**Developing Services for People with Disabilities:**

**a synthesis paper summarising the key learning**

**of experiences in selected jurisdictions as at October 2010**

# A Contemporary Developments in Disability Services Paper

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This report presents findings of NDA research on health, social care and specialist disability services for people with disabilities in England, Scotland, New Zealand, Norway, the Netherlands and Victoria in Australia. The report reviews and discusses the challenges that have arisen and considers how specialist disability services are organised in these jurisdictions. It incorporates learning from NDA site visits to disability services in the USA and examines strategic policy and practice developments in health, social care and disability services. These include the development of quality assurance and standards for services, changes in the provision of specialist supports such as employment and accommodation services and the development of monitoring systems that focus on personal outcomes for people with disabilities.



**October 2010**

Developing Services for People with Disabilities

A study as at October 2010 of experiences

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# Executive Summary

## Overview of service trends, service development and the report

This report presents findings of NDA research on health, social care and specialist disability services for people with disabilities in England, Scotland, New Zealand, Norway, the Netherlands and Victoria in Australia.[[1]](#footnote-1) The report reviews and discusses the challenges that have arisen and considers how specialist disability services are organised in these jurisdictions. It incorporates learning from NDA site visits to disability services in the USA and examines strategic policy and practice developments in health, social care and disability services. These include the development of quality assurance and standards for services, changes in the provision of specialist supports such as employment and accommodation services and the development of monitoring systems that focus on personal outcomes for people with disabilities. Readers are advised that a key finding from this project is that disability service systems in all of the selected jurisdictions are in transition, and in some areas systems are undergoing rapid development. We welcome any feedback on any of the jurisdictions investigated that can update or enhance our analysis. The jurisdictions investigated include those set out above and can be found at www.nda.ie.

NDA is also continuing to work on specific elements of this project, with further analysis and policy advice papers expected in the areas, for instance of resource allocation, early intervention services, and direct payments. NDA's policy advice paper to the government's Value for Money and Policy Review of Disability Services is another outcome of this work, and can be found at www.nda.ie.

Section 1 includes background information on the project including considerations around definitions and approaches to health, social care and specialist disability services research. Section 2 outlines trends in disability services that promote independent living for people with disabilities. Section 3 outlines trends in personalising services. Section 4 examines approaches to delivering cost-effective services. Section 5 examines developments in employment and community-based living services. Section 6 examines standards and inspection of services. Section 7 presents evidence from outcomes research across six jurisdictions.

Drawing on findings from the six jurisdictions and the USA, the executive summary highlights

* the importance of developing and articulating a clear vision of the service model desired;
* implementing it through strategic commissioning and service provision and
* developing and maintaining it through monitoring and outcome measurement and building up partnerships.

The report places the findings in the context of international analyses and commentary on contemporary service development in these jurisdictions. The executive summary contains background information on each of the key findings to illustrate some of the complexity involved.

International consensus is developing around priorities and values for public services. Service models based on these values include

* person-centred,
* self-directed and individualised services;
* services promoting community and independent living;
* joint working between health, social care and other services; and
* community services that utilise assistive and information communication technology and reach into home settings.

Priorities for public services internationally include cost-effectiveness, cost containment and sustaining adequate services in the future.

The orientation of policy towards individualised approaches, community and independent living and cost-effectiveness and cost-containment is reflected in similar trends in service provision. These include

* building expertise on resource allocation and costing;
* needs assessment;
* person-centred and self-directed plans;
* individualised funding and
* community support systems with suitable accommodation and housing.

Engaging users in the development of services, better data collection and monitoring outcomes for people with disabilities are an integral part of disability service and programme development.

Systems that can support these new developments in services include

* funding and resource allocation models for person-centred and individualised services;
* needs-based data collection at local, regional and national level to calculate unmet need accurately and to inform strategic commissioning and resource allocation;
* education and training of stakeholders around new service models and
* studying how to sustain quality health, social care and disability services into the future.

The pathways to achieve new service models are complex but Ireland can learn from efforts being made across jurisdictions to:

* operationalise policies and strategies and incorporate new concepts and principles into service planning
* formulate clear implementation plans to ensure delivery of new services.
* develop integrated public service frameworks and systems to support new services.

Key trends in service and system development across the jurisdictions studied include:

**At the Service Development Level:**

Self-directed services with individualised funding for individual support needs.

* Personalised/individualised support (Information, Advice, Guidance, Peer Support, Training, Person-centred planning and transformation of supply-driven services into more flexible, person-centred ones).
* Supported community accommodation in order to implement the move from institutionalisation to deinstitutionalisation and community living.
* Developing accessible environments including accessible services and supports (Transport, Technical Aids and Equipments, Adapted Housing).
* Outcome variation for people with intellectual disabilities in community-based services reflects

the characteristics of people with intellectual disabilities,

service design and, crucially

differences in staff performance, particularly the extent to which they provide facilitative assistance or ‘active support’.[[2]](#footnote-2)

**At the Systems Level Developments include:**

* The study, implementation and evaluation of funding and resource allocation frameworks that
	+ - promote individual and community supports,
		- decrease inequity in service provision and control costs.
* In addition to resource allocation, attention is directed to staff costs, non-payroll costs, the cost of various models of service and support, the intensity of supports and the impact of "natural supports" and other socio-economic factors on service costs
* The development of outcome measures that monitor the long-term changes which have occurred in the lives of people with disabilities as a result of policies, services and programmes
* In many jurisdictions, the introduction of market values into public services with the devolution of some responsibilities for the provision of services from governments to market, community action and citizens.

A systems framework that summarises the main developments in disability services is shown in table 1[[3]](#footnote-3).

**Table 1: A Systems Framework for Contemporary Disability Services Models**

|  |
| --- |
| **Environmental Contexts**(Historical + Political/Economic +Built Environment)(Community Families Technology) |
| **Inputs**→ | **Processes**→ | **Outputs**→ | **Outcomes**→ |
|  | Assessment and PCP → | Resource Allocation→ | Implementation Of program→ |  |  |
| **People** **with** **disability** **requiring** **support** **and** **accommodation** →**↑****↑** | Individual AssessmentIndividual PreferencesPerson centred PlanningSupported Living | Employment and Day ActivitiesSpecialised and Allied HealthRespiteAffordable HousingEquipmentAdministration Support | Administration supportManagement practicesProcess Auditing andQuality control | Homely AccommodationCommunity integration/Social-capitalChoice and self -determinationSkills and autonomy developedFriendship and expanded circle of support  | **Quality of life** |
| Monitor**↑****↑**← | ← | ← | AuditingStandards and service Management practices  ← | Adaptive BehaviourAssessments← | QOLAssessment← |

This framework shows that a range of environmental factors impact on service development. Development is taking place in the context of the continuing need to address social exclusion, deliver independent living and quality of life and link the development of community living and accommodation to wider issues, including the issues of housing and natural supports.

**Main elements of service development identified across jurisdictions**

The main elements include:

* Articulating a vision for disability services
* Delivering the vision through the formulation of clear implementation plans
* Maintaining and building on service development through ongoing evaluation including outcome measurement
* Strategic commissioning[[4]](#footnote-4) and service procurement
* Building expertise on funding models and maintaining quality while controlling costs
* Developing liveable communities
* Developing employment services

In addition, issues and conflicting trends in service development are identified and discussed.

## Articulating a vision and building consensus

In order to achieve independent living for people with disabilities a broad range of services and supports are required within a system wide approach. This includes a vision of how the whole system should be developed prior to planning and commissioning effective services. In the jurisdictions studied, difficulties with service innovation and reform were identified where fragmented approaches were taken to service development and funding.

Evidence shows that creating a vision was an important part of developing new frameworks for disability services with opportunities for contributions by stakeholders, including policy makers, staff and service users and their families. As well as contributing to better service design, participation can increase support for service development.

The development of a vision enables the building of consensus and enables stakeholders to work collaboratively

* clarifying concepts, principles and frameworks;
* identifying desired outcomes for service users, service providers and funders;
* identifying data required for service planning and collecting and analysing it;
* formulating strategies and implementation plans based on the above.

An Australian study reviewed international models of community support for people with high and complex support needs.[[5]](#footnote-5) A common feature of effective service models was a whole of government approach in partnership with the community sector and high level service co-ordination facilitated by inter-agency forums. Effective forums were mandated by government and staffed by senior managers with authority to direct financial and personnel resources (see section 2.3. of this report).

An evaluation in the UK of services for people with intellectual disabilities reiterated what a vision for good services based on contemporary priorities would look like:

* individualised and person-centred;
* treat the family as expert;
* focus on quality of staff relationships with the person with a disability;
* sustain the package of care and
* are cost-effective.[[6]](#footnote-6)

As illustrated in Table 1, creating a vision for services as well as planning and commissioning them, takes place within a context. Reform of legislation may support service and system development.[[7]](#footnote-7) Within European countries the impact of EU policies and regulation on the provision of health and social services is increasing.

The UK Government has actively engaged in creating a shared vision for self-directed services and budgets for social care. Its output of policy papers, strategies, pilots and initiatives and its efforts to win public support for service developments have been considerable. Consultation has included engaging the public on the need to devolve more responsibility to users, local communities and authorities. It is currently providing financial support to promote further user involvement in service development in three regions.

In the UK, a detailed Green Paper[[8]](#footnote-8) was published in 2009 following a period of consultation. It made the case for change and provided a vision for it. It engaged the public around funding including various insurance options. It highlighted that there was public agreement during consultation that individuals and families should share some responsibility with the state for paying for care. It invited further consultation to feed into the White Paper. The White Paper[[9]](#footnote-9)was published in March 2010. It proposed a service built on social care insurance.

In May 2010 the Australian Government produced an Issues Paper on disability care and support[[10]](#footnote-10) which is similar to the 2009 UK Green Paper. It outlines a range of issues and options for service users in Australia and invites and facilitates submissions from everyone.

The 2008 National Disability Agreement in Australia[[11]](#footnote-11) provided a framework that states and territories in Australia (and other jurisdictions) have used to stimulate and create a vision for disability services in the various states and territories. The framework has given impetus to the work of disability service development and many reports have been published in the last year in Australia[[12]](#footnote-12). Drawing on this agreement, the state of Victoria in Australia has attempted to formulate a vision for new disability services[[13]](#footnote-13). This includes a framework that contains the monitoring of outcomes for persons with a disability, their family and carers as outlined in the 2008 Agreement[[14]](#footnote-14).

In the UK the 2001 Valuing People White Paper aimed to create a vision for disability services by promoting societal participation for people with intellectual (learning) disabilities through person centred planning[[15]](#footnote-15). Promoting the outcomes of independent living, inclusion and choice for people with intellectual disabilities were emphasised. This was followed with a series of policy documents building on the vision including the 2009 report ‘Valuing People Now: a three-year strategy for people with learning disabilities’.[[16]](#footnote-16)

## Formulating a clear implementation plan

From the above there is evidence that establishing a vision is important to informing outcomes and system and service design. Change management, staff training, monitoring outcomes and continued leadership from government and commitment and clarity on its delivery have been important to successful implementation..

Guiding elements for implementing change in employment services for people with intellectual disabilities in the U.S. have been proposed by Wehman, et al. [[17]](#footnote-17) These principles can be applied to all disability services:

* Support the vision of self-determination and person-centred planning;
* Focus on outcomes and pay providers on the condition that recipients of supported employment achieve the outcomes defined:
* Expand relationships with business and community and keep a focus on the mission of supported employment which is real jobs of choice in integrated work places with individualised long-term supports and
* Align funding with the vision for services and fund people not programs.[[18]](#footnote-18)

Long-term partnerships between commissioners and service providers committed to developing local capability to serve people with disability are essential. Planning services for people with intellectual disabilities and challenging behaviour requires advocacy and coordination services in order that appropriate person-centred plans for current and future service needs can be formulated and translated into action for each person. In England, in order to achieve this, councils[[19]](#footnote-19) are working to strengthen their commissioning skills combining expertise with relevant competencies in order to develop the services needed[[20]](#footnote-20).

The way Norway ended deinstitutionalisation, replacing it with community living within 5 years is an example of clear decision making and planning which has been lauded and admired. The process included formulating a vision in 2001 and a policy based on it. Goals, implementation plans and timeframes were established including that all institutions would close by Dec 1995. The plan included the provision of housing of the same standards and form as any typical home in the community. Community supports including "habilitation" teams were set up to support people with intellectual disability and their families.

Similarly, in order to improve access for children with disabilities to preschool care, the Norwegian government mandated that children with disabilities should have prioritised access. Special grants were made available to existing pre-schools to introduce any adaptations needed. New pre-schools had to be accessible to everyone, indoors and outdoors, so that as far as possible no "special" adaptations for "special needs" would be required[[21]](#footnote-21).

In the UK, policy provides that commissioners of services work to ensure that a transition takes place away from the purchase of services that do not deliver on quality of life (outcome measurement) or that are too large to provide individualised support or which move people too far away from their communities and homes.[[22]](#footnote-22)

An Australian study reviewed international models of community support for people with high and complex support needs[[23]](#footnote-23) and proposed one best practice model as incorporating a three-tiered service system:

* generic community services available to the entire community,
* generic specialist services designed specifically to support people with disabilities and/or mental health issues and
* specialist services designed specifically for people with disabilities with complex needs.

## Maintaining service development through ongoing outcome measurement

* The ongoing evaluating and re-orienting of services is important to achieving the desired outcomes and maintaining the direction set by policy.
* While progress has been made in developing services for people with intellectual disabilities in England there is concern that development slowed down. A review of services for adults with profound intellectual and multiple disabilities was published by the Department of Health in 2010.[[24]](#footnote-24) This found that a major obstacle to development in line with the vision set was poor commissioning of specialist services. Other factors included funding cuts, conflicting service trends and an increasing focus on quantity over quality.[[25]](#footnote-25) The review concluded that while a shortage of resources may influence the speed with which service changes can be implemented, the direction of policy and practice should not change. Resource constraints may dictate the pace at which objectives are achieved but should not impact on the nature of the objectives themselves. Many obstacles to the development of services require reasonable adjustments to priorities and not large amounts of resources.[[26]](#footnote-26)
* The Netherlands, Norway and the UK have strong and well-established policy commitments to independent living which appear, largely, to be matched by continued good practice at local/practice level. [[27]](#footnote-27) There are on-going public policy concerns in the Netherlands that independent living support being provided mainly for people with physical/sensory impairments. In Norway there are concerns about possible moves towards larger forms of sheltered housing.[[28]](#footnote-28)
* Research conducted by the Victorian Department of Human Services (DHS) in Australia[[29]](#footnote-29) found gaps in the knowledge and understanding of stakeholders about the disability services being implemented as well as gaps in other skills essential for developing new service models. These findings were considered to be significant risks to establishing more personalised and individualised disability services in Victoria. Capacity building for stakeholders was recommended to increase support and understanding for the new disability service model.
* In New Zealand a vision was developed over two decades of giving everyone the opportunity to live an ‘ordinary life’ in the community. Progress has been made from a service model of institutional care to one of community participation and choice. However, New Zealand's learning on their needs assessment and service coordination system (NASC) illustrates that progress can slow down and the importance of ongoing evaluation of service innovations. Learning from the review conducted by the Disability Commission in New Zealand included the need
	+ to evaluate outcomes over time to ensure that the goals of service development are attained and
	+ return again to the original vision for NASC.
* This might be achieved through staff training around the original vision. The review contrasted NASC with the Local Area Coordination Model (LAC) of Western Australia and recommended incorporating elements of the LAC Model of Western Australia into NASC to improve the service (see Appendix 1 for details).[[30]](#footnote-30)
* A risk-averse bias in disability services was identified as an obstacle to the development of individualised disability services in New Zealand.[[31]](#footnote-31) This has also been documented in other jurisdictions including Victoria, Australia.[[32]](#footnote-32) There is a need to establish how risk management fits into flexible services and how to support people with disabilities to take risks.
* Will new service frameworks, service provision, instruments and tools improve the quality of life of people with disabilities over time? The ongoing and systematic evaluation of whether service development delivers the desired outcomes for people with disabilities is fundamental to maintaining new service developments over time.[[33]](#footnote-33)
* The extent to which outcomes of service modifications and new interventions can be monitored within and across services and countries depends, in part, on the use of agreed and clear definitions. The extent to which they impact on services will depend on the mechanisms put in place to follow up and act on outcome monitoring. Defining the relationships hoped for between the introduction of new practices and desired outcomes facilitates robust evaluations of the impact of service innovation on outcomes for service users. It is essential to outline clearly what the goals of the proposed developments are, what outcomes for users are desired and how these outcomes are going to be monitored.
* Most jurisdictions are attempting to set outcomes, standards and indicators for disability services. The outcome measurement models which provide useful examples focus on disability system level performance and include outcome indicators in their measurement. Over the last three years, these have been under development in England, Scotland and Victoria. They are based on data collection for service and system performance evaluations (See Section 7 of this report.)
* For example, in Victoria, Australia, five Outcome Standards have been proposed for people with disabilities: Individuality, Capacity, Participation, Citizenship and Leadership. Nine Service Standards include Service Access; Individual Needs; Decision Making and Choice: Privacy, Dignity and Confidentiality; Participation and Integration; Valued Status; Complaints and Disputes; Service Management and Freedom from Abuse and Neglect. Finally, a suite of evidence indicators for the 5 Outcome Standards were developed to help service providers to focus on the issues that are important for people with disabilities and their families and carers. Services can be constantly developed if action is taken on the results of ongoing monitoring and outcome measurements.[[34]](#footnote-34)
* Based on research on disability services in the UK, resources, costs and staff ratio were found to have little impact on the quality of outcomes for people with intellectual disability. There were links between outcomes and participant ability, staff support and service design and management practices. Staff training may be the missing link between resource input and quality of outcome and, in particular, training staff to provide active support.[[35]](#footnote-35) [[36]](#footnote-36) At times services have added more staff at greater cost in an attempt to deal with challenging behaviour where it could be more effective that commissioners fund higher levels of skill through training.[[37]](#footnote-37) Similar findings have been seen in other jurisdictions including New Zealand and Victoria, Australia.
* The Supporting People Programme which started in the UK in 2003 enabled the development of an increasing number of supported living services for people with intellectual disabilities.[[38]](#footnote-38) An evaluation found that, while there was consensus among tenants that these services offered them choice and control in day to day activities, key decisions were still made by commissioners and service managers. Sometimes, shared tenancies with accommodation based support were little different from the registered care homes they had replaced. The findings highlight that those delivering services must understand the legal and ideological differences between supported living and group homes that have 24-hour staff input. It highlights the need to enforce the rule, as was done in Norway, that staff could not have offices in people's homes and that tenants were to control access to their own homes.[[39]](#footnote-39)

## Strategic commissioning and service procurement

* In examining the commissioning of services in other jurisdictions, it is clear that good quality data and the input of specialist knowledge where necessary. It includes coordination of policy between departments at government level, commitment to service models of good practice and responsibility in developing services in a timely way; undertaking staff training and achieving value for money.
* Steps towards effective commissioning include
* putting people at the centre of commissioning i.e., starting with service users;
* understanding the needs of populations and individuals;
* sharing and using information more effectively;
* assuring high quality providers for all services;
* recognising the interdependence between work, health and well-being.[[40]](#footnote-40)

Appendix 2 shows a model for a commissioning strategy that is being used quite widely in UK statutory agencies.[[41]](#footnote-41) This covers many aspects of developing contemporary public services. The final review stage in this model would include monitoring the outcomes which guided service development in the first place. Outcomes would include the delivery of independent living, gaining and retaining employment and attaining full civic and social participation.

* Market-orientated reforms in public services in England, Scotland, New Zealand, the Netherlands and Victoria, Australia include competitive tendering. In Norway while the government promotes competition in the business and public sector, it remains clearly committed to "community solutions and public control instead of compulsory competitive tendering in important welfare fields like education and health care services".[[42]](#footnote-42)
* In Scotland, social care procurement exercises since 2006 attracted negative press coverage and led to intensive parliamentary scrutiny. The Scottish Government published draft guidance on social care procurement for consultation between January and April 2010.[[43]](#footnote-43) This guidance outlines principles to guide procurement activity. It acknowledges that social care services are significantly different to other goods, works and services to be procured by public bodies and that a distinct approach must be taken in relation to them. Therefore, procurement activity needs to take place within the context of a wider commissioning strategy. Priority needs to be given to quality in selection and award criteria. Alternative methods to competitive tendering for procuring services do exist and are approved by the EU. These include framework agreement, partnering arrangement, restricted tender, competitive dialogue and direct non-competitive negotiation and all of these have also been used by local authorities in Scotland.[[44]](#footnote-44) (See section 4.3)
* In the last decades experience is emerging on when competition is appropriate and where it does not work. Economic theory and limited empirical evidence suggest, for example, that tenders are likely to perform better than negotiations when the product or service being acquired is relatively simple, when most attributes of the deliverables are contractible and when there are enough bidders.[[45]](#footnote-45) (See section 4.3 for learning from other jurisdictions on purchasing services and competitive tendering).
* Issues to be addressed in the UK in commissioning of health and social care services outlined include: developing effective transition arrangements as people move into adulthood; recruiting and training personal assistants; using assistive technology in services; supporting families to access help and advice in securing and running self-directed services from user-led organisations, self-help groups or other families.[[46]](#footnote-46)
* According to Mansell, commissioning services for people with intellectual disabilities and challenging behaviour in England has sometimes been reactive.[[47]](#footnote-47) Many commissioners have purchased services for people with intellectual disabilities with challenging behaviour or mental health on the basis of the lowest cost in the short term. Hidden costs associated with poor commissioning of local services for people with intellectual disabilities and challenging behaviour in England in the last years include crises and placement breakdowns; out of area placements; re-institutionalisation; less choice of services; lower efficiency and public criticism. Similarly in New Zealand, community support and accommodation services for people with disabilities have been criticised as crisis-driven.[[48]](#footnote-48)

## Building expertise on funding models and maintaining quality while controlling costs

* Efforts to improve the effectiveness of resource allocation methodologies are seen across all jurisdictions: the USA, New Zealand, Victoria, Australia, the Netherlands, Norway, England and Scotland. A demand for transparency in funding provides an impetus for designing better funding methodologies.
* Expertise on implementing individual budget allocations and developing tools such as the Supports Intensity Scale in the USA (originally designed to support person-centred planning but increasingly used to develop funding models) is being developed.
* The introduction of cash for care or individualised payments is seen across jurisdictions: Direct payments and personal budgets in England and Scotland underpinned by legislation; Personal budgets for care and nursing in the Netherlands; direct payments for personal assistants at the discretion of the municipality in Norway and pilot projects on individualised funding in New Zealand and Victoria, Australia. (see Australia background country paper including Appendix 5) So far, however, uptake of direct payments is on a small scale in the jurisdictions studied.
* Cost variations exist within and across jurisdictions. Unit costs were found to be about 50% higher in Scotland than in England for learning disability services provided under the Supporting People Programme, a funding programme which delivers housing support services across Great Britain.[[49]](#footnote-49) Higher costs were due to the hours of care provided. Average costs for older people in England are reduced by the extensive use of alarm systems which are cost effective to run on a unit cost basis. Cost differences for older peoples’ services narrow once "alarm-based" projects are removed. Scottish services had between twice to three times as many hours per client per week as English services.[[50]](#footnote-50)
* England is considering the introduction of an insurance system for social care as the best way for funding these services into the future. The Australian government is also examining the possibility of funding long-term care in its territories with some form of social insurance. A mandatory, population-wide, ‘quasi-private’ or ‘private social scheme’ health insurance (HIA) replaced the former public and private health insurance systems in the Netherlands in January 2006.[[51]](#footnote-51) This regulated competition is a policy instrument introduced to transform health care from a supply driven system into a demand driven system. The objective is also to improve the quality and affordability of health care, while preserving the values of solidarity and universal access.[[52]](#footnote-52) HIA contains many regulations so that it does not violate the principles of solidarity in and universal access to health care. The impact of the HIA on the development of services is being studied. It may still be too early to capture the full effects of this change. There is almost universal insurance coverage in the Netherlands today. However, there is some evidence emerging that the reforms may not have led individual consumers to seek value and that the system of managed competition may in fact have led to a less competitive market.[[53]](#footnote-53)

## Developing liveable communities

High quality housing is an integral part of making a community more liveable for people with disabilities.A liveable community has been defined as one that:

* Provides affordable accessible housing;
* Ensures accessible affordable, reliable and safe transportation
* Adjusts the physical environment for inclusiveness and accessibility
* Provides work, volunteer and education opportunities
* Ensures access to key health and support services and
* Encourages participation in civic, cultural, social and recreational activities.[[54]](#footnote-54)

Community living has been defined as comprising the same range of accommodation available to the general population, in the same locations where the general population reside, offering people with disabilities choice over where and with whom they live and providing the necessary supports for community participation.[[55]](#footnote-55)

Community living requires both the closure of inappropriate accommodation and the development of accessible affordable housing, housing support and community support models for people with intellectual disability. The range of accommodation services currently available in lieu of residential accommodation can be classified into separate supported living accommodation models where individuals live in a private residence or comprehensive placement models which include institutions, cluster housing, group homes, hospital wards and smaller specialist residential facilities. In the latter models, governments purchase accommodation as part of an overall support package while in 'separate supported living accommodation' the funding is more fragmented.

Norway's housing policy based on the goal of home ownership for the majority of the population articulates clear goals to ensure adequate and secure housing:

* stimulate a well functioning housing market
* provide housing for disadvantaged groups on the housing market and
* increase the number of environment friendly and universally designed dwellings and residential areas.

Routes to improving supports in the community include the use of key workers such as case managers, local area coordinators or disability liaison officers. Disability Services Division of the Department of Human Services in Victoria undertook a consultation process in 2009 to gather the views of people with a disability, their families and carers, disability service providers and other interested community members on a framework they are working on for how flexible and individualised, self-directed planning supports will be provided. People with a disability indicated that where possible it would be helpful if the planning that takes place at three different points of their involvement in the disability service system (planning, facilitation and support coordination) could be undertaken or guided by a key contact or support person.[[56]](#footnote-56) Local Area Coordination (LAC) was introduced in Western Australia in 1988 and in Scotland in 2001. New Zealand (NZ) is currently studying experiences in Western Australia in order to learn how they might incorporate features of LAC into their services to address some weaknesses in their service innovation. (see Appendix 1 where the NZ Government compares features of NZ's Disability Support System with Western Australia's LAC system). The Disability Liaison officers for children with disabilities in parts of Ireland (Sligo, Leitrim, Donegal and part of Cavan) play a similar role to Local Area Coordinators.

