

# **A Review of International Outcome Measures in Disability Service Provision**

## **A Contemporary Developments in Disability Services Paper**

**This report is one of a suite of reports on independent living produced by the National Disability Authority during 2009 - 2010. The purpose of these reports is to inform discussion with regard to possible reconfiguration of health and personal social care services for people with disabilities in Ireland.**

**Date: October 2010**



# Evidence regarding Outcomes of Service Configurations for Independent Living

Developing meaningful outcome measures and indicators of performance is a challenge for all countries...

(P)erformance measures and initiatives need to be better aligned with overarching outcomes and high-level societal goals in order for the general public to understand the benefits of the Public Service.

(OECD 2008:13)

## Introduction

This report is one of a suite of reports on independent living produced by the National Disability Authority during 2009 - 2010. The purpose of these reports is to inform discussion with regard to possible reconfiguration of health and personal social care services for people with disabilities in Ireland. The first set of reports provided detailed overviews of the service configurations in six selected jurisdictions which were considered to provide models of good practice<sup>1</sup>. This report examines the topic of outcomes for the people with disabilities who are using health and social care services in those (and other) jurisdictions. It is based on available literature and government data, mainly in the English language.

The report concludes that the outcomes knowledge base is underdeveloped in all jurisdictions. It also identifies four emerging models of outcomes measurement which are recommended as useful for the development of an independent living system in Ireland. 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.

It is important to distinguish between outputs and outcomes, as these two concepts are sometimes conflated. Outputs have been defined as data or research findings on what has been done in the context of particular policies, services and programmes. Outcomes have been defined as data or research findings on the long term changes which have occurred in the lives of people with disabilities as a result of these policies, services and programmes (such as in people's participation rates in social and economic life, their income levels and quality of life). Researching outcomes is the most meaningful way to evaluate the benefits or otherwise of state policies, including those in the field of disability. Good outcome evaluations also contribute to assessing the value-for-money achieved, when costs are added to the analysis.

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<sup>1</sup> England, Netherlands, New Zealand, Norway, Scotland, Victoria

Of necessity, this outcomes report is constrained by the limitations in the current international and national knowledge bases, as discussed in this report. To summarise, 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 and the reports available are few, though increasing.

For these reasons it has not been possible to identify a full configuration of services in a single jurisdiction<sup>2</sup> 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.

Furthermore, the European Union is currently investigating this area as it develops its disability policies. The EU funded network ANED<sup>3</sup> 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.

## **1. The Knowledge Base**

### **1.1 Measuring outcomes**

The National Economic and Social Forum (2009)<sup>4</sup>, recommended that Ireland adopt an outcomes-oriented approach to policy development and implementation. It argued that this involves six factors, including:

- Strategy plans for the policy's implementation, which would contain agreed outcomes;
- Measurement of policy inputs (such as finance and staff), outputs (such as the number of services provided) and outcomes (such as long term benefits for an individual) which is used to feed into regular monitoring and periodic evaluation of the policy
- Links between the outcomes produced and the budget allocated.

(NESF, 2009: 9-19)

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<sup>2</sup> 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.

<sup>3</sup> <http://www.disability-europe.net/>

<sup>4</sup> Using the OECD report (2008) on the Irish public sector.

Three levels of outcome research, evaluation and measurement with regard to independent living have been identified for this report. These are:

**Societal level:** comprising national research and data, which provide an insight into the general outcomes for people with disabilities, of the full range of public policies and services (both mainstream and specialised) along with the societal context pertaining in each jurisdiction under consideration;

**Disability system level:** comprising national research and data, which focus on the specific national or regional configuration of disability health and social care services and their outcomes for the lives of people with disabilities;

**Service level:** comprising research and data relating to individual services or policies and their outcomes in the lives of people with disabilities.<sup>5</sup>

For the purposes of this investigation it is the disability system level research and data which has been found to be of most relevance. It is also the level which has received the least attention. However, in three of the jurisdictions (England, Scotland and Victoria) new initiatives with respect to performance monitoring of independent living policies and services now include explicit outcome indicators against which data is gathered, analysed and reported on a regular basis<sup>6</sup>. These provide useful examples for Irish policy makers and are further discussed in section 2 below, along with a longer standing example from the United States.

## 1.2 Overviews of the knowledge base

During this research, four overviews of the outcomes knowledge base in relation to national configurations of independent living services across a broad range of jurisdictions, were identified and examined (Hurstfield et al, 2007; KPMG, 2009; Mansell, 2007; Townsley, 2010). These will be discussed in order of date of publication, beginning with the oldest and moving to the most recent.

Firstly, Mansell et al (2007) in their report for the EU *Deinstitutionalisation and community living - outcomes and costs*, 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. They called on the EU to develop a harmonised data set at EU level, which would include data on outcomes.

With regard to outcomes data within the overall data set Mansell et al stated:

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<sup>5</sup> It will be noted that similar methods of differentiation have been given in other overviews of the outcomes knowledge base. They differ slightly from the one used in this report in the levels of analysis identified. The levels outlined above are deemed most appropriate for the purposes of this NDA exercise.

<sup>6</sup> The publication on websites of detailed and up-to-date results of these exercises is also a good practice which empowers people with disabilities and their families in making choices.

"Usually it is relevant to consider a range of outcome dimensions: not just symptoms (for people with mental health needs) or personal independence (for people with intellectual disabilities) for example, but also whether a changing care system improves an individual's ability to function (for example to get back to work or to build social networks) and their broader quality of life. It is generally the case that spending more on the support of disabled people will lead to better outcomes, but the relationship is not simple and decision makers may need to think carefully (and together with disabled people) about which outcomes they wish to prioritise within the care system." (2007:8)

Secondly, another overview was published in 2007 by the UK Office for Disability Issues. This was a review of selected documents (from eight countries and two international organisations), entitled *The Costs and Benefits of Independent Living*<sup>7</sup>, which was carried out by Hurstfield et al of SQW Consulting. The researchers conducted a literature search (both national and international) along agreed lines of inquiry and then identified and analysed the core set of 110 documents, which comprised:

- academic articles (40 documents),
- government funded research (14),
- independent research (43)
- others, including grey literature (13).

