

# Evaluation of the National Physical and Sensory Disability Database



Improving health through research and information





National Physical and Sensory Disability Database Committee

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**National Physical and  
Sensory Disability Database**



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# Acknowledgements

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- All participants who completed evaluation questionnaires and participated in focus groups
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- Joe Wolfe & Associates who facilitated and reported on the feedback from focus groups
- Gabriel Maguire, HRB, who assisted with data entry, data analysis, and the preparation of reports for the NPSDD Evaluation Working Group

## Foreword

It gives me great pleasure to introduce the report on the evaluation of the National Physical and Sensory Disability Database. This report highlights the experience of stakeholders, including their awareness of the database, their expectations and their concerns regarding participation on the database. It also makes several recommendations regarding future improvements to the database and proposes the development of an action plan for their implementation.

The completion of this evaluation is particularly timely, as it will provide an important input to the strategic review of services for people with disabilities which is currently being conducted by the Department of Health and Children.

The contribution of everyone - colleagues, service providers and clients - who partook in the evaluation process is much appreciated. The ongoing enhancement of the NPSDD will ensure that participation levels in the database continue to increase, allowing for more precise targeting of resources to areas of most need.

**Brendan Ingoldsby**

Chairperson

National Physical and Sensory Disability Database Committee

## Key recommendations

- Implementation of the NPSDD in a standardised manner should be a priority with health service management in an effort to increase database coverage in areas where progress has been slow. Efforts should also be made to target potential participants who are currently outside the existing network of specialised health services.
- The NPSDDC should become more strategic in its approach in the coming years. The earlier phase of this committee's work has, by necessity, been largely involved with operational issues.
- There has been a long period of development for the NPSDD during which high expectations have been raised. It is therefore crucial to recognise that there is a long history of people feeling that their needs have not been adequately met, and consequently
  - participants and potential participants need to be shown the relevance of the NPSDD and start seeing some results,
  - the Health Service Executive (HSE) needs to use the information, and
  - the Department of Health and Children needs to make sure this is happening.If this does not happen, people may become disillusioned and disengage from the process.
- The image of the NPSDD needs to be enhanced. The negative connotations associated with the existing name of the NPSDD are acknowledged and consideration will be given to changing this to a more publicly accessible name.
- The current voluntary nature of NPSDD participation is seen as a significant barrier to comprehensive identification of the specialised health service needs of people with physical or sensory disabilities. The NPSDD Committee (NPSDDC) should explore the potential for a statutory mandate to record and maintain a minimum dataset pertaining to all services users.
- The existing data form should be reviewed and an effort made to group hearing impairment, visual impairment and physical disability services for children, and physical disability services for adults, together in blocks to facilitate form completion.

- The feasibility of developing a unified disability services database incorporating all elements of specialised health and personal social service delivery to people with intellectual, physical and sensory disabilities, including those with mental health and neurological conditions, should be explored.
- The Department of Health and Children should convene a stakeholder network of government departments and agencies, based on their potential use of relevant NPSDD statistical information and their role in promoting the NPSDD.
- Each HSE area should implement the approved management structures for the disability database to enable the recommendations of this report to be implemented.

## Background

In late 2002 the National Physical and Sensory Disability Database Committee established a Working Group to conduct an evaluation of the National Physical and Sensory Disability Database (NPSDD). The evaluation focused on stakeholder expectations of the NPSDD and their experience of the database to date. The members of the Working Group are:

Mr Donal McAnaney, representing Not for Profit Business Association

Ms Breda Crehan Roche, representing the Health Service Executive<sup>1</sup>

Ms Pamela Gallagher, Dublin City University

Ms Sinead Dooley, Department of Health and Children<sup>2</sup>

Ms Fiona Mulvany, Health Research Board

Ms Karen Galligan, Health Research Board<sup>3</sup>

<sup>1</sup> Replaced by Ms Marion Meany in November 2003

<sup>2</sup> Replaced by Mr Daniel Ryan in December 2003

<sup>3</sup> Joined the Working Group in November 2003

## Method

The Working Group adopted a three-strand approach to the evaluation of the NPSDD.

1. A survey was carried out in September 2003 with organisations who have an interest in the operation and future development of the NPSDD. These included umbrella and representative bodies, relevant government departments and statutory agencies, and all HSE co-ordinating committees. Completed questionnaires were received from three umbrella and representative bodies, five government departments, three statutory agencies, and 76 members of HSE co-ordinating committees (23 statutory representatives and 53 non-statutory representatives). All HSE co-ordinating committees were represented in the responses. A full list of the organisations surveyed is presented in the Appendix.
2. All individuals who participated in their first NPSDD interview during the month of June 2003 (n=514) were invited to complete a self-administered questionnaire. A

total of 214 completed questionnaires were returned, giving a response rate of 42 per cent. During August and September 2003, four focus groups in four different HSE areas were conducted with a sample of NPSDD participants to explore issues that arose in the questionnaire responses.

3. In-depth surveys of staff involved in the day-to-day operation and overall management of the NPSDD were carried out. Those surveyed included keyworkers from HSE areas and non-statutory agencies, data collectors employed by the HSE areas to conduct NPSDD interviews, and the HSE database teams consisting of the regional director of disability services, the NPSDD administrator, resource officers and clerical staff. Responses were received from 17 keyworkers, 15 data collectors, and all ten HSE area database teams.

## Results

The data have been analysed and collated under a series of themes highlighting the current strengths of the NPSDD and areas for improvement, as identified by respondents.<sup>1</sup>

## Recommendations

Following consideration of the issues raised in the evaluation, the NPSDD Working Group drafted general and specific recommendations; these are reported in this evaluation under themed headings.<sup>1</sup> The NPSDDC and the Health Research Board have already addressed some of these recommendations and, where this has happened, the action is noted alongside the recommendation. It is anticipated that an action plan for the future development of the NPSDD will be developed by the NPSDDC based on this report and that a subgroup of the committee will be established to oversee the drafting and implementation of the action plan.

## Full report

This report and copies of the questionnaires used to gather feedback are available for download from the Health Research Board website at [www.hrb.ie](http://www.hrb.ie)

<sup>1</sup> In some instances, the topic/data under a particular heading does not lend itself easily to this type of subdivision. Where this was the case, the relevant heading has been omitted.

## Awareness of the NPSDD

### Strengths:

- Awareness of the NPSDD is high among the key stakeholders (HSE, non-statutory service providers and representative bodies), all of whom are represented on the regional co-ordinating committees of each HSE area.
  - ▶ All non-statutory service providers represented on regional co-ordinating committees reported some level of familiarity with the NPSDD prior to the evaluation questionnaire, with 77 per cent reporting a high level of familiarity. Almost all (96%) HSE representatives on regional co-ordinating committees reported some level of familiarity, with 65 per cent reporting a high level of familiarity.
- Eight of the 11 government departments, statutory bodies and representative groups surveyed reported general or substantial familiarity with the NPSDD. Six of the 11 organisations have a designated person who is responsible for co-ordinating information in relation to the NPSDD.
- For participants, local HSE areas and non-statutory agencies are the most effective means of informing people about the NPSDD.
  - ▶ 65 per cent of participants reported that they first heard about the database from their local HSE area, while 17 per cent said that the non-statutory agency with which they have contact was their first source of information. Another 8 per cent cited newsletters as their source of information and 3 per cent cited local organisations and both were most likely from the non-statutory sector. These sources account for 93 per cent of responses. In two HSE areas, the East Coast Area and the Northern Area, more participants were informed about the NPSDD by the non-statutory sector than by their local HSE area, suggesting that the non-statutory sector may be assuming more responsibility for the implementation of the NPSDD in these regions than has been the practice in other HSE areas.

### Areas for improvement:

- Some HSE areas have conducted extensive local media campaigns but very few participants heard about the NPSDD for the first time through this medium. Similarly, a very small proportion of respondents cited the NPSDD posters as their source of information.

- ▶ Only 1.5 per cent of participants said that they first heard about the NPSDD through the media, despite extensive local media campaigns undertaken by the HSE. Only 1 per cent of participants first became aware of the NPSDD through the publicity posters and 2.5 per cent cited their local GP surgery as their first source of information and it is possible this refers to NPSDD posters located in GP surgeries. The remaining 2.5 per cent first heard about the NPSDD from family, friends, or the Internet.
- Not all relevant government departments and statutory bodies, and in particular some whose remit overlaps with, or impinges upon, the provision of services to people with physical and sensory disabilities, were sufficiently aware of the NPSDD.
  - ▶ Three of the 11 organisations surveyed, two government departments (DEHLG and DEDSCI) and FÁS, reported no familiarity with the NPSDD prior to receiving the evaluation questionnaire.

#### Recommendations:

- Identify a link person in each stakeholder organisation to whom regular updates in relation to the NPSDD will be sent for dissemination. A regular newsletter or electronic newsletter is suggested.
- Link with the Health Promotion Unit in the Department of Health and Children to explore their possible role in promoting the NPSDD.
- The very low numbers identifying the NPSDD poster as their first source of information suggest that a review of poster locations needs to be undertaken by each HSE area to ensure that posters are located in key areas. This is particularly important in relation to reaching people who do not have current contact with either their local HSE or non-statutory service providers. The extension of the poster publicity campaign to the following locations, in line with the report of the NPSDDC Working Group that reviewed updating procedures for the NPSDD, is recommended:
  - Health centres
  - Hospital clinics & outpatient departments
  - Statutory and non-statutory service providers
  - Local libraries
  - PWDI offices
  - DFI offices

- NDA offices
- Community care offices
- Centres of education
- Resource centres
- GP surgeries
- Comhairle offices
- FÁS offices
- Websites
- Local authority offices

## Expectations

The objective of the NPSDD is to provide a picture of the specialised health and personal social service needs of people with a physical or sensory disability by monitoring current service provision and future service requirements within a five-year period. The stated aims include planning appropriate service developments, prioritising service needs, assisting in resource allocation decisions at national, regional and local level, and facilitating research.

It is important to realise that there are intrinsic limitations to this database. It is not intended to provide any definitive epidemiological statement on the number of people with a particular type of disability in a HSE area. Nor is it intended to be an individual clinical assessment tool, but rather a broad administrative tool that will allow more efficient planning. Therefore, if someone is not on the database, this will not preclude them from receiving services. Similarly, providing information for inclusion on the database does not imply the automatic provision of that service.

To assess stakeholders' perceptions of the purpose of the NPSDD, respondents were presented with a range of statements and asked to identify those which they, or their organisation, expected the NPSDD to deliver on. The statements and responses are presented in Table 1 on page 16.

Statements A, B, C, and G listed in Table 1 are the only aims that the NPSDD can achieve at this point in time:

- A. Identify gaps in existing services and highlight future service needs
- B. Help to plan health services for people with disabilities
- C. Help to get more money for services
- G. Involve people with disabilities in identifying their needs

### Strengths:

- Stakeholder agreement on the four core aims is high:
  - ▶ 93.7 per cent agree that the NPSDD will 'Help to plan health services for people with disabilities'.
  - ▶ 90.4 per cent agree that the NPSDD will 'Identify gaps in existing services and highlight future service needs'.

