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to promote better health and wellbeing*

Standardised Disability Flag for mainstream services

Data collection guide

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1 Introduction

What is the Standardised Disability Flag?

The Standardised Disability Flag is a set of questions intended for use by all mainstream services in their data collections to identify people with disabilities or long-term health conditions who experience difficulties and/or need assistance in various areas of their life, and demarcate them from people without such limitations or needs. The set of questions is designed to provide consistent and comparable information across mainstream services in all Australian jurisdictions over time and across administrative data collections.

While information is available on services especially designed for people with disabilities, information on the interaction of people with disabilities in mainstream services is not. Mainstream services are those services that people encounter in everyday life – such as healthcare, education, housing, transport, community services. In this context, mainstream services are in fact all services other than specialist disability support services.

Information on the principles underlying the development of the Standardised Disability Flag is included over the page. Details on the items making up the Flag can be found in Section 3.

What is the context for this Flag?

Commitment of all Australian governments in promoting the rights of individuals with disability has been at the forefront of the recent disability policy environment, and is articulated in the:

- National Disability Agreement (NDA) made between the Australian Government and state and territory governments (COAG 2012)
- National Disability Strategy (NDS) (COAG 2011)
- Productivity Commission's final report on the inquiry into disability care and support released in August 2011, which has led to the National Disability Insurance Scheme (PC 2011).

A key theme running through these documents is the need to ensure that all mainstream services and programs across the country address the needs of people with disability. To measure the effectiveness of these reforms, there is a need to have a consistent approach to the definition and concepts related to disability across services and programs.

In particular, the National Disability Strategy 2010–2020 provides a strong foundation to:

- establish a high level policy framework to give coherence to, and guide government activity across, mainstream and disability-specific areas of public policy
- drive improved performance of mainstream services in delivering outcomes for people with disability
- give visibility to disability issues and ensure they are included in the development and implementation of all public policy that impacts on people with disability
- provide national leadership toward greater inclusion of people with disability.

The Strategy looks beyond the specialist disability support system delivered by the Australian, state and territory governments under the NDA to address the support needs of people with a disability accessing mainstream services including health care, education, housing and homelessness, and criminal justice.

A critical first step to improve the capacity of mainstream services to better support the needs of people with disability is to achieve accurate and comparable identification of people with disabilities. Accurate identification is important to monitor the gap in health and social outcomes between people with disability and other Australians. Information collected will also provide a broader sense of the service needs of, and those provided to, people with disability.

The ability to better identify and meet the needs of people with disability in the mainstream services is a recognised priority of the Australian, state and territory governments listed in the NDA:

‘It is acknowledged that the disability services which are the focus of this Agreement are complemented by mainstream services. All governments recognise that achieving improved outcomes for people with disability, their families and their carers, is contingent upon the effective coordination of efforts across government services’ (COAG 2012).

In 2012–13, the Australian Institute of Health and Welfare (AIHW) was commissioned by Community and Disability Services Ministers to design a short set of questions to be used in public and private organisations to obtain some fundamental information on the extent to which long-term health conditions or disabilities affect everyday functioning.

What principles were used in the development?

The following principles were employed in the development of the Standardised Disability Flag:

- data should be readily collectable by all mainstream services:
 - reliance on clinical reports or other detailed knowledge of clients is to be avoided as this information is often not available
 - the set of questions should be short and easily incorporated into existing data collections
 - questions should not be offensive to people with disability or their carers, and should be relevant to all ages and all settings
- data should be comparable – similar experiences should be coded similarly across a service sector and between sectors, therefore judgements such as ‘degree of difficulty’ are to be avoided
- data should be meaningful:
 - the Flag should be sufficiently sensitive to capture all severity levels
 - the Flag should be sufficiently broad to capture all forms of disability (physical, intellectual, cognitive, psychosocial, etc.)
 - the Flag should be sufficiently specific to capture education and/or employment restrictions

- information about the disability status and experience of clients, at the individual or aggregate level, should:
 - be useful to service providers
 - contribute to better outcomes for people with disability using mainstream services
 - support better public accountability in terms of service accessibility
- the Flag should be consistent with the International Classification of Functioning, Disability and Health (WHO 2001)
- the Flag should be aligned with disability data items in population surveys and censuses
- the Flag should use existing national data standards, wherever possible.

