Improving Health and Lives:
Learning Disabilities Observatory

UK Learning Disability Consultant Nurse Network

NDTi
National Development Team for inclusion

The Health Equalities Framework (HEF)

An outcomes framework based on the determinants of health inequalities

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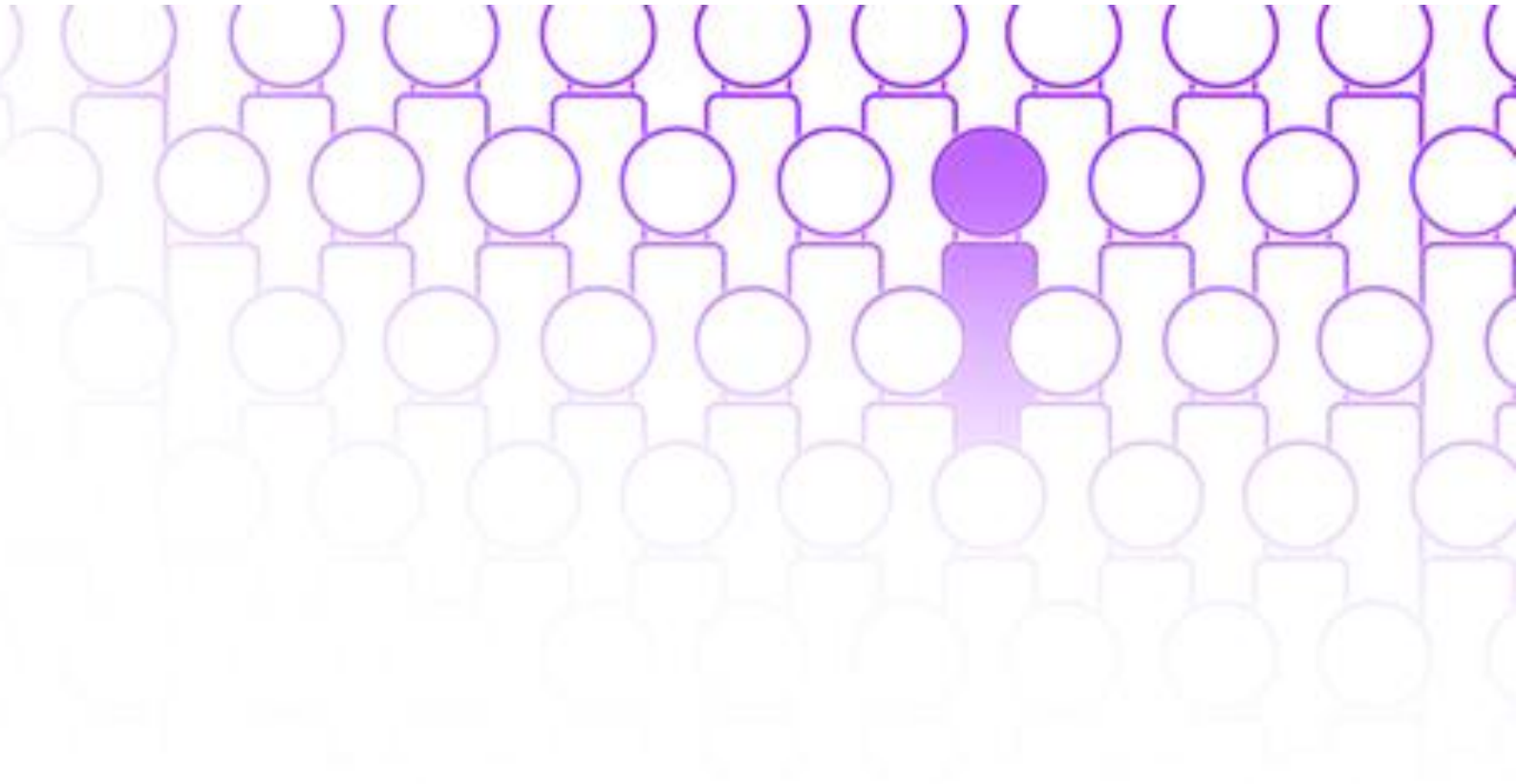

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NDTi and Improving Health and Lives

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Document Overview

This report contains the following key elements:	
The HEF Guide	**Guidance regarding the HEF structure, as well instructions on how to rate the presenting circumstances of a person with a learning disability.**
The HEF Commissioning Guide	**Advice for service commissioners as to how the HEF can be used to inform their essential commissioning functions**
Framework for identifying commissioning intentions	**Guidance on how the HEF evaluates performance against key outcomes frameworks**
The eHEF User Manual	**Instructions regarding the use of the eHEF electronic recording interface.** **Note: the eHEF can be downloaded freely from:** www.ihal.org.uk/gsf.php5?f=1686 **OR** www.ndti.org.uk/publications/other-publications/health-equality-framework-eHEF **Additionally, the eHEF Manager (a separate tool for undertaking more detailed data analysis can be down loaded from the same websites).**
The HEF Family carers guide	**Guidance for families who may wish to use the HEF independently of service providers / commissioners**
The HEF guide for people with learning disabilities	**Guidance for people with learning disabilities who may wish to use the HEF to review their own situation.** **Note: a fully accessible version of the HEF can be downloaded freely from:** www.ihal.org.uk/publications **or** www.ndti.org.uk

Foreword

People with learning disabilities experience significant health inequalities. *Death by Indifference: 74 deaths and counting* [1], detailed the continuing poor care that people with learning disabilities experience in health services, and *Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report* [2], both highlight the need for a clear and transparent way to measure outcomes. However determining and articulating outcomes for people with learning disabilities (across professional groups) has been attempted by a few local services, but there has never been a nationally agreed set of measures relating to health. Although the National Outcomes Frameworks apply to all people, data is not yet good enough to identify the impact on people with learning disabilities. However, the need to agree and measure outcomes is pressing. The professional groups represented on the Professional Senate have their own outcome frameworks, but until now it has been difficult to articulate outcomes for specialist multi-disciplinary learning disability services across the spectrum of provision from community teams through to in-patient services, let alone integrated health and social care teams.

The Health Equalities Framework (HEF), an outcomes framework based on the determinants of health inequalities, provides a way for all specialist learning disability services to agree and measure outcomes with people with learning disabilities. Indeed, it can be used by all services with regard to their effectiveness in tackling health inequalities for people with learning disabilities. It also has the potential to be developed for other vulnerable groups. Importantly, the tool can be used by family carers working in partnership with services, to agree personalised priorities and to monitor outcomes, particularly for people who may lack capacity to do this for themselves. For these reasons it is endorsed by the National Valuing Families Forum.

The HEF was initially developed by the UK Learning Disability Consultant Nurse Network in response to a request from the Department of Health following Winterbourne View. Since then it has been clinically tested by multi-disciplinary teams, and has had significant validation input from members of the Professional Senate. We hope it will lead to a clearer understanding of the impact of the determinants of health on the lives of people with learning disabilities, and a shared way of tackling these determinants.

Dr Alick Bush (Chair of the professional senate)
Jo Hough (National Valuing Families Forum Co-ordinator)

[1] Mencap (2012) *Death by indifference: 74 deaths and counting.*
[2] Department of Health (2012) *Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report*

Introduction

During 2011 the UK Learning Disability Consultant Nurse Network set about developing an outcomes framework that reflected the wide range of learning disabilities nursing approaches. The need for consistent outcome measures in healthcare services generally, was very much under the spotlight at this time. This sat alongside an acknowledged dearth of standards regarding the provision of learning disability nursing and indeed wider learning disability services with no consistent way of capturing or comparing the impact or outcome of what is provided. The 2010 consultation on the developing NHS outcomes framework[3] highlighted the need to:

> "*recalibrate the whole of the NHS system so it focuses on what really matters to patients and carers and what we know motivates healthcare professionals - the delivery of better health outcomes*"

We now have national outcomes frameworks across Public health[4], Social Care[5] and the NHS[6], all of which have equalities at their heart. The NHS outcomes framework specifically seeks the reduction in premature deaths of people with learning disabilities and there are further consistent themes which emerge across these frameworks:

- Moving away from top down targets to local accountability
- A focus on measuring outcomes
- A drive toward quality improvement
- Improved transparency and accountability

This focus on equality, outcome and accountability inspired our thinking for this work and has been the catalyst to the development of the Health Equalities Framework, or HEF. Our approach has been to develop an outcome measure that builds on the theme of tackling health inequalities, seeing this as the lynchpin to improving health and wellbeing and delivering against the national frameworks.

The Improving Health and Lives Learning Disabilities Public Health Observatory (IHaL) identified five broad determinants of health inequalities for people with learning disabilities[7]:

- 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
- Communication difficulties and reduced health literacy
- Personal health behaviour and lifestyle risks such as diet, sexual health and exercise

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[3] Department of Health (2010) *Transparency in outcomes: a framework for the NHS.* www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117583

[4] Department of Health (2012) *Healthy Lives, Healthy People: Improving outcomes and supporting transparency.* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358

[5] Department of Health (2012) *The Adult Social Care Outcomes Framework 2013/14.* www.dh.gov.uk/health/2012/11/ascof1314/

[6] Department of Health (2012) *The NHS Outcomes Framework 2013/14.* www.dh.gov.uk/health/2012/11/nhs-outcomes-framework/

[7] Emerson et al (2011) *Health Inequalities& People with Learning Disabilities in the UK 2011.* Learning Disabilities Public Health Observatory.

- Deficiencies in access to and the quality of healthcare and other service provision.

IHaL have recently provided a further way of structuring the evidence, utilising the following determinant categories: General Socio-Economic, Cultural and Environmental Conditions, Living and Working Conditions, Social & Community Networks, Individual Lifestyle Factors and Constitutional Factors[8].

However, it is the 2010 and 2011 organising structure that underpins the development of the HEF. The approach focuses on demonstrating reductions in the impact of exposure to these known determinants and thereby reducing the inequalities experienced by people with learning disabilities. By concentrating on the determinants of health inequalities the HEF proactively focuses on prevention and reduction rather than reactive approaches that merely address the symptoms of health inequalities.

Originally conceived as a way of capturing the outcome of learning disability nursing interventions, the model quickly generated interest and engagement from others with an interest in the health and wellbeing of people with learning disabilities - families, commissioners, other professions and people with learning disabilities themselves. In 2012, with support from IHaL and the National Development Team for Inclusion, a working group of commissioners and providers drawn mainly from the South West, but with some representation from other parts of the country, was set up to work alongside the Consultant Nurse group to develop supplementary commissioning guidance, based on the HEF. Consultation, engagement and validation meetings were held with representatives from the National Valuing Families Forum, the National Professional Senate and with local and national representatives of advocacy and service user groups.

The result of these efforts is the Health Equalities Framework and the supporting materials contained herein. The HEF has been developed into an electronic template (or eHEF) with step by step guidance, which organisations and individuals can use to collect and monitor health equality impact data. There is a framework for commissioners and guidance to enable services to be commissioned around health equality. We have also provided a sample Commissioning for Quality and Innovation (CQUIN) template to support commissioners in driving the roll out the HEF across provider organisations. We have included information for families and people with learning disabilities to further support the introduction of the HEF. Reducing health inequalities must be a central aim of all learning disability service provision whatever the setting, approach or needs of recipients. We believe that by monitoring the impact of the known determinants of health inequalities there is the opportunity to consistently and reliably demonstrate the difference that support from services is making to the health and wellbeing of people with learning disabilities of all ages, whether they are profoundly disabled, physically or mentally unwell, in hospital or living in the community.

The HEF is not intended to replace existing outcome tools that are used in specific settings or for specific interventions; its purpose is to provide a clear and transparent overarching health-focused outcomes framework with a common language which can aid understanding for everyone involved, particularly between commissioning and service provision and across health and social care settings.

The aim has been to provide a tool which makes sense to everyone, that is sensitive to outcomes at an individual level and which allows aggregation of data in order that population trends at different levels can be better understood. We hope you find it useful and that it contributes to a wider understanding of health inequalities amongst people with learning disabilities, highlighting and evidencing the approaches that make a real and positive difference.

[8] Emerson et al (2012) *Health inequalities and people with learning disabilities in the UK: 2012.* Learning Disabilities Public Health Observatory.

The HEF Guide

The HEF Guide

Background

In 2011, the Learning Disability Public Health Observatory[9] reviewed the wide ranging data gathering that takes place around the health circumstances and experiences of people with learning disabilities. They considered total-population health monitoring frameworks, along with those that apply within primary and secondary healthcare settings. It was noted that there was no authoritative comparative national dataset relating specifically to the health of people with learning disabilities as a discrete population. It was proposed that, as new commissioning arrangements evolve and modernise health settings, a wider information set would be required to inform commissioning decisions regarding how best to meet the healthcare needs of the learning disabled population, as well as to provide essential assurances that the public sector equality duty towards people with learning disabilities (established by the 2010 Equality Act[10]) is being honoured.

In 2012 a four UK country review of Learning Disability Nursing was undertaken and the resulting report *Strengthening the Commitment*[11] highlighted the need for an objective measurement framework by which learning disability nurses could clearly demonstrate their effectiveness at both individual and service levels. It was suggested that any such framework might have broader applicability across health and social care sectors.

In light of emerging new commissioning arrangements, a revitalised public health strategy and an acknowledged need for an overarching health outcomes framework which recognises the unique burden of healthcare needs experienced by people with learning disabilities, the UK Learning Disability Nurse Consultant Network undertook to develop a systematic approach to measuring the outcomes associated with learning disability nursing. During development, pilot and consultation work it became apparent that the emerging tool had broader application in capturing outcomes from all professions and the contribution of social care services to improving outcomes for people with learning disabilities. In developing the HEF, the UK Learning Disability Consultant Nurse Network aimed to develop a monitoring tool which would be both sensitive to outcomes at an individual level as well as allowing aggregation of data in order that population trends could be better understood.

The HEF works by monitoring the degree and impact of exposure of people with learning disabilities to acknowledged, evidence based determinants of health inequalities. The resulting profile is not dependent on the complexity of a person's needs, their specific conditions or presentations but rather on the systems around them that ensure that their needs and long-term conditions are appropriately identified and responded to and that individuals are receiving the right support.

The core outcome of service involvement should be a reduction in the adverse impact of exposure to such determinants and mitigation of any associated hazardous consequences.

In developing the HEF we have endeavoured to identify important and relevant indicators which help to establish a consensus around service delivery priorities. There is a focus on the key factors which compelling evidence suggests, underlie the health inequalities experienced by people with learning disabilities. The necessary data can be generated in a cost effective manner and interpretation has been simplified through the development of an electronic interface (the eHEF) which requires minimal IT infrastructure to support its operation. Data can be aggregated across services, professionals and teams

[9] Glover et al (2011) *NHS Data Gaps for Learning Disabilities* Learning Disabilities Public Health Observatory
[10] *Equality Act 2010* London: HMSO
[11] The Scottish Government (2012) *Strengthening the commitment The report of the UK Modernising Learning Disability Nursing Review*

which allows variation in service outcomes to be identified. Analysis of data can inform individual professional practice as well as supporting decision making to bring about improvements in service systems.

The HEF Structure

Detailed evidence reported by the Public Health Observatory[12] shows there to be five discernible determinants of the health inequalities commonly experienced by people with learning disabilities:

- Social determinants
- Genetic and biological determinants
- Communication difficulties and reduced health literacy
- Personal health behaviour and lifestyle risks
- Deficiencies in access to and quality of health provision

It is the differential exposure to each of these five determinants that, for any person with a learning disability, predicts that they will suffer health inequalities in comparison with the majority of the population. The consequences of these inequalities are significant and include premature mortality, increased experience of ill health and impoverished quality of life.

Review of the underpinning evidence and consultation during scale development, led to discrete sets of Health Inequality Indicators being identified for each of the five determinants. The breadth and range of these indicators helps to define the range and scope of legitimate health interventions i.e. it explains the need for health professionals to address important social factors which are associated with adverse health outcomes as well as to support mainstream health services to become more accessible to people with disabilities. Importantly (and particularly so for nursing) it provides a justification for working under the auspices of social models of health, whilst social care support activities which fall outside of such models might be viewed as a less than optimum use of (particularly nursing) skills.

