. The implementation of individual care plans is central to the Quality Framework and supports partial fulfilment of several quality standards. Thus the overarching aim of the MHC/HSE Collaborative is '*to develop and implement individual care and treatment plans to support recovery'*. The implementation of individual, recovery-focused care plans will have a significant benefit to service users and should bring about wider changes in the mental health services.

A steering group and reference group will be convened to guide and advise the collaborative and project teams from around the country will be selected to take part. A project manager and local facilitators will also be appointed. The collaborative will be in place for 18 months.

The learning that will take place among participating project teams will be substantial and the Collaborative methodology has been shown to bring about real and sustained change in mental health services. The learning should also provide services with the skills to be more effective in implementing other changes and thus should have long-term positive effects.

Advocacy

Service users and carers are involved in all aspects of the Collaborative, including the steering group, reference group and project teams, throughout the whole process. This gives a strong voice to service users and carers in the content and conduct of this Collaborative.

Research

The Collaborative will be continuously monitored throughout the 18 months. In addition, there will be an external evaluation of the Collaborative to assess the achievement of specified outcomes.

Microboards Association of Ireland

The Microboards Association of Ireland (MAI) is currently facilitated and funded by APT (Aontacht Pobal Teoranta)[148] in Tullamore. The MAI has been identified as a demonstration project.

Background

A Microboard is a group of committed family and friends (5 – 7 approx.) who work with a person with a disability (focus person) to create a small, not-for-profit association to address the individual's needs in an empowering and customised fashion. Microboards can also act as a link to the community, facilitating the person's valued participation.[149] Essentially Microboards are a way of formalising the 'circle of support' that is often used in person-centred planning, usually with the aim of assisting in administering direct funding to provide the person with the services and supports they need.

The first documented Microboard was formed in Canada in 1984 around a young man leaving an institutional setting. Microboards are now established throughout Canada, in some US states, in Europe and Australia. In their guidelines for bridging service provider gaps, the Disability Service Commission in Western Australia lists Microboards as an alternative service provider model.[150]

Development of the Microboards Project

The Microboards Project commenced in 2006 and currently employs one full-time facilitator. The initial funding for the project was provided by Pobal.[151] This funding has finished and APT currently funds the Microboards facilitator and associated costs. Following the successful completion of the project, the Microboards

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[148] APT (Aontacht Pobal Teoranta) is a registered charity whose aim is to help people living with disability to maximise their social and employment opportunities. APT was established in 1988 (under the then Midland Health Board) to fulfil this aim and also to identify and link in with funding opportunities (particularly EU funds) and identify opportunities for partnerships. APT receives HSE funding, funding from partnerships and is also partly self-financing through a chain of hospital-based shops.

[149] www.velamicrobaord.org

[150] www.disability.wa.gov.dscrw/-assets

[151] http://www.pobal.ie/ Pobal is a not-for-profit company with charitable status that manages programmes on behalf of the Irish Government and the EU. It works on behalf of Government to support communities and local agencies towards achieving social inclusion, reconciliation and equality.

Association of Ireland (MAI) was established to provide a formal support structure not only for the Microboards that were formed in the project, but for future Microboards. Six Microboards were established in the duration of the project. The six Microboards were formed around two people with intellectual disability and four wheelchair users with various disabilities. Each Microboard has between five and eight members.

Creating a Microboard is achieved through a person-centred planning (PCP) approach. The essential components of a Microboard are that:

- The process must be focused on the needs, dreams and wishes of the person for whom the board is being created;

- All Microboard members must be in a close, voluntary and committed relationship with the person for whom the board is being created;

- These close relationships are the foundation of the board and must be honoured above all other activities;

- A Microboard serves as a formalised circle of support for an individual and in instances where direct funding is available the board takes on the additional responsibility of administering this funding to provide a full service for an individual.

Research

A formal evaluation of the project was conducted[152] and received positive feedback from the focus persons and the Microboard members. For the focus person, the possibility of achieving choice and control over his/her life was welcomed and for families the burden of responsibility was shared. However, the person-centred planning process was found to be slow and conveying the central functions of Microboards was challenging at times. It is recognised that Microboards are not for everyone, but they do present an opportunity for some individuals to achieve a high level of control over their lives. While existing service providers are cautious about Microboards, they accept that they have a role in helping some individuals plan their services and supports. The evaluation noted that one difficulty establishing

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[152] Microboard Association of Ireland (2008) *Evaluation of the Microboards Project. Final Report.*

Microboards into the future is that there is currently no facility for direct funding in Ireland. This limits the potential of the Microboard to enable the person to fulfil their goals.

Midway - Meath Intellectual Disability Work Advocacy You

MIDWAY (Meath Intellectual Disability Work Advocacy You Ltd., formally Meath Sheltered Workshop), is a voluntary organisation that provides services to people with intellectual disability in the County Meath area. The whole Midway service has been identified as a demonstration project.

The individuals being supported

A total of 165 'team members' (the term used by MIDWAY for service users) are supported by MIDWAY services. These individuals have a range of intellectual disabilities, from mild to severe disabilities and additional needs such as autism and behaviours that challenge.

Background and Development

MIDWAY was established in 1982 by parents and friends of people with intellectual disabilities in Co. Meath. The initial focus of the organisation was the development of day services, with an emphasis on sheltered contract work. In 2001 the MIDWAY services changed focus to an 'all encompassing social model[153] of service delivery'. Person Centred Planning and Supported Employment were used as methods to change service delivery and to focus any future development of the organisation on the service user. The number, range and quality of services increased from 2001 to the present, and MIDWAY works to maintain its central focus on service user's individual needs. This presents challenges for the organisation as it has an older population of service users alongside younger service users with different needs who are newer to the service.

MIDWAY intends to further develop and extend person-centred planning in the organisation. The organisation is developing a multi-level training course to provide training to staff and to support this extension of person-centred planning. A person-centred planning advisory group has been established recently in the organisation to drive this process.