**Table 1 Respondents' rating of statements about what the National Physical and Sensory Disability Database may deliver**

	Participants		Organisations		Committees		Overall
	%		%		Statutory %	Non-Statutory %	
A. Identify gaps in existing services and highlight future service needs	90.2		100.0		100.0	84.9	90.4
B. Help to plan health services for people with disabilities	93.5		63.6		100.0	98.1	93.7
C. Help to get more money for services	78.5		36.4		91.3	77.4	77.7
D. Provide more and better services in this Health Service Executive area	89.7		36.4		91.3	64.2	83.4
E. Identify people who are without services	82.7		81.8		78.3	75.5	81.1
F. See if I qualify for services	61.7		n/a		n/a	n/a	61.7
G. Involve people with disabilities in identifying their needs	80.4		72.7		82.6	96.2	83.1
H. Hold the Health Service Executive/Department of Health and Children to account	48.6		18.2		39.1	35.8	44.5
I. Ensure money for services is spread equally nationally and throughout the Health Service Executive area	72.0		45.5		52.2	50.9	65.8
J. Get all of the services that have been identified for me	58.9		n/a		n/a	n/a	58.9
K. Make sure that those in most need get services first	76.6		45.5		56.5	47.2	68.8
L. Other	3.3		45.5		8.7	13.2	7.0
<b>Number of respondents</b>	<b>214</b>		<b>11</b>		<b>23</b>	<b>53</b>	

- ▶ 83.1 per cent agree that the NPSDD process will ‘Involve people with disabilities in identifying their needs’.
- ▶ 77.7 per cent agree that the NPSDD will ‘Help to get more money for services’. This statement received affirmation from only 36.4 per cent of government departments, statutory bodies and representative groups surveyed. Interestingly, no government department, apart from the Department of Health and Children, agreed with this statement, despite recent emphasis on having an evidence base for public service planning and the proven success of the National Intellectual Disability Database in this area.

#### Areas for improvement:

- Some of the statements listed, despite being unrealistic or inaccurate, received sufficiently high ratings to cause concern about some stakeholder expectations.
  - ▶ Statement D, which states that the NPSDD will ‘Provide more and better services in this HSE area’, is rated at 83.4 per cent. It is not a realistic expectation that the NPSDD, or indeed any information system, will ensure better quality services. Furthermore, there is no quality control measurement within the current dataset, and the quality of any additional services provided as a result of the NPSDD will be dependent on individual managers in each area.
  - ▶ Statement E states that the NPSDD will ‘Identify people who are without services’. It is important to emphasise that, at present, participation in the NPSDD is voluntary and therefore the numbers identified on the database as being without services will not accurately reflect the total numbers without services. It is also important to reiterate that the NPSDD was never intended for use as an individual assessment tool.
- In terms of the remaining statements:
  - ▶ The NPSDD is never intended for use as a tool to assess eligibility for services (Statement F).
  - ▶ The NPSDD does not guarantee services to registered individuals nor preclude non-registered individuals from receiving services (Statements J and K).
  - ▶ It is hoped that use of NPSDD data will ensure that resources are targeted at areas of most need rather than allocated on some other basis, such as per head of population (Statement I) but this will not happen without ongoing monitoring.
  - ▶ On its own, the NPSDD will not ensure accountability but, taken with other measures, it could be a useful resource in this area (Statement H).

- Some stakeholders identified *additional* valid aims for the NPSDD that had not been included on the original list of statements:

**Participants:**

Improving integration between services  
Increasing general awareness of disability-related issues

**Organisations:**

Providing accurate information for use by other statutory organisations  
Informing policy development  
Helping to plan training and employment services for people with disabilities  
Helping to plan education services for people with disabilities

**Regional co-ordinating committees:**

Ensuring the database is cognisant of emerging new services

Recommendations:

- Effective communication is required that makes participation in the NPSDD attractive but does not unrealistically raise people's expectations about what the database might deliver. The realistic expectations from the above list should be made explicit in all NPSDD awareness information, including the information leaflet and at interview stage.
- One of the significant barriers to the NPSDD meeting some of the expectations outlined above is the current voluntary nature of participation. To be fully effective as a planning tool the database would greatly benefit from the identification of a mandatory minimum dataset of service planning data gathered from all who avail of, or require, services. The feasibility of this should be explored.
- A set of responses to frequently asked questions about the aims of the NPSDD should be developed.

## Concerns about NPSDD participation

### Areas for improvement:

The principal concerns of NPSDD participants centre on four main areas:

- 67 per cent of participants are at least a little concerned that participation in the NPSDD is simply a form-filling exercise and that nothing will change. Focus group participants reiterated this concern.
  - This perception arises from participants' experiences of repeated form-filling and statements of their needs with no follow-up action. From the focus group feedback it is obvious that participants expect feedback and follow-up action based on the information they have provided to the NPSDD. A number of respondents also cited a lack of trust in either their local HSE area or service provider.

To convince them otherwise, they identified the following actions as being necessary:

- show positive results and action in the form of more services and facilities, reduced waiting lists, continuing development of existing services, adequate funding of services,
  - demonstrate publicly, particularly to politicians, that the NPSDD is the catalyst for enhanced service provision and publicise its use as a planning tool,
  - allow participants to have easy access to their own NPSDD record.
- 58 per cent of participants are at least a little concerned that the information recorded may not be an accurate reflection of their needs.
    - Participants did not feel that significant items were missing from the data form but they were concerned about their ability to identify and recommend changes to their existing service provision, given the length and complexity of the form, and the extent to which their choices were influenced by the interviewer. They were also concerned that the form did not explore the adequacy of existing services in terms of frequency and duration. During focus groups, participants found it difficult to recall the details recorded during interview and would have liked to receive a copy of their form. In addition, the need for a comments section at the end of the data form to record free text, and capture any omissions, was suggested.

- Participants are concerned that their information may not be treated in a confidential and secure manner. More than half, 52 per cent, were at least a little concerned that their details may be available to others; 42 per cent were at least a little concerned that their information may not be safe on computer; while 40 per cent were at least a little concerned that others may know too much about them. These concerns were reiterated at the focus group sessions.
  - Participants in the focus groups fully accepted the need to record NPSDD information on computer in order to facilitate data analysis and service planning. However, concerns were expressed about the access which other government departments or other sections of the HSE might have to their personal information. Particular concerns were expressed about the potential impact on benefits and entitlements and on an individual's eligibility for employment.
  
- 37 per cent of individuals were at least a little concerned that if they did not participate they might not get services in the future and 30 per cent were at least a little concerned that non-participation might result in the loss of services they already had. The majority of focus group participants expressed surprise at this finding and could not arrive at a reasonable explanation for such concerns. Those participating in focus groups saw NPSDD participation as something positive, that will assist in the future development of services, and articulated an onus on individuals to participate for the benefit of all who may require services in the future, rather than for individual gain. One focus group felt that the existence of the NPSDD may lead to greater general and political awareness of levels of need which could directly influence budget availability and result in increased service provision.
  
- Other concerns, expressed by participants indirectly through their interviewers or the HSE area disability database teams, included:
  - The possibility of being labelled 'disabled' through participation. This was expressed as a particular concern of those with hearing impairment.
  - The trauma of considering NPSDD registration in the early stages of a progressive illness.
  - Not all individuals considered for participation view themselves as eligible for the NPSDD, e.g. people with epilepsy.
  - The duplication of information across different organisations and the potential to reduce this through the use of a single 'master' database was raised.
  - Some participants were concerned that data collectors are not adequately equipped, in terms of education and training, to carry out NPSDD interviews.

- Concerns were expressed about the correspondence issued by the NPSDD and its potential to confuse people in terms of the actions required of them.
  - The current exclusion of those over 65 years from registration was questioned.
  - Some participants did not understand the full range of services that are available.
  - Some participants thought that registering on the NPSDD equated to being placed on a waiting list for a specific service; and it should be made clear that this is not the case.
- HSE area teams stated that some potential participants have to date refused to participate in the NPSDD because of the concerns outlined in this section.
- The two service provider representative bodies, the Not for Profit Business Association (NfPBA) and the Disability Federation of Ireland (DFI), and one representative body of people with disabilities, the Forum of People with Disabilities (FPD), were aware of member (both staff and potential participants) concerns, which included:
    - The exclusion of those aged 65 years and over from the NPSDD and the risk of these people being overlooked in service planning,
    - Concern about database implementation in certain HSE areas,
    - Lack of explicit identification of those with autism,
    - Reiteration by FPD of the concern expressed by 67 per cent of participants that the provision of the evaluation information would not lead to improvements/change.

#### Recommendations:

- This section communicates a strong message about the need for the NPSDD to demonstrate results, otherwise there is a risk that participants will become disillusioned and disengage from the process.
  - HSE areas need to ensure that the NPSDD reflects the need for services in their local area and to act on the information.
  - The Department of Health and Children needs to monitor that this is happening.
  - Participants need feedback and follow-up to ensure that they see their needs being addressed. The adoption by all HSE areas of the *Special Request Form* developed by the HSE North Western Area is actively encouraged. This form

captures crisis situations requiring urgent action and facilitates notification of appropriate staff members who may assist in relieving the crisis.

- ▶ Every opportunity to use NPSDD information and to highlight its value should be availed of, including:
  - Service planning and prioritisation
  - Review of annual activities
  - Performance Indicators
  - Regional co-ordinating committees
  - Local HSE management meetings
  - Regional Provider Forum (HSE)
- ▶ Develop a detailed protocol on access to NPSDD information. Ensure that interviewers are familiar with this protocol and in a position to reassure participants.
- ▶ Highlight existing confidentiality, security, and data protection arrangements in the information leaflet.
- ▶ Seek accreditation of NPSDD software to provide reassurance to participants about the security of their information. It is hoped that the soon-to-be-established Health Information and Quality Authority (HIQA) will be in a position to advise on this.
- ▶ Provide reassurance that no government department, including the Department of Health and Children, can access personal information.
- ▶ Highlight the benefits of NPSDD participation in all awareness material, particularly in the information leaflet and during interviewer training.
- Strengthen the security/confidentiality clause in the NPSDD Consent Form and read it to participants prior to interview.
- It is essential that all NPSDD interviewers fulfil the criteria for this role as stated in the NPSDD Protocols. It is preferable also if the interviewer is known to the participant (e.g. their established keyworker). If the interviewer is not known to the participant, they should explain who they are and outline their suitability to conduct the NPSDD interview.
- Encourage HSE and non-statutory agencies to track the reasons why people do not register on NPSDD master lists, or having registered on the master list do not proceed to NPSDD registration. These concerns should be reviewed and proactively addressed on an ongoing basis.
- Encourage use of statistical information unless personal details are absolutely necessary.

- Data form to be amended from June 2004 to allow for the identification of the need to enhance existing services.
- HSE to supply a handbook on entitlements and services to all participants.
- Facilitate participants to identify and request services that they are not familiar with and ensure that interviewers are equipped with the knowledge necessary to do this.
- Provide reassurance that access to new services and retention of existing services or allowances is in no way dependent on NPSDD registration.
- Communicate clearly that the NPSDD form is not a plan for an immediate package of care.
- Facilitate easy access by individuals to their NPSDD record. Copies of the updated form are made available on request either through the person's local service provider or through their local HSE disability database office. This fact should be highlighted in the NPSDD information leaflet and made known to the participant at the conclusion of the NPSDD interview.
- All individuals should receive a copy of their most recently completed data form by registered post prior to their annual review. Despite a small number of complaints about the inconvenience and cost, registered post is recommended given the sensitivity of the information on the data form. It is also significantly cheaper to send a data form by registered post for the purpose of telephone updating than to carry out the interview by personal visit.
- Consider the development of a unified disability services database which incorporates the comprehensive identification of the specialised health and personal social service requirements of people with autism.
- Develop a feedback sheet designed to gather comments from respondents on their NPSDD experience and to capture information that they feel is important but not currently captured on the data form. This feedback could be sought from every tenth participant in each region. The inclusion of a free-text section on the data form and software is discouraged because of the data protection implications of non-service-planning information being recorded in this field.
- Service providers, particularly keyworkers, have a pivotal role to play in providing reassurance to NPSDD participants about their concerns and promoting the benefits of participation.