For four of the determinants six indicators were identified whilst for the last one, five were agreed. The HEF is used to measure the impact of each of these indicators. Where there is a significant adverse impact, this clearly forms the target for healthcare intervention.

[12] Emerson et al (2011) *Health inequalities and people with learning disabilities in the UK: 2011.* Learning Disabilities Public Health Observatory.

The Health Inequality Indictors are shown against each of the five determinants below:

Health Inequality Indicators

1. Social

A. Accommodation
B. Employment & meaningful activities
C. Financial support
D. Social contact
E. Additional marginalising factors (such as ethnicity)
F. Safeguarding issues

2. Genetic and Biological

A. Assessment of physical & mental health needs and health checks
B. Long Term Condition pathways & planned reviews of need
C. Care Planning & Health Action Planning
D. Crisis / emergency planning & hospital passports
E. Medication
F. Specialist service provision

3. Communication

A. Poor bodily awareness & reduced pain responses
B. Difficulty communicating health needs to others
C. Carers failure to recognise pain / distress
D. Carers ability to recognise and respond to emerging health problems and / or promote health literacy
E. Understanding health information & making choices

4. Behaviour & Lifestyle

A. Diet
B. Exercise
C. Weight
D. Substance use
E. Sexual Health
F. Risky Behaviours / routines

5. Service Quality

A. Organisational barriers
B. Consent
C. Transitions
D. Health screening / promotion
E. Primary Secondary services
F. Non health services

Each Health Inequality Indicator has been stratified into five levels each of which describes the nature of impact and associated consequential level of risk – these are referred to as the Impact Levels. The impact levels are constructed in a manner compatible with the National Patient Safety Agency's risk matrix[13].

[13] NPSA (2008) *Risk Matrix for Risk Managers*

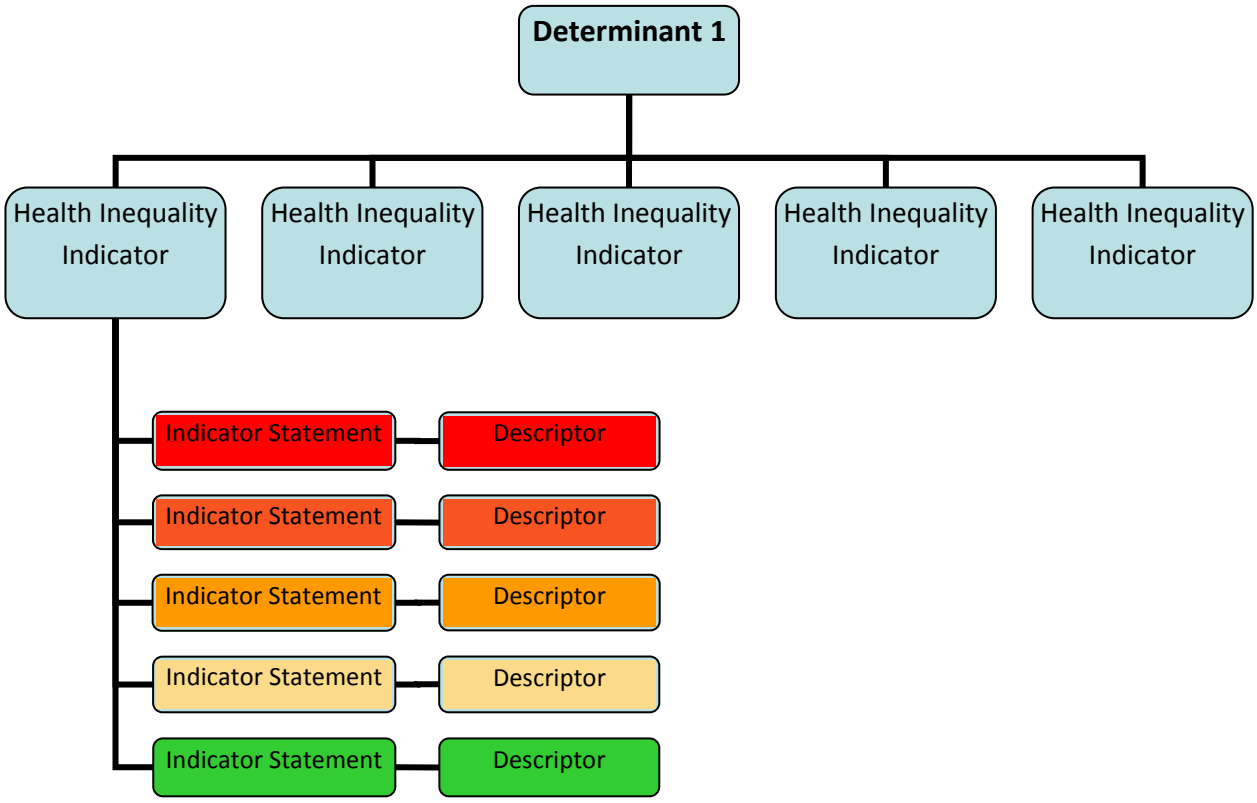
The five impact levels and their associated adverse health consequences are shown below:

Impact Level	Likely consequences if not addressed
Major	Health problems are associated with premature death. There may be multiple permanent injuries or irreversible significant long term health effects. Significant and prolonged restriction of normal activities and high risk of unplanned hospital admissions.
Significant	Major injuries and periods of ill health are likely, leading to long-term incapacity/disability and potential premature death. There may be prolonged periods of inability to engage in usual routines. May require complex and prolonged treatment. Likely to have recurrent unplanned hospital admissions.
Limited	Prone to moderate injury / illness requiring skilled professional intervention. Typified by recurrent breaks in engagement with normal routines. Recovery period following injury / illness several weeks longer than usual. Therapeutic intervention has significantly reduced in (?) effectiveness.
Minimal	The person is likely to suffer minor injuries or illnesses which are likely to require minor intervention. There may be some intermittent short lived (i.e. a few days) impairment of engagement in usual activities. Recovery from periods of ill health may be slightly slower than would otherwise be the case.
No impact	Minimal impact requiring no/minimal intervention or treatment.

So for each of the twenty nine Health Inequality Indicators which underlie the five determinants of ill health an individual's exposure can be rated against a five point impact scale.

For each Health Inequality Indicator a series of Indicator Statements have been developed therefore creating the basis of a series of independent scales. These describe the severity of impact of an Inequality indicator and guide the process of making the correct rating. They are supplemented by Descriptor statements which more fully describe the impact in order to inform judgements as to which is the appropriate rating for any individual service user.

These relationships between Determinants, Health Inequality Indicators, Indicator Statements and Descriptors is depicted below:



So there are five determinants, each of these is described in terms of a series of Health Inequality Indicators. Each Health Inequality Indicator has five indicators statements (and more detailed descriptors) which are graded according to the impact level.

Application

A Health Equalities Framework (HEF) profile for an individual service user is compiled by sequentially working through each of the Health Inequality Indicators for each Determinant and agreeing the appropriate Impact Rating at the time of profiling, after considering the associated Indicator Statements and Descriptors.

Each Health Inequality Indicator is given a rating between 0 and 4. Low scores indicate minimal adverse impact whereas high scores indicate a significantly detrimental impact.

For each Health Inequality Indicator, raters should begin by considering the Indicator Statement and Descriptor associated with the highest (or most adverse) Impact Rating. If this is not felt to be applicable they should then consider the next Impact Rating down, and so on until the one which best describes the person's current circumstance is identified.

When selecting the appropriate Impact Rating, raters should be mindful that Indicator statements and Descriptors are composite in that they combine a number of aspects. Descriptors do not need to be met in full, if any aspect of a service user's current situation is consistent with any part of a Descriptor then this is the correct Impact Rating.

By working through the framework in this way the relative impact of each Determinant can be established. The resulting data can be examined in more depth i.e. at a Health Inequality Indicator level, in order to understand the greatest individual sources of exposure. This more detailed information can prove helpful when planning care and choosing appropriate targets for intervention.

This process, when initially followed, establishes a baseline HEF profile for an individual. Outcomes are monitored through a programme of repeat profiling with individuals. This allows changes to be mapped over time. The effect of important events or changes such as moving house, bereavement, changes in employment or care and treatment can be tracked through such comparative profiling.

No paper based HEF recording sheet has been developed; rather data should be saved, collated and interpreted using the eHEF electronic interface. This freely available MS Excel spreadsheet has been specifically developed for this purpose and incorporates functions to allow aggregated data to be considered across caseloads, practitioners, teams or localities in order to inform the processes of service review, strategic planning and commissioning. Data can also be filtered in order to understand outcome variations across differing sub groups of people with learning disability (e.g. by severity of learning disability, according to additional disabilities or health conditions, age group, gender, ethnicity etc).

It is for local providers and/or commissioners to decide how best to make use of the framework. Options include:

- For community teams profile at point of referral and discharge.
- HEF scores at the point of referral may provide a basis for triage assessment processes.
- Within community teams, HEF scores may form part of a caseload weighting process in order to inform allocations.
- HEF scores may be reviewed during CPA meetings, Health Action Plan reviews, Person Centred reviews etc.
- Within long term forms of service provision e.g. residential care homes or supported accommodation, routine HEF scoring may be useful at regular intervals e.g. every three months.
- HEF scoring prior to and post hospital stays is useful in establishing whether valid outcomes have been achieved.
- For practitioners who carry a caseload, HEF monitoring can inform prioritisation.
- Reviewing HEF profiles before and after specific interventions can inform an understanding of their effectiveness
- Individual caseload data can be aggregated and analysed.
- For managers of services, the ability to aggregate outcomes data across teams and practitioners can inform performance management.
- For strategic service planners (and commissioners) the ability to correlate HEF profiles against biographical details and specific profiles of service user need allows service improvements to be planned around local population profiles.
- Professional groups can use the profile to demonstrate the unique value of their contribution.

Underpinning Evidence

The Improving Health and Lives Learning Disabilities Public Health Observatory has published a series of reports which have described the health inequalities experienced by people with learning disabilities[14,15,16]. They have cited established underpinning evidence relating to each of the determinants of health inequalities and this has proved central to the development of the HEF. There follows a summary of what has been reported in relation to each of the determinants. Readers should refer to the original reports for a fuller account.

1. Social Determinants

Refers to exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness.

People with learning disabilities, especially people with less severe learning disabilities and those who do not access specialist learning disability services, are more likely to be exposed to common 'social determinants' of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination. The link between exposure to these adversities and health status is at least as strong for people with learning disabilities as it is in the general population. Furthermore it has been shown that over time, families with a child with a learning disability are more likely to experience relative poverty and are less likely to be able to escape this situation than other families. It has been suggested that this increased exposure to socio-economic deprivation accounts for:

1. 20–50% of increased health adversity amongst children and adolescents with learning disabilities.
2. 32% of the increased risk of conduct difficulty and 27% of the increased risk of peer relation problems amongst 3 year old children with developmental delay.
3. 29-43% of the increased prevalence of conduct difficulties among children with learning disabilities or borderline intellectual disability as well as 36-43% of the increased difficulties with peer relations.
4. A significant proportion of increased rates of self-reported antisocial behaviour among adolescents with learning disabilities.

The importance of poverty, poor housing, unemployment and social isolation as factors leading to poorer health are well known; material deprivation is associated with poor housing, increased exposure to infection, poor nutritional status etc. People with learning disabilities are more likely to experience some or all of these factors.

[14] Emerson and Baines (2010) *Health Inequalities and people with learning disabilities in the UK: 2010.* Learning Disabilities Public Health Observatory.
[15] Emerson et al (2011) *Health inequalities and people with learning disabilities in the UK: 2011.* Learning Disabilities Public Health Observatory.
[16] Emerson et al (2012) *Health inequalities and people with learning disabilities in the UK: 2012.* Learning Disabilities Public Health Observatory.

Exposure to bullying at school and overt discrimination in adulthood, both predictive of poorer general health status amongst adults with learning disabilities, are frequently experienced by people with learning disabilities .

People with learning disabilities from black and minority ethnic groups are known to be more likely to be exposed to socioeconomic deprivation and overt racism, and are consequently also more likely to face health inequalities than people with learning disabilities from majority communities.

2. Genetic and Biological Determinants

Refers to genetic and biological conditions physical and mental health problems which are specifically associated with learning disabilities.

People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities. Many genetic and biological conditions which give rise to learning disabilities are also associated with an increased risk of further physical and mental health conditions, for example:

- Congenital heart disease is more prevalent among people with Down syndrome, Williams syndrome and Fragile X Syndrome;
- Early onset dementia is more common in people with Down syndrome;
- Hypothalamic disorders are more prevalent among people with Prader-Willi syndrome;
- Mental health problems and challenging behaviours are more prevalent among people with autistic spectrum conditions, Rett syndrome, Cornelia de Lange syndrome, Riley-Day syndrome, Fragile-X syndrome, Prader-Willi syndrome, Velocardiofacial syndrome / 22q11.2 deletion, Williams syndrome, Lesch-Nyhan syndrome, Cri du Chat syndrome and Smith-Magenis syndrome;
- Obesity is more prevalent among people with Prader-Willi syndrome, Cohen syndrome, Down's syndrome and Bardet-Biedl syndrome;
- Sleep problems are more prevalent among children with Williams Syndrome and Down's Syndrome.

Research has highlighted the possible interactions between genetic determinants of poorer health and the environment. For example, genetically determined preferences may create a motivational state that leads to the development of behaviours that are maintained by environmental contingencies. For example, individuals with Angelman syndrome often find social contact extremely pleasing and may therefore come to display aggressive or self-injurious behaviours in order to meet an otherwise unfulfilled need to access unusual amounts of social contact. Similarly, dysfunction of the Hypothalmic Pituitary Axis in people with Fragile-X syndrome is associated with social anxiety, consequently people may have a need to avoid busy social settings and develop behaviours which others consider challenging as a strategy to meet this need.

It is apparent that environmental conditions can increase the expression of genetically determined risks or that genetic factors and environmental factors may independently lead to the same health outcome. For example, Attention Deficit Hyperactive Disorder (ADHD) appears to have a genetic

component involving the regulation of dopamine and serotonin neurotransmitters in the brain (which can lead to problems with executive function control or impulsive behaviour); however, the in-utero environment can increase risk of ADHD if the developing foetus is exposed to alcohol or tobacco and the child-rearing environment can increase risk if the child has been exposed to trauma or neglect.

There are significant variations in NHS total expenditure and expenditure per person on specialist services for people with learning disabilities across different areas of England, with lower spending in rural areas and significant variation in the services provided to people with learning disabilities by specialist NHS Trusts.

3. Communication Difficulties and Reduced Health Literacy Determinants

Refers to the impact of a reduced ability to take in, understand and use healthcare information to make decisions and follow instructions for treatment on an individual's health status.

People with learning disabilities may have poor bodily awareness and a minority may have depressed pain responses. In addition, limited communication skills may reduce their capacity to convey identified health needs effectively to others (e.g., relatives, friends, paid support workers). As a result, carers (unpaid and paid) play an important role in the identification of health needs for many people with more severe learning disabilities. However, carers may have difficulty in recognizing expressions of need, or the experience of pain, particularly if the person concerned does not communicate verbally. Care workers may also feel that they do not have the knowledge, skills and training required to recognise emerging health problems or the resources to effectively promote health literacy.

People with learning disabilities experience a lack of knowledge and choice in relation to healthy eating. People with learning disability express feelings of frustration that they are not listened to, treated unfairly and excluded from decision making about important aspects of their lives and care. Information and support such as that related to breast cancer and mammography may not meet the needs of some people with learning disability.

4. Personal Health Behaviour and Lifestyle Risk Determinants

Refers to personal health behaviour (including behaviours that challenge) and lifestyle risks such as diet, sexual health and exercise.

Diet
Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables. Carers generally have a poor knowledge about public health recommendations on dietary intake.

Exercise
Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health's minimum recommended level, a much lower level of physical activity than the general population (53%-64%). People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity.

Obesity & Underweight
People with learning disabilities are much more likely to be either underweight or obese than the general population. Women, people with Down's syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity. The high level of overweight status amongst people with learning disabilities is likely to be associated with an increased risk of diabetes.