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[153] A 'Social model' of service delivery is one which adapts services to the needs of service users, rather than expecting people with disabilities to fit into the services that are provided.

Nature and organisation of services and supports

Person-centred planning is used throughout the MIDWAY services to create individualised programmes for 'members' (service users), although not all service users have fully developed plans in place. MIDWAY services are delivered in six centres throughout Meath. Each centre has a range of employment, training, social and recreational programmes depending on the needs of the individuals attending that centre. For example, Navan Employment Options (NEO) is a new social model of holistic supports for young adults with an intellectual disability in Meath. The ethos of this day service is grounded in transition, 'from learning to earning'. The core in-house programme is negotiated with and amongst the Team (i.e. service users and staff together). It provides the team member (service-user) with the basic personal and practical skills, knowledge and attitudes necessary for work (whether that is supported work, voluntary work or sheltered work). MIDWAY believes that this emphasis on skills and work also assists independence and integration both at home and in the community at large. Programme activities include: job sampling, work experience and work orientation, literacy, numeracy, computers, self-advocacy, personal development, life skills and sports and physical activities. All programme activity is person-centred and is organised to meet the personal goals of service users in a timely and appropriate manner.

Advocacy

MIDWAY service provides an advocacy programme to all service users. Service users are facilitated to meet on a regular basis to discuss issues of relevance to them and to provide feedback to others using the services throughout the organisation. In a collaborative project funded by the Citizen's Information Board, MIDWAY have worked with Meath Citizens Information Service to provide an independent advocate for all people with disabilities in Co. Meath. Service users in MIDWAY can avail of this independent advocacy service and are regularly briefed about the service. Service users are supported by staff to avail of this service at the service user's request. The independent advocate has attended person-centred planning meetings with some service users to support them during the planning process. Service users are encouraged and facilitated to take part in training and education to develop their self advocacy and group advocacy skills, for example the

Certificate in Leadership and Advocacy at Dundalk Institute of Technology. Service users also participate in conferences and advocacy forums on a regular basis.

Research

The organisation is currently developing a research proposal to examine the process of person-centred planning within the organisation in more detail, with a view to evaluating the effectiveness of current processes and extending the learning within the organisation.

Project within The Alzheimer Society of Ireland

The Alzheimer Society of Ireland (ASI) is the largest dementia specific service provider in Ireland. It is a voluntary organisation providing services and supports across most counties of Ireland. One activity of the ASI is submitted as the demonstration project: social clubs for couples which have been established in the past four years.

The individuals being supported

The ASI provides services and supports to people with Alzheimers and other dementias throughout Ireland. The demonstration project involves four social clubs which have approximately seventy members

Background and development

The ASI was founded in 1982 by a small group of people who were caring for a family member with Alzheimer's disease or a related dementia. It is now a national voluntary organisation with an extensive network of branches, regional offices and services that aims 'to provide people with all forms of dementia, their families and carers with the necessary support to maximise their quality of life'.[154] The ASI now has 3,000 members.

ASI is keen to expand services for people who develop early onset dementia as there is a gap in services for this group. There are also plans to establish an advocacy group with the support of a Social Inclusion Officer who has just been appointed to the organisation. Innovative housing support projects are also being examined.

Nature and organisation of services and supports

A range of services is provided by ASI, including day care centres, home care, support groups and a residential respite centre. The ASI network currently includes twenty two branches, twenty eight Carer Support Groups and six Social Clubs. The ASI also operates the Alzheimer National Helpline Service offering information and support to anyone affected by Alzheimer's disease/dementia.

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[154] www.alzheimer.ie

The focus of services and supports in ASI has shifted in recent years from carers to the affected individual. The service and support models are person-centred, and are augmented further by the model of 'couplehood' which aims to support both the person with dementia and their carer. Couple-centred programmes are being developed which offer activities in which the individual wishes to participate, rather than a primary emphasis on routine daily activities such as dressing. The social clubs were established in response to three service development needs in ASI: to cater for both the carer and the person with dementia together; to address the social isolation experienced by both the person with dementia and their carer, and to cater for people in the earlier stages of dementia. Service users and their carers make all decisions regarding the running of the club and staff act as facilitators.

Advocacy

An advocacy service has been established in conjunction with the Citizens Information Board in North County Dublin. ASI also supports service users and their families to self-advocate.

Research

The social club model has been subject to a formal evaluation.[155] A number of benefits have been identified by members of the clubs including providing space for 'worry-free' socialising, maintaining a social network and social skills, sharing of carer strategies and carers providing support to each other in informal settings.

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[155] Keogh, C. and McGettrick, G. (2008) *Social Space: Equal Place. The Social Club Model of Dementia Care: A Research Report.* The Alzheimer Society of Ireland.

Project within Cheshire Ireland

Cheshire Ireland is a not-for-profit organisation which provides services and supports to adults with physical disabilities and neurological conditions, including brain injury. The organisation is moving residents from two centres which are closing, to new mainstream, independent settings. It is this aspect of the work of Cheshire Ireland that is being included as a demonstration project, together with projects in Dublin and Cork which have supported a number of people with disabilities to remain within their own homes or in newly acquired accommodation, where Cheshire delivers the support each individual requires

The individuals being supported

Cheshire Ireland provides services and supports for adults with physical disabilities and neurological conditions throughout the country. Approximately forty eight service users will be involved in the demonstration project, representing 16% of service users in the organisation.