Research from the UK formed the bulk of the literature (85 documents) but studies from the USA (11), Australia (5) and the EU (4) were also included, as were one each from Canada, Ireland, Norway, the OECD and Sweden.

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 the 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."  
(Hurstfield et al, 2007:49)

To rectify this inadequacy of the knowledge base, the UK 2008 Independent Living strategy placed a strong emphasis on continuous monitoring, evaluation and data collection. The Hurstfield report provided an important resource for this new evidence based approach since it contained discussions

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<sup>7</sup> Independent living has been defined as the right of all persons regardless of age, type or extent of disability to live in the community; to have the same range or choices as everybody else in housing, transportation, education and employment; to participate in the social, economic and political life of their own communities; to have a family; to live as responsible respected members of their communities with all the duties and privileges that this entails, and to unfold their potential (Adolf Ratzka).

on methodological options for improved data collection and research (2007:45 - 49). Some suggested ways to achieve improvements included:

- shifting from the dominant attitude, which regarded independent living interventions as primarily relating to welfare, towards taking an investment perspective on such interventions;
- refining methodological approaches to researching quality of life and health status;
- taking a dynamic, long term view which would include examining possible outcomes, such as reduced reliance on health and social care services, better take up of employment opportunities and fuller participation in social and cultural activities.

Within the limits outlined above, the Hurstfield report identified some important findings from existing literature with regard to outcomes of independent living and other forms of support/services for people with disabilities up to 2007 (2007:30 - 37). The report distinguished three levels at which outcomes can be evaluated: the individual level, the service level and the societal level<sup>8</sup>. It found that, at individual level, there was substantial evidence in the literature that independent living produces significantly more benefits than 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 (8 - 9).

Some of the outcomes oriented patterns which were identified 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
- Challenges which still remained, such as the perceived burden of managing independent living for people with disabilities, especially older people, along with a lack of suitable and trained care workers and personal assistants.

Thirdly, 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

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<sup>8</sup> It should be noted that these levels differ from those proposed and used in this report (see page 3 for details).

of robust evaluation of existing policies and programmes for disability services in Australia and internationally' (2009:5).

Fourthly, and most recently, 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. This very recent 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. 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 next two sections consider the knowledge base with regard to subjective and objective outcomes respectively, based on the four overviews discussed above, along with literature and data identified with regard to the six jurisdictions covered in the NDA reviews.

### **1.3 Subjective outcomes: satisfaction with services; quality of life; perceived happiness; independence and control**

The UK literature review *'The Costs and Benefits of Independent Living'* which was discussed in section 1.2 above, provided some conclusions and examples in relation to subjective outcomes (Hurstfield et al, 2007). It argued that there was some research literature, though not in the form of large scale national evaluations of service configurations, which supported the argument that independent living increases quality of life as well as physical and emotional health status. The indicators used in the studies which were cited included perceived happiness, personal independence and control.

But Hurstfield et al also pointed out that the findings to date are limited and partial. Having made this caveat, they then indicated the need for a nuanced approach to independent living planning and policy, which recognises differences among different groups of people with disabilities. Quality of life improvements from aspects of independent living policies and projects were reported for some but not all groups of disabled people. For example, one UK study found that older people were less positive than younger people in relation to independent budgets (Glendinning et al, 2008: 63 -87)

The six country level literature searches for this project confirmed that the knowledge base with regard to subjective outcomes at national level of the six configurations of health and personal social care services is weak across the jurisdictions. In two, Norway and the Netherlands, no research or data in this area was identified. In New Zealand, insight can be gleaned from the report of the 2008 Parliamentary Inquiry<sup>9</sup>.

In their submissions to the New Zealand Inquiry, people with disabilities and their families identified the following problems with the current configuration and quality of service provision:

- lack of control over services
- inflexible funding
- a need to separate the needs assessment processes from service provision
- lack of focus on quality of life
- limited input into service provision by staff/people with disabilities/families
- poor HRM, and staffing problems at the front line
- insufficient dedicated advocacy services.

In addressing some of these issues, and working to improve satisfaction with services, a model called Local Area Coordination (LAC- which was developed in Western Australia in the 1980s) has been adopted by several Australian states as well as New Zealand and Scotland. This model has been comprehensively evaluated in a number of jurisdictions and it has consistently been found to improve satisfaction with services. (Bartnik, 2007; Government of Western Australia, 2003; New Zealand Parliament, 2008; Stalker et al, 2007). It is, therefore, worth considering further, for use in the Irish context.<sup>10</sup>

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<sup>9</sup> New Zealand also produces regular Social Reports with excellent data on indicators such as social connectedness, loneliness, trust etc. However, while these are disaggregated by some socio demographic characteristics such as age, gender and ethnicity, they are not disaggregated by disability. Reports contain a section on people with disabilities which includes some data on participation in education and employment and also on income. But they do not report on any of the Quality of Life indicators with regard to people with disabilities

<sup>10</sup> To summarise, local area coordination first emerged in response to long standing difficulties meeting the needs of people with learning disabilities and their families living in remote areas in Western Australia. Due to a lack of service infrastructure locally, individuals had to leave their families and communities to move into residential homes in cities many miles away. LAC aimed to change this situation by supporting people to remain in their own communities. It is characterised by the introduction of a fixed point of accountability to individuals with disabilities and to families caring for a family member with a disability. The approach has been described as generalist or eclectic, because it contains elements of case management, personal advocacy, family support, community development and direct consumer funding.

Since the aim of LAC is to make disability services and supports more personal, local and accountable, and to support local people with disabilities and their families in their local communities, the service is deliberately kept fluid to respond to the changing needs of the clients. Under this system, local area coordinators assist people with disabilities to plan, organise and access supports and services which enhance their participation in, and contribution to, their local community. The coordinators provide support that is personalised,



These limited findings on subjective outcomes, revealed in the literature, can be supplemented by the conclusions of a comprehensive HSE review of the evidence with regard to community-based models of care for people with intellectual disabilities, compared with the institutions they replace. This review covered more than the six jurisdictions considered for this report and generally shows a relatively clear picture.