Substance Use
Fewer adults with learning disabilities who use learning disability services smoke tobacco or drink alcohol compared to the general population. However, rates of smoking are considerably higher among adolescents with mild learning disability and among people with learning disabilities who do not use learning disability services. People with learning disabilities with identified substance misuse were more likely to be male (61%) and to misuse alcohol.

Sexual Health
Little is known about inequalities in the sexual health status of people with learning disabilities in the UK. There is, however, evidence to suggest that they may face particular barriers in accessing sexual health services and the informal channels through which young people learn about sex and sexuality. A population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases. High rates of unsafe sexual practices has been reported among gay men with learning disabilities.

Challenging behaviours
Severe self-injurious behaviours can result in damage to the person's health through secondary infections, malformation of the sites of repeated injury through the development of calcified haematomas, loss of sight or hearing, additional neurological impairments and even death. Serious aggression may result in significant injury to the person themselves as a result of the defensive or restraining action of others.

However, the health consequences of challenging behaviours go far beyond their immediate physical impact. Indeed, the combined responses of the public, carers, care staff and service agencies to people who show challenging behaviours may prove significantly more detrimental to their health and wellbeing than the immediate physical consequences of the challenging behaviours themselves. Social responses that are likely to have an adverse effect on health include abuse, inappropriate treatment, social exclusion, deprivation and systematic neglect.

- *Abuse:* Challenging behaviour has been identified as a major predictor of abuse in North American institutional settings. In the UK, recent analyses of the Count Me In Census indicated that in the previous three months 35% of people with learning disabilities in Assessment and Treatment Units had been assaulted, and 6% had been subject to 10 or more assaults.

- *Inappropriate Treatment:* Studies undertaken in North American and the UK suggest that approximately one in two people with severe intellectual disabilities who show challenging behaviours are prescribed long-term anti-psychotic medication. The widespread use of anti-psychotic medication raises a number of concerns as: (1) there is little evidence that anti-psychotics have any specific effect in reducing challenging behaviours; (2) such medication has a number of well documented serious side effects including weight gain and constipation; and (3) the use of anti-psychotics can be substantially reduced through peer review processes with no apparent negative effects for the majority of participants. The use of mechanical restraints and protective devices to manage self-injury also gives cause for serious

concern. Such procedures can lead to muscular atrophy, demineralisation of bones and shortening of tendons as well as resulting in other injuries during the process of the restraints being applied.

- *Social Exclusion, Deprivation and Systematic Neglect:* Challenging behaviours have been associated, among other factors, with families' decisions to seek an out-of-home residential placement for their son or daughter. Children and adults with challenging behaviours are significantly more likely to be excluded from community-based services and to be admitted, re-admitted to or retained in more remote and more institutional settings. Within community-based settings, challenging behaviours may serve to limit the development of social relationships, reduce opportunities to participate in community-based activities and employment, and prevent access to health and social services.

5. Deficiencies in Quality of and Access to Services Determinants

Refers to the impact of services failing to take account of peoples' abilities and disabilities.

Organisational barriers
A range of organisational barriers to accessing healthcare and other services have been identified. These include:

- scarcity of appropriate services;
- physical barriers to access;
- eligibility criteria for accessing social care services;
- failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by many people with learning disabilities;
- variability in the availability of interpreters for people from minority ethnic communities;
- lack of expertise and disablist attitudes among healthcare staff;
- 'diagnostic overshadowing' (e.g. symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities).

Consent
The National Patient Safety Agency has reported concern about 'consent being sought from a carer rather than taking the time to gain consent from the person with the learning disability'. In respect of the use of substitute (proxy) decision-making one study of residential care found that whilst there was general compliance with the Mental Capacity Act (2005) in relation to larger strategic decisions there was less compliance in respect of day-to-day decisions such as activity and food choices. A recent study in Wales of health care professionals and social workers identified gaps in knowledge and training needs in relation to the Mental Capacity Act (2005) and similar findings were reported from a study of healthcare emergency workers in England.

Transition
Transition between services has been reported as problematic for some people with learning disability; this may for example include transition from children's services to adult services, but equally could be transition between hospital services and home or community services, or transitions from one phase of education to another. One study of teenagers' transitions through health, social care and education services found weaknesses in transition planning, variable and mismatched eligibility criteria, lack of clarity from professionals and poor co-ordination between services together with low levels of satisfaction among family carers. A study of local authorities in Wales found that transition protocols for post-secondary education or employment were often vague with some lacking specific information about how young people would be involved and often failed to clarify the role of other agencies such as health services in these transitions.

Health Screening and Health Promotion
A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities. These include:

- Assessment for vision or hearing impairments;
- Routine dental care;
- Cervical smear tests;
- Breast self- examinations and mammography;

Access to health promotion may be significantly poorer for people with more severe learning disabilities and people with learning disabilities who do not use learning disability services. Staff in residential care homes had insufficient training and skills to effectively engage people with learning disabilities in health promotion activities and many did not have access to important relevant information such as a person's family history.

Primary and Secondary Health Care
People with learning disabilities visit their GP with similar frequency to the general population. However, given the evidence (above) of greater health need it would be expected that people with learning disabilities should be accessing primary care services more frequently than the general population. For example, comparison of general practitioner consultation rates to those of patients with other chronic conditions suggests that primary care access rates for people with learning disabilities are lower than might be expected. In a recent study mean consultation rates for adults with learning disability were found to be lower than for the general population; increased age, female gender and having a paid carer were associated with greater use of GP services.

Collaboration between GPs, primary health care teams and specialist services for people with learning disabilities is generally regarded as poor. Adults aged over 60 with learning disabilities are less likely to receive a range of health services compared to younger adults with learning disabilities.

A number of papers draw attention to the benefits of health screening to help identify unmet health needs. The introduction of special health checks for people with learning disabilities has been shown to be effective in identifying unmet health needs, suggesting that health checks

represent a ‘reasonable adjustment’ to the difficulties in identifying and/or communicating health need experienced by people with learning disabilities. However, at present less than 50% of adults who are eligible for health checks under an incentivised Directed Enhanced Service scheme receive them . While providing financial incentives to GPs may influence practice, incentives should be tailored to the particular health needs of people with learning disabilities rather than being based solely on general population health needs. Furthermore GP practices may experience difficulties in accurately identifying people with learning disabilities in order to offer them health checks and other services.

In the UK and in other countries, adults with learning disabilities and especially adults who show challenging behaviours, are commonly prescribed anti-psychotic medication. Such a widespread ‘off-label’ use of anti-psychotic medication is of concern as: (1) there is little evidence that anti-psychotics have any specific effect in reducing challenging behaviours; (2) such medication has a number of well documented serious side effects.

People with learning disabilities have an increased uptake of medical and dental hospital services but a reduced uptake of surgical specialities compared to the general population. A recent study found that people with learning disability living in areas which had higher levels of deprivation made less use of secondary outpatient care but more use of accident and emergency care than those living in less deprived areas.

People with learning disabilities with cancer are less likely to be informed of their diagnosis and prognosis, be given pain relief, be involved in decisions about their care and are less likely to receive palliative care. In one study nursing staff in UK general hospitals were found to have less positive feelings towards people with learning disability than people with physical disability.

Concern has been expressed with regard to the availability of and access to mental health services by people with learning disabilities. However, a very high proportion of people with learning disabilities are receiving prescribed psychotropic medication, most commonly anti-psychotic medication (40%-44% long-stay hospitals; 19%-32% community-based residential homes; 9%-10% family homes). Anti-psychotics are most commonly prescribed for challenging behaviours rather than schizophrenia, despite no evidence for their effectiveness in treating challenging behaviours and considerable evidence of harmful side-effects.

Non-health services

Wellbeing, health and quality of life are influenced by services other than health services including for example social care, education, employment, housing, transport and leisure services; this may be especially true for people with learning disabilities who may be regular users of these services. Evidence of how these services impact on the health of people with learning disabilities in the UK is scarce and researchers are faced with a number of methodological difficulties.

For example a recent literature review of supported housing found that smaller housing units had benefits in terms of choice, self-determination and participation but identified no measurable benefits for physical health. Whilst another review found evidence of better quality of life for people living in dispersed rather than clustered housing.

Similarly there is little recent research into the link between social care services and the health of people with learning disabilities; for example one review found no research into the role of social care staff in initiating or supporting access to annual health checks.

There is some recent evidence to suggest that supported employment can enhance the quality of life of some people with learning disabilities. However employment rates for people with learning disabilities in the UK remain low . Furthermore a study of people in Scotland drew attention to negative effects on people's psychological wellbeing resulting from the breakdown of supported employment which occurred in 13 of 49 people studied.

We are not aware of any recent UK research which specifically measures the impact of leisure services, travel services or education services on the health of people with learning disabilities.

Indicators of the Determinants of Health Inequality

The indicator statements associated with each impact level for the five determinants are presented on the following pages.

Determinant 1:	**Social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness**	
Health Inequality Indicators		
A. Accommodation	**Impact Rating**	**Level**
Accommodation presenting high risk or in hospital / prison with no discharge accommodation identified or homeless	**Major**	**4**
Inappropriate accommodation / accommodation at risk of breakdown	**Significant**	**3**
Shared accommodation with others not self-selected / living with family – not by choice	**Limited**	**2**
Settled single accommodation or shared with self-selected others	**Minimal**	**1**
Settled family accommodation or own tenancy / ownership reflecting personal choice	**None**	**0**
B. Activities	**Impact Rating**	**Level**
No meaningful activities / engagement	**Major**	**4**
Highly restricted activity / engagement levels	**Significant**	**3**
Limited meaningful activities / engagement	**Limited**	**2**
Voluntary work or other structured meaningful activity / engagement	**Minimal**	**1**
In paid employment or education, fully engaged	**None**	**0**
C. Finance	**Impact Rating**	**Level**
Minimal or no financial support	**Major**	**4**
Restricted access to adequate financial support	**Significant**	**3**
Limited financial support	**Limited**	**2**
Full financial support / benefits accessed	**Minimal**	**1**
Sufficient financial support	**None**	**0**
D. Social Contact	**Impact Rating**	**Level**
Minimal or no social contact	**Major**	**4**
Restricted social contact	**Significant**	**3**
Social contact reliant on paid support	**Limited**	**2**
Limited non paid social networks	**Minimal**	**1**
Wide range of established non paid social networks	**None**	**0**
E. Marginalisation	**Impact Rating**	**Level**
Single marginalising factor having major impact or a range or marginalising factors restricting lifestyle.	**Major**	**4**
Additional marginalising factors having significant impact with little support or action being taken.	**Significant**	**3**
Additional marginalising factors having limited impact	**Limited**	**2**
Minimal additional marginalising factors with no impact; appropriate support is in place and effective	**Minimal**	**1**
No additional marginalising factors	**None**	**0**
F. Safeguarding	**Impact Rating**	**Level**
Major safeguarding concerns / current abuse or hate crime	**Major**	**4**
Significant safeguarding concerns / risk of abuse or hate crime	**Significant**	**3**
Limited safeguarding concerns	**Limited**	**2**
Minimal safeguarding concerns	**Minimal**	**1**
No safeguarding concerns	**None**	**0**

Determinant 2:	Physical and mental health problems associated with specific genetic and biological conditions in learning disabilities	
Health Inequality Indicators		
A. Assessment of physical and mental health needs and health checks	**Impact Rating**	**Level**
Physical and / or mental health needs not assessed and / or no current annual health check	**Major**	**4**
Physical and / or mental health needs under assessment and / or health check planned	**Significant**	**3**
Physical and / or mental health needs assessed / health check done but actions not in place	**Limited**	**2**
Physical and / or mental health needs assessed, health check carried out and being acted upon	**Minimal**	**1**
Physical and / or mental health needs assessed and fully met	**No**	**0**
B. Long Term Condition (LTC) pathways and planned reviews of need	**Impact Rating**	**Level**
No Long Term Condition (LTC) pathway allocation or planned review	**Major**	**4**
Awaiting review and / or Long Term Condition (LTC) pathway allocation	**Significant**	**3**
Review of needs completed but not acted on such as allocation onto Long Term Condition (LTC) pathway	**Limited**	**2**
Review of needs completed and acted on such as allocation onto Long Term Condition (LTC) pathway	**Minimal**	**1**
Review of needs not required	**None**	**0**
C. Care Planning / Health Action Planning	**Impact Rating**	**Level**
No Care plans / Health action plans in place	**Major**	**4**
Non condition specific care plans / Health Action plans in place (not condition specific or NICE compliant)	**Significant**	**3**
Condition specific, NICE compliant care plans / Health Action Plans in place but not reviewed or person centred	**Limited**	**2**
Condition specific, NICE compliant care plans / Health Action Plans in place, person centred and regularly reviewed	**Minimal**	**1**
No care plans or Health Action Plans required	**None**	**0**
D. Crisis / emergency planning and hospital passports	**Impact Rating**	**Level**
No crisis, emergency or relapse plans (where appropriate) or hospital passport in place	**Major**	**4**
Crisis / emergency / relapse plans and hospital passport in place, not person centred or reviewed	**Significant**	**3**
Crisis / emergency / relapse plans and hospital passport in place, not reviewed	**Limited**	**2**
Crisis / emergency /relapse plans and hospital passport in place, are person centred and reviewed	**Minimal**	**1**
No crisis / emergency plans required, hospital passport in place	**None**	**0**
E. Medication	**Impact Rating**	**Level**
Inappropriate medication or unlawful covertly administered medication	**Major**	**4**
Medication not reviewed and / or not regularly monitored	**Significant**	**3**
Medication reviewed but not regularly monitored	**Limited**	**2**
Medication reviewed and monitored	**Minimal**	**1**
No medication	**None**	**0**
F. Specialist learning disability service provision	**Impact Rating**	**Level**
No Specialist learning disability service available	**Major**	**4**
Restricted Specialist learning disability service available; not able to meet all identified needs	**Significant**	**3**
Limited Specialist learning disability service available	**Limited**	**2**
Full Specialist learning disability service available	**Minimal**	**1**
Full Specialist learning disability service available but not currently required	**None**	**0**

Determinant 3:	Communication difficulties and reduced health literacy	
Health Inequality Indicators		
A. Poor bodily awareness, pain responses and communication support	**Impact Rating**	**Level**
Major lack of bodily awareness, pain responses & communication support	**Major**	**4**
Significant lack of bodily awareness, pain responses & communication support	**Significant**	**3**
Limited lack of bodily awareness, pain responses & communication support	**Limited**	**2**
Minimal lack of bodily awareness, pain responses & communication support	**Minimal**	**1**
No identified lack of bodily awareness, pain responses & communication support	**None**	**0**
B. Communicating health needs to others	**Impact Rating**	**Level**
Major restrictions of communicate with others and in support provided in relation to communication needs.	**Major**	**4**
Significant restrictions in ability to communicate with others and in support provided in relation to communication needs.	**Significant**	**3**
Limited restrictions in ability to communicate with others and in support provided in relation to communication needs.	**Limited**	**2**
Minimal restrictions in ability to communicate with others and in support provided in relation to communication needs.	**Minimal**	**1**
No identified restrictions in ability to communicate with others.	**None**	**0**
C. Ability of those providing support to recognise expressions of need and / or pain	**Impact Rating**	**Level**
Major restrictions with the ability of those providing support to recognise pain / distress	**Major**	**4**
Significant restrictions with the ability of those providing support to recognise pain / distress	**Significant**	**3**
Limited restrictions with the ability of those providing support to recognise pain / distress	**Limited**	**2**
Minimal restrictions with the ability of those providing support to recognise pain / distress	**Minimal**	**1**
No restrictions with the ability of those providing support to recognise pain / distress	**None**	**0**
D. Ability of those providing support to recognise and respond to emerging health problems and / or promote health literacy	**Impact Rating**	**Level**
Major restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy	**Major**	**4**
Significant restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy	**Significant**	**3**
Limited restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy	**Limited**	**2**
Minimal restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy	**Minimal**	**1**
No restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy	**None**	**0**
E. Understanding Health Information and Making Choices	**Impact Rating**	**Level**
Major restrictions related to capacity and appropriate support to access and understand health information and make choices	**Major**	**4**
Significant restrictions related to capacity and appropriate support to access and understand health information and make choices	**Significant**	**3**
Limited restrictions related to capacity and appropriate support to access and understand health information and make choices	**Limited**	**2**
Minimal restrictions related to capacity and appropriate support to access and understand health information and make choices	**Minimal**	**1**
No restrictions related to capacity and appropriate support to access and understand health information and make choices	**None**	**0**