## Employment Services

There is a shift across jurisdictions from passive measures towards active labour market integration policies. Innovative measures include personal advisors in promoting employment in the UK; and social enterprises in the Netherlands, Norway and the UK.

Netherlands is an example of a jurisdiction that operates quota schemes in both public and private sectors while the UK is an example of a country with no quota scheme.

International evidence suggests that on-the-job training and long-term support to the employee and employer are successful in creating sustainable employment for people with intellectual disability. Few people move from day services such as sheltered workshops to open employment. The job coach model has contributed substantially to people with disabilities gaining and retaining competitive employment in the USA.

With regards innovation in funding employment services, in Victoria, Australia, from end of December 2009 all funding for day services is individually attached and portable instead of being attached to service providers. Some people with disabilities already had individually attached and portable funding for day services via the Futures for Young Adults (FFYA) program or through Individual Support Package (ISP) funding. An interim document for 2010 “Guidelines for Day Supports, 1st January–31st December 2010” will be reviewed and consulted on during 2010 with a final version to take effect from 1st January 2011.

Governments in the USA and the UK have tried to address the limited effectiveness of employment policy measures for people with disabilities by co-ordinating employment service delivery. A One-Stop-Shopping approach attempts to integrate service delivery. In the US, the Workforce Investment Act (1998) brought together different employment and training programs but not Social Security into a comprehensive system. Employment services can be delivered by multiple agencies. The UK merged its Benefits Agency and the Employment Agency in 2001 into one integrated service called Jobcentre Plus with services provided through a network of local offices and coordinated by a central government department, the Department for Work and Pensions.[[57]](#footnote-57)

## Issues and conflicting trends

Some of the issues arising in service development identified in the jurisdictions under study include:

* Area disparity in service provision
* Lack of comprehensive data-collection
* An increase in the inflexibility in services and a risk-averse culture due to the use of national service specifications resulting in a reduced impact on service innovation and development
* No explicit models or frameworks for integrating disability services and/or health and social care services or the combination of services and supports required for people with intellectual disabilities or people with intellectual disabilities and challenging behaviour.
* New systems that, without the support of a co-ordinator, are difficult for service users to understand and navigate
* Insufficient staff training provided to achieve buy-in and to maintain the vision for new service models
* Under-financing of assessment systems with, for example, assessment processes for individual care being carried out via phone in some cases
* Insufficient resources allocated to flexible accommodation and community based models of support and system navigation supports such as key workers and advocates
* Segregated day programmes with less funding available for individualised programmes that enable community participation
* High levels of unmet need in some jurisdictions where crises become the driver in resource allocation
* The continuation of inappropriate placements due to a shortfall suitable services and supports for people with intellectual disabilities and challenging behaviour
* There can be confusion between procedural rights and financial resource allocation. Procedural participation, such as the right to a fair hearing and to complaint, redress and appeal mechanisms will not satisfy the substantive needs of people with disabilities. Assessment systems have the potential to reduce rights to circumscribed needs within systems that deliver what is economically feasible. While empowerment frameworks are commendable, they can break down when the system does not allow flexibility of service choice and participation in service design.[[58]](#footnote-58) (See section 2.2.)

Some examples of conflicting trends in service provision and policy across jurisdictions include:

**Promoting co-operation and competition simultaneously:**

* In Scotland service providers have expressed concern over the manner in which some social care re-tendering exercises were taken forward. A public procurement reform agenda promotes the advertising of social care services as contract opportunities to be awarded through competitive tendering while social care policy imperatives emphasise the need for a shift towards personalisation, greater involvement and control for individuals in the design and delivery of their support, and partnership working with service providers.[[59]](#footnote-59)
* An emphasis in policy documents on inclusion approaches and responses based on individual need, user outcomes and quality of life but meanwhile the market is promoted and increasingly operates to maximise quantity such as number of places over quality.
* In New Zealand when the first wave of health reforms were introduced health professionals felt that the competitive environment introduced into health services undermined the culture of collaboration and the sharing of ideas and innovation. Many senior personnel resigned and much institutional memory was lost. However, the culture of reform has itself been an important stimulus for innovation at service level.[[60]](#footnote-60)
* The market model has had implications for services research and evaluation in New Zealand because data that was previously publicly available is now sometimes protected on the ground that it is "commercially sensitive". This makes it difficult to undertake independent evaluations of service reforms.[[61]](#footnote-61)
* Competing developments such as efforts to develop liveable communities with individualised services for people with disabilities alongside the maintenance of institutional care or further developing group-oriented type services. This is creating competition for scarce financial resources between these more traditional services and newer forms of community support. Continuing to allocate major funding to resource-intensive models of accommodation such as institutions and group-oriented services and solutions can slow down service development.

**Choice and personal control versus flexibility and safety**

* Challenges arise when services that facilitate people living independently intersect with efforts to ensure safety and quality through regulation, standardisation and accountability.[[62]](#footnote-62) It requires consideration of where risk management should lie in current and future needs assessment and service planning processes. Also as to how can financial risk be managed while developing and improving assessment of need and the allocation of resources to support personalised services.
* It is important to acknowledge and study these issues and conflicting trends in service development and what can be done to resolve them.

## Summary of some learning points on service development

Policy on disability services and support and service development for people with disabilities is a complex field. Developing services, for example, for people with challenging behaviour is intrinsically complex. A partnership approach to the difficulties and dilemmas facilitates the enlisting of community, voluntary and natural supports and the ensuring of the good will, cooperation and collaboration of all enlisted in an explicit and formal manner. This is important in order to ensure the development of optimal person-centred services and supports over time.

The following steps have been identified in the study of the trend in service development: these steps do not necessarily take place in a chronological order.

* Development of a vision for services and involvement of all stakeholders in developing the vision is important for its effective implementation
* Design of a service delivery model based on the vision (See Section 4.1 for some learning on how the vision needs to be complemented by an implementation plan)
* It is important to be explicit about real difficulties and build on existing good practice
* Articulate difficulties and limitations of services clearly, including with service users. This is essential where there are person-centred plans and individual resource allocation. If services are person-centred there must be clarity, honesty and trusting communication of the realities of service development including the limitations.
* Clarification of how the model is going to work in practice, taking into account how contextual factors will influence development.
* Ensuring that everyone, in so far as possible, has the opportunity to contribute to, to understand and to buy into the model and support it in an ongoing way
* A critical competency in the new models of service provision is the ability to establish partnerships between national and local bodies, state/civil service departments, service providers, the community sector and people with disabilities and families and carers.
* Collaboration so that all the partners involved in service provision can agree on how to develop the various aspects of service development including how to define and address unmet need and develop the culture, attitudes and competencies required to deliver integrated and person-centred services.
* Partnerships also facilitate the provision of integrated services. They facilitate joint need assessment, case management approaches etc. Examples of service integration (See Section 5.3) include the following: In England and the USA a user orientated form of integration of services are the one stop shops for employment services. In Norway there is also a public service reform to integrate public employment services, social security and social assistance into one unified service. In England, the Individual Budget (IB) Projects in 13 English Local Authorities brought together a number of funding streams to provide a more integrated service for a range of service users
* Building a common understanding of definitions and concepts associated with service development and integration.. For example, an understanding of what is meant by individualised services was lacking in one jurisdiction and this had considerable consequences (See section 1.4). It is important to understand that terms may mean very different things at different levels e.g. the service, the agency and system levels. The findings on supported accommodation across jurisdictions illustrate the need to define carefully what acceptable community alternatives to institutional living should look like and how these models are to be maintained over time. Also to define what is best practice in community housing-related support and to establish how best to assess individual need, allocate individual budgets and organise service delivery so that autonomy and independence are respected and promoted. (see section 3.4 for a background on various aspects of integration).
* Implementing the service delivery model in phases. Developing supports and services that support ordinary life and participation for people with disabilities in the community including work and employment services and advocacy services take time to develop and embed. This includes allowing time to develop utilisation of natural supports in the community. It is also required for the steady development and coordination of services such as housing, income support, health, social care, and education - all of which may have been previously managed, for people with disabilities, under the auspices of a single institution. This new model of service delivery also will require different staffing structures and operating systems.
* Providing clear outlines of the roles and responsibilities associated with new planning models and the provision of training to develop capabilities of personnel so that they can implement and develop the model over time. Training programs should provide practical guidance on how partnership approaches can be built, maintained and reviewed
* Aligning and amalgamating the monitoring and regulatory systems so that they achieve their purpose while avoiding duplication, bureaucracy and confusion and keep administrative costs down
* Addressing the cost and quality together in the planning and development of services by developing robust systems for costing and funding of services including the allocation of individualised funding.[[63]](#footnote-63)
* Strengthening assessment and commissioning processes and reviewing them frequently. Expertise and guidance is required to guide procurement activity. Tendering for particular services needs to take into account the range of factors that make successful outcomes likely (See section 4.3).
* Ensuring that no group's needs are overlooked. Research on self-directed services and person-centred planning shows that unmet need is more likely to continue for those with complex or more severe disabilities. Also that this can be addressed by paying attention to appropriate commissioning of specialist services by developing the required expertise. More comprehensive baseline measurement of need enables the measurement of progress towards meeting need including measures of the amount of service provided and the range of options and the quality of services as assessed by the service users.[[64]](#footnote-64)
* Adopting person centred planning thoughtfully, carefully and in a way that is tailored to the individual at the centre of the planning effort. The NDA's guidelines on person centred planning for people with disabilities in Ireland (2005) may be found helpful in this regard.
* Keeping a focus on outcome measurement rather than output based measurement to ensure that development is in the direction of desired outcomes for people with disabilities. The best measure of the success of person centred planning may be that the individual who is at the centre of the planning process begins to experience a real change for the better in his or her life as a result of their plan being put into action (See Section 7 on the importance of outcome measurement).
* Service issues and policy dilemmas and the pros and cons of varying approaches to policy implementation must be clearly and openly acknowledged.[[65]](#footnote-65)

# Introduction

## Background

Many OECD countries are reorganising health, social care and disability services with the main drivers being a citizenship and human rights approach including independent living and customer orientation alongside dealing with financial constraint. New service models actively pursued are resulting in unprecedented change in health service and social care provision and in the channels and mechanisms through which services are being provided to people with disabilities.

Tackling financing systems and improving the efficiency of services is an important part of disability service development as funding structures drive how services are delivered. The goal is to replace historical and inefficient financing systems with higher performing systems that control costs better while delivering on defined outcomes for individuals and populations. However, it is recognised that there is no simple solution to the issue of designing robust financing systems for health, social care and disability services.

Independent living for people with disabilities is contributing to the reconfiguration of health, social and disability services. Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (‘UN Convention’), ‘Living Independently and being included in the Community’, places an obligation on the state to recognise the equal right of all persons with disabilities to live in the community with choices equal to others. The ‘UN Convention’ has fuelled a move in policy systems internationally to a person-centred and citizenship/inclusion approach.

As issues in designing disability services are similar in many OECD countries, it makes sense to examine service re-configuration in other jurisdictions and study 1) how issues are being addressed, identifying trends and unique features in service development and 2) how change is implemented and managed. Common issues across jurisdictions include:

* Identifying efficient ways to fund services and allocate resources
* Coordinating and integrating services and developing partnerships to make services more effective
* Developing services that promote independent living, person-centred approaches and that reflect a stronger human rights emphasis
* Designing quality management systems

A project was undertaken by the NDA to identify transferable lessons on some of these issues in disability service provision. The project involved the following tasks:

* Desk research supplemented by key informant interviews to document the configuration of disability services in England, Scotland, Norway, the Netherlands, New Zealand and Victoria in Australia. These jurisdictions were identified through key informant interviews as jurisdictions in which there had been considerable development in service provision for people with disabilities.
* Document and describe the services available for adults with disabilities in these jurisdictions with particular reference to health and personal social care services.
* Review and validate draft reports on each jurisdiction by an identified expert in disability services in each jurisdiction.
* Review and include any pertinent data on service development from the United States of America (USA), drawing on site visits by the NDA to the USA to review community services for people with intellectual disabilities.
* Review the systems of quality assurance and national standards and monitoring of disability services in the jurisdictions.
* Examine outcomes for people with disabilities across jurisdictions with particular regard to levels of income and indicators of societal participation.
* Investigate the cost/financing arrangements for specialist disability services in the six jurisdictions (this element has been commissioned).
* Examine standards for services, direct payments, pre-school services, residential services, employment services and resource allocation.[[66]](#footnote-66)

## Report structure and description

This report is structured in the following way:

* Section 1 includes background information on the project including considerations around definitions and approaches to health, social care and specialist disability services research.
* Section 2 outlines trends in disability services that aim to promote independent living (IL) for people with disabilities. These include person-centred planning and individualised supports.
* Section 3 outlines trends in personalising services.
* Section 4 outlines trends in services that aim to deliver cost-effective services through accurate needs-based planning and commissioning of services and better costing and resource allocation systems.
* Section 5 examines the development of employment services and community-based living services.
* Section 6 examines standards and inspection of services.
* Section 7 presents evidence from outcomes research across six jurisdictions.

In the background papers on each jurisdiction, disability services across jurisdictions with particular reference to health and personal social care services for adults with disabilities are described. From desk research and key informant interviews, descriptive data was collected on 1) health and personal social services for people with disabilities; 2) residential services, care services, personal assistants, supports to independent living, day services, individualised funding, aids and appliances and 3) other service parameters such as service user choice; user involvement and public/private/NGO mix.

This report elaborates on the trends in service development identified in the background country papers, the principles and goals which underpin these trends and the manner in which principles and goals are reflected in service development. Many service developments have the goals of attaining independent living, full social, civic and cultural participation for people with disabilities and at the same time controlling or reducing the costs of disability services.

It is hoped that the data can be used by readers to shed light and help them discuss and debate and develop solutions to the questions being asked on evolving health, social care and disability services:

* What combination of factors will improve choice and control for people with disabilities and drive service design toward independent living?
* What funding and resource allocation systems will best support independent living and person-centred and demand-driven services?
* What are the desired outcomes for contemporary disability services and which outcomes can and should be measured to monitor the effectiveness of services?
* How best to control health, social care and disability expenditure while continuously improving the quality of services and standards?
* How can the move from supply-driven service models where people with disabilities must fit into the services to more responsive and person-centred services be implemented and how should this be managed?

## The NDA and disability services in Ireland

The National Disability Authority (NDA) is an independent statutory agency that provides advice to Government on matters of disability policy and practice and universal design. The NDA's strategic priorities are set out in its Strategic Plan 2010-2012. Its aim is to contribute to a better life for people with disabilities by:

* Supporting the implementation of the National Disability Strategy
* Providing advice on promoting independence and quality of daily life for people with disabilities
* Promoting an accessible environment and Universal Design
* Building NDA’s capacity to deliver on it strategic goals

In Ireland the Department of Health and Children (DoHC) is chiefly responsible for disability service provision policy while service delivery is the remit of the Health Service Executive (HSE). Currently the DoHC and the Department of Finance are conducting a review of Disability Services under the Value for Money[[67]](#footnote-67) and Policy Review Initiative 2008-2011. To this end a steering group, a project group and an expert reference group have been established to oversee and advise on the project. The review is assessing whether current policies and investments are sustainable in the context of the economic climate and what policy changes are necessary[[68]](#footnote-68). It is expected that a report on current provision of disability services and on service development will be issued by Autumn 2010. This research aims to underpin NDA's input into the review.

In Ireland, in 2005, a Comptroller and Auditor General (CAG) Report, Value for Money Examination on the Provision of Disability Services by Non Profit Organisations in Ireland[[69]](#footnote-69), concluded that:

* Greater accountability, transparency and corporate governance within the state-funded non-profit sector and for greater clarity in the relationship between the State and the funded organisations.
* A review of procurement methods, a specification of services that aligns with assessed needs of clients and mechanisms to ensure compliance with standards is required. This will entail ensuring that there is a robust connection between the cost of the care being purchased for each level of dependency and the funding being provided.
* Clear agreements formulated on the respective roles of funder and service deliverer, and these should also provide for appropriate monitoring and reporting arrangements.

Since its establishment, the NDA has carried out a considerable body of research on service provision for people with disabilities and it is hoped that this project will assist all those who are involved in the process of developing disability service policy and provision not only in Ireland but also internationally.

## 1.4. Definitions and approaches

In the description of services within and across jurisdictions, a number of pertinent considerations are brought to the attention of the reader:

* Clarity is needed around definitions and terminology used. There are no internationally agreed definitions of healthcare, social care or specialist[[70]](#footnote-70) disability services.[[71]](#footnote-71) This makes the compilation of comparable data difficult. There is ongoing international work to agree definitions and harmonise service boundaries for the purpose of comparative research particularly on health systems, health and disability expenditure and long term care[[72]](#footnote-72). The data in this report is descriptive.
* Different terms are used to describe similar realities. Conversely, the same term is sometimes used with distinct connotations in different contexts within jurisdictions as well as across jurisdictions.[[73]](#footnote-73) The meaning of concepts and terms can evolve over time as their precise meaning is worked out in practice.
* Difficulties with definitions create problems not only for comparative research but also for policy makers and providers in developing services for people with disabilities. For example, States in the USA face challenges when trying to create "real choice" in accessing affordable accessible and integrated housing. One of the challenges is the differences in definitions related to housing and community living/integration, which makes it hard to show need, coordinate services and compare across States.[[74]](#footnote-74)
* Defining services and terms can pose problems within jurisdictions as well as across jurisdictions. In Victoria Australia, it was noted in the Review of out of Home Disability Services[[75]](#footnote-75) that while the term ‘individualised disability service’ was used among service providers there was inconsistency in understanding about what the individualised approach actually meant. Some interpreted individualised approaches as resource intensive e.g. 1 to 1 staff-service user ratio, adding to cost deficits.
* Building a common understanding of what individualised supports includes the following:[[76]](#footnote-76) At the system level, it means learning to negotiate a common vision, strategies and accountability among the people and agencies that provide and govern services; systematically shifting the system from group provision to individualised supports; clarifying the difference between individualised supports and improved versions of traditional approaches; discovering and communicating what is possible for people with intellectual disabilities; promoting learning from action by discovering and disseminating what works and what doesn’t work in providing individualised supports. At the direct service level it includes remaining available to people as their needs and interests change; increasing the effective control people have over their supports and the choices they make; and making the best possible use of available system funds. At the agency management level it means developing accessible housing, transport, employment and recreational opportunities; actively searching for community opportunities and problem solving; and making available system resources as flexibly as possible as opportunities and support needs change.[[77]](#footnote-77)
* Policy and service development is challenging and complex. An explicit recognition of this reality as well as recognising the time element in such endeavours as understanding and achieving integration or community supports will facilitate steady progress.

# Service trends: Towards ‘Independent Living’[[78]](#footnote-78)

## Understanding Independent Living (IL)

Services for people with disabilities have traditionally been provided in segregated institutions. The move from institutional care to community living requires community based services to support people with disabilities to live independently in the community. Community living has been defined as comprising the same range of accommodation available to the general population, in the same locations where the general population reside, offering people with disabilities choice over where and with whom they live and providing the necessary supports for community participation.[[79]](#footnote-79)

The trend towards community living involves closing inappropriate accommodation and developing alternatives including accessible affordable housing, housing support and community service models. Community living is addressed further in section 3 of this report.

Independent living does not necessarily mean doing things for yourself, or living on one's own. It means having choice and control over the assistance and/or equipment needed to go about your daily life and having equal access to housing, transport and mobility, health, employment, education and training opportunities.[[80]](#footnote-80)

Individuals and groups need different kinds of assistance or support and equipment to live independently. A definition of independent living that does not acknowledge the different ways that people with disabilities achieve independent living will not be inclusive.[[81]](#footnote-81) For instance, people with a hearing impairment may need access to communication support. People with an intellectual disability may need advocacy and supported decision-making. Some people with disabilities need short-term or long-term housing-related support services to enable them to live independently in their accommodation. Seven needs/services as essential for independent living for people with physical disabilities have been identified.[[82]](#footnote-82)

The Independent Living Centres in the USA[[83]](#footnote-83) have also highlighted the essential role that particular services play in enabling people with disabilities to live independently.

The needs/services identified as essential for Independent Living include

* Provision of information and referral
* Peer counselling and advocacy
* Independent living skills training
* Housing
* Technical aids
* Personal assistance
* Transport and access

The concept of Independent Living overlaps with the concept of Quality of Life. Three core Quality of Life domains representing the range of factors over which the quality of life concept extends are:[[84]](#footnote-84)

* Independence or Autonomy (includes personal skills, material wellbeing and choice and self-determination. A person can/has the opportunity to access life-long learning, income, resources required to have a good diet, housing and participation in family and community life and can choose and control services and manage risk in personal life)
* Social Inclusion and Civic Participation (includes social networks and friendships; community based activities and employment. A person can/has the opportunity to develop range of friendships, activities, relationships; take part in local affairs and decisions; vote; volunteer and access equal opportunities for education, training and employment)
* Well-being (includes emotional well-being/mental heath; physical health and personal life satisfaction. A person can/has the opportunity to receive protection from abuse and exploitation and access support in managing long-term conditions; experience clear and ordered living environment; undertake physical activity and access health screenings and care; access leisure; experience security at home and enjoy a full, purposeful life)

## Choice as a means to Independent Living (IL)

Choice for service users is a broad conceptual domain with relevance to all aspects of peoples' lives including choice in education, mobility, personal relationships etc.[[85]](#footnote-85) Key concerns for people with disabilities in order to achieve choice and control include accessible information, access to advocacy support services, access to equality of employment opportunities, accessible transport and access to adequate income. The concept of ‘choice and control’ thus overlaps to a large degree with having access to the goods and services required for independent living.[[86]](#footnote-86) For example, accessible information is a key driver for increasing control including the use of user led organisations.[[87]](#footnote-87) Equipment, too, can make a key difference to choice and control in people's lives and if the equipment supplied is of poor quality it can result in inefficiencies and lower satisfaction levels etc.[[88]](#footnote-88)

Efforts to move away from traditional modes of funding and service provision for people with disabilities and to provide alternatives that support people to make choices and to participate more fully in all aspects of life are called many different names. Examples include person-centred services; self-directed support; person-directed services; independent living; consumer control; self-determination; self-directed services; consumer-directed services; Individualised funding. All these ‘alternative’ models are based on the same principle: for people with disabilities to participate and contribute as equal citizens they must have choice and control over the funding and support they need to go about their daily lives.[[89]](#footnote-89)

Independent Living is most often used in the UK and Ireland to describe such models or modes of funding and service provision although ‘personalisation of services’ is also used in government documents in England to describe services facilitating ‘choice and control’.

In the USA, the terms, ‘consumer-controled’ or ‘consumer directed’ services are frequently used and are defined as services that involve both individual budgets and decision-making authority over the budget.[[90]](#footnote-90) In the USA different strategies are used to provide consumer-controlled services and development has been supported by incorporating the principles of person-centred support and self-determination. Choice is considered in the quality framework for home and community based services (HCBS) in the USA for people with disabilities. The response of providers to the wishes of people with disabilities is monitored. The choice that people with disabilities have not only of service providers but also of case managers is also monitored. This is an important feature of Medicaid law and the CMS Quality framework in the USA. [[91]](#footnote-91)

Research conducted on the disability sector in Victoria, Australia concluded that further capacity building was required across the sector to support the reorientation of services towards individualised approaches that delivered personal choice and autonomy.[[92]](#footnote-92)

Implementation of Independent living/ Empowerment principles depends on resources to create a support structure at the community level and flexibility for people with disabilities to access essential services.[[93]](#footnote-93) There is a danger that the concept of choice in service development may be understood as simply the attainment of consumer choice within a market place. The key question, however, remains whether ‘choice’ leads to Independent Living? This depends on the type and quality of services and supports on offer. Similarly, it is essential that key outcomes are measured rather than simply equating the attainment of IL with the presence of consumer choice in a market. While most every person wants a quality service as close to home as possible, they may not want a choice of services per se. Dutch citizens, for example, have shown little interest in individual consumer choice in health insurance.[[94]](#footnote-94)

In New Zealand, researchers evaluated whether the new Disability Support Services model led to substantial control by service recipients over economic resources and programmes that determine the material well-being of people with disabilities.[[95]](#footnote-95) Based on the empirical qualitative research, conclusions included that: empowerment concepts were superficially conceived in the reform process and were not put into practice. There is an expectation that service recipients will be empowered to be independent through self-help and community-based aid organisations. The state sector provides a minimum range of services and other needs are left to the community to supply. There is confusion between procedural rights and financial resource allocation. Procedural participation, such as the right to a fair hearing and to complaint, redress and appeal mechanisms do not have positive implications that will satisfy the substantive needs of people with disabilities. Assessment systems have the potential to reduce rights to tightly circumscribed needs within systems that deliver what is economically feasible. While empowerment frameworks are commendable, they break down when the system does not allow flexibility of service choice and participation in service design.[[96]](#footnote-96)

## Developing community services that deliver Independent Living

An Australian study reviewed international models of community support for people with high and complex support needs in Australia, New Zealand, the UK and the USA.[[97]](#footnote-97) A common feature of effective service models was found to be high level service co-ordination facilitated by inter-agency forums. This involved a whole government approach in partnership with the community sector. Effective forums were staffed by senior managers with authority to direct financial and personnel resources and were mandated by government. Typically, their operation was supported by formal bilateral and multilateral memoranda of understanding between agencies including government and non-government agencies. After identifying 26 service elements and studying many models, they proposed that a best practice model would incorporate a three-tiered service system:

* generic community services available to the entire community,
* generic specialist services designed specifically to support people with disabilities and/or mental health issues and
* specialist services designed specifically for people with disabilities with complex needs.