How was the Flag tested?

During the first half of 2013 a number of tests were conducted to assess the suitability of the Standardised Disability Flag questions for data collection from the mainstream population. The tests were conducted in three phases: focus groups, cognitive interviews and pilot test. More details about the testing program are provided in Appendix A.

What is this data guide and how is it organised?

This data collection guide is designed to assist all those anticipating the implementation of the Standardised Disability Flag into their data collections. It is organised in the following sections:

- Section 2 provides a step-by-step guide on how to prepare for inclusion of the Standardised Disability Flag into existing and new data collections. This section also includes an overview of methods for dealing appropriately with the issues of privacy and client's consent to participate in the data collection.
- Section 3 contains detailed information about the data items collected from the respondents. For most data items, the following explanations are provided:
 - data item name
 - associated question
 - definition
 - example of how this data item can be collected
 - how to complete and code responses
 - guide for use.
- Section 4 provides a summary of the privacy and data principles used in the AIHW data collections.

2 How to administer the Standardised Disability Flag

The Flag consists of simple questions that can be administered by an organisation's staff member or completed directly by the client. Organisations are asked to incorporate the Flag in the most appropriate way to fit in with their day to day operations. The performance of the Flag questions has been assessed through broad testing and the Flag can be readily incorporated into existing administrative data collections.

Responding to the Standardised Disability Flag questions is on a voluntary basis and clients need to be made aware of this prior to administering the module. The protocol requires consent for information that may be considered personal. This is consistent with client's rights and general ethics of data collection (for more information see Section 4).

Note that all people, both adults and children, are in scope for the Standardised Disability Flag questions.

Step-by-step guide to implementing the Flag

1. Ensure you have appropriate privacy principles and practices in place (see the following and Section 4 for more information).
2. Determine which data items you need to collect in addition to the Standardised Disability Flag (this will depend on the services you offer, your existing data collection, and preferred data collection mode – see 'The data items you need to collect').
3. Establish the preferred data collection mode, ensuring minimum disruption to your day to day operations (see 'How to collect and transmit data' later in this section).
4. Collect the data.
5. At the end of the data collection safely forward results to the relevant jurisdictional or national collection manager.

Ensuring you respect privacy and have appropriate information-handling practices in place

It is the responsibility of each organisation and/or outlet to inform every client that data about them will be sent to a relevant authority for analysis. This advice is to ensure compliance with privacy legislation and established privacy and data principles for data collections (for more information see Section 4).

It is important that the clients of each organisation and/or outlet are made aware that the information is collected independently of any services and/or entitlements and will be used only by the service or relevant authority to assess the support needs of people accessing mainstream services.

The following statement could be read or supplied to each client. This might occur at the time of contact/enrolment/admission/service at the individual outlet:

Please note that <organisation or outlet name> is collecting data aimed at improving information on people that have difficulties in everyday life areas because of a long-term health condition or disability.

We will forward information provided by you to the <relevant authority name>. The information will be kept confidential and will not affect your entitlements or your access to our services.

If a client does not wish to participate in the data collection or for their information to be transmitted to the relevant authority, the following points could be brought to their attention:

- results from the data collection will be used to better understand and meet the needs of all mainstream services clients
- participation is voluntary and it will substantially help improve data collection standards across Australia
- this data collection is consistent with privacy legislation – <this organisation> goes to great lengths to ensure that personal information remains confidential.

The data items you need to collect

The mandatory data items required for analysis of the Standardised Disability Flag are:

- activity and participation need for assistance cluster
- education participation restriction flag
- employment participation restriction flag.

These questions are to be asked of each client exactly as presented in this guide (for more information see Section 3).

It is recommended that data covering socio-demographic factors – such as age, gender, Indigenous status, country of birth, living arrangements, student status and employment situation – also be collected to provide contextual information about clients and assist in the analysis of client needs. However, as such data are likely to already be collected by each organisation, there is no further information about these data items in the following sections.

