

# National Disability Service Register<sup>1</sup>:

## Briefing paper 2: Principles and structure

### Overview

This paper is based on a review of databases currently in use in disability services in Ireland. It concludes that none of the existing databases are sufficient to meet the information requirements set out in the Value for Money (VFM) Review. Nevertheless much valuable learning has been obtained that can inform the development of a new management and information system for disability services, provisionally called the National Disability Service Register (referred to in this paper as 'The Register').

Although people with disability using specialist services are relatively small in number (around 75,000 in all), the amount of information required to effectively manage their health and social care can be very extensive and complex due to the heterogeneity of this population, their variety of needs and the diversity of services provided. This is further compounded by how specialist services had evolved in Ireland and the variety of autonomous service providers that exist (21 Section 38 providers and 32 Section 39 providers) plus HSE directly managed services.

A five-stage strategy is therefore proposed to ensure systematic consideration is given to the myriad issues involved in the development of any new management and information system. This paper proposes key information domains to be included in the Register in line with the VFM vision of future disability services and summarises the key principles that should underpin the development. It identifies the levels at which information will be gathered and analysed. It further proposes how more detailed specifications for the register could be developed and the steps involved in making it operational. However at this stage it is premature to detail the precise information to be gathered although that will need to be done when an agreement has been reached on the broad parameters of the new system. This paper should be read in conjunction with Paper 1 that scopes the broader issues relating to health information and the learning accrued from international experience.

The paper is primarily written to aid consultations with stakeholders that Working Group 5<sup>2</sup> (WG5) intends to undertake in the coming months. Key questions are noted within each section to guide their responses. A similar approach could also be used with further consultation papers that evolve in the coming months. The intention is to make the development process transparent and participative, although it will fall to WG5 to use their judgement in deciding on the format and content of a new management and information system. At best it would be 2017 before any new system starts to be implemented.

### Current Databases

A sample of 11 datasets (see Table 1) relating to disability was identified by WG5 and information was obtained on each one by a named informant using a standard pro forma; allied with interviews as needed. These were intended to reflect the various types of datasets that are currently in use: from those centred around individual service users to those focussed more on service delivery, as well as ones that contain information on small groups of persons to those that have national coverage. Moreover some databases are

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<sup>1</sup> This is an interim title and was chosen to distinguish the proposed new information system from existing databases. However the term Register is in line with the terminology widely used by health services for discrete populations.

<sup>2</sup> HSE & DoH (2104) Value for money and policy review of disability services in Ireland: Steering Group Project Initiation Document.

based on locally devised Excel spreadsheets whereas others were commissioned from software specialists who provide ongoing technical support to users.

**Table 1: A sample of datasets relating to disability**

Database
National Intellectual Disability Database
National Physical and Sensory Disability Database
Occupational Guidance Database
Disability Act Database
Congregated Settings
Mid West Children's Services
Brothers of Charity
COPE
Cheshire
Service Level Agreements
Key Performance Indicators <sup>3</sup>

Appendix 1 provides a summary of each dataset in the form of an Excel spreadsheet that summarises their purpose, information gathered, coverage and improvements. In addition detailed supplementary information was submitted for certain systems particularly in relation to definitions of the data gathered. These reports are held by the NDA and can be made available to WG5 as a reference source on which more detailed planning for any new system can be based.

The survey information was also supplemented by information from the online catalogue of all known national datasets related to health produced by HIQA<sup>4</sup>. However those relating to disability are few in number which suggests that people with disability are not identified on the health data systems used with general population. In due course, the use of Health identifiers across all health databases would overcome this drawback.

Also a survey of the data systems used by 20 voluntary service-providers in disability services was undertaken in July 2013 by the National Federation of Voluntary Bodies<sup>5</sup>. This included fourteen intellectual disability services providers, one sensory disability service, two physical disability services providers and two reconfigured services. (Information on HSE data systems, although requested, was not supplied). The survey was in connection with assessing the need for a common information system for the new teams formed by the HSE for Progressing Disability Services for Children and Young People (PDSCYP). Following on from the survey, a working group in the Mid-West contrasted three data systems in use in that region and which held promise as the basis of a common dataset for the children's teams<sup>6</sup>. From these, the one used in the Mid-West across teams

<sup>3</sup> This information is obtained by the HSE through a more extensive template that only Section 38 &39 organisations complete annually that collates information on services and staffing. It was devised for the VFM Review in 2009. See: ([http://www.hse.ie/eng/services/publications/Non\\_Statutory\\_Sector/Standard\\_Templates\\_Forms.html](http://www.hse.ie/eng/services/publications/Non_Statutory_Sector/Standard_Templates_Forms.html)). [Schedules 3, 9 and KPIs Disability Composite Template 2015- Section38\\_ Section 39\(Revised 17/02/2015\)](#).

<sup>4</sup> <http://www.hiqa.ie/healthcare/health-information/data-collections/online-catalogue>.

<sup>5</sup> Walls, M. (2013) *Survey of Electronic Client Record Systems to support the implementation of the PDSCYP*. Galway: National Federation of Voluntary Bodies.

