

Measure of Activity and Participation: origins and potential uses



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Summary

The Measure of Activity and Participation (MAP) is a tool capturing information on the barriers to activities and participation restrictions that people with disabilities experience in their everyday living. MAP forms part of the National Physical and Sensory Disability Database (NPSDD). The MAP can be used to gauge the effectiveness of services and policies relating to people with disabilities through monitoring changes over time, particularly before and after an individual receives a service, or before and after a policy is introduced.

This bulletin describes how MAP originated, its purpose and implementation, developments over time, uses to date, and importantly, an outline of how it could be expanded to other populations. This bulletin also examines recent changes in disability policy and the potential contribution of MAP data to implementing these changes.

Disability services have changed in recent years with a move towards a more person-centered approach to service provision and funding. This approach allows individuals with a disability more freedom to choose what they feel is right for them and what works best for them; and also allows service providers to effectively monitor funding rather than having a 'one for all' fit. The MAP data is the only national source of information of this kind in Ireland, and is invaluable as a tool for measuring the effectiveness of services and policies. MAP data could be expanded to a further cohort of people; including those with intellectual disabilities, children and young people to allow the effectiveness of services and policies to be measured in these areas. This bulletin explores these issues.

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Background

National Physical and Sensory Disability Database

The health strategy document 'Shaping a Healthier Future' (Department of Health, 1994) highlighted the need for information on the health service needs of people with physical and/or sensory disabilities. 'Towards an Independent Future', published in 1996 by the Review Group on health and personal social services for people with physical and sensory disabilities, highlighted the lack of reliable information on the number of people with physical and/or sensory disabilities and their service needs.

In response to this, the National Physical and Sensory Disability Database Committee (NPSDDC) was established in 1998 by the Department of Health (DoH) with the task of developing a national database that would collect information on the specialised health and social service needs of people with physical and/or sensory disability. Previous to this, the National Intellectual Disability Database (NIDD) had been set up in 1995. The purpose of the NPSDD is to provide a detailed and accurate information base resulting in evidence for decision-making and priority setting in relation to the planning, funding and management of services for people with a physical and/or sensory disability. Following a phased introduction between 1998 and 2001, the NPSDD was implemented on a nation-wide basis in 2002. The Database captures information only on those aged less than 66 years of age.

In 2001, the DoH endorsed the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF). The ICF classifies health components of functioning and disability at both individual and population levels and was implemented in 2001 after extensive international revision. The ICF provides a holistic framework that views disability as the interaction between a health condition (disease, injury or disorder) and the individual's environment. This approach recognises that disability is not simply a condition of the body or the mind, but is in fact, a multi-dimensional phenomenon that incorporates body function, activity limitations, participation restrictions and environmental factors. The ICF provides a 'common language' for describing an individual's functional status.

The ICF has the potential to increase awareness of the issues faced by people with disabilities including the social and cultural dimensions of disability (Kearney & Pryor, 2004). This perspective of viewing disability, if used correctly, supports policy makers and those responsible for funding/providing health and social care supports with the evidence required to ensure appropriate policies and services are in place for those that need them. The ICF can also provide a measurable indicator to ensure that such supports/policies are effective, and the use of the ICF allows for results to be statistically generalised (Hurst, 2003, Douglas et al, 2012).

Development of MAP

One of the key challenges of the NPSDD was that while the information and data generated could indicate the intensity of service needs specified by a person or group of people, it could not be related to the severity or complexity of a condition in terms of environmental barriers, reduced functioning, activity limitations and participation restrictions. Without this information, it was difficult to determine how effective priority setting and planning could be achieved. Consequently, it was agreed that the NPSDD would be reviewed in light of this framework to broaden data collection efforts in line with the ICF. The DoH recognised the value of expanding data collection efforts to include indicators of participation based on the ICF, and established the Measure of Activity and Participation (MAP) subgroup in 2002 to oversee the piloting of new questions.

The MAP subgroup was tasked with identifying appropriate questions to capture levels of and barriers to activity and participation of clients registered on the NPSDD. The WHODAS 2.0 (WHO's Disability Assessment Schedule version 2.0)

measures difficulties with daily activities was adopted as this scale was already in existence and widely used internationally. In the absence of an appropriate and well-developed tool that complied with the ICF available at that time and following consultation with the WHO and other leading experts in this field, the 'barriers and challenges' and the 'participation restrictions' sections were generated for inclusion on the NPSDD.