**Table 2 Respondents' rating of statements about National Physical and Sensory Disability Database participation**

	<b>Very concerned %</b>	<b>A little concerned %</b>	<b>Not concerned %</b>
Nothing will change - this is another form-filling exercise	31.8	34.9	33.3
The answers may not give a true reflection of my needs	22.0	37.2	40.8
My information may not be safe on computer	16.6	25.1	58.3
My details may be available to others	16.2	36.5	47.2
People may know too much about me	14.4	25.7	59.9
If I do not go along with this I may not get services	13.8	23.3	63.0
I am afraid that I may lose some services that I already have	10.5	19.9	69.6
<b>Number of respondents</b>	<b>214</b>	<b>214</b>	<b>214</b>

# The NPSDD process

## Background information

### Strengths:

Members of the regional co-ordinating committees were asked to rate the user-friendliness of the background information provided to them about the NPSDD.

- 32.5 per cent of all respondents found the background information to be completely user-friendly. Complete satisfaction was reported by 47.8 per cent of HSE representatives on the co-ordinating committees and by 26.4 per cent of non-statutory representatives.
- 53.2 per cent of all respondents found the background information to be moderately user-friendly, including 34.8 per cent of HSE representatives on the co-ordinating committees and 62.3 per cent of non-statutory representatives.
- Almost all participants reported that the interviewer was able to explain fully why a database was being developed and to answer their questions in relation to the database, suggesting that training provided to interviewers is appropriate and effective.
  - ▶ 95 per cent said that the interviewer was able to explain fully why the NPSDD was being developed.
  - ▶ 94 per cent reported that the interviewer was able to answer fully any questions they had about the database.

## Awareness material

For most participants in the NPSDD, their first contact with the database is a letter from their local HSE or a non-statutory agency. An NPSDD information leaflet accompanies this letter.

### Strengths

- Most participants (84%) understood some or all of the first contact letter.
- 85 per cent of participants understood some or all of the information leaflet and 85 per cent found the information leaflet either a little, or completely, helpful.
- Some NPSDD interviewers reported that the information leaflet was helpful, informative, and readable.
- Most HSE area teams reported no difficulties with the letter or information leaflet.

### Areas for improvement:

- Some participants reported that the first contact letter did not have any great impact on them. Some described the letter as an invasion of their privacy, raising anxieties about how they might have been identified, and what the implications of participation might be for them. For these reasons, some people were reluctant to respond to the letter. Others were unsure about what was to happen next. In the focus groups, some participants felt that personal contact, through support groups, non-statutory organisations, or HSE areas, might be preferable to a letter. Some participants felt that the gap between receiving the letter and subsequent follow-up by the HSE was too long. Twelve per cent of respondents (25 people in seven HSE areas) did not receive any information about the database prior to being contacted for interview.
- NPSDD interviewers reported that participants found the first letter confusing because it was too wordy. They felt that the letter should outline the benefits of participating in the NPSDD first and then invite them to participate. A number of HSE area disability database teams pointed out that some recipients of the letter thought that they were being invited to participate in a computer course.
- Feedback from some HSE area disability database teams suggests that people are given too many opportunities to withdraw from the process. However, it is important to note that these withdrawal opportunities were recommended by the Office of the Data Protection Commissioner to ensure that participants are fully informed about the NPSDD before consenting to participate.

- Some participants felt that the information leaflet was too clinical and therefore lacking in impact. Others mentioned that the introductory paragraphs of the information leaflet were not person-centred. Younger participants felt that the information leaflet was not user friendly for participants under the age of twenty years.
- Feedback from NPSDD interviewers backs up the comments of participants in relation to the information leaflet. They reported that it did not appear to have any major impact, with many of their client group either not having read it all or not having read it in detail. Others reported that participants did not understand the leaflet, found it too wordy, too detailed, too difficult, and too politically correct in its language. It was mentioned that the information leaflet was too oriented towards those with a physical disability.
- Some NPSDD interviewers mentioned that the time delay between receiving the letter and information leaflet and the follow-up contact in relation to the NPSDD interview was too long and needs to be shortened. It was also mentioned that some participants had not received the information leaflet prior to interview.
- Additional difficulties encountered by HSE area disability database teams in relation to the dissemination of the first contact letter included:
  - Letters being sent to people who were deceased, despite best efforts being made to screen lists,
  - People named on HSE lists as being in receipt of services who, when they received the letter reported that they were not receiving services, and
  - People contacted who did not have or did not consider themselves to have a disability.

#### Recommendations:

##### **General:**

- Improve the language and terminology used. In particular consider alternatives to the words 'disability', 'disabling condition', 'database', 'five-year plan', 'receiving financial assistance from the HSE'. Suggestions from the focus groups for an alternative word to disability include 'difficulties', 'special needs', 'physically challenged', and 'different abilities'. Consensus was not reached on an alternative but, overall, the focus should be on ability rather than disability.

##### **Letter content:**

- Highlight the benefits of the NPSDD to encourage people to participate.

- Be clear about how the person's name was sourced.
- Inform people that they are on a HSE list rather than making it explicit that they are in receipt of a service or receiving financial assistance, which some people found distressing.
- Clearly identify the next steps in the process.
- Include a freephone or lo-call telephone number at HSE area level to assist with queries. Consider having one national freephone number.

#### **Letter and information leaflet:**

- HSE area departments and non-statutory agencies should pay greater attention to screening lists of names forwarded to disability database team.
- To reduce anxiety levels of potential participants, the first contact letter and information leaflet should be sent out, wherever possible, by somebody known to the recipient and should clearly explain how they were identified.
- HSE areas should make every effort to ensure that all potential participants receive the information leaflet and letter prior to any contact to set up the NPSDD interview.
- Every effort should be made to ensure that only the minimum required timeframe of ten working days exists between the initial contact letter being sent out and the follow-up contact to arrange the interview.
- The first NPSDD letter should have larger print and should identify the key NPSDD messages.
- Large-print and video versions of the information leaflet are available for people with visual and hearing impairments and should be used where appropriate.
- Information on local services, and a brochure defining specialised health services and describing the actual services recorded on the NPSDD, should be sent to participants in advance of their interview.
- Develop a one-page flyer to accompany the first letter which 'sells' the benefits of participating in the NPSDD in the form of 'frequently asked questions' and includes contact details for follow-up.
- The more detailed information leaflet which outlines participants' rights in relation to their information will be made available at interview stage with the consent form, as its focus is to outline people's rights under data protection legislation.
- Consider developing three information leaflets: one for parents of children, one for teenagers, and one for adults. The requirement for separate information leaflets for people with physical and sensory disabilities should be examined.

- As has already been the practice, the National Adult Literacy Agency should continue to be consulted in relation to the content of information leaflets.
- Consult with a communications/marketing expert with some awareness of disability issues about the overall image of the NPSDD and associated materials. Consideration should be given to changing the name of the database so that the focus is on ability rather than disability.
- Consider the development of a NPSDD logo that includes images of people.
- Consider the merits of a national advertising campaign.

## Identification of participants

Members of the regional co-ordinating committees were asked to rate the user-friendliness of the process by which potential participants are identified for inclusion in the NPSDD.

### Strengths:

- 27.6 per cent of all respondents found the identification process to be completely user-friendly. Complete satisfaction was reported by 36.4 per cent of HSE representatives on the co-ordinating committees and by 24.5 per cent of non-statutory representatives.
- 43.4 per cent of all respondents found the identification process to be somewhat user-friendly, including 45.5 per cent of HSE representatives on the co-ordinating committees and 43.4 per cent of non-statutory representatives.

The workload, and perceived bureaucracy, involved in identifying potential participants is acknowledged, but is required in order to comply with data protection obligations in relation to the safeguarding of personal information.

### Areas for improvement:

- In terms of identifying people from allowance lists, HSE area disability database teams encounter the following difficulties:
  - Lists are inaccurate and out-of-date (containing names of many people who are deceased) and omit key information (for example, Domiciliary Care Allowance records do not contain the name of the child and Motorised Transport Grant records identify the grant recipient, who may not be the person with a disability).
  - Lists are not computerised, adding considerably to the workload.
  - HSE area departments responsible for the lists are reluctant to release the information, despite confirmation from the Office of the Data Protection Commissioner that it is appropriate to do so.
- In terms of identifying people who are receiving services from HSE professionals, HSE area disability database teams encounter the following difficulties:
  - Insufficient details are returned to initiate the NPSDD interview process.
  - Lists are not computerised, adding considerably to the workload.
  - HSE area departments do not have the manpower to undertake this labour-intensive exercise.

- Significant delays are experienced in some areas between requesting the lists and receiving the information.

#### Recommendations:

- Improve the promotion of the NPSDD within the HSE.
- Cultivate a sense of ownership of the NPSDD and its associated processes by HSE managers and ensure they seek the full co-operation of their staff in attending training sessions, returning lists, and conducting NPSDD interviews and reviews.
- Incorporate NPSDD activity into the daily work routine of HSE professionals and those who manage allowance lists.
- In an effort to prevent local difficulties, access to allowance lists should be approved at management level and communicated to staff working in this area.
- HSE allowances lists and client lists should be computerised.
- Implement a system, recommended in the report of the Working Group which reviewed management structures for the disability database and recommended updating procedures, whereby there would be a monthly flow of information from HSE professionals and those managing allowance lists to the HSE area disability database teams, particularly in relation to new referrals and deaths.
- Promote HSE co-ordination of lists of deceased clients.
- Encourage the return of comprehensive information to the HSE area disability database teams to expedite the screening and interview process.
- The correspondence confirming approval of an allowance should indicate to the individual that their name will be forwarded to the HSE area disability database team for future contact in relation to the NPSDD.

## Issues in allocating clients

### Strengths:

- Interviewers reported that HSE staff managed the process of allocating clients to keyworkers and data collectors efficiently. They specifically commented on good communication and support.
- While most participants did not know the person who conducted the NPSDD interview, almost all participants reported that the person who conducted the interview was the appropriate person to do so. This finding endorses the use of properly trained and appropriately qualified interviewers in the early stages of national implementation. In the HSE Northern Area and HSE East Coast Area significantly more participants knew their interviewer, possibly supporting earlier comments in this report about non-statutory agencies assuming responsibility for the NPSDD in these areas.
  - ▶ Overall, 22 per cent of participants knew the person who interviewed them for the NPSDD. In the HSE Northern Area and HSE East Coast Area, 50 per cent and 100 per cent respectively knew their interviewer.
  - ▶ 99.5 per cent reported that the person who interviewed them was the appropriate person to carry out this task.
- Where HSE areas encountered problems in allocating clients to interviewers, the level of problems was considerably reduced where data collectors were used.

### Areas for improvement:

- HSE area disability database teams identified the following difficulties:
  - ▶ Refusal by some HSE professionals to participate due to existing workloads
  - ▶ Many clients do not have an identified keyworker (although participants did not identify this as a problem)
  - ▶ Difficulties in identifying an appropriate keyworker when the individual is involved with many services
  - ▶ The employment conditions of data collectors are not attractive (sessional rather than full-time; inadequate pay)
  - ▶ The criteria for data collectors are too restrictive
  - ▶ The fact that clients are not known to data collectors has presented some problems
  - ▶ The existing staff ceiling in HSE areas impacts on their ability to recruit data collectors.