Background and development

The first Cheshire Home opened in 1961 in Co. Wicklow, providing residential care for adults with physical disabilities. There are now eighteen residential centres in operation, ranging from old-style residential homes accommodating between 12 – 30 people and supported accommodation such as 8 houses in a housing estate and 5 bungalows in a mainstream housing complex. The Cheshire organisation has undergone a significant reorientation in recent years, with an emphasis on providing person-centred supports, and moving away from institutional care. This new strategic direction was encapsulated in the Strategic Plan 2003–2006: Developing Quality – Promoting Choice. Part of this strategy focused on separating the provision of support and respite from the provision of physical accommodation. The organisation believes this will enable a clearer focus on the specific needs of individuals in a more person-centred way. Training of staff and reorganisation of services is ongoing to support this new strategic direction.

Nature and organisation of services and supports

Over 300 people receive services and supports in 15 residential centres and a range of community- based services throughout the country.

Residential services: Some residential centres have been redeveloped to provide self-contained apartments in a supported setting (on the campus of the centre). Approximately one third of service users now reside in such accommodation. A small number of service users have moved to independent living arrangements in the community.

Respite services: Residential services are used to provide respite accommodation to service users living in the community and service users from other agencies. Cheshire runs two stand-alone respite centres.

Community-based services: In the Eastern part of the country and in Cork, community-based services provide support with daily activities to people living in their own homes.

Training and quality: A staff training and development programme has been underway to train staff in Optimal Individualised Service Design (OISD).[156] A quality system called Shared Values and Basic Assurances is being implemented throughout the organisation. This is a quality assurance and continuous improvement process which will be certified by the Council for Quality and Leadership (CQL).[157] The Basic Assurances outline factors that must be present in all services. The quality plan also describes how each service user can choose a member of staff to be their 'link worker'.[158] This link worker spends time with the service user developing an individual plan and then supports the service user to achieve his/her goals. Service users can also be involved in the continuous improvement process of services through local quality groups.

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[156] Optimal Individualised Service Design (OISD) is a course focused on designing and delivering person-by-person, individualised lifestyle arrangements. It is a practical way of implementing person-centred planning.
[157] The Council for Quality and Leadership, an international, not-for-profit organisation has developed a total quality system for intellectual disability organisations. CQL undertakes training and accreditation in all its measures.
[158] A person who works closely and on a continuous basis with a specific individual. The term 'keyworker' is used in other organisations.

Advocacy

Cheshire Ireland has one national and three regional advocacy groups called Consumer Committees. In conjunction with the Citizens Information Board, Cheshire supports a citizen advocacy service in three Dublin residential services. There is a strong human rights and advocacy focus to the Shared Values and Basic Assurances system as described above.

Project within the Muirıosa Foundation/Sisters of Charity of Jesus and Mary Services (SCJMS), Midlands

The Muirıosa Foundation (SCJMS) has provided services for people with intellectual disability in the midlands for over 60 years and have recently established a person-centred 'division' to drive person-centred initiatives within the organisation. Within the demonstration project the immediate aim is to establish 15 exemplars of person-centred practice within an 18–24 month timeframe. A group of 9 individuals form the nucleus of the exemplar set.   The Muirıosa Foundation has a particular interest in exploring the application of person-centred principles to people with intensive support needs (people who traditionally would have been described as having severe and profound levels of intellectual disability). A further focus of interest within the project is that of developing methods of person-centred practice that will assist persons move from traditional institutional arrangements to progressively more realised person-centred, inclusive options.

Individuals being supported

Services and supports are provided to children and adults with a wide range of intellectual disabilities residing in five midland counties. (While the Muirıosa Foundation works with the full spectrum of intellectual disability, it has traditionally been associated with those who have higher support needs.)

Background and Development

Within the past three years the Muirıosa Foundation has made a major commitment and investment in consciousness raising of a) the limitations of traditional group-based approaches and b) the potential, feasibility and operational principles of person-centred practice. This training has relied heavily on a group of international visiting consultants (from Canada, United States, Australia and New Zealand). The vision statement which has emerged from this process of reflection is firmly rooted in the values of self-determination, community inclusion, and the mobilisation of strong networks of 'natural' supporters and advocates in the life of the citizen with an intellectual disability.

To promote and embed the vision within 'the hearts and minds' of stakeholders, a leadership development programme was run for 40 key managers within the organisation from 2008 to 2009. The programme consisted of monthly, full-day, facilitated sessions within a small group format supplemented by individual mentoring sessions. There is a follow-up phase and extension of this work commencing in 2009 to 2010, which will involve further in-depth work for the same group of 40 managers. There is also a widening of participation in the 2009–2010 programme to a number of other key stakeholder groups (members of the Local Managers' Forum; clinicians such as psychologists, physiotherapists, occupational therapists, and a group of specifically targeted community-based staff members).

Nature and organisation of services and supports

Services and supports are organised within three separate geographical regions: South Kildare; Laois/Offaly; Westmeath/Meath/Longford. The range of services and supports provided by the Muiriosa Foundation span residential services (285 adults), daytime lifestyle supports (434 adults), respite services (135 adults, 88 children), early intervention pre-school supports (391 children) and 'day' supports for children (43 children).

Advocacy

Several advocacy initiatives are underway. Under a Citizens Information Board Advocacy Development Programme, Inclusion Ireland employ an independent advocate for people with intellectual disability in the Muiriosa Foundation's residential services. In addition, a self-advocacy group of 12 service users has been actively supported over the past two years.

Project within The Irish Wheelchair Association (IWA)

The Irish Wheelchair Association (IWA) is one of the largest providers of services to people with limited mobility throughout the country. Part of the IWA is included as a demonstration project.

The individuals being supported

There are over 20,000 members of IWA. These individuals have a physical disability and are not necessarily wheelchair users. In terms of service provision, services are availed of depending on the changing needs. Thus, an individual might require several services and supports in an early post- injury phase, but not require IWA services for some time after this initial contact.

Background and development

The IWA was founded in 1960 by a small group of wheelchair users committed to improving the lives of people with physical disabilities in Ireland. The early focus of the organisation was rights-based, with an emphasis on issues such as accessibility. There has always been a very strong volunteer base in the organisation and this continues today. Through the 1970s, 1980s and 1990s the organisation moved into service provision, while maintaining a strong focus on advocacy.

