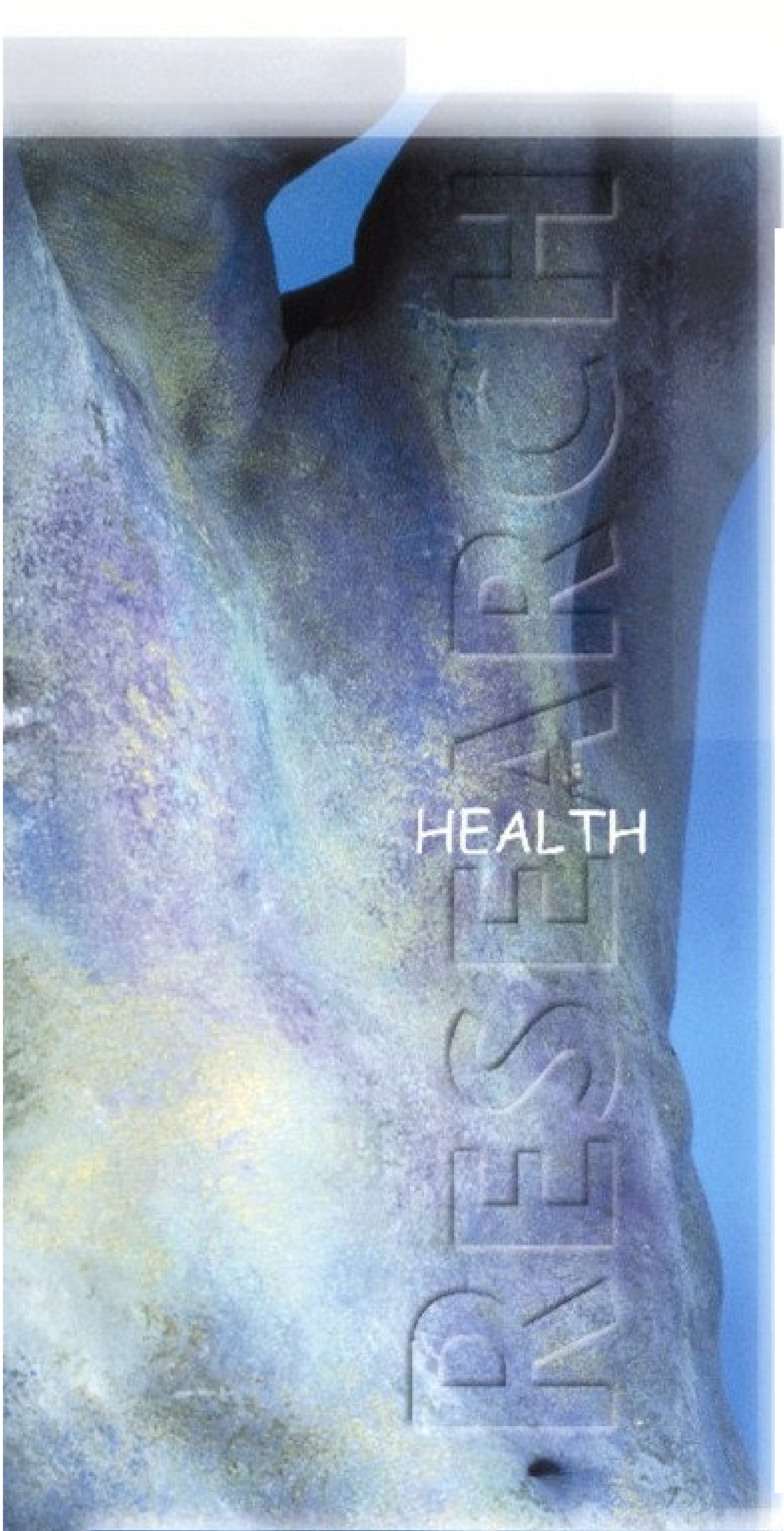

Evaluating the Impact of
Valuing People

# Report of Phase 3: Moving towards evaluating *Valuing People* in practice

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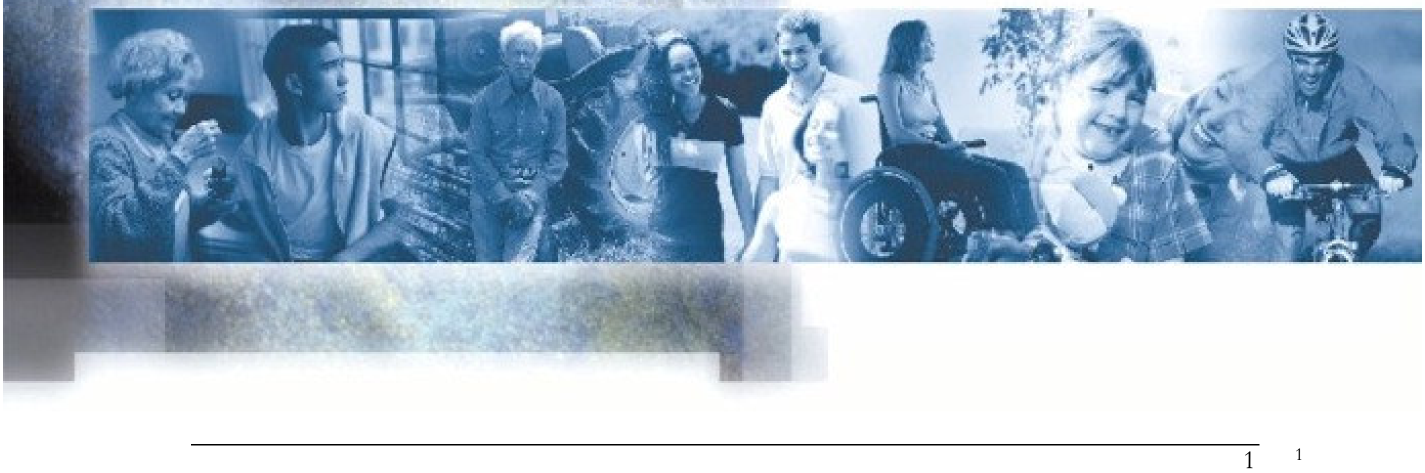

# Evaluating the Impact of *Valuing People*

## Report of Phase 3:
## Moving Towards Evaluating *Valuing People* In Practice

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*August 2006*

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# Contents

# Summary

## The Project

In March 2001, the Department of Health published the White Paper "*Valuing People*", designed to establish a framework for the delivery of health and personal social services for children and adults with learning disabilities in England (Department of Health, 2001). To provide clear guidance concerning the desired direction of services for people with learning disabilities, *Valuing People* includes a comprehensive set of 11 overall objectives to be reached for people with learning disabilities, with specific sub-objectives for each overall objective.

This report outlines the findings of the third phase of a research project commissioned as part of the Department of Health's Learning Disability Research Initiative, a policy research programme designed to investigate aspects of the implementation of *Valuing People*. This research project has the overall objective of helping the Government to develop ways of evaluating the impact of *Valuing People* at a national level. The project has three phases:

> **Phase 1**: To locate and map existing national data sources relevant to services for people with learning disabilities, and to assess their potential usefulness for evaluating the impact of *Valuing People* (Hatton, Emerson & Lobb, 2005).
> **Phase 2**: To work with people with learning disabilities, family members and other stakeholders to identify what information should be collected at a national level to enable the Government to evaluate the impact of *Valuing People* (Hatton, Emerson & Lobb, 2006; Lobb, Hatton & Emerson, 2006)
> **Phase 3**: To develop practical ways of collecting, analysing and reporting national information to enable the Government to evaluate the impact of *Valuing People*.

This third phase of the research project aims to develop practical ways of collecting, analysing and reporting national information to enable the Government to evaluate the impact of *Valuing People*. This phase of the project consisted of two strands of activity:

1) The development of a comprehensive framework for evaluating outcomes concerning people with learning disabilities relevant to Valuing People.
2) Working with various agencies to develop practical methods for outcome measurement that could form the basis of national data collection systems.

## Developing an outcomes framework

Since the publication of Valuing People in 2001, there has been further rapid development in policies concerning disabled people and people using social care services (Department of Health, 2005, 2006; Prime Minister's Strategy Unit, 2005). In these policies there is an explicit emphasis on judging the success of policy initiatives by the outcomes (broadly defined) experienced by people using services and disabled people generally, an emphasis endorsed by people with learning disabilities and family carers in Phase 2 of this project (Hatton et al., 2006). In contrast, the findings of Phase 1 of this project (Hatton et al., 2005) showed that existing national statistics and performance indicators concerning people with learning disabilities are almost exclusively focused on inputs, process and outputs rather than outcomes.

To reflect new policy priorities and taking into account the findings of Phases 1 and 2 of this project, we propose five principles for the development of national performance indicators concerning people with learning disabilities:

1) National statistics and performance indicators should place a much greater emphasis on outcomes (the life experiences of people with learning disabilities) rather than on resources or service activities.
2) People with learning disabilities and family carers should be given a central role in shaping the outcomes agenda, particularly in terms of which types of information should be collected, and should be able to access and use the information obtained.
3) Data collection systems should be designed around the totality of the lived experience of people with learning disabilities rather than producing aggregate statistics concerning the activities of specific services.
4) National statistics should reflect current Government policies and their associated objectives.
5) National statistics should be able to document potential areas of inequality; between people with learning disabilities and the general population; and within the population of people with learning disabilities.

We have developed an outcomes framework based on these five principles, as well as taking into account issues of feasibility, cost-effectiveness and the burden of data collection on service agencies. For the purposes of performance indicator development, two levels of outcome measurement are particularly pertinent:

***Level 1: General outcomes*** that are about the totality of a person's life and that are unlikely to be solely and directly attributable to the impact of any particular service/support agency (or indeed, all services/support agencies combined), such as citizenship. These general outcomes are, however, crucial for evaluating the effectiveness of policy and for assessing inequalities between people with learning disabilities and the general population. We suggest that these types of outcome indicators are collected on a regular basis (for example, every three or five years) using national survey methodologies that would recruit nationally representative samples (including people with learning disabilities not known to services).

***Level 2: Outcomes that can be directly attributable to service/support agency activities*** (e.g. choice and control within a self-directed support process). These are crucial for evaluating the effectiveness of both policy and individual services. The report provides extensive details of potential outcome-focused performance indicators drawn from existing national and international projects, within 9 outcome domains: choice and control; housing; families; social inclusion; transition; employment; health; economic well-being; experience of services.

This framework is focused on outcome indicators rather than service resources, processes and outputs. However, it is clearly that such information is regular collected locally and nationally. This report proposes that a small set of national performance indicators (involving a substantial reduction of the current number of PIs concerning service resources, processes and outputs) are developed. However, there should be an increased emphasis on services conducting self-assessment for much of this information.

## Developing practical methods for evaluating outcomes

This phase of the project consisted of working with other agencies and individuals to take forward the findings and ideas from this project into the development of performance indicators. We decided that this approach of working with other agencies was a more effective use of project resources compared to a stand-alone project phase developing outcome indicators in isolation, as several relevant agencies are already reviewing performance indicators in the light of recent policy developments. Activities in this phase of the project included:

***Commission for Social Care Inspection Performance Indicators: Services for people with learning disabilities***. The project team were part of a group advising the Commission for Social Care Inspection on the development of new performance indicators for services for people with learning disabilities. In July 2006 this group produced a set of recommendations for new performance indicators; these recommendations are currently being evaluated by the Commission for Social Care Inspection with the aim of implementation for 2007/2008 (see Appendix 1).

***Progressing In Control: Minimum Information Collection System (PICMICS)***. The project team has been working with in Control and local authorities to develop a minimum dataset for local authorities supported by in Control (approximately 60 local authorities) to administer to all people using self-directed support within these local authorities. PICMICS is currently being piloted by local authorities to assess the feasibility of data collection using this system, and the progress of PICMICS is being monitored by the Commission for Social Care Inspection for its implications for future developments in the collection of performance indicators and self-assessment information from local authorities (see Appendix 2).

***Better Metrics***. Extensive consultation and support was provided for the development of the 7th Version of Better Metrics (http://www.osha.nhs.uk/publicpage.aspx?id_Content=455), an ongoing project sponsored by the Healthcare Commission to develop more clinically relevant measures of performance for local self-assessment within health services.

***Healthcare Commission National Audit of NHS and independent healthcare providers of services for people with learning disabilities***. Extensive consultation and support was provided for the development of questions for the self-assessment tools to be used in this audit (at the time of writing, these self-assessment tools are not publicly available).

***Quality Outcomes Framework.*** Consultation and support was provided for the development of a learning disability indicator to be included from 2006/2007 within the Quality Outcomes Framework (http://www.nhsemployers.org/primary/primary-890.cfm), a system of financial incentives for primary care practices who provide high quality information.

## Conclusions and recommendations

Drawing from the findings of the three phases of this project, five major conclusions can be drawn.