- Interviewers also identified some problem areas and a small number of areas where the process could be improved:
  - ▶ Some data sources are inaccurate and incomplete.
  - ▶ Setting up appointments can be time-consuming.
  - ▶ There has been some duplication in the process of allocating clients.
  - ▶ Better geographical co-ordination is possible in setting up interviews, thus reducing the need for repeated visits to the one area.
  - ▶ Data collectors sometimes find it difficult to contact keyworkers in advance of scheduled interviews.
  - ▶ Some interviewers were inappropriately assigned interviewees with hearing impairment who required the use of sign language.
  - ▶ While only one participant felt that the assigned interviewer was not the most appropriate person, the reason cited was lack of awareness of deaf issues and this is felt to be sufficiently important to be highlighted.
  - ▶ Some clients are allocated for interview to people whom they do not know (although participants did not identify this as a problem).
  - ▶ Some keyworkers feel that there should be dedicated NPSDD interviewers.

#### Recommendations:

- The Department of Health and Children should prioritise the NPSDD with HSE senior management and ensure the co-operation of HSE managers and staff.
- HSE managers should promote and support the NPSDD and direct staff to become involved in both the supply of lists and in data collection.
- The NPSDDC should ensure that the NPSDD is rolled out in a uniform way across all HSE areas.
- The keyworker system, as advocated in the national health strategy, *Quality and Fairness*, should be strengthened in both the statutory and non-statutory sectors.
- Where clients are involved with a number of professionals or service providers, they should be empowered to nominate their own keyworker.
- NPSDD activity should become an integral part of job descriptions.
- Initial NPSDD interviews should become part of the referral process.
- During the period while data collectors are still being used to conduct interviews, the existing criteria for data collectors should be adhered to, particularly in view of

participants' level of satisfaction with their interviewers expressed in this evaluation and comments from data collectors about the critical need for data collectors to have an in-depth knowledge of disability services.

- Every effort should be made to ensure that interviewers are allocated a number of individuals in one geographical area, or within the one household, for interview on the same day.
- Ensure accurate and up-to-date contact details for keyworkers are made available to data collectors.
- Better management of HSE master lists should mitigate against duplicate allocation of clients.
- Every effort should be made to allocate clients to interviewers who will know them, but it is acknowledged that, in the absence of all interviews being conducted by keyworkers, this is not always possible.
- Ensure people with hearing impairment are allocated to an appropriate interviewer.

## Data collection training

### Strengths:

- The majority of keyworkers and data collectors felt that all components of the data collection training programme were necessary and it was reported by some respondents that the training sessions were excellent.
- Some HSE area disability database teams reported no difficulties in arranging or delivering training sessions.
- Members of the regional co-ordinating committees were asked to rate the user-friendliness of the data collection training programme for the NPSDD.
  - 48.1 per cent of all respondents found the data collection training programme to be completely user-friendly. Complete satisfaction was reported by 52.2 per cent of HSE representatives on the co-ordinating committees and by 47.2 per cent of non-statutory representatives.
  - 31.2 per cent of all respondents found the data collection training programme to be a little user-friendly, including 21.7 per cent of HSE representatives on the co-ordinating committees and 34.0 per cent of non-statutory representatives.

It is possible that some of these respondents did not have first-hand experience of the data collection training programme and their ratings may reflect their feelings related to the inconvenience of releasing staff for training.

### Areas for improvement:

- Where HSE disability database teams encountered difficulties, the following issues were identified:
  - Arranging time and location to suit all participants
  - Locating suitable premises
  - Access to laptop computer and projector
  - Preparation of training materials is time consuming
  - Time lapse between training and data collection resulted in loss of knowledge
  - Releasing staff to attend training sessions
  - Some staff put forward by non-statutory agencies were not suitable for data collection
  - One HSE area felt that the data collection training session was too long and contained too many slides

- One HSE area felt that there was considerable overlap between the content of the information session and the data collection training. It is important to note that a) the same people may not always attend both training sessions and b) if the NPSDD process is followed there should be a time lapse between the information session and the data collection training programme.
- Issues raised at training sessions included:
  - Access to completed data forms for HSE professionals
  - The need for a procedure for handling complaints received about HSE services during NPSDD interview
  - Health and safety issues
  - Negative impact of NPSDD data collection on clinical workload
  - Payment for data collectors has not been formalised nationally. (Note: payment to data collectors has always been at the discretion of HSE areas, who were encouraged to agree terms and conditions across HSE areas.)
- Areas for improvement and items that could be considered or covered in future training include:
  - The professional production of NPSDD information manuals
  - General disability awareness training
  - Interpersonal skills
  - Dealing with emotional issues raised during the interview
  - Dealing with legal issues raised during the interview
  - Information on entitlements
  - Information on therapies and services listed on the NPSDD
  - Useful local contacts in terms of accessing services
  - Frequently asked questions about the NPSDD
  - Involve a HSE professional in the delivery of training to deal with clinical issues
  - Some respondents felt that training was too long, while others felt that more time should be given to training
  - Clarify sections of data form most relevant to people with sensory disabilities
  - More emphasis on form completion rather than on theory
  - More information on review and update procedures
  - More practice or role play and more use of case studies, particularly in relation to complex cases
  - Training made the interview process appear more complicated than it is in practice

### Recommendations:

- All HSE staff engaged in provision of training should attend a 'Training the trainers' course which is customised for the disability database.
- Disability Database Teams should have access to appropriate training resources (laptop computer and projector).
- General disability awareness training should be made available to all NPSDD interviewers as required.
- The Resource Officer or, going forward, the holder of the proposed new post of Database Development Officer, who will have a clinical background, should be closely involved in the delivery of training.
- Heads of HSE departments and management in non-statutory agencies should actively participate in the planning and scheduling of training to ensure that only appropriate staff members are trained and that training takes place at an appropriate time.
- Promote benefits of staff and client participation in NPSDD training sessions.
- Provide orientation to the definition of therapies and services as currently documented in the NPSDD Information Manual and provide local examples of each service.
- Incorporate more time for case studies and role play in local training sessions.
- HSE areas to implement the provision of referral forms (as developed by HSE North-Western Area and HSE East Coast Area) to interviewers in advance of NPSDD interviews to deal with urgent or crisis cases.
- The standard HSE complaints procedure should be followed in the event of interviewers receiving a complaint.
- Ensure HSE guidelines on health and safety and on dealing with suspected cases of abuse are made available to each interviewer.
- Consider a half-day refresher training session after interviewers have had a chance to become familiar with the NPSDD material.
- Explore feasibility of having the NPSDD Information Manual professionally produced, given that: a) the core content will change every year; b) certain content is dynamic within the year; and c) the original intention was that relevant local information could be inserted into the ring binder.
- Implement evaluation sheets at all training sessions, set key performance indicators for satisfaction ratings, and monitor achieved ratings.

## Supporting documentation

### Guidelines for completing the National Physical and Sensory Disability Database form

#### Strengths:

- 78 per cent of all interviewers rated the *clarity* of the Guidelines for Completing the NPSDD form as good or very good (87% of data collectors and 71% of keyworkers).
- 78 per cent of all interviewers rated the *usefulness* of the Guidelines for Completing the NPSDD data form as good or very good (93% of data collectors and 65% of keyworkers).

The observed discrepancy in rating between data collectors and keyworkers may be due to the familiarity of keyworkers with this area, which may lead them to perceive detailed guidelines as an unnecessary burden.

- Interviewers and HSE disability database teams commented that the Guidelines are easy to understand, concise, well-structured and comprehensive.

In particular, some HSE disability database teams commented that the service definitions are clear and are a good reference source.

#### Areas for improvement:

- Suggested areas for review and improvement concentrated mainly on some service definitions which are currently unclear or are felt to be inadequate. These items have been documented and will be considered by the NPSDDC.
- Clarification is needed on the categories included in the 'Required Coding Box'.
- Guidelines can be a little wordy and too technical.
- Section on data protection needs to be updated.

#### Recommendations:

- The NPSDDC should review all items which are considered unclear or inadequate and prepare an action plan to address the issues raised.
- In training, local examples of each service should be used to aid understanding.
- Where possible, the document should be presented in simple, non-technical language.

- Consider presenting the document in booklet style for interviewers, with clearer headings.
- In managing master lists, HSE disability database teams should track the reasons for non-participation, review issues emerging on an ongoing basis, and communicate significant issues to the NPSDDC.

## National Physical and Sensory Disability Database Protocols

### Strengths:

- 63 per cent of all interviewers rated the clarity of the NPSDD Protocols as good or very good (80% of data collectors and 47% of keyworkers).
- 59 per cent of all interviewers rated the usefulness of the NPSDD Protocols as good or very good (80% of data collectors and 41% of keyworkers).
- Most interviewers and HSE disability database teams commented positively about the Protocols, identifying them as thorough, comprehensive and easy to understand.

### Areas for improvement:

- Include a contents page in the Protocols (implemented June 2004).
- Provide a mechanism for ongoing information exchange between HSE areas to ensure there is a standardised approach to NPSDD management.
- Develop a flowchart to outline the protocol governing contact of clients. (Note: flowcharts mapping the process from first contact to NPSDD registration are included in the appendices to the November 2004 Report of the NPSDDC Working Group which reviewed update procedures and made recommendations for the management and delivery of the national datasets.)
- Provide clarification about access to NPSDD information. (Note: protocol on access to the disability database approved October 2004.)
- Make recommendations on the content of a manual NPSDD client file.
- Provide further clarification on certain registration issues, namely:
  - the definition of 'ongoing disability'
  - the area of dual disability/registration, particularly in relation to those with moderate, severe, or profound intellectual disability where physical needs are more significant

- ▶ greater clarity around speech and language therapy clients
- ▶ exclusion of those aged over 65 years
- ▶ the inclusion of certain diagnostic categories
  - diabetes
  - cancer
  - sensory motor integration disorder/dysfunction as a primary diagnosis
- ▶ clear definition of specialised health and personal social services required
- ▶ clarification as to whether need for services, rather than use of services, makes one eligible for registration

#### Recommendations:

- Promote strict adherence to all six NPSDD registration criteria.
- NPSDDC to prepare detailed protocol on access to ensure that NPSDD information is used to its maximum potential. (Note: approved October 2004.)
- HSE areas will be asked to explore the observed discrepancy in rating of NPSDD guidelines and protocols between data collectors and keyworkers and report back to the NPSDDC.
- NPSDDC Working Group established to review NPSDD registration criteria to re-convene as soon as possible following publication of disability legislation and consider the registration issues raised in this evaluation.
- Consider the development of a unified disability services database which would facilitate the comprehensive identification of specialised health and personal social service requirements of people with dual disability.
- Establish the National Disability Database Operations Group as recommended in the Report of the Working Group that reviewed management structures and updating procedures for the NPSDD.

## Consent

### Strengths:

- 95 per cent of participants fully understood the consent form that they were asked to sign before the NPSDD interview.
- In general, HSE disability database teams and interviewers reported few difficulties in the area of consent.

### Areas for improvement:

- A small number of interviewers identified the following issues:
  - Obtaining consent on behalf of children who are under 18 but have left the family environment (e.g. third-level students) and older children under 18 years where parents are happy for them to consent themselves can be problematic.
  - Signing of consent form raises anxieties about confidentiality.
  - Some people have a fear of being labelled as disabled through participation in the NPSDD.
  - A small number of participants do not have the capacity to sign the consent form.
  - Because of the issues raised when obtaining consent, it was suggested that it may be more appropriate to obtain consent at the end of the interview. (Note: this is not possible as the person is consenting to participate in the interview and provide their personal information and therefore this consent must be obtained up-front.)
  - Add address and date of birth to consent form to ensure it is traceable if it becomes separated from the NPSDD data form.