The review concluded that many studies have shown community-based services to be superior to institutions. Key findings were that:

- Community living offers the prospect of an improved lifestyle and quality of life over institutional care for people with intellectual disabilities.
- This applies to old and new institutions, whatever they are called.
- Community living is no more expensive than institutional care once the comparison is made on the basis of comparable needs and comparable quality of care.
- Successful community living requires close attention to the way services are set up and run, especially to the quality of staff support.
- Dispersed housing in the community delivers a better quality of life than clustered housing for people with disabilities.

However, the review emphasised that shifting from institutional to community-based models of care is not simply a case of replacing one set of buildings with another. Successful community-based services need to be carefully planned around the needs and wishes of individual people and then continually monitored and adjusted as people's needs and wishes change. Much evaluative research and comment emphasises the risk that community-based services fail to provide sufficiently skilled help for people with complex needs such as profound intellectual and multiple disabilities, challenging behaviour or mental health problems (HSE 2010, forthcoming).

## **1.4 Objective outcomes: income levels and social participation**

In all six jurisdictions reviewed by the NDA, which have more developed systems of independent living, the gaps in income levels between disabled and non disabled people remain significant and, where such data is available, participation rates in education, employment, vocational training and social life, are shown to be lower for disabled people, as compared to non disabled people. All jurisdictions have some data on participation by disabled people in

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flexible and responsive. They work with family members and others involved in supporting people with disabilities so that they are strengthened and supported in their caring role. They also work with people with disabilities and their families/carers to make local communities more inclusive and welcoming through education, advocacy and development of partnerships with local community members and organisations, government agencies and businesses.

education and employment. However, only some have similar data on vocational training and social life. This leads to the conclusion that independent living initiatives need to be augmented by other targeted disability policies in key areas such as employment and education, if participation by people with disabilities is to be increased.

## **INCOME LEVELS AND RISK OF POVERTY**

In all six jurisdictions, income levels remain lower for disabled people as compared to non disabled people and are strongly linked to their different employment patterns. People with disabilities are at greater risk of poverty than non disabled people in all six jurisdictions. The statistics/data available for the various jurisdictions are not directly comparable but the patterns are similar. The following are some examples:

- In the UK, figures from 2004-07 show that disabled adults are more likely to live in persistent poverty than non disabled adults. Figures from 2004-07, excluding housing costs, state that 11% of disabled adults were living in persistent poverty compared to 5% of non disabled adults. After housing costs, 10% of disabled adults were living in persistent poverty, compared to 6% of non disabled adults.<sup>11</sup>
- In the Netherlands, a 2007 report on the disabled showed that in 2003 the average gross annual income of 18 - 64 year olds without disabilities was EUR 35,500, while for people with moderate or severe disabilities it was EUR 21,800 (DeKlerk, 2007, summary).
- New Zealand figures relate to disabled and non disabled people in employment. They state that in 2006, about 50% of disabled people in employment had a total annual income of \$30,000 or less, compared with 40% of non disabled people in employment. In addition adults with disabilities were more likely than non disabled adults to rely on state benefits. (New Zealand Ministry of Health, 2004)
- For Victoria, the Australian Bureau of Statistics reported that in 2003 for those aged between 15 and 64 the median gross personal income per week was \$274 for those with a reported disability and \$501 for those with no reported disability<sup>12</sup>
- Norway reported that disabled people aged 18 - 66 have a mean income of about 75% that of the total population in that age group. (Tøssebro, 2009)

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<sup>11</sup> British Household Panel Survey, cited in ODI Disability Equality Indicators <http://www.officefordisability.gov.uk/docs/res/annual-report/indicators/c5.pdf> (accessed 16 March 2010)

<sup>12</sup>AUSSTATS.<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02003?OpenDocument> (accessed 22 October 2009)

## SOCIAL PARTICIPATION

In all six jurisdictions significant gaps remain between the levels of participation by disabled and non disabled people in all those areas of life examined, for which data is available. The following list provides illustrations of the data/statistics identified. These show that while deinstitutionalisation and independent living are likely to help to reduce these gaps, they do not do so alone. Their impact is likely to be significant only as part of a more comprehensive strategy of change in areas such as attitudes, accessibility, transformation of mainstream services etc

### Examples of Education Data

- In New Zealand, adults with disability were more likely than adults without disability to have no educational qualifications and adults with disability were less likely than adults without disability to have a post-school qualification<sup>13</sup>.
- In Norway, significant differences with regard to education remain between disabled and non disabled people. The ANED country report for Norway states that the proportion of disabled people with higher education (more than 12 years) is lower than among non-disabled people (23% compared to 37%). The difference is constant through the age span from 20-66 years of age. It is also constant across gender and between people becoming disabled before or after the age of 30. The last finding suggests that it is not just that disabled people have less education, but also that people with lower levels of education have a higher risk of becoming disabled in later life. (Tøssebro, 2009)

### Examples of Employment Data

- In the Netherlands it was reported that the percentage of people with disabilities who were employed had decreased from 44% in 2002 to 39% in 2005, while employment for non disabled persons had remained stable at 68%. Among the current 156.000 Wajong recipients, 9% had a regular job and some 17% had a job in sheltered employment (Greve, 2009).
- In New Zealand, 57 % of people aged 15-64 with disability living in households were employed, as compared to 71% of those without disability in the same age group.<sup>14</sup>

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<sup>13</sup> Statistics New Zealand, Office for Disability Issues (2008) Disability and Education in New Zealand in 2006 <http://www.stats.govt.nz/> (accessed 4 November 2009)

<sup>14</sup> Statistics New Zealand, Office for Disability Issues (2008) Disability and the Labour Market in New Zealand in 2006 <http://www.stats.govt.nz/> (accessed 4 November 2009)