Determinant 4:	Personal health behaviour and lifestyle risks such as diet, sexual health and exercise	
Health Inequality Indicators		
A. Diet and hydration	**Impact Rating**	**Level**
Major restrictions to healthy eating and drinking	**Major**	**4**
Significant restrictions to healthy eating and drinking	**Significant**	**3**
Limited restrictions to healthy eating and drinking	**Limited**	**2**
Minimal restrictions to healthy eating and drinking	**Minimal**	**1**
No restrictions to healthy eating and drinking	**None**	**0**
B. Exercise	**Impact Rating**	**Level**
Major restrictions related to exercise	**Major**	**4**
Significant restrictions related to exercise	**Significant**	**3**
Limited restrictions related to exercise	**Limited**	**2**
Minimal restrictions related to exercise	**Minimal**	**1**
No restrictions related to exercise	**None**	**0**
C. Weight	**Impact Rating**	**Level**
Major restrictions to maintaining appropriate weight	**Major**	**4**
Significant restrictions to maintaining appropriate weight	**Significant**	**3**
Limited restrictions to maintaining appropriate weight	**Limited**	**2**
Minimal restrictions to maintaining appropriate weight	**Minimal**	**1**
No restrictions to maintaining appropriate weight	**None**	**0**
D. Substance use	**Impact Rating**	**Level**
Dependence on drugs, alcohol, or other harmful substances	**Major**	**4**
Harmful use of drugs, alcohol, tobacco or other harmful substances	**Significant**	**3**
Hazardous use of drugs alcohol, tobacco or other harmful substances	**Limited**	**2**
Minimal misuse of alcohol or tobacco.	**Minimal**	**1**
No harmful pattern of substance abuse	**None**	**0**
E. Sexual health	**Impact Rating**	**Level**
Very high risk sexual behaviours. Sexual abuse or sexual offending	**Major**	**4**
Unsafe and risky sexual behaviours	**Significant**	**3**
Inappropriate sexual behaviours increasing vulnerability.	**Limited**	**2**
Safe sexual behaviours of a restricted nature	**Minimal**	**1**
Healthy sexual behaviours	**None**	**0**
F. **Risky Behaviour and Routines**	**Impact Rating**	**Level**
Major health implications related to presentation of severe behavioural disturbance.	**Major**	**4**
Behaviours / routines have significant impact on health status.	**Significant**	**3**
Limited impact of risky behaviours / routines on health.	**Limited**	**2**
Behavioural presentation has minimal impact on health status.	**Minimal**	**1**
No presentation of risky behaviours / routines.	**None**	**0**

Determinant 5:	Deficiencies in access to and the quality of healthcare and other service provision	
Health Inequality Indicators		
A. Organisational barriers	**Impact Rating**	**Level**
Major restrictions in the quality of or access to services associated with organisational barriers completely preventing access.	**Major**	**4**
Significant restrictions in the quality of or access to services associated with organisational barriers	**Significant**	**3**
Limited restrictions in the quality of or access to services associated with organisational barriers	**Limited**	**2**
Minimal restrictions in the quality of or access to services associated with organisational barriers	**Minimal**	**1**
No restrictions in the quality of or access to services associated with organisational barriers	**None**	**0**
B. Consent	**Impact Rating**	**Level**
Consent or best interest process not in place or not being implemented	**Major**	**4**
Consent or best interest processes in place but being ignored or wrongly applied	**Significant**	**3**
Consent and best interest processes in place and being applied but not consistently	**Limited**	**2**
Consent and best interest processes in place and generally being applied effectively	**Minimal**	**1**
Consent and best interest processes are robust and rigorously applied	**None**	**0**
C. Transitions between services	**Impact Rating**	**Level**
Complete breakdown in transitions between services	**Major**	**4**
Significant breakdown in transition between services	**Significant**	**3**
Transition between services is delayed or disrupted	**Limited**	**2**
Transition between services is successful with additional support	**Minimal**	**1**
Transition between services is successful with no additional support	**None**	**0**
D. Access to and quality of Health screening / promotion	**Impact Rating**	**Level**
Major restrictions in the or quality of or access to health promotion / screening	**Major**	**4**
Significant restrictions in the or quality of or access to health promotion / screening	**Significant**	**3**
Limited restrictions in the or quality of or access to health promotion / screening	**Limited**	**2**
Minimal restrictions in the or quality of or access to health promotion / screening	**Minimal**	**1**
No restrictions in the or quality of or access to health promotion / screening	**None**	**0**
E. Access to and quality of Primary / secondary care	**Impact Rating**	**Level**
Major restrictions in the quality of or access to primary and / or secondary care	**Major**	**4**
Significant restrictions in the quality of or access to primary and / or secondary care	**Significant**	**3**
Limited restrictions in the quality of or access to primary and / or secondary care	**Limited**	**2**
Minimal restrictions in the quality of or access to primary and / or secondary care	**Minimal**	**1**
No restrictions in the quality of or access to primary and / or secondary care	**None**	**0**
F. Access to and quality of Non- health services	**Impact Rating**	**Level**
Major restrictions in the quality of or access to non-health services	**Major**	**4**
Significant restrictions in the quality of or access to non-health services	**Significant**	**3**
Limited restrictions in the quality of or access to non-health services	**Limited**	**2**
Minimal restrictions in the quality of or access to non-health services	**Minimal**	**1**
No restrictions in the quality of or access to non-health services	**None**	**0**

Indicators of Exposure to Determinants of Health Inequality

There follows a detailed breakdown of the Indicator Statements and Descriptors for each impact level for the Health Inequality Indicators associated with each of the determinants.

1. Social Indicators.

A. Accommodation

The quality of living standards for people with learning disabilities can vary widely. When considering accommodation it is important to consider the physical and the social environment. Risks may exist because of the physical environment (extreme damp, unsafe electrics, lack of adaptation around mobility problems etc.), or arise from the social environment (overcrowding, bullying, aggression from others, etc).

Impact Level & Indicator Statement		Descriptor
4A	Accommodation presenting high risk, or in hospital / prison with no discharge accommodation identified or homeless.	*This level applies to a person who has no settled accommodation, who may be in temporary short term accommodation with no appropriate move-on accommodation identified, or in accommodation that is directly impacting on their health and wellbeing. This includes those who are living in restrictive settings such as hospitals or prison. There may be serious safeguarding concerns in relation to accommodation.*
3A	Inappropriate accommodation / accommodation at risk of breakdown.	*This level applies where a person is in accommodation which is does not meet to their identified health and social needs; or where the accommodation is fragile and likely to break down (e.g. due to negative relationships with peers / neighbours, lack of suitably skilled support, offending behaviour, or where notice has been served by the accommodation provider).*
2A	Shared accommodation with others / family – not by choice.	*This level applies where accommodation is shared with others though not either chosen by the individual, or agreed through an appropriate best interest process. Similarly, where individuals continue to live with their family despite the fact that they or their family would prefer independence move to more independent living.*
1A	Settled single accommodation or shared with self-selected others.	*This level applies where a person lives in accommodation either of their choosing or following appropriate best interest processes. This will however be in some form of registered care or where they do not have tenancy rights or full control over their care and / or support.*
0A	Settled family accommodation or own tenancy / ownership reflecting personal choice.	*This level applies where a person is in settled accommodation either of their choosing or following a appropriate best interest process. Either the person themselves of their family have control over their tenancy, care and support.*

B. Employment, meaningful activities and engagement

Being engaged in meaningful activity is not dependent on degree of disability; it will be unique for everyone, what is meaningful for one person may not be meaningful to another. Activity can range from different types of employment, education, training, home or community based activities, and these may be formal or informal. A good measure of meaningfulness is the degree of engagement in the activity. A meaningful activity for someone with profound intellectual and multiple learning disabilities may be massage, or listening to music, for more independent people it may be cooking or attending a club, for others it could be fulltime employment or attendance at a college course of their choice.

Impact Level & Indicator Statement		Descriptor
4B	No meaningful activities / engagement.	*This level applies where a person has no meaningful activities or engagement. They will be spending long periods of time with no stimulus or engagement; or they may be engaged in activities that are not meaningful to them. There may be serious safeguarding concerns in relation to levels of activity and engagement.*
3B	Highly restricted activity / engagement levels.	*This level applies when a person's access to meaningful activities is extremely restricted, either for very brief periods or only intermittently available. It may be that very few appropriate activities have been identified. Activities may only be provided within the person's home environment and there is little or no access the wider community.*
2B	Limited meaningful activities / engagement.	*This level applies where a person has some activities which are meaningful to them, or a range of activities have been identified but nonetheless access to them is limited or unpredictable.*
1B	Voluntary work or other structured meaningful activity / engagement.	*This level applies where a range of meaningful activities are available; they are most likely structured and accessed regularly. There may be a combination of formal and informal activity; or for people who are able to work, opportunities exist for engagement in voluntary employment.*
0B	In paid employment or education, fully engaged.	*This level applies where a person is engaged with a range of meaningful activities that include paid employment or education of their choice and / or engagement in a range of meaningful activities in different environments with different people.*

C. Financial support

The links between financial security and health are clear from the evidence. The majority of people with learning disabilities are in receipt of some sort of benefit, however sometimes there is a sense that finances are inadequate to meet an individual's needs. Material poverty can affect a person's ability to take a nutritious diet or to engage in activities within their community. Where entitlements are not taken up or monies are being held back by another party (see safeguarding) this can directly impact on an individual's health and well being.

Impact Level & Indicator Statement		Descriptor
4c	Minimal or no financial support.	*This level applies where a person is in receipt of either no or else very limited financial support. This could be because benefits are not being accessed, have been withdrawn or are being withheld. There may be serious safeguarding concerns in relation to finances.*
3c	Restricted access to adequate financial support.	*This level applies where a person has restricted financial support and / or restricted choice and control over the use of their finances (in the absence of robust best interest decision making processes). This could be because some benefits are not being accessed or access to full entitlements is being restricted.*
2c	Limited financial support.	*This level applies where there is some financial support but of a limited nature and / or limited choice and control over its use (in the absence of robust best interest decision making processes. This could be because entitlement criteria are not met, benefits only cover essential requirements or access to full entitlements is being restricted.*
1c	Full financial support / benefits accessed.	*This level applies where full benefits are accessed and provide adequate financial support with choice and control to maintain a reasonable quality of life.*
0c	Sufficient financial support.	*This level applies where there is sufficient financial support to maintain a good quality of life with finances available to support choices, control and security.*

D. Social contact

Social contact can take many forms but is a clear indicator within quality of life measures and health and wellbeing. A strong social network will typically include family and friends though this may be disrupted due to remote and distant placements, lack of financial resource or availability of support. Other important social contacts may include neighbours, people with similar recreational interests or those with similar cultural backgrounds.

Impact Level & Indicator Statement		Descriptor
4D	Minimal or no appropriate social contact.	*This level applies where there is very little or no appropriate social contact. This may mean that a person is removed from societal contact and socially isolated, with little or no contact of any sort other than with paid support and others placed in the same service. There may be serious safeguarding concerns in relation to social isolation or the influence of inappropriate social contacts.*
3D	Restricted levels of social contact.	*This level applies where access to appropriate social contact is available but is fragile or is at risk of being lost. This may be for a wide range of reasons including behaviour, living situation, risk, staffing levels etc.*
2D	Social contact reliant on paid support.	*This level applies where some appropriate social contact is maintained but is reliant on paid support. There may be restricted choice and control over social contact.*
1D	Limited non paid social networks.	*This level applies where a person is able to maintain appropriate social contact independently or where social contact is controlled by the person through use of a personal budget or - social contact may however be limited.*
0D	Wide range of established non paid social networks.	*This level applies where a person is in full control of access to a wide range of appropriate social contacts with established social networks.*

E. Additional marginalising factors (such as ethnicity)

This indicator can cover a wide range of issues that can increase an individual's marginalisation. This can be linked to ethnicity, gender, behaviours, sexuality, appearance, physical features, speech differences etc. etc.

Impact Level & Indicator Statement		Descriptor
4E	Single marginalising factor having major impact or a range or marginalising factors restricting lifestyle.	*This level applies where there is a major impact on a person's quality of life because of marginalising factors in addition to their learning disabilities. This may mean that they are more vulnerable or their life is further restricted to a major degree. There may be serious safeguarding concerns as a result of additional marginalising factors.*
3E	Additional marginalising factors having significant impact with little support or action being taken.	*This level applies where a significant negative impact on a person's life is experienced because of additional marginalising factors. This may mean that they are not able to do certain preferred activities or lead as full a life as they otherwise would be able or choose to. There is little support or action being taken.*
2E	Additional marginalising factors having limited impact.	*This level applies where there are additional marginalising factors present and these have a limited impact on the person. This may mean they feel more vulnerable or feel less able to do the things they otherwise would be able or choose to do. Some support is in place but may not be appropriate or effective.*
1E	Minimal additional marginalising factors with no impact; appropriate support is in place and effective.	*This level applies where there are additional marginalising factors which are managed and supported in such a way as to have no or minimal impact on the person's life.*
0E	No additional marginalising factors.	*There are no marginalising factors beyond the learning disabilities.*

F. Safeguarding

The inclusion of safeguarding issues within the framework enables the capture of any issues that may be impacting on the individuals' safety. Such factors may have been captured within another indicator (financial for example) however this indicator captures the formalisation of such risk areas including hate crime. It also includes issues related to the safety of others including children.

Impact Level & Indicator Statement		Descriptor
4F	Major safeguarding concerns / current abuse or hate crime	*This level applies where there are current or major safeguarding issues that need to be, or are being addressed. This may be because of concerns of active abuse or hate crime occurring, or there is an immediate serious risk to the person or others.*
3F	Significant safeguarding concerns / risk of abuse or hate crime	*This level applies where there are major risks that could require a safeguarding response. There may be indications of possible abuse, hate crime or risk to others that require monitoring; there may be a lack of recording, monitoring and transparency in support systems.*
2F	Limited safeguarding concerns.	*This level applies where there are concerns of a safeguarding nature that may impact on the person or others. This could be where the person is in shared accommodation where abuse or hate crime toward another individual has been identified. There may be cultural issues within the support environment which need to be addressed.*
1F	Minimal safeguarding risks.	*This level applies where a person may be vulnerable but the current safeguarding or hate crime risks are minimal and there is good monitoring, transparency and recording in place.*
0F	No safeguarding concerns.	*This level applies where there are no current safeguarding or hate crime concerns and any risks are minimal and well managed.*

2. Genetic and Biological Indicators.

A. Assessment of physical and mental health needs and health checks

The assessment of physical and / or mental health needs can be complex
Many specific health conditions are considerably more prevalent in the learning disability population, epilepsy, respiratory conditions, anxiety for example
There can be difficulties in detecting and recognising conditions and symptoms (often atypical) of specific health conditions. Understanding interactions between specific learning disability conditions and the environment also requires consideration. Annual Health checks can help to reduce some of these difficulties.