How to collect and transmit data

The data collection process

The Standardised Disability Flag has been designed to be as simple as possible while still capturing the required information. It is intended for collection of data from the general public accessing services offered by various organisations across Australia. This guide is based on the concept of an organisation with individual ‘outlets’ that provides services from a discrete location. An organisation may provide more than one service type through numerous outlets. For example, an organisation may provide library services for a particular state/territory, with each library being an ‘outlet’ providing services at particular location. It

is desirable for each organisation to incorporate the Standardised Disability Flag into their administrative data collection by all outlets.

Data collection mode

The Flag questions can be completed by the client (or the client's proxy, such as parent, guardian or carer), or by a staff member 'interviewing' the client or their proxy. It can be completed using paper forms or an online form as part of the organisation's systems.

Each organisation will need to determine which mode of data collection is most suited to its operation and currently used data collection systems. For example, educational institutions or libraries may consider directing their clients to fill in an online form, while health or housing services may administer the Flag using a paper form at the time of service, or the services' electronic registration system.

Collecting and transmitting data

Organisations are asked to record key information about service users on an ongoing basis, so that they can analyse or transmit the required information to funding bodies or jurisdictions for agreed reporting periods. For some organisations information may be transmitted only at the end of a financial year.

For those organisations with their own software solutions in place or those who would prefer to purchase a commercial software product, a Data Transmission Strategy may have to be developed internally or with a funding agency to ensure that your own system will produce data consistent with the requirements.

3 The Standardised Disability Flag

The Standardised Disability Flag aims to identify people with activity limitations through a functional/needs assessment approach across specified activity and participation life areas. Although there is an expectation that the questions would be completed directly by the respondent, it has been designed in such a way that if it is completed by a proxy or staff member there is little risk of it being misinterpreted. It is expected that the presentation and wording will be standard across all services and settings, although there is some flexibility in terms of formulating questions to allow a proxy/carer to answer the Standardised Disability Flag questions on behalf of a person who would be unable to complete the questions themselves.

The Standardised Disability Flag includes three components:

- activity and participation need for assistance cluster
- education participation restriction flag
- employment participation restriction flag.

Data from the first component is then used to produce two output components:

- extent of activity limitation
- activity limitation flag (a summary version of 'extent of activity limitation').

The questions comprising the Standardised Disability Flag need to be asked directly of a respondent or via proxy, and answers to these questions should not be substituted/transferred from existing records. The Flag does not include a question on disability type: this information may be collected in addition to the Flag by individual organisations, as required.

Activity and participation need for assistance cluster

This data item collects the respondent's perception about whether a long-term health condition or disability restricts their everyday activities. It is designed to be consistent with the International Classification of Functioning, Disability and Health (WHO 2001). This classification is endorsed by the World Health Assembly and all participating countries are encouraged to use the classifications and thereby increase comparability of data across countries and – perhaps more importantly – comparability of a wide range of data sets within Australia.

Question: For each of the following activities, do you need help/supervision, have difficulty, or use aids/equipment or medications?

Defined as: The degree of assistance and/or supervision a person needs to perform tasks and actions in an activity/participation life area such as self-care or managing things around the home.

It is critical that the information in the box preceding the question is available to the respondent at the time of completing the question.

The next question is about whether a long-term health condition or disability restricts your everyday activities.

A long-term health condition is one that has lasted, or is expected to last, 6 months or more.

Examples of long-term health conditions that might restrict your everyday activities include severe asthma, epilepsy, mental health condition, hearing loss, arthritis, depression, autism, kidney disease, chronic pain, speech impairment, stroke.

Disability is a general term that covers:

- impairments in body structures or functions (for example, loss or abnormality of a body part)
- limitations in everyday activities (such as difficulty bathing or managing daily routines)
- restrictions in participation in life situations (such as needing special arrangements to attend work).

Q1. For each of the following activities, do you need help/supervision, have difficulty, or use aids/equipment/medications?

Choose one answer for each row.