### Recommendations:

- All interviewers should be trained to highlight the benefits of NPSDD participation and to provide reassurance about confidentiality and labelling concerns.
- In relation to older children under 18 years, the Data Protection Commissioner is of the view that consent can be obtained from a 16 or 17 year old once he or she can appreciate the nature and effect of such consent. The age of understanding may vary from case to case, depending on an individual's maturity, and cases should be dealt with on this basis.

- NPSDDC should obtain legal direction from the Office of the Data Protection Commissioner on how to obtain evidence of informed consent from somebody who cannot sign a consent form.
- The consent form should be made available in accessible formats, i.e. large-print, Braille, and audiotape.
- As happened in one HSE area, people who verbally consent to participate but are unwilling to sign a form have given a valid consent under the data protection legislation and their information can be recorded and used. It is recommended that the interviewer make a note of the provision of verbal consent on the consent form.

## The NPSDD interview

- Members of the regional co-ordinating committees were asked to rate the user-friendliness of the data collection process for the NPSDD.
  - 39.0 per cent of all respondents found the data collection process to be completely user-friendly. Complete satisfaction was reported by 39.1 per cent of HSE representatives on the co-ordinating committees and by 39.6 per cent of non-statutory representatives.
  - 31.2 per cent of all respondents found the data collection process to be a little user-friendly, including 26.1 per cent of HSE representatives on the co-ordinating committees and 34.0 per cent of non-statutory representatives.
- It is possible that some of these respondents did not have first-hand experience of the data collection training programme and their ratings reflect this. It is also possible that the low level of complete satisfaction is due to the time commitment involved in conducting the first in-depth NPSDD interview.

Interviewers were asked to comment on difficulties they encountered in arranging interviews, factors influencing the duration of the interview, and difficulties encountered during data form administration. The three areas are reported on individually.

### Difficulties encountered in arranging interviews

#### Strengths:

- No difficulties were encountered, because of preparatory work by local HSE staff.
- No difficulties reported where interviewer was flexible and interviewed people at a location and time that suited them.

#### Areas for improvement:

- Difficulties encountered included:
  - Making contact to set up the interview, which was sometimes problematic due to
    - Inaccurate or incomplete contact details for interviewees
    - Getting people at home
    - Length of time taken to hear back from interviewee to arrange interview
  - Getting a time that suited interviewee (need to facilitate interviewees in employment, need to co-ordinate calls in one geographical area, seasonal issues).

- In a number of instances, a standard letter was sent to people who were visually impaired, causing them distress.
- The need to work outside of regular office hours.
- Some people did not want to meet with HSE staff.
- Some interviewers were seeking payment for telephone expenses, postage, and out-of-hours working.
- Person was not interested in participating but had not flagged this at any point prior to day of interview.

#### Recommendations:

- To ensure maximum accuracy of information (including contact details) provided to interviewers, all service providers should review and update their records before providing information to HSE master list.
- Make it clear in correspondence to potential participants that interview can take place outside of regular office hours, in the person's home or in another location that suits them.
- All information should be available in accessible formats:
  - Letters sent to people who are visually impaired should be in large print and should have a note in Braille at the end of the letter saying that the letter is available in Braille and informing them how to access this.
  - People who are hearing impaired can be contacted by text message if that is their choice. Their preferred method of correspondence can be recorded on the new data form introduced for 2004/2005.
- HSE areas should make it clear to all interviewers that the needs of interviewees should be accommodated, and that they may be required to work irregular hours.
- Where interviewee is not available on day of scheduled interview, provide cards from HSE to let the person know that the interviewer called and providing contact details for follow-up.
- Establish an agreed number of contact attempts before the person is deemed non-contactable.

## Factors influencing duration of NPSDD interview

- Factors affecting the length of interview included:
  - The severity or complexity of the person's disability
  - Their existing level of service use
  - The extent of their future requirements
  - Informing people about suitable services and supports
  - Interruptions during interview
  - Communication difficulties
  - Complexity of questions
  - Explaining the background to the NPSDD
  - Dealing with issues relating to their disability or their experience with services but not strictly related to the NPSDD.

### Areas for improvement:

- Make disability awareness training available to all interviewers.
- Ensure interviewers have the necessary skills to deal with difficult or traumatic issues that arise.
- Ensure interviewers have good listening skills.
- Respect interviewee and follow their pace.
- Keep the interview focused.
- Produce a booklet that explains services and therapies.
- Reduce number of questions on NPSDD data form.
- Re-order data form so that children's services, physical disability services and sensory disability services are grouped together.
- Consider having a separate form for people with physical disabilities and those with sensory disabilities.
- Shorten the time delay between sending out the letter and information leaflet and the interview taking place so that basic information about the NPSDD does not have to be repeated.

### Recommendations:

- Interviewers should aim to select an appropriate location and time for interview when the interviewee is free from distractions and interruptions. The need for a quiet location within the interviewee's home or the offer of an alternative, neutral location should be made clear in the letter.
- Develop a booklet, in clear, non-technical language, which describes all services and therapies listed on the NPSDD form.
- Ensure that general disability awareness training is made available to all interviewers who need it.
- NPSDDC to examine possibilities around the format of the data form in terms of grouping similar-type services together or having different forms for different groups.
- HSE areas should make every effort to ensure that all potential participants receive the information leaflet and letter prior to any contact to set up the NPSDD interview.
- Every effort should be made to ensure that only the minimum required timeframe of ten working days exists between the initial contact letter being sent out and the follow-up contact to arrange the interview.

### Difficulties encountered in data form administration

#### Strengths:

- Approximately half of the NPSDD interviewers who responded, both data collectors and keyworkers, encountered no difficulties in administering the data form.

#### Areas for improvement:

- Those who encountered difficulties described the following:
  - Data collector had problems in making contact with keyworker prior to interview
  - Locating homes, particularly in rural areas, can be difficult and time-consuming
  - Location of some interviewees' homes can be intimidating
  - Interviewee did not expect interviewer to complete form and this caused some awkwardness
  - Incorrect codes were used on some forms
  - Coding was time consuming

- Interview is long
- Some questions were seen as intrusive
- Rare cases of illiteracy
- Interviewer's lack of awareness of certain services
- Need for comment box on each page of data form to capture qualitative information
- Deal with current use of, and future requirement for, services at the same time
- Not able to capture need for enhancement of existing services
- Much of the form is not relevant to people with sensory disabilities

#### Recommendations:

- Ensure accurate and up-to-date contact details for keyworkers are made available to data collectors.
- Letter sent to interviewees to set up interview should make it clear that the interviewer will complete the form and highlight the fact that the assistance of trained personnel to complete the data form accurately is essential.
- HSE areas were formally notified in 2002 that two of the requirements of data collectors are that they *'are experienced in the area of disability, and are familiar with the specialised health and personal social services available in the health board region'*. It is critical for the long-term integrity of the NPSDD that this requirement is strictly adhered to.
- The 'Required Coding Box' should appear on each relevant page of the data form (implemented June 2004).
- Current and future service should be located together on the data form (implemented June 2004).
- The ability to record a requirement for an enhanced level of an existing service should be incorporated into the NPSDD data form (implemented June 2004).
- Consider streamlining the data form so that specific sections deal with specific age groups and specific disabilities.
- All interviewers should be familiar with, and adhere to, HSE guidelines on personal safety.
- HSE areas should, where possible, make a venue available for holding interviews e.g. local health centres.
- The inclusion of a free-text section on the data form and software is discouraged

because of the data protection implications of non-service-planning information being recorded in this field. As previously recommended in this report, a feedback sheet should be developed to gather comments from respondents on their NPSDD experience and to capture information that they feel is important but not currently captured on the data form. This feedback could be sought from every tenth participant in each region.

## Content of data form

### Strengths:

- Most participants reported that the questions on the data form are clear and easy to understand, which suggests that the data form content is good.
  - 93 per cent responded that the questions on the data form were clear and easy to understand.
  - Of those experiencing difficulties, 92 per cent said that their interviewer was able to help them understand the questions being asked.
  - 76 per cent of participants said that their interviewer helped them to answer some of the questions asked.
  - Only three per cent of participants reported that questions on the data form made them feel uncomfortable, the details of which have been documented for consideration by the NPSDDC.
  - No participants in focus groups could identify information which they felt was missing from the data form.
- Members of the regional co-ordinating committees were asked to rate the user-friendliness of the NPSDD data form in terms of data content:
  - 26.0 per cent of all respondents found the content of the data form to be completely user-friendly. Complete satisfaction was reported by 39.1 per cent of HSE representatives on the co-ordinating committees and by 20.8 per cent of non-statutory representatives.
  - 42.9 per cent of all respondents found the content of the data form to be a little user-friendly, including 47.8 per cent of HSE representatives on the co-ordinating committees and 41.5 per cent of non-statutory representatives.

It is possible that some of these respondents did not have first-hand experience of the data collection training programme and their ratings may relate to having to release staff for training.

### Areas for improvement:

- 23.4 per cent of all regional co-ordinating committee respondents, comprising only non-statutory representatives, reported that the data content was not at all user-friendly. The majority of these respondents (10/18) were from NAD and NCBI.  
The dissatisfaction expressed by the sensory disability agencies is reflected in

other feedback received during the evaluation. However, both agencies were involved in the development of the database, either on the Development Committee, its associated working groups, or both, where the data content for the NPSDD form was agreed.

- The small number of participants who found some questions difficult cited the differentiation between the various services listed on the form and distinguishing between current and future service need as their main areas of difficulty.
- Interviewers and HSE disability database teams identified a number of questions that caused discomfort to participants, even though only three per cent of participants reported that they felt uncomfortable with certain questions. The areas causing discomfort have been documented for consideration by the NPSDDC. Among the reasons listed for the discomfort were:
  - ▶ Lack of understanding on behalf of interviewee of services or therapies listed on the form.
  - ▶ People who were recently diagnosed were reported to experience more discomfort.
  - ▶ The individual may not have been aware of their condition, or the extent of it, and the interview exposed this, causing distress to the individual and sometimes to family members.
  - ▶ Some people were uncomfortable discussing their existing service provision, particularly if they felt they were criticising their service provider.
- Interviewers and HSE disability database teams identified a number of questions that participants found difficult to understand and these have been documented for consideration by the NPSDDC. The main reason given for the difficulty in understanding was that people had not heard of a particular service and found it hard to understand the explanation, which sometimes gave rise to embarrassment.
- 59.4 per cent of interviewers (47 per cent of data collectors and 71 per cent of keyworkers) feel that the NPSDD data form is comprehensive.
  - ▶ Interviewers identified a number of additional topics which they felt should be included on the NPSDD form and these have been documented for consideration by the NPSDDC.
    - Some interviewers requested the inclusion of services that are already contained on the data form, namely home teaching, adult education, peer counselling, and specific diagnostic categories (PKU and Parkinson's Disease).
    - The inclusion of services on the data form that are not currently available in specific HSE areas can raise expectations and lead to frustration.
    - There is a risk that the NPSDD may reflect what the HSE thinks it needs to know rather than what the service user might think their needs are.

- Interviewers and HSE disability database teams were asked to identify questions where the response categories were incomplete or unsuitable and their responses have been documented for consideration by the NPSDDC.
- Some interviewers highlighted the fact that parts of the form are not relevant to people with sensory disabilities and suggested that interviewers be given the discretion to filter out questions deemed irrelevant. However, during focus groups, which included participants with sensory disabilities, participants stated that some interviewers already exercised this discretion, which made them question the objectivity of the NPSDD process if all participants are not given the opportunity to answer all questions.