- By contrast, in England some closing of the employment gap is reported between 1998 and 2007: the employment rate of the working age disabled population rose from 38.1% to 47.2%, and the gap between the employment rate of disabled people and the overall employment rate is 26.5%, which fell from 35% in the same period<sup>15</sup>
- In Norway the employment rate among disabled people was 45.3% in the second quarter of 2008, the same level as in the previous year. In the whole population aged 15-66 years, 77.3% were employed. The difference in the employment rate between the population as a whole and the disabled population was 11 percentage points among people aged 15-24 years. In older groups the difference was much larger, near 35 percentage points. Among the eldest aged 60-66 years, however, the difference was reduced to 25 percentage points).<sup>16</sup> Part time employment is more common among disabled people. In 2007, 48.3% of the employed disabled people worked part time, compared to 26.6% of all employed. 30% of the employed disabled people worked less than 20 hours per week. A rough calculation suggests that about 15% of all employed disabled people are in some kind of sheltered or supported employment (Greve, 2009).
- In New Zealand in 2006, close to one in every six people of working age (aged 15 years and over) had a disability (17%). This translates to 539,000 people, of whom less than half (45%) were in the labour force, compared with over three-quarters (77%) of non-disabled people of working age. The labour force includes people who are employed, and those who are unemployed and actively seeking work. People with disabilities consistently recorded lower rates of labour force participation than those without disabilities over the 10-year period 1996–2006. (Statistics New Zealand, 2008a).
- In Victoria the main occupation for people with disabilities is as intermediate clerical, sales and services workers. The unemployment rate of people with disabilities is higher than the rate of people without disabilities. The participation rate of people with disabilities is much lower than the rate for people without disabilities. These two phenomena are exacerbated for women with disabilities.<sup>17</sup>

### **Examples of Data on Training and on Social and Cultural Participation**

Data is lacking in the area of training and of participation in social and cultural life. Where it exists it shows a continuing gap in participation rates, although some improvements are also reported.

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<sup>15</sup> <http://www.officefordisability.gov.uk/research/facts-and-figures.php#em> (accessed 23 September 2009).

<sup>16</sup> ANED (2009) Country Report: Norway. Leeds: University of Leeds

<sup>17</sup> <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02003?OpenDocument> (accessed 16 November 2009)

- For example, according to the Australian Bureau of Statistics, people with moderate core activity limitation have the lower participation rate in social and cultural life among people with disabilities.<sup>18</sup>
- In the Netherlands 13% of people with severe disabilities visit a museum at least once a year, compared with 38% of people without disabilities. The differences between people with and without disabilities remained unchanged between 1995 and 2003. (De Klerk, 2007)

## 2. Outcomes measurement: good practice models

### 2.1 Societal level research and data

With regard to individual jurisdictions, Norway has some of the most comprehensive recent, research based, disability data sets for the societal level and provides an example of using national and EU statistics for this purpose. However, as with most national disability statistics, the findings which are available relate not just to people with disabilities using health and personal care services, but to all persons with disabilities. They do not, therefore, provide a focussed evaluation of the outcomes of service configurations.

The societal level findings are available through national studies conducted by Statistics Norway, and from EU comparative studies. Such data sets are strong in the areas of recent comparative (between disabled and non disabled people) participation rates in education and employment along with comparative income levels. But there seem also to be major gaps as no data has been identified in the following key areas: data with regard to satisfaction levels for independent living services; for quality of life of disabled people using these services; and for their participation in social and cultural life, and in training.

There are also good major sources of data on some societal level outcomes from Statistics New Zealand but they have similar limitations to those from Norway. There is also a further problem of timeliness as some of the reports are based on dated data, that from 2001 disability surveys, while others are based on the 2006 surveys<sup>19</sup>. This means they are reflecting the outcomes of older systems rather than the current configurations of services.

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<sup>18</sup> <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02003?OpenDocument> (accessed 16 November 2009)

<sup>19</sup> In 2001, Statistics New Zealand conducted two national disability surveys:

- The Household Disability Survey examined the day-to-day living arrangements and activity restrictions of 7,256 adults and children with disability living in households.

A more recent comprehensive source for New Zealand, was based on the parliamentary inquiry which reported in 2008 (Parliament of New Zealand, 2008, see also page 6 of this paper). The Inquiry received 150 submissions from organisations and individuals as well as advice from government ministries and input by an independent disability expert. It showed significant dissatisfaction with disability services and with the implementation of the government's disability strategy, although support remained high for the content of the strategy. The Inquiry argued for a more targeted and evaluative approach with a stronger emphasis on quality of life.

## **2.2 Disability systems level research and data**

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. Each will be discussed, and references for further information are provided.

Four good practice models are outlined: England, Scotland, Victoria and USA (which has a longer standing and more fully developed system)

### **2.2.1 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

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- The Disability Survey of Residential Facilities gathered a smaller set of information from 928 adults with disability living in institutions such as homes for older people and hospitals.

A 2004 report entitled "Living with Disability in New Zealand" comprehensively described the results from the two surveys, covering all the main themes and issues which they had examined.

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

Taking one of these as an example i.e. subjective outcome "No.2 Improved Quality of Life" : the outcome aimed for is described as follows:

"People who use service, and their carers, enjoy the best possible quality of life. Support is given at an early stage, and helps people to stay independent. Families are supported so that children do not have to take on inappropriate caring roles. Carers are able to balance caring with a life of their own. People feel safe when they are supported at home, in care homes and in the neighbourhood. They are able to have a social life and to use leisure, learning and other local services."

(NHS, 2009:11)

The system outcome performance of the local authority is then summarised as:

1. Performing poorly
2. Performing adequately
3. Performing well
4. Performing excellently

Then each of these is explained. For example, under "performing excellently" the outcome is described as follows:

"Skilled teams support people who use services and their carers in their family and social life. They are flexible and can adapt supports as needs and preferences change."

(2009:11)

The first reports by individual local authorities were released in 2009 and are accessible on the Web<sup>20</sup>. It can be assumed that eventually combined reports will be produced which provide an overall national picture.

At the service level, within local authority areas, performance of individual home care services, registered by each local authority, is inspected and

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<sup>20</sup> <http://www.nhs.ic.uk/> (accessed 24 August 2009)

reported by the Quality Care Commission .<sup>21</sup> 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. The outcomes are stated to be as follows:

"High quality care should:

- be safe
- have the right outcomes, including clinical outcomes
- be a good experience for the people that use it
- help prevent illness and promote healthy, independent living
- be available to those who need it when they need it."