First, people with learning disabilities, family carers and existing policies concerning health and social care all emphasise the importance of outcomes (whether people's life experiences reach generally accepted standards of acceptability and decency, and whether people are in control of their lives and achieving their aspirations).

Second, existing information collected nationally concerning people with learning disabilities does not reflect the importance of outcomes, being largely focused on the resources and activities of particular services.

Third, a major shift will be required in both the content of the information collected and the methods used to collect it if outcomes are to be placed at the heart of national data collection.

Fourth, the methodology and technology required to collect outcome information from people with learning disabilities and their families already exists; the major challenge is to translate existing knowledge into feasible methods for collecting national information for the purposes of service inspection and national policy evaluation.

Finally, people with learning disabilities and family carers need to have a much bigger role in deciding the priorities for information collection, giving and collating information, and accessing information in ways that are useful for the purposes of public accountability.

To facilitate a move towards outcomes-focused data collection, the Department of Health and other Government agencies need to address the following issues:

- Definitions and terms. A consistent and clear definition of learning disabilities should be agreed across Government departments, this agreed definition should be reflected in a single term to be used for people with learning disabilities, and the Department of Health should ensure that people with learning disabilities are not treated as a sub-group of people with mental health problems in national statistics.
- Setting priorities. A mechanism for agreeing priorities for information collection across Government agencies and inspectorate commissions should be agreed that includes people with learning disabilities and family carers and that encourages cross-agency information collection.
- Individually focused outcomes. The Department of Health and other relevant agencies should focus on the collection of outcome indicators directly from people with learning disabilities and family carers concerning their lived experience rather than the activities of specific services.
- There should be a regularly repeated national survey of the life experiences of people with learning disabilities.
- An Observatory for Learning Disability Statistics should be set up to provide a central point for people with learning disabilities, family carers, professionals and policy-makers to easily access nationally available information.

# Introduction

In March 2001, the Department of Health published the White Paper "*Valuing People*", designed to establish a framework for the delivery of health and personal social services for children and adults with learning disabilities in England (Department of Health, 2001). To provide clear guidance concerning the desired direction of services for people with learning disabilities, *Valuing People* includes a comprehensive set of 11 overall objectives to be reached for people with learning disabilities, with specific sub-objectives for each overall objective. These objectives and sub-objectives have been designed to allow the Government to evaluate the impact that *Valuing People* is having on people with learning disabilities in England.

To evaluate the objectives and sub-objectives in *Valuing People*, information is needed on aspects of resources, processes and outcomes, with a particular emphasis on outcomes for people with learning disabilities and their families. This research project has the overall objective of helping the Government to develop ways of evaluating the impact of *Valuing People* at a national level.

## The Project

This report outlines the findings of the third phase of a research project commissioned as part of the Department of Health's Learning Disability Research Initiative. The Learning Disability Research Initiative is a policy research programme designed to investigate aspects of the implementation of the White Paper *Valuing People*. This research project has the overall objective of helping the Government to develop ways of evaluating the impact of *Valuing People* at a national level. The project has three phases:

**Phase 1**: To locate and map existing national data sources relevant to services for people with learning disabilities, and to assess their potential usefulness for evaluating the impact of *Valuing People* (Hatton, Emerson & Lobb, 2005).
**Phase 2**: To work with people with learning disabilities, family members and other stakeholders to identify what information should be collected at a national level to enable the Government to evaluate the impact of *Valuing People* (Hatton, Emerson & Lobb, 2006; Lobb, Hatton & Emerson, 2006)
**Phase 3**: To develop practical ways of collecting, analysing and reporting national information to enable the Government to evaluate the impact of *Valuing People*.

This third phase of the research project aims to develop practical ways of collecting, analysing and reporting national information to enable the Government to evaluate the impact of *Valuing People*. This phase of the project consisted of two strands of activity:

1. The development of a comprehensive framework for evaluating outcomes concerning people with learning disabilities relevant to Valuing People.
2. Working with various agencies to develop practical methods for outcome measurement that could form the basis of national data collection systems.

# 1) Developing an Outcomes Framework

Since the publication of Valuing People in 2001, there has been further rapid development in policies concerning disabled people and people using social care services (Department of Health, 2005, 2006; Prime Minister's Strategy Unit, 2005). Current legal frameworks, particularly the Disability Discrimination Act, the Human Rights Act and the Race Relations Amendment Act (HM Government, 1995, 1998, 2000), are increasingly providing public bodies with legal duties that support developments in policy, and provide frameworks for service activities and self-assessment of these activities.

In recent policy there is an explicit emphasis on judging the success of policy initiatives by the outcomes (broadly defined) experienced by people using services and disabled people generally. Many of these outcomes are expressed in terms of reducing the inequality and disadvantage experienced by disabled people across a comprehensive range of areas of life, including self-determination, independence, social inclusion, health and economic well-being. The consultations conducted in Phase 2 of this project (Hatton et al., 2006) demonstrated that people with learning disabilities and family carers share this emphasis on outcomes as a way of judging the success of Valuing People.

In contrast to this policy emphasis on outcomes, the findings of Phase 1 of this project (Hatton et al., 2005) demonstrated that existing national statistics and performance indicators concerning people with learning disabilities are almost exclusively focused on inputs, processes and outputs rather than outcomes. Professionals consulted during Phase 2 of the project (Lobb et al., 2006) agreed that performance indicators and information collection systems should be more outcome-focused, although there was also a recognition of the challenges involved in devising practical methods for collecting outcome measures concerning people with learning disabilities.

Clearly, new performance indicators need to be developed if the outcomes of policy initiatives and service supports are to be evaluated.

## Issues in the development of performance indicators for people with learning disabilities

Performance indicators (PIs) concerning services for people with learning disabilities are fragmented across several government departments, inspectorates and other information collection agencies, which use very different definitions of learning disabilities and different methods of information collection (Hatton et al., 2005). Partly due to this fragmentation, the development of PIs concerning people with learning disabilities has been piecemeal within different agencies, with little attention paid to developing a comprehensive and coherent set of PIs across agencies.

In contrast to the current position on information and PIs, current policies being developed concerning people with learning disabilities and other groups (disabled people more generally, people using social care services) are increasingly coherent and cross-governmental (Department of Health, 2005, 2006; Prime Minister's

Strategy Unit, 2005). Concepts such as reducing inequality, promoting self-determination and promoting quality of life are found consistently across policy documents, and provide a sound foundation for the development of a coherent framework for assessing outcomes. Such a framework could equally apply to family carers, and would theoretically apply across service user groups.

These new policy frameworks mean that we need to think about outcomes in a different way. Historically, policy concerning people with learning disabilities (and many other groups) has encouraged services to develop certain models of service that are assumed to be associated with better outcomes for service users. Many PIs reflect these policy assumptions, in that they assess resources and processes that are assumed to be proxies for outcomes (e.g. the quantity and proportion of different types of housing services used by people with learning disabilities). Historically, policies have also assumed that services would be largely delivered by a small number of public sector organisations, resulting in PI information collection systems focusing on the activities of specific public sector services. Taken together, these historic policy assumptions have resulted in PIs that are collected from and organised according to service provider sector, and that concentrate on measurable aspects of service resources, processes and outputs.

Research evidence, new policy frameworks, and existing trends in the design and delivery of service supports to people with learning disabilities, present a considerable challenge to the current way in which PIs are collected:

1) Research consistently shows that service resources, processes and outputs (e.g. costs, staff ratios, service model) generally have weak or no associations with outcomes for people using services (Hatton, 2001).
2) New policy directions emphasise self-determination (choice and control) – supporting people to do what they want to do with their lives. If people are truly self-determined, it is extremely unlikely that there will be universally preferred service models which can be used as a proxy for user outcomes.
3) New policy directions emphasise outcomes (particularly in terms of quality of life). A substantial proportion of relevant outcome data will need to be collected (or is certainly most efficiently collected) from people using services themselves or, for some, from proxy respondents, and cannot be derived from service activity data.
4) New policy directions emphasise reducing inequality. This requires the collection of data that enable (a) direct comparison with ‘normative’ life experiences and (b) the identification of potential inequalities within ‘vulnerable groups’ (e.g., on the basis of socio-economic position, ethnicity, age, gender).
5) Both new policy directions and existing trends in service provision highlight partnership. Developing policies and services are increasingly moving towards partnership working between social care, health and education agencies, with a rapidly increasing mixed economy of support developing. People accessing social care will increasingly be using a wider range of support agencies. Collecting PIs using a particular service agency as the unit of analysis will yield data that are increasingly fragmented, inefficient to collect, partial and uninterpretable.
6) Both new policy directions and existing trends in service provision point to support being provided from multiple sources, reducing the importance of specialist public sector services as direct providers and increasing the amount of

support from mainstream sources outside the social/health/education system. Assessing PIs (especially outcomes) by asking about particular specialist services will render service users increasingly invisible within these information systems (as they use these specialist services less and less) and will result in PIs capturing less and less about the lives of service users.

To reflect new policy priorities, PIs will need to focus more on:
- Whether a person is in control of their life, and whether this control is resulting in the kind of life the person wants to lead (self-determination indicators).
- Whether a person's lifestyle and standard of living meets general societal notions of decency and acceptability (quality of life indicators).
- Whether services are supporting the person in a way that increases that person's self-determination and supports their aspirations, without resulting in a generally recognised unacceptable standard of living (indicators of service processes and resources, and self-assessment).
- Whether service supports and the outcomes of these supports are equally accessible to and effective for everyone (assessing variations in all indicators across groups thought to be vulnerable to a poor experience of service supports).

From the findings of Phase 1 and Phase 2 of this project, we propose five principles for the development of national PIs concerning people with learning disabilities:
- National statistics and performance indicators should place a much greater emphasis on outcomes (the life experiences of people with learning disabilities) rather than on resources or service activities.
- People with learning disabilities and family carers should be given a central role in shaping the outcomes agenda, particularly in terms of which types of information should be collected, and should be able to access and use the information obtained.
- Data collection systems should be designed around the totality of the lived experience of people with learning disabilities rather than producing aggregate statistics concerning the activities of specific services.
- National statistics should reflect current Government policies and their associated objectives.
- National statistics should be able to document potential areas of inequality; between people with learning disabilities and the general population; and within the population of people with learning disabilities.

Of course, these five principles need to realised in a way that is practical and feasible for the agencies that will be collecting, analysing and disseminating the information.

Technical and methodological issues concerning the collection of reliable and valid information from people with learning disabilities (and proxy informants where necessary) will also need to be considered (Bradley et al., 2006). Many of these issues have been addressed by researchers working with people with learning disabilities, although more work needs to be done. The issues identified below may also be relevant to some other groups of people using services.
- Getting reliable and valid information from people with learning disabilities. Issues here involve assessing the capacity of the person to answer questions and

ensuring questions are accessible to the maximum number of people with learning disabilities.
- The role of proxy respondents in reporting the life experiences of a person with learning disabilities. What sort of information can be provided in a reliable and valid way by proxies, and when should information be gained from proxies?
- Gaining information from people with learning disabilities (and possibly some proxy informants) is likely to involve face-to-face interviews rather than questionnaires, with training and resource implications.
- Ensuring that PIs and associated questions are valid cross-culturally.
- Identification issues. Given likely differences in eligibility criteria across areas, and the possibility that some people with learning disabilities may not be in contact with services (Emerson, Malam, Davies & Spencer, 2005), it will be necessary to be able to quickly and reliably assess if a person has a learning disability.

## Developing an outcomes framework

This section of the report will focus on potential methods for evaluating the outcomes of policy and practice for people with learning disabilities (and, to a limited extent, their families). We would like to emphasise that outcomes are only one aspect of the information that needs to be collected for the purposes of evaluating the effectiveness of policy and service support, where monitoring service resources, processes and outputs are also crucial in coming to a judgement about policy and practice effectiveness. When developing an outcomes framework, it is also important to consider issues such as:

- The importance of not increasing the burden of information collection on participating agencies.
- Ensuring that policies and services are evaluated at the appropriate level (for example, monitoring the proportion of people with learning disabilities voting in elections may be appropriate in evaluating policy initiatives concerning citizenship, but may be less appropriate for evaluating a particular service agency).
- What information it is practically feasible to collect.
- The resources required to collect the information.
- How the collection of outcomes information fits in with the collection of other important information for monitoring purposes.
- The collection of information that is relevant and accessible to the wide range of stakeholders who may wish to use the information.
- To what extent can outcome measures (and other performance indicators) be applied consistently across different groups of people using services.

As mentioned above, new policy directions emphasise outcomes based on conceptual frameworks of equality, self-determination and quality of life. For the purposes of PI development, two levels of outcome measurement are particularly pertinent:

- Level 1: General outcomes that are about the totality of a person's life and that are unlikely to be solely and directly attributable to the impact of any particular service/support agency (or indeed, all services/support agencies combined), such as citizenship. These general outcomes are, however, crucial for evaluating the

effectiveness of policy and for assessing inequalities between people with learning disabilities and the general population.
- Level 2: Outcomes that can be directly attributable to service/support agency activities (e.g. choice and control within a self-directed support process). These are crucial for evaluating the effectiveness of both policy and individual services.