Note: All items concerning data content, items concerning layout of the data form, and items concerning NPSDD protocols were referred to the NPSDDC for consideration in advance of the revision of the NPSDD data form for 2004/2005 and a number of the requested changes were approved and applied to the NPSDD in June 2004.

#### Recommendations:

- Interviewers need to reassure interviewees about the annual review process that allows additional needs to be identified or existing requirements to be reviewed and updated.
- Information should be provided, in booklet form, on the range of services and therapies listed on the NPSDD data form and also covering entitlement to allowances.
- The NPSDDC should consult with services providers to people with sensory disabilities about the reported difficulties encountered by this sector.
- The development of a separate data form for people with sensory impairments should be considered.
- Consider the development of a unified disability services database which could have a separate module identifying the specialised health and personal social service requirements of people with sensory impairments.
- Interviewers should be very familiar with the definition of therapies and services as currently documented in the NPSDD Information Manual and be in a position, where appropriate, to provide local examples of these service.
- The inclusion of a free-text section on the data form and software is discouraged because of the data protection implications of non-service-planning information being recorded in this field. As previously recommended in this report, a feedback sheet should be developed to gather comments from respondents on their NPSDD experience and to capture information that they feel is important but not currently captured on the data form. This feedback could be sought from every tenth participant in each region.

## Layout of data form

### Strengths:

- Overall, interviewers were positive about the layout of the data form, describing it as good, well-presented, making the form easy to follow, and facilitating a flowing conversation.
- A comment was made that use of the form improves with repeated use.
- The data form and the NPSDD software follow the same flow, which allows for faster data inputting.

### Areas for improvement:

- A number of interviewers and HSE disability database teams suggested grouping current and future services together. This change has been implemented in the 2004/2005 data form.
- One interviewer commented that the form was quite lengthy and suggested reducing the number of questions.
- Other suggestions include:
  - Moving the variables Details of Disability and Diagnostic Category 1 and 2 to the front of the form as they would provide immediate information on the client which would inform the rest of the interview
  - Increasing the space available for recording addresses
  - Locating Chiropody directly under Public Health Nurse to improve flow of questioning
  - Locating Home Help directly under Homecare Assistant to improve flow of questioning
  - Ensure relevant 'Required Coding Box' is shown on each page (implemented June 2004)
  - Coding box for future services is confusing
  - Coding of future requirements for aids and appliances is confusing.

### Recommendations:

- Comments on the layout of the NPSDD data form which have not been implemented to date should be considered by the NPSDDC as part of the annual process of reviewing NPSDD content.

## Health Service Executive support

### Strengths:

- Members of the regional co-ordinating committees were asked to rate the user-friendliness of the NPSDD process in terms of support available from their local HSE area:
  - 57.1 per cent of all respondents found the support available from their local HSE area to be completely satisfactory. Complete satisfaction was reported by 52.2 per cent of HSE representatives on the co-ordinating committees and by 60.4 per cent of non-statutory representatives.
  - 29.9 per cent of all respondents found the support available from their local HSE area to be somewhat satisfactory, including 21.7 per cent of HSE representatives on the co-ordinating committees and 32.1 per cent of non-statutory representatives.

### Areas for improvement:

- Interviewers suggested the following areas for improvement:
  - Ensure disability database staff are well trained
  - Make every effort to ensure client contact details are correct
  - Ensure contact is made with client prior to interviewer contact to set up interview
  - Ensure letter notifying the client about the forthcoming interview is clear about the role of the interviewer, i.e. that the interviewer will be completing the data form
  - Reduce time lag between first contact letter and interview
  - HSE to arrange date and time of interviews rather than leaving this up to the interviewer
  - Facilitate pre-interview contact between keyworkers and data collectors
  - Provide detailed ordnance survey maps to facilitate co-ordinated planning of interviews
  - Allow keyworkers more time to conduct interviews
  - Provide information on entitlements
  - Supply list of local services and supports
  - Provide contacts for accessing services
  - Provide safety guidelines for interviewers

- ▶ Include comments section on data form
- ▶ Be aware that the interviewer plays a much larger role than simply that of a data collector, i.e. listening to complaints, dealing with requests, dealing with personal trauma, fulfilling the role of counsellor, and provide support for these additional roles.

#### Recommendations:

- The Disability Database Manager in each health region should ensure that all interviewers have received comprehensive training before conducting NPSDD interviews.
- Client contact details should be updated as soon as disability database personnel become aware of changes.
- The process for setting up and conducting NPSDD interviews as outlined in the NPSDD Protocols should be followed.
- Disability database teams should make every effort to reduce the time lag between contacting potential participants about the NPSDD and conducting the NPSDD interview to the recommended minimum of ten days.
- Disability database support officers should facilitate the setting up of NPSDD interviews.
- All interviewers should be provided with the Comhairle booklet on entitlements and, where available, a local directory of disability services prior to embarking on interviews
- All interviewers should be aware of the HSE area's Health and Safety Guidelines.

## Questions asked about NPSDD

### By interviewers

- Interviewees generally ask interviewers questions about the following areas:
  - What impact will NPSDD participation have on their existing allowances?
  - Who can access their information?
  - Are they *entitled* to the services requested on the NPSDD form?
  - What impact will the NPSDD have?
  - What is the difference between a psychologist and a counsellor?
  - Is a Public Health Nurse (PHN) the same as the GP Practice Nurse?

### By Health Service Executive staff

- HSE staff generally ask HSE disability database teams questions about the following areas:
  - What impact will the NPSDD have?
  - What happens to the information?
  - Who can access it?
  - Why should they participate?
  - Who has ongoing responsibility for the data form?
  - How many people are registered?
  - What is the difference between the master list and the database?
  - Does completion of the NPSDD data form constitute a referral?
  - Does completion of the NPSDD data form guarantee service provision?
  - Will interviewers get the information back?
  - Can I get clarification on registration criteria?

### By non-statutory agency staff

- Non-statutory agency staff generally ask HSE disability database teams questions about the following areas:
  - What level of access can they have to the information, particularly if they did not conduct interviews? (Access protocol approved October 2004)

- Getting feedback from the information contained in the database
- How to deal with cases who have not consented to participation in NPSDD, and where the HSE is not aware of their needs.
- Other issues raised with HSE disability database teams include:
  - Whether the data collected will determine future resource allocation
  - Justification for spending on NPSDD versus expenditure on service provision
  - Asking people about their need for services that do not exist on the ground
  - Why are those over 65 years excluded?
  - When will results be obvious?
  - When/how will the information be reviewed?
  - Who will benefit?
  - Where is money allocated to HSE Northern Area for NPSDD development being spent?

#### Recommendations:

- Develop a protocol governing access to NPSDD information (approved October 2004).
- Provide regular progress reports to service providers, key workers, umbrella bodies and the primary care sector in the form of newsletters.
- Develop a reports module within software (implemented January 2004).
- Renewed support is required from HSE management to extend NPSDD coverage.
- Ensure there is a close link made publicly between service developments and NPSDD information.

## Getting questions answered

### Strengths:

- 20 (9%) of the NPSDD participants surveyed contacted their local HSE to ask questions about the NPSDD. Of these, 76 per cent reported that the HSE could fully answer their questions, 14 per cent said that the HSE could answer some of their questions and 10 per cent said that the HSE could not answer their questions at all.
- 8 (4%) of the NPSDD participants surveyed contacted a non-statutory agency to ask questions about the NPSDD. Of these, 75 per cent reported that the agency could fully answer their questions, and 25 per cent said that the agency could answer some of their questions.
- Respondents who experienced difficulties during their interview said that their interviewer was able, either partly or in most cases fully, to ensure that they were able to understand the questions on the data form. This feedback further emphasises the importance of interviewers having an in-depth understanding of the NPSDD and being fully aware of the full range of specialised health and personal social services available to support people with disabilities in daily living.
  - Where respondents found questions difficult to answer, 92 per cent said that their interviewer was able to help them to understand fully the questions being asked, while eight per cent reported that their interviewer helped a little to improve their understanding of the questions.

## Impact on interviewers' workloads

- Keyworkers were asked to comment on the impact of NPSDD data collection on their existing workloads. Comments included:
  - NPSDD data collection resulted in keyworker being absent from their regular work
  - The visit to conduct the NPSDD interview in some instances re-activated cases, adding to the keyworker's active caseload
  - A locum replacement was required in keyworker's absence
  - NPSDD data collection sometimes proved time-consuming due to:
    - Contact details being out of date
    - Following up on NPSDD interview, e.g. making referrals
- Comments from HSE disability database teams largely supported the views expressed by keyworkers who took part in data collection. However, they pointed out that many keyworkers did not undertake data collection or stopped after a small number of interviews.

### Areas for improvement:

- A number of keyworkers identified areas where the data collection process could be improved, including:
  - The employment of dedicated data collectors for NPSDD interviewing
  - Ensure interviewers with sign language skills are available to interview people with hearing impairment
  - Simplify the content of the contact letters and reduce the number of letters involved in the process
  - Separate NPSDD data collection from regular case work
- One HSE area reported that HSE departments requested reimbursement for their time commitment. (Note: this has already been allowed for in the payment of a contribution to HSE departments in return for completed interviews.)
- HSE disability database teams would like to see the following improvements:
  - More support from HSE managers and department heads
  - Uniform approach to use of NPSDD funding across the country
  - Automation of the flow of information into HSE disability database teams from HSE departments and non-statutory agencies
  - More involvement of keyworkers in data collection

- NPSDD responsibilities built into the job descriptions of HSE professionals and into service agreements with non-statutory agencies
- Closely link NPSDD interview and review procedures to initial assessment and ongoing review of clients as recommended elsewhere in this report
- Training programme for HSE staff on using NPSDD information
- Good working relations between HSE and voluntary agencies
- Direct information sessions involving HSE disability database teams and clients
- Ongoing availability of Resource Officers to support NPSDD management (Note: the new management structures for the disability database include the permanent appointment of a Disability Database Development Officer (with similar responsibilities to those of a Resource Officer) in each local health area (CCA) to support the NPSDD and NIDD).

#### Recommendations:

- Explore the possibility of database support officers (clerical officers) taking responsibility for dealing with referrals arising out of NPSDD interview.
- Emphasise the potential of NPSDD to deliver additional development money for services.
- Implement the proposed Notification System outlined in the Report of the Working Group that reviewed updating procedures for the NPSDD.
- NPSDDC should actively seek to completely integrate NPSDD work into the job role/description of professionals, with minimal impact on existing caseload, i.e. data form would initially be completed as part of first assessment and reviewed and updated as client is seen for review.
- The enhanced staffing structures for the disability database as recommended in the Report of the Working Group that reviewed management structures and updating procedures for the NPSDD should be implemented immediately and the Department of Health and Children should monitor compliance by HSE areas with this recommendation.
- Make NPSDD accessible to health service managers and explore possibility of formal training for managers on the use of NPSDD information. (Appropriate access levels have been approved since October 2004 and can be implemented by local HSE areas as required.)
- Ensure that everybody understands that the approved procedures for contacting clients, which are often perceived as unnecessarily protracted, and the number of letters involved, exist in order to comply with data controllers' obligations under the Data Protection Act 1998 and the Data Protection (Amendment) Act 2003.

## Improving roles of interviewers/teams

### Strengths:

- A number of keyworkers and data collectors commented that the existing support they receive from their local HSE area is excellent.