	Always/some- times need help and/or supervision	Have difficulty but don't need help and/or supervision	Don't have difficulty but use aids/ equipment/ medications	Have no difficulty
Self-care e.g. showering or bathing; dressing or undressing; toileting; eating food.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobility e.g. moving around the house; moving around outside the home; getting in or out of a chair; using public transport.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication e.g. understanding or being understood by other people, including people you know; using a telephone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learning, applying knowledge e.g. keeping focused on things; learning new things; solving problems; making decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing things around the home e.g. getting groceries; preparing meals; doing washing or cleaning; taking care of pets.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Managing tasks and handling situations e.g. managing daily routine; managing time; planning activities; coping with pressure or stressful situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal relationships e.g. making friends; meeting new people; showing respect to others; coping with feelings and emotions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community life e.g. participating in sports, leisure or religious activities; being part of a social club or organisation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How to complete and code responses

All adults and children are in scope for the activity and participation need for assistance cluster. The cluster is seeking to identify the extent to which, due to a long-term health condition or disability, a respondent cannot undertake everyday activities that other people in a similar age group would normally be able to carry out. Explain to the respondent that the question is asked in the context of a long-term health condition or disability that has lasted, or is expected to last, 6 months or more.

For each of the life areas with examples of activities ask if the respondent always/sometimes needs help and/or supervision, has difficulty, or use aids/equipment/medications.

Code only one response per life area.

Guide for use

For this purpose, an activity is the execution of a task or action by an individual. An activity limitation is a difficulty an individual may have in executing an activity. Activity limitation varies with the environment, and is assessed in relation to a particular environment; the absence or presence of assistance, including aids, equipment and/or medications, is an aspect of the environment.

Activity is limited when an individual, in the context of a long-term health condition or disability, either has need for assistance in performing an activity in an expected manner, or cannot perform the activity at all.

A long-term health condition is one that has lasted, or is expected to last, 6 months or more. Examples of long-term health conditions that might restrict a person's everyday activities include severe asthma, epilepsy, mental health condition, hearing loss, arthritis, depression, autism, kidney disease, chronic pain, speech impairment, stroke.

Disability is a general term that covers:

- impairments in body structures or functions (for example, loss or abnormality of a body part)
- limitations in everyday activities (such as difficulty bathing or managing daily routines)
- restrictions in participation in life situations (such as needing special arrangements to attend work).

Note that:

- A long-term health condition or disability does not have to be medically diagnosed – it should be self-reported from the perspective of the respondent or a proxy/carer answering on their behalf. For example, the service worker may presume that the respondent is experiencing difficulty but the respondent may have found ways of overcoming their limitations and report that they have no difficulty. Alternatively, the respondent may be experiencing difficulties that are not readily apparent to the worker.
- Pregnancy, itself, is not considered to be a disability or long-term health condition although it lasts more than 6 months. If a respondent has developed an adverse health condition as a result of their pregnancy which has lasted, or is expected to last, 6 months or more, then the respondent should report any restrictions that arise from having this long-term health condition.
- Clients including children who do not have any limitations due to a long-term health condition or disability should be recorded as 'Have no difficulty'. It is important to collect data on every client so that the proportion of clients who have a restriction due to long-term health condition or disability can be measured.
- Children should be assessed on the basis of their age and appropriateness of activities that other children in a similar age group would normally be able to carry out.

Where a life area includes a range of examples (for example, 'Self-care' lists showering or bathing, dressing or undressing, toileting, eating food), if the respondent requires assistance in any of the tasks then the highest level of support should be recorded.

Where need for assistance varies markedly over time (for example, episodic psychiatric conditions), record the average level of assistance needed.

Animals used for personal mobility (that is, guide dogs and companion animals) are generally considered to fall into the category of aids and/or equipment. Also included within this category are prosthetic and orthotic devices, wheelchairs, transfer devices, and so forth.

For the 'Communication' life area, a person's level of difficulty is assessed in terms of whether they can understand, or be understood, in their native language or preferred method of communication. This can include both written and verbal communication and it does not refer to situations where the respondent can't read or write because they did not have an opportunity to access education. Interpreters for language are considered to provide personal assistance, and are not considered aids and/or equipment.

This data item records information about a person's level of difficulty and need for assistance in life areas, leading to classification of 'extent of activity limitation'. A need for assistance in a particular life area may or may not be directly relevant to a service provided at the outlet collecting this information.