As mentioned above, it is also crucial to collect information on aspects of service resources, processes and outcomes. The framework presented below proposes three levels of information collection concerning general outcomes, service outcomes and service resources/processes/outputs. This framework is designed to ensure:
- a much greater emphasis on relevant outcomes;
- maximum cost-effectiveness of data collection;
- no increase in the number of PIs or burden of information collection on service agencies.

The implementation of such a framework will require:
- co-ordination across government agencies and inspectorates;
- re-configuration of the information collection systems currently used by service agencies;
- further work to develop consistent outcome indicators across groups of people using services (with the recognition that additional modules of outcome indicators specific to particular service user groups may be required);
- a commitment to fund a regularly repeated national survey of people with learning disabilities.

### Level 1: General outcomes for service users and families

There are several general outcome indicators that would be appropriately collected on a nationally representative sample of people with learning disabilities, to establish:
- Changes in the life circumstances of people with learning disabilities over time, to help evaluate the effectiveness of policy in general in improving important aspects of people's lives.
- The life circumstances of people with learning disabilities compared to the general population, to evaluate the effectiveness of policy in reducing inequality.
- Inequalities in access to and experiences of services, to evaluate the effectiveness of policy in ensuring equality of access and outcomes for 'vulnerable' groups, for example people with learning disabilities who differ by ethnicity, age, gender, or level of need.

It is suggested that these types of outcome indicators are collected on a regular basis (for example, every three or five years) using national survey methodologies that would recruit nationally representative samples (including people with learning disabilities not known to services). There are several reasons for this, including:
- Annual surveys are unnecessary for evaluating the impact of broad policy initiatives on major aspects of people's lives, and therefore are not cost-effective.
- National survey agencies and sampling methodologies are vital if the experiences of people with learning disabilities who are not known to services are to be included.

- In addition to the core outcome indicators set, particular editions of a regular national survey could include additional questions on an area of current concern to policy-makers, or over-sample particular groups of particular concern to policy-makers (for example, people with high support needs or people from particular ethnic groups).
- Because these outcome indicators are general, they cut across different service agencies and are unlikely to be solely or directly attributable to the activities of any single service agency. This means that the responsibility for data collection and use will not obviously lie within any service inspectorate or service agency.
- Information would not be collected by service agencies, reducing their burden of information collection, and would be insufficient in sample size to enable comparisons between localities (such as local authorities), meaning that data emerging from regular surveys would not count as performance indicators.
- A successful national survey of this type has recently been completed, demonstrating the feasibility and utility of this approach (Emerson et al., 2005)

### Level 2: Outcomes directly attributable to service/support agency activity

In addition to the general outcome indicators outlined above, it is also vital to collect information on outcomes that are directly attributable to the activities of services and support agencies. Such outcome indicators will be core PIs for government and inspectorate agencies, and will be collected in sufficient numbers at a local level to enable comparisons between localities. Several issues need to be considered when developing such a set of outcome indicators:

- A small number of these service-level outcome indicators may also be appropriately collected in the regular national survey proposed above, if they are crucial to general policy directions.
- Inspectorates and government agencies may wish to consider if they need to distinguish between outcome indicators that concern minimum standards and outcome indicators that will reflect continuing improvement or developmental standards.
- Inspectorates and other government agencies will need to consider which outcome indicators can be used consistently across groups of people using services, and which outcome indicators may need to be developed as additional modules for specific groups of people using services.
- Information concerning service-level outcomes will need to be collected directly from people with learning disabilities and family members. This has a number of implications for information collection systems:
    - Current local information collection systems will need to be reconfigured to allow for the collection of outcome information directly from service users and family members, possibly with some transitional additional costs concerning training and information system development.
    - Information collection systems will need to ensure that PIs based on service-level outcome indicators can be broken down into sub-groups potentially associated with inequalities in the experience of services, such as gender, age, ethnicity, support needs, socio-economic position etc.
    - The cost-effectiveness of collecting outcome information directly from service users and family members can be maximised in the following ways:

- Some outcome indicators can be collected on random samples of service users, rather than entire local communities of service users.
- Some outcome indicators may be able to be built into routine service assessment or review systems.
- A single comprehensive set of service-level outcome indicators across all service domains should be collected from service users and families, with the resulting information shared across all relevant government departments and inspectorates. This would reduce the burden of information collection on local agencies and service users or family members, and would provide a comprehensive picture of the use of mainstream supports as well as particular specialist services.

### Level 3: Service-level resources, processes and outputs

As mentioned above, this framework is focused on outcome indicators rather than service resources, processes and outputs. However, it is clearly crucial for the evaluation of both national policy and individual services that such information is regular collected at a local level and collated nationally. The types of questions that might be answered by such information include:

- Are services doing what they're supposed to be doing?
- How much money are they spending and how are they spending it?
- What other resources do services have at their disposal (e.g. staff)?
- Are services doing strategic planning (do they know the levels of need, demand and service uptake in their local area? Do they know if there are inequalities in access? How do they plan resource allocation? How are they planning to make things better?)
- How do services know the impact of what they're doing?
- Are services meeting legal requirements, and how do they know this?

Both the Commission for Social Care Inspection and the Healthcare Commission are currently collecting and using a substantial amount of this information for the purposes of policy evaluation and service inspection. This paper proposes that a small set of national PIs (involving a substantial reduction of the current number of PIs concerning service resources, processes and outputs) are developed. However, there should be an increased emphasis on services conducting self-assessment for much of this information, with the following advantages:

- Self-assessment would be less restrictive in terms of having to set national PIs – services could work out themselves how to generate relevant information.
- Self-assessment would promote more reflective and analytic organisational cultures.
- Self-assessment would give services the space to highlight success, good practice and innovation – these could usefully be collated nationally for information-sharing purposes.
- Central guidance and support for collecting self-assessment information could provide a process for the ongoing improvement and refinement of PIs.
- Information from self-assessment would be more useful to services and more useful to inspectors looking in depth at a particular service.

## Developing Outcome Indicators

Within the broad framework outlined above, the rest of this section of the report collates outcome indicators for development and possible use in both a regularly repeated national survey and in annual monitoring and evaluation of service-level outcomes. The outcome indicators presented here have all been used in large-scale surveys in the UK, the USA or Australia. In selecting outcome indicators for inclusion, the following guidelines were used for indicating preferred characteristics of outcome indicators (although not all outcome indicators have every preferred characteristic):

- They should be direct measures of outcome.
- They should be relevant to current government policies.
- They should be sensitive to change over time
- They should be sensitive to potential inequalities experienced by vulnerable groups.
- They should have been used with people with learning disabilities or family members.
- They should have been used in the UK.
- They should allow for comparisons to UK general population data.

It is important to note that this paper only contains already existing outcome indicators – for policy and service evaluation purposes, it may be necessary to develop new outcome indicators in areas where current outcome indicators are weak or absent. It may also be necessary to reshape current outcome indicators to ensure that they meet policy concerns, are reliable and valid, and are practically feasible to collect. Finally, these outcome indicators concern adults with learning disabilities, although it is hoped that many of the outcome indicators in this paper would be readily applicable across different groups of service users.

### Organising outcome indicators

There are clearly a huge number of potentially relevant outcome indicators concerning people with learning disabilities. Within this paper, outcome indicators have been grouped into domains according to three recent policy documents:

#### Improving The Life Chances of Disabled People (Prime Minister’s Strategy Unit, 2005)

This policy document concerns all disabled people in England, and proposes that the success of policy should be evaluated using four domains:

- Increasing disabled people’s ability to live independently – to enjoy the same choice, control and freedom as any other citizen – at home, at work, and as members of the community.
- Enabling young disabled children and their families to enjoy ‘ordinary’ lives, through access to childcare, early education and early family support to enable them to care for their child effectively and remain socially and economically included.
- Supporting disabled young people and their families through the transition to adulthood. Transition will be better planned around the needs of the individuals and service delivery will be smooth across the transition.

- Increasing the number of disabled people in employment while providing support and security for those unable to work.

**Independence, Well-being and Choice (Department of Health, 2005)**
This Green Paper concerning social care services for adults in England proposes evaluating outcomes in seven domains. The Green Paper was used in preference to the subsequent White Paper Our Health, Our Care, Our Say (Department of Health 2006) as it was consistent with the White Paper and contained more detail concerning outcomes:

- Improved health: enjoying good physical and mental health (including protection from abuse and exploitation). Access to appropriate treatment and support in managing long-term conditions independently. Opportunities for physical activity.
- Improved quality of life: access to leisure, social activities and life-long learning and to universal, public and commercial services. Security at home, access to transport and confidence in safety outside the home.
- Making a positive contribution: active participation in the community through employment or voluntary opportunities. Maintaining involvement in local activities and being involved in policy development and decision making.
- Exercise of choice and control: through maximum independence and access to information. Being able to choose and control services. Managing risk in personal life.
- Freedom from discrimination or harassment: equality of access to services. Not being subjected to abuse.
- Economic well-being: access to income and resources sufficient for a good diet, accommodation and participation in family and community life. Ability to meet costs arising from specific individual needs.
- Personal dignity: keeping clean and comfortable. Enjoying a clean and orderly environment. Availability of appropriate personal care.

**Valuing People (Department of Health, 2001)**
This White Paper concerning people with learning disabilities in England proposes 11 objectives against which the success of Valuing People can be evaluated:

- 1: Disabled children and young people: to ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.
- 2: Transition into adult life: as young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family, and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.
- 3: More choice and control: to enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need.
- 4: Supporting carers: to increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.
- 5: Good health: to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care

delivered to a consistently high standard, and with additional support where necessary.

- 6: Housing: to enable people with learning disabilities and their families to have greater choice and control over where, and how, they live.
- 7: Fulfilling lives: to enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.
- 8: Moving into employment: to enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work.
- 9: Quality: to ensure that all agencies commission and provide high quality, evidence based, and continuously improving services which promote both good outcomes and best value.
- 10: Workforce and planning: to ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.
- 11: Partnership working: to promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

These three policy documents are highly consistent in their policy aspirations, although different policy documents emphasise different domains of outcome. Table 1 below presents a crosswalk of the outcome domains proposed across the three policy documents, and a list of the outcome domains to be covered in this report.

**Table 1: Crosswalk of outcome domains**

| Improving Life Chances | Independence, Well-being and Choice | Valuing People | Outcome Domain in This Paper |
|---|---|---|---|
| Increasing disabled people's ability to live independently | Exercise of choice and control | More choice and control | Choice and control |
| | Improved quality of life | Housing | Housing |
| | | Supporting carers | Families |
| | | Fulfilling lives | Social inclusion |
| | Freedom from discrimination or harassment | | |
| | Personal dignity | | |
| Enabling young disabled children and their families to enjoy 'ordinary' lives | | Disabled children and young people | [Not covered in this paper as this domain concerns children] |
| Supporting young people and their families through the transition to adulthood | | Transition into adult life | Transition |
| Increasing the number of disabled people in employment | Making a positive contribution | Moving into employment | Employment |
| | Improved health | Good health | Health |
| | Economic well-being | | Economic well-being |
| | | Quality | Experience of services |
| | | Workforce and planning | |
| | | Partnership working | |

In addition to the 9 outcome domains covered in this report, an additional domain concerning indicators likely to be associated with variation in outcome indicators (particularly in terms of potential 'vulnerability' factors to poor outcomes) is included.

Finally, it is important to note that although some indicators concerning satisfaction with services and life in general are included here, they are not strictly speaking outcome indicators, and research has demonstrated that measures of satisfaction (or subjective well-being) are relatively insensitive to changes in people's circumstances, living conditions or lifestyle (Perry & Felce, 2005) and record largely positive results in the face of objectively poor life circumstances (Emerson et al., 2005).

## Sources of outcome indicators

Outcome indicators have been largely drawn from sources that have involved collecting information from large samples of people with learning disabilities for the purposes of evaluating policy. The main sources are:
**Adults with Learning Difficulties in England 2003/2004** (Emerson et al., 2005), a national survey of almost 3,000 adults with learning disabilities.
**The National Core Indicators Project** (Human Services Research Institute, 2006), an ongoing US project where currently 25 states voluntarily subscribe to the project to collect information on substantial samples of people with learning disabilities and their families using services.
**The National Satisfaction Survey of Clients of Disability Services** (E-QUAL and Donovan Research, 2000), a national Australian survey of over 2,000 adults using disability services and family members.

All these projects have used/adapted outcome indicators from other sources, including general population surveys and each other. Where this is the case, the ultimate reference for the outcome indicator is shown in the relevant table. Some additional questions, which have not yet been tested with people with learning disabilities, have been added from the Social Capital Harmonised Question Set (Green and Fletcher, 2003).