To take one example, user focussed services, these are defined as follows:

"People are confident that the agency can support them. This is because there is an accurate needs assessment, which they, or someone close to them, have been involved in. This tells the agency all about them and the support they need and is carried out before they are offered a personal domiciliary care service.

People and their relatives can decide whether the agency can meet their support needs. This is because they, or someone close to them, have got full, clear, accurate and up to date information about the agency. People know that the agency can meet their needs because the staff have the skills and experience to give them the care they need. If they decide to use the agency, they know about their rights and responsibilities because there is an easy to understand contract or statement of terms and conditions between them and the agency that includes how much they will pay and what the agency provides for their money. People are confident that the agency handles information about them appropriately. This is because the agency follows their policies and procedures. They get a consistent and flexible care service from reliable and dependable staff members."

The full inspection reports were available, for 5,650 services.<sup>22</sup> This system was discontinued on 30 June 2010.<sup>23</sup>

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 (Forder et al, 2008).<sup>24</sup>

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<sup>21</sup> <http://www.cqc.org.uk> (accessed 20 May 2010)

<sup>22</sup> <http://www.cqc.org.uk> (accessed 19 May 2010).

<sup>23</sup> <http://www.cqc.org.uk/registered-services-directory/rsquicksearch.asp> (accessed 22 September 2010)

<sup>24</sup> <http://www.PSSRU.ac.uk> (accessed 19 May 2010)



## 2.2.2 Scotland

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.<sup>25</sup>)

Taking Aberdeen City Council as an example, it outlined the SOA as follows:

### "Single Outcome Agreement - Performance

The [Single Outcome Agreement 2009-10](#) lays down a series of local priorities for action in the context of the Scottish Government's national aspirations – and spells out how the city council and its community planning partners will work together to meet agreed targets.

The commitments made in the SOA represent a shared direction for all the partner organisations, based on the Concordat between the Scottish Government and community planning partners. The document aims to stimulate even closer co-operation to make services more effective and deliver ever-improving results for the citizens of Aberdeen.

Targets and timescales are laid down under a range of themes, including the economy, education, health, housing, children and young people at risk, crime and disorder, sustainability, the environment, sport and culture, and public services."

The following is the list of 15 agreed national outcomes for Scotland. A summary of how Aberdeen reported on Outcome 7 which relates to tackling inequalities is given in Appendix 1 of this report.

<b>National Outcome</b>	<b>Description</b>
<a href="#">National Outcome 1</a>	<b>We live in a Scotland that is the most attractive place for doing business in Europe</b>
<a href="#">National Outcome 2</a>	<b>We realise our full economic potential with more and better employment opportunities for our people</b>
<a href="#">National Outcome 3</a>	<b>We are better educated, more skilled and more successful, renowned for our research and innovation</b>
<a href="#">National</a>	<b>Our young people are successful learners, confident</b>

<sup>25</sup> <http://www.communityplanningaberdeen.org.uk/SOAPerformance/SOAPerformance.asp> (accessed 3 December 2009)

<a href="#">Outcome 4</a>	<b>individuals, effective contributors and responsible citizens</b>
<a href="#">National Outcome 5</a>	<b>Our children have the best start in life and are ready to succeed</b>
<a href="#">National Outcome 6</a>	<b>We live longer, healthier lives</b>
<a href="#">National Outcome 7</a>	<b>We have tackled the significant inequalities in Scottish society</b>
<a href="#">National Outcome 8</a>	<b>We have improved the life chances of children and young people and families at risk</b>
<a href="#">National Outcome 9</a>	<b>We live our lives free from Crime, Disorder and Danger</b>
<a href="#">National Outcome 10</a>	<b>We live in well-designed, sustainable places where we are able to access the amenities and services we need</b>
<a href="#">National Outcome 11</a>	<b>We have strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others</b>
<a href="#">National Outcome 12</a>	<b>We value and enjoy our built and natural environment and enhance it for future generations</b>
<a href="#">National Outcome 13</a>	<b>We take pride in a strong, fair and inclusive national identity</b>
<a href="#">National Outcome 14</a>	<b>We reduce the local and global environmental impact of our consumption and production</b>
<a href="#">National Outcome 15</a>	<b>Our public services are high quality, continually improving, efficient and responsive to local people's needs</b>

### 2.2.3 Victoria

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 that used in 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. (2009:6-7).

The first service system outcome in the list relates to data collection and analysis and states that "services are...informed by robust research and evaluation". The table in Appendix 2 gives the example of one of these outcomes and its related indicators. This new system is at an earlier stage than those in England and Scotland so information on the content of the outcomes standards has been accessed, but no reporting has yet been published.

Independent monitoring of agency performance against the Standards for Disability Services in Victoria was trialled in 2008–09, in the Barwon-South

Western Region of the state. Depending on the findings of the independent evaluation, independent monitoring is anticipated to be implemented from 2009–2012. These findings have not yet been published and cannot yet be made available (email query, May 2010).<sup>26</sup>

#### 2.2.4 United States

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.<sup>27</sup> Participation in NCI is voluntary. At the last count thirty states were participating.<sup>28</sup> For a complete list of NCI states, visit [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org).<sup>29</sup>

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. So for example, in the 2007-8 annual report, data on 24 States is included. Comparative evaluations through time are also made. See appendix 3 for an example of one indicator and details of the consumer surveys conducted for the project. These National Core Indicators Consumer Surveys collect information directly from individuals with developmental disabilities and their families or advocates. The survey questionnaire is designed to measure over half of the original 60 core indicators. Many of the questions used in the survey were drawn from survey instruments already in use in the field; other questions were developed specifically for NCI. NCI staff routinely test and refine the instrument based on feedback from interviewers.

The consumer survey instrument is composed of a pre-survey form, two sections, and an interviewer feedback form. The pre-survey form collects information necessary to schedule face-to-face interviews, including contact information for consumers, and the names of guardians, advocates, or other individuals who might be asked to provide responses. The background information section requests data that would most likely be found in agency records or information systems. Section 1 of the questionnaire, which contains questions aimed at obtaining expressions of satisfaction and opinions from

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<sup>26</sup> <http://www.dhs.vic.gov.au/about-the-department/annual-reports/year-in-revi> ; [http://www.dhs.vic.gov.au/\\_\\_data/assets/pdf\\_file/0004/375430/Annual-Report-2008-09-Full.pdf](http://www.dhs.vic.gov.au/__data/assets/pdf_file/0004/375430/Annual-Report-2008-09-Full.pdf) (accessed 17 February 2010)

<sup>27</sup> See Appendix 4 for more details on the development of the NCI.