### Areas for improvement:

- Data collectors would like to
  - ▶ have access to a named keyworker for each interviewee
  - ▶ see more keyworkers involved in data collection
  - ▶ have more accurate and comprehensive contact details for interviewees
  - ▶ have a diagnosis for each interviewee prior to interview
  - ▶ have access to a HSE office in which to conduct interviews
  - ▶ have dedicated office space and secretarial back-up
  - ▶ have a laptop available for capturing data during interviews
  - ▶ see a comments box added to the data form to record free text and capture any omissions (Note: The inclusion of a free-text section on the data form and software is discouraged because of the data protection implications of non-service-planning information being recorded in this field. As previously recommended in this report, a feedback sheet should be developed to gather comments from respondents on their NPSDD experience and to capture information that they feel is important but not currently captured on the data form. This feedback could be sought from every tenth participant in each region.)
  - ▶ see more pro-active follow-up on information captured during the interview.
- Keyworkers would like to
  - ▶ see more general awareness by clients of the NPSDD prior to interview
  - ▶ have more accurate and comprehensive contact details for interviewees
  - ▶ see the development of a separate questionnaire for those with visual impairment
  - ▶ see a reduction or streamlining in the number of letters involved in the pathway to NPSDD registration
  - ▶ see the imposition of a deadline covering the period from sending out the first letter to completion of interview

- be released from their regular casework to focus on NPSDD interviews
- receive better remuneration for conducting NPSDD interviews
- see NPSDD data collection separated from their regular case work
- HSE disability database teams would like to see
  - more support from HSE managers and heads of departments
  - a uniform approach to the use of NPSDD funding across the country
  - automated flow of information into database teams from HSE departments and non-statutory agencies
  - more involvement of keyworkers in data collection
  - NPSDD work built into job descriptions of HSE professionals and into service agreements with agencies
  - NPSDD interview and review procedures closely linked to initial assessment and ongoing review of clients
  - development of a training programme for HSE staff on the use of database information
  - good working relations between HSE and non-statutory agencies
  - the provision of information sessions directly to clients
  - ongoing availability of resource officers to support NPSDD management (Note: the new management structures for the disability database include the permanent appointment of a disability database development officer (with similar responsibilities to those of resource officer) in each local health area (CCA) to support the NPSDD and NIDD.)

#### Recommendations:

- The Report of the Working Group that reviewed update procedures for the NPSDD and recommended enhanced management structures for the disability database within HSE areas needs to be fully implemented as a matter of priority. This report recommends enhanced management structures for the NPSDD and NIDD at HSE area level and identifies processes and workflows which would ensure an ongoing supply of updated information from HSE departments and non-statutory agencies to HSE disability database teams.

## Use of NPSDD information

### Strengths:

- Some HSE areas and, to a much lesser extent, non-statutory agencies, are already using NPSDD information for a variety of service-planning-related purposes.
  - ▶ 56.5 per cent of HSE representatives, and 13.2 per cent of non-statutory representatives on regional co-ordinating committees reported that their local HSE had used the NPSDD for service planning purposes. The low level of use by non-statutory representatives is expected, given that they do not currently have direct access to the NPSDD information system.
  - ▶ 60.9 per cent of HSE representatives, and 30.2 per cent of non-statutory representatives on regional co-ordinating committees reported that the HSE area on whose co-ordinating committee they sit, had used the NPSDD for service planning purposes. HSE areas reported to have used NPSDD information included the HSE Midland Area, HSE Mid-Western Area, HSE North-Eastern Area, HSE North-Western Area, HSE South-Eastern Area, HSE Southern Area and HSE Western Area. There was no reported use of NPSDD information by the three HSE areas in the Eastern Region. There is significantly more reported use of the NPSDD information by local HSE areas than the non-statutory sector appears to be aware of.
- The database has been used by HSE areas to:
  - Provide the evidence base to underpin annual service plans submitted to the Department of Health and Children
  - Frame longer-term initiatives (revenue and capital)
  - Identify numbers using services
  - Identify numbers requiring specific services
  - Plan resources (identifying number of therapists required based on numbers requiring services)
  - Plan inter-care group service provision
  - Plan local educational needs in partnership with the Department of Education and Science
  - Meet demands for information, e.g. parliamentary questions, national performance indicators
  - Provide the impetus for new service developments
  - Facilitate research

- Non-statutory agencies reported that they have used the NPSDD to
  - Verify and update information on agency database
  - Identify numbers with disabilities in local region (Note: it is important to be aware that the NPSDD is not designed to, and does not, serve this purpose.)
  - Provide baseline measurement of service use
  - Prioritise future needs
  - Meet with their client group
  - Verify that applicants for services are on database (Note: it is important to note that this is an inappropriate use of the database and is not supported by the NPSDDC.)
- Four government departments (Health and Children, Social and Family Affairs, Justice, Equality and Law Reform, and Education and Science) and one statutory body (Comhairle) expressed interest in using NPSDD information. The data to meet the majority of the information requirements of these groups, as identified through this evaluation, are either currently gathered on the NPSDD or will be gathered from June 2004.
- Representative bodies see value in using the NPSDD for lobbying purposes and for improving service planning and ultimately service provision. One group proposed that individuals' experiences of services should be captured.

#### Areas for improvement:

- Some HSE areas are using the NPSDD but concerns were expressed that the NPSDD does not currently represent a full and accurate picture.
- Other HSE areas and non-statutory agencies are not yet using NPSDD information for service planning as the database has not yet achieved sufficient coverage.
- One HSE area reported that information required for service planning is not easily accessible.
- One non-statutory representative feels that the information gathered, and the NPSDD process, are not completely suitable for people with sensory disabilities.
- There was a low level of HSE concern that the information gathered may be subjective.
- Concern was expressed by a non-statutory representative that their HSE area has not used ring-fenced money to implement the NPSDD.

#### Recommendations:

- There is a need to focus on capacity-building among potential users.
- A protocol on access to information (particularly by the non-statutory sector) and appropriate use of information is required (approved October 2004).
- Promote use of NPSDD information by non-statutory service providers.
- The new software launched in February 2004 has built-in service planning reports and also contains a user-friendly report generator for ad-hoc reporting requirements. The use of both components should be encouraged.
- Encourage sharing of useful reports across HSE areas. Syntax used to generate useful reports can be submitted to HRB and reports can then be made available to all regions via the national software programme.
- Adapt the NPSDD data form so that services with particular relevance to people with hearing or visual impairments are easily identifiable and, at training sessions, encourage keyworkers to ask these questions first during the interview. This has been attempted with the telephone prompt which was introduced for the purpose of reviewing and updating existing records in early 2004.
- Engage with sensory disability sector to explore concerns expressed throughout the evaluation.
- Promote the fact that NPSDD development is an evolutionary process and reduce emphasis on 'completion' of database. The NPSDDC should identify what it considers *reasonable coverage* and encourage the use of the information once this target is attained.
- Explore what can be done in terms of resources (time, funding and personnel) to facilitate expansion of NPSDD coverage.
- Consider the development of a unified disability services database which would facilitate the comprehensive identification of specialised health and personal social service requirements of all people with disabilities.
- Publish national statistics from the NPSDD as soon as possible (Note: the first national data from the NPSDD was published in December 2004)
- The Department of Health and Children should engage with other government departments to ascertain their potential use of NPSDD statistical information and the format in which that information would be made available to meet their information requirements.

# Review and update of NPSDD records – timeframe and method

## Timeframe for review and update

Prior to the evaluation of the NPSDD it was proposed that NPSDD information for each registered individual would be reviewed and updated on an annual basis and that benchmark data from the NPSDD would be generated on 31 December each year. The evaluation sought feedback on this proposal.

### Strengths:

- The value of having factual and up-to-date information available on the numbers availing of services and the pattern of service needs is acknowledged.

### Areas for improvement:

- There was almost unanimous rejection of the proposed timeframe. Almost all respondents requested that service planning information be available in the autumn of each year.
- Respondents drew attention to the need for resources to follow so that plans can be realised.
- The view was expressed that an annual update may be too frequent for most cases and not frequent enough for some cases.
- There is a need for ring-fenced resources for data collection to ensure information is kept up to date.

### Recommendations:

- On receipt of the feedback in relation to the annual benchmark data, the timeframe was immediately changed from 31 December to the last working day of May, with effect from May 2004.
- When HSE areas have easy access to a comprehensive database of records that are regularly updated, the frustration experienced by service providers who receive frequent, and often urgent, requests for information should be significantly reduced.
- The centralised, web-enabled software implemented in February 2004 facilitates the updating of information as changes happen and ensures that up-to-date information is available to service planners outside of the scheduled benchmarking period.

- Review procedures have been recommended by a NPSDDC Working Group for records requiring more frequent review than once a year and should be implemented by local HSE teams. The NPSDD software facilitates the notification of more frequent reviews.
- The Department of Health and Children should consider multi-annual service planning, for example, over a three-year timeframe.
- In the near future, priority should be given to the review and update of records registered on the NPSDD since national implementation commenced in January 2002.

### Method of review and update

The possibility of reviewing and updating NPSDD data forms by telephone was discussed in the focus groups.

#### **Reaction:**

- Participants highlighted the need for regular review of their information to capture changing circumstances but were unsure how this could happen.
- Some participants felt that the opportunity to spend time on a one-to-one basis with an interviewer to update their information was preferable to a telephone call.
- Some participants felt that the risk of inaccuracies occurring was high where the only contact was by telephone. They also felt that there was a higher risk of omitting important information in a telephone conversation.
- The focus groups recognised that use of a telephone would be restricted for some individuals because of physical, sensory or practical needs.
- Some people may not have access to a landline and some concern was expressed about the security of mobile telephones if used for this purpose.
- Other participants felt that if the process by which telephone updates would take place was pre-defined then they would be willing to participate.
- Others felt that once participants could choose their preferred method of update they would have no objections to telephone interviews being one of the options.

Since the evaluation took place, records completed during pilot implementation of the NPSDD have been reviewed and updated by means of telephone calls. Individuals whose records are due for review and are deemed potentially suitable for review by telephone are given a choice of having this done by telephone or by personal interview. This choice is offered on a number of occasions during the contacts to set up the

review. The vast majority have opted for telephone review and on evaluation has been found to be very successful. Individuals for whom review by telephone would not be appropriate have had their information reviewed during a personal visit. Individuals due for review receive a copy of their most recently completed NPSDD data form by registered post prior to the review. The subsequent telephone conversation is guided by a clearly defined telephone prompt which was tested before live implementation. The process was kept under ongoing review by the three HSE areas involved in reviewing and updating records first completed during pilot implementation. Overall, the process has worked very well. Some concerns were expressed about the inconvenience and cost of registered post and these are dealt with in the section 'Concerns about NPSDD participation'.

#### Recommendations:

- Update the NPSDD telephone prompt to take account of changes to the data form which were implemented in June 2004.

## Value of NPSDD in addressing Health Service Executive priorities

### Strengths:

- Respondents saw significant potential for the NPSDD in addressing priority areas. Among the major contributions identified which the NPSDD could potentially make include:
  - ▶ Drawing attention to service needs, gaps in service provision, and the concerns of people with a disability
  - ▶ The availability of accurate information to support the annual service planning process and longer-term strategic planning
  - ▶ Identifying priority areas
  - ▶ Improved budgeting
  - ▶ Fair distribution of resources
  - ▶ Enhanced co-ordination of service provision
  - ▶ Ultimately helping to maintain people at home
- Respondents sitting on regional co-ordinating committees were asked to identify the priority areas for people with physical or sensory disabilities in their region. Four key priority areas emerged:
  - ▶ Residential and respite services
  - ▶ Personal support services (including personal assistant and assisted living)
  - ▶ Therapy services
  - ▶ Technical aids and appliances

At least two of these areas were listed in the top three priorities of each HSE area. The NPSDD contains a considerable amount of planning data on all four areas identified and will provide information on the numbers currently availing of these services and the numbers requiring these services, and a demographic profile of both groups including age, sex, geographical location, current living arrangements, etc.