Impact Level & Indicator Statement		Descriptor
4A	Physical and / or mental health needs not assessed and / or there is no current annual health check.	*This level applies where there has been no appropriate or effective assessment of needs and / or no annual health check. There is likely to be undiagnosed illness because signs and symptoms have not been recognised. Health problems may be seen as part of the learning disability (diagnostic overshadowing). There will be a lack of health surveillance for people who have problems communicating. There may be serious safeguarding concerns in relation to the assessment of health needs.*
3A	Physical and / or mental health needs remain under assessment and / or an annual health check is planned but has not been completed.	*This level applies where there have been delays in completing assessment processes. It may be that inconsistent approaches have been taken to diagnosis of illness because signs and symptoms have not always been recognised or understood. Pain assessment is likely to be very limited.*
2A	Physical and / or mental health needs have been assessed / health check done but actions are not in place.	*This level applies where an assessment has been carried out but there are delays in meeting the needs that have been identified. It may be that the needs are not being prioritised or that the complexity of meeting the need is preventing appropriate action from being taken or referral for other interventions has not been made.*
1A	Physical and / or mental health needs have been assessed, a health check carried out and are being acted on.	*This level applies where needs have been properly assessed and appropriate action is being taken. The identified needs are not yet resolved but progress is being made.*
0A	Physical and / or mental health needs assessed and fully met.	*This level applies where needs have been fully assessed and appropriate action has been taken that fully meets those needs.*

B. Long Term Condition (LTC) pathways and planned reviews of need

Many people with learning disabilities have long term conditions, however the established pathways for the treatment of such conditions (dementia, epilepsy, diabetes etc.) are not always provided. People's needs change over time and therefore require regular review. Some people with learning disabilities can continue to receive treatments that are no longer appropriate or required

Impact Level & Indicator Statement		Descriptor
4B	No Long Term Condition (LTC) pathway allocation or planned review.	*This level applies where there are health issues which have not been, or are not being followed up. There may be a lack of sensitivity or awareness of health signs and symptoms. Recognition of changes in health state is likely to be very poor. Indicated long term care pathway allocation has not been made. There may be serious safeguarding concerns in relation to care pathway allocation or review of needs.*
3B	Awaiting review and / or Long Term Condition (LTC) pathway allocation.	*This level applies where the need for a review is acknowledged but has not taken place. There will be known health issues that need to be followed up. Recognition of health signs, symptoms and changes in health state is likely to be inconsistent.*
2B	Review of needs completed but not acted on such as allocation onto Long Term Condition (LTC) pathway.	*This level applies where a review of needs has been carried out but the required actions have yet to be implemented. It may be that the actions are not being prioritised or that the complexity of making the required changes is preventing appropriate action from being taken.*
1B	Review of needs completed and acted on such as allocation onto Long Term Condition (LTC) pathway.	*This level applies where a review of needs has been carried out and the actions arising from it are being implemented. This could be that long term condition pathway actions are being carried out with reasonable adjustments.*
0B	Review of needs not required.	*This level applies if there are no needs indicated or identified which require review. There is no requirement for any intervention.*

C. Care Planning / health action planning

Care planning is the means by which care needs are identified. The care plan is an important focus for good communication; it should guide the work of others and be a basis for continuity of care. Health Action plans identify what needs to happen and who needs to do it. There can be difficulties if these plans are unclear, inadequate, misleading, contradictory or not acted on appropriately.

Impact Level & Indicator Statement		Descriptor
4c	No Care plans / Health action plans in place.	*This level applies where the person has needs requiring specific actions but no care plans are in place. This means that the person is not getting adequate support with their health needs; there may be serious safeguarding concerns in relation to care planning.*
3c	Non condition specific care plans / Health Action plans in place (not condition specific, or NICE compliant).	*This level applies where a person has care plans in place but they do not address the specific conditions that are known to exist. For example someone with Down's syndrome who does not have thyroid function testing identified in their care planning, or someone with epilepsy who does not have a care plan for the management of seizures that is in line with NICE guidance.*
2c	Condition specific, NICE compliant care plans / Health Action Plans in place but not reviewed or person centred.	*This level applies where care plans are in place to address specific known conditions; however the plans are generic and not individualised or person centred. It is likely that the care plans have not been effectively reviewed.*
1c	Condition specific, NICE compliant care plans / Health Action Plans in place, person centred and regularly reviewed.	*This level applies where there are known assessed needs for which specific care plans exist. The care plans will be based around the specific needs of the person in a personalised way. The care plans will be regularly and effectively reviewed.*
0c	No care plans or Health Action Plans required.	*This level applies where there is no requirement for care plans as a full and thorough assessment has not identified any unmet needs.*

D. Crisis / emergency planning and hospital passports

Emergency plans can prevent a lot of the difficulties associated with a crisis or urgent admission to hospital. They are only effective if they are regularly reviewed and updated and they focus on the specific needs of the individual, are person centred and take account of local circumstances. Hospital passports help to ensure that an individual's needs are met if and when they need to be admitted or if they require hospital treatment or assessment.

Impact Level & Indicator Statement		Descriptor
4D	No crisis, emergency or relapse plans (where appropriate) or hospital passport in place.	*This level applies where there are no plans to respond to a crisis of health need. A hospital passport has not been completed. There may be serious safeguarding concerns in relation to crisis or emergency planning.*
3D	Crisis / emergency / relapse plans and hospital passport in place, not person centred or reviewed.	*This level applies where crisis and / or emergency plans, and a hospital passport have been completed but are inadequate or out of date; this may be because they are not person centred, not robust or fit for purpose.*
2D	Crisis / emergency / relapse plans and hospital passport in place, not reviewed.	*This level applies where crisis and / or emergency plans, and a hospital passport are person centred but have not been reviewed.*
1D	Crisis / emergency / relapse plans and hospital passport in place, are person centred and reviewed.	*This level applies where crisis, emergency and, where appropriate, relapse plans and a hospital passport are all in place. These plans are person centred, individualised and regularly reviewed.*
0D	No crisis / emergency plans required, hospital passport in place.	*This level applies where a person does not require any emergency or crisis plans; they are likely to have good networks of support and good communication. A hospital passport is complete, person centred and up to date.*

E. Medication

Due to increased co-morbidity, people with learning disabilities often take multiple medications giving rise to complex interactions. In some instances they are more prone to adverse and atypical effects of medications and yet may have difficulty reporting side effects which are hazardous to health and wellbeing. People who present challenging behaviour may be subjected to unlicensed prescribing of anti-psychotics. On occasion people may require covert administration of medication; this should always be subject to appropriate capacity assessment and best interest processes.

Impact Level & Indicator Statement		Descriptor
4E	Inappropriate medication or unlawful covertly administered medication.	*This level applies where medication is being used that is not in keeping with the individual's identified needs e.g. not prescribed for a diagnosed and / or licensed use, or in excess of recommended dose limits. Medication recommended for short term use may have been taken for prolonged periods without regular review (e.g. benzodiazepine anxiolytics, prophylactic antibiotics); Or medication which has hazardous side effects and a narrow therapeutic window: or where medication is being given covertly without consent (where there is capacity) or best interest decision. Those providing support are not managing medication safely or there are major problems with compliance. There may be serious safeguarding concerns in relation to medication.*
3E	Medication not reviewed and / or regularly monitored.	*This level applies where despite poly-pharmacy medication continues to be administered without a specialist review; or the effectiveness, or side effects are not being adequately monitored. A full review of all medication should occur annually as a minimum. Those providing support are not managing medication appropriately or there are significant problems with compliance.*
2E	Medication reviewed but not regularly monitored.	*This level applies where medication may be being reviewed (perhaps annually) but there is poor on-going monitoring of effectiveness or side effects. Those providing support are not monitoring or recording medication effectively or there are limited problems with compliance.*
1E	Medication reviewed and monitored.	*This level applies where medication is carefully monitored and recorded with regular and appropriate review. Those providing support are monitoring and recording medication effectively and there are minimal problems with compliance.*
0E	No medication.	*This level applies where there is no current medication required.*

F. Specialist learning disability service provision

This indicator relates to the access and quality of specialist learning disability services and their ability to provide a level of support that meets an individual's specialist health needs that would otherwise not be met in a mainstream setting alone.

Impact Level & Indicator Statement		Descriptor
4F	No specialist learning disability service provision available.	*This level applies where a specialist learning disability service is not available to an individual. This may be because there is a lack of specialist service provision locally or that access is being denied or withheld. There may be serious safeguarding concerns. In relation to the lack of appropriate specialist service provision.*
3F	Restricted specialist learning disability services available, not able to meet all identified needs.	*This level applies where some specialist learning disability service is available but access may be restricted, delayed or not available locally. There is no support to access the service available. There may be areas of identified need that cannot be met.*
2F	Limited specialist learning disability service available.	*This level applies where a limited specialist learning disability service is available locally and being provided but there are limitations in the quality or scope of the service available. There is limited support to access the service.*
1F	Full specialist learning disability service available.	*This level applies where a full high quality specialist service is available and being accessed by the individual. There is adequate support to access the service.*
0F	Full specialist learning disability service available but not currently required.	*This level applies where a full, high quality and appropriate service is available but not currently required.*

3. Communication Difficulties and Reduced Health Literacy Indicators.

A. Poor bodily awareness, reduced pain responses and communication support

The ability of individuals to recognise normal and abnormal bodily sensations including pain can vary. Some people may be at serious risk because of their inability to express themselves effectively and the inability of others to understand / or respond appropriately. Some people present behaviours described as challenging in response to pain.

Impact Level & Indicator Statement		Descriptor
4A	Major restrictions of bodily awareness, pain responses and communication support.	*This level applies where a person is completely unable to recognise abnormal bodily sensations and is able to show little or no discernible response to pain; they receive no appropriate support with identifying needs. There may be serious safeguarding concerns in relation to bodily awareness, pain responses and communication support.*
3A	Significant restrictions of bodily awareness, pain responses and communication support.	*This level applies where a person is significantly restricted in their capacity to recognise abnormal bodily sensations including pain and distress, and who receives inadequate appropriate support with identifying needs. Non-verbal indicators of pain and distress have not been identified.*
2A	Limited restrictions of bodily awareness, pain responses and communication support.	*This level applies where a person has some limitations in recognising abnormal bodily sensations including pain, and who receives limited support from others with identifying needs. Non-verbal indicators of pain / distress will have been assessed and described but are not always acted on.*
1A	Minimal restrictions of bodily awareness, pain responses and communication support.	*This level applies where a person has some limitations in bodily awareness or shows largely normal responses to pain. They receive appropriate support with identifying needs.*
0A	No identified lack of bodily awareness, pain responses and communication support.	*This level applies where a person has good bodily awareness and can show normal adaptive responses to pain / distress.*

B. Communicating health needs to others

People with learning disabilities have varying ability to communicate their health issues to others. Those offering support may miss the significance of behavioural indicators of pain / discomfort / distress.

Impact Level & Indicator Statement		Descriptor
4B	Major restrictions in ability to communicate with others and in support provided in relation to communication.	This level applies where there are major difficulties as a result of highly complex needs in relation to a person's communication, such that they are completely unable to communicate with others. They do not receive appropriate support or resources to aid communication of health needs. There may be serious safeguarding concerns in relation to communication of health needs.
3B	Significant restrictions in ability to communicate with others and in support provided in relation to communication.	This level applies where there are significant difficulties as a result of complex needs and extremely limited communication with others. They receive inadequate or inappropriate support to aid communication of health needs.
2B	Limited restrictions in ability to communicate with others and in support provided in relation to communication.	This level applies where there are some difficulties as a result of complex needs and limited communication with others. They receive some appropriate support to aid communication of health needs.
1B	Minimal restrictions in ability to communicate with others and in support provided in relation to communication.	This level applies where there are minimal difficulties as a result of a person's ability to communicate with others. They receive appropriate support and resources to aid communication of health needs.
0B	No identified restrictions in ability to communicate with others.	This level applies where there are no identified difficulties related to the person's ability to communicate with others. They can articulately describe their signs, symptoms, concerns and health needs to others.

C. Carers ability to recognise expressions of needs / pain

It is important that people providing care or support, have access to training or support about communication and the identification and management of pain, illness and distress. Health action plans, hospital and communication passports should include information on how the person communicates pain/distress and how this is managed.

Impact Level & Indicator Statement		Descriptor
4c	Major restrictions with the ability of those providing support to recognise pain / distress.	*This level applies where there are major difficulties associated with failure to recognise pain, distress or ill health resulting in a likely deterioration of physical and / or mental health and wellbeing. There may be serious safeguarding concerns relating to the recognition of needs / pain.*
3c	Significant restrictions with the ability of those providing support to recognise pain / distress.	*This level applies where there are significant difficulties associated with the failure to recognise pain, distress or ill health resulting in a potential deterioration of physical and / or mental health and wellbeing. Those providing support have received minimal training around the health needs of people with learning disability.*
2c	Limited restrictions with the ability of those providing support to recognise pain / distress.	*This level applies where there are limited difficulties associated with the inconsistent recognition and treatment of pain, distress or ill health. Those providing support have received basic training around the health needs of people with learning disabilities.*
1c	Minimal restrictions with the ability of those providing support to recognise pain / distress.	*This level applies where there are minimal difficulties associated with occasional misinterpretation of signs and symptoms indicating pain, distress or ill health. Those providing support have received training specifically relating to the health needs of people with learning disabilities.*
0c	No identified restrictions with the ability of those providing support to recognise pain / distress.	*This level applies where there are no identified difficulties associated with recognition of signs and symptoms indicating pain, distress or ill health. The person is able to self-report or there is a robust person centred process in place for ensuring effective, timely interventions to treat pain, distress and ill health.*

D. Carers ability to recognise and respond to emerging health problems and / or promote health literacy

People with learning disabilities can present atypically in response to changing health status. There may be behavioural or emotional changes to pain or distress. People may lack the cognitive or communicative skills to describe their experiences, understand the nature of their condition or the importance of adherent to treatment plans. There may be a degree of dependence on carers to recognise changes in presentation which when considered in totality may be indicative of a health problem and carers may be supported in enabling people to understand their health through access to resources.

Impact Level & Indicator Statement		descriptor
4D	Major restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy.	*This level applies where there are major difficulties resulting from the inability of people who provide care or support to recognise emerging health problems. There is no utilisation, creation or sourcing of accessible information on health needs or interventions. There may be serious safeguarding concerns relating to carers abilities in this area.*
3D	Significant restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy.	*This level applies where there are significant difficulties resulting from the inability of those who provide care or support to fully recognise emerging health problems. There is limited ability to utilise, create and source accessible information on health needs or interventions.*
2D	Limited restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy.	*This level applies where there are limited difficulties resulting from inconsistency of those providing support in recognising emerging health problems. There is some evidence of accessible information on health needs or interventions being provided.*
1D	Minimal restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy.	*This level applies where there are minimal difficulties relating to the ability of people who provide care or support to recognise emerging health problems. Accessible information on health needs or interventions is usually evident.*
0D	No identified restrictions related to the ability of those providing support to recognise emerging health problems and / or promote health literacy.	*This level applies where there are no identified difficulties related to the ability of people who provide care or support to recognise emerging health problems. Individuals have full access to appropriate person-centred health promotion and education; and to clear understandable information about health care and treatment.*

E. Understanding Health Information and Making Choices

People who have learning disabilities often have difficulty in understanding health information this can affect their ability to make informed choices. It is essential that people are empowered wherever possible to make choices based on information that is designed to meet their needs.

Impact Level & Indicator Statement		Descriptor
4E	Major restrictions related to capacity and appropriate support to access and understand health information and make choices.	*This level applies where there are major difficulties resulting from a person's complete lack of understanding and awareness of health information. There is no support or they (and those who know them best) are excluded from decisions relating to their own health and wellbeing. There may be serious safeguarding concerns relating to understanding health information and making choices.*
3E	Significant restrictions related to capacity and appropriate support to access and understand health information and make choices.	*This level applies where there are significant difficulties' resulting from a person's restricted understanding and awareness of health information. There is limited support to enable people to make their own decisions (along with those who know them best) in relation to health and wellbeing.*
2E	Limited restrictions related to capacity and appropriate support to access and understand health information and make choices.	*This level applies where there are limited difficulties resulting from a person's restricted understanding and awareness of health information. There may be some support to enable this, leading to partial involvement in decision making and inappropriate actions in relation to health and wellbeing.*
1E	Minimal restrictions related to capacity and appropriate support to access and understand health information and make choices.	*This level applies where there are minimal difficulties resulting from a person's restricted understanding and awareness of health information. There is usually good support to ensure the person is included in making choices about their health.*
0E	No identified restrictions related to capacity and appropriate support to access and understand health information and make choices.	*This level applies where there are no identified difficulties related to an individual's understanding and awareness of health information and where there is full involvement in planning for good health.*

4. Personal Behaviour and Lifestyle Indicators.

A. Diet and hydration

People with learning disabilities commonly take poor diets. In some instances, due to reduced health literacy, they have a poor understanding of what a healthy diet is. Other people are dependent on carer knowledge to ensure they receive a balanced and nutritious diet. Some people risk health complications associated with excessive or restricted fluid intake. People may have specific dietary requirements due to other health conditions, or medication side effects. Given the high incidence of swallowing difficulties, some people require food and drinks to be of a modified safe consistency.