Piloting of MAP

In 2003, the MAP subgroup piloted the new survey questions which were later added to the NPSDD in 2004. The MAP is an adult measure only and captures information on people aged 16 years or over:

- The **Barriers and challenges** section highlights the social-environmental factors that potentially serve to exclude or restrict participation of people with disabilities in society. It also attempts to ascertain whether these identified factors act as barriers or challenges to the participation of the people included in the NPSDD over a period of twelve months (from date of data form completion).
- The **Participation** section identifies the extent to which the individual's participation has been restricted in certain life areas such as education, employment, socialising, shopping and family life and the extent to which this experience of restriction has bothered them.
- The **WHODAS 2.0** is a measure of the difficulty the individual has had with performing particular daily activities over a period of 30 days (prior to date of data form completion), and the extent to which these difficulties have interfered with his/her life. The WHODAS has several important uses on the NPSDD in that it offers a measure of difficulty in varying domains of life which can be linked to disability types.

These measures can also be linked to varied types of services and interventions. The link to barriers and participation restriction can also be explored and further analysis of WHODAS 2.0 measures over time, may show the impact of services on improving the experiences of those with a physical and/or sensory disability.

The inclusion of the MAP provides an opportunity to capture a more complete picture of the experience of disability and the service needs of the person with a disability. This is a positive development in the collection of disability data and highlights a move away from a medical, individualised approach to data collection towards a focus on society as disabling. The MAP crucially has the capacity to distinguish between those individuals with severe, complex and persistent needs and those with transitory or moderate impairments. Importantly, the services required can be related to an individual's level of functioning and his/her everyday experience of barriers to activity and restricted participation. This in turn can lead to more effective prioritisation of interventions. The aim is to demonstrate that the provision of services will improve individual participation and functioning experience. The information can also help identify the actual benefit or otherwise of receiving such services on the broader ability of a service user to participate more fully in society. The MAP also has the potential to track this over time.

Functioning

In recent years work was undertaken within the MAP subgroup in recognition of the fact there was a gap in the MAP in that it does not capture the level of difficulty in body functioning an individual might have. The NPSDD captures data on diagnosis but does not record the severity of the condition or levels of functioning. This limited the extent to which services requested could be related to an individual's level of functioning, activity limitations or restrictions in participation. A Body Function Questionnaire (BFQ) aims to complement the pre-existing MAP and WHODAS sections of the NPSDD but this work has yet to be finalised.

Summary of MAP findings to date

MAP data has been used for many purposes. Six MAP bulletins produced between 2006 and 2012 summarise the experiences of people living with disability. MAP data have also been analysed and published in four internationally peer-reviewed journal articles.

MAP bulletins series

1. The first bulletin (O'Donovan & Doyle, 2006) presented an overview of key findings in relation to activity limitations and participation restrictions for those who had completed the MAP section and demonstrated the relevance of capturing such information to inform service planning and provision. The key findings were:
 - Transport was identified as a major barrier for people with visual disability in particular.
 - Participation restriction was experienced most prominently in the areas of sports and physical recreation, employment and job seeking, socialising, and shopping and approximately one in four people were completely restricted from participating in sports and physical recreation (25.7%) and employment (27.3%) respectively.
 - 68.7% of people were emotionally affected to some extent by their physical and/or sensory disability.
 - Climate/weather, physical environment, and income were the main barriers to participation.
 - It was also found that having a Personal Assistant improved participation.
2. Issue 2 (O'Donovan & Doyle, 2007) documented the results from the WHODAS II section of the MAP data and highlighted the value of this information to service planning. The key findings showed that WHODAS II has several important uses in the NPSDD system. It offers a measure of difficulty in varying domains of life and:
 - These measures can be linked to disability types and to varied types of services and interventions.
 - The link to barriers and participation restriction can also be explored.
 - Key services such as a Personal Assistant reduced barriers and increased participation.
 - Further analysis of WHODAS II measures over time, may show the impact of services on improving the experiences of those with a physical and/or sensory disability.
3. Issue 3 (Doyle & O'Donovan, 2008) focused on the social participation of people with neurological conditions and illustrated the link between this experience and the impact of service interventions. The key findings were:
 - The areas that represented the largest barriers for people with neurological conditions were physical environment, climate/weather and income.
 - People with a neurological diagnosis experienced the most restriction in participating in sports or physical recreation followed by socialising shopping, leisure/cultural activities and family life.
 - 77.8% of those with a neurological condition were emotionally affected by their disability. 89.0% of people with a neurological condition reported an overall interference in their lives due to performing daily activities.
 - The three areas that individuals experienced the most difficulty in were: standing for long periods such as 30 minutes, walking a long distance such as a kilometre and taking care of household responsibilities.
 - The impact of the provision of key services, such as a Personal Assistant, was evident as barriers were reduced and participation was increased when such services were in place.
4. The fourth bulletin (O'Donovan & Doyle, 2009) investigated participation and ageing. The analysis found that experience of barriers, participation restriction and difficulties with daily activities differed when different age groups are examined. In addition, it was found that diagnosis was also a factor in type of barriers and areas of