<sup>6</sup> Comparison of the function specification of three systems. Papers available from Ann Bourke (chair) of the National IT Subgroup for Progressing Disability Services.

is proposed as the basis for a national PDS Information System. This was included as one of the 11 databases in this survey.

The longitudinal study of ageing and people with intellectual disability directed by Mary McCarron and Philip McCallion at TCD<sup>7</sup> contains extensive data on a representative sample of persons aged 40 years mostly living in residential accommodation. Although this dataset is not as yet publically available, it contains examples of possible outcome indicators for inclusion in any new system.

Finally it should be noted that it was not possible to determine the actual numbers of databases involving children and adults with disability currently in use across Ireland. A minimum would be 29 based on the foregoing details but with potentially many more held by individual service providers.

### **Strengths of existing databases**

- Existing databases provide national, regional and local coverage of persons with disabilities. This is particularly so with the long-established National Intellectual Disability Database which is one of the few national databases in use internationally.
- The feasibility of gathering information across a wide range of data fields relating to individuals and to services has been established. This includes information relating to the new styles of services envisaged in the VFM review.
- Electronic data systems are well established with most service providers. Direct access to these databases is being rolled out to increasing numbers of service managers and clinical staff for live data entry and reports.
- Information is being exchanged between certain databases: for example between those held by service providers and the National Intellectual Disability Database.
- Latterly new databases of persons with disability have been created to accord with legislation or to monitor the progress with specific policy initiatives such as moving on from congregated settings. There appear to have been nearly 100% returns to these datasets.
- New databases have also been developed and implemented by the HSE to report on service level agreements with non-statutory providers and the key performance indicators specified by the Operational Plan of the Social Care Division - Disability Services in 2015. Again returns have been high.
- A substantial amount of human and financial resources continues to be invested in the development and maintenance of the databases although informants mostly found it difficult to determine exact amounts.

*Do you agree with this summary? Are there other strengths not noted here?*

### **Weaknesses in current databases**

Nonetheless there are substantial weaknesses across existing systems that have been identified also in other reports<sup>8</sup>.

<sup>7</sup> <http://www.idstilda.tcd.ie/info/about/>

<sup>8</sup> Recommendations for a more integrated approach to National Health and Social Care Data Collections in Ireland, HIQA, 2014.

- The ad hoc development of databases that has occurred over the past 20 years means a lack of uniformity in the information gathered, its quality, the coverage attained and the purposes for which the information is gathered. This culture continues with various investments currently being planned by agencies in relation to their specific datasets but without any overall guidance towards a more unified approach.
- Duplication of effort follows on from the above, in that new databases have been created to address specific issues but this means information recorded on one dataset has to be re-entered or summated into other formats.
- Lack of linkages among the databases. With some exceptions, the databases generally do not interlink both with other datasets relating to disability as well as with databases that cover the whole population so that contrasts can be drawn between people with disabilities and those who are non-disabled: for example in their use of hospital in-patient services.
- Existing datasets contain limited information on the personal outcomes from using specialist services and a person's quality of life. This is a major focus within the Value-for-Money review. Current databases tend to record mainly service activity and inputs.
- New models of service, such as those proposed for the clinical teams for early intervention and school-age children under Progressing Disability Services<sup>9</sup>, do not have a functioning IT system.
- Children with ASD are not readily identified in existing databases they are a growing population of service users<sup>10</sup>. Moreover information on people with physical and sensory disabilities is not as well captured nationally as it is for persons with intellectual disabilities.
- The existing national datasets do not provide 'live' data that service directors and managers can access. They are reliant on historical reports prepared by database staff. Some of these staff mention the need for greater 'buy-in' from operational staff in supplying and monitoring data.
- There has been limited engagement with service-users in the development of existing databases nor can they have easy access to the information held on them which is contrary to the ambition for greater self-determination expressed in Objective 2 of the VFM review.

*Do you agree with this summary? Are there other weaknesses not noted here?*

## **Risks to change**

Addressing these weaknesses will not be easy. Some of the risk factors to revising or developing new management and information systems for disability services include:

- The diversity of agencies holding information on people with disabilities and the services provided. Obtaining their 'buy-in' and increasing their capacity for improved data gathering and reporting will be crucial to creating improved systems as well as clarifying the 'ownership' of information which providers collect and assurances around confidentiality that they make.