They also found that case management services and specialist clinical services have an important role in coordinating and ensuring effective services.

Approaches to transitioning from institutional services to community living services for people with disabilities include:

* Support people with disabilities in formulating personal plans and negotiating systems and services to attain their goals through for instance, person centred planning, case managers, micro-boards, support-service co-ordination
* Resource allocation approaches with budget management: give individuals a budget from which they can organise their own support and purchase services and support them where necessary to do this
* Develop community based services and supports that focus on helping people to live independently using natural and community supports as well as helping people access other services. For example Local Area Coordination (LAC) models or equivalents such as LAC in Scotland, the disability liaison officer in some parts of Ireland, USA, and England
* Practical coordinated action across services and sectors including service integration; shared coordinating mechanisms or delivery systems to make services more person-centred e.g. joint needs assessment and strategic commissioning. In England local authorities with social services responsibilities are required to carry out a Joint Strategic Needs Assessment (JSNA) between Adult and Children’s services and Primary Care Trusts.
* Support services in the community such as information and advocacy provision and personal assistance and well established processes for seeking services/ funding such as needs assessment.

**Case management models:**

These provide a connection between people with disabilities and the system of services and supports and assure that services meet reasonable standards of quality and lead to important life outcomes for individuals. As case management evolves, different terms such as ‘service co-ordination’, ‘support coordination’ and resource management are being used.[[98]](#footnote-98) Establishing key contact points for people with disabilities decreases their need to deal with multiple persons within the disability, health and social care systems. With the development of self-directed support and services for people with disabilities, the role of the case manager also embraces that of "service broker". The disability liaison officer model operating in part of the HSE in Ireland for children with disabilities; Local Area Coordination Models in Australia and Scotland; and other integrating models such as the ‘transmural’ care model in the Netherlands attempt to focus on user needs and address them in a coordinated fashion. The ‘transmural’ approach partly overlaps with the concepts of 'shared care' and 'hospital at home care' (UK) and 'managed care' (USA).[[99]](#footnote-99) It originated in the Dutch health care system where ‘transmural’ care chains were introduced in the early 1990s to bridge organizational and financial gaps between community and hospital care.[[100]](#footnote-100)

**Local Area Coordination (LAC):** This was started in Western Australia and introduced into Scotland in 2000[[101]](#footnote-101). The local area co-ordinator works with individuals and families in communities and helps to find and build on different kinds of support. There is a focus on developing natural and community supports but the coordinators help people with disabilities to access government funded supports. The implementation of this is being studied by the Ministerial Committee on Disability Issues in New Zealand. Rather than import local area co-ordination and duplicate responsibilities, however, the government is examining similarities and differences between their support system and LAC in order to improve the current system in New Zealand. LAC coordinators take a more holistic approach to working with people and explore a wide range of options for achieving what a person wants whereas a Needs Assessment facilitator with NASC focuses on what support is needed and, in particular, accessing supports within the limited supports funded by the state. See Appendix 1 for more information on Local Area Co-ordination.

**Advocacy services:** Some level of advocacy provision can be found in all jurisdictions. "Advocacy has become a focus of interest for people who are disadvantaged, with many seeing it as a way of enhancing equality of opportunity. In particular, it has become part of the new approach to disability, with much new disability legislation incorporating an advocacy element".[[102]](#footnote-102) "Advocacy is a means of empowering people by supporting them to assert their views and claim their entitlements and where necessary representing and negotiating on their behalf. Advocacy can often be undertaken by people themselves, by their friends and relations, or by persons who have had similar experiences".[[103]](#footnote-103) "Advocacy, like other personal services to people who are disadvantaged, is underpinned by strong values and principles, both among practitioners and within the projects and organisations that employ them.[[104]](#footnote-104)

## Delivering independence with AT and ICT

Assistive Technology (AT) can be defined as any product or service designed to enable independence for people with disabilities and older people.[[105]](#footnote-105) . Information and communications technology/technologies (ICT) is an umbrella term that includes any communication device or application, encompassing: radio, television, cellular phones, computer and network hardware and software, satellite systems and so on, as well as the various services and applications associated with them, such as videoconferencing and distance learning. The importance of ICT lies in its ability to create greater access to information and communication in under-served populations.[[106]](#footnote-106)

It facilitates disadvantaged individuals and groups to acquire the skills required to benefit from the knowledge society.[[107]](#footnote-107) When a society is geared towards digital solutions there can be adverse consequences if people with disabilities are excluded. Provision of accessible and timely ICT is part of developing effective and efficient contemporary services that play a role in facilitating independent living of people.

**In Norway**

The Norwegian government has a cross-sectoral action plan for a universally designed Norway by 2025: new Information and Communications Technology (ICT) aimed at the general public should be Universally Designed from 2011 and existing ICT aimed at the general public should be Universally Designed by 2021.

The quality of public websites is under review. Approximately 700 public sites are reviewed annually by 36 criteria for accessibility, usability, and quality of content. Results of the assessments are presented on Norge.no and the websites are awarded stars according to the total score achieved. IT Funk is a commitment relating to persons with disabilities, universal design and new technology. Its aim is to improve accessibility to information and communication for persons with disabilities, using ICT-based products and services that are on the general market and used by everyone. There will be a review to find out if there is a need for a set of general requirements for subtitling and sign language interpretation on TV etc[[108]](#footnote-108).

Goals[[109]](#footnote-109) are set for the length of time it should take to receive an assistive device. In 2008, the average time for handling applications for adaptive equipment and devices was 1.8 weeks and 77% of devices were delivered within a 3-week goal There are 3 resource centres at national level and each of the 19 Norwegian counties also has an Assistive Technology Centre (ATC).[[110]](#footnote-110)

There is a national committee to ensure involvement of people with disabilities in the area of assistive aids. Committees have been established in each county. A user pass has been introduced which gives experienced users of assistive equipment more responsibility in replacing, adjusting and repairing the assistive equipment. They can contact suppliers directly. With this option, people tend to experience less delays and more self-determination. A minority of assistive equipment users, mostly younger people, have this pass.[[111]](#footnote-111) Provision of assistive equipment is rights based: if a person is deemed to be in need of a device, it must be acquired even if the budget is exceeded.

**The Netherlands** has an e-Citizen Charter and ranks in the top five of OECD and United Nations countries for the provision of e-services to citizens.[[112]](#footnote-112)

**In England** proactive telephone support is offered to improve community living for people with long-term conditions. The UK Jobcentre Plus, which has brought together employment and benefits services, offers people the choice of accessing services and support over the phone or the internet or in person. The use of online communication has also delivered more than £450 million in efficiency savings between 2004-2005 and 2007-2008.[[113]](#footnote-113)

**In Scotland** the government has a multi-agency information sharing framework called e-Care. It covers, consent, standards, security, procurement, organisational development and technical issues relating to the electronic sharing of personal data. E-Care has 14 Data Sharing Partnerships managing their own data and handles electronic [Single Shared Assessments](http://www.scotland.gov.uk/Topics/Health/care/JointFuture/SSA) (SSA) for community care. This is a streamlining of the assessment process to enable the needs and outcomes for the individual to be identified and subsequent interventions and services put in place. Shared Assessment ensures that at any one time a lead professional, rather than a number of different people, co-ordinates the assessment, ensures that agreed services are put in place and acts as a point of contact[[114]](#footnote-114).

Adaptations and equipment for people with disabilities can yield better outcomes while producing savings to health and social care budgets and housing adaptations and equipment can sometimes save money on a massive scale when they are an alternative to residential care.[[115]](#footnote-115) These were the findings from a survey of the international literature on outcomes and costs in relation to adaptations and equipment for the Office for Disability Issues in England.[[116]](#footnote-116) Adaptations save money in a number of ways. They reduce the cost of residential care e.g. adaptations and equipment that enable someone to move out of a residential placement can produce direct savings, often within the first year. Adaptations can also reduce the need for home care, noting for example that, an hour’s home care per day cost £5,000 a year. Significant savings in home care costs are mainly found in relation to younger and middle aged people with disabilities. Adaptations that reduce or remove the need for daily visits pay for themselves within a few months to three years and then produce annual savings.[[117]](#footnote-117)

# Service trends: Towards personalised services

## Person centred planning

Person-centred approaches include person-centred planning (PCP), individual needs assessment, personal budgets and user involvement. PCP as a specific approach originated in North America in the late 1980s[[118]](#footnote-118). In Ireland, the NDA (2005) published guidelines that clarify the purpose and application of PCP within disability services[[119]](#footnote-119). The guidelines set out principles of PCP and recommendations on implementing PCP and monitoring progress.

PCP is a way of discovering how a person wants to live their life and what is required to make that possible. It is takes as its primary focus a person - as opposed to a disability or a service or some other particular issue. Person centred planning is ‘whole person’ oriented as opposed to disability-management focused. It is about citizenship, inclusion in family, community and the mainstream of life and self-determination. PCP should facilitate independent living if it helps a person work out what he or she wants and how services can support achieving desired outcomes. Service providers can use PCP planning to determine what the person and the family/advocate want for the person and how the services can support this[[120]](#footnote-120).

Key features of PCP include: 1) that the person is at the centre; 2) family members and friends are partners; 3) planning reflects a person's capacities and what is important to that person; 4) the plan specifies the support a person requires to make a valued contribution to the community; 5) building a shared commitment to action that will uphold a person's rights; 6) listening, learning and action that helps a person to get what they want out of life.[[121]](#footnote-121) Person-centred plans can be developed from individual needs assessments.

Person centred planning (PCP) has been central to the UK Governments strategy for the development and delivery of health and social care services for people with intellectual disabilities although there has been little evidence until recently regarding the impact of introducing PCP or the factors that facilitate or impede the introduction and effectiveness of PCP.[[122]](#footnote-122) A longitudinal study on the impact of PCP conducted in England showed that PCP had a positive benefit on the life experiences of people with intellectual disabilities. The benefits identified come without additional service costs once initial training costs are taken into account. However, the benefits associated with PCP do not extend into employment or more inclusive social networks. What is of note is that, in contrast to research on outcomes in supported housing, greater participant ability was not linked to the outcomes of PCP, with the exception of increased contact with friends. Rather, the findings were that people with mental health, emotional or behavioural problems, or people with more health problems were less likely to receive a plan and less likely to benefit if they did receive a plan. The results indicate inequalities in receiving a person-centred plan. The study also found that committed facilitators are important in ensuring the success of PCP.

## Individual needs assessment and resource allocation

Across jurisdictions individual assessments are primarily carried out to confirm eligibility for services and to determine what supports a person needs. Sometimes they are used to calculate individualised funding allocations such as personal budgets. In fact, all individualised resource allocation methods start with individual needs assessment and individual plans. Individual resource allocation methods involve assessing support needs and the amount of unpaid support available to the person and starts with individualised planning. New Zealand is to introduce a support need profiling tool. A range of standardised needs assessment and resource allocation tools are emerging in practice in the USA[[123]](#footnote-123) and across local authorities in the U.K.

The research on assessment practice points to effective assessment tools as those that 1) identify needs of each individual, taking into account the variety and strength of those needs and the variety of functional limitations including contextual factors and complexities associated with the use of aids and equipment, potential for skills development etc, 2) are reliable and objective, so that different assessors reach the same conclusions and the risk of ‘needs-inflation’ is reduced, 3) are able to assess needs for a variety of different types of support, so that people do not have to have multiple, overlapping assessments to get access to aids, home modifications and care, and 4) are easy to administer and acceptable to people. Truncated or more detailed versions of the assessment instrument can be applied depending on whether the purpose of assessment is to determine an individual's eligibility for services and the associated costs, or broader program planning purposes. New models for needs assessment have attempted to include these features such as the I-CAN instrument and the D-Start and eFHROM tools.[[124]](#footnote-124) The I-Can instrument has 98% reliability with the use of good data. This new wave of instruments are known as the supports-outcome models, reflecting a more flexible allocation of resources based on an individual's needs and participation goals/desires (meaningful activities), rather than on what programs choose to provide.[[125]](#footnote-125)

The Supports Intensity Scale (SIS) Assessment Tool in the USA allows service planning for persons with intellectual disabilities in 85 life areas based on measuring individual support needs and goals. The SIS assessment, in combination with supplemental information, is used to build person-centred systems and develop funding methods for Disability Services in the USA. It ties public funding and individual budgeting to assessment results. Developed by the American Association on Intellectual and Developmental Disabilities (AAIDD) it has been used over the last five years within many US states and provinces[[126]](#footnote-126). There is some evidence that an amended and shortened version of the SIS is valid for people with other than intellectual disabilities.[[127]](#footnote-127)

In Norway the right to an individual plan for anyone who needs long-term care is underpinned by legislation. One of the purposes of the plan in Norway is service coordination and one person is nominated to organise this[[128]](#footnote-128).

Some jurisdictions have disability specific redress system for needs assessment while other jurisdictions have a generic redress system e.g. local authority, Ombudsman. See Appendix 4 for a table of redress systems for needs assessments in different jurisdictions.

"In Control" in England has continued to develop and refine needs assessment and currently are promoting self-assessment. In England local authorities with social services responsibilities are required to carry out a Joint Strategic Needs Assessment (JSNA) between Adult and Children’s services and Primary Care Trusts[[129]](#footnote-129).

 In Victoria, the State Disability Plan 2002 - 2010 commits to develop the disability "industry plan", which sets out an implementation plan for personalised individualised disability supports. The industry plan provides a blueprint for the disability support system to improve its capacity to deliver individualised support for people with a disability. It focuses on workforce development and training, organisational governance, building partnerships with mainstream agencies and on developing supports in the community. The 2006 Act requires that anyone with a disability receiving on-going support *must* have a support plan prepared for them within 60 days of receiving a service.

In the Netherlands assessment for care is made on the basis of a nationally used protocol and carried out by care needs assessment centres. People can chose a personal budget (PGB) or care services (called care in kind) for the care they require. In 2005/2007, 93% of people opted for care in kind. In 2008 91% chose care in kind, 6.8% chose a PGB while 2.2% opted to combine a PGB with some care services (care in kind). Care can be domestic (home-care), personal care, nursing, supportive guidance, activity guidance and temporary accommodation (temporary stay in a residential setting)

The development of a standard uniform assessment process has been developed in New Zealand. An outline of the Needs Assessment and Service Co-ordination is shown in Table 3.

Table Three: Outline of Needs Assessment and Service Coordination (NASC) in New Zealand[[130]](#footnote-130)

|  |  |
| --- | --- |
| Objective  | Facilitating a process for people to: identify their strengths, resources and needs; explore their support options; and access support services.  |
| Eligibility Screening  | NASCs are required to have processes to determine whether people who are referred to them are eligible for services funded by the Ministry of Health (the Ministry). People must use NASCs if they wish to access supports funded by the Ministry.  |
| Facilitated needs assessment  | The outcome of the needs assessment process is a comprehensive needs assessment report. The objectives of the process are to: • confirm whether a person is eligible for Ministry funded support • work with the person to identify their current abilities and resources • work with the person to identify prioritised goals and support needs arising from their impairment • refer for specialised assessments where appropriate.  |
| Service co-ordination  | Service planning and service co-ordination involves: • providing information to people on all their options, including available service providers, and support available through natural networks; • developing an individualised support plan with the person, focusing on support for prioritised needs and goals; • prioritising access to publicly funded services, and ensuring that their service package is cost effective, affordable and equitable and can be provided within the NASC budget; and • coordinating packages of service (including, for some people, those provided by other agencies) and making services funded from the NASC budget accessible. Intensive Service Coordination involves developing an ongoing relationship with a person who has high and complex needs, who requires ongoing problem solving and input from multiple providers.  |
| Budget management  | Each NASC manages, on behalf of the Ministry, a defined indicative budget. The NASC needs to ensure that people with the highest priority needs receive access to services first, and that the commitments made do not exceed the indicative budgets. NASCs allocated NZ$617 million of support (= €343 million) in 2008/09 for the following services: residential care, home and community support, supported living, behavioural support, respite and carer support, day services and individualised funding.  |
| Limits on NASCs  | • There must be a clear, auditable, separation between needs assessment facilitation and service coordination. • High cost packages are referred to the Ministry in some instances. • NASCs are not involved in allocating environmental supports. • Some services, e.g. Child Development, may be accessed by disabled people and their families/ whānau without going through the NASC process.  |
| Number of NASCs  | The Ministry contracts with 15 organisations to provide Needs Assessment and Service Coordination services. These organisations are mainly owned by DHBs and NGOs, although one is a private company.  |
| Annual cost  | The cost of NASC was NZ$17.1 million in 2008/09 (NZ$16.4 million in 2007/08 (€9million).  |
| Number of people  | In 2008/09, 30,169 people received Government funded support that was allocated through the NASC process. Each person receiving support: • Has initial assessment and service coordination. • Has their support reviewed at least once every 12 months. • Has a reassessment at least once every 3 years.  |
| Cost per person  | The average cost of the NASC process was NZ$567 (€315) per person who received government funding for services in 2008/09. While most people have a relatively low level of input from NASCs, people requiring initial assessments and people requiring intensive service coordination can require considerable input.  |

## Individualised funding (IF) schemes

Individualised Funding (IF) schemes entail a significant shift in service design and delivery. They exist across jurisdictions at pilot or at national level and, in the USA, at county or state level. While IF has existed for decades in some countries such as Canada[[131]](#footnote-131) it is far from uniform in its application or scope. It is still in a developmental phase worldwide. Currently, it is mainly operated to fund adult social care services.

Individualised funding covers a wide range of funding mechanisms based on the principle that the funding is put under the control of the individual. Rather than funding from the state to service providers, the funds go directly to the individual who requires assistance. A variety of mechanisms has been developed to implement individualised funding including service brokers, personal agents, voucher systems etc. Some individualised schemes exclude certain disabilities or age groups; some schemes provide vouchers rather than cash in the bank to the budget holder; some schemes are means tested; and the number of people participating in individualised funding schemes varies enormously etc[[132]](#footnote-132).

Individually attached and flexible funding allocations are important factors in developing individual, person-centred approaches to service design that delivers Independent Living outcomes in the jurisdictions explored. Funding that attaches to the person rather than the service, facilitates community and individualised support strategies and choice. This linkage of funding to individual need can increase efficiency as well as effectiveness and respect for equality/ diversity. Emerging evidence from the UK suggests that personalising services to meet the needs of social care users results in better outcomes and deliver cashable savings to the public sector of 5-10% which amounts to £1-2 billion across the whole sector although in the transition period there will be an increase in transaction costs.[[133]](#footnote-133)

There is a longer history of individualised funding in North America than in England. Impetus was given to these services in the USA by legislative changes in 2006. In 2002 some form of individual funding was already in place in nearly three quarters of the 43 states surveyed. It is rapidly becoming a mainstream funding mechanism in the US.[[134]](#footnote-134) A recent study showed that 13 states had state-wide availability of individual budgets and consumer control for at least some Home and Community Services based service recipients.[[135]](#footnote-135) Eleven additional states had a consumer-directed option available as a pilot project to a limited number of people within a limited geographic area. Eight states reported that they were in the final stages of developing a consumer-directed option.[[136]](#footnote-136) Themes related to success included

* not having to fit people into program-specific slots,
* seeing people succeed after experiencing frustration with traditional services,
* real change has occurred in people's lives,
* hiring people of one's choice with less staff turnover,
* reaching more diverse service users and
* collaboration between stakeholders with increased participation by self-advocates.[[137]](#footnote-137)

IF in the form of Direct Payments (DPs) are mainstream welfare policy and part of social care provision in England since 1996. The individual receives the cash equivalent of a directly provided social care service. They have to be assessed as needing particular care services including personal assistance and then they can get cash to arrange and pay for these services f they choose. They are used in lieu of social care services to contract with private or voluntary sector agencies or to become an employer oneself by hiring staff. DPs cannot be used to purchase services from public care providers - only private or voluntary care providers - and they cannot be used to purchase health care.

Their stated purpose is to give choice and flexibility in how services are provided. Resource allocation systems are being developed and refined by councils to calculate the budget a person may get and to facilitate clients using direct payments. Take-up of DPs has to-date been uneven and very low across the UK compared to the eligible population but they have increased.[[138]](#footnote-138)

IF in the form of Personal Budgets are also available in England and are set to be extended to all who need social care. They are funding allocations given to users to meet their assessed care needs. They are more flexible than DPs. Users can choose to have a trust fund, use a broker to manage the money for them, ask the local authority to pay for particular services e.g. day care etc or they can get the budget transferred to a special bank account to organise the care they need. Currently personal budgets are for social care supports alone. They can be used to purchase support, equipment from public, private or voluntary sector providers.[[139]](#footnote-139) A national social enterprise, In Control, which started as a project to fund new ways of organising social care and is now an independent charity, developed the concept of personal budgets for social care supports as a step in the concept of self-directed support. This was later adopted as national policy.[[140]](#footnote-140)

Another form of IF has been piloted in England. Individual Budgets (IB), where funding streams were integrated, were piloted in 13 areas in England in 2008. Individual budgets (IBs) differ from personal budgets in covering a multitude of funding streams, besides adult social care. The idea was that in the IB pilots there would be integration of at least 5 funding sources. In the pilots difficulties with alignment and integration across funding streams included incompatibility in eligibility criteria, parallel and sometimes conflicting monitoring and review arrangements, variation in local arrangements and poor engagement between central and local government agencies.[[141]](#footnote-141)

**The Netherlands**

Long-term care is provided through a social insurance program. Since 1995 people with long-term care needs have the choice of receiving services from an agency or consumer-directed home care, using “personal budgets” (PGBs). Under personal budgets, people who have been assessed for care are allocated a budget that they can use to buy services from independent providers or agencies. There were 109,000 personal budget receivers at the end of 2008 while 335,000 people received home care delivered by institutions and 253,000 received institutional care. PGBs have proved to be cost-effective. In the Netherlands a high percentage of workers providing PGB care services are friends and relatives. This is not possible in the UK . In the Netherlands, the PGB is calculated by multiplying the number of hours needed for each service by the national payment rate and then reducing that amount by 25 percent to account for lower overhead and by an amount for an income-related co-payment. The availability of informal care is taken into account in determining the number of hours needed. In the Netherlands, the rapidly increasing numbers of persons using consumer-directed home care is in response to supply constraints on nursing home beds and home care agencies' inability to hire service workers.[[142]](#footnote-142)

**England**

For persons who choose DPs, the localities attach a monetary value to these services and add funds for fringe benefits and recruitment and training costs. Although there is no nationally determined specific maximum budget amount, DPs usually do not exceed the cost of residential care.[[143]](#footnote-143)

**New Zealand**

The government began contracting with a disability organisation to provide IF services in 2005.[[144]](#footnote-144) This is an administrative arrangement that allows some people with a disability to hold, manage or govern their own needs-assessed disability support budgets.

**Victoria**

In a recent review of accommodation and support services for people with disabilities[[145]](#footnote-145), the recommendation was made that the provision of IF based on support needs should be expanded. An evaluation of a pilot of direct payments in Victoria showed that all used the payments successfully.[[146]](#footnote-146) Users experienced benefits of flexibility and control as a result of being able to negotiate the nature of disability service provision directly with service providers and managing the expenditure of funding in line with the goals of their funding plan and changing need. The Transport Accident Commission (TAC) in Victoria developed a system of Direct Payment called Self-Purchasing to promote client choice, control and autonomy over the services they receive. Clients or their nominated decision makers enter into an individual funding agreement with TAC. The agreement can involve self-management or broker assistance.[[147]](#footnote-147)

Further details on findings on individualised funding can be found in Appendix 4.

## Service integration

Integration refers to a range of approaches or methods for achieving greater coordination and effectiveness between different services in order to improve outcomes for service users and possibly to achieve cost advantages.[[148]](#footnote-148)

Many service developments such as person-centred planning and addressing local need adequately require an integrated approach. Integration of services is especially important for people with learning disability who often require support from a variety of organisations or individual care workers.

Despite the prevalence of the integration trend and a range of efforts at service integration, there appears to be a lack of precision regarding what it is and how to define it. It is an unfolding field that lacks a clear and complete knowledge base.[[149]](#footnote-149) According to Kodner, service systems are now attempting to address key issues such as fragmented services, difficult-to-control costs and poor quality and access.[[150]](#footnote-150) As the care needs of people with disabilities are rarely strictly social or medical, it has been suggested that a logical and practical approach would be to, for example, integrate health and social care services to meet individuals' health and care needs in a more coordinated manner.[[151]](#footnote-151) Integration of services is, of course, not confined to health and social care services. It would seem worthwhile to strive for the right combination of vision, strategies, resources and circumstances that could bring the benefits of integration to populations and service systems[[152]](#footnote-152).

It is recognised that integrating services that have different administrative functions and deal with barriers and facilitators separately requires organisational change and is unlikely to be achieved easily. Research findings present a range of barriers including bureaucracy and managerialism.[[153]](#footnote-153) Also, differing priorities, budget pressures and political imperatives can combine to create barriers to effective joint working. The rules governing access to health and social care can also create challenges for those trying to provide integrated services.[[154]](#footnote-154)

That integration of services and programme supports is difficult to achieve is demonstrated by the fact that the provision of co-ordinated services and support is not found in any jurisdiction. So while streamlined, integrated, joined-up, transparent service system models, coordinated across departments and delivering mainstream services to people with disabilities are often proposed, they are not easily achieved. There are no explicit models or frameworks for effectively integrating disability services and/or health and social care services or the combination of services and supports required for people with intellectual disabilities or people with intellectual disabilities and challenging behaviour to live in the community.

Research findings conclude that key change strategies for integration include:[[155]](#footnote-155)

* people-centred care;
* reducing variance arising on either the demand or supply side;
* organising the care continuum; and
* process improvement.

Also that change strategies are connected by a dynamic which needs to be made explicit so that the system capacity can match supply with demand. However, there are measurable capacity limits. Organisations need to measure and understand those limits and work to improve capacity and, meanwhile, make the limits clear and explicit.[[156]](#footnote-156) Proposed pre-conditions for creating an environment where change can be realised include:[[157]](#footnote-157)

* Consistent and realistic national policy documents.
* Address local planning contexts: overcome cultural suspicions and fragmented planning environments and jointly identify and accept local unmet need.
* Address operational factors including the need to develop a practical understanding of how the other operates and to be open, flexible and risk taking in the pursuit of clear goals supported by strong management.