restriction experienced in that as people age, conditions such as diabetes and stroke/hemiplegia are more common and the barriers and restrictions experienced can vary by comparison with younger age groups.

5. Issue 5 (O'Donovan & Doyle, 2011) presented a comparison of two major data sources in Ireland - the National Disability Survey (NDS) and the NPSDD. The purpose of the bulletin was to determine how comparable the data sources are in their use of the ICF and to explore the potential for decision makers to mine the data from both sources for more effective decision making.
6. Last year's bulletin (Carew & Doyle, 2012) examined the types of assistive technology (AT) used and required by people with a physical and/or sensory disability in Ireland and evaluated the relationships between AT use and levels of participation in areas of life activities, social-environmental participation and difficulties with daily activities. The key finding was that AT improved MAP scores. Having AT was associated with fewer barriers, less activity restriction and less participation. Across each disability group there is a substantial number of people who still require additional AT and a further group who have received no AT yet at all.

Additional research

Gallagher and Mulvany (2004) explored the relationships between socio-demographic variables, causes of disability and the domains of ability and functioning of the WHODAS II using data collected during the pilot implementation. The key findings were:

- 'Life activities', 'getting around' and 'participation in society' were the domains with greatest difficulty
- An increase in age was associated with an increase in the difficulty of getting around and undertaking life activities and less difficulty in getting along with people.
- There was also a significant difference in each domain in respect of diagnostic category.
- A high level of difficulty in 'Participation in Society' was recorded for each of the diagnostic categories.

O'Donovan *et al* (2009) used MAP data to investigate and explore the relationship between the barriers, participation restriction and functioning levels experienced by people with disabilities. The key findings were:

- Significant differences in barriers, participation restriction and activity limitations experienced by people with different types of disabilities.
- Low functioning and experience of barriers were indicators of participation restriction.
- Elements of the ICF have been successfully operationalised in a service planning tool through the development of the MAP, providing a more holistic view of disability.

O'Donovan and Good (2010) examined how disability was measured and understood within Irish data sources in the period 2000–2006, by carrying out a detailed examination of the Census of Population (2006), National Disability Survey (2006), National Physical and Sensory Disability Database (2006), Survey of Lifestyles, Attitudes and Nutrition (2002) and Euro Student Survey (2003) and then mapping these data sources to the ICF. The authors found that the MAP section had a strong focus on activity and participation, incorporated environmental factors and covered the largest number of personal factors compared with all other data sources.

Gallagher *et al* (2011) utilised MAP data to investigate the barriers, participation restriction and functioning levels experienced by people with a major limb amputation. The authors highlight the benefits of describing major limb amputation along with associated activity limitations, participation restrictions and environmental barriers to help

identify appropriate evidence-based policy, interventions and provide a benchmark to assess the impact of such policy and interventions. The authors found:

- The most common environmental barriers encountered by people with major limb amputation were climate, physical environment and income.
- Participation restriction was most commonly experienced in sports/physical recreation, leisure/cultural activity and employment/job-seeking.
- The most common difficulties for daily activities and functioning were with standing for long periods, walking long distances and the emotional effects of disability.
- Differences were found between people with an upper limb and lower limb prosthesis.