<sup>9</sup> <http://www.hse.ie/eng/services/list/4/disability/progressingservices/>

<sup>10</sup> <http://www.hse.ie/eng/services/publications/Disability/autismreview2012.pdf>

- The extent and complexity of information to be gathered will affect the costs and time involved in designing and implementing systems. Assuming that the aim is for a low cost, improved information system that can be quickly implemented, it would be essential to identify the main rationale for a new system and to agree a minimum dataset for inclusion in it. These features may be hard to negotiate among the competing interests.
- Competing priorities within the HSE Office of Chief Information Officer for developing new information systems pose another risk. What arguments can be marshalled to ensure priority is given to disability services over those IT initiatives already identified as priorities and within the constricted budget available to the HSE<sup>11</sup>?
- The extent of IT support and expertise varies greatly across agencies as well as access to computers and electronic systems. The factors too have budgetary implications.
- Public reaction to personal information being held by State bodies. The recent concerns expressed by the Data Protection Commissioner among others around the introduction of the primary school database may be replicated in proposing a new disability database unless the benefits for persons with disabilities are readily apparent<sup>12</sup>.
- Proposals for revised information systems have been delayed. The VFM report suggested that a review be undertaken by the Disability Unit in the Department of Health and completed by the end of Quarter 4, 2012. This did not happen and the reasons for delay may still pertain.
- Who will champion and manage the development of new systems within HSE and the Department of Health? Who will have the authority to make decisions and monitor the implementation of new systems?
- The rationale for new systems is founded on new styles of services being implemented nationally but if these are slow to materialise, then the incentive to implement new information systems is reduced. Conversely the new information system will monitor and could drive change. How will this balance be achieved in the coming years?

These risks - among others - will be further explored in the proposed consultations with stakeholders.

*Do you agree with the risks listed? Are there other risks that should be added?*

## Charting the way ahead

The following process is proposed to help chart the way ahead and guide consultations with all stake-holders which will need to include service users and their advocates/supporters; service providers; HSE directors and managers both locally and nationally; and the Disability Division in the Department of Health.

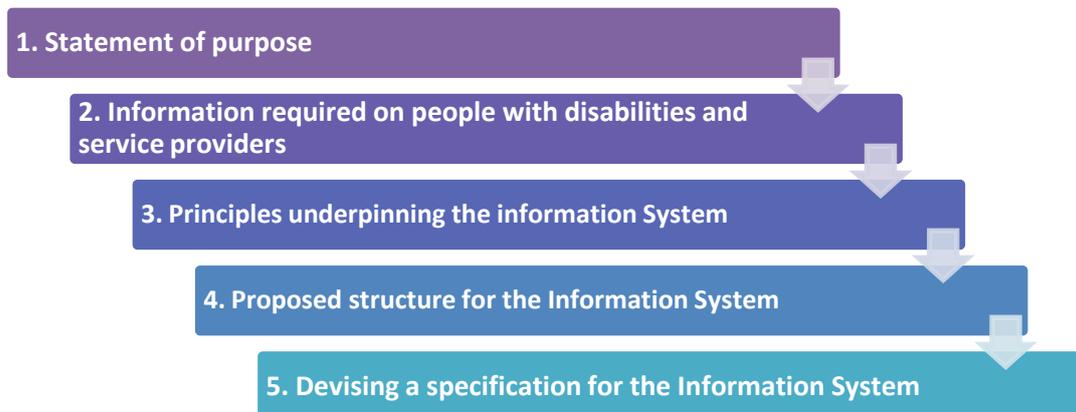
Figure 1 summarises the main phases envisaged in the development of a new information system for disability services.

<sup>11</sup> HSE (2015) National Service Plan p. 60.

<sup>12</sup> <http://www.irishtimes.com/news/education/q-a-is-the-database-of-primary-pupils-a-crucial-planning-tool-or-a-data-grab-1.2084239>

## Stage 1: Statement of Purpose

The Vision for the Disability Services Programme is clearly stated and agreed in the Implementation of the Value-for-Money review. Its two key objectives are:



**Figure 1: Stages in developing a new information system for disability services**

- *Objective 1: The achievement of full inclusion and self-determination for people with disabilities through access to the individualised personal social supports and services needed to live a fully included life in the community.*
- *Objective 2: The creation of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities.*

This represents a radical but evolving change in current service provision and none of the existing national databases were designed to reflect these objectives. Hence a new information system may be required: one that will both drive changes in the ways services are managed and delivered whilst monitoring the extent to which this is happening on an on-going basis at all levels – locally, regionally and nationally.

A possible counter argument is that an existing system – rather than a new system - could be extended to achieve these outcomes. However this may prove to be false distinction as it is likely the development of a ‘new’ information system for disability services will want to build on existing systems.

**Note on terminology.** For ease of reference, in this paper the term ‘Register’ will be used in connection with the proposed development so as to distinguish it from existing databases.

*Are there any other objectives that need to be considered beyond the two noted?*

## Stage 2: Information requirements

The value of any information system lies in the reports that can be obtained from the information gathered. Currently information is gathered on people with disabilities and also on services provided to persons. This duality needs to continue.

### Information on people with disabilities and services

Figure 2 proposes the core information that is needed on individuals receiving/needing specialist disability services based on the foregoing statement of purpose and the proposals put forward in the Value for Money review. (At a later stage, the specification of information

to be gathered and how it is done, can be proposed and debated. This process would be informed by the information currently gathered in existing databases).



**Figure 2: Core information to be gathered on people with disabilities**

**Needs, barriers and aspirations:** A common assessment framework has been proposed by the NDA for assessing the needs of adult persons with disabilities. Additional information on the needs of particular individuals may be required. The needs of family carers also need to be obtained.

Account also needs to be taken of the barriers that people and families experience. Also risks to ongoing family support through parental ill-health for example.