Within each table, the following information on each outcome indicator is provided:

- A brief description of the outcome indicator.
- The reference/origin of the outcome indicator.
- The source of the information required for the outcome indicator.
- Whether the indicator is a general outcome.
- Whether is indicator is a service outcome (these two categories are not mutually exclusive).
- Whether the indicator has previously been used with people with learning disabilities or family members.
- Whether the indicator has previously been used in the UK.
- Whether the indicator can be compared to the UK general population.

During the Phase 2 consultations (Hatton et al., 2006), people with learning disabilities and family carers identified their priority outcome areas. Because many of these are at a general level (e.g. “Going out when you want”; “Having a sense of control”) these could not be mapped directly on to the specific outcome indicators in the following tables. Phase 2 also gained suggested performance indicators from professionals; although these suggested performance indicators were specific, they were not generally concerned with outcomes for people with learning disabilities, and therefore also could not be mapped directly on to the specific outcome indicators below. However, when considering which outcome indicators to prioritise, it is important for the reader to take into account the priorities identified during the Phase 2 consultations.

# Choice and Control

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| Did you choose or pick the place where you live?<br>IF YES, did you have any help choosing? | NSALDE<br>NCI | User or Informant | Yes | Yes | Yes | Yes | |
| Did you choose or pick the people you live with?<br>IF YES, did you have any help choosing? | NSALDE<br>NCI | User or informant | Yes | Yes | Yes | Yes | |
| If the person with learning disabilities is not in a private household with parents/partner/family: Are there any rules about what you can do where you live?<br>IF YES, are you happy with these rules? | NSALDE<br>SP | User or informant | | Yes | Yes | Yes | |
| Do you choose who helps you at home? | NCI CS | User or Informant | Yes | Yes | Yes | | |
| Who chose the place where you work (or go to during the day?) | NCI CS | User or Informant | Yes | Yes | Yes | | |
| Did you choose what job you would do? | NSALDE<br>NCI | User or informant | Yes | Yes | Yes | Yes | |
| Do you choose who helps you at work? | NCI CS | User or Informant | Yes | Yes | Yes | | |
| Would you like to have more say in what to do in your everyday life? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Do you choose what you do in the daytime or do other people tell you what to do?<br>And do you choose what you do in the evenings? | NSALDE<br>NCI | User or informant | Yes | Yes | Yes | Yes | |
| Who decides your daily schedule? | NCI CS | User or informant | Yes | Yes | Yes | | |

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| Who decides how you spend your free time? | NCI CS | User or informant | Yes | Yes | Yes | | |
| If in a paid job, is the money paid to you personally for you to choose what to do with it or is it paid to someone else for them to look after for you? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Do you choose how much money you spend each week (or does someone else decide how much money you can have)? | NSALDE<br>NCI | User or informant | Yes | Yes | Yes | Yes | |
| Do you choose the things you buy with your money? | NSALDE<br>NCI | User or informant | Yes | Yes | Yes | Yes | |
| Do you have control over your own budget? | NCI CS (proposed) | User or Informant | Yes | Yes | Yes | | |
| Can you see your friends when you want to see them? | NCI CS | User | Yes | Yes | Yes | | |
| Can you see your family when you want to see them? | NCI CS | User | Yes | Yes | Yes | | |
| If not in residential care: Does anyone ever open your letters without asking? | NSALDE<br>NCI | User of informant | | Yes | Yes | Yes | |
| If not in residential care: When people come to visit can you be alone with them or does someone have to be with you? | NSALDE<br>NCI | User of informant | | Yes | Yes | Yes | |
| Are you allowed to use the phone when you want to? | NCI CS | User or Informant | | Yes | Yes | Yes | |
| If not in residential care: Does anyone come into your home without asking or when you don’t want them to? | NSALDE<br>NCI | User or informant | | Yes | Yes | Yes | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| If not in residential care:<br>Does anyone come into your room without asking or when you don't want them to?<br>IF YES, who does this? | NSALDE<br>NCI | User or informant |  | Yes | Yes | Yes |  |
| If not in residential care:<br>Can you be by yourself as much as you want to? | NSALDE<br>NCI | User or informant |  | Yes | Yes | Yes |  |
| Do you have a person other than your family who helps you to speak up?<br>IF YES, are they paid to help you speak up or do they do it in their own time? | NSALDE<br>NCI | User or informant | Yes | Yes | Yes | Yes |  |
| Do you know about any groups in your area which can help you speak up (e.g. self-advocacy groups)?<br>Have you ever taken part in a meeting where you put forward your views and help say what sort of services you need?<br>IF YES, do you go to these sorts of meetings often?<br>Do these let people with learning difficulties speak up? | NSALDE<br>NCI | User | Yes | Yes | Yes | Yes |  |
| Did you choose your case manager/service co-ordinator? | NCI CS | User or informant | Yes | Yes | Yes |  |  |
| To what extent do you agree or disagree with the following statements:<br>I can influence decisions affecting my local area?<br>By working together, people in my area can influence decisions that affect the local area? | SCHQS | User or informant? | Yes |  |  | Yes | Yes |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| In the last 12 months, have you taken any of the following actions in an attempt to solve a problem affecting people in your local area:<br>(list of options, including contacting local media outlets, contacting councillor or MP, attending public meetings, organising petitions etc) | SCHQS | User or informant? | Yes | | | Yes | Yes |
| In the last 12 months, have you taken any of the following actions to show your concern over a national issue:<br>(list of options, including contacting media outlets, contacting MP, attending public meetings, organising petitions etc) | SCHQS | User or informant? | Yes | | | Yes | Yes |

# Social Inclusion

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Do you have friends you like to talk to or do things with? (staff, family, other people) | NCI CS | User | Yes | Yes | Yes | | |
| Do have friends you like to talk to or do things with? (outside of your family)<br>IF YES, do any of these friends have a learning difficulty?<br>IF YES, do you see them every day or nearly every day?<br>IF NO, do you see them every week or nearly every week?<br>IF NO, do you see them at least a few times a year?<br>Do you have any friends who do not have a learning difficulty outside of your family?<br>IF YES, are these/your friends all paid support workers?<br>IF NO, can you think about your friends who don't have learning difficulties and who are NOT support workers? Do you see any of them every day or nearly every day?<br>IF NO, do you see them every week or nearly every week?<br>IF NO, do you see them at least a few times a year? | NSALDE PSE | User or informant | Yes | Yes | Yes | Yes | Yes |

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| Do you have a best friend, or someone you are really close to? | NCI CS | User | Yes | Yes | Yes | | |
| Frequency of visits between family member and adult not living in family home | NCI FGS | Family member | | Yes | Yes | | |
| Do you ever see anyone in your family (apart from the people you live with)?<br>IF YES, do you see them every day or nearly every day?<br>IF NO, do you see them every week or nearly every week?<br>IF NO, do you see them at least a few times a year? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Can you see your friends and family as often as you want to see them or would you like to see them more often?<br>IF NO, what stops you seeing them more often?<br>Not enough money<br>Not enough time<br>Travel problems – can't get there/too far<br>Too ill/disabled – can't get out<br>Fear of going out (e.g. bullying)<br>Need someone to help me – not always anyone to help<br>Other | NSALDE PSE | User or informant | | Yes | Yes | Yes | Yes |
| Do you ever feel lonely? | NCI CS | User | Yes | Yes | Yes | | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Have people been rude or nasty to you because of your learning difficulty in the past year?<br>IF YES, who was rude or nasty to you? (paid support worker/carer/staff at residential home, some you live with [not support worker], someone at day centre [not support worker], someone you work with, a stranger/someone you did not know, other) | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Do you have someone you can ask for help if you are feeling a bit down or sad? | NSALDE PSE | User or informant | Yes | Yes | Yes | Yes | Yes |
| Not counting the people you live with, how often do you do any of the following?<br>Speak to relatives on the phone<br>Write a letter or note to relatives<br>Text or email relatives, or use chatrooms on the internet to talk to relatives<br>Speak to friends on the phone<br>Write a letter or note to friends<br>Text or email friends, or use chatrooms on the internet to talk to friends<br>Speak to neighbours<br>How often do you meet up with relatives who are not living with you?<br>How often do you meet up with friends? | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |
| You are ill in bed and need help at home. Is there anyone you could ask for help?<br>If yes, who? | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| If you had a personal crisis, how many people, if any, do you feel you could turn to for comfort and support? | SCHQS | User or informant? | Yes | Yes |  | Yes | Yes |
| Are you married or living with a partner? (if no, have you ever been married) | NSALDE | User or informant | Yes |  | Yes | Yes |  |
| If living with anyone and not in residential care. Caring for children:<br>Do you have any children?<br>IF YES, how many?<br>Do you look after your children/child?<br>Does anyone help you look after them (parent, partner, child, other relative, friend, paid help/professional support person/staff at residential home, social services, other)?<br>How happy are you with the help you receive?<br>Would you like (more) help looking after your child/children? | NSALDE | User or informant | Yes | Yes | Yes | Yes |  |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| If living with anyone and not in residential care. Caring for an adult:<br>Does anyone live with you who is old, sick or disabled?<br>IF YES, do you have to look after them?<br>IF YES, who is it you look after? (parent, partner, child, other relative, friend)<br>What do you do to help them? (cooking, washing/ironing, cleaning, shopping, personal care)<br>Does anyone help you to look after them?<br>IF YES, who helps you? (parent, partner, child, other relative, friend, paid help/professional support person/staff at residential home, other)<br>How happy are you with the help you get?<br>Would you like more help looking after them? | NSALDE GHS/HSE | User or informant | Yes | Yes | Yes | Yes | Yes |
| When you want to go somewhere, do you always have a way to get there? | NCI CS | User |  | Yes | Yes |  |  |
| When you want to go somewhere, do you usually need someone to go with you?<br>IF YES, is there usually someone around who can help you when you want to go somewhere or do you usually have to wait until some other time?<br>IF NO/DEPENDS, when you want to go somewhere can you usually get there? | NSALDE NCI | User or informant |  | Yes | Yes | Yes |  |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| How do you usually get to places? (walk/in wheelchair, taken by family/friends in car, taken by special bus/car with other people with learning difficulties, taxi, bus/tram (public transport), train, tube, bike) | NSALDE | User or informant |  | Yes | Yes | Yes |  |
| Do you ever have problems using public transport?<br>Do you feel safe using public transport?<br>How easy is it for you to use public transport?<br>How helpful do you usually find the staff on public transport? | NSALDE | User or informant |  | Yes | Yes | Yes |  |
| Have you had training in using public transport?<br>Would you like some training? | NSALDE | User or informant |  | Yes | Yes | Yes |  |
| Do you ever go to a day centre?<br>IF YES<br>How many days a week do you go to (name of day centre)?<br>Are the staff at (name of day centre) nice and polite to you? | NSALDE NCI | User or informant |  | Yes | Yes | Yes |  |
| If go to day centre:<br>Do you like going to (name of day centre)? | NSALDE | User or informant |  | Yes | Yes | Yes |  |
| Do you like working at [your job or day activity]? | NCI CS | User | Yes | Yes | Yes |  |  |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Are you doing any courses or doing any training at the moment?<br>IF YES, is this at college, at work, at a day centre or somewhere else?<br>What courses are you doing?<br>IF NO, would you like to do a course or some training? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Do you go shopping? | NCI CS | User or Informant | | Yes | Yes | | |
| Do you go out on errands or appointments? | NCI CS | User or Informant | | Yes | Yes | | |
| Do you go out for entertainment? | NCI CS | User or Informant | | Yes | Yes | | |
| Do you always eat at home, or do you sometimes go out to eat? | NCI CS | User or Informant | | Yes | Yes | | |
| Do you go to religious services? | NCI CS | User or Informant | | Yes | Yes | | |
| Do you go to clubs or other community meetings? | NCI CS | User or Informant | | Yes | Yes | | |
| Do you exercise or play sports? | NCI CS | User or Informant | | Yes | Yes | | |