In summary, MAP data provides a useful framework through which functioning and participation issues can be examined.

Potential contribution of MAP to national policy

Value for Money and Policy Review of Disability Services in Ireland

The Value for Money and Policy Review (VFM) was published in July 2012 (Department of Health, 2012) and is an evaluation of the efficiency and effectiveness of disability services in Ireland including the statutory and non-statutory sectors. The Review was conducted under the auspices of the Government's programme of Value for Money Reviews for 2009-2011.

The purpose of the Review was to assess how well current services for people with disabilities meet their objectives and support the future planning and development of services and to make recommendations that will ensure that the very substantial funding provided to the sector is used to maximum benefit for persons with disability, having regard to overall resource constraints which affect all sectors at this time.

The Review proposes a fundamental change in approach to the governance, funding and focus of the Disability Services Programme, moving from provision which is predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports.

The recommended model of supports is designed to be a more effective method of assessing need, allocating resources and monitoring resource use. A re-articulated vision and goals is proposed, with a recommendation that a set of realistic, meaningful and quantifiable objectives be developed to support their realisation. The achievement of measurable outcomes and quality for service users at the most economically viable cost underpins the recommendations.

The Review outlines 5 priorities for implementation:

- 1. Administration and governance**
Strengthening the national disability function within the Health Service Executive (HSE).
- 2. Person centred services and supports**
Driving migration towards a person-centred model of services and supports.
- 3. Commissioning and procurement**

Re-shaping of certain services and models of service delivery based on a new commissioning and procurement framework.

4. Resource allocation

Developing a national resource allocation model based on a standardised assessment of need process, a methodology for associating standard costs with assessed needs and transparent protocols for determining the basis for allocating finite resources.

5. Information infrastructure

Establishing the strategic information requirements needed for the effective management of the Disability Services Programme, and putting an implementation plan in place.

Within these priorities it is clear that a well-defined process for monitoring change and identifying outcomes will be needed and the ICF provides the framework to do so.

In addition to the VFM and Policy Review, two other policy documents are of particular interest in this regard and will serve to exemplify how the MAP might contribute to policy implementation:

- *Time to Move on from Congregated Settings – A Strategy for Community Inclusion*

This report (Health Service Executive, 2011) proposes a new model of support in the community. The model envisages that people living in congregated settings will move to dispersed forms of housing in ordinary communities, provided mainly by housing authorities. They will have the same entitlement to mainstream community health and social services as any other citizen, such as GP services, home help and public health nursing services, and access to primary care teams. They will also have access to specialised services and hospital services based on an individual assessment. People will get the supports they need to help them to live independently and to be part of their local community. A core value underpinning this proposal is that people should make their own life choices. The HSE and the non-statutory service providers have a responsibility to support people to maximise their independence. The focus on independent living and opportunities to make choices in relation to everyday living also provides an opportunity to test out the value of measures of activity and participation as captured in the MAP section of the NPSDD which will enable service providers to measure the impact of provision on aspects of the environment and the barriers and restrictions experienced.

- *New Directions – Personal Support Services for Adults with Disabilities*

The proposed new approach to adult day services envisages all the supports available in communities being mobilised so that people have the widest possible choices and options about how they live their lives and how they spend their time (Health Service Executive, 2012). It places a premium on making sure that being part of one's local community is a real option. It recognises that people with severe and profound disabilities may need specialised support throughout their lives. The guiding principle for the future is that supports will be tailored to individual need and will be flexible, responsive and person-centred.

Day services for adults with disabilities provide a vital network of support for over 25,000 people. The people who use these services have a widely diverse set of interests, aspirations and personal circumstances. They are people with physical and sensory disabilities, with learning disabilities and with mental health difficulties. They include young people, people who have been in day services for many years and older people of retirement age. They live in small communities, in isolated rural areas and in cities and towns.

The spectrum of need ranges from those with severe and profound disabilities, challenging behaviours and high support needs who are likely to need long-term, specialist service provision to people with lower support needs and greater potential for community participation and inclusion. The central approach focuses on the core values of person-centeredness, community inclusion, active citizenship and high quality service provision. The aim is to provide people with the personal, individualised supports they require to access a whole range of community services as well as providing for their health related needs.