Education participation restriction flag

This information assists in analyses of the level of support that may be required from the education sector to accommodate people with education participation restrictions.

Question: Does a long-term health condition or disability affect your participation in education?

Defined as: The ability to take part in activities and tasks or take actions to perform at school or another educational institution (such as TAFE, university, or skills centre). Participation in education is considered to be affected if a person:

- is attending a special school/institution or special class, or
- needs special support or equipment to learn, or
- needs special access or transport arrangements, or
- needs special assessment procedures, or
- frequently needs time off (one day per week or more), or
- is unable to attend the school/institution full-time or at all.

It is critical that the information in the box preceding the question is available to the respondent at the time of completing the question.

Only complete the next question if you are 5 years or older

The next question is about whether a long-term health condition or disability affects your participation in education, including school or another educational institution (such as TAFE, university, or skills centre).

Participation in education is considered to be affected if you:

- are attending a special school/institution or special class, or
- need special support or equipment to learn, or
- need special access or transport arrangements, or
- need special assessment procedures, or
- frequently need time off (one day per week or more), or
- are unable to attend the school/institution full-time or at all.

Q2. Does a long-term health condition or disability affect your participation in education?

Yes

No

How to complete and code responses

Prior to asking the question, ensure that the respondent is 5 years or older and explain that this question is asked in context of a long-term health condition or disability that has lasted, or is expected to last, 6 months or more.

If the respondent is less than 5 years of age, leave the item blank.

Guide for use

This item is collected for people aged 5 and above. It is applicable to all people aged 5 and above, irrespective of actual attendance and/or enrolment at any educational institution. The concept focuses on restrictions affecting a respondent's ability to participate in education.

The nature of the restriction may differ across early childhood, primary, secondary education, tertiary and vocational education.

Employment participation restriction flag

This information assists in analyses of the level of support that may be required from employers to accommodate people with employment participation restrictions.

Question: Does a long-term health condition or disability affect your participation in work?

Defined as: The ability to take actions, perform tasks and exhibit behaviours to obtain and retain paid and/or unpaid employment (including volunteering).

Participation in work is considered to be affected if a person:

- needs their employer to provide special equipment, modify the work environment or make special arrangements, or
- needs a support person at work, or needs ongoing assistance/ supervision, or
- receives assistance from a disability job placement service, or
- frequently needs time off work, or is unable to work full-time or at all.

It is critical that the information in the box preceding the question is available to the respondent at the time of completing the question.

Only complete the next question if you are 15 years or older

The next question is about whether a long-term health condition or disability affects your participation in work.

Participation in work is considered to be affected if you:

- need your employer to provide special equipment, modify the work environment or make special arrangements, or
- need a support person at work, or need ongoing assistance/supervision, or
- receive assistance from a disability job placement service, or
- frequently need time off work, or are unable to work full-time or at all.

Q3. Does a long-term health condition or disability affect your participation in work?

Yes No

Work includes paid employment and/or volunteering.

How to complete and code responses

Prior to asking the question, ensure that the respondent is 15 years or older and explain that this question is asked in context of a long-term health condition or disability that has lasted, or is expected to last, 6 months or more.

If the respondent is less than 15 years of age, leave the item blank.

Guide for use

This item is collected for people aged 15 and above. It is applicable to all people aged 15 and above, irrespective of actual participation in work. The concept focuses on restrictions affecting the respondent's ability to participate in work.

Participation in work is not restricted to economic activities, and covers paid and unpaid work.

Note that:

- respondents using special equipment to modify the work environment for work health and safety, or preventative purposes only, should respond 'No' to this question
- respondents frequently needing time off work or working part-time for reasons other than a long-term health condition or disability (such as caring for a child or parent) should respond 'No' to this question.

Extent of activity limitation

This data item is derived from the 'activity and participation need for assistance cluster' and aims to identify people with activity limitations through a functional/needs assessment approach across specified activity and participation life areas. Respondents are assigned to categories on the basis of the reported level of assistance or supervision required with activities across all life areas.