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| For each item below, ask the following:<br>I want you to think now about other things you do in your free time. In the last month have you gone…<br>FOR EACH ITEM YES: And do you like going…<br>FOR EACH ITEM NO: Would you like to go … more often?<br>Shopping<br>To the pub or club<br>For a meal in a restaurant or pub or café<br>To the library (includes mobile library)<br>To play sport or go swimming<br>To visit friends or family<br>To a hairdresser<br>To watch sport (not on TV)<br>To the cinema, or to plays or concerts | NSALDE PSE | User or informant | Yes | Yes | Yes | Yes | |
| IF NOT MENTIONED MEAL IN RESTAURANT AT LEAST ONCE A MONTH: Do you always eat at home or do you sometimes go out to eat? | NSALDE NCI | User or informant | | Yes | Yes | Yes | |
| Have you been on holiday in the last year? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Do you sometimes go out on day trips? | NSALDE | User or informant | | Yes | Yes | Yes | |
| What do you enjoy doing most of all in your free time?<br>Do you get to do this often enough? Would you like to do this more? | NSALDE | User | | Yes | Yes | Yes | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| In the last 12 months, have you been involved with any groups of people who get together to do an activity or to talk about things? These could include evening classes, support groups, slimming clubs, keep-fit classes, pub teams and so on? (list of options of types of groups presented) | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |
| In the last 12 months, have you taken part in any (other) group activities as part of a local community group, club or organisation? These could include residents' associations, sports groups, parent-teacher associations, school or religious groups and so on. (list of options of types of groups presented) | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |
| In the last 12 months, have you taken part in any (other) group activities as part of a national group, club or organisation? These could include pressure groups, charities, political groups, environmental groups and so on. (list of options of types of groups presented) | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| During the last 12 months have you given any unpaid help to any groups, clubs or organisations in any of the ways shown on this card? (list of options presented)<br>Thinking about the unpaid help you have mentioned, would you say that you give this kind of help (at least once a week …less often than every three months) | SCHQS | User or informant? | Yes | | | Yes | Yes |
| When you want to know something, is it easy to find out in a way you can understand? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Are you ever afraid or scared when you are out in your neighbourhood? | NCI CS | User | Yes | Yes | Yes | | |
| Do you feel safe in the area where you live? | NSALDE SP | User or informant | Yes | Yes | Yes | Yes | |
| Have you been the victim of a crime in the past year?<br>IF YES<br>How many times?<br>What happened to you last time?<br>Did you tell the police about it?<br>IF YES, what did they do? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| How satisfied are you with this area as a place to live? | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |
| In general, what kind of neighbourhood would you say you live in – would you say it is a neighbourhood in which people do things together and try to help each other, or one in which people mostly go their own way? | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| To what extent do you agree or disagree that this neighbourhood is a place where people from different backgrounds get on well together? | SCHQS | User or informant? | Yes | Yes |  | Yes | Yes |
| Would you say that…(most of the people in your neighbourhood can be trusted, some can be trusted, a few can be trusted or that no-one can be trusted? | SCHQS | User or informant? | Yes | Yes |  | Yes | Yes |
| In your neighbourhood, how much of a problem is/are…<br>people being drunk or rowdy in public places?<br>rubbish or litter lying around?<br>vandalism, graffiti and other deliberate damage to property or vehicles?<br>people using or dealing drugs?<br>people being attacked or harassed because of their skin colour, ethnic origin or religion?<br>teenagers hanging around on the street?<br>troublesome neighbours? | SCHQS | User or informant? | Yes | Yes |  | Yes | Yes |
|  |  |  |  |  |  |  |  |
| Did you vote in the last general election? | NSALDE | User or informant | Yes |  | Yes | Yes |  |
| Have you heard of the Government White Paper Valuing People before today?<br>Have you heard of the National Forum for people with learning difficulties? | NSALDE | User | Yes | Yes | Yes | Yes |  |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Have you heard of your local Learning Disability Partnership Board?<br>Have you or your family been involved in your local Partnership Board? | NSALDE | User | Yes | Yes | Yes | Yes | |

# Employment

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| The average monthly earnings of people who have jobs in the community | NCI CSS | User or Informant | Yes | Yes | Yes | | |
| The average number of hours worked per month for people with jobs in the community | NCI CSS | User or Informant | Yes | Yes | Yes | | |
| The percent of people earning at or above the state minimum wage | NCI CSS | User or Informant | Yes | Yes | Yes | | |
| Of people who have a job in the community, the percent who were continuously employed during the previous year | NCI CSS | User or Informant | Yes | Yes | Yes | | |
| Of people who have a job in the community, the percent who receive job benefits | NCI CSS | User or Informant | Yes | Yes | Yes | | |
| Of people who have a job in the community, the average length of time people have been working at their current job | NCI CSS | User or Informant | Yes | Yes | Yes | | |
| Do you have a job at the moment? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| IF NO JOB, why don't you have a job?<br>If no job and able to work:<br>Would you like a job?<br>Are you worried that if you got a job you might lose some of your benefits?<br>Would you like a job even if it meant losing some of your benefits? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| IF HAVE A JOB:<br>What job do you do?<br>How many hours a week do you usually work in this job?<br>Is this the number of hours you want to work?<br>IF NO, would you like to work more hours or less hours?<br>Are you paid to do this job?<br>Are you paid per hour you work, or are you paid for each shift, each time you work, each thing you do etc.?<br>How much are you usually paid each time/paid per hour?<br>When you started working, did you lose any of your benefits?<br>IF YES, did this cause any problems? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Do you think your pay is fair? | ANSS | User | Yes | Yes | Yes | | |
| Do you get to learn new things at work? | ANSS | User | | Yes | Yes | | |
| Do you want to change the hours you work? | ANSS | User | | Yes | Yes | | |
| Do you want to leave your job? | ANSS | User | Yes | Yes | Yes | | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Finding a job.<br>Ask all who work or want to work:<br>Which of these have you heard of: (the WORKSTEP programme; the Jobs-Help programme (DUMMY); The New Deal (for Disabled People); Connexions Service (only ask people<25)?<br>For each heard of:<br>Have you used them?<br>Are you happy with them?<br>Have you been offered any training to help you take up a job?<br>Do/did you get any help looking for a job?<br>IF YES, who from (parent, partner, other relative, friend, paid support person/carer/staff at residential home, social services, WORKSTEP, New Deal, Connexions, Job Centre, other) | NSALDE | User or informant |  | Yes | Yes | Yes |  |
| Do you like your job? | NSALDE | User or informant | Yes | Yes | Yes | Yes |  |
| If in a job:<br>Do you have someone who can help you out at work? | NSALDE | User or informant |  | Yes | Yes | Yes |  |
| If in a job, does anyone ever bully you at work? | NSALDE | User or informant | Yes | Yes | Yes | Yes |  |

# Housing

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Do you live in (fully private household, supported housing, residential care, long-stay hospital or retained NHS bed)?<br>If residential, who runs (name of residential care) (NHS, private, charity/voluntary organisation)?<br>If fully private or supported, is the place you live owned or rented?<br>If rented, is it rented from council/housing association or private landlord? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Have you ever had any help with your housing?<br>IF YES for paid help: How happy were you with the help you received from (each type of paid help)…<br>IF NO HELP MENTIONED, did you know that there are people who you can go to for information about housing? | NSALDE | User or informant | | Yes | Yes | Yes | |
| If person with learning disabilities is not in residential accommodation:<br>Does someone help you at home?<br>IF NO-ONE HELPS, would you like someone to help you at home?<br>IF SOMEONE HELPS:<br>Did you choose or pick who helps you?<br>Who helps you? Is it a relative or a paid support person?<br>How often do you get help from (each person mentioned as supporting)? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Do you like your home or where you live? | NCI CS | User | Yes | Yes | Yes | | |
| Do you like living there (in current home)?<br>IF NO, what don't you like about it? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| Do you want to move out of the place where you live? | ANSS | User | Yes | Yes | Yes | | |
| Are you ever afraid or scared when you are at home? | NCI CS | User | Yes | Yes | Yes | | |
| Do you feel safe when you are at home at night? | NSALDE SP | User or informant | Yes | Yes | Yes | Yes | |
| Is [staff who helps you at home] nice and polite to you? | NCI CS | User | | Yes | Yes | | |
| Do the staff where you live treat you with respect? | ANSS | User | | Yes | Yes | | |
| Are the staff where you live able to understand what you want? | ANSS | User | | Yes | Yes | | |
| Do you understand the staff where you live when they talk to you? | ANSS | User | | Yes | Yes | | |
| Do the staff who support you in your home change too often? | ANSS | User | | Yes | Yes | | |
| Can you learn new things where you live if you want to – so that you can do more for yourself? | ANSS | User | | Yes | Yes | | |

# Health

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| When was his/her last physical exam? | NCI CS | Informant | | Yes | Yes | | |
| If you were ill, who would you go to for help? (doctor, hospital, partner, child, other relative, friend, paid support person/carer/staff in residential home, other)<br>IF NOT DOCTOR, do you have a doctor who you can see if you get ill?<br>IF YES, do you get on well with your doctor?<br>Have you been to the doctor in the last year? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Have you had any toothache or pain in your teeth in the last 6 months?<br>Have you been to the dentist in the last year?<br>Do you just go to the dentist when your teeth hurt, or do you go for a check up as well? | NSALDE HSE | User or informant | Yes | Yes | Yes | Yes | Yes |
| Have you had your eye sight tested this year?<br>Have you had your hearing tested this year? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| WOMEN ONLY<br>Have you ever had a cervical smear test?<br>Have you ever had your breasts checked for lumps by a doctor or nurse? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Is (name of person with learning disabilities) registered with a GP?<br>And are they registered with a dentist? | NSALDE | Informant | Yes | Yes | Yes | Yes | |
| Does this person currently take medications for:<br>Mood disorders<br>Anxiety<br>Behavior | NCI CS | Informant | | Yes | Yes | | |

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| Do you maintain healthy habits in:<br>Smoking<br>Exercise<br>Your weight | NCI CS (proposed) | User or Informant | Yes | Yes | Yes | | |
| In the last year would you say your health was very good, fairly good or not good? | NSALDE Census | User or informant | Yes | Yes | Yes | Yes | Yes |
| Do you smoke cigarettes nowadays? | NSALDE HSE | User or informant | Yes | Yes | Yes | Yes | Yes |
| Do you ever do any exercise these days that make you out of breath and sweaty?<br>How many days a week do you do this? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| How satisfied are you with your life in general? | NCI CS (proposed) | User | Yes | | Yes | | |
| How do you feel about your life at the moment? | NSALDE SP | User or informant | Yes | | Yes | Yes | |
| All of us feel a bit unhappy or worried at times.<br>Do you ever feel sad or worried?<br>IF YES, is that a lot or just sometimes?<br>Do you ever feel left out of things?<br>IF YES, is that a lot or just sometimes?<br>Do you ever feel helpless?<br>IF YES, is that a lot or just sometimes?<br>Do you ever feel confident about yourself?<br>IF YES, is that a lot or just sometimes? | NSALDE PSE | User or informant | Yes | Yes | Yes | Yes | Yes |

# Economic Well-Being

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Indices of neighbourhood deprivation of dwelling | NSALDE | Postcode | Yes | Yes | Yes | Yes | Yes |
| Household income (for children and adults living with family members) | NCI CFS/AFS | Family member | Yes | Yes | Yes | | |
| If not living alone and not in residential accommodation: Including yourself, how many people live here? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Is it usually warm enough where you live? | NSALDE | User or informant | | Yes | Yes | Yes | |
| Is there enough room for everyone where you live? | NSALDE | User or informant | | Yes | Yes | Yes | |
| If not in private household with parents/partner/family:<br>Do you share a bathroom with other people?<br>IF YES, do you like sharing a bathroom?<br>Do you share a kitchen with other people?<br>IF YES, do you like sharing a kitchen? | NSALDE SP | User or informant | | Yes | Yes | Yes | |
| Would you say (person's) accommodation is suitable for them given his/her needs? | NSALDE | Informant | | Yes | Yes | Yes | |
| Have special changes been made to where you live because of your problems? (long-standing illness/physical disability) | NSALDE | User or informant | | Yes | Yes | Yes | |
| You are in financial difficulty and need to borrow some money to see you through the next few days. Is there anyone you could ask for help?<br>If yes, who? | SCHQS | User or informant? | Yes | Yes | | Yes | Yes |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Sometimes, when money is tight, people have to go without things. In the last year, have you had always had enough money for (each item in list) when you wanted it/them?<br>New Clothes<br>New Shoes<br>Food<br>Heating<br>Telephoning friends or family<br>Going out<br>Visits to the pub or a club<br>A hobby or sport<br>A holiday | NSALDE PSE | User or informant | Yes | Yes | Yes | Yes | Yes |
| Do you have enough money to do the things you want to do (or would you like more)? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Do you receive any benefits?<br>IF YES, what benefits do you receive? (Disability Living Allowance, Severe Disability Allowance, Income Support, Incapacity Benefit, Housing Benefit, Other)<br>Do you receive your benefits yourself or does someone else receive them for you? (parent, partner, child, other relative, friend, paid help/professional support person/staff at residential home, social services, other)<br>Would you like to get the benefits yourself?<br>[To informants only} Can I just check whether (name of person with learning disabilities) does receive all of their own benefits, or whether somebody else receives them and manages them on their behalf? | NSALDE | User or informant | Yes | Yes | Yes | Yes | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Have you heard of Direct Payments? This is where you get money yourself and you buy the services you need with that money. This is instead of other people choosing things for you.<br>Have you applied for Direct Payments?<br>Do you get Direct Payments?<br>[Some doubts about the wording of this question in distinguishing between direct payments and the direct payment of benefits into the person's bank account] | NSALDE | User or informant | Yes | Yes | Yes | Yes | |
| Does someone help you look after your money?<br>Who helps you? (parent, partner, child, other relative, friend, paid help/professional support person/staff at residential home)<br>Would you like any (more) help with looking after your money? Who from? (parent, partner, child, other relative, friend, paid help/professional support person/staff at residential home) | NSALDE | User or informant | | Yes | Yes | Yes | |

## Experience of Services

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Thinking about all the things you need support or help with…<br>How happy are you with the support you get?<br>Who arranges this support for you? (family member, friend [not paid], paid support person/staff at residential home, social worker/care manager, key worker/care worker, other)<br>Have you ever wanted to complain about the support you get? | NSALDE | User or informant | | Yes | Yes | Yes | |
| If you ask for something, does [your case manager/service co-ordinator] help you get what you need? | NCI CS | User | | Yes | Yes | | |
| Does [your case manager/service co-ordinator] ask you what you want? | NCI CS | User | | Yes | Yes | | |
| Do you know your case manager/service co-ordinator? | NCI CS | User | | Yes | Yes | | |
| Do you get the services you need | NCI CS | User or informant | | Yes | Yes | | |
| Do people help you do new things you want to do? | NCI CS | User | | Yes | Yes | | |

## Transition

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Do you still go to school or college? | NSALDE<br>Census | User or informant | Yes | Yes | Yes | Yes | Yes |

Note: Assessing the outcomes of transition planning should largely concern evaluating the outcomes listed throughout all the tables to young people.