Measuring the effectiveness of these policies

It is clear that both the policies mentioned above aim to improve the ability of people with disabilities to actively participate in those areas which are of interest and importance to them. Identifying where that is, and is not, being achieved and identifying any barriers to improved participation are obviously key to addressing issues of concern and to the identification of what is working for individuals.

As the aim of providing support services to a person with a disability is to increase their ability to take part in activities of their choosing and to improve their levels of participation in their community, it is important that we have a way of measuring the extent to which this is actually happening as a result of the provision of particular supports. The MAP offers such a measure.

Future developments

MAP and its relevance to intellectual disability

In keeping with best international practice, the development of the MAP in Ireland using the ICF framework was in recognition that a wide range of data are needed to describe the status of people with disabilities and their access to services. Equally, it is useful as a means of understanding and improving outcomes for people with disabilities. There has been some attention given to the use of the ICF to those with intellectual disability. Obvious examples are the findings of the National Disability Survey (Central Statistics Office, 2006) which captured data using a definition of disability that was ICF-based and that included activity limitations in areas such as mobility and dexterity and remembering and concentrating. The National Disability Survey collected data using ICF-based measures for all of a selected sample of people with a range of disabilities including intellectual disability. The survey reported information on how people with intellectual disability experienced nine important areas of life:

- Caring and help from other persons
- Attitudes of other people
- Transport
- Built environment accessibility
- Education
- Work and training
- Social participation
- Sport and exercise
- General information.

Many of these areas are consistent with the measures captured on the NPSDD MAP and as part of the bulletin series,

differences between the two cohorts of people have been compared (see HRB, 2011). In the work undertaken on the TILDA longitudinal study on ageing, which has an intellectual disability supplement, questions based on the ICF were applied (McCarron, et al. 2011). The study's underlying structure focused on the main areas that are likely to be key to understanding the process of ageing in people with intellectual disability; physical and behavioural health, mental and cognitive health, health utilisation, social networks and supports, employment retirement, day services and lifelong learning and experiences of quality of life. In this latter category the study found that people with intellectual disability often need considerable supports to enable them to participate more fully.

In principle, therefore, there is much value in the application of the MAP measures to people with intellectual disability as the debate about participation and quality of life gathers momentum. Already there are many measures applied in the provision of services to people with ID (including Personal Outcomes Measures and other measures. The ICF, however, provides an internationally recognised and standardised approach to the measurement of outcomes. The National Intellectual Disability Database currently captures service use and need for over 27,000 people with intellectual disability. The development of an assessment tool based on the ICF that can be applied to this cohort – as is currently the case with the NPSDD - is necessary if the value of such service interventions is to be assessed.

Consideration has been given to the development of a single, integrated, and inclusive information system in relation to planning for people with a disability (Department of Health, 2012). In relation to the NIDD and NPSDD this would inevitably involve the merging/migrating of the two existing databases and developing a more integrated approach to the collection of and reporting of information about people with disability. The added-value of ICF based measures in developing this integrated solution to disability information would be significant.

MAP and the application to children and young people

United Nations Convention on the Rights of the Child/Convention on the Rights of Persons with Disabilities

When Ireland signed up to the United Nations Convention on the Rights of the Child (UNCRC) in 1992 (see United Nations General Assembly, Convention on the Rights of the Child, 1989), it demonstrated a commitment to ensure children's rights were top of the agenda for the government, legislators and key decision makers. In summary, the UNCRC states that every child (under 18 years of age) has the right to an adequate living standard and access to medical services, to education, information and leisure/cultural activities, freedom to express opinions and opportunities to participate in activities of society. Specifically, a child with a disability 'should enjoy a full and decent life in conditions which ensure dignity, promotes self-reliance and facilitates the child's active participation in the community' (United Nations General Assembly, 1989). Furthermore, the Convention on the Rights of Persons with Disabilities (2006) recognises the importance of enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms.

