



The Health Equalities Framework (HEF)

An outcomes framework based on the
determinants of health inequalities

A Guide for Family Carers

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About this guide

This guide is part of a series about the Health Equalities Framework. The Framework was initially developed by the UK Learning Disability Consultant Nurse Network. It has been further developed and tested with multi-disciplinary service teams, commissioners and the Learning Disability Professional Senate. It has been welcomed by the National Valuing Families Forum and people with learning disabilities.

Alongside this guide for family carers is a full guide for services, setting out the theory and detailed guidance on use of the tool in practice: See: <http://www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1/>

The same webpage includes:

- a guide for commissioners
- an easier read guide
- a separate document containing the detailed indicators

The Health Equalities Framework – a guide for family carers

Introduction

People with learning disabilities experience significant health inequalities. Yet health services and even specialist learning disability services have never had an agreed way of measuring what difference they make to the health and wellbeing of people with learning disabilities.

The Government has produced a series of ‘outcome frameworks’ for health, social care and public health. From April 2013 these will be used to collect better information on what difference services make (the outcomes they achieve). These national frameworks will apply to everyone, but the information systems are not yet good enough to measure what happens specifically for people with learning disabilities.

The reports ‘*Death by Indifference: 74 deaths and counting*’ and ‘*Transforming care: A national response to Winterbourne View Hospital*’ showed how important it is to have good measures of what services are doing to make a difference for people with learning disabilities.

The Health Equality Framework (HEF)¹ provides a way for all specialist learning disability services to agree and measure outcomes for people with learning disabilities. It can be used by other services as well. Importantly, the tool can be used by family carers in partnership with services, to agree priorities and to monitor outcomes for their relatives, particularly for people who may lack capacity to do this for themselves. For these reasons it is endorsed by the National Valuing Families Forum.

A brief explanation of the background

We see tackling health inequalities as the linchpin to improving health and wellbeing. Improving Health and Lives (IHaL, the Learning Disabilities Public Health Observatory) identified five factors that affect health inequalities for people with learning disabilities. These are called the ‘determinants’:

- Social determinants of poorer health, such as poverty, poor housing, unemployment and social disconnectedness
- Physical and mental health problems associated with specific genetic and biological conditions in learning disabilities
- Personal health behaviour and lifestyle risks, such as diet, sexual health and exercise
- Communication difficulties and poor knowledge about health
- Problems in access to health care and other services, and problems with the quality of services.

¹ The HEF was initially developed by the UK Learning Disability Nurse Consultant Network in response to a request from the Department of Health, following Winterbourne View. Since then it has been tested by multi-disciplinary teams, and commissioners have also been involved in its development.

See Appendix 1 for a bit more information about each of the determinants,

The HEF focuses on what is needed to prevent or reduce the *impact* of these determinants on an individual person, so reducing inequalities for them. The HEF can also be used at the level of a whole service, or by commissioners, family carer groups, self advocacy groups and HealthWatch to look at changes for whole groups of people across health and social care. The HEF offers a common 'language' and understanding for everyone involved.

We believe that monitoring the impact of the determinants of health inequalities will show what difference support from services is making to the health and wellbeing of people with learning disabilities: whether they are young or older, profoundly disabled, physically or mentally unwell, whilst in hospital or living in the community.

Illustrative example

Information on the Improving Health and Lives website showed that people with learning disabilities locally were accessing health checks at well below the national average. Annual health checks identify unmet health needs and lead to actions to address these needs. Therefore they are an important reasonable adjustment for reducing health inequalities. The commissioner recorded the information in the Joint Strategic Needs Assessment and made a plan with the community learning disability team (CLDT) to work with GP practices to improve uptake. The plan formed part of the Joint Health and Wellbeing Strategy. The CLDT used the HEF to show how their work was improving access to primary care services and health checks for people with learning disabilities.

How does it work?

Under each determinant of health inequalities there is a series of indicators. For example, under 'personal health behaviour and lifestyle' the HEF lists:

- a. Diet
- b. Exercise
- c. Weight
- d. Substance use
- e. Sexual health
- f. Challenging Behaviour

In turn, each of these indicators has a series of descriptions under it, which describe the impact of different situations on the individual. For example, under 'diet', the descriptions and scores are shown in the chart on the next page:

Example:

Determinant: Personal health behaviour and lifestyle

A. Diet

Impact Level & Indicator Statement		Descriptor
4	Major restrictions to healthy eating and drinking	<i>This level applies where the person has known swallowing difficulties but does not have consistency of food modified. Takes little or no food or fluid without considerable encouragement which is not readily available. Eats hazardous (otherwise inedible) items with no restrictions. Takes foods hazardous to known health status e.g. high sugar foods if diabetic or foods contraindicated by medication with no support to modify. Or there are serious safeguarding concerns</i>
3	Significant restrictions to healthy eating and drinking	<i>This level applies where food consistency is not wholly safe. Drinks excessively or alternately very little. Has a complete omission of one or more essential components (e.g. fruit, veg or dairy products) OR an extreme excess of an unhealthy constituent of food (e.g. salt or saturated fat etc.) OR wholly inadequate calorific intake. With little support to modify. Amount of food taken is a significant concern.</i>
2	Limited restrictions to healthy eating and drinking	<i>This level applies where the person takes a mix of grain based foods, milk, meat, veg and fruit though widely discrepant from normal recommended daily amounts – some support to address these issues and support healthy intake. If food consistency is an issue there may be occasional lapses of stringency in support.</i>
1	Minimal restrictions to healthy eating and drinking	<i>This level applies where the person takes adequate food and fluid of safe and appropriate consistency. There may be relative excesses or limitations of some key areas of nutritional intake. Meals may lack variety or have modestly excessive salt content. Support is available to address known issues</i>
0	No restrictions to healthy eating and drinking	<i>This level applies where the person takes a healthy balanced diet consistent with their needs and prepared in a manner which can be taken without risk. They take 6-8 glasses of water (or other fluids) per day and carers are well informed and provide support regarding public health recommendations on healthy eating.</i>

So the way it works is that an initial score would be given against each of the indicators. Looked at together, all these would show a health inequalities profile for the person. Then a plan would be made for action on the areas that were of most concern. Some actions would take longer than others to have an effect, so it might be a few months before it would be sensible to check the scores again. If the actions have worked, there should be an improvement in the scores.

Sometimes the score on some indicators might have improved, but others might have got worse. There might be good reasons for this and it is important to understand *why* changes have happened. It is also important to know the individual in order to know whether this represents an improvement overall! Using the HEF helps you to ask the questions.

How can family carers use the HEF – for an individual?

One of the benefits of the HEF is that it gives the person themselves and everyone who knows and cares about them a tool they can use together. It can support an individual's person centred plan and health action plan.

You can use the whole HEF tool or just the parts of it that seem most important for your relative.

You and your relative can look at the HEF tool together and talk about the indicators and descriptions. You can talk about each area with the health and social care staff who work with your relative. You might each have slightly different ideas or things you have noticed. You might have different ideas about the most important things to change.

Using the HEF can help you to have these discussions and come to shared agreements about priorities and action. Then it helps you to check what difference the actions have made.

How can family carers use the HEF – for a service or a local area?

The results of a number of individual HEF scores can be looked at together. This can show whether lots of people have problems with the same issues. For example, it might show that lots of people using a particular service are not having a very healthy diet. Or you could look at the scores for people living in your area and that might show, for example, that lots of people have poor housing that is affecting their health.

Used like this, the HEF can help family carer groups, self advocacy groups and HealthWatch talk to commissioners and the Health and Wellbeing Board about priorities for the whole area. Then – just like for an individual – you can discuss what actions should be taken, and you can use the HEF to check what difference the actions make. In this way you can use the HEF to feed into the Self Assessment (Big Health Check) that is done every year.

Appendix 1

A bit more about the determinants of health inequalities

The social determinants of poorer health

The impacts of poverty, poor housing, unemployment and social isolation on health are well known. People with learning disabilities are more likely than their non-disabled peers to experience some or all of these factors. Bullying and discrimination are also related to poorer health, and are a common experience for people with learning disabilities.

Tackling these issues requires joint strategic planning between local authorities, health and public health, and effective joint health and social care team working. The HEF can be used to inform discussion between health and social care about priorities and ways of working.

Increased risk of health problems associated with specific genetic and biological causes of learning disabilities

A number of syndromes associated with learning disabilities are also associated with specific health risks. For example, congenital heart disease is more common in people with Down's syndrome, as is early onset dementia.

Specialist learning disability staff can look at the possible interactions between specific causes of learning disability and the environment, and can enable environmental modifications to be made, increasing an individual's quality of life. Specialist health staff can ensure that the specific health needs of individuals with learning disabilities are understood and responded to in mainstream healthcare. They can help support providers to understand specific risks and any potential interactions between genetic, biological, psychological, social and environmental factors, so that appropriate reasonable adjustments can be put in place to improve quality of life.

Communication difficulties and low knowledge about health

People with learning disabilities may have a poor awareness of their bodies and health issues generally. They may not express pain or discomfort in a way that others recognise. Limited communication skills may reduce their ability to let others know that something is wrong.

Specialist health staff support people with learning disabilities to understand their own health needs, and let people know when they are not well. They also enable those who support people with learning disabilities (family carers, providers and mainstream health staff) to recognise health needs and take appropriate action.

Personal health risks and behaviours

People with learning disabilities take less exercise than the general population, and their diet is often unbalanced. They can also find it hard to understand the consequences of lifestyle on health, and are much more likely to be overweight (or underweight) than the general population.

Specialist health staff support people with learning disabilities to understand the relationship between health, lifestyle and behaviour, and to develop healthier lifestyles. They also enable those who support people with learning disabilities to gain a better understanding of lifestyle/health issues so that they can help people with learning disabilities become healthier and stay healthier.

Access to and the quality of health care and other services

People with learning disabilities can find it hard to access mainstream health services for a number of reasons, including the failure of health services to make reasonable adjustments to enable access, disablist attitudes among health care staff and 'diagnostic overshadowing'.

Specialist health staff work with mainstream health services (primary, secondary and health promotion/screening) to put reasonable adjustments in place, including health checks, and thus improve access.