- Categories:**
- Profound/severe limitation or restriction
 - Moderate limitation or restriction
 - Mild limitation or restriction
 - No limitation or restriction
 - Not stated/inadequately described

How to derive this data item

Ensure that the 'activity and participation need for assistance cluster' has been fully completed by the respondent and that the question was asked in the context of a long-term health condition or disability that has lasted, or is expected to last, 6 months or more.

The values in the matrix below are used to show the derivation of the 'extent of activity limitation'.

	Always/sometimes need help and/or supervision	Have difficulty, but don't need help /supervision	Don't have difficulty, but use aids/ equipment/ medications	Have no difficulty
Self-care	1a	1b	1c	1d
Mobility	2a	2b	2c	2d
Communication	3a	3b	3c	3d
Learning, applying knowledge	4a	4b	4c	4d
Managing things around the home	5a	5b	5c	5d
Managing tasks and handling situations	6a	6b	6c	6d
Personal relationships	7a	7b	7c	7d
Community life	8a	8b	8c	8d

The derivation of each category is specified as follows:

- Profound/severe limitation or restriction – if any of 1a to 8a.
- Moderate limitation or restriction – if none of 1a to 8a and any of 1b to 8b.
- Mild limitation or restriction – if none of 1a to 8a and none of 1b to 8b AND any of 1c to 8c.
- No limitation or restriction – if all of 1d to 8d.
- Not stated/inadequately described – if any rows missing and other answers only in range of 1d to 8d.

Activity limitation flag

This data item is also derived from the 'activity and participation need for assistance cluster' and is effectively a summary version of 'extent of activity limitation'. Respondents are assigned to one of two categories, based on whether assistance or supervision is required with activities across all life areas.

Categories: Has activity limitation or participation restriction

Does not have activity limitation or participation restriction

Not stated/inadequately described

How to derive this data item

Ensure that the 'activity and participation need for assistance cluster' has been fully completed by the respondent and that the question was asked in the context of a long-term health condition or disability that has lasted, or is expected to last, 6 months or more.

The values in the matrix below are used to show the derivation of the 'extent of activity limitation'.

	Always/sometimes need help and/or supervision	Have difficulty, but don't need help /supervision	Don't have difficulty, but use aids/ equipment/ medications	Have no difficulty
Self-care	1a	1b	1c	1d
Mobility	2a	2b	2c	2d
Communication	3a	3b	3c	3d
Learning, applying knowledge	4a	4b	4c	4d
Managing things around the home	5a	5b	5c	5d
Managing tasks and handling situations	6a	6b	6c	6d
Personal relationships	7a	7b	7c	7d
Community life	8a	8b	8c	8d

The derivation of each category is specified as follows:

- Has activity limitation or participation restriction – if any of 1a to 8c.
- Does not have activity limitation or participation restriction – if all of 1d to 8d.
- Not stated/inadequately described – if any rows missing and other answers only in range of 1d to 8d.

4 Privacy and data principles

Organisations implementing the Standardised Disability Flag are urged to familiarise themselves with the Privacy Act, health data collection principles and relevant state and territory policies and/or practices.

The Privacy Act and Australian Privacy Principles

The *Privacy Act 1988* includes thirteen Australian Privacy Principles, which govern the conduct of Australian government agencies in the collection, management, use and disclosure of records containing personal information. More information on the Privacy Act and how it applies to various organisations can be found on the Office of the Australian Information Commissioner website <www.oaic.gov.au>.

State and territory public authorities are also bound by the requirements of specific state and territory privacy legislation.

Relevant state and territory policies and practices

All organisations and/or outlets implementing the Standardised Disability Flag into their data collections are advised to familiarise themselves with their jurisdiction's privacy laws and practices.

The National Aboriginal and Torres Strait Islander Health Data Principles

All organisations with significant responsibilities in Aboriginal and Torres Strait Islander data should encourage the application of these principles and establish meaningful partnerships with Aboriginal and Torres Strait Islander Australians. The principles can be found at <www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442472790>.

Appendix A: Summary of Flag testing

During the first half of 2013 a number of tests were conducted to assess the suitability of the Standardised Disability Flag questions for data collection from the mainstream population. The tests were conducted in three phases: focus groups, cognitive interviews and pilot test.