In England and the USA one user-orientated form of integration of services are the one stop shops for employment services (See Section 5.3). In Norway there is also a major public service reform to integrate public employment services, social security and social assistance into one unified service.[[158]](#footnote-158) In England, the Individual Budget (IB) Projects in 13 English Local Authorities brought together a number of funding streams to provide a more integrated service for a range of service users including people with disabilities and people with chronic conditions. In addition to adult social care, funding streams included: Access to Work; the Independent Living Fund (both the responsibility of the Department for Work and Pensions); Supporting People and the Disabled Facilities Grant (both the responsibility of the Department for Communities and Local Government); and local Integrated Community Equipment Services, funded from pooled social care and NHS resources. These projects are promising and have been evaluated.[[159]](#footnote-159)

In the UK efforts have been made over the last decades to integrate health and social care services to improve services for service users as well as to contain costs. These efforts include the establishment of Care Trusts set up on a voluntary[[160]](#footnote-160) basis to deliver both health and social care. Partnership has an important role to play in service integration just as it has in all aspects of service development including commissioning, joint need assessments and delivering services. Joint Strategic Needs Assessment (JSNA) provides an opportunity for integrated working and planning. Different approaches have been taken to conducting JSNA in the UK; one in Cambridgeshire, for example, for people with intellectual disabilities has striven to engage service users through a User Parliament, which enabled users to contribute fully to setting out their needs.[[161]](#footnote-161)

The states of Maryland and Washington in the USA are attempting to bring all services for people with disabilities under age 65 years of age into a unified system. Initiatives in Washington include an information management system in which information flows from assessment, to planning, to monitoring, to incident reporting, to quality assurance, across disability and other groups[[162]](#footnote-162).

Coordination (the relation of parts) is sometimes distinguished from integration (the combination of parts into a working whole).[[163]](#footnote-163) Case management is a co-ordination approach to the provision of social care and health services that can be very effective. It is a comprehensive and systematic process and includes assessing, planning, arranging, coordinating and monitoring multiple services for users with long-term needs across time, settings and disciplines.[[164]](#footnote-164)

Key points from a series of expert-led seminars in 2009 in England on best policy options for integrating health and social care[[165]](#footnote-165) include:

* Start from service users and from different agencies agreeing what they are to achieve rather than from organisational solutions and structures
* Successful partnerships depends on leadership by senior personnel
* The flexibilities in Section 31 of the Health Act have enabled collaboration and integration of health and social care services where there was leadership and a good understanding of the need for closer integration

Different aspects of integration have been distinguished:[[166]](#footnote-166)

* Types of integration: 1) functional (the degree to which support functions and back-office are coordinated); 2) organisational (between agencies); 3) professional (provider relationships within and between organisations); 4) service or clinical (coordination of services and care in one process across time, place and discipline); 5) normative (shared mission, work values and culture); and 6) system (alignment of policies at the systems level).
* Levels of integration: These are related to the types of integration: 1) funding, 2) administrative, 3) organisational, 4) service delivery and 5) clinical
* Breadth of integration: 1) horizontal integration where similar organisations at the same level join together and 2) vertical integration which involves the combination of different organisations/units at different levels.
* Degree of integration :1) linkage (providers work together within major system constraints; 2) coordination (structured inter-organisational response involving defined mechanisms to facilitate information sharing, collaboration and communication while retaining separate eligibility criteria, funding and service responsibilities and 3) full integration (a “new” entity consolidating resources, funding etc in a single system to deliver and pay for the entire continuum of services)[[167]](#footnote-167)

Integration can also be approached from different viewpoints: [[168]](#footnote-168)

* The service user’s perspective (easy access and navigation; seamless services and care). From the service user’s viewpoint, the point of integration is to ensure that their needs are met in a coordinated fashion. Both co-ordination and continuity of services are crucial to achieving quality outcomes for service users.
* The provider’s perspective (coordination of tasks, services and care across institutional and professional boundaries; interdisciplinary teamwork)
* The manager’s perspective (building and maintaining a shared culture; managing complex structures and interagency relationships; overseeing combined funding streams, coordinating joint performance targets, supervising professionally diverse and enlarged staff)
* The policymaker’s perspective (designing integration-friendly policies, regulations and financing arrangements, evaluation of systems/programs)

Finally, principles for integrated health-social care services have been outlined in research as follows:[[169]](#footnote-169)

* Cooperation between health and social care to provide comprehensive services across the care continuum with access at multiple points of entry
* User-centred services with population based needs assessment
* Geographic coverage, maximising access, minimising duplication and with responsibility for identified populations
* Standardised care with provider-developed and evidence based care guidelines to enforce one standard of care regardless of where it is delivered
* Performance management with commitment to quality of services, evaluation and continuous improvement and linking interventions to outcomes
* Efficient information systems that enhance information flow and communication across continuum of care
* Organisational culture with leaders with vision who create a strong cohesive culture
* Engage physicians in process of integration
* Strong, focused and diverse governance with representation from all stakeholder groups
* Financial management and equitable funding distribution for different services.

These principles could be extended to apply to and to include other services.

# Service trends: Developing cost-effective services[[170]](#footnote-170)

## Context

In each jurisdiction, creating a vision for services as well as planning and commissioning them, takes place within a particular socio-economic, historical and legal context, policy environment and combination of system factors. The context and the system elements must be addressed in service development.

Within a system each of the core system attributes needs to be addressed so that they work together in a mutually supportive way in service development. Distinct core system attributes include

* financial drivers,
* management and accountability processes,
* information systems, and
* the planning of services and the workforce.[[171]](#footnote-171)

Desirable financial drivers of health reform, for example, can include funding populations by a needs adjusted capitation formula and ensuring a level playing field in funding as well as flexibility in payment arrangements. Management and accountability processes are important with a core element being the promotion of desirable behaviours in service providers. Accountability is facilitated by community engagement and governance models and can include service delivery targets, standards and quality of care benchmarks, targets for access to care and financial results.[[172]](#footnote-172) High quality information systems facilitates coordinated care and continuity of care and the planning of health services and its workforce.[[173]](#footnote-173)

## Costs and Resource allocation systems[[174]](#footnote-174)

Some issues within health, social care and disability services and systems relate to the use of resources as well as to the amount of resources available. In service development there is an increasing focus on equity, transparency of public investment and value for money.[[175]](#footnote-175) Together with increasing competition for diminishing resources, this focus is leading to a concerted search for a clearer understanding of how costs and benefits can be weighed up in public service delivery in order to implement systems that deliver on outcomes and efficiency.

The shift of service delivery from institutions and large service providers to community supports also requires flexible resource allocation systems. Flexibility facilitates change in demand, innovation and professional and technological developments.[[176]](#footnote-176) Funding allocation which addresses individual need in a way that is person-centred means that people with the least needs would be allocated the least amount and vice versa. Individualised funding approaches requires clear relationships between individual support needs and funding and payment for services. Improving the delivery of contemporary services can be guided by [[177]](#footnote-177)

* Studying existing, emerging and alternative models of service delivery and resource allocation and comparative cost effectiveness.
* Developing better methodologies to justify the allocation and use of limited resources
* Using appropriate evaluation of programs
* Studying the public policy implications of the findings

Resource allocation can be driven by supply or it can be based on a needs-adjusted funding formula to meet equity objectives. It can be driven by the way resources are allocated between programmes and services and this can be ad hoc or based on formal priority setting mechanisms.[[178]](#footnote-178) Historically resource allocation has been in the form of block funding to institutions and large service providers who then provide a range of services to their client groups. This form of resource allocation tends towards institutional solutions which can be expensive, inappropriate and result in a system characterised by ‘Parkinson's law’, that is, the demand will always increase to match supply and budgets will be spent to justify similar budgets the following year.[[179]](#footnote-179) Block commissioning where service providers receive an agreed budget from which residential and other services are funded can also be service-led rather than user-led.[[180]](#footnote-180) Where there is block funding different amounts of funding can be associated with people who have similar support needs.

An emerging framework for funding community services takes into account differences in individual support need as well as provider costs. It has the following elements: Funding is allocated at the individual level and not at the program or service level. This allocation of funding at the person level enhances the capability to develop individualized support strategies, contributes to portability, and promotes individual choice. Managing funding at the person level hinges on developing funding methods that are service independent. The goal is to determine the amount of funding that attaches to the person and thereby is not contingent on the person’s being slotted into a particular type of service. Support needs must be factored into the amount of funding that is assigned to a person. If funding does not reflect support needs, then it will be impossible to achieve critical goals for individuals. Payments to organizations that furnish specific types of services should also take into account differences in individual support needs as well as provider costs.[[181]](#footnote-181)

The funding of the disability services sector in Queensland, Australia, including their resource allocation strategy was evaluated and compared with other States in Australia including Victoria. The disability and other human sector services across Australia did not enunciate pricing principles as the economic sector did.[[182]](#footnote-182) Pitfalls in the funding approach of the disability sector included:

* No clear resource allocation strategy,
* Funding guidelines that provided unintended incentives to use unutilised funds rather than achieving efficient cost savings to invest in future programmes and
* No methodology to determine how funding was to be decided with this lack of transparency and predictability providing little incentive to providers to pursue long-term investment in services.[[183]](#footnote-183)

There is a need to articulate pricing objectives and the principles by which objectives should be achieved.[[184]](#footnote-184) Costing of services can be complex. The different levels at which costs may be considered include:[[185]](#footnote-185)

* Micro - the individual service user
* Mezzo - the facility or provider level
* Macro - the system level

Historically the most common cost analyses have been at the mezzo level. Macro analyses are rare because of the problems of aggregation bias.[[186]](#footnote-186) The UK literature focuses on estimating unit costs at the micro (packages of support) and mezzo level (different service types and care workers). A key building block in these costing efforts is a census of service users to assist in building up an understanding of service usage for different client costs e.g. the annual unit cost reports of the Personal Social Services Research Unit in the UK. Knowledge of unit costs can be used for benchmarking, for evaluating value for money and for resource allocation.[[187]](#footnote-187)

Costing algorithms for disability support services can be worked out in different ways. A suggested costing algorithm based on consultation with stakeholders was calculated in the following manner.[[188]](#footnote-188) Costs incurred were converged into three cost types: administration, human resources and cost of service and are shown in table 2 below. Based on these, a general formula for determining the unit cost of disability services is:

Administration + Human Sources + Cost of Service = Unit cost of disability support

|  |
| --- |
| Table 2: Detailed explanation of disability services cost items  |
| Administration  | Human Resources | Cost of Service |
| Legal CostsAudit CostsProvision of informationTendering Risk ManagementLabour  | RecruitmentTraining and DevelopmentUse of volunteer labourLabour  | Compliance & reportingGovernanceBrandingAids and EquipmentFluctuating needs of clientsGeographyTransport DepreciationLabour |

Any detailed presentation of the funding of services is beyond the scope of this report.

In terms of innovation, England is set to introduce an insurance system to fund social care services into the future. The Australian government is also examining the possibility of funding long-term care in its territories with some form of social insurance. In the Netherlands, population-wide health insurance replaced the former public and private health insurance systems in the Netherlands in January 2006. It may still be too early to capture the full effects of this change. However, there is some evidence emerging that, apart from almost universal coverage, there is less competition and less consumer choice.[[189]](#footnote-189) After only two years, the Dutch insurance market has become dominated by a few players that control the market and supply and there is no evidence that individual consumers are seeking value: "facts and theory have not coincided in the Dutch system".[[190]](#footnote-190)

In some jurisdictions energy and resources are being directed towards institutional care for people with intellectual disabilities as well as towards developing community individualised support structures. The evidence suggests that proceeding in the two directions simultaneously i.e. developing both traditional, group and facility based services, alongside individualised support services is incompatible, programmatically and philosophically.[[191]](#footnote-191)

## Needs based planning, commissioning and tendering

Commissioning services can be defined narrowly as the process by which a body specifies, secures and monitors services using contracts and purchasing arrangements. A broader view includes

* strategic planning;
* consultation with service users, carers and the public;
* involving people in how to meet their individual care needs;
* working in partnership with other agencies and providers;
* managing limited resources and matching to local needs which may involve setting clear eligibility criteria;
* using best value mechanisms to improve the quality of care;
* using contracts and purchasing arrangements to specify,
* secure and monitor services;
* being accountable to local communities and users by providing information on services and performance.[[192]](#footnote-192)

The trend internationally is towards a broad view of commissioning with resource allocation and service planning based on a needs analysis a part of the process. The needs analysis is carried out in order to plan services that meet need and to purchase them in a timely, efficient manner and at a quality that meets stated minimum requirements. Needs-based planning combines evidence from various sources and converts the combined evidence into plans for commissioning and resource allocation.[[193]](#footnote-193) Sources include population needs assessment,[[194]](#footnote-194) individual needs’ assessment, information on supply, policies and resource constraints and the cost of services.

The number of people with a disability needing, but not able to access, assistance is referred to as ‘unmet need’. In Australia, the National Disability Agreement which came into force in January 2009 recognises that reducing unmet need is a key priority. It sets, as a priority for disability services reform, to improve the measurement of unmet need. There is no nationally consistent approach to the recording of unmet need data in Australia although all State and Territory Governments in Australia report that unmet need for disability services is increasing.[[195]](#footnote-195) In times of economic difficulty more stringent eligibility criteria is often used to decrease ‘unmet need’. Research on self-directed services and person-centred planning demonstrates that unmet need is likely to continue for people with complex or more severe disabilities.

In Victoria, Australia, unmet demand is much larger than waiting lists portray.[[196]](#footnote-196) More comprehensive measurement of need, both in terms of numbers of people and the quality of their lives is needed. Population-based estimates are required so that the effect of ageing, for example, is understood and predicted. Quality of life measures need to look at all aspects of a person's life, not just those which are the focus of a particular programme or organisation.[[197]](#footnote-197) Measurement of progress towards meeting need is also required.[[198]](#footnote-198)

Appendix 2 outlines a commissioning strategy.[[199]](#footnote-199) It includes consultation and partnership; formulating a vision; collecting data and making a plan based on an analysis of the data - comprehensive information on individuals and populations, needs and future demands, current resources and resource use, and financial information such as individual package and unit costs. At this point, option appraisal and decisions around policy direction can be made. A commissioning plan is drawn up to meet identified needs in appropriate and cost effective ways The commissioning plan needs to include capacity, financial and workforce plans. It also involves managing performance and seeking service improvement through parallel management of various relationships with providers and commissioning partners. Within the context of this broader commissioning plan, procurement is the process involved in identifying and selecting a provider of goods or services[[200]](#footnote-200). Procurement options are often considered where a commissioner is seeking to secure investment in new service models or an existing service delivered in a different way, or, as in the case of Primary Care in England, when a service is being enhanced.[[201]](#footnote-201)

Tenders can be sensitive to context, including the market environment. Different types of tender formats perform well in different circumstances.[[202]](#footnote-202) According to Menezes, a decision to tender, for particular services needs to take into account:

* the broader system/reform agenda
* that tenders are superior to negotiation only under certain circumstances and
* design of tenders is crucial.[[203]](#footnote-203)

EU public procurement rules generally require that public services provided by third parties are sourced through open, transparent tendering processes. However, while procurement processes for social services must be open and fair, they are not subject to all of the detailed rules of the Public Procurement Directive. [[204]](#footnote-204)

Commissioners of social services therefore have greater flexibility in choosing an appropriate means to procure services. The Scottish Executive, for example, has outlined a number of procurement processes for social services which are compatible with EU procurement framework:

* Open tendering
* Restricted tendering
* Negotiated procedure with a call to competition
* Competitive dialogue
* Framework agreements[[205]](#footnote-205).

For Scottish service providers there has been "tension between a public procurement reform agenda which promotes the advertising of social care services as contract opportunities to be awarded through competitive tendering, and social care policy imperatives that emphasise the need for a shift towards personalisation, greater involvement and control for individuals in the design and delivery of their support, and partnership working with service providers. The manner in which a number of recent service re-tendering exercises have been taken forward has highlighted this tension and caused considerable concern within the sector.[[206]](#footnote-206) The Scottish Government published draft guidance on social care procurement in 2010.[[207]](#footnote-207) The guidance acknowledges that social care services are significantly different to other goods, works and services to be procured by public bodies and that they require a distinct approach. The guidance notes that procurement activity must take place within the context of the wider commissioning strategy and that priority should be given to quality in relation to selection and award criteria. Alternative methods to competitive tendering for procuring services used by local authorities in Scotland and approved by the EU include those outlined above.[[208]](#footnote-208)

Competitive Dialogue was created by the 2004 Public Procurement Directives[[209]](#footnote-209) as a new, more flexible solution for public authorities wanting to award contracts for large and complex projects, for example those in the Public Private Partnership arena.[[210]](#footnote-210) The competitive dialogue differs fundamentally from the ‘ordinary’ public and restricted procedures. It begins with a question for which there is no known, unequivocal answer.[[211]](#footnote-211) An optimum solution depends on the quality of the dialogue between the contracting authority and the parties submitting the tenders.[[212]](#footnote-212) The contracting authority uses the solutions submitted by various candidates to conduct a dialogue that results in an optimisation of the request and offer. It is meant to allow a public entity which knows what outcome it wants to achieve but does not know how best to achieve it to discuss, in confidence, possible solutions in the dialogue phase of the tender process with short-listed bidders before calling for final bids.[[213]](#footnote-213) The use of the Competitive Dialogue procedure is explicitly though not exclusively linked with the implementation of Public Private Partnerships. It was introduced to overcome the difficulties with the Restricted Procedure and the Negotiated Procedure which was intended to be an exceptional procedure and designed to be difficult to justify under former EU Public Procurement Directives.[[214]](#footnote-214) Competitive dialogue was introduced into England and Scotland in 2006.[[215]](#footnote-215) The top three concerns from bidders in England are that the process can be slow, expensive and resource intensive.[[216]](#footnote-216)

Learning is accruing from jurisdictions on purchasing services, competitive tendering etc. Ashton and Bautista (2010), for example present an analysis of some of the experiences from New Zealand through the last 20 years of reform.[[217]](#footnote-217) Of note is the success of the Pharmaceutical Management Agency (PHARMAC) a single purchasing agency for community medicines. It has been so successful that legislative proposals are underway to expand its remit to other devices. It is a Crown Agency which operates independently with the primary remit of managing the pharmaceuticals subsidy. This involves negotiating prices with pharmaceutical companies as well as deciding which drugs to subsidise. Through the use of techniques and tools widely adapted internationally including the use of formulary, reference pricing, tenders, price volume contracts, PHARMAC has increased volumes of purchases with costs contained to just under 3% per year.

A summary of the potential benefits and risks of competitive tendering in social care, disability and health services by social care service providers has been summarised by Community Care Providers Scotland (CCPS) in a position statement to the Council of Europe. [[218]](#footnote-218) According to the CCPS potential benefits include:

* the stimulation of choice and diversity of provision for people with disabilities;
* the creation of opportunities for service providers to bring their particular approach to service provision;
* the stimulation of a labour market where support and social care staff can seek a reward for their skills and experience;
* tendering can become a tool for purchasers to diversify the local market and promote improvements in both cost and quality.

Also, according to the CCPS, the risks to competitive tendering are heightened when tendering is driven chiefly by cost considerations. According to their position statement, re-tendering can introduce significant uncertainty about the future of services for people with disabilities and it can cause disruption to the continuity of service. The CCPS pointed out that, in their view, competitive tendering can curtail rather than promote user choice. In their view competitive tendering can be a major disincentive for providers to invest in and develop the workforce and the service if contracts are systematically re-tendered upon contract expiry and where there is a likelihood that business will be lost or retained mainly on cost-grounds. Finally, they point out that, in their view, tendering can trigger a price war among providers. Although delivering short-term cost savings, this may have a significant impact on providers’ ability to recruit skilled staff, potentially affecting the quality of service.

## User involvement

User involvement[[219]](#footnote-219) in services includes user-led organisations, person centred planning and, of course, the significant innovation of individualised funding for social care users.[[220]](#footnote-220) Nordic countries and the Netherlands have legislation, policies and practical arrangements for user involvement that reflect orientation towards citizens' rights.[[221]](#footnote-221) In Australia, New Zealand, England and Scotland there are also efforts to promote user involvement in service development. However, while national policies and legislation promoting user involvement in services are important, translation into genuine involvement at local level is the critical test.

**England**

* User Led Organisations (ULOs) support personalisation of services and independent living for people with disabilities. Government encourages local authorities (LAs) to work with ULOs and currently funds relationships between ULOs and LAs in three regions through the Deputy Regional Directors for Social Care and Partnerships.[[222]](#footnote-222)
* Since the 1960s there has been growth in service provider organisations that are ULOs at national, regional and local level in England. Legislation in 2001 and 2006 strengthened involvement of users in service design and delivery. A 2003 review of the impact of user involvement and ULOs on the quality of social care services for people with physical disabilities[[223]](#footnote-223) showed that most ULOs offered a range of services. However, none offered all the services identified as necessary for independent living for people with physical disabilities: information; counselling; housing; technical aids; personal assistance; transport and access. ULOs were found to be responsive to people's needs and advocacy and peer support were seen as key services. Services provided by the ULOs included support for recipients of direct payments, education and employment advice and support and disability equality training. Some provided information and advice on services elsewhere.[[224]](#footnote-224)
* Local authority agreements promote partnerships, user involvement and the mobilisation of informal family and community networks.
* Equality 2025, a network of disabled people, advises the Westminster Government on how to achieve disability equality.
* The Independent Complaints Advocacy Services assists users who wish to make a complaint about health services. The Patient and Advice and Liaison Service helps patients and carers address concerns in relation to care and treatment, liaising with staff, managers and other organisations.[[225]](#footnote-225)

**The Netherlands**

* There is a tripartite mixture of policies, legislation and funding to embed user involvement in the social care and health fields. The individual legal position of patients and clients has been strengthened and the influence of the organised patients/clients has been increased by funding these user movements and regulating the funding.[[226]](#footnote-226), [[227]](#footnote-227)
* Users have become known as ‘the third party’ at agency level, along with financiers and practitioners. Clients have the right to access their personal medical and social services files and to receive full information about their situation and prognosis. Service users have the legal right to complain. A National Ombudsman represents an independent expert body with strong powers of investigation. This was created by law in 1981 and enshrined in the constitution in 1999. Individual redress is facilitated while also driving wider service improvements.[[228]](#footnote-228)
* Organisations representing people with disabilities and those with long term illnesses have obtained the right to participation in the running of residential services.[[229]](#footnote-229)

**Norway**

* There is a system of user involvement at the local agency level. There is an effort in social services across the 432 municipalities to involve users at all stages of the service delivery process. Some municipalities use surveys to obtain feedback from users. Some have written service declarations specifying what formal rights users have and specifying what kind of services to expect. While there are no participation rights for family members and other personal carers of adults with disabilities, the parents of a child with a disability have the right to participate in drawing up an individual plan.
* Families with children with disabilities are often active in achieving participation at the local level and user participation in Norway is also channelled through representatives of political parties in the municipalities.[[230]](#footnote-230)
* The principle of user participation is laid out in measures such as the Social Services Act. A stronger user role in organising and managing health services is laid out in the Government's National Health Plan (2007-2010).
* New legislation will require all users to have their needs evaluated and to participate at all stages of service delivery.[[231]](#footnote-231)

**New Zealand**

* According to Coney there are few practical mechanisms for identifying and communicating with service users and their organisations in New Zealand.[[232]](#footnote-232) However, there have been many recent changes in service configuration. The District Health Boards include a disability representative on their boards and the Office of Disability Issues maintains a database of appropriately skilled people with disabilities for inclusion on various state boards.
* The Disability Support Services Group of the Health and Disability National Services Directorate operates a Disability Support Services Consumer Consortium. The consortium provides input and advice to Disability Support Services on its planning, policy and service development. The establishment of the Consumer Consortium emerged from Disability Consumer Forums which the Ministry of Health has run since 2004. These are regional meetings (20 in 2009) run by the Ministry of Health to ascertain service consumer views on relevant issues (see Country Background Paper for details).

**Victoria, Australia**

* In Victoria Australia, the Disability Act 2006 established the Victorian Disability Advisory Council and a majority of its members are persons with a disability.
* At the federal level there is a statutory advisory body made of people with disabilities and families /carers, advocates and representatives. National People with Disabilities and Carers Council's primary function is to advise on the development of a National Disability Strategy. On its establishment it was announced that the Council would consult widely with stakeholders and the community to ensure people with disability, their families and carers have a significant voice in the development of the Strategy. In 2009 the Council produced a document entitled SHUT OUT: The Experience of People with Disabilities and their Families in Australia, which was based on the submissions of several hundred disability stakeholder groups and on over 50 consultation events held throughout Australia.
* There is a statutory based independent Disability Services Commissioner and Commission since July 2007. The Commissioner provides a free confidential and supportive complaints resolution process working with people with a disability and disability service providers to resolve complaints. The Commission dealt with 421 enquires and complaints in 2008 /2009 (see Country Background Paper for details).

**Scotland**

* In Scotland the health boards often involve people with disabilities by using results of surveys they have conducted and by organising meetings of specific groups around a particular aspect of service development. Some local authorities chose to consult with people with disabilities on the issue of community care with local authorities varying regarding the priority community care has on their agenda. (See Country Background Paper for details)

# Trends in the provision of specialist disability services

## Deinstitutionalisation and transformation of residential institutions

Deinstitutionalisation has been defined as the process by which a care system, originally aiming to protect people with disabilities by segregating them from society, transforms into a care system that aims to facilitate social participation by offering a wide range of services provided at community level, respecting the principle of choice and decision. The concept of de-institutionalisation must thus be differentiated from the notion of “transformation of residential institutions”, which is the process of reforming those institutions’ mandate and the services they provide.[[233]](#footnote-233) Similarly, others point out that deinstitutionalisation must extend beyond the closure of institutions to societal change and individualised support to people with intellectual disabilities.[[234]](#footnote-234)

Comparative studies on the quality of community-based settings versus institutions show that people living in community settings fared better on almost every quality of life indicator than they did in institutions.[[235]](#footnote-235) [[236]](#footnote-236) They provide support for the view that people with all levels of a disability can and should live in small homes in community settings, to honour their right to self-determination, to deliver appropriate care and to promote their full development as individuals. Research shows that institutional care is not necessary even for challenging cases: “based on the current state of the research literature on care for people with intellectual disabilities, it appears that the institutional model is obsolete and discredited, its last remnants preserved purely by political and social inertia in the face of broad policy consensus among advocates, governments and social bodies.”[[237]](#footnote-237) People, regardless of level of disability, complexity and severity of medical or behavioural needs, and history of living in institutions, have been successfully integrated into community settings.[[238]](#footnote-238) The fact that most people prefer to live in their own home with a good quality of life rather than in institutional care is now acknowledged by governments and service providers with a worldwide shift from the provision of residential accommodation to community living.