<sup>28</sup> 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. More recently, Ohio and New Hampshire have joined and Illinois has rejoined thus bringing the total to 30 participating states plus Orange County, CA.

<sup>29</sup> <http://www2.hsri.org/nci/index.asp?id=about>, accessed 27 May 2010

each individual, may be completed only through a direct interview with the individual; proxy responses are not acceptable. Section 2 questions are to be answered by the individual if possible. If the person is unable to respond, an advocate is asked to answer. The last page of the questionnaire is the Interviewer Feedback Sheet. Surveyors are asked to record the length of the interview with the individual and describe any problematic questions.

All persons selected in the survey sample are given an opportunity to respond to questions in a face-to-face interview. There is no pre-screening procedure. Exclusion of responses is done at the time of data analysis, based on specific criteria. A person's responses are excluded if:

1. the consumer responded to less than half of the questions in Section I.
2. the interviewer recorded that the person did not understand the questions being asked.
3. the interviewer recorded that the person gave inconsistent responses.

Each state is asked to conduct a random sample of individuals over age 18 who are receiving at least one service, besides case management. The goal of each state was to conduct a minimum of 400 interviews. Most states draw an over-sample to account for refusals. Some states may not complete 400 interviews, and others may exceed this goal. A sample size of 400 allows valid comparisons across states with a 95% confidence level. Those that did not complete 400 are also included in the report; however, readers are cautioned to take sample sizes into consideration.

In the NCI, not only has a core indicator set been developed and used as outlined above, but also three scales have also been created by amalgamating groups of related indicators. These scales are titled and defined as follows:

**a. Community Inclusion:**

"People have support to participate in everyday community activities"

**b. Life Decisions and Everyday choices**

" People make choices about their lives and are actively engaged in planning their services and supports"

**c. Relationships**

" People have friends and relationships".

Reporting across time and space is then also done for the three scales.

### **3. Conclusion**

The following observations are made based on the outcomes review:

In any reconfiguration of health and personal social care services in Ireland it will be 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, more detailed consideration when more information is released into the public domain, along with those used in England, Scotland and the USA which have been outlined in this paper. It would be useful to undertake some cross-walking of the four systems to identify commonalities. As has been done in these jurisdictions, outcomes and their indicators in Ireland should be developed in close consultation with people with disabilities and their organisations.

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. These differences and complexities merit further investigation which should be informed by the NDA work already carried out in relation to person-centred planning<sup>30</sup>.

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<sup>30</sup> Person centred planning is a way of discovering how a person wants to live their life and what is required to make that possible. It 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. Person centred planning can require some very fundamental changes in thinking, established balances of power, systems of provision, the implications of which are potentially enormous and far reaching. In order to be effective, it is important that person centred planning be adopted 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 may be found helpful in this regard. The NDA believes that the best measure of the success of person centred planning is that the individual at the centre of the planning process

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## **Appendix 1: Scottish outcome measurement (example Aberdeen)**

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Reporting on outcome 7 (2009), which includes some disability dimensions

### **"NO07 - We have tackled the significant inequalities in Scottish society**

The Community Planning Conference held in December 2007 identified regeneration and improving the quality of life in our most deprived areas as a strategic priority that impacts on this outcome.

A part of supporting actions to tackle poverty and deprivation, following the establishment of the Fairer Scotland Fund by the Scottish Government, the Aberdeen City Alliance established its Fairer Scotland Fund Board, involving a cross section of partner representatives to review previous programmes and determine the best use of the Fund in the future.

Following this, programmes of work targeted towards need, and aimed at achieving accelerated impact for the city's most deprived communities, have been development based on the following themes:-

- Employment and Training – focused on employability issues, skills gap and Linking Opportunities And Need by providing services supporting those furthest from the job market to take up employment opportunities.
- Income and Financial Inclusion – improving access to financial services such as credit unions; improving welfare benefits, debt and other advice services, delivery of financial education initiatives and tackling income inequalities.
- Health – Reducing health inequalities, mental health and wellbeing and substance misuse.
- Education – improving adult literacy and numeracy and supporting community based learning, culture and arts activities.
- Community Safety – aimed at supporting communities to be safer and stronger.

On this latter point, Grampian Police continue to work closely with the City Council to make best use of the City Wardens. Grampian Police provide daily briefings and tasks to the City Wardens, operate joint police/warden patrols where appropriate and have ensured that the Wardens are able to feed in any intelligence that they gather on crime and antisocial behaviour to police intelligence systems. Also as part of the "Community Focus" Force Priority, Grampian Police are committed to delivering accountable policing which meets the specific needs of the 37 Neighbourhoods with Aberdeen City.

With changes in housing policy, action is also being taken to deliver new council houses for the city as part of tackling homelessness and contributing to improved provision of social housing for the future.

Tackling the significant inequalities that exist in the city has also included the following activity in relation to disadvantaged groups and individuals.

The Equalities Action Network operates as a small, strategic group reporting to The Aberdeen City Alliance (TACA) on progress towards mainstreaming equalities across Community Planning. Several of the partners within TACA have moved, or are moving, towards a Single Equality Scheme to provide an integrated and coherent framework around the legal duties. We continue to work with partners on the equalities agenda, for example, in organising an Equalities Fortnight for mid-November 2009 to raise awareness and involve our employees, partners and citizens in promoting equality and diversity. A drop-in surgery on Equality Impact Assessments is planned as part of the fortnight, which will also see the launch of Aberdeen City Council's Single Equality Scheme. Within the Scheme will sit individual Council Services' Equality Action Plans, shaped and informed by the needs of and issues around their particular service users, identified through community consultation March - August 2009.