The plans specific to the demonstration project are to train staff so that Enhanced Person Centred Planning (EPCP) can be implemented throughout the organisation.

Nature and organisation of services and supports

IWA employs 2,500 staff nationally working in every county. These staff are supported by a branch network of volunteers. IWA maintains close links with local communities through participation in community activities, and by making its premises, transport and other resources available for other community groups nationally. The Assisted Living Service (ALS)[159] is the largest part of the work of IWA, with close to 1 million hours of ALS provided to around 1,500 service users per annum. There are Resource and Outreach centres in 68 locations around the country, providing a range of programmes to meet the needs of individuals using the

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[159] The Assisted Living Service involves the provision of personal assistants to service users to help them with daily activities.

centres. IWA also enables people to be independently mobile, by providing driving tuition and assessment. A peer counselling service is offered in conjunction with the National Council for the Blind of Ireland. IWA offers full-time training courses for people with a physical disability focused on life-skills and independence. A housing support service is available to provide advice and assistance on accessing suitable housing.

The demonstration project focuses on the use of Enhanced Person Centred Planning throughout the organisation. IWA has always provided services and supports based on individual need, although EPCP enables a more systematic delivery and monitoring of a person-centred process. Enhanced Person Centred Planning developed from the implementation of Personal Outcome Measures (POMS) in one of the Association's four regions. POMS were introduced as a means of individualising service provision and putting a greater focus on person-centred approaches. This has been found to work well but in evaluating outcomes from the project it emerged that a more tailored response was needed, hence the development of the EPCP as a more appropriate tool for IWA. Plans are now in place to extend EPCP to the three other regions in the organisation.

Advocacy

IWA encourages and supports people to self advocate and to make representations on their own behalf at a local and national level. For example, some IWA members have been trained in media skills and are available as 'spokespersons' for local radio and newspapers. IWA has partnered with a number of organisations around the country to provide independent advocacy services to people with disabilities (e.g. Wexford and Tipperary). At the organisational level, advocacy is one of the strategic action areas of IWA.

IWA is also involved at a national level in advocacy, particularly in relation to transport, housing, employment and access. IWA representatives participate in user groups and other fora for a number of Government and other state agencies.

Research

An evaluation of the usefulness of the Personal Outcomes Measure (POMS)/EPCP in one region has been undertaken and will inform future developments in the organisation.

Slı Eile Housing Association

Slı Eile[160] comprises two separate but integrated companies: a Housing Association providing social housing and Support Services providing staff and resources. The whole of Slı Eile is considered as a demonstration project.

The individuals being supported

All tenants of Slı Eile have long-term mental health difficulties and have had multiple admissions to psychiatric hospitals.

Background and development

Slı Eile is a recovery oriented therapeutic community with the aim of providing another way of supporting people to recover from mental distress through community living. Slı Eile promotes personal control and self determination through supporting tenants in taking responsibility in their own recovery. Slı Eile was formed when a group of family and friends of individuals with long-term mental health problems came together in 2000. A board was formed in 2001 to set up a supported housing project. Contacts with the Irish Council for Social Housing led to the establishment of a Housing Association. In this way Slı Eile could qualify for capital funding from the Department of the Environment under their Capital Assistance Scheme for Social Housing. There were several unsuccessful attempts to procure houses but a house in North Cork was eventually purchased in 2005. Slı Eile experienced direct and indirect opposition to the sitting of a house for people with mental health difficulties in several different neighbourhoods.

Following discussions and a collaborative decision by tenants a small bakery was established in the house next door which bakes, delivers and sells bread and scones to local pubs, shops and businesses.

Slı Eile has put considerable time and effort into extending this model to other areas. This work has been hampered by local authority planning delays and objections. The current financial climate is a further obstacle to expansion. Slı Eile is now considering other avenues to extend this model.

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[160] Slı Eile means 'another way' in Irish.

Nature and organisation of services and supports

Five tenants are currently supported by Slı Eile. Support workers work in the house with tenants and a team approach to all aspects of the running of the house is adopted. Tenants are supported to pursue training, educational, work and recreational opportunities in their local community. A good deal of work has been undertaken to support the tenants in running the house and developing collaborative decision making. Three house meetings are held each week, which are tenant-led, and attended by all tenants and a support worker. Community Feedback Meetings are held daily at staff change-over, where the support staff and tenants have an opportunity to discuss events of the previous twenty four hours. Once a week there are full community meetings for all tenants and all staff. These meetings all provide a new opportunity for the tenants to make decisions and have control over their own environment, an experience they have not had for many years.

The bakery has provided an opportunity for the tenants to take part in meaningful activities and has been progressing very well. When the project first opened there was a requirement for one support staff to be present twenty four hours a day, seven days a week. Since March of 2009 the house is no longer staffed from 11pm until 7.30am due to the increased confidence and responsibilities of the tenants. There is good evidence of integration with the local community. Local volunteers are involved in specific projects with the tenants and good links have been formed with community organisation and local schools.

Advocacy

This house is run by service users with support. All the tenants are encouraged and supported to self-advocate. Three tenants have participated in a Self-Advocacy training programme which has been developed by an advocate in the Irish Advocacy Network.

Research

An evaluation of the housing association was carried out by the social studies department of University College Cork. Both tenants and support staff were very positive about the experience to date and possible changes were also suggested.

SOS Kilkenny

SOS Kilkenny is a voluntary, non-profit organisation providing services to people with intellectual disability. The whole of the SOS service has been identified as a demonstration project.

The individuals being supported

SOS provides supports and services to over 145 service users with a wide range of intellectual disabilities in County Kilkenny.