In advancing the development of community based services, discussion needs to focus on which array of community supports and services yield the best outcomes at affordable prices [[239]](#footnote-239) Improved outcomes for community-based services are complicated by variation and this can be used to undermine consensus supporting community living. Outcome variation reflects the characteristics of people with intellectual disabilities, service design and differences in staff performance, particularly the extent to which they provide facilitative assistance or ‘active support’.[[240]](#footnote-240)

**England**

From the 1980s the independent living movement developed an alternative model of community services based not on buildings but on the provision of personal assistance and championed legislative changes so that direct payments could be made in lieu of services.[[241]](#footnote-241) There were 129,548 residential placements in the UK, of which: 48,781 were in large institutions of more than 30 people; 33,530 in smaller settings and 47,327 in unclassified settings.[[242]](#footnote-242) Precision has not been possible about the size of residential homes in Scotland, Wales or Northern Ireland, nor the size of health service institutions like long stay hospitals.[[243]](#footnote-243)

**Scotland**

In Scotland the number of care homes in operation for people with disabilities is declining. On 31 March 2009 there were 311 care homes for adults with learning disabilities in Scotland. These homes offered a total of 2,857 places and had 2,448 residents. 205 (66 per cent) of the care homes in this client group and 1523 (53 per cent) of the registered places were in the voluntary sector whilst 69 care homes (22per cent) were in the private sector and 37 (12 per cent) were run by local authorities. The average size of these care homes varied between sectors. There were, on average, 7 places in voluntary sector homes, 9 places in local authority homes and 14 places in privately operated care homes. Since March 2000, the number of care homes has fallen by 69 from 380 in 2000 to the current level of 311 homes. There has been a corresponding drop in the number of places from 3,598 to 2,857. This is a reduction of 741 places (21 per cent). The number of residents in care homes for adults with learning disabilities has fallen by 847 from 3,295 in March 2000 to 2,448 in March 2009.[[244]](#footnote-244)

**The Netherlands**

The Netherlands is developing community-based services although service structures are still dominated by institutional models.[[245]](#footnote-245) From the 1970s the Netherlands tried to improve institutions turning them into community-like villages. Approximately 120,000 people with intellectual disabilities live in the Netherlands and a significant proportion continue to live in institutional settings.[[246]](#footnote-246) In addition, many people with physical disabilities, particularly elderly people, live in nursing homes or care homes. In 2004 approx. 100,000 lived in care homes and 60,000 in nursing homes.[[247]](#footnote-247)

Persons with intellectual and psychiatric disabilities do not enjoy the same history of progress made in independent living that people with physical disabilities have had since the 1960s. Many of them still live in residential and semi residential institutions and concern has been expressed that a significant number of institutions provide a low quality of care and choice to their residents.[[248]](#footnote-248) A key informant for the background paper on the Netherlands pointed out that, under recent legislation, the NZA, the supervisory body for all healthcare markets in the Netherlands, has introduced a system of indicators to measure the quality of health care that people receive and, in particular, people with disabilities. It is hoped that this indicators system will promote a reasonable price for health services and that by 2011 there will be a transparent market of health care provision in the Netherlands.[[249]](#footnote-249)

**Norway**

Norway is acknowledged for their leadership in replacing institutions for people with intellectual disabilities by a network of community-based services. What is striking is the speed with which Norway achieved deinstitutionalisation. Of note is that many institutions for people with intellectual disabilities before deinstitutionalisation in Norway were comprised of small and large group homes while other countries actually used small and large group homes to achieve deinstitutionalisation.[[250]](#footnote-250) Norway crafted a well-defined implementation plan to achieve deinstitutionalisation underpinned by legislation and which included a housing strategy. Between 1990 and 1995, 90% of people with intellectual disabilities in Norway were moved from institutions to the community. By 2000, institutions for people with intellectual disabilities no longer existed. A number of people with severe impairments (177 in 2005), however, are housed in nursing homes.[[251]](#footnote-251) There are concerns in Norway that some community settings are evolving into more institution-like arrangements over time. So, although physical and administrative normalization progressed rapidly and well in Norway, full social integration has not yet been attained.[[252]](#footnote-252)

**The USA**

In the USA the nation moved from large facility-centred to community residential services between 1977 and 2008. In 1977, an estimated 84% of the people with ID/DD receiving residential services lived in residences of 16 or more people. By 2008, an estimated 87% lived in community settings of 15 or fewer people and 75% lived in residential settings with 6 or fewer people.

By 2008 nine states have closed all public residential institutions with 16 or more residents with ID/DD. By 2008, 11% of residential service recipients lived in state residential settings compared to 63% in 1977.

The number of residential settings and residential options for people with ID/DD is growing rapidly. Between 1977 and 2008 the total number of residential service recipients grew 76%. The number of people living in host family/foster care is slowly increasing. About 27% of people receiving ID/DD residential services live in homes that they own or lease.

Community Based and Medicaid Home Services (HCBS) are on the increase with 525,119 people in 2008 compared to 239,021 HCBS recipients in 1998. The number of people receiving support to live in the community 2008 was 5.6 times more than the number living in Intermediate Care Facilities for People with mental retardation (ICFs-MR). Medicaid expenditures are disproportionately greater for people in ICFs-MR than HCBS recipients. There remains wide variation among states in ICF-MR and HCBS utilisation rates.[[253]](#footnote-253)

Approximately 80% of people with intellectual disabilities live with their families or independently. People with intellectual disabilities often live in family home settings with home supports to family members or in host family settings i.e., where home supports are provided to unrelated persons with disabilities.[[254]](#footnote-254)

In 2005 the US Congress enacted the Money Follows The Person Demonstration funding stream. (P.L>109-171, Deficit Reduction Act (DRA), Section 6071). This has the goals of

* transitioning those in long-term institutional care who are Medicaid beneficiaries to home and community based settings and
* rebalancing state Medicaid long-term care systems so that states rely less on costly institutional care.

In Jan 2009, 29 states and the District of Columbia were participating in the programme and proposing to transition 34,000 individuals, supported by federal grant funds, between 2007 and 2011. In reviewing the scheme, significant variation was found among states in their experience and infrastructure to undertake large-scale transitions and also pursue different strategies to achieve and complete deinstitutionalisation.[[255]](#footnote-255)

## Community Living and accessible housing

Community living has been defined as “comprising the same range of accommodation available to the general population, in the same locations where the general population reside, offering people with disabilities choice over where and with whom they live and providing the necessary supports for community participation” [[256]](#footnote-256) and involves the closure of inappropriate institutional accommodation and the development of housing and related support options for people with disabilities including accessible housing, housing support and community support models for people with intellectual disability. A vision of what constitutes a ‘liveable community’ for people with disabilities can guide design of innovative disability service models.[[257]](#footnote-257) A liveable community is one that:

* Provides affordable accessible housing
* Ensures accessible affordable reliable safe transportation
* Adjusts the physical environment for inclusiveness and accessibility
* Provides work, volunteer and education opportunities
* Ensures access to key health and support services
* Encourages participation in civic cultural social and recreational activities.[[258]](#footnote-258)

#### Housing provision

Affordable accessible[[259]](#footnote-259) housing is an integral part of making any community more liveable for people with disabilities.[[260]](#footnote-260) Demand for accessible housing with care and support is increasing as populations in many countries age and as community living becomes the preferred service option. Accessibility is promoted mainly by mainstreaming, exclusive legislation or a progressive approach.

A mainstreaming approach means that all dwellings, not just those within specialised disability services, would meet access standards for people with disabilities. Across the jurisdictions in our study, this is the case in Norway and the Netherlands. In Victoria, Australia ResCode applies to accessible multi-unit developments.[[261]](#footnote-261) Regulatory frameworks vary across jurisdictions from achieving a low level of accessibility for public buildings through to a comprehensive requirement for new buildings to be built to universal design.

Key points from research in relation to achieving accessible housing include:

* Complex barriers can make it difficult to create and sustain safe, accessible, affordable, and integrated housing. These barriers can arise from the interaction of poverty, inaccessibility, funding rules related to acquiring supportive services, and a disability policy system rooted in an outmoded model of segregating people with disabilities from the community mainstream.[[262]](#footnote-262)
* The introduction of universal and accessible design will improve the housing stock for people with disabilities, their families and for everyone over time. Accessible housing should not be seen as a matter of modification only in response to an individuals' demand and as a responsibility of the disability sector alone.
* According to Saville- Smith et al, capacity building is required in the housing and disability sectors in New Zealand to optimise accessibility in new stock, renovated stock and housing stock requiring modification for a particular person with a disability.[[263]](#footnote-263)
* In most countries social housing still provides the majority of accessible housing units. Generally local authorities or municipalities are responsible for the housing needs of people who cannot provide their own housing.
* Potential pathways through which houses of accessible design may be promoted include:
* Incentives such as low cost loans for new housing; grants for modification work to existing housing; planning consent advantage for housing developers who include a percentage of accessible housing in new developments
* Market capacity development - developing quality assurance systems is a key part of capacity development with collaborations between the private, public and community sectors being characteristic of these initiatives. Support the construction industry to provide well-designed stock using voluntary design guidelines; promoting accessible design principles among design, planning and building industries. Some countries offer national awards to designers and architects or community service awards for accessible housing projects e.g. UK.
* Regulation
* Branding of universal home designs such as Life Time Homes and Smart Homes in the UK is becoming more common with the aim of stimulating the supply of accessible homes through raising consumer demand.[[264]](#footnote-264)

In Norway, for instance, accessible housing is promoted through comprehensive strategy and planning. A Housing Office in each municipality administers Norwegian State Housing Bank support schemes which assist people with disabilities in their housing needs. Municipalities also have their own housing grant schemes. Norway's housing policy based on the goal of home ownership for the majority of the population articulates clear goals to ensure adequate and secure housing[[265]](#footnote-265):

* stimulate a well functioning housing market
* provide housing for disadvantaged groups on the housing market and
* increase the number of environment friendly and universally designed dwellings and residential areas.

The state sets the policy goals, the legal framework and provides economic assistance for special purposes. The municipalities have primary responsibility for planning and organising construction and renovation of housing and residential areas including access to housing for disadvantaged groups. The private sector owns, builds and administers the housing stock. Recognising that the interest rate level is the single economic factor that exerts the greatest impact on the housing market, the Norwegian government aims to maintain stable low interest rates that facilitates development of the housing market, high employment levels and reduces risks for stakeholders. Financial instruments include loans from the State Housing Bank, housing grants and housing allowances[[266]](#footnote-266).

Norway relies on financial incentives to encourage the private sector to build to accessible design. The Norwegian government has an accessible design housing action programme. The universal design home is branded as Lifecycle Housing and greater market acceptance has been achieved by linking accessibility with quality design and encouraging partnerships between architects, disability groups and builders. The Norwegian Housing Bank offers a programme of low cost, entry level basic loans, designed to increase the number of dwellings built to the standard. The incentives include enhanced loans from the Bank, which, overall, finances 50% of new Norwegian housing. From 1996-2005, a 1% lower interest rate was offered.[[267]](#footnote-267)

The range of accommodation services currently available to people with intellectual disabilities instead of residential accommodation can be classified into comprehensive placement models and supported living models. In comprehensive placement models, governments purchase accommodation as part of an overall support package while in supported living, sometimes called 'separate accommodation', the funding is more diverse. Comprehensive placement models include institutions, cluster housing, group homes, hospital wards and smaller specialist residential facilities.

Clustered settings are defined as three or more living units with an on-site day centre forming a separate community from the surrounding population. Some of these settings can be classified as specialist residential facilities (Mansell & Beadle-Brown, 2009; Emerson, 2004). Different formats of clustered housing included village communities, residential campuses and cluster housing. Village communities comprise approximately 2% of accommodation services in England (Emerson, 2004) and the UK government plans to close residential campuses, which are smaller residential sites built on the campus of an institution, because of concerns over quality of care.

Supported living models are where individuals live in a private residence. This can be the family home; their own home, rented or owned; or a private home owned by a non-family member. There is an increasing range of these supported living models which include the provision of necessary social and health supports to maintain a person living in separate accommodation.

A systematic review of the research evidence conducted for the NDA[[268]](#footnote-268) has shown that, across most quality of life measures, better outcomes are achieved where people with disabilities live in housing which is dispersed throughout the community (housing arrangements comparable to that used by the general population) rather than in group housing schemes or similar clustered housing arrangements. Clustered housing is less expensive than dispersed housing because there is less staff but it cannot provide the same quality of life as dispersed housing.[[269]](#footnote-269)

Clear pathways to housing and supports in the community for those moving from congregated settings are needed and local authorities as housing providers have a critical role to play in this regard. As highlighted by research, it appears that individual supported housing units or individual group homes, rather than group housing schemes, should be the norm for publicly-funded housing for people with disabilities[[270]](#footnote-270).

Problems with institutions can be replicated in cluster homes although advantages over institution models are still apparent.[[271]](#footnote-271) Setting size and location, grouping size and composition can have negative effects on the competency development of individuals, increasing their stigma and social isolation and opportunities for inclusion. Analysing the characteristics of the disability cluster models shows that many basic human needs are less likely to be met than in individualised housing. However, small individual units and more home-like surrounds share some of the characteristics of group homes that have been found to rate more positively on service evaluations than institutions.[[272]](#footnote-272)

Supported housing is defined in many ways depending on the context.[[273]](#footnote-273) It generally means some combination of housing plus the support required to live in such housing. The Housing Corporation in the UK, for example, makes a distinction between purpose designed supported housing and designated supported housing.[[274]](#footnote-274) The Tenant Services Authority (TSA) is the new regulator for social housing in England having taken over responsibility for Housing Associations from the Housing Corporation. Part of its function is to ensure that associations provide a good service to tenants living in Supported Housing as well as in their General Needs stock. However, questions are arising around the definition of Supported Housing and whether standards should be developed specifically for Supported Housing.[[275]](#footnote-275)

**Victoria Australia**

In Victoria, while funding for individual support packages has increased for people with disabilities, service providers have experienced difficulty in obtaining appropriate housing options to pair with support packages. There is a need for investment in supportive housing models which provide secure and supportive housing for those who need it.[[276]](#footnote-276) An evaluation[[277]](#footnote-277) in Victoria of 13 disability services accommodation innovation grants arrived at the following five main conclusions:

* Formal and informal support is integral to developing and maintaining housing and this should ideally be cooperative and coordinated
* Informal supports take time to develop. They include circles of support and locality-based mutual support groups for parents and for people with disabilities where preparatory processes with individuals and families around preferred living arrangements can be teased out.
* The development of housing and support requires a range of functions which are not necessarily sequential - establishing that a person wants housing; building and coordinating support requirements and understanding around living in ones own home; preparing to move; developing and locating housing; making the transition to a new home and providing follow-up housing support. These functions provide a framework for developing a local housing strategy.
* A local network approach is needed to plan, coordinate and implement effective accommodation supports for people with disabilities. In the absence of a systemic approach to housing development, there is a risk that supports will be provided in an ad-hoc or crisis driven manner. Smaller scale developments when isolated are at risk of becoming facilities dominated by organisational arrangements and risk limiting choice and decision making for potential residents.
* There is a need to have access to expert advice re housing e.g., specialised knowledge regarding complex lease and finance arrangements and it is more efficient to have experts in housing in a geographic area

**England**

The Supporting People Funding Programme in the UK was started in 2003 to provide short-term or long- term housing related support services through the local authorities to vulnerable people to enable them to live independently in their accommodation[[278]](#footnote-278).

This programme has enabled many people with disabilities to live independently. Short-term supports were provided free and could last for up to 2 years with the aim of moving the individual on to independent living or increasing their ability to live independently[[279]](#footnote-279). Following this, longer term services were means tested. The programme was introduced after pilot programmes and their evaluation and brought together a number of funding streams. The programme has been delivered largely by the third sector i.e. the voluntary and community sector, and housing associations.

Findings from an evaluation of the tenants with intellectual disabilities who participated in the Supporting People programme are of note. While people with disabilities were generally happy with the support received and their new homes, some supported living services were found to be largely indistinguishable from high-quality, small-scale registered care homes. This was particularly the case when the basic principles of supported living appeared to be overlooked[[280]](#footnote-280) e.g. staff offices within peoples’ homes, staff routinely holding and using front door keys and staff hours of work based on a set pattern of shifts which limited the flexibility of support. Choice was often limited although tenants were happy and proud of their independence e.g., being able to watch TV when they wanted to. Choice over where to live, who to live with and who to receive support from, however, were still often made by service commissioners and managers with little or no input from service users. Services were often limited to those with mild learning disabilities and low support needs to keep down costs.[[281]](#footnote-281) Fyson et al (2007) summarise some of the advantages and disadvantages found in two primary support options provided by the Supporting People Programme in England are outline in Table 3.[[282]](#footnote-282)

**Table 3 Advantages and disadvantages of two approaches to housing support[[283]](#footnote-283)**

|  |  |
| --- | --- |
| **Shared tenancies with accommodation based support** | **Individual tenancies with floating support** |
| Key Advantages: * Maximum flexibility of support
* Less chance of being lonely
* Housing and support often provided by same body providing more seamless service
* Possibility of minimising costs per hour of support
* 24-hour staff cover sometimes possible

Key Disadvantages: * Danger of less individualised support
* Less privacy/time alone
* Greater consistency of support
 | Key advantages * Separation between landlord and support provider
* Fully individual support
* More privacy/time alone

Key Disadvantages * More chance of service user being lonely
* Difficult to change support hours at short notice
* Potentially higher costs per hour of support for those with complex needs
* Less consistency of support
 |

In England attention is being drawn to the number of people with intellectual disabilities who are housed out of area because of a dearth of local suitable services.[[284]](#footnote-284)

## Employment Services for people with disabilities

Before examining developments in the provision of specific employment and day services for people with disabilities a brief overview is given of the situation of people with disabilities in the labour market and the general measures that exist to improve their employment opportunities.

People with disabilities face barriers to gaining employment in the open labour market resulting in high unemployment rates with many people with disabilities of working age claiming benefits.[[285]](#footnote-285) In an overview of employment services internationally the OECD found that the greatest predictor of employment levels of persons with disabilities was variation within the general employment level. They concluded that policies promoting employment among the general population will promote employment among those with disabilities.[[286]](#footnote-286)

General measures in different countries to increase employment opportunities for people with disabilities include:

* Disability specific non-discrimination or anti-discrimination legislation.[[287]](#footnote-287)
* Quota schemes[[288]](#footnote-288) and targets to promote the entry of people with disabilities into the labour market.
* Programmes to increase opportunities for people with disabilities to work or to prepare them for employment.
* Diversity policies in, for example, New Zealand, Norway and the UK.

The purpose of these policies is to build diverse, competent public services able to serve diverse societies; the UK and Norway have set up collaborative networks to pursue diversity. In the Norwegian diversity program, employers in public service recruitment must invite at least one applicant with an immigrant background and one applicant with a disability to interview from among qualified applicants - currently the public workforce in Norway is 138,000 of which 8.5% of workers have a disability and 10% are immigrants. The Netherlands and the UK have set targets for integrating people with disabilities into the public labour force. In Australia some public posts are open only to people with disabilities. Promoting leadership among employers to improve employment of people with disabilities is addressed in the equality and diversity strategies in Australia and the UK.[[289]](#footnote-289)

The range of specialist day/employment services for people with disabilities across jurisdictions differs in name, categorisation and configuration but there are many commonalities.

In many English speaking countries the services available for people with disabilities can be broadly categorised as follows

* Day Care Programmes (not work-related): High-support services focused on health needs
* Facility-based day activation programmes(not work-related): Training in independent living skills; social/recreational activities; health-related and therapeutic supports; some programmes promote community participation and the utilisation of mainstream services
* Rehabilitative Training (some training in work-related skills): programmes to equip participants with basic skills including personal, social and work related skills
* Sheltered Work[[290]](#footnote-290): 1) therapeutic and non-pay; 2) commercial where service-users may/may not receive remuneration for products/services provided; 3) ‘like work’ where service users assist in service provider organisations e.g., in catering, gardens, shops, maintenance work often with discretionary payment
* Sheltered Employment: employment in enterprise specifically established for the employment of people with disabilities
* Supported Employment[[291]](#footnote-291): This is paid employment in the open labour market with the provision of supports such as that of a job coach.
* Open Employment: employment in open market, for all or part of the week

**The Netherlands**

In the Netherlands in 2005, about 45% of the estimated 73,000 people with an intellectual disability were in either supported employment or sheltered employment. The majority of people were in sheltered employment, mainly work-like activity in day centres, while 4% were in supported employment although a much larger proportion had applied for support. The government had allocated substantial funds to transition young people to the labour market but in some cases local government seemed reluctant to implement supported employment policies. Sheltered employment is well-established in the Netherlands. Where workers are under contract they receive pay on a scale negotiated through collective bargaining and have the opportunity to build skills. Few people, however, transition from sheltered employment to the open labour market. The demand for sheltered employment exceeds supply.[[292]](#footnote-292)

**Norway**

Supported employment started in Norway in 1992. An evaluation a decade later found that many people who obtained employment, lost it within the year after the supported employment process had ended. Recommendations included extending support measures to assist workers with disabilities to keep their jobs.[[293]](#footnote-293) Disability-specific programmes in Norway are categorised as follows: assessment (2,200 in 2009), preparatory training for work (5,700), sheltered workshops (3,100), supported employment (6,000) and permanently adjusted employment (7,800).[[294]](#footnote-294)

**Australia**

In Australia day and employment services are funded and run by different levels of government. Day services are funded and run at the state level while employment services are funded and run by federal government. Day services in Victoria are delivered by 146 non-government organisations and funding for day places is to be made individual and portable. In 2007/2008, 8,329 people were in receipt of day services[[295]](#footnote-295). Disability Employment services, the Disability Employment Network (DEN) and Vocational Rehabilitation Services (VRS), are funded by the Australian federal government and delivered by non-governmental agencies. In 2006-2007 in Victoria there were 21,314 people with disabilities receiving support from these agencies: 16, 661 were in open employment, 4, 859 were in supported employment while 57 were in targeted support. [[296]](#footnote-296)

The federal government in Australia issued a discussion paper in Dec 2008 on a new disability employment service model to be implemented in March 2010. Features proposed include: that the disability employment programme become demand-driven with removal of the ‘cap’; the establishment of a separate programme for jobseekers with ongoing support needs (programme B); retain services specialising in assisting clients with intellectual disability; promote early intervention partnerships with schools; direct a greater percentage of funding towards outcomes and simplify the funding system.[[297]](#footnote-297)

**New Zealand**

In New Zealand, the Ministry of Social Development funds and administers day and vocational programmes for people with disabilities. While the Ministry of Health has funded non-vocational day activities for adults with intellectual disabilities the administration of these services is to be transferred to the Ministry of Social Development.[[298]](#footnote-298) Several agencies deliver supported employment programmes to people with disabilities[[299]](#footnote-299) but, because of funding levels[[300]](#footnote-300), they support those who are comparatively job ready. In 2006/07, 9,000 of the 21,300 people with a disability receiving a vocational service were placed in employment or assisted to remain in open employment compared to 3000 in 2001.[[301]](#footnote-301)

**The UK**

A ‘family’ of national New Deal Programmes for distinct client groups was introduced in the UK in 1998 with the programme for people with disabilities commencing in 2001[[302]](#footnote-302). A network of job brokers/personal advisers, paid on the basis of outcomes, provide advice and support to find and prepare for work. Outcomes include registering participants, job entries and sustained employment. This policy is an active, supply-side welfare policy based on the belief that flexible, integrated, personalised or caseworker services backed by investment in information and communication technology can increase employment rates.[[303]](#footnote-303) The personal Adviser model is now a feature of the mandatory work-focused interviews conducted in Jobcentre Plus Offices. In general customers and staff like the personal adviser model. However, the service focuses on work outcomes for unemployed people so those claiming other benefits, especially people with complex needs, receive a limited service.[[304]](#footnote-304)

In Scotland, as in other parts of the UK, different organisations provide employment services for people with disabilities. There is some duplication between the policies of Jobcentre Plus and the Scottish Executive. In 2003 there were 3024 people with learning disabilities and/or ASD being supported by 69 separate employment support providers with the main individual funding for employment support coming from Scottish local authorities followed by the voluntary sector.[[305]](#footnote-305)  Key findings in a 2010 Scottish Government report on a supported employment scoping exercise[[306]](#footnote-306) included that while many areas had developed good practice approaches into the development of services, this is variable and not developed in a systematic manner and, therefore, good practice does not spread to other areas in Scotland; lack of consistency of approach, with Supported Employment services being lost in other employability services; lack of consistent standards, working practices, roles, salaries, training and qualifications; an urgent need for organisational/strategic ownership within Local Authorities and the designing of Supported Employment services using a strategically planned approach. To this end the Supported Employment Framework for Scotland was launched in February to ensure that supported employment is seen as a valued and integral part of local mainstream employment services.[[307]](#footnote-307)

**Innovative practice in supported employment: social firms including social farms**

Social firms are social enterprises specifically designed to create jobs for people with disabilities or other people disadvantaged in finding employment. They are a modern development of the sheltered employment models. A high profile example of social enterprises includes Cafédirect which is a social enterprise combining the strengths of business and charity and outperforming both by delivering sustainable poverty relief while at the same time taking market share from the largest multinational companies. These new forms of social enterprise models are promising. They take on board ideas around social and financial inclusion - employing both people with and without disabilities in real jobs - and the idea of the broader social enterprise movement - that it is possible to use self-financing business structures and methods to achieve social benefits. Because they are quite new there is little research carried out on them although the evidence available is positive. Sheltered employment or therapeutic work may be successfully transformed into a social firm over a timescale of probably at least 5 years. Social firms represent less than 1% of social enterprise. The UK had 119 social firms in 2005 employing 1550 people of whom 55% had a disability and the number of these enterprises has continued to grow in the UK.[[308]](#footnote-308) A study suggests that 35% of all new entrepreneurs are social entrepreneurs.[[309]](#footnote-309) The Department of Health in England has established a £100 million Social Enterprise Investment Fund financing business structures and methods to achieve social benefits.[[310]](#footnote-310)

Social farming[[311]](#footnote-311) describes farming practices aimed at promoting well-being for people with disabilities and other disadvantaged groups. In the jurisdictions under study both Norway and the Netherlands have supported social farming with 550 such farms in Norway and 700 in the Netherlands with a few, e.g. 45 farms, in England.[[312]](#footnote-312) The farms in the Netherlands started in 2002 and family social farms have grown rapidly with strong regional and national networks developing. The farms have tax free services, access to budgets and regional associations are recognised as care institutions. In Norway the farms are also largely family farms and 80% of those working on the farms are men.