The person's aspirations– obtained through person-centred planning for the immediate and longer term – need to be recorded as these determine their personal outcomes. This information will be gathered on people

receiving services as well as those referred to services.

**Supports and services:** This domain covers the supports which the person receives including those provided by/to family carers and by mainstream services. The specialist services that the person currently receives will be described along with the number of support hours. These may be provided by different agencies. In addition, details of new/improved services urgently required by the person can be recorded (e.g. within 12 months). The need for possible future services (e.g. beyond 12 months time) might also be noted.

**Costs:** The costs of current services would be recorded for the individual. This would be calculated by service providers perhaps initially as an average costing if the person uses group-based services but ultimately the aim would be to arrive at individualised support costs.

**Outcomes:** This could be done in terms of outcomes that hold for most persons with disabilities (e.g. quality of life indicators) as well as those that are particular to the individual. The review of outcomes would feed into a further assessment of needs, barriers and aspirations so that a cyclical process is maintained.

**(Note:** Identifier and demographic information on each person would also be gathered. Appendix 2 summarises the domains of information proposed by the Department of Health)

*Do you agree with these four domains? Are there other domains that should be included?*

#### *Examples of reports available from the Register of individuals with disabilities*

- A report can be generated for each individual that records the information held on the Register under each domain.
- Each service unit/provider can readily report on the demographics and support needs of their clients.

- For each Community Health Organisation area, the numbers of persons receiving different services can be identified along with the costs of each. Comparisons can be made across these areas.
- The number of persons requiring new or improved services can be identified by services, CHOs and nationally along with the likely additional costs of providing these services.
- Nationally the outcomes from using disability services can be identified and linked to the costs of providing the services.

*Are there other reports that are essential for service management and planning?*

### Information required on service providers

As happens at present, information on clients needs to be complemented by information on service providers: that is by having a register of services. However the two registers would be inter-linked through use of health Identifiers. The service register could contain information for larger service providers as a whole but also in terms of the 'units of service' they provide such as the individual group homes, or personalised support to an individual. Four domains of information could be included in this register as shown in Figure 3.



**Figure 3: Core information to be gathered on service providers**

**Governance/Compliance:** A register of services would enable services to provide data on their compliance with HIQA standards which at present seems to be a recurrent failing in inspection reports<sup>13</sup>. Similar standards could also be applied to non-registered services within key areas such as individualised supports and care. Governance information, accreditation and quality systems can also be collated here.

**Staffing:** Details of the staffing establishment – numbers, grade, qualifications and type of staff – as well as vacancies and turn-over in each calendar year could be recorded.

**Budgets:** Information on pay and non-pay budgets for the current financial year could be noted for the service/service unit.

**Key Performance Indicators (KPIs):** Data on requested KPIs could be collated in this section. This data would also draw on information recorded for individual clients: for example in determining the number of people with ID and/or Autism in receipt of respite services.

*Do you agree with these four domains? Are there other domains that should be included?*

<sup>13</sup> <http://www.irishtimes.com/news/social-affairs/inspectors-find-failings-in-every-hse-disability-care-home-1.2315327>

*Examples reports would include:*

- A profile could be derived for each publically funded service both in total or for each individual service unit.
- For each Community Health Organisation, the pay and non-pay budgets can be ascertained for all disability services. This information could also be accumulated nationally and variations across CHOs identified.
- Changes in the number and type of staff within disability services can be monitored over time by CHOs and nationally.
- Information relating to specific Key Performance Indicators can be compared across service providers and Community Health Organisations.

**Note:** The examples of the types of reports to be provided by the Information System are only illustrative. Further consultations and debate will help to identify the priority reports to emerge from the system.

*Are there other reports that are essential for service management and planning?*

### Stage 3: Proposed Principles

Translating information requirements into reality requires certain decisions to be made with respect to the overall design of the Information System; referred to here as the principles underpinning the Register. However these principles need to be debated and ultimately owned by the various stake-holders.

The following set of principles have been identified from the review of the existing databases (see Appendix 1) and the wider issues relating to health information summarised in Briefing Paper 1. Seeking agreement on these principles is an essential first step in the design of the 'new' system.

- *The Register is designed to facilitate the shift towards individualised personal social supports and services for persons with disabilities and promote their self-determination.* This is the overarching principle that marks out the register from existing databases that largely reflect a group-based model of services.
- *The Register will be held by the HSE.* It would contain details of persons with disabilities and service providers who are supported financially by the HSE including services directly managed by them. A requirement to supply information for the Register would be written into service-level agreements with non-statutory providers. Given appropriate safeguards, the information on the Register would be directly accessed by HSE/Department of Health personnel as a live system.
- *The register is a management rather than clinical tool.* Although the Register may draw information from, and provide information to clinical records, it will not replace the need for clinical or service records or for data systems that allow document sharing.
- *The Register should be accessible to individuals and services.* The data held on individuals should be accessible to them and be capable of being updated by them or their advocates. Likewise the information recorded on service providers should be accessible to them for checking and correction of their own records. The extent to which information on the data base in relation to services is made publically available

needs consideration especially if the goal is to provide people with disabilities more choice and control.