In relation to transport activity, the City Council continues to work with partners such as NESTRANS, Aberdeenshire Council, Transport Scotland, NHS Grampian, Emergency Services, Bus Operators as well as many others to implement the range of activities and actions detailed in the respective Local, Regional and National Transport Strategies that will enable us to meet our collective objectives. Progress on the delivery of the Local Transport Strategy and Regional Transport Strategy is demonstrated in the recent monitoring reports to be found at the following web links:

- [http://www.aberdeencity.gov.uk/Planning/sl\\_pla/pla\\_transportstrategy.asp](http://www.aberdeencity.gov.uk/Planning/sl_pla/pla_transportstrategy.asp) (accessed 17 February 2010)
- [http://www.nestrans.org.uk/docs\\_info/docs\\_info.asp?doc\\_cat\\_id=11](http://www.nestrans.org.uk/docs_info/docs_info.asp?doc_cat_id=11) (accessed 17 February 2010) "

## Appendix 2: Victoria

### VICTORIA: AN EXAMPLE OF AN OUTCOMES STANDARD AND THE RELATED INDICATORS

#### Outcome Standard 2 - Participation

Each individual is able to access and participate in their community.

Please note that the numbers on the left side of each indicator show how they will be cross-referenced with one of the 16 Life Areas in the Quality Framework for Disability Services in Victoria (2007).

- 2.1 People with a disability are supported to use facilities, resources and services in the community that reflect their interests and preferences.
- 2.2 People with a disability are supported to participate in a range of recreation, leisure and sporting activities in the community that reflect their interests and preferences.
- 2.3 People with a disability are supported to participate in a range of cultural events in the community that reflect their interests and preferences.
- 2.4 People with a disability are supported to experience a variety of social roles through membership and affiliation with cultural, recreational, leisure or sporting groups that reflect their interests and preferences.
- 2.5 People with a disability are supported to access educational opportunities in inclusive educational environments.
- 2.6 People with a disability are supported to access health services in the community.
- 2.7 People with a disability are supported to access information about their community.
- 5.1 People with a disability are supported to have contact with family and friends.
- 5.2 People with a disability are supported to extend hospitality to family and friends in their own homes.
- 5.3 People with a disability are supported to build new social networks.
- 12.4 People with a disability are supported to access natural areas and public spaces.
- 13.1 People with a disability are supported to participate in physical activity.
- 14.1 People with a disability are supported to access and use their environments.
- 14.2 People with a disability are supported to experience personal mobility with the greatest independence.
- 14.3 People with a disability are supported to access mobility aids

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## Appendix 3: United States National Core Indicators: example

**"Overview:** Consumer outcome indicators concern how well the public system aids adults with developmental disabilities to work, participate in their communities, have friends and sustain relationships, and exercise choice and self-determination. Other indicators in this domain probe how satisfied individuals are with services and supports."

### Example

CONCERN	INDICATOR	DATA SOURCE
People have support to find and maintain community integrated employment.	The average bi-weekly earnings of people who have jobs in the community.	Consumer Survey
	The average number of hours worked bi-weekly by people with jobs in the community.	Consumer Survey
	The percent of people earning at or above the State minimum wage.	Consumer Survey
	Of people who have a job in the community, the percent who were continuously employed during the previous year.	Consumer Survey
	Of people who have a job in the community, the percent who receive vacation and/or sick time benefits.	Consumer Survey
	Of people who have a job in the community, the average length of time they have been working at their current job.	Consumer Survey
	The proportion of people who have a goal of integrated employment in their individualized service plan.	Consumer Survey
	The proportion of people who have a job in the community.	Consumer Survey
	The proportion of people who do not have a job in the community but would like to have one.	Consumer Survey
	The proportion of people who go to a day program or have some other daily activity.	Consumer Survey
	The proportion of people who do volunteer work.	Consumer Survey
	The proportion of all individuals who receive daytime supports of any type who are engaged in community integrated employment.	System

People have support to participate in everyday community activities.	The proportion of people who regularly participate in everyday integrated activities in their communities.	Consumer Survey
People make choices about their lives and are actively engaged in planning their services and supports.	The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, what to spend money on, and social activities.	Consumer Survey
	The proportion of people who report having been provided options about where to live, work, and go during the day.	Consumer Survey
People have authority and are supported to direct and manage their own services.	The proportion of people who are currently using a self-directed supports option.	Consumer Survey
	The proportion of people self-directing who report that someone talked with them about their individual budget/services.	Consumer Survey
	The proportion of people self-directing who have help in deciding how to use their individual budget/services.	Consumer Survey
	The proportion of people self-directing who report that they can make changes to their budget/services if they need to.	Consumer Survey
	The proportion of people self-directing who report that they need more help in deciding how to use their budget/services.	Consumer Survey
	The proportion of people self-directing who receive information about their budget/services that is easy to understand.	Consumer Survey
	The proportion of people self-directing whose support workers come when they are supposed to.	Consumer Survey
	The proportion of people self-directing who get the help they need to work out problems with their support workers.	Consumer Survey
People have friends and relationships.	The proportion of people who have friends and caring relationships with people other than support staff and family members.	Consumer Survey
	The proportion of people who have a close friend, someone they can talk to about personal things.	Consumer Survey
	The proportion of people who are able to see their families and friends when they want.	Consumer Survey
	The proportion of people who feel lonely.	Consumer Survey
	The proportion of people who talk with their neighbours.	Consumer Survey
	The proportion of people who can go out on a date if they want to.	Consumer Survey
	The proportion of people who report that they get to help others.	Consumer Survey

Measured by consumer surveys, described in Appendix 4.

## **Appendix 4: United States National Core Indicators: information on consumer surveys**

### **Extracts from Consumer Outcomes Phase X Final Report, 2007-2008 Data**

#### **(Human Services Research Institute, Cambridge, Massachusetts, 2009)**

In December 1996, the Board of Directors of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) launched the Core Indicators Project (CIP). The aim of CIP was to support state developmental disabilities authorities in developing and implementing performance/outcome indicators and related data collection strategies that would enable them to measure service delivery system performance. This project, now called National Core Indicators or NCI, aims to support efforts to improve system performance and thereby to better serve people with developmental disabilities and their families.