The introduction of the ICF as a common global language and classification of functioning and disability represented a major breakthrough in how disability is defined and measured as definitions of disability, measures and data collection strategies vary from country to country. The ICF provides a valuable framework for monitoring the UN Convention on the Rights of Persons with Disabilities and can serve as a universal standard to realise the rights of children with disabilities under the UNCRC and recognition that disability is a human rights issue (Hurst, 2003).

ICF for Children and Youth (ICF-CY)

When the ICF was initially published in 2001 it soon became apparent that it had its limitations. It was focused on adult populations and there was difficulty classifying the functional characteristics of a developing child, particularly very young children. Work therefore began on developing a new version of the ICF for children reflecting a period of life

characterised by rapid growth and development and as such, significant changes in children's physical, social and psychological functioning. The ICF standardises data concerning all aspects of functioning and disability in children taking into account the environmental changes from infancy to adolescence (Riva, 2010).

The ICF version for children and youth (ICF-CY) was published in 2007. Grounded in the UNCRC, it incorporates the body functions and structures, activities, participation and environments specific to children from birth through 17 years of age (as per the age range covered by the UNCRC) (Simeonsson *et al*, 2003). ICF-CY contains a classification of external factors including the immediate and wider environment of a child and is especially extended with learning and playing aspects and the developmental process. A number of questionnaires for application of ICF-CY are developed for four age groups:

1. 0-36 months. This includes focusing on exploring objects, watching and listening, maintaining or changing body position, alertness, vision/hearing functioning, eating and drinking, motor reflexes, posture and their environment including health service, family and food/drink.
2. 3-5 years. This includes moving around (with or without equipment), learning through play, speech, interaction with people, education, sleep and memory functions, immune response, heart/respiration functions and environmental factors including family, food/drink, products and technology for mobility, education and play.
3. 6-12 years. This includes learning to read/write/calculate, problem solving, making decisions, handling stress and other psychological demands, having a conversation, caring for oneself (including washing and dressing), engaging in activities and body function code sets including sleep/attention/heart/respiration/memory functions, weight maintenance and movement and muscle tone etc and environmental factors including family/friends, food/drink, health and social support services.
4. 13-17 years which includes activities and participation codes for calculating, problem solving, thinking, handling stress, caring for body, interacting with people and doing housework. Body function codes include energy and drive functions, temperament and personality functions, attention/memory/thought functions, emotions regulation and weight/growth maintenance. Environmental codes include transportation, design, construction and building products and technology of buildings for public use, attitudes of friends and family, drugs and food/drink.

Clinical research on the validity of the ICF-CY has demonstrated its use in assessment and classification of childhood disability and provides a common language to describe the functioning of children with disabilities from various backgrounds, in various settings and across age ranges and health conditions, as such, it can be used to assist those in the health field as well as those who work in educational, social, and rehabilitation settings (Simeonsson, 2009, Ibragimova *et al*, 2009). In this regard, the ICF-CY or a version of MAP for children, could contribute to policy, practice and research. The ICF-CY or a similar measure could provide a more meaningful basis for resource allocation for services and supports for children with disabilities especially if data is measured over time identifying the effectiveness of services used (Bjorck-Akesson *et al*, 2010) and has been shown to improve the efficiency of the service provision (Bortolot *et al*, 2013). Using a common framework such as the ICF-CY ensures comprehensive and importantly, comparable, data for children's health which is important for developing effective child health measures across Europe. It should be noted that the WHO has decided to incorporate the ICF-CY into the ICF and thus, the ICF-CY will no longer be used.

MAP and children under 16 years

The core purpose of the NPSDD is to look at service needs of people with disabilities. A version of MAP for children could identify the service needs of children as they move from one age group to another and the significance that planning can have on their growth and development. Ultimately, an ability and functioning measure for children, if used properly, can contribute to enhanced participation and quality of life of children, youth and adults with disabilities (Simeonsson, 2009). When the MAP section was added to the NPSDD dataform in 2004 a children's version did not exist in the WHODAS 2.0 format.

Evidence from other studies have shown that the key factor in implementing an ICF-based measure for children is the need to involve parents (see Adolfsson *et al*, 2010) as parents feel empowered and heard and the professional has an increased awareness of families' views which in turn leads to improved communication between professionals and families.