- *It builds on existing systems.* This will ensure past investment is maximised and provides immediate access to information already held in datasets. The Register would 'capture data' from existing datasets rather than data having to be re-input. However existing service databases may need to be extended to provide the required information for the Register.
- *It contains nearly complete information on selected (core) data fields.* In order to increase the efficiency of the Register, selective information will be gathered with the aim of minimising missing information within core data fields.
- *It should assist service providers to develop their own information systems.* The Register would provide a common software system for use by providers who hold service-level agreements with HSE and who are upgrading or investing in new information systems.
- *The information on the Register must be regularly updated and audited.* Certain data fields may require weekly updates whereas for others, quarterly updates to the Register may prove sufficient. However systems for auditing the accuracy and quality of data need to be devised in addition to the current practice of sign-off by managers.
- *The costs of developing and implementing the system should be minimised.* It would be unacceptable for the HSE to invest in expensive information systems when funds for disability services are constrained. The Register may have to be implemented in a phased basis. It should require minimal additional personnel to support the Register.
- *The Register should be developed as a priority in 2016.* The register will be essential to the implementation of the Value for Money review.
- *The register may make some existing data systems and reporting procedures redundant and avoid duplication of information gathering.* This will become apparent when agreement is reached on the content of the register.

*Do you agree with principles listed? Are there other principles that should be noted?*

#### **Stage 4: Possible Structure of the Register**

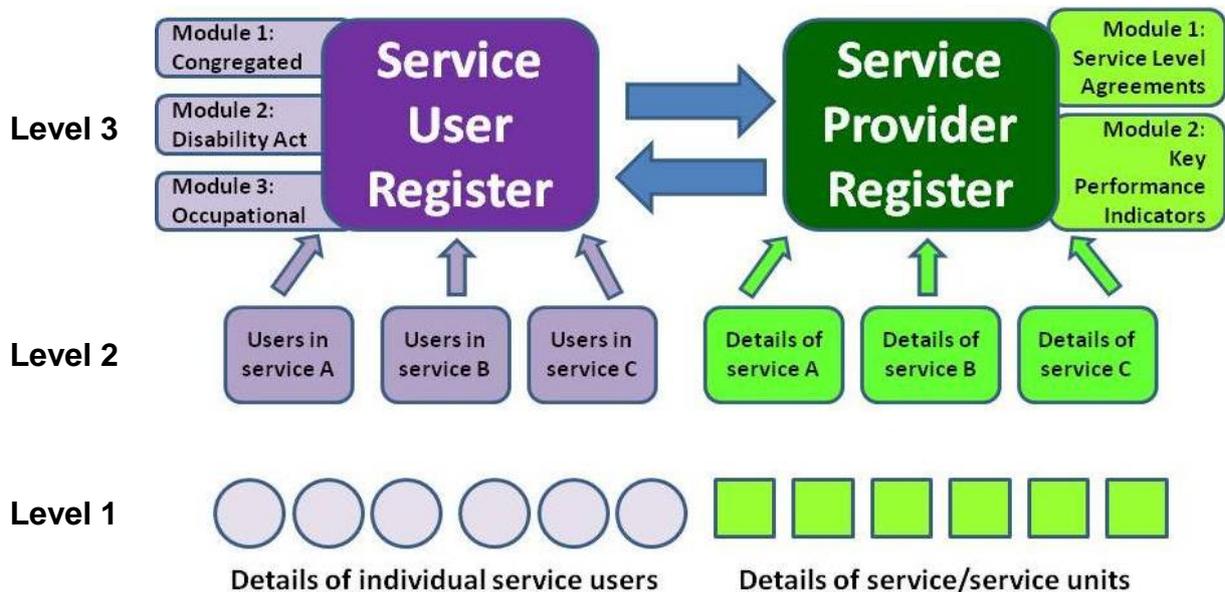
Existing disability databases fall into two broad groupings. There are ones which provide information on persons using services or who require services: for example, the National Intellectual Disability Database. The second group are those which describe the characteristics of the services which are managed by, or contracted with the HSE; such as Key Performance Indicators. It would be difficult to combine both set of requirements into a unified database. Rather it is proposed that two linked registers are developed as shown in Figure 4.

Moreover a major aim of any new system should be to provide continuity with existing databases so that historical information is not lost and also to minimise the changes required to implement the new Register.

Three levels of information gathering are proposed in each register. Access to different levels of information can be controlled through access rights.

## Service User Register

**Level 1:** Details of individual service-users would be obtained by service staff on all persons in receipt of a specialist disability service or who had been referred as potentially being in need of a service. This is usual practice and such data is often part of a person’s clinical record. However in some, perhaps most services, additional information may need to be gathered in line with the data fields in the proposed Service User Register.



**Figure 4: Proposed Structure for the Register**

An individual health identifier would be recorded in line with recent Act. This would have to be done retrospectively for users recorded on existing databases but in any case this would be good practice whether or not a new information system was being implemented. This identifier will ensure that persons receiving services from different providers can be identified: a scenario that may occur more frequently in the future. The Health Identifier also makes it possible for individuals to directly and securely access, check and correct their details on the Register.