Background and development

The SOS service provided a traditional residential and day service to people with intellectual disability in the Kilkenny area for many years. In 2003 the organisation commenced the process of becoming a person-centred service provider, based on quality outcomes for service users and their families. Values-based training was provided to all staff and this has been central to changing the culture of the organisation. Personal Outcomes Measures (POMS) are used and linked with an in-house database to ensure each service user has an individual plan that is regularly reviewed. This forms the basis for the entire management of the organisation, such that SOS describes itself as a 'service user-led organisation'.

The organisation plans to continue person-centred work throughout all service provision. There are plans to move all residents to community based settings (off campus) in smaller homes closer to the person's original home. There are also plans to expand the range of activities and opportunities available to service users and to expand the home support outreach service.

Nature and organisation of services and supports

Every service user has a key-worker (a member of staff who works most closely and consistently with a person). Over 130 service users access day services which provide a range of activities and sports. A pre-retirement service has been developed to support older service users. There is a strong emphasis on integrating with the local community and links have been made with groups from the youth and community sector, schools, and services for older people. Residential services are provided to 90 service users. A range of residential options are available, including

group homes, independent living, a respite service and a retirement home, with 90 service users living off campus. A behaviour support service was established to provide support and assistance to individuals who exhibit challenging behaviour. A new outreach service, the Home Support Outreach Service, has been developed to provide support to individuals living in their own homes.

There is a strong emphasis on training and development within the organisation, for both staff and service users. A variety of courses is available to service users as well as supported employment opportunities. Key learning needs of staff were identified following a review of the service and these are being addressed through pre-existing and newly developed training modules. SOS received an 'Excellence Through People' award, which is an accredited standard which measures how well an organisation values their staff and actively develops the full potential of their staff.

Advocacy

Service users are consulted extensively on service developments and provision. A wide range of creative methods (such as art and drama) are used to ensure all service users can express their views. In this way, service users are actively included in the management and planning of services in SOS. In addition, through the South East Regional Forum on intellectual disability, a novel means of representing service users and hearing their contribution was developed called Seasamh.[161] Seasamh is an open forum, led by a peer-elected leadership-team operating on a parliamentary basis. In partnership with providers, this group works to improve the quality of life of persons who access intellectual disability services throughout the South-East. The work involved in the establishment of Seasamh led to the development of a Certificate in Leadership and Advocacy in The Waterford Institute of Technology. This is a third-level college course designed in direct consultation with people with intellectual disability. The course has accreditation in three institutes. From its inception, Seasamh has operated on a partnership basis involving forty-four voluntary and statutory organisations providing intellectual disability services.

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[161] Seasamh is an Irish word meaning "Stand up"

The Sisters of the Sacred Hearts of Jesus and Mary have been providing services in St. Anne's, Roscrea, for almost forty years. The Daughters of Charity have recently taken over the service.

The individuals being supported

Services are provided to people with an intellectual disability. Predominately, service users of St Anne's Service, are adults, although some children also avail of services. People with a wide range of intellectual disability use services provided by St. Anne's.

Background and development

The Sisters of the Sacred Hearts of Jesus and Mary began providing a service in 1970 for children with intellectual disability. Initially, residential services only were offered to children and this was subsequently followed up in later years with the addition of a special school on the main campus. In 1990, the Order began to provide adult services to address the needs of those children who had 'grown up' while in the services.

Over the past 15 years, services have moved from an institutional base at Sean Ross Abbey to community living in a wide variety of locations in a real demonstration of person-centred planning and supports. The overall service is in the final stages of deinstitutionalisation and there are now only thirty service users in congregate day service settings on the campus of the old institution.

The strategic plan of the organisation was to work towards reshaping day services into smaller units of provision (10 maximum) and to proceed with closing down the old institution. However, the extent to which this plan specific to St Annes will be executed is uncertain, due to its being taken over by a larger organisation.

Nature and organisation of services and supports

Services and supports in St. Anne's are person-centred and focus on the needs of individuals as citizens; members of families and communities. There is a strongly

developed model of person-centred support which has been in place since the early 1990s.

Day services: There are ten day resource centres in Tipperary and Offaly providing a wide range of activities and employment for 120 service users. There is a range of day services supporting individual and activity-specific opportunities for service users in a flexible manner.

Residential service: A residential service is provided for approximately 129 service users of varying ages, needs and abilities. There is a variety of residential options available to service users depending on their needs; independent living in apartments, semi-independent living with minimal support from staff teams, community group homes and homes for service users with specific individual needs. There are now circa thirty community location options, accommodating a number of service users, ranging in capacity from seven to one resident. The residential staff work continually with service users and their circle of support[162] to address the changing needs of each individual.

Respite and Outreach services: Respite services provide short breaks away from home in a dedicated respite house, with a focus on community/social/fun and daily activities.

The Outreach Service provides individualised needs-led supports within the community and within individual's homes, to people with intellectual disability and their families. Supports include:

- Needs assessment/s;

- Carer support;

- Provision of Home Supports;

- Provision of Recreational/Leisure Supports;

- Educational/Training Supports;

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[162] A 'circle of support' refers to the people who come together to assist the individual in implementing their plan. There is an emphasis on family, friends and unpaid support, although paid staff can also be part of a circle of support.

- Advice on Allowances/Entitlements.

Specialist services: The service has developed a novel approach to obtaining specialist services for service users as and when required. If a need has been identified for specialist input (for example, a GP identifies a need for specialist mental health input or speech therapy), St. Anne's engages (buys in) such specific specialist input as required by service users. Accredited professionals provide specialist assessment, train the support person in the ongoing intervention, and conduct a follow-up review within a specified time. This approach contrasts with other organisations which tend to employ specialist professionals on an ongoing basis.

Advocacy

The St. Anne's Service engages an independent professional advocate for service users as required. This advocate works on complex matters such as inheritance and housing arrangements and focuses primarily on individual rather than family or organisational concerns.