Impact Level & Indicator Statement		Descriptor
4A	Major restrictions to healthy eating and drinking.	*This level applies where the person has known swallowing difficulties but is not having the consistency of their food modified. May take little or no food or fluid without considerable encouragement and this is not readily available. Eats hazardous (otherwise inedible) items. 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.*
3A	Significant restrictions to healthy eating and drinking.	*This level applies where food consistency is not wholly safe. The person may drink excessively or alternately takes minimal fluids. The amount of food taken is a significant concern. There may be a complete omission of one or more essential component (e.g. fruit, veg or dairy products) OR an extreme excess of an unhealthy constituent of food (e.g. salt or saturated fat) OR wholly inadequate calorific intake. Little support to modify nutritional intake.*
2A	Limited restrictions to healthy eating and drinking.	*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.*
1A	Minimal restrictions to healthy eating and drinking.	*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.*
0A	No restrictions to healthy eating and drinking.	*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.*

B. Exercise

People with learning disabilities often lead a more sedentary lifestyle than non-disabled peers. There may be issues of motivation or inadequate levels of support to allow engagement in exercise. Some people have extremely complex physical disabilities that mean traditional activities by way of exercise are difficult to engage in. Exercise can be a 'lifestyle activity' (in other words, walking to the shops or taking the dog out) or structured exercise or sport, or a combination of these; it does need to be of at least moderate intensity, measured by it making the person slightly breathless or a little warm.

Impact Level & Indicator Statement		Descriptor
4B	Major restrictions related to exercise.	*This level applies where the person takes little or no exercise of an even mild intensity. May be immobile or just sedately mobilising around living environment. Poses risks to skin integrity, cardiovascular system, bones and joints. Alternatively may undertake high intensity, vigorous activity despite significant underlying medical conditions which mean excessive cardio vascular work load should be avoided. No appropriate support with exercise in place. There may be serious safeguarding concerns in relation to exercise.*
3B	Significant restrictions related to exercise.	*This level applies where the person takes little or no moderately vigorous exercise, or undertakes energetic activity for brief periods only; no more than once or twice a week. Restricted access to support, understanding in relation to exercise of those providing support is minimal.*
2B	Limited restrictions related to exercise.	*This level applies where the person takes less than a weekly total of an hour and a half of moderately vigorous activity. Takes such exercise on less than four days per week. Support available but not appropriately implemented or utilised.*
1B	Minimal restrictions related to exercise.	*This level applies where the person undertakes moderate intensity activity on four or five days per week, or for less than 30 minutes in a day. Appropriate support and encouragement is provided.*
0B	No restrictions related to exercise.	*This level applies where the person takes a degree of exercise of a nature and quantity appropriate to age and general health condition. A mixture of aerobic and muscle strengthening activities on five or more days per week. No support required.*

C. Weight

People with learning disabilities are prone to being either overweight or underweight. Obesity brings a whole range of risks in its own right and can also increase the hazardous nature of exposure to other determinants of health in (e.g. genetic cardio vascular problems or hazardous medications). Being underweight or malnourished increases risk of serious medical complications including recurrent infection and impaired renal function.

Impact Level & Indicator Statement		Descriptor
4c	Major restrictions to maintaining appropriate weight.	*This level applies where BMI is less than 15 or over 40.* *There has been unplanned loss of more than 10% weight over 3-6 months.* *No support available to achieve or maintain appropriate weight.* *There may be serious safeguarding concerns in relation to weight.*
3c	Significant restrictions to maintaining appropriate weight.	*This level applies where BMI is between 15-16 OR 35-40* *There is unplanned loss of 5-10% weight over 3-6 months.* *Restricted access to support to achieve or maintain appropriate weight.*
2c	Limited restrictions to maintaining appropriate weight.	*This level applies where BMI is between 16-18.5 OR 30-35.* *There is unplanned loss of less than 5% weight over 3-6 months.* *Support available but not appropriately implemented or utilised to achieve or maintain appropriate weight.*
1c	Minimal restrictions to maintaining appropriate weight.	*This level applies where BMI is between 25-30. Weight is stable.* *Appropriate support and encouragement is provided to achieve or maintain appropriate weight.*
0c	No restrictions to maintaining appropriate weight.	*This level applies where BMI is between 18-25.* *Weight is stable. No support is required to achieve or maintain appropriate weight.*

D. Substance Use

Vulnerable people can be become engaged in the harmful use of alcohol, smoking and non-prescription drugs and other harmful substances. This can make them particularly vulnerable to exploitation and may result in problems with relationships, finances and offending behaviour. They may find it difficult, or be reluctant to engage with activities to change their behaviours. Some people may have developed ritualised behaviours or be dependent on routine.

In addition people often need support from others, who may not be well informed about the harmful impact of alcohol, smoking and other dangerous substances, or skilled in supporting and managing risky behaviours.

Impact Level & Indicator Statement		Descriptor
4D	Dependence on drugs, alcohol, or other harmful substances.	*This level applies where there is evidence of a strong compulsion to take the desired substance, where a withdrawal state is associated with abstinence There may be evidence of tolerance (indicated by increasing quantities of the desired substance being required to achieve the desired effect). Alternative pleasures are neglected. No support or access to services in place. There may be serious safeguarding concerns in relation to substance use.*
3D	Harmful use of drugs, alcohol, tobacco or other harmful substances.	*There is an evident pattern of substance use which has significantly contributed to physical, psychological or social harm. Limited support or access to services.*
2D	Hazardous use of drugs alcohol, tobacco or other harmful substances.	*This level applies where consumption is associated with a significantly increased risk of harm, albeit that there is currently no evidence of actual harm. This is the minimal level that is associated with recreational drug use. Some support provided.*
1D	Minimal misuse of alcohol or tobacco.	*This level applies where there is evidence of some risky behaviour in relation to the use of alcohol or tobacco. Behaviours demonstrated are considered to pose a limited risk to the person's health and wellbeing with potential for morbidity. E.g. where the person generally keeps alcohol consumption to a safe level, but occasionally drinks an excessive amount. Support available if needed.*
0D	No harmful pattern of substance use.	*This level applies where there is use of no substances other than alcohol and where drinking is within Public Health recommended safe limits. (or where there is no use of alcohol). Consumption poses a minimal risk to health and wellbeing. E.g. Where the person consumes alcohol regularly but the amount is considered acceptable (Per week: at least two alcohol-free days, Men: no more than 21 units & no more than four units a day, Women: no more than 14 units, & no more than three units a day).*

E. Sexual Health

Many people with learning disabilities engage in appropriate and healthy sexual acts and relationships. If they do this without having accessed sexual health services / education this may place their health at risk. Others are vulnerable and at risk of exploitation or given a lack of appropriate role models may engage in behaviours that are considered to be sexually unusual or unsafe (if not illegal).

Impact Level & Indicator Statement		Descriptor
4E	Very high risk sexual behaviours. Sexual abuse or sexual offending.	*In an abusive / exploitative sexual relationship.* *Engages in sexual offending behaviour.* *Has unprotected sex with people who are at high risk for sexually transmitted disease.* *No positive role models for normal, adaptive sexual relationships.* *No support provided.* *There may be serious safeguarding concerns in relation to sexual health.*
3E	Unsafe and risky sexual behaviours.	*Has frequent unprotected sex of a nature that is hazardous to health, poses serious safeguarding issues or is illegal.* *Has been exposed to sexually inappropriate role models. Has had (and failed to detect) chronic sexually transmitted disease.* *Restricted support provided* Limited support or access to services.
2E	Inappropriate sexual behaviours increasing vulnerability.	*Has limited awareness of sexual rights / norms though is sexually active.* *Has limited access to sexual health services. Limited understanding of what constitutes safe sex.* *Has had a lack of sexually positive role models.* *Lives in an environment where others display sexually inappropriate behaviours.* *Sexually active but not using contraception. Some support provided.*
1E	Safe sexual behaviours of a restricted nature	*Has accessed contraceptive advice both to avoid pregnancy and the risk of sexually transmitted diseases. Is interested in sex though is sexually isolated. Appropriate support provided.*
0E	Healthy sexual behaviours.	*Engages in safe sexual practices or does not engage in sexual activity by choice. Ready access to sexual health screening services.*

F. Risky Behaviour / Routines

Presentations of behaviours that may be described as 'challenging' i.e. place the safety and wellbeing of the service user and / or others in jeopardy or which increase the likelihood of a person being excluded from ordinary community living, may increase the risk of poor health. Such behaviours include aggression, self injury, destructive behaviours and other difficult or disruptive behaviours (in some instances this latter category may include people who have rigid and fixed routines / habits of such intensity that they prevent the person from engaging in positive health behaviours). Clearly self injury carries such risks as may the defensive or restraining actions of others. Consequences of all behaviours include greater exposure to abuse, inappropriate treatments, social exclusion, deprivation and neglect; each of these can have significant additional negative impacts. People who present such behaviours may be at heightened risk of such behaviours being viewed as being inevitably associated with their learning disability rather than indicative of poor health. Some fixed routines mean that people are resistive to making lifestyle changes which promote improved health.

Impact Level & Indicator Statement		Descriptor
4E	Major health implications related to presentation of severe behavioural disturbance.	*The person presents behaviours which are of a frequency, severity or intensity that there is a high risk that unplanned hospital attendances will be required due to severe injury. Or the person's behaviours mean they have no access to usual health provision. Or the person's situation is such that they are exposed to abusive contingencies. The factors that predict the occurrence or, and maintain behaviours are unknown.*
3E	Behaviours / routines have significant impact on health status.	*The person presents behaviours for reasons which are poorly understood, which mean that they commonly require first aid or occasionally suffer more serious illness / injury which require medical attention. There may be occasional dramatic escalations in the severity / frequency of behaviours of concern. In an attempt to manage risks the person may be subjected to restrictive environment or hazardous treatments.*
2E	Limited impact of risky behaviours / routines on health.	*The person presents with a range of behaviours of concern. Causative factors have been partially assessed and are partly understood. Access to routine healthcare provision may be difficult to arrange or investigations not pursued as not felt justifiably to be in the person's best interests. The impact of behaviours is relatively stable and their frequency / severity is neither increasing nor reducing.*
1E	Behavioural presentation has minimal impact on health status.	*The person presents occasional hazardous behaviours or has some rigidity however these have been assessed and a package of proactive and reactive strategies agreed. These are consistently implemented and the outcomes of these strategies are closely monitored and regularly reviewed. The person has unimpaired access to the usual range of local health provision.*
0E	No presentation of risky behaviours / routines.	*The person does not present culturally abnormal behaviours which place themselves or others safety / wellbeing in serious jeopardy or risk the person being denied access to ordinary community facilities.*

5. Deficiencies in Service Quality and Access Indicators.

A. Organisational barriers

There are a wide range of organisational barriers to accessing healthcare and other services. Some services are scarce and there may be eligibility criteria preventing access. It is not always easy for people to physically access services e.g. they may be in a location that is far away and transport may be a problem. Services often do not understand / or recognise the need to make 'Reasonable Adjustments'. Generic health care staff often lack knowledge, skills and confidence, and on occasion, has negative attitudes in relation to caring for people who have learning disabilities. This can lead to 'diagnostic overshadowing'.

Impact Level & Indicator Statement		Descriptor
4A	Major restrictions in the quality of or access to services associated with organisational barriers completely preventing access.	*This level applies where there are major difficulties resulting from an organisation's complete lack of understanding and awareness about the nature of learning disabilities, there is a complete lack of recognition of diagnostic overshadowing and no evidence of reasonable adjustments. Services are refused or inaccessible, Treatment or intervention is withheld, delayed or inappropriate. There is no support to access or even register with services. There may be serious safeguarding concerns in relation to organisational barriers to services.*
3A	Significant restrictions in the quality of or access to services associated with organisational barriers.	*This level applies where there are significant difficulties resulting from an organisation's limited understanding and awareness about the nature of learning disabilities, There is poor recognition of diagnostic overshadowing and limited evidence of reasonable adjustments. Service provision is inadequate or difficult to access. There is very little support to access services Treatment or intervention is delayed. There is no training available.*
2A	Limited restrictions in the quality of or access to services associated with organisational barriers.	*This level applies where there are some difficulties associated with organisational barriers. The understanding and awareness of those providing support about the nature of learning disabilities, the recognition of diagnostic overshadowing and importance or reasonable adjustments is inconsistent. Some training or support will be in place, but services are inadequate or treatment or intervention may be delayed. There is limited support to access services.*
1A	Minimal restrictions in the quality of or access to services associated with organisational barriers.	*This level applies where there are minimal difficulties associated with organisational barriers. The organisation shows a good understanding and awareness about the nature of learning disabilities, the recognition of diagnostic overshadowing and importance or reasonable adjustments. Training is in place for staff, although this is not mandatory and some staff have not been trained leading to some inadequacy and inconsistency in service provision. There is some support to access services.*
0A	No identified restrictions in the quality of or access to services associated with organisational barriers.	*This level applies where there are no difficulties associated with organisational barriers. The organisation shows a good understanding and awareness about the nature of learning disabilities, the recognition of diagnostic overshadowing and importance or reasonable adjustments. Mandatory learning disability training is in place for staff. There is adequate support to access services.*

B. Consent

People with learning disabilities may or may not have capacity to give consent and capacity may vary. Sometimes professionals do not take the time to gain consent from the person with the learning disability, even if they may have capacity, consulting the person's carer or family member instead. Understanding of the mental capacity act or other appropriate national legislation can be limited and appropriate best interest processes are not always followed when making decisions for those who lack capacity. Training is not always available or accessed.

Impact Level & Indicator Statement		Descriptor
4B	Consent or best interest process not in place or not being implemented.	*This level applies where there are major difficulties resulting from unlawful practices in not assessing capacity gaining consent, or in not following appropriate best interest or deprivation of liberty (DoLS) processes.* *No training is in place.* *There may be serious safeguarding concerns in relation to consent.*
3B	Consent or best interest processes in place but being ignored or wrongly applied.	*This level applies where there are significant difficulties resulting from unlawful and / or inappropriate practices in not assessing capacity and gaining consent, or in not following appropriate best interest or deprivation of liberty (DoLS) processes.* *No training in place.*
2B	Consent and best interest processes in place and being applied but not consistently.	*This level applies where there are difficulties resulting from inconsistency in assessing capacity and gaining consent, or in following appropriate best interest or deprivation of liberty (DoLS) processes.* *Training is in place but is not mandatory.*
1B	Consent and best interest processes in place and generally being applied effectively.	*This level applies where there are minimal difficulties resulting from inconsistency in assessing capacity and gaining consent, or in following appropriate best interest or deprivation of liberty (DoLS) processes.* *Mandatory training is in place.*
0B	Consent and best interest processes are robust and rigorously applied.	*This level applies where there are no difficulties related to consent issues. There are good practices in place for assessing capacity and gaining consent, and in following appropriate best interest approaches or deprivation of liberty (DoLS) processes.* *Mandatory training is in place monitored and fully complied with.*

C. Transitions between services

Transition between services is often reported as problematic for some people with learning disability; this may for example include transition from children's services to adult or adult to older people's services, but equally could be transition between hospital services and home or community services, or transitions from one phase of education to another. Common problems include poor planning, variable and mismatched eligibility criteria, lack of clarity from professionals and poor co-ordination between services, together with low levels of satisfaction among family carers

Impact Level & Indicator Statement		Descriptor
4c	Complete breakdown in transition between services.	*This level applies where there are major difficulties resulting from poor practices in transition processes. There will be no named coordinator to enable transition and policies protocols will be non-existent or completely inadequate. This may result in no appropriate service or completely unsafe services being provided and serious delays in the effective transition of services. There may be serious safeguarding concerns in relation to transition between services.*
3c	Significant breakdown in transition between services.	*This level applies where there are significant difficulties resulting from poor practices in transition processes. There will be very little coordination available to support transition; policies protocols are inadequate, ineffective and require updating This results in unsafe or inadequate services being provided and significant delays in the effective transition of services.*
2c	Transition between services is delayed or disrupted.	*This level applies where there are limited difficulties resulting from poor practices in transition processes. There may be a named coordinator available to support transition but the role may not be effective; policies protocols require updating This may result in unsafe or inadequate services being provided and delays in the effective transition of services.*
1c	Transition between services is successful with additional support.	*This level applies where there are minimal difficulties resulting from transition processes. There will be a named coordinator available to support transition, policies/ protocols are current. Local services may have some limitations resulting in occasional delays in the effective transition of services requiring additional support.*
0c	Transition between services is successful with no additional support required.	*This level applies where there are no identified difficulties related to transition processes. There will be a named coordinator available to support transition, policies/ protocols are current. Local services are well placed to ensure smooth and effective transition pathways no additional support is required.*

D. Health screening / promotion

Access to health promotion may be significantly poorer for people with more severe learning disabilities and people with learning disabilities who do not use learning disability services. In particular people are less likely to access assessment for vision or hearing impairments; routine dental care; cervical smear tests undertake breast self-examinations or attend for mammography.