# Standards and inspection for services

Quality assurance, independent monitoring and evaluation are critical in developing and delivering effective health and personal social services for people with disabilities. Learning from the present review suggests that in order to be fully effective, standards and regulations need to be developed and implemented as part of a comprehensive, interoperable, overall quality framework, copper-fastened by robust, ongoing surveillance activities at national level, based on agreed indicators. Jurisdictions in which this type of framework has been developed include, for example, the U.K., Victoria (Australia)[[313]](#footnote-313).

Issues for quality assurance and independent monitoring and evaluation observed across six jurisdictions are:

* Regulation: registration and inspection
* Outcomes-oriented standards
* Streamlining and quality assuring the quality framework to ensure cost effectiveness and value for money

Provider registration and inspection against agreed national standards continue to be internationally accepted as valuable mechanisms of quality assurance and monitoring across a variety of both older and newly emerging models of service provision. Even in the Netherlands, where provision has now become substantively insurer-led, insurers continue to maintain approved provider registers and the national inspectorate (IGZ) continues to implement an ongoing programme of inspection. Northern Ireland’s Regulations II (7) and (8) on registered providers are a good example of a set of robust, minimum licensing criteria.

In 2008, a government inquiry into the quality of care and service provision for people with disabilities in New Zealand, gave rise to a number of recommendations on streamlining monitoring activities and costs while refocusing the scope of these activities more so on quality of life than systems and processes. These recommendations are indicative of a trend which may be observed internationally to move towards developing:

* Outcome oriented standards
* National surveillance indicators to track the effectiveness of provision.

Amongst the 6 jurisdictions reviewed in the context of the present research, the trend to move away from setting out minimum levels of performance to be achieved towards setting out outcomes can best be observed in the stated intent of England's new Care Quality Commission to replace National Minimum Standards with Compliance Guideline Criteria. The essential difference between minimum performance standards and outcome oriented standards is as follows:

* Minimum performance standards set out minimum actions to be taken or levels of performance to be achieved on the part of the provider of a service
* Outcome oriented standards are essentially statements of required outcomes for the user of a service or support.

Victoria, Australia has adopted a hybrid approach in presenting its new standards for designated service providers, in 2008 as two separate sets of mandatory outcomes standards and mandatory 'industry' or performance standards. Such an approach may be considered appropriate where there is concern for ensuring a consistent minimum baseline of quality across all providers. Scotland's National Care Standards for care in the home are also notable for the manner in which they:

* capture outcome and performance dimensions of each standards statement as needed and
* present these statements in an exceptionally service user focused and service user friendly way.

The research demonstrated that increasingly service systems are seeking to introduce interoperable quality assurance systems as a means of reducing the burden of assessing quality and achieving improved efficiencies in quality assurance, monitoring and evaluation. Interoperability refers to:

* Harmonisation of standards and related performance criteria across standards bodies
* Ensuring broader applicability of standards and criteria across various forms of service provision (e.g. residential and day services)
* Reducing the burden of inspection, audit or review through agreement to take certain standards and criteria as measured for all, if measured by at least one concordant standards body.

The U.K.'s Healthcare Inspection Concordat provides an example of interoperable working. The Concordat is made up of 10 objectives that enable 20 organisations involved in the regulation, audit or review of health and social care to work together to:

* Remove unnecessary burdens of cost, structures and administration associated with quality assurance, monitoring, inspection, audit and review
* Achieve common goals on quality assurance and measurement.

The Concordat is a voluntary code and does not affect the statutory remit of individual signatories. Each of the Concordat's 10 objectives is underpinned by a number of agreed principles and practices that focus on commonly agreed activities on areas that will help to secure effective implementation.

In Victoria, Australia, care has also been taken *a priori* to minimise duplication with other jurisdictions in developing the new monitoring mechanism for service providers. The research also revealed that a number of jurisdictions are seeking to develop or pilot innovative monitoring and inspection mechanisms. These include, for example:

* In New Zealand where contract relationship managers within the Ministry of Health and Disability Systems and lawyers are appointed as inspectors under the Intellectual Disability (Compulsory Care and Rehabilitation) Act, 2003[[314]](#footnote-314)
* In Victoria, Australia where statutory regional community visitors are appointed to support residential services.

# Evidence on outcomes across six jurisdictions[[315]](#footnote-315)

Services provision systems are increasingly investigating mechanisms by which they can measure not only outputs for investment, but also lasting impact and personal outcomes for the individuals who use their services.

Incorporating outcomes measurement into service development is constrained by the limitations in the current international and national knowledge bases. There is a general lack of focus on outcomes, especially at societal and disability systems levels rather than individual or service level; data on quality of life and other subjective measures is limited; participation data is also limited and/or out of date in the context of changing policies. Where there are improvements in outcome investigation, they are of recent origin.

For these reasons it has not been possible to identify a full configuration of services in a single jurisdiction[[316]](#footnote-316) which has been proven by robust data collection, evaluation and/or research to significantly improve outcomes for people with disabilities, across the full range of disabilities, with regard to such indicators as quality of life, income levels and participation rates in economic and social life. However, some jurisdictions are actively addressing this problem and will be releasing more comprehensive outcome data and evaluation in the coming years. The European Union is currently investigating this area as it develops its disability policies. The EU funded network ANED[[317]](#footnote-317) is a dynamic source of research-based information with regard to disability policy and services, including those related to independent living, and their impact on the lives of people with disabilities across the Member States. Further relevant research reports in this field are expected from ANED over the next year.

The outcomes knowledge base is underdeveloped in all jurisdictions. Four emerging models of outcomes measurement were identified. Three of these are among the six jurisdictions reviewed during the NDA project (England, Scotland and Victoria) and the additional model comes from the United States. During this research, four major overviews of the outcomes knowledge base in relation to national configurations of independent living services were identified and examined. All four overviews related to one or several of the six jurisdictions under consideration. The message from these four comprehensive overviews is clear: there is as yet no robust outcomes knowledge base on which to base an evaluation of the different configurations of health and social care services which underpin the independent living policies and programmes of different jurisdictions.

A 2007 report for the EU, *Deinstitutionalisation and community living - outcomes and costs*,[[318]](#footnote-318) placed a strong emphasis on the need for more and better data in relation to this major policy shift from institutions to the community across Europe. The recommendation was that the EU should develop a harmonised data set at EU level, which would include data on outcomes.

Another overview, *The Costs and Benefits of Independent Living,* published in 2007 by the UK Office for Disability Issues reviewed selected documents from eight countries and two international organisations.[[319]](#footnote-319) The authors concluded that research into the benefits of independent living service systems was scarce and unsatisfactory, while costs related research was more developed. They said that examination of 110 documents included in the core set showed that: "there is very little discussion of macro level benefits to the exchequer and to society (net social benefits) as a result of independent living support, possibly related to the corresponding lack of evidence at micro level (individual and service delivery level) on benefits."[[320]](#footnote-320)

In order to build a knowledge base the UK 2008 Independent Living strategy placed a strong emphasis on continuous monitoring, evaluation and data collection. The *Costs and Benefits of Independent Living* Report provided an important resource for this new evidence based approach since it contained discussions on methodological options for improved data collection and research.[[321]](#footnote-321) The report distinguished three levels at which outcomes can be evaluated: the individual level, the service level and the societal level[[322]](#footnote-322). It found that, at individual level, there was substantial evidence in the literature that independent living produces significantly more benefits that more traditional service provision. But the report also acknowledged that the evidence is less developed with regard to the outcomes at service or societal levels. Some of the outcomes oriented patterns which were identified in this report included:

* Continued and very significant barriers to full participation for people with disabilities
* A strong relationship between disability and economic as well as social disadvantage
* Financial disincentives which impact negatively on the economic and other outcomes from independent living
* Evidence of variations in outcomes depended on geographical location, showing the need for coherence and consistency

An overview of outcomes research was produced for the Victoria Department of Human Services in Australia in 2009 by KPMG entitled *The Contemporary Disability Service System*. This report also found the knowledge base to be inadequate, especially for outcomes at the disability systems and societal levels. The report commented on 'the limited availability of robust evaluation of existing policies and programmes for disability services in Australia and internationally' (2009:5).

A 2010 report on 26 EU member states entitled *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report*, includes a section on outcomes.[[323]](#footnote-323) This shows there has been very little research in the EU member states which has looked at outcomes; that there has been little published research on costs and benefits (and where there is such research, that it looks at savings rather than costs/benefits) and that there are no clear examples of the involvement of disabled people in research on independent living.

The message from these four comprehensive overviews published between 2007 and 2010 is clear: there is as yet no robust outcomes knowledge base on which to base an evaluation of the different configurations of health and social care services which underpin the independent living policies and programmes of different jurisdictions. This is the case not alone in the six jurisdictions which were the focus of the NDA investigation, but also in the thirty jurisdictions considered in the overviews cited.

The outcome measurement models which provide more useful examples for the current investigation, and for informing Irish initiatives in this field, are those which focus on disability system level performance and include outcome indicators in their measurement. Over the last three years, these have been under development in England, Scotland and Victoria. They are based on data collection for service and system performance evaluations.

As these new systems are currently being rolled out, full evaluation of their effectiveness is not yet possible. However, on evidence to date, they seem to be starting to achieve both timeliness and comprehensiveness in measuring and reporting on a broad range of outcomes produced by the relevant service configurations. These indicators have been agreed during detailed stakeholder consultations, including with people with disabilities and their organisations. They also reflect greater openness and transparency regarding outcomes, with detailed results available on the Web.

In England, local authorities are responsible for many of the services which support people with disabilities to live independently in their communities. Each local authority is required to report annually on social care performance against nine outcome measures (which include both subjective and objective measures). These are:

1. Improved Health and Well being;
2. Improved Quality of Life;
3. Making a Positive Contribution;
4. Increased Choice and Control;
5. Freedom from Discrimination and Harassment;
6. Economic Well-Being;
7. Maintaining Personal Dignity and Respect;
8. Leadership;
9. Commissioning and Use of Resource

At the service level, within local authority areas, performance of individual home care services, registered by each local authority, is inspected and reported by the Quality Care Commission .[[324]](#footnote-324) The inspection reports provide an overall rating; then comments on, as well as ratings of, five agreed outcome indicators and the evidence on which those ratings and comments are based. In addition, at the societal level, work is currently under way at the Personal Social Services Research Unit (PSSRU) of the University of Kent, London School of Economics and University of Manchester, to develop social care outcome measurement for the UK government. This work forms part of a larger project called the Quality Measurement Framework, 2006-2010 and involves development of a toolkit for local authorities to assess and monitor performance, including in the area of social care.[[325]](#footnote-325)

In Scotland, single outcome agreements based on national indicators, are made between local authorities and Health Boards and the Scottish government. These agreements are beginning to include aspects of independent living. Reports are issued on these agreements and trends are reported annually. The reports are available on the Web (see for example Aberdeen City Council, Single Outcome Agreement Report 28 August 2009 which covered 15 national outcomes, with a minor disability component to some of these.[[326]](#footnote-326)

The KPMG report's first recommendation for the development of a best practice disability service system was that a statement of outcomes should be created against which outcomes could be measured. This recommendation included a list of outcomes which, like the Hurstfield analysis, was divided into outcomes for the service system; outcomes for communities and outcomes for people with a disability, their families and carers.[[327]](#footnote-327)

The example from the United States concerns a performance measurement and evaluation system relating to developmental disability services called the National Core Indicators (NCI). The NCI produces disability system level measurement, in relation to developmental disability, based on service level data and research. The system was created between 1996 and 2000 and is now used by many of the States.[[328]](#footnote-328) Participation in NCI is voluntary. At the last count thirty states were participating.[[329]](#footnote-329) The NCI makes it possible, not alone to evaluate outcomes within States, but also to compare results between States across the agreed list of outcome indicators.

In any reconfiguration of health and personal social care services it is important to plan for disability system level data collection, monitoring and evaluation in relation to outcomes, thereby permitting continuous review and learning for future planning, including comprehensive cost/benefit analysis. Depending on the design of the data collection exercises, these may produce both local and national statistics.

The Victorian model seems to merit further consideration when more information is released into the public domain, along with those used in England, Scotland and the USA.

The knowledge gleaned from examining the six jurisdictions included in the NDA project indicate that deinstitutionalisation programmes and community based supports alone do not ensure improvements in income or reduce gaps in participation in economic and social life for people with disabilities, although they provide a better basis for such improvements than does institutional care. It will be important to examine the learning from these and other jurisdictions with regard to how independent living strategies can be incorporated within larger programmes to improve participation by people with disabilities in all aspects of life. Work being undertaken at EU level, including that by Academic Network of European Disability Experts (ANED), should help to inform this process.

The international knowledge base available (albeit limited) indicates that independent living is at the core of the range of changes required in order to ensure better lives and full participation by people with disabilities in society. However, it is also clear, that a 'one size fits all' approach to health and personal care services for independent living will not produce the desired results. Therefore, it will be important to develop a nuanced approach to reconfiguring services, one which takes into account the differences between groups of people with disabilities (such as those based on age or type of disability) with regard to independent living systems and practice.

## Appendix 1: Disability Support Systems and Local Area Coordination

Local area coordination (LAC) was introduced in Western Australia in 1988 while, in NZ, Needs Assessment and Service Co-ordination organisations (NASC's) were introduced in the mid 1990s (LAC was introduced into Scotland in 2001. It is also of note that the Disability Liaison Officers in Leitrim, Sligo and Donegal and part of Cavan in Ireland play a similar role to Local Area Coordinators but for children.)

Local Area Coordinators in Western Australia develop working relationships with people with disabilities and their families and focus on developing natural and community supports although they also help people with disabilities to access government funded supports.

Key differences between the LAC approach and the Ministry of Health's Needs Assessment and Service Coordination (NASC) approach include:

Different basic questions are asked. Co-ordinators start from person and what they want. They ask: "What constitutes a good life for you?" Needs Assessment Coordinators in NZ ask: "What supports do you need?"

Needs Assessment Facilitators in NZ tend to have episodic contact with clients and focus at an early stage on the availability of relatively inflexible government-funded support. Co-ordinators work with people over time and seek to develop working relationships with them, exploring a wide range of options including developing natural and community supports to achieve what people need and want. The original intention in NZ that Needs Assessors and Service Coordinators would take a holistic approach has in many cases been lost. It was also originally intended that NASC's would operate across agencies. In practice however they only have a mandate to focus on Vote: Health funded services although they will make referrals to other government services.

Rather than importing LAC into NZ with additional costs and duplication of responsibilities, NZ hope to incorporate key elements of the LAC-type processes into their NASC system while also increasing control and choice for people with disabilities with other changes such as making individualised funding and supported living more widely available (Individualised funding in NZ is only available for home and community support services for people with high support needs while in Western Australia it is available for most people who receive funding for disability supports.

LAC type processes are already provided in part through NASC intensive service coordination, supported living and supported lifestyle facilitators and some disability information and advisory service field officers[[330]](#footnote-330).

**Comparison of Western Australia’s & New Zealand’s Disability Support Systems[[331]](#footnote-331)**

|  |  |  |
| --- | --- | --- |
|  | **Western Australia** | **Closest New Zealand equivalents** |
| Information  | Coordinators.  | Disability Information and Advice Services (DIAS).  |
| Personal assistance  | Coordinators.  | No direct comparison. Provided in part by NASC intensive service coordination, supported living facilitators, supported lifestyle service & some DIAS field officers.  |
| Process for seeking funded supports  | People submit written applications for support to the Commission. People may be assisted to complete applications by a Coordinator or contracted service provider.  | Face to face assessment by a Needs Assessment Facilitator. [Note: equipment and modifications are accessed through a separate process].  |
| Service coordination  | Coordinators or other Commission staff (if people are not using Coordinators)  | Service Coordinators within NASCs.  |
| Approach to resource allocation  | Most funding is allocated on the basis of need relative to other eligible people. A small amount of support is allocated on the basis of ‘strengths’ and outcomes.  | Funding is allocated on the basis of assessedneed relative to other eligible people.  |
| Funding decisions  | Decisions made by panels of Commission staff for lower cost packages and independent panels for higher cost packages.  | Decisions normally made by Service Coordinators within NASCs. Some high cost packages are referred to the Ministry of Health.  |
| Budget management  | Pre-determined amounts of funding are allocated by panels during 3 – 4 funding rounds each year. There are normally waiting lists for support – some people may wait several years for high cost support.  | NASCs manage an indicative budget, with ongoing decisions being made. Support funded through NASCs does not normally have waiting lists, although they are emerging e.g. for residential services.  |
| Types of support funded  | Funding is allocated in 3 broad categories: • Accommodation Support, which includes community residential services and supported living arrangements. • Individual and Family Support, which includes therapy services, day options, respite and family support. • Local Area Coordination. Home and community services are funded by the Department of Health.  | Funding is allocated through referring people to the following categories of support: • residential care; • home and community support; • supported living; • behavioural support; • respite; • carer support; and lay services (for some people).  |
| Individualised funding/ supported living  | • Wide availability of individualised funding enables supported living to develop. • In most cases, coordinators facilitate individualised funding and supported living.  | • Limited availability of individualised funding, supported by separate coaches. • Supported living is a programme, with separate supported living facilitators (a similar role to Coordinators in WA).  |
| Support providers  | • NGOs - 58% of support by value. • Commission - 42% of support by value.  | NGOs and private organisations - almost 100% of support by value. DHBs - small %.  |
| Some key differences in approach between LAC and NASC  | • A Coordinator’s basic question is “what’s a good life for you?” • Strong focus on government funded support as a last option • Emphasise both individual/ family and community development. • Actively help people to access other agencies and natural support networks • People can choose to use coordinators. • Work across all areas of a person’s life.  | • A NASC’s basic question is “what support do you need?” • Earlier focus on Ministry funded support. • Focus is primarily on the individual/ family. • Refer to other agencies and take account of natural support networks that are already available. • Access to funded support through NASCs • Original intention of a cross-agency mandate not implemented.  |

## Appendix 2 Developing a Commissioning Strategy[[332]](#footnote-332)



## Appendix 3 Mechanisms used to shape Health, Social Care and Disability Services

|  |  |  |
| --- | --- | --- |
| **Victoria, Australia**The National Disability Agreement (2009), a framework for disability services in Australia, clarifies responsibilities of federal, state and local levels of government and specifies shared strategic priorities. The 2006 Victorian Disability Act requires all government departments and prescribed statutory agencies and corporations to develop disability action plans for public services under their remit to increase access for people with disabilities The Victorian State Disability Plan 2002-2010 is a cross-disability plan with the intention of promoting a whole government and community approach to disability services and supports.The Department of Health is responsible for prevention, mental health and drugs, public health, health services including hospitals, community and rural health and aged care The Department of Human Services (DHS) has responsibility for housing; disability services; concessions; children, youth and families (since August 2009). It is divided into 8 administrative regionsAll main disability service areas are funded by both state and common-wealth dollars (except employment supports).  | **Norway**In 1993 a Committee of State Secretaries was set up to work on disability policy.The Ministry of Children and Equality has overall responsibility to co-ordinate disability policy across government departments. There is a government Action Plan 2009-2013 for Universal Design and Improved Accessibility with a goal that by 2025 Norway would be universally designedBoth the health-care and social services systems are based on a decentralised model with the municipalities bound by legislation to deliver services432 municipalities are responsible for primary and community care and are governed by locally elected councils Overall responsibility for health care rests at the national level with the Ministry of Health and Care Services and this serves as the political decision-making body. Norway has long been a highly decentralised health care system but the hospital reforms of 2002 have led to increased centralization of hospital services[[333]](#footnote-333) . While having to remain within the limits of legislation each municipality is free to deliver services in the manner it choosesThe Norwegian health care system is funded primarily from taxes and transfers from central government. The municipalities and counties also have the right to levy taxes. There is no earmarked tax for health care. | **Netherlands**Each of the 13 ministries/govt departments is responsible for disability policySocial and Economic Council submitted a series of service reforms which the govt endorsed in 2008: 1) Introduce protocols, benchmarking and permanent supervision of the assessment process to improve needs assessment 2) separate financing for care and for accommodation 3) accommodation is no longer reimbursed by public insurance 4) replace provider based budgeting by client based budgeting 5) transfer short term rehabilitation to public insurance scheme 6) bring social care under responsibility of municipalities There is one national organisation for needs assessment Healthcare is in the process of being decentralised to private independent health insurers with 32 regional health care insurer officesSince 2006 there is mandatory social insurance for all. There are two types of mandatory insurance for people with disabilities. The AWBZ/Exceptional Medical Expenses Act (2006) for people with disabilities who have long term care needs. WMO Insurance (2007) to fund supports for independent living such as accessible accommodations for houses, mobility devices (scooters, chairlifts, etc) home household help and transportation |
| **New Zealand*** Overall responsibility for the health and disability system rests with the Minister of Health and the Disability Support Services group in the Ministry of Health.

There is a cross governmental disability strategy (2001)There is an Office of Disability Issues to monitor progress on the strategy and in 2009 a Ministerial Committee on Disability Issues was established Disability functions are dispersed across ten Government Departments.Ring-fenced disability budget within Vote: HealthDistrict Health Boards (DHBs) are the local tiers of the New Zealand health-care system and comprise a mixture of locally elected members and centrally appointed members. They hold the budget for primary and secondary health services and community support services and either provide services themselves or purchase from non-government organisations. However, the DHBs are accountable to the MinisterThe funding and admin responsibilities for disability support services for those under 65 is to be devolved to DHBs. There are 15 Needs Assessment Service Coordination (NASC) offices performing a gate-keeping role. While the money follows the person through NASC the actual allocation of funds comes from the Ministry of Health.  | **Scotland** The Cabinet Deputy Minister for Scotland's Department of Health and Wellbeing is responsible for the delivery of all health and care services in Scotland. The Director General Health and Chief Executive of NHS Scotland and the Scottish Health department report into the Minister. Scotland's revised Disability plan (2008-2011) emphasises collaboration between health-boards, local authorities, voluntary bodies, trade unions and employers.Key principles on delivering care to those with long term conditions in Scotland include: focus on self-care; provide care in community settings; pathways of care; partnerships between professionals and individuals and between primary care, social care and other agencies and integrated solutionsScotland had 14 regional NHS boards and 8 special NHS board which dealt with central functions across the 14 regional areas. These boards were responsible for providing and managing primary health services including hospitals and general practice in their regions. In 2004 the NHS trusts were devolved and replaced with Community Health Partnerships. The CHPs provide a focus for the creation of a single integrated system for delivery of primary care, specialist and social care services. There are 40 CHPs mandated to work with 32 local authorities in delivery of these services.  | **England**There is a Minister for people with Disabilities in the Department for Work and Pensions An Office for Disability Issues helps the government to deliver on the commitment made in the report, '[Improving the Life Chances of Disabled People](http://www.cabinetoffice.gov.uk/strategy/work_areas/disability.aspx)' (2005) by working with government departments to develop and improve policy and services for disabled peopleIndependent living and self-directed support are key movements within the English health and social care system There is a movement towards integrating and the personalisation of care services in EnglandThe Local Authority and Primary Care Trusts provide the entry point to health and social care servicesThe English health system -National Health Service (NHS) is a tax based system and is free at point of entry. The NHS is a complex hierarchical system. Strategic Health Authorities (SHA) report directly to the Department of Health and manage/monitor the local NHS bodies such as Primary Care Trusts (PCT) and NHS TrustsThe Minister for Health has responsibility for the Department of Health (DoH)Social care is means tested and disability related benefits are not means tested. |

## Appendix 4 Experience with individualised funding

Experience with individualised funding in the UK and internationally was summarised by the Social Care Institute for Excellence (2007) as follows:

* Most individualised funding schemes share the goals of improving freedom of choice, independence and autonomy and using public funds more efficiently.
* There is emerging international evidence that self-directed care such as that facilitated by individualised funding can lead to health gains and consequent efficiency gains. However, reliable evidence is not yet available on the long-term social care cost implications for individual budget schemes for the UK. Emerging findings from the US suggest that personal budgets in social care may result in savings for health services. For example, the Cash and Counselling programme in the USA was found to have reduced nursing home use by 18 per cent over a three-year period.
* To avoid paying for support that carers would otherwise give for free, "cash and counselling" assessments in the US determines what assistance the individual requires beyond what can reasonably be expected from family caregivers. The individual is then free to spend the budget for the assessed extra support to employ whoever they think is most suitable. A similar approach has been developed under the UK Resource Allocation System. Assessments in the Netherlands also account for ‘available family support’.
* The support infrastructure for brokerage and support[[334]](#footnote-334) has often not been sufficiently well developed.
* When given the right level of support, user views are positive with reports of improved quality of life.
* Older people and people with complex needs may need greater time and support to help them get the most from individual budget schemes, particularly the cash direct payment option.
* Schemes vary to take account of national context, but central government leadership is a vital component.
* Schemes have taken time to embed and need strong local leadership and investment in targeted training and support for frontline staff.[[335]](#footnote-335)

Bigby (2008) in the state of Victoria in Australia also reviewed individualised funding. She found positive outcomes including higher satisfaction and quality of life and more control over decisions with cost-savings of up to 30-40%. Individualised funding involves redefinition of purchase, provider and user relationships. However, research designs have not compared or examined the relative benefits of different forms of funding. Issues arising from individualised forms of funding included administrative burden; complexity of resource allocation; the need to train staff and a lack of knowledge by users and families together with a fear of more responsibility and work.