Research

The St. Anne's Service has undertaken research with University College Dublin to identify what those on the waiting list and their families wanted in terms of service provision. Most service users and families wanted non-specialist supports that were relatively easily provided (for example, training and classes). Links were made so that these could be provided by locally available training facilities or on a one-to-one basis until the person could avail of other facilities.

Walkinstown Association

Walkinstown Association (WA) is a not-for-profit service provider, based in Dublin South Central, that provides residential, community inclusion, respite, rehabilitative training and day services to people with intellectual disability, mental health issues, and challenging behaviour in the local community. Walkinstown Association services as a whole have been identified as a demonstration project.

Background and development

Walkinstown Association was founded in 1967 by a group of parents and friends in response to a local need for community based services for people with intellectual disability. The first services provided were social clubs and day services. In 1994 WA received recognition as a service provider under Section 65 of the 1953 Health Act. This enabled WA to secure regular grants. In 1995 WA opened its first community residential house in partnership with the Eastern Health Board. WA describes itself as 'a progressive organisation where people who have learning disabilities are supported to live self-determined lives within socially inclusive communities'.[163]

Walkinstown Association is independently accredited as meeting international quality standards in providing community based services;[164] which are based on a person-centred approach and provided using a 'human rights based approach'. WA aims to develop more residential options for service users and continues to engage with the local community and build links and partnerships.

The individuals being supported

On a weekly basis over 150 service users link with WA services. Many of the service users in WA exhibit challenging behaviours. The organisation is known for its low arousal, non-aversive approach to support service users with challenging behaviours.[165]

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[163] www.walk.ie

[164] The Council for Quality and Leadership (CQL www.thecouncil.org) and the Excellence Through People National Human Resource Standard.

[165] A behavioural management approach which focuses on positive techniques to encourage the learning of appropriate behaviours. Non-aversive approaches place a strong emphasis on the dignity of the person. WA views that it cannot 'fix' others. People must reach and obtain solutions to their own problems. The most WA

Nature and organisation of services and supports

WA uses the Personal Outcomes Measures (CQL POMS)[166] to drive their person-centred services and supports. Service users participate in all committees within WA. A variety of services and supports are offered to service users:

Residential service: Six homes currently provide a residential service for twenty three service users (every service user has his/her own room in his/her home);

Community inclusion: Service users are supported to view themselves in socially valued roles and are supported by staff and volunteers to actively engage in activities of their own choosing. Links are made with agencies such as the Vocational Educational Committee (VEC, a national third level training provider) and the County Council to enhance services. Resources are focused on linking service users with their local community and the positive generation of socially valued roles for all;

Day services: The emphasis is on individualisation and service users make their own decisions concerning participation in group activities. Individual programmes are provided which focus on training, education, social, recreational and occupational activities;

Respite services: Non-residential respite is flexible to suit the individual and is provided in various locations. Residential respite is provided in community-based residences;

Rehabilitative training: Rehabilitative training services are offered with the emphasis on individualised learning and meeting individual requirements for people using the service.

Recreational service: A recreational service operates two evenings per week and Sunday afternoons. This offers service users a social outlet in which

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can do is offer them assistance in finding that solution. WA must change their approaches to suit the people supported.

[166] CQL is the Council for Quality and Leadership, an international, not-for-profit organisation which has developed a total quality system for intellectual disability organisations. CQL undertakes training and accreditation in all its measures, the best known of which is POMS – Personal outcomes measures – a 21 item tool which measures where an individual is on various life domains. It facilitates person-centred planning and review.

service users can meet and form friendships in a supportive and relaxed environment;

Other services: A community gardening project provides free garden maintenance to older people in the area and grows plants for sale to Dublin City Council. This project was developed in partnership with the local County Council and the VEC which provides horticultural training. An individually tailored range of holistic and complementary therapies is also available to service users.

Advocacy

An independent advocate is available to service users from a local community organisation. A Human Rights Committee operates in WA to review decisions which may affect an individual's rights. This committee meets approximately every two months, or as required, and consists of a cross section of staff, service users, an independent advocate, a family member and other external representatives. A number of service users have recently graduated from the 'I am' project run by Trinity College Dublin. The aim of this project is to ensure people understand and are empowered to advocate for themselves and on behalf of others. An annual election is held for service users to nominate and elect persons to act as service user representatives. There is a strong emphasis on self-advocacy in WA.

Research

A research project is currently underway in WA. It is being conducted by the assistant psychologist and is examining the benefits of holistic therapy, especially for people with challenging behaviour.

West Cork Mental Health Service

The West Cork Mental Health Service provides a specialist adult mental health service to the population of West Cork. All of the West Cork Mental Health Service has been identified as a demonstration project.

The individuals being supported

The West Cork Mental Health Service provides mental health services to people over eighteen years in the West Cork area which has a total population of over 50,000. Adults in this area who are experiencing mental health difficulties can access the service, usually through referral from a GP.

Background and development

The service developed in 1996 with the opening of an 18 bed psychiatric unit in Bantry General Hospital. This unit was designed to replace an in-patient unit in St. Anne's Hospital in Skibbereen and patients were moved from St. Anne's to Bantry when it opened. The West Cork Mental Health Service has adopted a recovery approach to service delivery for some time and service users receive individual care plans with an emphasis on supporting their recovery. This community based mental health service has a low reliance on inpatient beds and an emphasis on supporting people in their homes and communities.

The service has plans for the further development of recovery-oriented services, particularly in the community.

Nature and organisation of services and supports

One community multidisciplinary team serves the sector. As recommended in A Vision for Change,[167] a team coordinator has been appointed to manage referrals to the mental health team and to direct referrals to the most appropriate individual on the multidisciplinary team. The team uses integrated case notes.[168] The West Cork service is one of few mental health services in Ireland to work in this way.

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[167] Department of Health and Children (2006) A Vision for Change: Report of the Expert Group on Mental Health Policy
[168] All members of the multidisciplinary team use one set of case notes.