Sometimes care staff are not sufficiently trained and have limited skills to effectively engage people with learning disabilities in health promotion activities and many don't know important relevant information such as a person's family history.

Impact Level & Indicator Statement		Descriptor
4D	Major restrictions in the or quality of or access to health promotion / screening.	*This level applies where health screening / promotion programmes and activities are not available to meet identified needs. This may be because there is a lack of service provision or support or that access is being denied or withheld. Those providing support have no training and skills to promote and support good health. There may be serious safeguarding concerns in relation to health screening or health promotion.*
3D	Significant restrictions in the quality of or access to health promotion / screening.	*This level applies where some health screening / promotion programmes and activities are available but access or support may be restricted, delayed or not available. It is likely that no reasonable adjustments are in place. Those providing support have very little training or skills to promote and support good health. There may be areas of identified need that are not being met.*
2D	Limited restrictions in the quality of or access to health promotion / screening.	*This level applies where health screening / promotion programmes and activities are being provided but there are limitations in the scope of the service or support available and the degree or effectiveness of reasonable adjustments Those providing support have limited training and skills to promote and support good health.*
1D	Minimal restrictions in the quality of or access to health promotion / screening.	*This level applies where health screening / promotion programmes and activities are available to meet identified needs and are being accessed with minimal restrictions. There are some accessible materials, Those providing support have some training and skills to promote and support good health. Reasonable adjustments are negotiated and implemented.*
0D	No identified restrictions in the quality of or access to health screening / promotion.	*This level applies where there is full access and support to health screening / promotion programmes and activities. There are accessible materials, and person centred reasonable adjustments. Those providing support are adequately trained and skilled to promote and support good health.*

E. Primary / secondary care

People who have learning disabilities may access primary and secondary health care less frequently than the general population for screening, assessment, treatment and other interventions. Annual health checks including health screening should be conducted by primary care; and follow up and treatment provided appropriately to ensure health needs are met in a timely manner. All health services should be ensuring reasonable adjustments are made to enable access to the same health outcomes as would be expected for people who do not have learning disabilities.

Impact Level & Indicator Statement		Descriptor
4E	Major restrictions in the quality of / or access to primary / secondary care.	*This level applies where a primary / secondary care service is not available to meet identified needs. This may be because there is a lack of service provision locally or that access or support is being denied, or withheld.* *There may be serious safeguarding concerns in relation to primary or secondary health care services.*
3E	Significant restrictions in the quality of / or access to primary / secondary care.	*This level applies where some primary / secondary care service is available to meet identified needs but access or support may be restricted, delayed or not available locally. It is likely that no reasonable adjustments are in place.* *There may be areas of identified need that are not being met.*
2E	Limited restrictions in the quality of / or access to primary / secondary care.	*This level applies where a limited primary / secondary care service is available locally to meet identified needs and is being provided but there are limitations in the scope of the service or support available and the degree or effectiveness of reasonable adjustments.*
1E	Minimal restrictions in the quality of / or access to primary / secondary care.	*This level applies where a full high quality primary / secondary care service is available to meet identified needs and is being accessed with appropriate support and minimal restrictions.* *Reasonable adjustments are negotiated and implemented.*
0E	No identified restrictions in the quality of or access to primary / secondary care.	*This level applies where a full high quality primary / secondary care service is available to meet identified needs and is being accessed with no restrictions.* *Reasonable adjustments are in place and person centred.*

F. Non health Services

Wellbeing, health and quality of life are influenced by services other than health services including for example social care, education, employment, housing, transport and leisure services; this may be especially true for people with learning disabilities who may be regular users of these services.

All public services should be ensuring reasonable adjustments are made to enable access and equal outcomes as would be expected for people who do not have learning disabilities.

Impact Level & Indicator Statement		Descriptor
4E	Major restrictions in the quality of or access to non-health services.	*This level applies where a (non-health) service is not available to meet identified needs. This may be because there is a lack of service provision locally or that access or support is being denied or withheld.* *There may be serious safeguarding concerns in relation to non-health services.*
3E	Significant restrictions in the quality of or access to non-health services.	*This level applies where some (non-health) service is available to meet identified needs but access or support may be restricted, delayed or not available locally.* *It is likely that no reasonable adjustments are in place.* *There may be areas of identified need that are not being met.*
2E	Limited restrictions in the quality of or access to non-health services.	*This level applies where a limited (non-health) service is available locally and being provided to meet identified needs but there are limitations in the scope of the service or support available and the degree or effectiveness of reasonable adjustments.*
1E	Minimal restrictions in the quality of or access to non-health services.	*This level applies where a full high quality non-health service is available to meet identified needs and is being accessed as required with appropriate support and minimal restrictions.* *Reasonable adjustments are negotiated and implemented.*
0E	No identified restrictions in the quality of or access to non-health services.	*This level applies where a full high quality (non-health) service is available to meet identified needs and is being accessed as required with no restrictions.* *Reasonable adjustments are in place and person centred.*

The HEF Commissioning Guide

The Commissioning Guide

Improving the Health and Wellbeing of People with Learning Disabilities: Commissioning for health equality outcomes

A guide for commissioners of health and social care services for people with learning disabilities

Introduction

This guide explores the application of the Health Equalities Framework within commissioning. Commissioning for health equality outcomes is the responsibility of public health, social care and the NHS; data from the HEF can help commissioners to determine the impact and effectiveness of the services they are commissioning. This may be particularly useful in relation to specialist health services, where there has been a lack of evidence about outcomes. This guide places the HEF within the national commissioning context, and sets out other evidence and information sources that can be used to measure the impact of local services. Information on health inequalities is included, illustrating how the HEF can be applied in practice. The guide supports *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)*[17].

National commissioning context

The NHS and other public services should be focused on improving outcomes for those who use them. To support this ambition the Department of Health has published an inter-related series of outcomes frameworks:

- NHS: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700
- public health: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358
- social care: www.dh.gov.uk/health/2012/11/ascof1314/

NICE has drafted a Clinical Commissioning Group Outcomes Indicator Set, linked to the NHS outcomes framework: www.nice.org.uk/aboutnice/cof/cof.jsp

The frameworks contain little that is specific to people with learning disabilities, but the Department of Health has undertaken to see how data on people with learning disabilities could be extracted in order to check how the NHS is meeting its equality duties. Therefore in future it may be possible to compare data for people with learning disabilities against other population groups under each of the outcomes.

[17] http:/www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-based_Commissioning_Guide_for_Clinical_Commissioning_Groups

An NHS Commissioning Board objective is to: *ensure that CCGs work with Local Authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people* [18]. Measuring outcomes for people with learning disabilities will be particularly important to demonstrate improvements as commissioners implement the requirements of *Transforming Care*[19], whilst sustaining a focus on improving the general health of people with learning disabilities.

To support the implementation of the outcomes frameworks, national policy emphasises the importance of joint working between NHS commissioners (Clinical Commissioning Groups and the NHS Commissioning Board), Public Health and social care under the aegis of the local Health & Wellbeing Board:

- gathering and analysing information on population need through the Joint Strategic Needs Assessment (JSNA)
- developing and agreeing the Joint Health & Wellbeing Strategy (JHWS)
- taking a collaborative approach to investment in local services to deliver agreed priorities.

Information about people with learning disabilities should be included in the JSNA, to enable good joint service planning to take place. People with learning disabilities should be enabled to access mainstream services, and may need support to do this from specialist learning disability services. Historically there has been a lack of evidence about the contribution of specialist learning disability health services and the outcomes they achieve, particularly through their facilitating and supporting roles.

The purpose of specialist learning disability health services may be summarised briefly as [20]:

- To improve health, wellbeing and access to health care for people with learning disabilities, reducing health inequalities
- To help to remove or reduce the health barriers to independence, autonomy and citizenship for people with learning disabilities.

The roles required to deliver this purpose include:

- direct clinical and therapeutic interventions
- health promotion and health facilitation (supporting mainstream health services)
- teaching and support (families, social care and other services)
- service development (contributing their knowledge to planning processes).

[18] Department of Health (2012). *The NHS Mandate.*
[19] Department of Health (2013). *Transforming Care: A National Response to Winterbourne View Hospital. Department of Health Review. Final Report.*
[20] Department of Health (2007) *Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance, 2007*

For further information about commissioning specialist services, please refer to *Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs).*

Evidence about determinants of health inequalities

Commissioners will need good intelligence about the pattern of determinants of health inequalities in their local populations to inform JSNAs, decisions about investment in health care and their contributions to social care and public health outcomes.

NHS commissioners need to map determinants of health against NHS and other Outcomes Frameworks to ensure that the work of specialist learning disability health services is targeted to reducing health inequalities and thereby delivering NHS outcomes. (See the framework tool; pp 75-81).

Information gathered can be fed into the Equality Delivery System (EDS), which is designed to help NHS organisations improve equality performance, embed equality into mainstream NHS business and meet their duties under the Equalities Act. Intelligence from this framework will also be useful to inform completion of the annual Joint Health and Social Care Learning Disability Self Assessment (replacing the Health Self Assessment from April 2013).

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. There is clear evidence that annual health checks identify unmet health need, and lead to actions to address these needs. Therefore they are an important* ***reasonable adjustment*** *for reducing health inequalities. The commissioner included this information in the JSNA, and commissioned 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 demonstrate how their interventions were improving* ***access to primary care services*** *and health checks for people with learning disabilities. The information was used by the commissioner to demonstrate the impact the team were having, along with improved health check numbers the following year.*

Health inequalities and people with learning disabilities

People with learning disabilities have poorer health than their non-disabled peers. These differences in health status are to an extent avoidable, and as such represent health inequalities.

There are five key determinants of health inequalities[21]:

1. Exposure to social determinants of poorer health, such as poverty, poor housing, unemployment and social disconnectedness.
2. Physical and mental health problems associated with specific genetic and biological conditions in learning disabilities.
3. Communication difficulties and reduced health literacy.

[21] The full evidence is given in the HEF guide, pp.18-25

4. Personal health behaviour and lifestyle risks such as diet, sexual health and exercise.
5. Deficiencies in access to and the quality of healthcare and other service provision.

The following sections include case studies that illustrate some of the ways that learning disability services work with people with learning disabilities to reduce health inequalities. Work on one determinant of health inequalities often has a positive impact on other 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. The JSNA should include good information about the local population of people with learning disabilities.

This determinant also has the potential to be a good indicator of effective joint health and social care team working. For example, the Report of the NHS Review of commissioning of care and treatment at Winterbourne View (NHS South of England, 2012) found no examples of comprehensive health and social care policies on how best to respond to patient needs and prevent continued escalation. Good joint working has the potential to reduce the likelihood of people ending up in accommodation such as Winterbourne View; the HEF can be used to inform a dialogue between health and social care about priorities and ways of working.

Case study

John was referred to the intensive response team because of high levels of aggression and self-injury. He had a history of failed placements, and admissions to assessment and treatment services. His current placement was breaking down.

The multi-disciplinary assessment noted that there had been a recent change of staff team. John was autistic and needed clear and consistent communication. This was not happening. The health team worked with social services on developing a ***stable environment and home*** *for John using a personal budget. They worked with John's support staff to* ***adjust their communication*** *to meet his needs. John is now much calmer, and is now being supported to use community facilities, including the local gym, which has reduced his* ***social isolation****.*

Physical and mental 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 provide direct support to people with learning disabilities and their families when their needs cannot be met by mainstream services alone. This includes detailed

assessment and formulation of needs, which can help develop an understanding of 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.

In addition, specialist health staff can ensure that the specific health needs of individuals with learning disabilities are understood and responded to in mainstream healthcare.

Health staff also have a role in enabling 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.

Case study

Jean has Prader-Willi syndrome and lives in a small residential home. She was referred to the team by the GP as she was becoming dangerously obese. When the team assessed Jean they realised that, although the staff had been given guidance on how to manage her diet, some staff did not understand the full implications of Jean's condition, and thought that she should be able to choose what she ate. The inconsistent approach was also leading to behaviour problems as Jean could not understand why her access to food varied. The team worked with the residential staff group to enable them ***all to understand the implications of Jean's syndrome****, and put in place an* ***effective plan*** *to* ***modify the environment****, manage Jean's diet and* ***improve her quality of life****.*

Communication difficulties and reduced health literacy

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.

Case study

A GP requested support from the community team with Marcella, a patient with a five year history of vaginal bleeding, who had refused investigation. The team worked with Marcella and her partner ***to develop an understanding of their needs, and used a range of accessible information to help them understand the health issues involved, and the treatment proposed.*** *They also worked with the acute liaison nurse to implement* ***reasonable adjustments*** *prior to the proposed procedure. This included developing the understanding of hospital staff regarding working with people with a learning disability,* ***enabling better access to services****.*

Following a successful surgical intervention, there were a number of other physical, social and emotional benefits. Marcella has subsequently lost three stone in weight since referral, ***reducing her risk of developing other health problems****. Marcella has been on holiday four times since the operation (something that she had not done for 5 years due to fear of poor bladder control), which has reduced her* ***social isolation****.*

Personal health behaviour and lifestyle risks such as diet, sexual health and exercise

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.

This determinant also covers the risks to health that may be posed by behaviour, such as challenging behaviour or offending behaviour.

Specialist staff support people with learning disabilities to understand the relationship between health, lifestyle and behaviour, and 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.

Case study

Raju, a 35 year old man, was referred to the team after a diagnosis of mouth cancer. Owing to Raju's history of alcohol abuse and self-neglect, the family have struggled to obtain appropriate treatment and support for him.

The team carried out desensitisation work and ***enabled Raju's understanding*** *of the proposed procedure through use of a DVD that explains radiotherapy in an appropriate manner.*

Following successful treatment for cancer, Raju has been ***enabled to take more control over his own health*** *and consequently his life****, maintaining a healthier lifestyle*** *by not drinking alcohol for 2 years. Subsequently Raju contributed to the development of a DVD about how it was for him and his mother to receive 'bad news' and he felt* ***empowered to tell his story*** *through the support he received.*

Deficiencies in access to and the quality of healthcare and other service provision

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.

Case study

A practice nurse was unable to contact Sharifa regarding her cervical screening appointment. The health facilitator managed to make the necessary ***contact with Sharifa through use of easy read information.***

The practice arranged a ***double appointment time for Sharifa to visit.*** *Sharifa attended with the health facilitator and a friend. During the appointment Sharifa decided that she would like to have the procedure there and then.*

Sharifa and the practice staff both indicated that ***in the future they would feel more confident*** *at undertaking such appointments.*

Introducing the Health Equalities Framework

The Health Equalities Framework (HEF) is an Outcomes Framework based on the determinants of health inequalities for people with learning disabilities, as described above. It is designed to measure the impact of interventions on reducing exposure to the known determinants of health inequalities. It is not an eligibility tool or a needs assessment. It was developed by the consultant nurse group, but can be used by all specialist services for people with learning disabilities.

The HEF uses five-point (Likert) impact scales, alongside Indicators for each determinant in order to profile the impact of each determinant on any given person with learning disabilities. High scores indicate a significant detrimental impact of exposure to the determinants, whilst low scores indicate minimal impact. The central role of learning disability services is seen as tackling the impact of exposure to the determinants of health inequalities, which can be demonstrated through individual and population HEF profiles.