### Areas for improvement:

- Some concerns were expressed about the impact the NPSDD will have if
  - ▶ coverage is not comprehensive and participation is not mandatory

- funding does not match identified need
- data is not reliable
- resources are not provided to ensure NPSDD information is kept up to date
- NPSDD role is not recognised or widely supported within the HSE

Recommendations:

- The contribution that the NPSDD can make to the service planning process should be emphasised.
- HSE areas should avail of every opportunity to use the NPSDD for service planning purposes.
- The NPSDD's potential to eliminate the laborious compilation of statistics from manual records should be highlighted.

## Enhancing local operation of NPSDD

### Strengths:

- The operation of the NPSDD at regional level was described as well-organised and well-resourced. Among the key factors influencing its successful operation are good working relationships with the database administrator who manages day-to-day NPSDD operations and the existence of a regional database committee. Those involved in data collection recognise the opportunity that the NPSDD presents to the HSE to become more aware of the holistic needs of people with physical and sensory disabilities. Respondents highlighted the increasing use of NPSDD information to support service planning.

### Areas for improvement:

- Respondents identified a number of areas that could be further developed or enhanced at this stage of NPSDD development, including:
  - Clarifying existing registration criteria
  - Increasing coverage of NPSDD (including accelerating data collection, inclusion of those who acquire their disability after the age of 65 years, mandatory inclusion of all in receipt of or in need of specialist disability services, and promoting a wider definition of health services to incorporate provision of information, community development initiatives and courses)
  - Improving awareness of the NPSDD and highlighting the benefits of participation particularly through the use of local media campaigns. The merits of a national awareness campaign should also be considered
  - Simplifying the registration process
  - Improving the data form (particularly by making it more relevant to those with sensory impairments)
  - Providing greater support for those engaged in data collection (including ring-fenced resources, payment of mileage to data collectors from non-statutory sector, employment of data collectors)
  - Identifying the most appropriate person to conduct NPSDD interviews: feedback from data collectors recommends that keyworkers take ownership of the process for the benefit of their client group. Keyworkers' in-depth knowledge of services, their ability to deal with newly-diagnosed individuals, and the importance of continuity of interviewer were the main reasons cited. On the other hand, keyworkers called for the employment of dedicated full-time data

collectors to speed up the process of data collection

- ▶ Allowing greater flexibility in conducting interviews (use of telephone interviews, out-of-hours availability to conduct interviews, access to location other than family home for interview)
- ▶ Implementing and monitoring reviews to ensure information is up to date
- ▶ Implementing revised management structures proposed in 2003
- ▶ Facilitating improved access to database information by HSE managers and service providers (by developing guidelines on appropriate access, increasing availability of software, devising an improved report generator, training in use of NPSDD for service planning, and providing registered PINs to service providers)
- ▶ Standardising NPSDD practices across HSE areas
- ▶ Validating NPSDD data by national audit
- ▶ Making more visible use of NPSDD information, particularly in promotional material about the database
- ▶ Developing a comprehensive IT system for disciplines that would feed into the NPSDD in terms of screening eligible clients and recording activity; the NPSDD would become an operational tool for those involved in service delivery and the summary information could be extracted for planning purposes
- ▶ Improving communication links between HSE personnel and those engaged in data collection and between HSE personnel, Health Research Board, NPSDDC and Department of Health and Children
- ▶ Encouraging local service providers to take ownership of NPSDD and be responsible for upholding the NPSDD (including the completion and updating of information for people availing of their services) and ensuring continuity of interviewer
- ▶ Increasing HSE commitment, particularly at programme manager and general manager levels or their equivalents, within the new structures (including securing the ongoing co-operation of HSE departments and the incorporation of NPSDD data collection activities into job descriptions of therapists)
- ▶ Ensuring that NPSDD information leads to action
- ▶ Seeking more ownership and support of NPSDD by Department of Health and Children

#### Recommendations:

- Regional NPSDDC's should be established, where they are not already in existence, and re-energised where they may have lapsed. Committees should meet regularly

and consist of representatives from statutory and non-statutory service providers and members of the local HSE database team, and should adhere as closely as possible to their terms of reference.

- NPSDD induction programme should be devised for service providers, to cover
  - proposed use of NPSDD by Department of Health and Children and HSE
  - Benefits of NPSDD to service providers
  - Benefits of NPSDD participation to service users
- Explore how the NPSDD could become a resource for therapists.
- Consider the development of a unified disability services database which would facilitate the comprehensive recording of therapist activity.
- Re-emphasise adherence to NPSDD protocols and guidelines for data collection.
- There is a need for clear direction from Department of Health and Children to the HSE on the integration of NPSDD work into the core activities of keyworkers.
- Review awareness-raising strategy and explore opportunities to link with the Health Promotion Unit in the Department of Health and Children.

## Potential of NPSDD

Service users, government departments, statutory organisations, representative bodies, and HSE database teams were asked to comment on the future potential of the NPSDD.

### Strengths:

- The NPSDD has the potential to assist in achieving a continuum of service for individuals with physical and sensory disabilities by:
  - Providing an accurate evidence base of the use of, and demand for, services for people with disabilities
  - Addressing information deficits, including those of government departments other than the Department of Health and Children
  - Ensuring greater individual, general, government, and political awareness of the level of need and what is required to meet this need
  - Securing additional resources for service developments and assisting in the allocation of resources
  - Planning and prioritising service needs
  - Providing regional comparison of levels of service provision and identification of gaps and disparities
  - Aiding the design and delivery of additional services and facilities
  - Assisting in the completion of service and operational plans
  - Improving standards in service provision and co-ordination
  - Including people with disabilities in the development of new services
  - Representing an official recognition of the needs of people with physical and sensory disabilities
- One umbrella body observed that the potential of the NPSDD would be maximised if it were allied to the individual assessment of need and individual service statements expected to be contained in the forthcoming disability legislation. (Note: this legislation, including these provisions, was published in September 2004.)

### Areas for improvement:

- Potential will only be achieved if the critical success factors identified throughout the report, namely, the embracing of the NPSDD by service providers and HSE management and the ongoing co-operation of keyworkers, are secured.

- Potential to assist in the identification of the additional costs incurred by people with disabilities.
- Using the PPSN as a unique identifier. (Note: at present this can only be used by public sector bodies.)
- The coding of disability across government departments should be synchronised.

## Key challenges

Respondents, including government departments, statutory organisations, representative bodies, NPSDD interviewers and HSE database teams, were asked to identify the key challenges to the effective operation of the NPSDD. The following challenges were identified:

- Defining disability
- Identifying conditions to be included on NPSDD
- Ensuring an organised and consistent approach to data collection across the HSE, with continued emphasis on training
- Obtaining a high level of coverage, including the ongoing identification of new clients and in particular the identification of those not known to 'the system'
- Identification and elimination of duplication
- Prompt return of completed information
- Giving people with disabilities a real voice in service planning
- Ensuring appropriate structures and personnel are in place at HSE level to maximise successful implementation of NPSDD
- Good communication between NPSDD staff and keyworkers
- Ensuring service providers have the resources and time to dedicate to NPSDD activities
- Obtaining buy-in from HSE staff, organisations, and individuals in terms of promotion and participation
- Establishing meaningful co-ordination between government departments and agencies at local level
- Ensuring NPSDD is viewed positively
- Good software package to support NPSDD
- Effective use of data to plan services and conduct research
- Dissemination of good quality, policy-relevant, data
- Returning the information to service providers so that they have a useful information system
- Ensuring service planning takes account of all those in need of services and not just those registered on the NPSDD
- Securing adequate resources to respond to the identified need in terms of service provision

- Regular review and update of information
- Facilitating participants to identify and request services that they are not familiar with and ensuring that interviewers are equipped with the knowledge necessary to do this
- Facilitating individuals in receiving services (in particular following up on identified need for assessments) thereby seeing benefits of NPSDD participation
- Addressing issues of overlap in relation to data collected or to be collected by the National Council for Special Education
- Building the confidence of people with disabilities in the NPSDD as a planning tool, and explaining its relevance to them
- NPSDD provides HSE with an opportunity to alter people's negative views of HSE services.

# Maximising NPSDD participation

## Strengths:

- Service provider representative bodies have been very active in promoting the NPSDD among service providers in terms of both understanding the database and identifying the inputs required from service providers.

## Areas for improvement:

- Increased and improved publicity identifying the NPSDD's purpose and its outcomes, and highlighting the positive benefits of participation
- Ease of communication between HSE, non-statutory service providers and potential participants
- Raising awareness among the general public
- Ensuring NPSDD information is made publicly available
- Make HSE plans to address identified need publicly available
- Introduce self-administration of NPSDD data forms

## Recommendations:

- Improve the existing information leaflet to raise the profile of the NPSDD.
- Raise the profile of the NPSDD through local and national media.
- Encourage participation in, and support of, NPSDD by voluntary agencies, support groups, and service providers.
- Inform and reassure potential participants about the positive benefits of NPSDD participation.
- Use freephone services for telephone advice and freepost services for obtaining and returning information.
- Engage with representative organisations and relevant statutory bodies in relation to advice on how to encourage people with disabilities to engage with NPSDD, dissemination of information about the NPSDD, and information published from the database, dissemination of information on service needs, awareness-raising among information providers, and monitoring response to identified needs.
- Publicise NPSDD in pharmacies, GP surgeries, health centres, post offices, libraries, schools, hospital social work departments, and citizen information centres.

- While self-administration of the NPSDD data form is probably not a viable option and would involve a complete overhaul of how the database is constructed, it would be useful to engage with those representative groups suggesting this option to explore how this issue might be progressed.

## Abbreviations used in this report

<b>CCA</b>	Community Care Area
<b>DEDSOI</b>	Department of the Education and Science
<b>DEHLG</b>	Department of the Environment, Heritage and Local Government
<b>DFI</b>	Disability Federation of Ireland
<b>DJELR</b>	Department of Justice, Equality and Law Reform
<b>FPD</b>	Forum of People with Disabilities
<b>NAD</b>	National Association of the Deaf
<b>NCBI</b>	National Council for the Blind of Ireland
<b>NDA</b>	National Disability Authority
<b>NfPBA</b>	Not for Profit Business Association
<b>PHN</b>	Public Health Nurse
<b>NIDD</b>	National Intellectual Disability Database
<b>NPSDD</b>	National Physical and Sensory Disability Database
<b>NPSDDC</b>	National Physical and Sensory Disability Database Committee
<b>PPSN</b>	Personal Public Service Number
<b>PWDI</b>	People With Disabilities in Ireland

# APPENDIX

## Structured questionnaires were sent to:

### Participants:

All participants who completed first NPSDD interview during June 2003

### Organisations:

Government departments

- Department of Education and Science
- Department of Justice, Equality and Law Reform
- Department of Social and Family Affairs
- Department of the Environment and Local Government
- Department of Health and Children

Statutory bodies

- Comhairle
- National Disability Authority
- FÁS
- National Educational Psychological Service
- National Council for Special Education

Representative bodies

- People with Disabilities in Ireland (PwDI)
- Forum of People with Disabilities

Umbrella organisations

- Disability Federation of Ireland (DFI)
- Not for Profit Business Association (NfPBA)

HSE co-ordinating committees

- Statutory representatives
- Non-statutory representatives

### NPSDD interviewers

### HSE NPSDD personnel

Focus groups were conducted with a sample of NPSDD participants in four HSE areas.





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