In partnership with the National Learning Network,[169] the West Cork service established the 'Home Focus Project', a small team which has the flexibility and time to visit people identified as needing mental health services and assistance with employment, but who were reluctant to access services. The Home Focus team works on engaging with these individuals and encouraging them to access services, with a specific focus on employment.

The West Cork service has worked hard to ensure there are good links with other services and with community organisations. This enables service users to be more integrated with the local community and fosters natural supports in local neighbourhoods. The mental health service has worked on creating a 'context of support' in order that service users can more easily access the many services that already exist in the community. As part of this work, the service worked with other organisations to establish the West Cork Mental Health Forum. This is a group of mental health service users, carers and representatives from many of the voluntary and community organisations in the Bantry/West Cork area. It provides a means to link in with community organisations and is not confined to those focusing on mental health per se. The Forum is regarded as being very successful and is now facilitated by a community development officer from the local HSE Community Services.

Advocacy

The West Cork Mental Health Service works collaboratively with the Irish Advocacy Network to make advocacy services available to service users. The service is also involved with the 'Leadership Programme' run by Dublin City University.[170] This programme encourages cooperative working between service users, advocates, carers and service providers in the delivery of mental health services.

Research

The Home Focus project was independently evaluated by University College Cork. An audit of service users' needs, experiences and opinions is being undertaken by the three people who took part in the Dublin City University Leadership Programme.

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[169] The National Learning Network is a non-government training organisation for people with disabilities and mental health difficulties.
[170] For a description of this programme see page 87

West Dublin Mental Health Service

Overview

The West Dublin Mental Health Service provides a specialist adult mental health service to a population of over 250,000 in West Dublin. All of the West Dublin Mental Health Service has been identified as a demonstration project.

Background and development

This mental health service has always had a 'community orientation'. Unlike most other mental health services in Ireland which have developed from a large institutional base,[171] there was only ever a small psychiatric hospital in this area (built in the 1950s). The West Dublin Mental Health Service was the first to develop (in 1989) an innovative model of community-based treatment, based on work carried out in Wisconsin and London. This took the form of home care teams, whose function was to provide acute mental health services to people in their own homes (or their chosen location) as an alternative to hospitalisation. This new way of working was evaluated and found to be preferred by service users while not increasing the burden on their families.[172] Clinics were located in shopping centres and other mainstream community locations. The innovative community-based work remained confined to one sector of the large catchment area for a number of years, although this model has now been adopted in the whole catchment area of a quarter of a million population. The old hospital has been completely closed and acute beds are now located in the psychiatric unit of the regional general hospital. The availability of community-based services has resulted in one of the lowest acute bed usage rates in the country.

The individuals being supported

The West Dublin Mental Health Service provides an adult mental health service for the population of the suburbs of West Dublin in Tallaght, Clondalkin, Ballyfermot and Crumlin. Other specialist services are provided within the West Dublin service,

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[171] Almost all mental health services in Ireland were located in large, old (Victorian era) mental hospitals until the 1970s. This has had a significant effect on the resourcing and modernisation of mental health services throughout Ireland.

[172] Keogh, F. (1997) Family burden and mental illness in Ireland. PhD Thesis. Trinity College Dublin.

including a mental health service for older people and a rehabilitation and recovery mental health service for people with severe and enduring mental health problems.

Nature and organisation of services and supports

The catchment area is divided into four sectors, and four multidisciplinary teams provide specialist treatment for adults with acute mental health difficulties. Two multidisciplinary teams provide treatment for other groups: one for those with severe and enduring mental illness and one for older people. Services are provided in 27 locations in the community, such as day hospitals, an acute inpatient unit and clinics in the community.

Home-care teams operate in each sector. Mental health nurses visit service users who are acutely ill, in their homes as an alternative to hospitalisation. Treatment and support are provided to the service user and the family/carer is also supported. The location and provision of specialist care in the community means that service users can more easily maintain their links to family, friends and community. The service has developed a stronger recovery focus in the last number of years, with links made to groups and organisations in the community to increase the natural supports available to service users.

Advocacy

Peer advocates from the Irish Advocacy Network are actively encouraged and facilitated by the service to support service users, and a carer advocate is also in place. These advocates represent service users and carers on the planning and advisory management committee of the West Dublin Mental Health Service.

Research

There is a strong emphasis on research and evaluation within the service among all disciplines.[173]

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[173] Dowling, M. in progress Exploration of Service Users Perception of Home based and Acute Mental Health Care.
Fell, M. and Sweeney, L. (2006) Service users perspectives on home care services. Mental Health Commission
Kehoe, S (2007) De-institutionalisation: Quality of Life and Functional Ability among persons with enduring mental illnesses after moving from a locked unit to open residences.

West Limerick Centre for Independent Living (CIL)

West Limerick Centre for Independent Living (CIL) is a not-for-profit company providing services for people with disabilities. The West Limerick CIL has been identified as a demonstration project.

Background and development

The first Irish Centre for Independent Living (CIL), CIL Carmichael House, was established in 1992 by and for people with disabilities. Its main aim was to ensure that people with disabilities achieved independent living and full participation in society. This was a grassroots organisation, which offered an advocacy and a campaigning representation role for people with disabilities. The formation of this first CIL in Ireland encouraged others to do the same around the country. The West Limerick CIL was founded in 1996 to respond to the need for services in that area. It has now expanded to cover Limerick City and the whole County. The stated aim of the CIL is to develop and deliver high quality Personal Support Services for people with disabilities in the Mid West region of Ireland. The initial personal assistant (PA)[174] service commenced with 12 Community Employment Scheme (CES) workers. This worked well and the HSE agreed to fund the service after this first year. The CIL has also developed a transport service and has received funding from the Citizens Information Board (CIB) to fund an independent advocate.