# Families

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Family members with an adult with developmental disabilities living with them:<br>Do you or your family member choose the agencies or providers that work with your family?<br>Do you or your family member choose the support workers who work with your family?<br>If your family member gets day or employment services, does the agency providing these services involve you in important decisions?<br>Do you or your family member have control and/or input over the hiring and management of your support workers?<br>Do you or your family member want to have control/input over the hiring and management of your support workers?<br>Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?<br>Do you or your family member get to decide how this money is spent? | NCI AFS | Family member | | Yes | Yes | | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Family members with an adult with developmental disabilities living elsewhere:<br>Does the agency providing residential services to your family member involve you in important decisions?<br>If your family member gets day or employment services, does the agency providing these services involve you in important decisions?<br>Do you or your family member choose the support workers who work with your family?<br>Do you or your family member have control and/or input over the hiring and management of your family member's support workers?<br>Do you or your family member want to have control/input over the hiring and management of your family member's support workers?<br>Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?<br>Do you or your family member get to decide how this money is spent? | NCI FGS | Family member | | Yes | Yes | | |
| Does family of adult with developmental disabilities living with family receive:<br>Financial support<br>In-home support<br>Out-of-home respite care<br>Day/employment supports<br>Transportation<br>Other | NCI AFS | Family member | | Yes | Yes | | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Does family of adult with developmental disabilities living elsewhere receive:<br>Residential supports<br>Day/employment supports<br>Transportation<br>Other services/supports | NCI FGS | Family member | | Yes | Yes | | |
| For families with an adult with developmental disabilities living with them:<br>Do you receive information about the services and supports that are available to your family?<br>If you receive information, is it easy to understand?<br>Do you get enough information to help you participate in planning services for your family?<br>If your family member has a service plan, did you help develop the plan?<br>If your family member has a service plan, does the plan include things that are important to you?<br>Do the staff who assist you with planning help you figure out what you need as a family to support your family member?<br>Do the staff who assist you with planning respect your choices and opinions?<br>Are the staff who help you with planning generally respectful and courteous?<br>Can you contact the staff who assist you with planning whenever you want to? | NCI AFS | Family member | | Yes | Yes | | |

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| For families with an adult with developmental disabilities living elsewhere:<br>Do you get enough information to help you participate in planning services for your family member?<br>If your family member has a service plan, did you help develop the plan?<br>If your family member has a service plan, does the plan include things that are important to you?<br>Are the staff who assist you with planning generally respectful and courteous?<br>Are the staff who assist you with planning generally effective?<br>Can you contact the staff who assist you with planning whenever you want to? | NCI FGS | Family member | | Yes | Yes | | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| For families with an adult with developmental disabilities living with them:<br>When you ask the service/support coordinator for assistance, does he/she help you get what you need?<br>Does your family get the services and supports you need?<br>Do the services and supports offered meet your family's needs?<br>Are supports available when your family needs them?<br>Do families in your area request that different types of services and supports be made available in your area?<br>If yes, does either the state agency or provider agency respond to their requests?<br>If you have ever asked for services or supports in an emergency or crisis, was help provided to you right away?<br>If English is not your first language, are there support workers or translators available to speak with you in your preferred language?<br>If your family member does not speak English or uses a different way to communicate (e.g. sign language), are there enough support workers available who can communicate with him/her?<br>Does your family member have access to the special equipment or accommodations that he/she needs (e.g. wheelchair, ramp, communications board)?<br>Do you have access to health services for your family member?<br>Do you access to dental services for your family member?<br>Do you have access to necessary medications for your family member?<br>Are frequent changes in support staff a problem for your family?<br>Do you feel that your family member's day/employment setting is a healthy and safe environment?<br>Are support staff generally respectful and courteous? | NCI AFS | Family member | | Yes | Yes | | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| For families with an adult with developmental disabilities living elsewhere:<br>When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?<br>Does your family member get the services and supports he/she needs?<br>If your family member does not speak English or uses a different way to communicate (e.g. sign language), are there enough support workers available who can communicate with him/her?<br>Does your family member have access to the special equipment or accommodations that he/she needs (e.g. wheelchair, ramp, communications board)?<br>Are frequent changes in support staff a problem for your family?<br>Do you feel that your family member's residential setting is a healthy and safe environment?<br>Do you feel that your family member's day/employment setting is a healthy and safe environment? | NCI GFS | Family member | | Yes | Yes | | |

| **Indicator** | **Reference** | **Source** | **General Outcome** | **Service Outcome** | **Learning Disability** | **UK** | **UK General Population** |
|---|---|---|---|---|---|---|---|
| For families with an adult with developmental disabilities living with them:<br>If you want to use typical supports in your community (e.g. through recreation departments or churches), do either the staff who help you plan or who provide support help connect you to these supports?<br>If you would like to use family, friends, or neighbours to provide some of the supports your family needs, do either the staff who help you plan or who provide support help you to do this?<br>Do you feel that your family member has access to community activities?<br>Does your family member participate in community activities? | NCI AFS | Family member | | Yes | Yes | | |
| For families with an adult with developmental disabilities living elsewhere:<br>If your family member wants to use typical supports in your community (e.g. through recreation departments or churches), do either the staff who help plan or who provide support help connect him/her to these supports?<br>If your family member would like to use family, friends, or neighbours to provide some of the supports your family needs, do either the staff who help plan or who provide support help him/her do this?<br>Do you feel that your family member has access to community activities?<br>Does your family member participate in community activities? | NCI FGS | Family member | | Yes | Yes | | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| For families with an adult with developmental disabilities living with them:<br>Overall, are you satisfied with the services and supports your family member currently receives?<br>Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?<br>Are you satisfied with the way complaints/grievances are handled and resolved?<br>Do you feel that services and supports have made a positive difference in the life of your family?<br>Have services made a difference in helping keep your family member at home?<br>Would your family member still be at home if you did not receive any services?<br>Overall, do you feel that your family member is happy? | NCI CFS | Family member | | Yes | Yes | | |
| For families with an adult with developmental disabilities elsewhere:<br>Overall, are you satisfied with the services and supports your family member currently receives?<br>Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?<br>Are you satisfied with the way complaints/grievances are handled and resolved?<br>Do you feel that services and supports have made a positive difference in the life of your family?<br>Overall, do you feel that your family member is happy? | NCI CFS | Family member | | Yes | Yes | | |

# Added Domain: Factors Potentially Associated with Outcomes

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Do you live in the countryside or in a town? | NSALDE | User or informant | | | Yes | Yes | |
| Who do you live with? | NSALDE | User or informant | | | Yes | Yes | |
| Do you live in a caravan or in a flat or in a house?<br>About how long have you lived there? | NSALDE – Census<br>NSALDE | User or informant | | | Yes | Yes | Yes |
| How old are you? | NSALDE | User or informant | | | Yes | Yes | Yes |
| Are you male or female? | NSALDE | User or informant | | | Yes | Yes | Yes |
| Which ethnic group do you consider you belong to? | NSALDE - Census | User or informant | | | Yes | Yes | Yes |
| Is English your main language? | NSALDE | User | | | Yes | Yes | |
| Do you have any qualifications or exams?<br>IF YES, what have you got? (NVQs, GCSE/O levels, A levels, Degree/HND, City & Guilds, Btec, Other<br>IF HAVE GCSE/O levels:<br>How many GCSEs/O levels have you got?<br>What is the highest grade you got at GCSE or O level? (A* - G)<br>IF HAVE A levels:<br>How many A levels have you got?<br>What is the highest grade you got at A level? (A – E, N, U)<br>[partly used in survey as additional screening item for learning disability] | NSALDE | User or informant | Yes | Yes | Yes | Yes | Yes |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| If person with learning disabilities lives with parents: About how old are they? | NSALDE | User or informant | | | Yes | Yes | |
| Do you have an illness or physical disability that you have had for a long time?<br>IF YES, what is this? (physical disability, difficulty seeing, difficulty hearing, difficulty speaking, mental health problem, epilepsy, autism, other) | NSALDE | User or informant | | | Yes | Yes | Yes |
| 1) I want you to tell me for each thing whether you can do it on your own, or you need a bit of help, a lot of help or someone to do it for you…<br>2) (For each thing), and do you get any help with…<br>Getting dressed in the morning<br>Putting on a pair of shoes<br>Having a shower or bath<br>Ordering something to eat or drink in a café<br>Drinking a cup of tea<br>Washing your clothes<br>Making a sandwich<br>Filling in a form (for example if you were applying for a job)<br>Finding out what is on the TV tonight?<br>Paying money into your bank or Post Office<br>Making an appointment (for example to see your doctor) | NSALDE | User or informant | | | Yes | Yes | |

| Indicator | Reference | Source | General Outcome | Service Outcome | Learning Disability | UK | UK General Population |
|---|---|---|---|---|---|---|---|
| Background Information Variables:<br>Age<br>Gender<br>Legal status<br>Level of learning disability (none, mild, moderate, severe, profound)<br>Diagnosis (profound and multiple learning disability, autism, cerebral palsy, chemical dependency, sensory disability, physical disability, communication disorder, Alzheimer's, other)<br>Seizure disorder, brain injury, neurological problems<br>Expressive language<br>Mobility<br>Requires medical care<br>Challenging behaviour | NCI | Informant | | | Yes | | |

## Notes to Tables

| | | |
|---|---|---|
| NCI | | National Core Indicators Project (USA) |
| | CS | Consumer Survey – interview with service user (and informant if person wishes) |
| | CSS | Consumer Survey Supplement – interview with service user (and informant if person wishes) |
| | CSF | Child Family Survey – postal questionnaire with families with a child with developmental disabilities |
| | ASF | Adult Family Survey – postal questionnaire with families with an adult with developmental disabilities living with them |
| | FGS | Family Guardian Survey – postal questionnaire with families with an adult with developmental disabilities not living with them |
| NSALDE | | National Survey of Adults with Learning Difficulties in England (UK) |
| | Census | Used/adapted from ONS 2001 Census |
| | SP | Used/adapted from Supporting People survey |
| | NCI | Used/adapted from National Core Indicators Project |
| | GHS | Used/adapted from General Household Survey |
| | HSE | Used/adapted from Health Survey for England |
| | PSE | Used/adapted from the Poverty & Social Exclusion Survey |
| ANSS | | National Satisfaction Survey of Clients of Disability Services (Australia) |
| SCHQS | | Social Capital Harmonised Question Set |

# 2) Developing Practical Methods for Evaluating Outcomes

This part of the project consisted of working with other agencies and individuals to take forward the findings and ideas from this project into the development of performance indicators. We decided that this approach of working with other agencies was a more effective use of project resources compared to a stand-alone project phase developing outcome indicators in isolation. Several relevant agencies are already reviewing performance indicators in the light of recent policy developments, and we thought the findings of this project would have a greater impact if we worked within the framework of other agencies' reviews rather than developing a stand-alone set of indicators outside these review processes.

**Commission for Social Care Inspection Performance Indicators: Services for people with learning disabilities**. The project team were part of a group advising the Commission for Social Care Inspection on the development of new performance indicators for services for people with learning disabilities. In July 2006 this group produced a set of recommendations for new performance indicators; these recommendations are currently being evaluated by the Commission for Social Care Inspection with the aim of implementation for 2007/2008. The full document with details of the recommended performance indicators is presented in Appendix 1. Some crucial aspects of these recommendations include:

- Routinely including within CSCI performance indicators all adults with learning disabilities receiving support funded by social services or the NHS within a local authority.
- Developing a number of joint indicators with the Healthcare Commission.
- Ensuring that all performance indicators can be broken down by ethnic group to enable the investigation of inequalities in access across ethnic groups.
- Scaling all indicators according to number of people per 10,000 local adult population, to improve comparability between local authorities.