Focus groups

Three versions of the Standardised Disability Flag modules were pre-tested in two focus group sessions conducted in early 2013. The first session (a lunchtime session) focused on people aged 40–79 years and comprised a mix of employed people (including full-time, part-time and casually employed, as well as two participants who were business owners or self-employed), people looking for work and people not in the labour force (retired or attending to home duties). This was a mixed gender group. The second session (an evening session) focused on a younger cohort of adults aged 18–39 years, mixed gender. All of these participants were employed, including university/TAFE students in part-time casual employment.

The focus group participants completed a short questionnaire to record their initial private thoughts and reactions to the proposed Flag modules. This procedure allowed each participant to carefully consider specific issues before exploratory discussion and debate occurred. The discussion was moderated through unstructured questioning about alternative modules probing each component of the Flag.

Cognitive interviews

Based on the outcomes from the focus groups, a series of cognitive one-on-one interviews were conducted in Sydney, with people drawn from the general public (8 participants) and participants with a disability or their carer (6 participants). The cognitive interviews were undertaken in three waves:

- an initial wave of four interviews with people drawn randomly from the general public, mixed male and female, covering younger (28 years) to older people (68 years); then
- two days later a second wave of five interviews with people with a disability (including schizophrenia, anxiety and depression) or their carers; then
- three days later a final wave of four cognitive interviews with the general public and people with a disability.

In addition to this an interview with an expert working for over 40 years in the field of disability program operations for public and private (NGO) sectors was conducted. The purpose was to gain an expert overview assessment of the proposed Standardised Disability Flag questions.

The Standardised Disability Flag questions were refined throughout the cognitive testing process to eliminate complexities and to ensure that the Flag is appropriate for all people using mainstream services. In general, the final Flag module and in particular the 'activity and participation need for assistance cluster' were easily understood, and completed by respondents in a very short time (within 5 minutes). However, it was found that some respondents with a disability were taking medications to assist in their day to day activities,

and this aspect was incorporated into the final Flag module (consistent with the ICF concept of aids).

Pilot test

The pilot test was conducted from 1–31 May in the ACT, and had two main purposes, namely to:

- collect real data to assess the performance of the instrument
- understand the implementation issues in a variety of settings.

The test provided an opportunity for the organisation and its clients to test the Flag questions and provide comments from their perspective on the performance and suitability of the test module for implementation in the organisation's data collection(s).

The AIHW prepared an online form and a paper form of the pilot test, which comprised the Standardised Disability Flag module being embedded into a short 'health and wellbeing' survey. The online form was hosted in SurveyMonkey.

Participating organisations were asked to conduct the pilot test in the most appropriate way to fit in with their day to day operations, such as:

- handing a paper form to the client (or their proxy/carer if appropriate)
- referring the client to the online version of the questionnaire
- 'interviewing' the client and recording their answers on either the paper or online form.

A total of 220 responses were collected, from six 'collectors' (Table 1). The majority of responses were received from AIHW staff who were invited to participate through an all-staff email. AIHW staff were also requested to complete the form as a proxy for their child (or youngest child if more than 1) instead of completing it for themselves.

Table 1: Number of responses by collector and form

Collector	Form	Number
ACT Public Library Service	Online	25
Canberra Connect	Online	40
AIHW internal	Online	133
ACT Justice Health Service	Paper	6
Private dental practice	Paper	15
Private medical practice	Paper	1
Total		220

The pilot test confirmed that the Standardised Disability Flag module was suitable for completion by the general public in a range of settings. Additional information has been incorporated into Section 3 of this guide to address some key concerns that were raised during the pilot test, including the:

- relevance of specific activities to children less than 15 years of age: specific activities are listed as examples under each life area in the 'activity and participation need for assistance cluster'. Clarification of the assessment of participation in each life area is included in this guide

- applicability of the 'education participation restriction flag' to people not attending an educational institution: the definition of the population in scope for this question has been updated in the guide
- treatment of special equipment used for preventative purposes at work: additional information about the special equipment used to modify the work environment for work health and safety, or preventative purposes, has been included in the guide.

References

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