NCI Phase I began in January 1997. In August 1997, the Phase I Steering Committee selected a “candidate” set of 61 performance/outcome indicators in order to test their utility/feasibility. Six states agreed to conduct a field test of these indicators, including administering the NCI consumer and family surveys and compiling other data. Field test data were transmitted to NCI staff during the summer of 1998. The results were compiled, analyzed and reported to participating states in September 1998.

NCI Phase II was launched in January 1999. Phase II data collection finished in June 2000 and set the stage for continuation and further expansion of the NCI. During Phase II, the Phase I indicators were revised, and data collection tools and methods were improved. The Version 2.0 indicator set consisted of 60 performance and outcome indicators. Since then the NCI has expanded its scope to include services for children with developmental disabilities and their families. It has also continued to develop and refine the indicators, and has recruited additional states to participate in the collaboration. Phase II data are considered baseline NCI data. Phase II technical reports and other selected documents are available online at [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org).

### **III. Consumer Survey**

The National Core Indicators Consumer Survey was initially developed by a technical advisory subcommittee with the purpose of collecting information directly from individuals with developmental disabilities and their families or advocates. The survey is designed to measure over half of the original 60 core indicators. Many questions were drawn from survey instruments already in use in the field; other questions were developed specifically for NCI. NCI staff have routinely tested and refined the instrument based on feedback from interviewers.



## **Organization of the Survey**

The Consumer Survey is composed of a pre-survey form, three sections, and an interviewer feedback form.

THE PRE-SURVEY FORM collects information necessary to schedule face-to-face interviews, including contact information for consumers, and the names of guardians, advocates, or other individuals who might be asked to provide responses. The form also was used by surveyors to identify special communication needs that individuals might have prior to conducting the interview, define terms the individual would be most familiar with (such as “case manager” or acronyms), and document that informed consent was obtained. In most instances, information for the pre-survey form was obtained from the individual’s case manager. [Note: Individual identifying information was excluded from data submitted to HSRI.]

THE BACKGROUND INFORMATION SECTION requests data that would most likely be found in agency records or information systems. In some states, case managers complete this section at the same time the pre-survey form is completed. In other states, surveyors complete the section during the direct interview.

SECTION I of the survey, which concerns questions aimed at obtaining expressions of satisfaction and opinions from each individual, may be completed only through a direct interview with the individual; proxy responses are not acceptable.

SECTION II questions are to be answered by the individual if possible. If the person is unable to respond, an advocate is asked to answer.

The last page of the survey is the INTERVIEWER FEEDBACK SHEET. Surveyors are asked to record the length of the interview with the individual and describe any problematic questions.

Note: The DAY/VOCATIONAL/EDUCATIONAL SUPPLEMENT is an optional add-on to the survey instrument. These data are generally collected at the same time the background information section is completed.

## **IV. Methods**

### **Criteria for Exclusion of Responses**

All persons selected in the survey sample are given an opportunity to respond to questions in a face-to-face interview. There is no pre-screening procedure. Exclusion of responses is done at the time of data analysis, based on specific criteria described below.

Section I is administered only to **the person receiving services**. A person’s responses are excluded if any of the following criteria are met:

- The consumer responded to less than half of the questions in Section I.

- The interviewer recorded that the person did not understand the questions being asked.
- The interviewer recorded that the person gave inconsistent responses.

Section II allows multiple respondents. Other informants (e.g., family, friend, support worker) may provide answers to some of the questions.

### Sampling

The goal of each state was to conduct a minimum of 400 interviews. Each state is asked to conduct a random sample of individuals over age 18 who are receiving at least one service, besides case management. Most states draw an over-sample to account for refusals. Some states did not complete 400 interviews, and others exceeded this goal. A sample size of 400 allows valid comparisons across states with a 95% confidence level. Those that did not complete 400 are also included in this report; however, readers are cautioned to take sample sizes into consideration

### Results: Core Indicator Outcomes

The data from the Consumer Survey were analyzed to assess Core Indicator outcomes for the sample as a whole and separately by state. The following brief summary highlights national results from 2007-2008 NCI data.

#### Summary of Aggregate Results by Indicator 2007- 2008 Consumer Survey

<b>Question:</b>	<b>Core Indicator and Results:</b>
BI-16	<b>47.3%</b> of people take medications for mood disorders, anxiety, behaviour problems, or psychotic disorders.
BI-19	<b>87.2%</b> of people have had a physical exam in the past year.
BI-20	<b>49.8%</b> of women have had an OB/GYN exam in the past year.
BI-21	<b>52.7%</b> of people have had a routine dental exam in the past six months.
BI-22, BI-23, BI-24	Most people maintain healthy habits in such areas as smoking ( <b>92.1%</b> ), weight ( <b>67.3%</b> ), and exercise ( <b>76.8%</b> ).
Q1	Most people are satisfied with their job or day program ( <b>95.2%</b> ).
Q2, Q7	Most people feel that day support staff ( <b>93.9%</b> ) and residential support staff ( <b>90.0%</b> ) treat them with respect.
Q3	Most people are satisfied with where they live ( <b>94.6%</b> ).
Q4	<b>91.6%</b> of people are satisfied with the amount of privacy they have. ( <i>Adjusted value</i> )
Q5, Q6	Most people feel safe in their home ( <b>83.0%</b> ) and neighborhood ( <b>83.3%</b> ).
Q8, Q9, Q46, Q47, Q48	Most people indicate that their basic rights are respected by others: Most people say others do not enter their home ( <b>86.1%</b> ) and bedroom ( <b>80.9%</b> ) without permission. <b>88.1%</b> of people

do not have their mail opened by others without permission, and most people have no restrictions on being alone with guests (**87.7%**) and using the telephone (**91.0%**). (*All adjusted values*)

**Q10**

**83.8%** of people have a close friend, someone they can talk to about personal things.

**Q11**

**69.8%** of people have friends and caring relationships with people other than support staff and family members.

**Q12, Q14**

Most people are able to see their friends (**81.3%**) and families (**78.0%**) when they want.

<http://www2.hsri.org/docs/NCI%20CS%2007-08%20FINAL%20REPORT.pdf>,  
(accessed 29 June 2010)