There are 15 recommended performance indicators, grouped under the outcome headings of the White Paper Our Health, Our Care, Our Say (Department of Health, 2006):

*Improved health and emotional well-being:*

- Number of people with completed health action plans (proposed joint indicator with the Healthcare Commission)

*Improved quality of life:*

- Number of people supported to live in the community
- Number of carers receiving support from the council
- Number of carers receiving short-term breaks and emergency support
- Number of people living in each of the following types of housing
    - Living in housing owned or rented by a family member aged under 65
    - Living in housing owned or rented by a family member aged 65 or over
    - Homeowner
    - Shared ownership
    - Tenant in self-contained accommodation
    - Tenant in shared accommodation (3 people or more)
    - Supported lodgings or adult placement
    - Residential care home
    - Nursing home
    - NHS residential accommodation
    - Other
- Number of people living as tenants or homeowners

- Number of people living in residential services (proposed joint indicator with the Healthcare Commission)
- Number of people living outside the local authority boundary (proposed joint indicator with the Healthcare Commission)

*Making a positive contribution:*
- Number of people doing voluntary work and work experience

*Choice and control:*
- Number of people receiving a direct payment
- Number of people receiving another form of individual budget
- Local authority spend on advocacy

*Freedom from discrimination:*
- Number of reports of harassment and abuse against people with learning disabilities

*Economic well-being:*
- Number of people in full-time employment (16+ hours per week at minimum wage or above)
- Number of people in part-time employment (less than 16 hours per week at minimum wage or above)

*Personal dignity:* No performance indicators recommended

**Progressing In Control: Minimum Information Collection System (PICMICS)**. The project team has been working with in Control and local authorities to develop a minimum dataset for local authorities supported by in Control (approximately 80 local authorities) to administer to all people using self-directed support within these local authorities. This minimum dataset has been designed to monitor aspects of the self-directed support process and outcomes for all adults using self-directed support, and is designed to be collected on an ongoing basis (every six months) directly from people using self-directed support. As such, it covers outcomes directly relevant to the outcomes framework described above. PICMICS is currently being piloted by local authorities to assess the feasibility of data collection using this system, and the progress of PICMICS is being monitored by the Commission for Social Care Inspection for its implications for future developments in the collection of performance indicators and self-assessment information from local authorities. The full pilot version of the PICMICS is presented in Appendix 2. The PICMICS includes two types of outcome indicator: the first asks 12 questions about people's lifestyles:

1) What kind of home do you live in?
2) How many people altogether live in your current home (including you)?
3) Did you choose the place where you live now?
4) Who employs the people who provide your support at home?
5) Not counting the people you live with, how often do you meet up with relatives?
6) Not counting the people you live with, how often do you meet up with friends?
7) In the last 12 months, have you been involved with any groups of people who
1. get together to do an activity or to talk about things? These could include
2. evening classes, support groups, slimming clubs, keep-fit classes, pub
3. teams and so on?
8) Do you have a paid job that pays at least the minimum wage?
9) In the past year, would you say your health was…(very good, fairly good, not good)
10) Do you feel safe when you are at home at night?
11) Do you feel safe when you are out of the house in your local area?
12) Thinking of your whole life, are you… (very unhappy, unhappy, neutral, happy, very happy)

The second type of outcome indicator asks people for their aspirations, and later whether these aspirations have been met:

- What are the three most important things you want to change about your life in the next year? (please circle up to 3 answers)
    - The home you live in

- The neighbourhood you live in
- Who you live with
- Who supports you to do things
- Getting a paid job
- Changing your job
- The money you get
- What you do during the weekdays
- What you do in the evenings
- What you do at weekends
- Holidays
- Relationships with your family
- Relationships with friends
- Close relationships
- Your physical health
- Your mental health
- The control you have over your life
- Something else (please describe)

**Better Metrics**. Extensive consultation and support was provided for the development of the 7th Version of Better Metrics (http://www.osha.nhs.uk/publicpage.aspx?id_Content=455), an ongoing project sponsored by the Healthcare Commission to develop more clinically relevant measures of performance for local self-assessment within health services. The 12 metrics developed under the Learning Disability section are:

1) Number of people with learning disabilities known to General Practitioner (GP) practice but not yet coded using a locally agreed and appropriate Read code.
2) Number of people with learning disabilities with or offered a comprehensive health check prior to a Health Action Plan (per 10,000 of Primary Care Trust (PCT) general population) in last 3 years AND Number of people with a Health Action Plan (per number offered).
3) Each PCT should have a system for identifying local health facilitators.
4) Number of patients with learning disabilities who have been invited, in the past year, for a comprehensive health check if they have not visited the GP surgery in the last 3 years.
5) A system is in place within each PCT to review the treatment plans of patients in NHS funded hospital beds (in and out of district) at least annually by a qualified clinician AND Number of people with learning disabilities who are in NHS hospital funded beds where duration of stay has exceeded 12 months (per 10,000 of PCT general population).
6) Number of people with learning disabilities in out of area treatment provision who are described as severely challenging or who have a mental health or forensic need.
7) The PCT has a system and protocols in place to ensure that people with learning disabilities and mental health needs are able to swiftly access local mental health services.
8) How many people with learning disabilities have been screened for dysphagia in the last 3 years AND How many people have a plan for dysphagia in place that has been regularly reviewed.
9) Regular survey to ascertain how easy to understand information provided about their health and treatment is for patients with learning disabilities and their family carers.
10) Number of patients with learning disabilities on any patient forums AND Number of people with learning disabilities in health provision who are inpatients (including long stay and campus provision) who are receiving support from independent health advocacy services.
11) Acute hospitals have a system in place to ensure patients with learning disabilities are identified and appropriate support provided.

12) PCTs have a system in place to ensure access and take up rates are monitored by the PCT Executive Board quarterly for people with learning disabilities to check and promote equal access to benefits in mainstream services, NSFs and plans.

**Healthcare Commission National Audit of NHS and independent healthcare providers of services for people with learning disabilities**. Extensive consultation and support was provided for the development of questions for the self-assessment tools to be used in this audit (at the time of writing, these self-assessment tools are not publicly available).

**Quality Outcomes Framework.** Consultation and support was provided for the development of a learning disability indicator to be included from 2006/2007 within the Quality Outcomes Framework (http://www.nhsemployers.org/primary/primary-890.cfm), a system of financial incentives for primary care practices who provide high quality information. The QOF LD1 indicator is:

- The practice can produce a register of patients with learning disabilities.

# Conclusions and Recommendations

Drawing from the findings of the three phases of this project, five major conclusions can be drawn.

First, people with learning disabilities, family carers and existing policies concerning health and social care all emphasise the importance of outcomes (whether people's life experiences reach generally accepted standards of acceptability and decency, and whether people are in control of their lives and achieving their aspirations).

Second, existing information collected nationally concerning people with learning disabilities does not reflect the importance of outcomes, being largely focused on the resources and activities of particular services.

Third, a major shift will be required in both the content of the information collected and the methods used to collect it if outcomes are to be placed at the heart of national data collection.

Fourth, the methodology and technology required to collect outcome information from people with learning disabilities and their families already exist; the major challenge is to translate existing knowledge into feasible methods for collecting national information for the purposes of service inspection and national policy evaluation.

Finally, people with learning disabilities and family carers need to have a much bigger role in deciding the priorities for information collection, giving and collating information, and accessing information in ways that are useful for the purposes of public accountability.

To facilitate a move towards outcomes-focused data collection, the Department of Health and other Government agencies need to address the following issues:

- Definitions and terms. A consistent and clear definition of learning disabilities should be agreed across Government departments, this agreed definition should be reflected in a single term to be used for people with learning disabilities, and the Department of Health should ensure that people with learning disabilities are not treated as a sub-group of people with mental health problems in national statistics.
- Setting priorities. A mechanism for agreeing priorities for information collection across Government agencies and inspectorate commissions should be agreed that includes people with learning disabilities and family carers and that encourages cross-agency information collection.
- Individually focused outcomes. The Department of Health and other relevant agencies should focus on the collection of outcome indicators directly from people with learning disabilities and family carers concerning their lived experience rather than the activities of specific services.
- There should be a regularly repeated national survey of the life experiences of people with learning disabilities.
- An Observatory for Learning Disability Statistics should be set up to provide a central point for people with learning disabilities, family carers, professionals and policy-makers to easily access nationally available information.

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# Appendix 1

## CSCI learning disability group
## Recommendations for future performance measures
## July 2006

### Background

The Valuing People White Paper published in 2001 set out an ambitious programme to improve the life chances of people with learning disabilities and their families.

The existing performance framework for local authorities provides only limited evidence of progress towards the goals in Valuing People. The only specific PAF indicator - the number of people "helped to live at home" – does not distinguish between people living in their own homes and those who remain living with family carers. The report *Valuing People – the story so far* produced in 2005 called for a new approach, with a focus on outcomes.

The White Paper *Our Health Our Care Our Say* will lead to a new performance framework covering both health and social care. This report provides recommendations for new performance indicators relevant to Valuing People which are linked to the outcome headings in *Our Health Our Care Our Say.*

### Process

In May 2004 a group convened by the Department of Health with representation from the Social Services Inspectorate, councils, Lancaster University and the Valuing People Support Team produced a draft report on developing new performance indicators.

The work of this group was not completed due to the transfer of responsibility for performance to CSCI and other changes at the Department of Health. In 2005 a new group was convened by CSCI to review the proposals. The membership of the group was extended to include the Healthcare Commission. The recommendations in this report take account of:

- the draft report produced in May 2004
- work in the East of England piloting new local performance measures relevant to people with learning disabilities
- a minimum dataset being developed with support from Lancaster University as part of the In Control initiative

### Rationale

The rationale for the recommended performance measures is that they focus on the life chances that people with learning disabilities experience, not the process of service delivery. This requires collection of data in a different way than in the past, and giving priority to issues such as health, housing, paid employment and voluntary work, which are relevant to public services as a whole, rather than to the specific responsibilities of social services. Despite the importance of these issues to determining the life chances of people with learning disabilities, very little data is currently available.

The proposed measures include the number of people in full-time work, and the number of people living as tenants or homeowners in self-contained accommodation, which are likely to be much lower among people with learning disabilities than for the general population, and lower than for other adults receiving social care. This should provide a stimulus to tackle these inequalities through a cross-agency approach to improving outcomes, for example through local area agreements.

Apart from residential care, there is no data available on the accommodation in which people with learning disabilities are living. We have proposed that this is addressed through a multiple choice question which should be completed for every person in the target group. This would allow measures to be derived to show how many people live in homes of their own, as well as how many are in institutional care.

Though this is outside the scope of the group that has developed these recommendations, several of these proposed measures could also be considered for **all adults aged 18-64 receiving social care**, with a breakdown by user group. The housing and employment measures in particular would be relevant for all adults.

## Link to self-assessment

The performance measures would support and provide evidence for the council's self-assessment. Some of the outcomes in Our Health Our Care Our Say are hard to evidence by quantitative measures. These areas should be supported by qualitative evidence in the self-assessment. These include:

- Improved health and emotional well-being (including access to mainstream general health and mental health services)
- Making a positive contribution (in particular self-advocate and family carer leadership, and participation in public life, and response to the disability equality duty)
- Personal dignity
- How people with high support needs are supported to achieve the outcomes (it is not possible to get evidence of this from performance measures)

## Recommendations for new performance measures

The recommendations are shown in the table below. The first column shows the outcome headings from Our Health Our Care Our Say. The recommendations include retaining some existing items from the DIS. Some proposed indicators would make use of data already collected by the Department of Health, with modifications where shown.

## Definitions and target group

All the measures should be collected in the following basis:

- Measures would provide a **national dataset** to support the new performance framework for health and social care. Local authorities would also be able to develop additional local performance measures, for example linked to the local area agreement.
- Measures should cover **all people with learning disabilities aged 18 – 64 receiving social care.**
- This target group should be extended to include **people whose health care and social care is only funded by the NHS** (such as people in living in NHS residential accommodation, private hospitals and residential homes funded by the NHS). The recent joint investigation in Cornwall has shown how this group is particularly at risk, and currently excluded from the performance framework for local authorities.
- All new measures should be separately broken down to show the **number of people from black and minority ethnic groups** (this already happens for direct payments).
- All measures should be reported both **as raw numbers** and **per 100,000 population aged 18-64** to allow comparison between councils.
- Percentage measures should be avoided as they can be distorted by high eligibility thresholds
- Further work will be needed on detailed definitions of new performance measures to ensure that the data is collected in a consistent way.