**Level 2:** Information on service users would be collated at a service level to provide a database of all users within that service. This is common practice across many disability service providers and presumably also in directly managed HSE services. These user records would contain information on the services each person is currently receiving using the Service Health Identifier proposed under recent legislation. Collating the data at this level ensures that the Register is also of benefit to service providers and enables access to historical records.

Included at this level is the Children’s data that will be held on the new Management and Information system that is proposed for the Integrated Service Teams in the 25 Local areas. (see later).

**Level 3:** The data required for the national Register will be transferred from the service databases at Level 2. This is modelled on the arrangements that some providers, such as the Brothers of Charity, have instituted for transferring data to the National Intellectual Disability Database. Using the unique personal identifier, the national register will be able to identify people who may receive services from two or more agencies thus allowing the totality of the services individuals receive to be documented.

## Modules

The Service User Register will also provide the information that is currently collected separately under what is termed here as ‘modules’. Thus reports from the Register would be set up that import the information from the Register to the three existing databases (provided the necessary fields are included when entering information on service users at Level 1):

1. People resident in congregated settings.
2. Assessments under the Disability Act.
3. Occupational Guidance Database.

This means that service providers would not need to make a separate return in either spreadsheet or paper forms as is the case at present. As the Register becomes established these separate databases would no longer be required.

*Do you agree with the Structure proposed for the Service User Register? What modifications should be made to it?*

## Service Provider Register

Information relating to service providers would be entered into a separate register. Again this information could be gathered at one of three levels.

**Level 1:** This register would allow for individual service units to be identified within the one provider agency; for example, different residential facilities as registered with HIQA. The amount of detail collected on each unit would be determined by the requirements of the National Register (see above). If the person receives individualised support (for example through a personalised payment), details of this support can be recorded at this level. Moreover it would be possible to record services provided by multi-disciplinary team members using their unique Health Identifier. All users of the particular service unit can be readily identified from the Service User Register using the service identifier codes in the records.

**Level 2:** Information on individual service units would be collated for the provider agency; for instance those holding a service level agreement with the HSE. This level would also record information common across the service units. Service providers could substitute these returns from information that they currently provide using Excel templates (see below).

**Level 3:** The data required for the national Register would be transferred from the service provider database. These records will enable a national description to be made of the specialist services currently being contracted and provided including their costs. This information could be used to build an information resource for service users or their advocates as to the range of services that are available in their locality.

**Note:** The two registers will also interlink at Levels 1 and 2 as described above although these links are not shown in the diagram.

## Modules

The Service Provider Database should also be able to provide information for the two systems currently used by HSE:

1. Service Level Agreements
2. Key Performance Indicators.

Again reports from the Register would be set up that capture the information that is currently collected separately from providers thereby reducing the extra work this places on them. It is also likely that a richer information base will be available given the additional information that will be held in the two linked Registers.

*Do you agree with the Structure proposed for the Service Provider Register? What modifications should be made to it?*

## Stage 5: Devising a Specification for the Register

The following listing contains decisions that are required in order to provide more detail about the content of the two Registers and to guide their implementation.

- *Criteria for inclusion on the service-user register.* The following criteria are proposed based on current practice in the two National Databases, namely: persons who are receiving specialist disability services and supports or who may require a specialist disability service or supports. It will include children and adults up to age 66 years, although the upper age limit has been questioned as the numbers of people aged 66 years and over in specialist services is rising. The definition of disability is largely as per the Disability Act (2005)<sup>14</sup>. The register will include people with intellectual, physical and sensorial disabilities including autism. However people with mental health problems only will not be included as they fall under another Directorate within the HSE. The inclusion of short-term users of one-off services needs to be considered and arrangements for re-registration of persons. Criteria for updating and deleting personal records need to be decided.
- *Criteria for inclusion on the service-user register.* This register will include all directly managed HSE services as well as non-statutory agencies holding service-level agreements and/or in receipt of public funding. People in receipt of personalised payments might be registered also as a provider and details of the supports provided would be recorded. Services that are wholly privately funded would not be included although clarification is required if a service user uses a personalised payment to purchase services from a 'private' provider. Guidance would also be needed on the definition of service units within larger providers, for example the unit would have dedicated staffing, a distinct budget and a designated leader/manager. A particular issue may arise over services provided by clinicians and social workers to individuals and groups. In children's services these are likely to be considered as members of a team and this approach could also be used in services for adults. But if information is required for each clinical specialism then they would need to be recorded individually using their unique health identifier.
- *Roll out of the Health Identifiers.* The Register is reliant on unique health identifiers. Hence their use needs to commence as a matter of urgency and the allocation of Identifiers to service users and service provider/service units should be a requirement in service-level agreements and in HIQA inspections.
- *Children's services.* The prospect of a new Register should not inhibit the development of other IT resources within disability services. A particular case in point is the IT requirements of the new teams working in children's services which have been drawn from different agencies and who no longer have access to shared electronic information

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<sup>14</sup> The definition of Disability given in the 2005 Act is: "a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment".

systems. Their needs are primarily for managing clinical records and information sharing across team members as well as holding data on the child and family. In line with the proposals for the Register, these teams would be considered as service-providers from whom required details about the children would be extracted along with details of the services provided to them. The proposals which the national lead for Progressing Disability Services (Ann Burke) is about to make for a new information system should be progressed separately as their need is urgent, but with the proviso that the chosen system is capable of expansion to meet the requirements of the new Register.