## Appendix 5 Appeals processes in other jurisdictions

|  |  |  |  |
| --- | --- | --- | --- |
| Jurisdiction | Organisation for needs assessment and/or appeal | Further information | Contact |
| New Zealand | NASC (Needs Assessment and Service Coordination Service) undertake needs assessment. Appeals to NASC, independent advocacy service, Health & Disability Commissioner. | www.ihc.org.nz.Awaiting a response from the Health & Disability Commissioner Office, Disability Initiatives Manager (email 08.06.2010) | hdc@hdc.org.nz |
| Victoria, Australia | Needs assessment can be made by service provider, but in practice the Department of Human Services, Intake and Response Services typically carry out these assessments. Appeals can be brought to the Disability Services Commissioner. | Awaiting a response from the Disability Services Commissioners Office.  | complaints@odsc.vic.gov.au |
| Vermont, USA | Assessment of need is undertaken by Division of Disability and Ageing Services (DDAS) a Designated Agency (DA) or a Specialised Services Agency (SSA). Appeal is by internal review first, then to the Human Services Board for a 'Fair Hearing'. Arbitration and mediation options are available.  | http://www.ddas.vermont.gov/ddas-policies/policies-dds/policies-dds-documents/dds-appeal-procedure-2009 | Chas Moseley at NSDDDS (see email 08.06.2010) |
| England, UK | NHS community care - assessments carried out by social workers/OTs. Appeals to the local authority and if dissatisfied, to the Local Government Ombudsman.Appeals for special educational needs go to Special Educational Needs and Disability Panel.  | http://www.nhs.uk/CarersDirect/guide/assessments/Pages/Overview.aspxhttp://www.lgo.org.uk/ - note this is not needs assessment/disability specificOmbudsman in England, Northern Ireland, Wales & Scotland - first two have completed satisfaction surveys.http://www.lgo.org.uk/about-us/surveys/http://www.lgo.org.uk/guidance-inv | England T.Davey@lgo.org.uk(Walesask@ombudsman-wales.org.uk - awaiting responseNorthern Irelandlinda.argent@ni-ombudsman.org.uk - have satisfaction survey summary) |
| Netherlands  | Needs assessment conducted by Centrum Indicatiestelling Zorg, CIZ. Care can be funded in kind or in the form of a personal budget. The care liaison officer (zorgkantoor) decides on the personal care budget. Redress? | - mostly in Dutch http://www.aquima.com/en/content/customers/care-needs-assessment-centre |  |

1. Note: A background report is available on each of these six jurisdictions. Some aspects of how services and supports are organised in each jurisdiction for people with disabilities can be seen in Appendix 3 of this report. [↑](#footnote-ref-1)
2. Mansell, J (2006) Deinstitutionalisation and community living: progress, problems and priorities. Journal of Intellectual and Developmental Disability, 31 (2), 65-76 [↑](#footnote-ref-2)
3. Parmenter, T.R. & Arnold, S. (2008). Disability Accommodation and Support Framework Report Prepared for the Victorian Department of Human Services. Victoria: Centre for Developmental Disability Studies [↑](#footnote-ref-3)
4. As outlined in diagrammatic form in Appendix 2 and explored in section 4.3. of this report, strategic commissioning is a term used for activities involved in assessing and forecasting needs, agreeing desired outcomes, considering options and planning the nature, range and quality of future services and working in partnership to put these in place: taken from Social Work Inspection Agency, Scotland (SWIA): Guide to strategic commissioning - accessed at http://www.scotland.gov.uk/Publications/2009/09/17112552/2 on May 17th 2010 [↑](#footnote-ref-4)
5. Centre for Developmental Disability Studies (DDS), University of Sydney (2004) Innovative Models of Community Support for people with high and complex support needs. Sydney, N.S.W. Department of Ageing, Disability and Home Care. Accessed at http://www.dadhc.nsw.gov.au/dadhc on 26th August 2010  [↑](#footnote-ref-5)
6. Mansell, J (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_114346 (Accessed 23rd June 2010) [↑](#footnote-ref-6)
7. In the UK, for example, social care law is fragmented and difficult to understand and apply, for both users and service providers. A patchwork of conflicting statutes, enacted over a period of 60 years, do not facilitate good service design. One of the ongoing projects of the Law Commission’s Tenth Programme of Law Reform is to review the law under which residential care, community care and support for carers is provided in England and Wales. The aim is to provide a coherent and effective legal structure, preferably in the form of a single statute, for these services. Service providers and users can then look to this in order to understand whether services can or should be provided, and what kinds of services. See http://www.lawcom.gov.uk/docs/cp192\_summary.pdf [↑](#footnote-ref-7)
8. HM Government (2009) Green Paper: ‘Shaping the Future of Care together’. Norwich: The Stationery Office Limited [↑](#footnote-ref-8)
9. HM Government (2010) White Paper: ‘Building the National Care Service’ Norwich: The Stationery Office Limited [↑](#footnote-ref-9)
10. The Australian Government's Productivity Commission (2010) Issues Paper ‘Disability Care and Support’ accessed at http://www.pc.gov.au/projects/inquiry/disability-support on the 25th June 2010 [↑](#footnote-ref-10)
11. From 1st January 2009, the National Disability Agreement (NDA) replaced the Commonwealth State/Territory Disability Agreement (CSTDA) for the provision of disability services in Australia - accessed at http://www.aihw.gov.au/disability/natpic/ [↑](#footnote-ref-11)
12. Examples include the Australian Government's 2010 Issues Paper on Disability Care and Support mentioned in footnote 5 and the 2009 KPMG report on Contemporary Disability Service Systems for the Department of Human Services, Victoria mentioned in footnote 7. Other reports include the 2009 Consultations Report on the Model of Self-Directed Planning by the Disability Services Division of the Department of Human Services, Victoria; the 2009 Operational Frameworks for Disability Services by the Department of Human Services in Tasmania and the 2009 Funding and Service Options for people with Disabilities in Queensland. [↑](#footnote-ref-12)
13. KPMG for Victorian Department of Human Services (2009) The Contemporary Disability Service System - accessed at http://www.nda.gov.au/cproot/553/2/Contemporary%20Disability%20Service%20System%20Summary%20Report.pdf on January 25th 2010 [↑](#footnote-ref-13)
14. See final section of this report on outcomes [↑](#footnote-ref-14)
15. Department of Health (2001) ‘Valuing People: a new strategy for learning disability for the 21st century’. London: Department of Health. [↑](#footnote-ref-15)
16. Department of Health (2009) ‘Valuing People Now: a three-year strategy for people with learning disabilities’. London: Department of Health. [↑](#footnote-ref-16)
17. Wehman, P., Revell, G., Brooke, V. (2003) Competitive employment: Has it become the first choice yet? Journal of Disability Policy Studies, 14 (3), 163-173. Wehman, P., Revell, WG (2005) An excerpt from expanding the human potential and employment capacity of individuals with mental retardation and developmental disabilities: Implementing system change - accessed at http://www.start-labor.org/filedir/Implementing%20Systems%20Change%20Wehman%20Revell%20excerpt.doc on 10th June 2010 [↑](#footnote-ref-17)
18. ibid [↑](#footnote-ref-18)
19. Councils in England are a unit of local government. The set-up of UK local government can be confusing due to re-organisations in 1973, the 1980s and 1990s. Up until the 1990s there were two tiers of councils outside major urban areas. County councils looked after services including education, social care and transport. District councils catered for services including housing, building regulations, environmental health and local planning. In the 1990s County Councils were abolished and functions transferred to district councils. Smaller districts were merged together. However, while in Scotland and Wales this was done, in England there was a process of local consultation which led to the single tier model being supported and implemented in some places but rejected in others. There are 34 county councils and 238 district councils in the UK with all purpose authorities in London (32 London boroughs) and other metropolitan areas [↑](#footnote-ref-19)
20. Mansell, J (2007) Services for people with learning disabilities and challenging behaviour or mental health needs Department of Health Accessed at http://www.dh.gov.uk/en/Policy and guidance on May 13th 2010 [↑](#footnote-ref-20)
21. See background country report on Norway on the NDA website. [↑](#footnote-ref-21)
22. Mansell, J (2007) Services for people with learning disabilities and challenging behaviour or mental health needs, Department of Health Accessed at http://www.dh.gov.uk/en/Policy and guidance on May 13th 2010 [↑](#footnote-ref-22)
23. Centre for Developmental Disability Studies (DDS), University of Sydney (2004) Innovative Models of Community Support for people with high and complex support needs. [↑](#footnote-ref-23)
24. Mansell, J (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities -accessed at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_114346 on the 23rd June 2010 [↑](#footnote-ref-24)
25. ibid [↑](#footnote-ref-25)
26. ibid [↑](#footnote-ref-26)
27. Townsley, R. Ward, L., Abbott, D., Williams, V. (2010) The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report. This can be accessed at http://www.disability-europe.net/en/themes/Independent%20living?jsEnabled=1 [↑](#footnote-ref-27)
28. ibid [↑](#footnote-ref-28)
29. PricewaterhouseCoopers (2009) Review Out of Home Disability Services Report conducted for the Victorian Department of Human Services (DHS) in Australia [↑](#footnote-ref-29)
30. http://www.moh.govt.nz/moh.nsf/pagesmh/5362/$File/local-area-coordination-paper-mar2010.pdf - accessed May 17th 2010 [↑](#footnote-ref-30)
31. Bonardi, A. (2009) The Balance between Choice and Control: risk management in New Zealand Intellectual Disability Services. Wellington: Ian Axford (New Zealand) - accessible at http://www.fulbright.org.nz/voices/axford/2009\_bonardi.html [↑](#footnote-ref-31)
32. See page 9 on risk aversion, for example, in Bigby, C., Fyffe, C., and Mansell, J. (2006) From Ideology to Reality: Current issues in implementation of intellectual disability policy. Proceedings of the Roundtable on Intellectual Disability Policy. La Trobe University, Victoria, Australia. This can be accessed online at http://www.latrobe.edu.au/socialwork/schoolstaff/attachments/pdf/2006La%20Trobe%20ID%20Policy%20Roundtable%20Bigby%20Fyffe%20Mansell%20(2).pdf [↑](#footnote-ref-32)
33. In a consultation process around the development of a disability service model in Victoria, Australia, service providers and users made some simple recommendations. These included 1) that the language used to explain the model needed to be clarified; 2) that non-technical English and less jargon should be used; 3) and that greater clarity was needed in the definitions of roles, criteria etc associated with the model. Clearly-articulated definitions, concepts and models are needed in good service design. [↑](#footnote-ref-33)
34. LDC Group (2007) Evaluation of the Direct Payments Project Final Report. Department of Human Services, Victoria, Australia as cited by Chenoweth, L., Clements, N. (2009) Funding and service options for people with disabilities, School of Human Services and Social Work, Griffiths University: Queensland, Australia - accessed at http://www.griffith.edu.au/\_\_data/assets/pdf\_file/0020/153425/funding-support-options.pdf on the 25th June 2010 [↑](#footnote-ref-34)
35. Scottish Executive (2006) Joint Improvement Team Conference Report: Improving the Quality of Life for People with intellectual disabilities - Accessed at http://www.scotland.gov.uk/Publications/2006/05/04153635/4 on May 17th 2010 [↑](#footnote-ref-35)
36. Mansell, J (2005) Deinstitutionalisation and community living: an international perspective. Tizard Learning Disability Review, 10 (1), 22-29. [↑](#footnote-ref-36)
37. Mansell, J (2007) Services for people with learning disabilities and challenging behaviour or mental health needs, Department of Health Accessed at http://www.dh.gov.uk/en/Policy and guidance on May 13th 2010 [↑](#footnote-ref-37)
38. See background paper on England for details: these papers are or will be accessible on the NDA website: http://www.nda.ie/ [↑](#footnote-ref-38)
39. Fyson, R., Tarleton, B., Ward, L (2007) Supported living through Supporting People: the experiences of people with learning disabilities. *Housing Care and Support* 10 (3), 35-40 [↑](#footnote-ref-39)
40. Department of Health (2007) Commissioning framework for health and wellbeing. London: Department of Health [↑](#footnote-ref-40)
41. Joint Improvement Team Commissioning strategy for Learning Disability Services accessed at www.jitscotland.org.uk [↑](#footnote-ref-41)
42. http://www.regjeringen.no [↑](#footnote-ref-42)
43. Scottish Government (2010) [Social Care Procurement Scotland: Guidance on procurement of social care for consultation - draft](http://scotland.gov.uk/Publications/2010/01/13125045) Accessible at http://www.scotland.gov.uk/Publications/2010/01/13125045/1 [↑](#footnote-ref-43)
44. http://www.ldascotland.org/index.php?option=com\_content&view=article&id=88:alternatives-to-competitive-tendering&catid=2:making-sure-people-are-consulted&Itemid=10 [↑](#footnote-ref-44)
45. ibid [↑](#footnote-ref-45)
46. Mansell, J (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities -accessed at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\_114346 on the 23rd June 2010 [↑](#footnote-ref-46)
47. Mansell, J (2007) Services for people with learning disabilities and challenging behaviour or mental health needs, Department of Health Accessed at http://www.dh.gov.uk/en/Policy and guidance on May 13th 2010 [↑](#footnote-ref-47)
48. ibid [↑](#footnote-ref-48)
49. Scottish Government (2007) Housing Regeneration and Planning: Supporting People Unit Costs. The Scottish Government Social Research: Edinburgh. Report available at www.scotland.gov.uk/social research [↑](#footnote-ref-49)
50. Scottish Government (2007) Housing Regeneration and Planning: Supporting People Unit Costs. The Scottish Government Social Research: Edinburgh, p.37. [↑](#footnote-ref-50)
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58. ibid [↑](#footnote-ref-58)
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62. Bonardi, A. (2009) The Balance between Choice and Control: risk management in New Zealand Intellectual Disability Services. Wellington: Ian Axford (New Zealand) - accessible at http://www.fulbright.org.nz/voices/axford/2009\_bonardi.html [↑](#footnote-ref-62)
63. The determinants of the costs of disability services including context, service and funding models, procurement, administration and staff costs etc is being undertaken in a separate NDA research project. [↑](#footnote-ref-63)
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65. An analysis of contextual factors that shed light on different policy approaches to service development and change across jurisdictions is beyond the scope of this report. See, however, Matland’s Ambiguity-Conflict Matrix on policy change in Section 4.1. as it illuminates the complexity of service development as outlined in some of the background country papers and alluded to in this report. [↑](#footnote-ref-65)
66. Subsequent and separate investigation underway in the NDA includes 1) collating relevant information on residential and community services for people with intellectual disabilities emanating from the literature as well as site visits, round tables and in-house studies conducted by the NDA. 2) presenting findings on the development of contemporary disability services, and disseminating them through presentations, papers, reports and dialogue/debate in a range of fora including workshops, seminars, conferences and roundtables 3) preparing and presenting a range of papers and reports [↑](#footnote-ref-66)
67. Value for money requires priority setting, resource allocation, financial transparency and accountability and measuring outcomes to show that quality has improved. Achieving value for money is often described in terms of economy - using resources to save expense, time or effort; efficiency - delivering the same level of service for less cost, time or effort and effectiveness - getting better outcomes for the same amount of expense, time or effort (Bartlett, J., 2009, Getting more for less: efficiency in the public sector. Demos: London). Value for Money (VfM) takes into account the mix of quality, cost, resource use, fitness for purpose, timeliness, and convenience in order to judge whether or not, when taken together, a service constitutes value. http://www.admin.cam.ac.uk/offices/secretariat/vfm/guide.html Accessed 27th Jan 2010 [↑](#footnote-ref-67)
68. http://www.dohc.ie/press/releases/2009/20090918.html accessed 27th Jan 2010 [↑](#footnote-ref-68)
69. Comptroller and Auditor General (CAG) Report on Value for Money Examination on the Provision of Disability Services by Non-profit Organisations (2005, p.41) [↑](#footnote-ref-69)
70. Specialist services generally indicate the availability of specialised expertise, that is, particular levels of skill, experience and environmental requirements necessary to manage people with uncommon or complex needs. Because of the specialist nature of particular services and the low volume of activity, specialist services are usually not provided in all local areas. Within the health services in England and Ireland, for example, primary, secondary and tertiary health services refer to services where increasing levels of specialist expertise can be accessed: this expertise ranges from generalised expertise available locally at the primary care level (GPs and primary health centres) to further specialisation at secondary health services level (general/ regional hospitals) to high levels of expertise in national tertiary referral centres (e.g. hospitals specialising in heart, chest, neurosurgery etc). [↑](#footnote-ref-70)
71. Specialist disability services include employment and occupational supports such as day centres and sheltered workshops, 24-hour care support services, special education and centres for rehabilitation... [↑](#footnote-ref-71)
72. An example of this is the ongoing work of the OECD, Eurostat and WHO on definitions of long-term care expenditure etc for comparison of health accounts [↑](#footnote-ref-72)
73. There is no consensus around a definition of what mainstreaming in the disability sector is for example. The principle of mainstreaming is defined as the systematic consideration of the specific needs of people with disabilities when designing social inclusion and social protection policies (accessed at http://ec.europa.eu/social) In wikipedia, accessed at http://en.wikipedia.org/wiki, the definition of mainstreaming, taken from [http://encarta.msn.com/dictionary,](http://encarta.msn.com/dictionary_/mainstreaming.html) defines it as the integration of special students: the practice of educating students with special needs in regular classes during specific time periods based on their skills. Similarly other definitions vary between jurisdictions or depending on contexts. [↑](#footnote-ref-73)
74. National Council on Disability (2010, p.14) The State of Housing in America in the 21st Century: A Disability Perspective Accessed at on 5th May 2010 [↑](#footnote-ref-74)
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77. ibid [↑](#footnote-ref-77)
78. Independent Living can be defined as 'the right of all persons regardless of age, type or extent of disability to: live in the community, as opposed to living in an institution; have the same range of choices as everyone else; participate in the social, economic and political life of their communities; have a family; live as responsible respected members of their communities with all the duties and privileges that this entails, and; unfold their potential' (Ratzka, a well-known international disability activist as cited on the Limerick Centre for Independent Living (Ireland) website: <http://www.limerickcil.com> accessed on 26th April 2010. Another definition clarifies what Independent Living is not: "Independent Living is not doing things by yourself. It is being in control of how things are done". (Heuman as cited at the Mayo Centre for Independent Living (Ireland) website: http://homepage.eircom.net/~andyh/cil/cilmayo1.htm Accessed 26th April 2010) [↑](#footnote-ref-78)
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http://www.griffith.edu.au/\_\_data/assets/pdf\_file/0020/153425/funding-support-options.pdf. [↑](#footnote-ref-89)
90. While one may mistakenly think that terms such as ‘consumer-controlled’, ‘self-determination’, ‘personalisation’ are about individualism, in fact, such services require community networks, partnership and coordination to facilitate choice, control and community participation. [↑](#footnote-ref-90)
91. Amado, A (2008) Innovative Models and Best Practices in Case Management and Support Coordination. Accessed 6th May at http://www.ici.umn.edu/products/prb/191/default.html [↑](#footnote-ref-91)
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101. A similar arrangement is seen in the Disability Liaison Officers in the former North Western Health Board in Ireland now the HSE Western Region (?). [↑](#footnote-ref-101)
102. Citizens Information Board Advocacy Guidelines (revised edition 2007, p.5) http://www.citizensinformationboard.ie/publications/advocacy/advocacy\_index.html