Martin Cattermole
14 July 2006

## Proposed performance measures

| Outcomes framework | Measure | Rationale | Basis of data collection | Priority |
|---|---|---|---|---|
| Improved health and emotional well-being | 1. Number of people with completed health action plans | **Proposed joint indicator with the Healthcare Commission.** People with learning disabilities have poor health compared to the general population. Health action plans help to ensure that people's health needs are considered and that they access mainstream primary and acute health services. | Based on Better Metrics | High |
| Improved quality of life | 2. Number of people supported to live in the community | Provides a measure of overall of support provided and the level of the council's eligibility criteria.<br>Retains "helped to live at home" to provide trend data. | **Existing measure** (PAF C29, C30, C31) | Medium |
| | 3. Number of carers receiving support from the council | Retains existing measure on support for carers, but with breakdown between user group. | **Revision** of PAF C62 broken down by user group. | Medium |
| | 4. Number of carers receiving short term breaks and emergency support | Our Health Our Care Our Say says that short term breaks and 24-hour emergency support should be available. | **Revision** of DIS measure on short term breaks. | Medium |

| | | | | |
|---|---|---|---|---|
| | 5. Number of people living in each of the following types of housing:<br>Living in housing owned or rented by a family member aged under 65<br>Living in housing owned or rented by a family member aged over 65<br>Homeowner<br>Shared ownership<br>Tenant in self-contained accommodation<br>Tenant in shared accommodation (3 people or more)<br>Supported lodgings or adult placement<br>Residential care home<br>Nursing home<br>NHS residential accommodation<br>Other | Provides for the first time an overall picture of housing arrangements at a local level. | **New data collection** based on pilot work in East of England. Multiple choice item to be completed for the whole target group (as defined above) | High |

|  |  |  |  |  |
|---|---|---|---|---|
|  | 6. Number of people living as tenants or homeowners | Shows how many people supported by the council are living in a home of their own. | Derived from item 5.<br>Counts people in self-contained accommodation as a tenant, homeowner or in shared ownership. Excludes people in shared accommodation. | High |
|  | 7. Number of people living in residential services | **Proposed joint indicator with the Healthcare Commission.** Shows reliance on institutional forms of care. | Derived from item 5.<br>This measure should explicitly include everyone in NHS residential accommodation or whose accommodation and support is funded only by the NHS. | High |
|  | 8. Number of people living outside the local authority boundary | **Proposed joint indicator with the Healthcare Commission.** Shows the extent to which the council and PCT(s) succeed in keeping people close to home. | **Revision** of existing collection broken down by age (DH community care statistics table s10). This measure should explicitly include people living out of area in NHS residential accommodation or whose accommodation and support is funded only by the NHS. | High |
| Making a positive contribution | 9. Number of people doing voluntary work and work experience | Voluntary work and work experience may be valued by people who are not in paid work. | **New data collection** based on pilot work in East of England. | High |
| Choice and control | 10. Number of people receiving a direct payment | Retains existing measure which is a key threshold | **Existing measure** (PAF C51) already broken down by user group and ethnicity (DIS 3235-3337) | High |

| | | | | |
|---|---|---|---|---|
| | 11. Number of people receiving another form of individual budget | | **New data collection** based on pilot work in East of England and In Control minimum dataset.<br>Include people who have taken up an individual budget allocation other than a direct payment. | High |
| | 12. Local authority spend on advocacy | Investment in advocacy is a key factor in promoting change.<br>Measuring spend is the only practical approach. | **Revision** of existing collection (DIS 2208) extended to all adults. | Medium |
| Freedom from discrimination | 13. Number of reports of harassment and abuse against people with learning disabilities. | Councils, the police and other agencies should be encouraging the reporting of hate crime and abuse. | **New data collection** could be based on reporting through local authority vulnerable adults procedures and through reporting of hate crime against disabled people. | Medium |
| Economic well-being | 14. Number of people in full-time employment | Low numbers of disabled people in work (especially full-time). | **Revision** of existing collection (DIS 2217) extended to all adults and broken down into full-time and part-time work.<br>Full-time: in work for over 16 hours/week at the minimum wage or above. | High |
| | 15. Number of people in part-time employment | | Part-time: in work for under 16 hours/week at the minimum wage or above. | High |
| Personal dignity | | No suitable measures are available | | |

## Membership of the learning disability PI reference group

| | |
|---|---|
| Martin Cattermole | Valuing People Support Team |
| Carl Evans | Department of Health |
| Chris Hatton | Lancaster University |
| Steve Holmes | Commission for Social Care Inspection |
| Nick Miller | Commission for Social Care Inspection |
| Andrew Nash | Greater Peterborough Primary Care Partnership |
| Fiona Ritchie | Healthcare Commission |
| Alan Rosenbach | Commission for Social Care Inspection |

# Appendix 2: Progressing In Control: Minimum Information Collection System (PICMICS)

# Progressing In Control: Minimum Information Collection System (PICMICS)

## Pilot Version: June 2006

## Cover Sheet

| | |
|---|---|
| **Name of person responsible for getting the information** | |
| **Name of person using self-directed support** | |
| **Name of Local Authority** | |
| **Date of this information collection (day, month, year)** | |

---

For office use only

| | |
|---|---|
| Code number | |

## PICMICS

PICMICS is a simple way for Local Authorities and in Control to collect information on how self-directed support is progressing both for you and across the country.  In Control will provide support to Local Authorities to help you collect the information.  In Control and the Institute for Health Research, Lancaster University, will be analysing and feeding back information from PICMICS on an ongoing basis.

PICMICS should be updated every six months on all people identified as wanting or likely to benefit from self-directed support.

PICMICS should be collected directly from the person who is going to be using self-directed support.  PICMICS can be completed by doing an interview with the person or by the person themselves completing it directly as a questionnaire.  In an interview, the person may want someone else with them to support them.  Other people or records might need to be consulted about some specific questions.

Please read the questions carefully and answer them according to the instructions.

# About You

**1) What is your name?** ____________________________

**2) What is your date of birth?** _____/_____/__________
**(day, month, year)**

**3) What is the post code of your current home?** ______________________

**4) Are you (please circle one answer)…** Male Female

**5) Are you (please circle one answer)…**

Single Married/Living As Married
Widowed Divorced/Separated

**6) What ethnic group do you consider yourself to belong to?**
**(please circle one answer)**

White British
White Irish
Other White Background
Mixed White & Black Caribbean
Mixed White & Black African
Mixed White & Asian
Other Mixed Background
Indian or British Indian
Pakistani or British Pakistani
Bangladeshi or British Bangladeshi
Other Asian or British Asian Background
Black or Black British Caribbean
Black or Black British African
Other Black or Black British Background
Chinese
Any Other Background

**7) According to your council/local authority, are your needs mainly about…**
**(please circle one answer)**

Physical impairment Sensory impairment
Learning disabilities Mental health difficulties
Older person Carer

# About Your Life Now

**1) What kind of home do you live in? (please choose one answer)**

Own my home outright

Buying my home with a mortgage

Pay part rent and part mortgage

Tenant, rented from:

Private landlord    Housing association    Council/local authority

My home is owned or rented by another member of my family

A residential care home, nursing home or hospital run by:

The NHS    Social services    Another organisation

I am homeless/rough sleeping

I am staying with friends

Another kind of home (please describe) ______________________________

**2) How many people altogether live in your current home (including you)?** ___

**3) Did you choose the place where you live now? (please choose one answer)**

Yes, I made the choice on my own

Yes, I made the choice with other people

No, other people made the choice

**4) Who employs the people who provide your support at home? (please circle any/all that apply)**

I don't get any paid support at home

Me

An independent advocate or broker

The NHS

A member of my family

The council/local authority

Another organisation

Another person (please describe) ____________________________________

**5) Not counting the people you live with, how often do you meet up with relatives? (please circle one answer)**

On most days

Once or twice a week

Once or twice a month

Less often than once a month

Never

**6) Not counting the people you live with, how often do you meet up with friends? (please circle one answer)**

On most days

Once or twice a week

Once or twice a month

Less often than once a month

Never

**7) In the last 12 months, have you been involved with any groups of people who get together to do an activity or to talk about things? These could include evening classes, support groups, slimming clubs, keep-fit classes, pub teams and so on? (please circle any/all that apply)**

Hobbies/social clubs

Adult education groups

Groups for older people

Political groups

Trade union groups

Groups for children or young people

Local community or neighbourhood groups

Environmental groups

Health, disability & welfare groups

Religious groups, including going to a place of worship

Sports/exercise clubs (including taking part, coaching, or going to watch)

Other group (please describe) ______________________________

**8) Do you have a paid job that pays at least the minimum wage?** Yes No
**(please circle one answer)**

**IF YES…**

**How many hours a week do you normally do in this job?** _____

**How much are you usually paid per week in this job?** _____

**9) In the past year, would you say your health was… (please circle one answer)**

Very good Fairly good Not good

**10) Do you feel safe when you are at home at night? (please circle one answer)**

Very safe Fairly safe A bit unsafe Very unsafe

**11) Do you feel safe when you are out of the house in your local area? (please circle one answer)**

Very safe Fairly safe A bit unsafe Very unsafe

**12) Thinking of your whole life, are you… (please circle one answer)**

Very unhappy Unhappy Neutral Happy Very happy

# About Self-Directed Support

**1) How far have you got in using self-directed support? (please circle one answer)**

Have not started

Currently doing self-assessment (working out my personal budget)

Have agreed a personal budget

Currently working out my support plan

Have completed and agreed a support plan

Have reviewed how my support plan is going

**2) Overall, how happy are you with the way self-directed support is working for you? (please circle one answer)**

Very happy Quite happy Quite unhappy Very unhappy

## Step 1: Self-Assessment

**3) What are the maximum number of points possible to obtain under the Resource Allocation System being used for you?** __________

**4) How many points have you scored under this Resource Allocation System?** __________

**5) What is the amount of the personal budget offered to you? (in pounds per week)** __________

**6) Have you accepted or rejected the personal budget offered to you? (please circle one answer)**

Accepted Rejected Other (please describe) ____________________

**7) Have you started using your personal budget allocation? (please circle one answer)** Yes No

## Step 2: Plan Support

**8) Who is identified as the lead support planner for your support plan? (please circle any/all that apply)**

Me

My son or daughter

An independent advocate

A service provider

My partner/spouse

Another family member

An independent broker

My parent(s)

A friend

A care manager

Another person (please describe) ____________________________________

## Step 3: Agree The Plan

**9) What are the three most important things you want to change about your life in the next year? (please circle up to 3 answers)**

The home you live in
The neighbourhood you live in
Who you live with
Who supports you to do things
Getting a paid job
Changing your job
The money you get
What you do during the weekdays
What you do in the evenings
What you do at weekends
Holidays
Relationships with your family
Relationships with friends
Close relationships
Your physical health
Your mental health
The control you have over your life
Something else (please describe) ______________________________

______________________________

## Step 4: Manage The Personal Budget

**10) Who is identified as managing your personal budget? (please circle any/all that apply)**

Me
My partner/spouse
My parent(s)
My son or daughter
Another family member
A friend
An independent advocate
An independent broker
A care manager
A service provider
Another person (please describe) ______________________________

## Step 5: Organise Support

**11) Who is organising the support agreed in your support plan? (please circle any/all that apply)**

Me
My partner/spouse
My parent(s)
My son or daughter
Another family member
A friend
An independent advocate
An independent broker
A care manager
A service provider
Another person (please describe) ______________________________

**Step 6: Live Life** **Step 7: Review And Learn**

**12) Who has been involved in reviewing how your support plan is going? (please circle any/all that apply)**

Me
My partner/spouse
My parent(s)
My son or daughter
Another family member
A friend
An independent advocate
An independent broker
A care manager
A service provider
Another person (please describe) ______________________________

**13) Have there been any good changes in your life since you got your support plan? (please circle any/all that apply)**

The home you live in
The neighbourhood you live in
Who you live with
Who supports you to do things
Getting a paid job
Changing your job
The money you get
What you do during the weekdays
What you do in the evenings
What you do at weekends
Holidays
Relationships with your family
Relationships with friends
Close relationships
Your physical health
Your mental health
The control you have over your life
Something else (please describe) ______________________________

**14) Have there been any bad changes in your life since you got your support plan? (please circle any/all that apply)**

The home you live in
The neighbourhood you live in
Who you live with
Who supports you to do things
Getting a paid job
Changing your job
The money you get
What you do during the weekdays
What you do in the evenings
What you do at weekends
Holidays
Relationships with your family
Relationships with friends
Close relationships
Your physical health
Your mental health
The control you have over your life
Something else (please describe) ______________________________

**15) What are the three most important things you want to change about your life in the next year? (please circle up to 3 answers)**

The home you live in
The neighbourhood you live in
Who you live with
Who supports you to do things
Getting a paid job
Changing your job
The money you get
What you do during the weekdays
What you do in the evenings
What you do at weekends
Holidays
Relationships with your family
Relationships with friends
Close relationships
Your physical health
Your mental health
The control you have over your life
Something else (please describe) ______________________________

______________________________

**Is there anything else you want to tell us about self-directed support?**
**Please use the space below**

# Thank you