- *Live reports.* Although a great deal of information is collected in existing databases, sparse details are available as to usage of the reports that are produced from the data gathered. For example, the annual reports prepared by HRB staff from the two national databases tend to be mostly descriptive of service users, the services received and future service requirements. In addition local area bulletins are sent to HSE summarising data for that area. However the link is not direct between the information gathered and with service planning and commissioning because the data often cannot be accessed on a live basis by service planners at a national/CHO level. Hence a major focus of the consultations by WG5 should be on the reports that are essential for the planning and delivery of more effective services at national and more local levels and ensuring that service decisions are based on the most recent information.
- *Identifying information to be gathered:* In addition the specific information to be gathered under each of the proposed domains will need to be defined. To a large extent, this will draw on the information that is currently being collected in existing databases. Moreover this will confirm the viability of obtaining the information and reassure stakeholders that the register is a development of, rather than a replacement for existing systems. In addition, future consultations with stake-holders will provide an opportunity for them to suggest data fields to be included in the Register. In due course, a data dictionary will need to be developed for the Register and again examples are available to guide this process.
- *Unmet needs:* A major aim for the Register is to identify unmet needs to assist with planning service supports and identifying resource requirements. Some of these needs will be urgent and require immediate attention whereas others are likely to become apparent in the longer term. Audits of the NIDD have identified that future needs are not reliably recorded nor did these records predict actual uptake of residential placements for example. Hence definitions need to be devised regarding the urgency of need for services and regularly updated to ensure their validity.
- *Outcomes for service-users:* This domain is least well covered in existing databases although various outcome schema have evolved internationally and Irish services have promoted their use<sup>15</sup>. The paradox here is that outcomes should be personal to the individual but in order for outcomes to be summated across groups of service-users, often selected indicators have to be used. Another approach is to use Quality of Life indicators that hold for the general population and for whom comparable contrast data might be available such as ratings of health; social engagement. An outcomes framework has been developed for Children and Young People's Disability services<sup>16</sup>

<sup>15</sup> International examples include: Council on Quality and Leadership (<http://www.c-q-l.org/the-cql-difference/personal-outcome-measures>) and National Core Indicators (<http://www.nationalcoreindicators.org/indicators/>).

<sup>16</sup> Progressing Disability Services for Children and Young People (2013) *Outcomes for Children and their Families: Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams*

and the HSE Strategic Plan (2015) includes the intention to create Quality Framework and Outcomes Measurement Framework (presumably for support services to adult persons). However a specific project might need to be commissioned - similar to that undertaken by the NDA in identifying a needs assessment tool - to assist with the identification of a standardised suite of outcome indicators for use nationally in the Register.

- *Ensuring compliance with data protection and clinical governance:* Once the content of the Register is clarified, the proposals will need to be proofed against the rules set out in Data Protection Acts. Also issues around clinical governance, ownership of data and permissions on data sharing will need to be addressed.
- *Historical records:* The system must be capable of tracking individuals over time so that trend data is also available. Moreover historical data presently held on existing databases needs to be accessible to the new Register.
- *Advice on the IT requirements and likely development costs.* The broad proposals for the Register should be assessed in terms of their IT requirements. This might be facilitated by the HSE Office for Chief Information Officer and HSE Procurement. This would help inform the development of the Register on a phased basis if costs are constrained. In due course a business case would need to be prepared once agreement has been reached on the structure and content of the database.
- *Managing the Register and Technical Support.* Consideration should also be given as to how the Technical support to implement and maintain the Register will be provided along with the analysis and the preparation of reports from it. This may be better contracted to an agency with specific expertise in disability databases such as the Database section of the Health Research Board given their long involvement with the National Disability Databases. Engagement with *eHealth Ireland* would be essential (see paper 1).
- *Notification of impending change.* The Health Research Board has plans to merge on a new platform the two national databases that they manage on behalf of the Department of Health. Likewise some service providers are intending to upgrade their systems. It would be important to give early notice of HSE intentions so that any developments planned are in line with the broad thrust of proposals emerging in the VfM process.
- *Communication Strategy:* WG5 should prepare a communication strategy to promote the positive benefits of the Register for service users and service providers. This would aim to pre-empt any misinformation or misunderstandings. This is urgent as consultations will commence from mid-September onwards.

*Do you agree with the list of topics above? Are there other issues that need to be considered in drawing the specification of the proposed Register?*

## Wider considerations

At the consultation workshop, participants identified various wider considerations beyond the proposed Register. Advice may need to be sought from, and consultations held with other Departments, agencies and advocacy organisations on these matters. Decisions around these issues will need to be incorporated into the specification of the new Register.