Accessed 4th February 2010 [↑](#footnote-ref-102)
103. ibid, p.7 [↑](#footnote-ref-103)
104. ibid, p.10 [↑](#footnote-ref-104)
105. http://www.fastuk.org/about/definitionofat.php Accessed 9th April 2010 [↑](#footnote-ref-105)
106. http://searchcio-midmarket.techtarget.com/sDefinition/0,,sid183\_gci928405,00.html Accessed 25th June 2010 [↑](#footnote-ref-106)
107. http://www.ictforumforscotland.org [↑](#footnote-ref-107)
108. Accessed at http://www.medialt.no/news/en-US/universally-designed-norway-by-2025/609.aspx on the 19th April 2010 [↑](#footnote-ref-108)
109. The target is that 80% of devices will be delivered within 3 weeks from acceptance of applications. The remaining 20% of devices do not have this 3-week goal because of special adaptations which require more time. [↑](#footnote-ref-109)
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115. Heywood & Turner (2007) [↑](#footnote-ref-115)
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123. **See, for example, Agosta, J., Kimmich, M., Fortune, J., Melda, K., Smith, D. (2009) Information Brief: Overview of Rationale and Process for Developing Individual or Level-Based Budget Allocations. Available at http://www.sageresources.org or Fortune, J., Agosta, J., Smith, D. (2009) Ten Issues to Consider When Implementing Individual or Level-Based Budget Allocations. NASDDDS Annual Conference in Alexandria, Virginia Available at http://www.sageresources.org (Accessed Sept 15th, 2010)**  [↑](#footnote-ref-123)
124. The Australian Government's Productivity Commission Issues Paper (2010) ‘Disability Care and Support’ -accessed at http://www.pc.gov.au/projects/inquiry/disability-support on the 25th June 2010 [↑](#footnote-ref-124)
125. ibid [↑](#footnote-ref-125)
126. Information on the SIS is available on [www.siswebsite.org](http://www.siswebsite.org). [↑](#footnote-ref-126)
127. Bossaert G., Kuppens S., Buntinx W., Molleman C., Van den Abeele A., & Maes B. (2009). Usefulness of the Supports Intensity Scale (SIS) for persons with other than intellectual disabilities. *Research in Developmental Disabilities*, 30, 1306–1316. [↑](#footnote-ref-127)
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129. Local Government & Public Involvement in Health Act 2007 s.116 Took effect in England from April 2008. The Secretary of State for Health has the power to direct the preparation of further Joint Strategic Needs Assessments. [↑](#footnote-ref-129)
130. Taken from http://www.moh.govt.nz/moh.nsf/pagesmh/5362/$File/local-area-coordination-paper-mar2010.pdf Accessed May 17th 2010 [↑](#footnote-ref-130)
131. In Canada virtually every province has some form of IF underway particularly in the areas of supports to people with intellectual or physical disabilities. In Alberta IF has been in place since the mid 1980s and in 1990 it became the official way for service delivery (Chenoweth and Clements, 2009). [↑](#footnote-ref-131)
132. Taken from http://www.moh.govt.nz/moh.nsf/pagesmh/2957/$File/IndividualisedFunding.pdf [↑](#footnote-ref-132)
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160. Partners can decide to withdraw from the arrangement [↑](#footnote-ref-160)
161. Appleton, S (2009) Integration and learning disability: A briefing paper for the Integrated Care Network. http://www.dhcarenetworks.org.uk/\_library/Resources/ICN/ICN\_advice/ICN\_FINAL\_Integration\_and\_learning\_disability2.pdf Accessed on 26th August 2010 [↑](#footnote-ref-161)
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173. ibid [↑](#footnote-ref-173)
174. The determinants of the costs of disability services including context, service and funding models, procurement, administration and staff costs etc is being undertaken in a separate NDA research project. [↑](#footnote-ref-174)
175. It is of note, for example, that in England, since April 2009, local authorities and their partners have a legal duty to secure value for money through combining economy, efficiency and effectiveness. Outcomes include16 statutory priorities and 30 indicators and these are to be measured through a reporting system called Comprehensive Area Agreements (CAA) as stated by Bartlett, J (2009) *Getting more for less: efficiency in the public sector*. Demos: London. [↑](#footnote-ref-175)
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177. Alam, K., Robb, W (2009) Issues of Economic Efficiency of Human Service Delivery in Australia *International Review of Business Research Papers*, 5 (2), 52-61. [↑](#footnote-ref-177)
178. Segal L, Chen Y. (2001) Priority setting for health. A critique of alternative models. Report to the Population Health Division, Department of Health and Aged Care . Accessible at http://www.buseco.monash.edu.au/centres/che/che-publications.html [↑](#footnote-ref-178)
179. Bartlett, J (2009, p.25) Getting more for less: efficiency in the public sector. Demos: London [↑](#footnote-ref-179)
180. Victorian Auditor-General (2008) Accommodation for people with a disability Melbourne: Author. [↑](#footnote-ref-180)
181. Smith, G., Fortune, J (2008) The Supports Intensity Scale and Resource Allocation in Resource Allocation and the Supports Intensity Scale™: Four Papers on Issues and Approaches Eds Schalock, RL., Thompson, JR and Tassé, MJ (2008) AIDD, Washington. [↑](#footnote-ref-181)
182. KPMG (2006) Pricing Principles for Disability Services Sector [↑](#footnote-ref-182)
183. ibid [↑](#footnote-ref-183)
184. Unit price is the price per unit paid by the government agency to service provider. Unit cost is the cost per unit incurred by a service provider in delivering the service. The unit cost may not be the same as the unit price. The government may think that the unit cost is not the efficient cost and fund the agency at a lower level or alternatively the agency may recover some of its costs through service user changes or other funding sources such as private sector and philanthropic organisations (KPMG, 2006). [↑](#footnote-ref-184)
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187. Australian Institute of Health and Welfare 2002, ‘Unmet need for disability services: effectiveness of funding and remaining shortfalls’, Disability Data Briefing*,* no. 22*. Accessible at* <http://www.aihw.gov.au/publications/index.cfm/title/7741> [↑](#footnote-ref-187)
188. ibid [↑](#footnote-ref-188)
189. See, for example, Lynch, R., Altenburg-van den Broek, E. (2010) The drawbacks of Dutch-style health care rules: Lessons for Americans. The Heritage Foundation: Washington DC Accessible at http://www.heritage.org/Research/Reports [↑](#footnote-ref-189)
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191. O’Brien, J. (1995, Winter). Issues and challenges in developing individualized supports. In Individualized services in New York State (Policy Bulletin No. 4). Accessed June 25th 2010 from Syracuse University, Center on Human Policy Web site: <http://thechp.syr.edu/bullnys.htm>. [↑](#footnote-ref-191)
192. Audit Scotland (2004) Commissioning Community Care Services for older people. Accessible at http://www.audit-scotland.gov.uk/publications/pdf/2004 [↑](#footnote-ref-192)
193. Care Equation, in collaboration with Oxford Consultants for Social Inclusion (OCSI,) are piloting the Planning4care commissioning tool for older people to adult mental health and learning disability in England in six pilot areas. The team is building on the [Planning4care Older People](http://www.care-equation.co.uk/needs.htm#proj07-01#proj07-01) tool, which built the model around a clearly defined needs classification, linking this to locally adjusted prevalence data and to typical service figurations and cost, and estimating current and future levels of need and resource requirements (http://www.care-equation.co.uk/needs.htm). [↑](#footnote-ref-193)
194. Population needs assessment is carried out to plan services for populations/ territories and to allocate resources at national, regional and local level. In England population needs assessment/ analysis has been defined as the systematic review of health, wellbeing, and housing-related support issues facing a population resulting in a gap analysis and agreed commissioning priorities to improve outcomes and reduce inequalities over a period, usually between three and five years Accessed at http://www.communities.gov.uk/documents/housing/doc/needsanalysisresource on 20th April 2010 [↑](#footnote-ref-194)
195. http://www.sa.gov.au/upload/franchise/Community%20Support/Disability/Information%20sheets%20-%20Disability%20SA/Disability%20SA%20provision%20of%20disability%20services%20in%20south%20australia%202008%202009%20-%20Word.doc [↑](#footnote-ref-195)
196. Mansell, J (2006, p.9-10) Aims, context and obstacles to achieving better lives for people with intellectual disabilities in Eds Bigby, C., Fyffe, C., and Mansell, J. (2006) From Ideology to Reality: Current issues in implementation of intellectual disability policy. Proceedings of the Roundtable on Intellectual Disability Policy. La Trobe University, Victoria, Australia [↑](#footnote-ref-196)
197. ibid [↑](#footnote-ref-197)
198. ibid [↑](#footnote-ref-198)
199. http://www.communities.gov.uk/documents/housing/doc/needsanalysisresource - based on Whoriskey, M., Reid, (2007) A Commissioning Strategy for Learning Disability Services Capacity for Change Programme accessed at http://www.achp.scot.nhs.uk/Documents/April2007ConfLandSupp/ and also at www.jitscotland.org.uk [↑](#footnote-ref-199)
200. ibid [↑](#footnote-ref-200)
201. http://www.ccpanel.org.uk/content/PCT-procurement-guide-for-health-services.pdf [↑](#footnote-ref-201)
202. Menezes, FM (2010) Submission to the review of the funding arrangements for pathology services. Accessed at http://health.gov.au/internet/main/publishing.nsf/Content/MBRT-Pathology-submissions [↑](#footnote-ref-202)
203. ibid [↑](#footnote-ref-203)
204. Article 21 of the Directive states that only certain specific rules of the Directive are applicable to such social services. In particular, technical specifications have to be drawn up at the beginning of the procurement process and the outcome of the procurement process has to be published. Furthermore, the basic principles of Community law, have to be respected for the award of contracts for social services with cross boarder interest. [↑](#footnote-ref-204)
205. Scottish Government (2010) [Social Care Procurement Scotland: Guidance on procurement of social care for consultation - draft](http://scotland.gov.uk/Publications/2010/01/13125045) Accessible at http://www.scotland.gov.uk/Publications/2010/01/13125045/1 [↑](#footnote-ref-205)
206. http://www.ccpscotland.org/policy/tendering-and-procurement [↑](#footnote-ref-206)
207. ibid [↑](#footnote-ref-207)
208. http://www.ldascotland.org/index.php?option=com\_content&view=article&id=88:alternatives-to-competitive-tendering&catid=2:making-sure-people-are-consulted&Itemid=10 [↑](#footnote-ref-208)
209. Competitive Dialogue was introduced by Article 29 (1) of EU Directive 2004/18/EC to complement the existing open, restricted and negotiated procedures used by contracting authorities. [↑](#footnote-ref-209)
210. http://www.eipa.eu/files/repository/eipascope/20100114121857\_Eipascope\_2009\_2\_Article2.pdf [↑](#footnote-ref-210)
211. http://www.primo-europe.eu/2010/06/competitive-dialogue [↑](#footnote-ref-211)
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214. http://www.eipa.eu/files/repository/eipascope/20100114121857\_Eipascope\_2009\_2\_Article2.pdf [↑](#footnote-ref-214)
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224. ibid [↑](#footnote-ref-224)
225. McEvoy, R., Keenaghan, C., Murray, A (2008) Service user involvement in the Irish Health Service: A review of the evidence [↑](#footnote-ref-225)
226. Munday, B. (2007): Report on user involvement in personal social services for the Council of Europe (Accessed Feb 12rh 2010 at http://www.coe.int/t/dg3/socialpolicies/socialrights/source/ISSrepMunday\_en.doc) [↑](#footnote-ref-226)
227. Key country informants for the country report on the Netherlands, Jacqueline Schoonheim and Jose Smits, consider that in the Netherlands there could be more involvement from people with disabilities. It is Schoonheim’s opinion that the country needs a strong disability rights movement and that insufficient government resources are given to user-led or advocacy organisations. Smits considers that the current coalition for inclusion organised by care providers and disability organisations could be further developed to represent the issues of people with disabilities. [↑](#footnote-ref-227)
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236. Flynn (1980, 1999), Wolfensberger and Glenn (1969) and Wolfensberger and Thomas (1983) as cited by Jackson (2007) in Australia demonstrate that institutions provide low-quality accommodation, are inappropriate for meeting human needs and do harm when analysed systematically. [↑](#footnote-ref-236)
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244. Accessed 1st July 2010 at http://www.scotland.gov.uk/Publications/2010/04/27111958/5 [↑](#footnote-ref-244)
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257. See, for example, a series of reports from the National Council on Disability on various aspects of liveable communities including Liveable Communities for adults with Disabilities (2006) and Inclusive Liveable Communities for people with Psychiatric Disabilities (2008). These are accessible at [↑](#footnote-ref-257)
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262. ibid [↑](#footnote-ref-262)
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264. Scotts, M., Saville-Smith, K., & James, B. (2007). International trends in accessible housing foe people with disabilities: A selected review of policies and programmes in Europe, North America, United Kingdom, Japan and Australia. Centre for Housing Research Aotearoa New Zealand. [↑](#footnote-ref-264)
265. The Norwegian Government consider that an adequate dwelling should, as a minimum, satisfy the individual's fundamental needs with regard to safeguarding health and life, personal hygiene and rest. It recognises that legal and financial components must be incorporated into the definition of adequate and secure housing and that predictable, and stable financial frameworks and systems reduce the risks for households. [↑](#footnote-ref-265)
266. http://www.regjeringen.no/upload/KRD/Vedlegg/BOBY/internasjonalt/on\_housing\_policy\_summary\_in\_english.pdf Accessed 25th March 2010 [↑](#footnote-ref-266)
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268. Mansell J and Beadle-Brown J (2008) Dispersed or clustered housing for disabled adults: a systematic review. Canterbury: Tizard Centre. Copies of the report are available from the National Disability Authority, 25 Clyde Road, Dublin 4, Ireland. [↑](#footnote-ref-268)
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273. Examples of definitions include: 1) "Supportive housing is a combination of housing and services intended as a cost-effective way to help people live more stable, productive lives accessible at http://www.[en.wikipedia.org/wiki/](http://www.google.ie/url?q=http://en.wikipedia.org/wiki/Supported_housing&sa=X&ei=dWpqTNzsDpbKjAfP-5iIAQ&ved=0CAQQpAMoAA&usg=AFQjCNET-MJD_pz4C9ZGBvQrog3weNYpzg) 2) "Homes in which vulnerable residents are offered a range of housing related support services to enable them to live independently" accessible at http://www.[mayor.london.gov.uk/london-plan-eip/docs/glossary.rtf](http://www.google.ie/url?q=http://mayor.london.gov.uk/london-plan-eip/docs/glossary.rtf&sa=X&ei=dWpqTNzsDpbKjAfP-5iIAQ&ved=0CAUQpAMoAQ&usg=AFQjCNEGcbxgjNHDl1WLD5Azcq6xvi2Lyw) [↑](#footnote-ref-273)
274. Purpose-designed supported housing are buildings that are purpose designed or remodelled to enable residents to adjust to independent living or to enable them to live independently and which require specific design features. There must be support services provided by the landlord or another organisation. At a minimum, a building or scheme must have basic facilities including a laundry for residents or washing machines in living units provided by the landlord. There must also be a communal lounge. The entrance area into the building, communal areas and some living units must be designed to wheelchair user standards. Designated Supported Housing are buildings with some or no special design facilities and features but that are designated for a specific client group with support services in place to enable them to adjust to independent living or to enable them to live independently. Accessed at http://www.housingcorp.gov.uk/upload/pdf/circular0304.pdf [↑](#footnote-ref-274)
275. "Is Supported Housing a concept that can be adequately defined? This challenge has been inherited by the Tenants Service Authority in England.... The Corporation and now the TSA have been clear that they have no role in regulating support or care services, even where they are being provided by a Housing Association to its own tenants. Although the focus has been on property and other landlord activities, a number of questions have still remained unanswered. These include: Does the term Supported Housing refer only to developments that were treated as such for capital (and historically – pre 2003 - for revenue) funding purposes? If funding drives the definition, is this confined to Housing Corporation (now Homes and Communities Agency) grants, or are other public funding (eg Health Service) sources relevant? Alternatively, should the definition be driven by the needs of the tenants for whom the scheme was originally intended? What happens if individuals who no longer have support needs are still living in properties that have been designated as Supported Housing? Conversely, what happens where tenants are getting support, but live either in General Needs housing or ordinary housing that has been re-designated for supported use say, as move-on accommodation? How should schemes transferred from a local authority, or owned by a local authority but managed by an Arms Length Management Organisation, be regulated? Phil Saunders of SITRA considering definitions, concepts and standards at http://www.sitra.org/1076 [↑](#footnote-ref-275)
276. VCOSS (2008) Submission to the inquiry into the provision of supported accommodation for Victorians with a disability or mental illness [↑](#footnote-ref-276)
277. Fyffe, C., McCubbery, J., Bigby, C. (2008) Learning from the evaluation of the disability services accommodation innovation grants: developing and coordinating housing and support for people with disabilities. [↑](#footnote-ref-277)
278. The Government has invested over £8.7bn since the programme began in 2003; and announced a further £4.9bn funding up to 31 March 2011.  It is the biggest single source of Government revenue funding for the Third Sector - over £1 billion per year. From April 2009, for the first time, Supporting People has been allocated to councils as a non-ring-fenced named grant, paid separately to, but with the same financial flexibility as, Area Based Grants. This removal of the ring fence provides councils with the opportunity to come up with new and innovative ways to support vulnerable people in a range of different situations. See http://www.communities.gov.uk/housing/supportandadaptations/supportingpeople. Accessed 25th March 2010.

See http://www.spkweb.org.uk Accessed 25th March 2010. [↑](#footnote-ref-278)
279. See http://www.spkweb.org.uk Accessed 25th March 2010. [↑](#footnote-ref-279)
280. While what is meant by supported living services and housing related support has not been clearly defined, services and support were based on legal tenancies and tenants were supposed to have keys to their properties, control over who entered their homes, and support staff were not to have offices on the premises. Different authorities chose a variety of ways of operationalising their definition but each had one thing in common: to ensure that the cost of individual support packages was limited using 4 common means of limiting costs in Fyson, R., Tarleton, B. and Ward, L (2007) Supported living through Supporting People: the experiences of people with learning disabilities. Housing Care and Support - Pavilion Journals [↑](#footnote-ref-280)
281. ibid [↑](#footnote-ref-281)
282. ibid [↑](#footnote-ref-282)
283. ibid [↑](#footnote-ref-283)
284. Beadle-Brown J, Mansell J, Whelton R, Hutchinson A and Skidmore C (2005) Too far to go? People with learning disabilities placed out-of-area. Canterbury: Tizard Centre. [↑](#footnote-ref-284)
285. For example, 10.6 million people with disabilities in the US (Dec ‘07), and 2.64 million in Great Britain (Aug ’07) were unemployed: 35% of men and 28% of women with a disability aged 16-64 years employed in the US in Oct ‘08 compared to 79% of men and 69% of women without a disability. In the UK the employment rate of people of working-age (16-60 years for women and 16-65 years for men) with a long-term disability was 51% compared with 80% for those without disabilities in the three months prior to September 2008 as cited by Boeltzig et al, 2009. According to Norway's Labour Force Survey (Statistics Norway, ‘08) 52% of people aged 15-66 years with disabilities (n=288,000) were not in the labour force; 45% were (n=251,000) while 3% (16,000) were unemployed. [↑](#footnote-ref-285)
286. OECD (2003) Transforming Disability into Ability: Policies to promote work and income security for disabled people. Paris: OECD as cited by the National Disability Authority (2009) in US practices with regard to providing supports in sheltered or integrated work settings for people with disabilities. Paper available at http://www.nda.ie [↑](#footnote-ref-286)
287. In the EU there have been directives (European Union Law) on non discrimination legislation adopted by the Council of Europe which obliges member states to introduce legislation or amend legislation. Australia has disability specific anti-discrimination laws and sectoral disability laws that cover employment and a national plan of action on disability but doesn’t have comprehensive disability law. New Zealand has neither comprehensive disability law or specific anti-discrimination laws nor does it have an employment quota scheme, New Zealand has a national plan of action on disability UN: ESCAP (2009 ) Disability at a Glance 2009: a Profile of 36 Countries and Areas in Asia and the Pacific. Available at http://www.unescap.org (Accessed Sept 15th 2010) [↑](#footnote-ref-287)
288. In some of the countries under study quota schemes had been introduced e.g. the Netherlands had a quota scheme for both public and private sectors but later abandoned this in favour of targets. Quota schemes can generally be divided into three kinds 1) binding quota backed up with an enforced sanction, 2) binding quota not backed up with an effective sanction and/or with an effective enforcing mechanism or 3) a non-binding quota based on a recommendation such as a government circular (International Labour Office, 2004). [↑](#footnote-ref-288)
289. OECD (2009) Fostering diversity in the public service: Public governance and territorial development directorate. Paris: OECD - accessed at http://www.oecd.org/dataoecd/46/57/44212841.pdf on February 21st 2010 [↑](#footnote-ref-289)
290. Sheltered workshops are an alternative to working in the open labour market for people with disabilities. Work is often the main focus but work has different meanings from occupational therapy to sources of income. Concerns over sheltered workshops include working conditions; lack of self-determination; limited transition to open employment and non-compliance with international standards (Migliore, 2009). The NDA (2009) state that sheltered workshops are typically defined as segregated work settings where most employees have a disability and where the business is owned and operated by a service provider. Though EU Directives protect the awarding of contracts specifically to these facilities in Europe and US legislation permits the payment of a ‘commensurate wage’ based on productivity levels, the use of segregated settings conflict with the principles of normalisation and integration embedded in legislation, policy and good practice (NDA, 2009). [↑](#footnote-ref-290)
291. Supported employment provides assistance such as job coaches, transportation, assistive technology, specialised job training and individually tailored supervision. “Supported Employment is a systematic approach that provides flexible support to enable people with disabilities or other disadvantaged groups to secure and maintain paid employment in the open labour market. This definition is concurrent with the European Union of Supported Employment definition.” Many countries have some model, albeit limited, of supported employment services for people who have limited access to the labour market. Supported employment was developed in North America in the 1970's to assist people with significant intellectual disabilities to access ordinary employment. Over time, supported employment has been found to work for different groups of people that have difficulty entering the labour market. Supported employment is evolving from a model of “training and placing” people in work to one of “place and train” (Scottish government/COSLA, 2009 Accessed at <http://www.cosla.gov.uk>, 21st Feb 2010). [↑](#footnote-ref-291)
292. Open Society Institute (2006) The Rights of People with Intellectual Disabilities, Access to Education and Employment, The Netherlands. New York: Open Society Institute. [↑](#footnote-ref-292)
293. Aasnaess, S (2007) New strategy to integrate disabled people into employment Accessed 21st Feb 20101 at http://www.eurofound.europa.eu/ewco/2006/10/NO0610029I.htm; and Spjelkavik, Ø., Frøyland, K. and Evans M., (2004) [Supported employment in Norway – A national mainstream programme (KF)](http://www.afi-wri.no/stream_file.asp?iEntityId=896), Work Research Institute’s Occasional Papers, No. 6/04, Oslo, 2004. Accessed at http://www.eurofound.europa.eu/ewco/2006/10/NO0610029I.htm [↑](#footnote-ref-293)
294. Sivertsen, E.R. (2009) NAV (Norwegian Labour and Welfare Service) Cited from Background Country Paper and information emanated from personal correspondence between author background paper on Norway in October 2009. [↑](#footnote-ref-294)
295. Department of Human Services, 2008, Annual Report 2007 - 2008; http://www.dhs.vic.gov.au/\_\_data/assets/pdf\_file/0010/273952/DHS-Annual-Report-2007-08.pdf [↑](#footnote-ref-295)
296. Australian Institute of Health and Welfare, 2008, National data on services provided under the Commonwealth State/Territory Disability Agreement; http://www.aihw.gov.au/publications/dis/dss06-07/dss06-07.pdf [↑](#footnote-ref-296)
297. http://www.workplace.gov.au/NR/rdonlyres/37EBCE3B-A06A-4D57-B5AC-DEA754770BAC/0/Future\_of\_DES.pdf Accessed January 21st 2010 [↑](#footnote-ref-297)
298. Ruth Dyson, 2008, Day service funding change to benefit disabled people http://www.beehive.govt.nz/release/day+service+funding+change+benefit+disabled+people [↑](#footnote-ref-298)
299. For example the supported employment umbrella body ASENZ lists eight supported employment agencies for people with disabilities in Dunedin, which has a population of 122000 [↑](#footnote-ref-299)
300. ASENZ (Association of Supported Employment New Zealand), 2004, Member Survey shows that agencies contract with MoSD on a price per outcome basis, which was $NZ 3,252 in 2004 on average. http://www.asenz.org.nz/resources/MemberSurveyResult.doc [↑](#footnote-ref-300)
301. Ruth Dyson, 2007, Disabled people to receive equal employment rights http://www.beehive.govt.nz/node/28729 [↑](#footnote-ref-301)
302. In 1998 programmes were introduced for lone parents (voluntary), young people,18 to 24 years (mandatory) and people 25 years and over (mandatory) in 1998. In 2000 programmes for people 50 + years, musicians and for partners of recipients of jobseeker's allowance, income support, incapacity benefit, severe disablement allowance and carers allowance. In 2001 the New Deal for Disabled People began. [↑](#footnote-ref-302)
303. Stafford, B., Kellard, K. (2007) Reforming the public sector: personalised activation services in the UK in Making it personal, Individualising activation services in the EU, Eds Rik van Berkel and Ben Valkenburg Policy Press Bristol [↑](#footnote-ref-303)
304. Kelleher, J., Youll, P., Nelson, A., Hadjivassiliou, K., Lyons, C. and Hills, J. (2002) Delivering a Work-focused Service Final findings from ONE case studies and staff research, DWP Research Report No. 166, Leeds: CDS as cited by Stafford and Kellard (2007) - see footnote above [↑](#footnote-ref-304)
305. Ridley, J and Hunter, S. June (2005) ‘Go for it!! Supporting people with learning disabilities and/or autistic spectrum disorder in employment’ Scottish Executive. [↑](#footnote-ref-305)
306. The Scottish Government (2010) Supported Employment Scoping Exercise: Final Report - accessed at http://www.scotland.gov.uk/Publications/2010/02/23093735/10 on 25th June 2010 [↑](#footnote-ref-306)
307. The Scottish Government (2010) The Supported Employment Framework for Scotland - accessible at <http://www.scotland.gov.uk/Publications/2010/02/23093849/0> [↑](#footnote-ref-307)
308. Social Firms: Key Issues Study Number 4 by RIPFA (Research in Practice For Adults Department, a national research utilisation organisation for adult social care and part of the Dartington Trust) - accessed at http://www.cspda.org/articles/downloads/ripfa\_keyissues\_04.pdf on 17th May 2010 [↑](#footnote-ref-308)
309. Harding R (2008) Social Entrepreneurship in the UK, Delta Economics cited in Social Firms - see previous footnote [↑](#footnote-ref-309)
310. A 2005 EU study suggested that there were 8000 social firms in the EU employing 80000 workers, 30000 with disabilities. Italy had the greatest number of firms, followed by Germany with 500 social firms employing 16500 people of whom 50% had disabilities. The size of the German and Italian social firm movements is enabled by Government support. Social Firms UK argue for a waiver of PAYE and NI for any company that employs more than 25% people with disabilities. (Taken from Social Firms as cited in previous footnote) [↑](#footnote-ref-310)
311. Social farming is sometimes knows as care farming or green care. [↑](#footnote-ref-311)
312. Hassink J, Zwartbol Ch, Agricola H, Elings M and Thissen J. 2007. Current status and potential of care farms in the Netherlands. Wageningen Journal of Life Sciences NJAS 55(1) [↑](#footnote-ref-312)
313. Canada also has this type of framework although this was not a jurisdiction studied in this research. [↑](#footnote-ref-313)
314. These roles are broadly similar to previously established statutory rights enforcement roles such as protection and advocacy (P&A) and client assistance program (CAP) agents in the U.S. [↑](#footnote-ref-314)
315. This section is based on the outcomes report. The full 30 page report is available on the NDA website: http://www.nda.ie [↑](#footnote-ref-315)
316. Either from the six jurisdictions reviewed in the NDA project or from the longer list covered in the various literature reviews identified, and discussed in section 1.2 below. [↑](#footnote-ref-316)
317. http://www.disability-europe.net/ [↑](#footnote-ref-317)
318. Mansell, J., Knapp, M., Beadle-Brown, J. , Beecham, J. (2007). *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volumes 1 - 3* Available from:

http://www.kent.ac.uk/tizard/research/DECL\_network/Project\_reports.html (accessed 22nd July 2009).

Mansell et al (2007) [↑](#footnote-ref-318)
319. This overview was carried outby Hurstfield et al of SQW Consulting: Hurstfield et al, 2007. *The Costs and Benefits of Independent Living*. Office for Disability Issues

http://www.odi.gov.uk/research/knowledge/independent-living.php (accessed August 2009) [↑](#footnote-ref-319)
320. ibid, p.49 [↑](#footnote-ref-320)
321. Hurstfield et al, 2007, p45-49, The Costs and Benefits of Independent Living. Office for Disability Issues

http://www.odi.gov.uk/research/knowledge/independent-living.php (accessed August 2009) [↑](#footnote-ref-321)
322. It should be noted that these levels differ from those proposed and used in this report (see page 3 of Outcomes Report on http://www.nda.ie for details [↑](#footnote-ref-322)
323. Townsley et al (2010) shows that the Academic Network of European Disability Experts (ANED) has reached a similar conclusion with regard to outcomes data and research to the previous three reviews. [↑](#footnote-ref-323)
324. http://www.cqc.org.uk [↑](#footnote-ref-324)
325. http://www.PSSRU.ac.uk [↑](#footnote-ref-325)
326. http://www.communityplanningaberdeen.org.uk/SOAPerformance/SOAPerformance.asp [↑](#footnote-ref-326)
327. KPMG for the Victorian Department of Human Services (2009, p.6-7) The Contemporary Disability Service System. http://www.nda.gov.au/cproot/553/2/Contemporary%20Disability%20Service%20System%20Summary%20Report.pdf (Accessed January 25th 2010) [↑](#footnote-ref-327)
328. See Appendix 4 for more details on the development of the NCI. [↑](#footnote-ref-328)
329. Twelve states participated in Phase II. Four additional states joined during the following year and seven states joined in 2001 Virginia, Nebraska, Iowa, Minnesota, Montana, and Utah are currently on hiatus. South Dakota, South Carolina, and Maine signed on in 2002. Arkansas, Georgia, New Mexico, and Texas joined in 2005. Over the next two years, New Jersey, Louisiana and New York joined and Missouri rejoined. Since last year’s report, Ohio and New Hampshire have joined and Illinois has rejoined thus bringing the total to 30 participating states plus Orange County, CA. [↑](#footnote-ref-329)
330. Taken from http://www.moh.govt.nz/moh.nsf/pagesmh/5362/$File/local-area-coordination-paper-mar2010.pdf Accessed May 17th 2010 [↑](#footnote-ref-330)
331. Taken from http://www.moh.govt.nz/moh.nsf/pagesmh/5362/$File/local-area-coordination-paper-mar2010.pdf Accessed May 17th 2010 [↑](#footnote-ref-331)
332. Whoriskey, M., Reid, (2007) A Commissioning Strategy for Learning Disability Services Capacity for Change Programme accessible at http://www.achp.scot.nhs.uk/Documents/April2007ConfLandSupp/ and also at www.jitscotland.org.uk [↑](#footnote-ref-332)
333. The hospital reforms of 2002 took away county ownership of hospitals and four Regional Health Enterprises are now responsible for secondary care and effectively act as holding companies for regional hospitals. Within these regional health authorities, the public-sector specialist health services is organised into 32 health enterprises. Responsibility for public-sector dental care and some speech and language therapy lies at county level. [↑](#footnote-ref-333)
334. Support is required 1) to access the scheme 2) to manage money 3) to budget and account 4) to access the required services employing and managing staff (SCIE Briefing 20) [↑](#footnote-ref-334)
335. SCIE Briefing 20, 2007, updated March 2009. Accessed 17th February 2010 at http://www.scie.org.uk/publications/briefings/briefing20/index.asp [↑](#footnote-ref-335)