The ICF and other measures for children

Numerous measures have been developed in order to measure disability in children, some of which include:

- **WeeFim** - measures the functional status of a child with a disability (Ottenbacher et al, 2000) and is completed by a health professional
- The **Parents' Evaluation of Developmental Status (PEDS)** (Glascoe, 1997)- a screening test for children's language, motor, self-help, early academic skills, behaviours and social-emotional/mental health.
- The **pediatric quality of life inventory (PedsQL4.0)**- a short, practical, multi-dimensional model measuring physical, emotional, social, school functioning (Amiri et al, 2012)
- **Paediatric Evaluation of Disability Inventory (PEDI)** (Haley, 1992) – assess key functional capabilities and performance in children 6 months-7 years- measures capability and performance by observing self-care, mobility and social function.
- **Ten Questions** - designed to identify children who have congenital and developmental disabilities. This easy to administer screening instrument has scientific validity (Durkin et al, 1994).

A review of these and other measures indicated that there are disparities between them, including age restrictions for a number of the measures, some are completed by a health professional where others can be completed by a family/caregiver with or without an interview with a professional and some which are relatively quick to complete (10 questions) whereas others such as the PEDI contain 237 items. The ICF-CY, however, provides a valid tool for working with children and young people and their parents in order to establish their needs and the impact of service interventions on their everyday lives. However, when considering a measure of ability and functioning for children that will accommodate for developmental differences in children ages between 0 and 18, a number of practicalities have to be considered:

- The NPSDD would require a number of age-specific measures of ability and functioning rather than a single measure
- The measure could be adapted depending on the child's diagnosis/condition. Administration of a measure would ideally be completed by those currently working on the NPSDD rather than by a health professional,
- Consideration would be given to the length of time taken to complete a children's measure,
- The comprehensiveness of a measure, i.e. the number of questions within the measure and whether it captures what is needed within a reasonable time frame,
- Establishing the aim of any addition to the NPSDD, i.e. the parameters of the information to be gathered, how it relates to services and what could be done with it if it was collected

- Practical considerations such as cost implications and training staff on its use.

Ultimately, regardless of the challenges faced in relation to restrictions and practicalities, it is imperative that those aged less than 16 years on the NPSDD are given an opportunity to voice their experience of living with a disability.

Conclusions

When the DoH endorsed the WHO ICF, it showed a positive move from viewing disability as an ‘impairment’ with limitations towards viewing disability as the outcome of a complex relationship between an individual’s health condition, personal factors and the external factors of the environment in which they live. The ICF provides a common language for describing disability. It ‘mainstreams’ the experience of disability and recognises it as a universal human experience.

The MAP subgroup extensively researched and developed the addition of an assessment tool based on the ICF for the NPSDD. The final product was the MAP, which was added to the data form in 2002. Valuable information derived through MAP ensures that the experience of the individual with a disability is recognised. MAP can be used to effectively monitor services and policies and provides evidence for service planners and providers. Previous MAP bulletins highlight the benefits of having such a tool incorporated into a service planning database. In particular, MAP bulletin analysis investigating the use of key services such as PA, and found that having a such a service ensured that the individual with a disability experienced less restriction in participating in daily activities than those who did not have a PA and required one. This clear evidence of the usefulness of MAP data highlights how it can be used to observe the value of receiving a service.

However, future applications of the MAP need to be addressed. At present, there are two databases in existence, one for those with a physical and/or sensory disability (NPSDD) and one for people with intellectual disabilities (NIDD).

1. The NIDD does not currently have an ICF component.
2. The NPSDD does not capture MAP data on those aged less than 16 years.
3. Work is needed to introduce an assessment tool based on the ICF to capture information on both these cohorts of people. In doing so, it would ensure the development of a common language for disability for children with physical/sensory disabilities and people with intellectual disabilities.
4. The next step for the MAP subgroup is to investigate existing assessment tools and examine the possibility of adding such to both databases and furthermore, to explore how the MAP measure could be modified for children/people with intellectual disability. This would involve a commitment to the development of an effective measure for all.
5. The benefits of including such a measure have been highlighted in this document and also in previous bulletins. With government policies changing to a more person-centred approach, it is vital that an effective tool is in place to monitor such policies. The MAP is an ideal example of how to gauge the effectiveness of policy changes.

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