*Inclusion of supports/services beyond health and social care:* For example, housing requirements, employment and recreational pursuits over which HSE may have little control.

*Linkages with other information systems for general population, e.g. primary care, primary school database.* With the necessary safeguards and permissions, the two-way flow of information would be mutually beneficial and would avoid duplication of information being gathered from people with disabilities and their carers.

*Inclusion of 'sensitive' information, how it is defined and who has access to it:* This can apply throughout: in assessment of needs, supports received/required and personal outcomes.

*Requirement placed on service users and providers to provide information and arrangements for ongoing and specific consent.* Legal advice may be needed to clarify issues around the ownership of information gathered and consents around passing on information.

*Procedures for ongoing consultations with stake-holders during further phases.* Ongoing consultations will be needed with the main stake-holders on the specification for the Register, the piloting of it and decisions around its implementation.

*The integrity of the system if managed by HSE.* Concerns were expressed about the selective reporting of national information if the Register was solely available to HSE personnel.

*Making the system accessible to people with disabilities and family carers.* Special arrangements may need to be put in place to ensure that the system for data inputting and review are accessible to people with sensory and intellectual impairments.

*Investment needed in training and supporting people inputting information and in analysing information.* The Register depends on frontline service staff and managers inputting the required information and their training and support needs must be factored into the development of the register. Likewise, training and support at analysing the information contained in the Register needs to be offered at the appropriate levels so as to maintain

*Convincing users and providers that the investment in information systems will bring added value over their priorities.* Perhaps most crucial of all, is 'selling' the need for improved information systems to users and providers at a time when resources are constrained in responding to unmet needs. The benefits to users and providers need to be made quickly apparent to them.

*Do you agree with the list of topics above? Are there other considerations that should be added?*

## Next Steps

The process for refining the proposals contained in this document is as follows.

1. A shorter consultation paper will be prepared and approved by WG5 subgroup by 24 September. This will be distributed in advance of the consultations noted below.
2. Individual or Group Interviews will be sought with persons identified by WG5 to obtain their comments and suggestions.
3. Written responses will be obtained from a range of stake-holders identified by WG5.
4. A final report summarising proposals for the new Management and Information system will be agreed by WG5 by the end of October.
5. WG5 will submit their proposals to the Steering Group for the VFM review for approval to proceed to the development phase (steps 8 to 12 below).

6. WG5 will enlist the help of HSE IT personnel to develop the business case for the new system.
7. WG5 will undertake further work on specifying the data fields to be included in the new system.
8. A budget for designing, testing and implementing the new system will be identified.
9. An implementation team to oversee the development of the new system will be appointed.
10. The new system would be piloted in selected areas and adjustments made to the system.
11. The new system will be commissioned and rolled out in a phased basis.

**Note:** The earliest that the implementation of a new system is likely to begin is 2017, assuming that the necessary human and financial resources are available throughout 2016.

## Conclusions

The development of a new management and information system to guide and monitor new styles of disability support services in the coming decades is an ambitious undertaking and one which few jurisdictions internationally have taken. However Ireland is well placed because of its size, past history of national databases and government endorsed policy for future service provision, to make this a reality. It is a feasible endeavour even if an ideal system proves to be elusive in the short or medium term. Rather the immediate goal is to lay the foundation for a system that will deliver value-for-money for all the stake-holders and especially for people with disabilities who use publically-funded services.

*Report compiled by Roy McConkey,*

*Further Revised: 21<sup>st</sup> September, 2015 following consultation workshop.*

## Disclaimer:

The views expressed in this report are those of the author and do not represent those of Working Group 5 or the Steering Group for the Implementation of the Value for Money and Policy Review.

## Appendices

**Appendix 1: Excel file summarises the main features of a sample of 11 databases (see attached file).**

**Appendix 2: Proposed categories of information proposed by Disability Unit in the Department of Health.**

The Strategic Information Framework drafted by the Disability Unit in the Department of Health (2015) has suggested that the following categories of information are collated nationally in relation to individuals but also in terms of the service delivery information.

### Demographics

- ▶ Demographics: basic demographic details
- ▶ Disability: level and type of disability

### Health and Wellbeing

- ▶ Quality of life indicators
- ▶ Health Indicators

### Services and Supports

- ▶ Service plan: annual targets, priorities, key actions and key performance indicators
- ▶ Services delivered
- ▶ Services required now
- ▶ Services required in the next five years

### Quality

- ▶ Quality domains: efficiency, effectiveness, equity, patient-centredness, safety, timeliness.
- ▶ Evidence of best practice
- ▶ Complaints

### Costs

- ▶ Allocation
- ▶ Expenditure
- ▶ Staff

### Policy Implementation

- ▶ Progress on governance and administration reform
- ▶ Progress on cost containment
- ▶ Progress on migration to person centred supports

This document also outlines a Strategic Information Planning approach for determining key information needs in order for organisations to attain their objectives. This approach has informed the proposals contained in this paper.