The individuals being supported

Limerick CIL supports individuals with physical and sensory disabilities in Limerick City and County aged 18 years and over. There are some service users in neighbouring areas such as West Tipperary and North Kerry. There is a small number of service users with intellectual disability or mental health difficulties who occasionally receive a PA service from the CIL, usually in conjunction with another agency.

Kehoe, S. in progress: Evaluation of a Rehabilitation Day Programme Based on the Recovery Approach.

[174] Personal assistant services involve the provision of a paid assistant for a number of hours per week to help the person with a disability in their daily activities.

Nature and organisation of services and supports

The main supports provided by West Limerick CIL are as follows:

The Personal Assistant service: The CIL provides an individualised Personal Assistant (PA) service to 120 service users and employs almost 100 PAs. Over 63,000 hours of PA service were provided in 2008. The process of accessing PA hours for a service user firstly involves an assessment of their needs. The CIL has three Independent Living Advisors to assist with this task. The identified need determines the level of service required (i.e. number of hours and how many PAs each person needs) to enable an individual to conduct their daily activities.

Following assessment the person with a disability is approved for an agreed number of PA hours per week. The service is funded through the HSE, and is currently administered by a number of service providers in Limerick, e.g. West Limerick Independent Living and other CILs, Enable Ireland and the Irish Wheelchair Association (IWA). The number of hours the person receives depends on the funding available to the HSE, and service users rarely get all the hours they need according to their assessment. The service user (called a 'leader' in the context of PA provision) has a contract with one of these providers and following training they either recruit Personal Assistants directly, or in conjunction with the service provider. The leader provides most of the training, while the service provider provides essential health, hygiene and safety training. Although the PA is employed by the service provider, the leader is the PA's line manager, determining the work to be done and the hours of duty. The leader then submits timesheets to the service provider in order for the PA to be paid.

In order to deliver a high quality service, the CIL has prepared a number of policy documents, including a booklet on quality and standards (with a section on complaints procedures), an employee handbook for service users/leaders who employ the PA (Service User and PA Handbook) and a Safety Statement.

Transport service: There is a limited public transport service in West Limerick which creates practical difficulties for people with disabilities trying to access other services. The CIL has one minibus and also links in with other providers such as IWA, Enable Ireland and Cheshire Ireland to ensure best coverage around the

county. The CIL also links with the rural transport initiative to ensure accessible transport is available.

A Disability Awareness Programme is offered to youth services, community and youth organisations, youth groups, employers and primary, secondary schools and third level institutes with two aims: promoting the inclusion of disabled people and encouraging employers to recruit more people with disabilities into the work force. The programme encourages interactive participation through discussion, worksheets, questions and answers, debates, role-plays and exercises, as well as the use of video and guest speakers.

Advocacy

Advocacy is central to the Independent Living philosophy and when the West Limerick Centre for Independent Living was founded it was essentially a self advocacy group. Half of the members of the board of directors are people with disabilities. An independent advocate is employed by the CIL and funded by the Citizens Information Board. The advocate is available to people with a physical or sensory disability in Limerick City and West Limerick.

Western Care Association Mayo

Western Care Association (WCA) is a voluntary organisation providing services and supports for children and adults with intellectual disability and autism in County Mayo. The whole of the Western Care Association has been identified as a demonstration project.

The individuals being supported

Services and supports are provided to approximately 893 service users in County Mayo. Services cover the whole age spectrum from children to adults. People with a wide range of intellectual disabilities and autism are supported.

Background and development

Western Care Association was founded in 1966 by families and friends of people with intellectual disability in Mayo. The organisation is representative of service users, parents, guardians, families and friends. The ethos of the WCA is based on the belief that services can best be provided locally in a person-centred manner.

The organisation plans to continue to move in a family/person-centred direction for all.

Nature and organisation of services and supports

Western Care Association provides services to approximately 893 people, of whom 390 are children and 503 are adults. Supports and services are provided across a range of locations including family homes, people's own homes, apartments, rented accommodation, general community settings and Association facilities such as Group Homes, Respite Homes and Day Centres.

Families with young children (0–5) are supported using a Family Centred model in which the family is seen as the focus of support. These supports are provided by multi-disciplinary and In-Home services directly in family homes and also through supports to attend local pre-schools. A total of 52 families with young children are in receipt of this service. There is an autism specific service for 22 families with young children which is comprised of a multi-disciplinary team and Autism Resource Workers who provide direct supports in family homes and pre-schools.

There are some 183 school age children (6–18) who are supported through a mix of support in the home, such as social work and family support workers. Additional options are also offered through family placement services and facilities for respite. Some children with complex challenges, such as significant medical needs, avail of shared care arrangements. In a few cases, older children live in Group Homes. There is also an autism specific team for the school age population. Multi-disciplinary staff and Autism Resource Workers provide a range of supports in family homes and after school as well as clinical support for schools to 131 children and families.

Supports for 503 adults are provided through both regular and intermittent services ranging from yearly contact to full 24/7 arrangements. Intermittent services are generally provided through disciplines such as social work or psychology. Some 46 people also receive ongoing supports through models such as community facilitation or personal assistants as part of the social work structure. The majority of adults (396) are supported largely through a network of Day Centres, Group Homes and Respite Services. Over recent years, support options for people living or renting their own homes have expanded significantly and increasingly, people are being facilitated to move from group based living arrangements where this is their preference. No new group living situations have been developed in the last five years. The pattern of service provision is changing to more individualised options.

The Association uses the Personal Outcome Measures as a learning and external independent accreditation process since 1998. This Quality Measurement System both informs and holds accountable organisational performance in delivering on the expressed wishes of people and families.

Advocacy

Western Care has established a Rights Review Committee which provides an independent advocacy function to service users in the area of due process and rights promotion. The inclusion of families as power sharing partners in circles of support has shown strong examples of how advocacy can be designed into the process of developing and operating support arrangements.

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