The HEF rates the *consequence* of exposure to determinants of health inequalities for individuals, rather than merely profiling the complexity of a person’s needs, specific conditions or presentations. People with learning disabilities are much more likely to have medical conditions, require more hospital care and are more likely to suffer premature death than the general population. Rather than focusing on individual diagnoses, the intention is to ensure that long-term conditions and needs are identified and that individuals are receiving appropriate support. For example, someone with complex epilepsy or severe challenging behaviour receiving a good level of care and support in appropriate accommodation may score lower than someone else with a less complex presentation whose needs are being less well met. It is also feasible for an individual’s health to deteriorate but for outcome scores to improve (as a result of being in receipt of good quality palliative care, for example). The approach aims to quantify the success

of interventions in reducing the impact of these known determinants and therefore demonstrate reduced probability of exposure to health inequalities.

Each determinant consists of a number of health inequality indicator statements; these indicators have been drawn from a body of evidence [22] and have been further validated through a process of consultation with the learning disability leads from each of the relevant Professional Bodies, the National Valuing Families Forum and local groups of people with learning disabilities. These indicators are considered in turn to determine the indicative level of impact of each indicator within each determinant. For example, within social determinants, accommodation status is a key indicator:

- Being homeless or in hospital with no agreed discharge destination is viewed as having a major impact on health and therefore scores the maximum of 4.
- However, being in appropriate, settled accommodation that reflects personal choice, or is the result of a 'best interests' decision making process, is viewed as having no negative impact on health and so scores the minimum of 0.

Each indicator statement within each of the determinants is identifiable which enables a personal HEF profile to be developed for each individual. People with learning disabilities and their families can initiate the process themselves; where a practitioner or multi-disciplinary team does so, they will involve the individual and their family wherever possible and appropriate, in order to rate each determinant area both prior to and after any intervention, giving an indication of the impact the intervention has had on reducing health inequalities. An electronic template (eHEF) has been designed to enable a team to record this information easily, and enable data to be aggregated to monitor health equality impact and for commissioning purposes.

A template Commissioning for Quality and Innovation (CQUIN) payment framework can be found at the end of the commissioning guide, and is designed to support commissioners with implementation. CQUINs enable commissioners to link a proportion of English healthcare providers' income to the achievement of local quality improvement goals.

[22] Emerson, Baines, Allerton and Welsh (2011). *Health Inequalities and People with Learning Disabilities in the UK 2011.*Improving Health and Lives Public Health Observatory.

Illustrative example - using the HEF

Eileen has mild learning disabilities and was admitted to an assessment and treatment unit one year ago with paranoid delusions and depression. She was malnourished and had been neglecting herself and her accommodation. Since being admitted, her illness has been treated and she is now ready for discharge on a section 117, but, as she lost her tenancy, she is homeless. The community team has therefore scored her 4 on the HEF for accommodation under determinant 1. Health and social care commissioners need to ***work together to agree a support package and accommodation****. They need to find housing and a support provider who can meet Eileen's needs. A flat is found for Eileen, and she is visited regularly by the community team who* ***monitor her mental health and check she is taking her medication****. Although she is now in settled accommodation, she has little in the way of meaningful activity. In addition, the community team has become aware that Eileen is vulnerable to sexual and physical abuse as she is regularly engaging in sexual activity with strangers. Therefore, although she now scores a 2 for accommodation, she scores a 3 for sexual health. Her HEF profile shows the changing balance of risks against each indicator under every determinant and helps to inform discussions with Eileen. The team continue to work with Eileen to help her* ***understand the impact of her lifestyle****.*

Conclusion

The HEF offers people with learning disabilities and family carers a way of measuring health equality outcomes and tracking the impact of actions aimed at reducing health inequalities. The development of a personal profile helps everyone to have a shared understanding of which determinants of health inequalities are having an impact on an individual at any point in time. The HEF gives practitioners and service managers a valuable tool to demonstrate the impact of their work across the range of roles that specialist learning disability services should fulfil. Using the determinants of health inequalities approach also offers commissioners a way of linking population need to the service activity to be commissioned and the outcomes to be measured.

Draft CQUIN for implementation of the Health Equality Framework for services to people with learning disabilities

CQUIN Table 1: Summary of goals

Goal Number	Goal Name	Description of Goal	Goal weighting (% of CQUIN scheme available)	Expected financial value of Goal (£)	Quality Domain (Safety, Effectiveness, Patient Experience or Innovation)
	Health Equality Framework: outcome measurement for services to people with learning disabilities	To implement use of the Health Equality Framework, capturing how interventions have resulted in improvements for the target group agreed for initial implementation [specify, e.g. 5 referrals from each clinician during Q2]			Safety; effectiveness; patient experience

CQUIN Table 2: Summary of indicators

Goal Number	Indicator Number	Indicator Name	Indicator Weighting (% of CQUIN scheme available)	Expected financial value of Indicator (£)
	1			
		Totals:	100.00%	

CQUIN Table 3: Detail of indicator (to be completed for each indicator)

Indicator number	1
Indicator name	Health Equality Framework: outcome measurement for services to people with learning disabilities
Indicator weighting (% of CQUIN scheme available)	
Description of indicator	To implement use of the Health Equality Framework, using it to capture salient outcome measures for people with learning disabilities using the service. The tool will be implemented in phases to allow for training to be completed and any necessary systems put in place. ***Q1 Familiarisation and training*** Introduce the tool to the staff who will be using it. Discuss data capture with these staff and with information systems colleagues; agree on a system. Agree a sampling approach with commissioners to build up coverage over the year [e.g. one team to start in Q2, another in Q3, etc]. ***Q2 Implementation*** Implement the tool in the phased approach agreed. Carry out initial baseline scoring. ***Q3 Relate to practice*** Report on baseline scores and agree on a sampling frame for audit. Audit of 20% of care records of the initial group to show how outcomes are being built in. ***Q4 Assess progress*** Reassess the initial group, score and evidence outcomes. Report on reassessments compared to baseline figures to evidence changes in scores and relate these (where relevant) to the impact of the interventions offered to date. Report on roll-out agreed in Q1.
Numerator	
Denominator	

Rationale for inclusion	There have not previously been adequate outcome measures to demonstrate the impact of service interventions on the health and wellbeing of people with learning disabilities. The Health Equality Framework (HEF) has been developed to fill this gap. It is based on the five determinants of health inequalities set out by the Public Health Observatory for learning disabilities and can be linked firmly to the NHS, Public Health and Social Care Outcomes Frameworks. The HEF enables services to demonstrate the impact of interventions on individuals. Individual outcomes can also be collated to demonstrate impact on priorities for the population.
Data source	Reports on progress against the plan agreed in Q1 Change against individual baseline scores
Frequency of data collection	Quarterly
Organisation responsible for data collection	
Frequency of reporting to commissioner	Quarterly
Baseline period/date	
Baseline value	
Final indicator period/date (on which payment is based)	March 20xx
Final indicator value (payment threshold)	
Rules for calculation of payment due at final indicator period/date (including evidence to be supplied to commissioner)	At end of Q3 Report on baseline scores and agree on a sampling frame for audit. Audit of 20% of care records of the initial group to show how outcomes are being built in.
Final indicator reporting date	April 20xx
Are there rules for any agreed in-year milestones that result in payment? (see Table 4 below)**?**	Yes
Are there any rules for partial achievement of the indicator at the final indicator period/date? (see Table 5 below)	Yes

CQUIN Table 4: Milestones (only to be completed for indicators that contain in-year milestones)

Goal No.	Indicator No.	Date/period milestone relates to	Rules for achievement of milestones (including evidence to be supplied to Commissioner)	Date milestone to be reported	Milestone weighting (% of CQUIN scheme available)
	1	Q1	Introduce the tool to the staff. Agree on a data capture system. Agree a sampling approach with commissioners.	July 20xx	50%
	1	Q2	Implement the tool in the phased approach agreed. Report on initial baseline scores.	September 20xx	15%
	1	Q3	Audit of care records to show outcomes built in.	December 20xx	20%
	1	Q4	Report on reassessments compared to baseline figure to evidence improvements in scores. Report on roll-out.	March 20xx	15%
				Total:	100%

CQUIN Table 5: Rules for partial achievement at final indicator period/date (only complete if the indicator has rules for partial achievement at final indicator period/date)

Goal No.	Indicator No.	Final indicator value for the part achievement threshold	% of CQUIN scheme available for meeting final indicator value

CQUIN Table 6: Maximum aggregate CQUIN Payment

Contract Year	Maximum aggregate CQUIN Payment
2013/14	2.5% of Actual Annual Value
Subsequent years	To be determined nationally and inserted locally

CQUIN Table 7: **CQUIN Payments on Account**

Commissioner	Payment	Frequency/Timing	Agreed provisions for adjustment of Payments on CQUIN Account based on performance

A framework for identifying evidence based commissioning intentions and service priorities

A framework for identifying evidence based commissioning intentions and service priorities

How to use this tool

This tool can be used by commissioners to summarise evidence of health inequalities locally, priorities for action, plans to reduce health inequalities, and evidence of change. It is not designed to capture detailed information, but to provide an overview.

Column 1 – lists the determinants of health inequalities

Column 2 – describes the National Outcome Framework domains relating to each determinant (NHS, Public Health and the Adult Social Care Outcomes Framework)

Column 3 – having considered the determinants of health inequalities, and how these relate to the National Outcome Frameworks – this column is for local services to add sources of evidence of health inequalities in the local population. It may be helpful to categorise this information into evidence that provides:

- **Numbers** (for example: IHaL health profiles, which include numbers of people known to GPs and numbers of people who have had health checks);
- **Objective outcome indicators** (for example: HEF data analysis)
- **Subjective outcome indicators** (for example: results of Patient Reported Outcome Measures – PROMS)
- **Individual stories**

Some examples are given in the template provided.

Column 4 – having considered the evidence, including the HEF profile, this column is for summarising priority outcomes relating to the health inequalities identified.

Column 5 – a summary of local plans to tackle the determinants of health inequalities should be added to this column.

Column 6 – this column should be used initially for noting sources of evidence that might help determine whether changes have taken place, and can be used in the longer term to track impacts on the determinants of health inequalities. The information can be categorised as for column 3.

Outcomes framework for commissioning improved health equalities for people with learning disabilities

Determinants of health inequalities	Related National Outcome Framework domains	Where to find evidence of health inequalities in population	Priority outcome (examples)	Plans to reduce health inequalities (examples of what services can do)	Evidence of change (examples of measures)
Social determinants: • Accommodation • Employment & activities • Financial support • Social contact • Additional marginalising factors (e.g. ethnicity) • Safeguarding	**Public Health** 1. Improving the wider determinants of health **NHS** 2. Enhancing quality of life for people with long term conditions (2.2) Improving functional ability (including employment) **ASCOF** 1. (1.E) Proportion of adults with LD in employment (1.G) Proportion of adults who live in their own home or with their family 4. Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm	**Numbers** IHaL health profiles **Objective outcome indicators** JSNA SAF SAAF LDPB reports HEF	e.g. Supporting more people into work. e.g. Reducing hate crime.	e.g. Occupational therapist works with an individual enabling them to use the bus so that they can get to work. e.g. Team members work with the police, self-advocacy group and family carers' group on staying safe and reporting abuse or hate crime.	**Numbers** Number of people with learning disabilities in work. Number of people who live in their own home. Number of reports of hate crime. Number of safeguarding alerts. **Objective outcome indicators** SAF C1, C3, C4, C5, C7, C8, C11 HEF data **Subjective outcome indicators** Questionnaires **Individual stories.**

Determinants of health inequalities	Related National Outcome Framework domains	Where to find evidence of health inequalities in population	Priority outcome (examples)	Plans to reduce health inequalities (examples of what services can do)	Evidence of change (examples of measures)
Genetic and biological determinants: • Assessment of health needs • LTC pathways, review of health needs • Care plans, HAPs • Crisis plans, hospital passports • Medication • Availability of specialist services	**NHS** 2. Enhancing quality of life for people with long term conditions **Public health** 4. Preventing premature mortality	**Numbers** QOF data SAF **Objective outcome indicators** JSNA LDPB report HEF	e.g. Supporting providers to recognise and respond to the health needs of people with autism, thus enabling them to live successfully in the community. e.g. Supporting people with Down syndrome to have regular thyroid function tests	e.g. The intensive response team develops a multidisciplinary training and support package. e.g. Nurses support GPs to provide regular tests and source easy read materials about thyroid problems.	**Numbers** Number of people with Down Syndrome on QOF register. Number of people with Down Syndrome who have had thyroid function tests. Number of people with autism known to local services. Data on number of people out of area (new placements and plans for resettlement) Number of health checks/health action plans/hospital passports **Objective outcome indicators.** HEF data Audits **Subjective outcome indicators** PROMs **Individual stories**

Determinants of health inequalities	Related National Outcome Framework domains	Where to find evidence of health inequalities in population	Priority outcome (examples)	Plans to reduce health inequalities (examples of what services can do)	Evidence of change (examples of measures)
Communication and health literacy: • Body and pain awareness • Communication of health needs • Recognition by others of pain • Recognition of health needs and response by others • Understanding health information, making choices	**Public health** 2. Health improvement (people are helped to live healthy lifestyles, make healthy choices and reduce health inequalities) **NHS** 2. Enhancing quality of life for people with long term conditions (2.1) Ensuring people feel supported to manage their condition	**Numbers** QOF data **Objective outcome indicators** HEF	e.g. Hospital staff need to know when people with learning disabilities are in pain and unable to communicate this. e.g. Women with learning disabilities need support to understand what happens when they attend breast screening, and why this is important.	e.g. Acute liaison nurse provides training and support to hospital staff regarding use of a pain recognition tool. e.g. The team develop a photo journey for breast screening in their local area, and a DVD to help women understand what happens.	**Numbers** **Objective outcome indicators** HEF data Take-up of screening Audit of available easy read information and tools such as hospital passports/pain recognition documents **Subjective outcome indicators** Patient/carer satisfaction surveys **Individual stories**

Determinants of health inequalities	Related National Outcome Framework domains	Where to find evidence of health inequalities in population	Priority outcome (examples)	Plans to reduce health inequalities (examples of what services can do)	Evidence of change (examples of measures)
Behaviour and lifestyle: • Diet • Exercise • Weight • Substance use • Sexual health • Risky behaviours	**Public health** 2. Health improvement (people are helped to live healthy lifestyles, make healthy choices and reduce health inequalities) **NHS** 1. Preventing people from dying prematurely (1.7) Reducing premature death in people with learning disabilities	**Numbers** QOF data **Objective outcome indicators** JSNA LDPB report HEF	e.g. Improved skills of supported living staff regarding diet/exercise and informed choice. e.g. Improved inclusion in substance misuse programmes.	e.g. The team work with support staff on balancing risk and choice, and the physiotherapist and dietician work with the provider on an exercise and healthy diet plan. e.g. The nurse and psychologist work with the CARATS team in prison to identify prisoners with learning disabilities and offer reasonable adjustments so they can access treatment programmes	**Numbers** Number of people with learning disabilities who have type 2 diabetes. Number of people who are obese. Number of people accessing health promotion opportunities. **Objective outcome indicators** HEF data Audit of PCPs/HAPs **Subjective outcome indicators** Feedback from providers. Training evaluations **Individual stories**

Determinants of health inequalities	Related National Outcome Framework domains	Where to find evidence of health inequalities in population	Priority outcome (examples)	Plans to reduce health inequalities (examples of what services can do)	Evidence of change (examples of measures)
Deficiencies in access to and the quality of healthcare and other service provision • Organisational barriers • Consent • Transitions • Health screening/ promotion • Primary and secondary health services • Other services	**NHS** 1. Preventing people from dying prematurely (1.7) Reducing premature death in people with learning disabilities 4. Ensuring people have a positive experience of care 5. Treating and caring for people in a safe environment and protecting them from avoidable harm. **ASCOF** 2. Delaying and reducing the need for support. **Public health** 2. Health improvement (people are helped to live healthy lifestyles, make healthy choices and reduce health inequalities)	**Numbers** QOF data HES data DES IHaL health profiles Data re screening uptake compared to general population. **Objective outcome indicators** SAF HEF Audits	e.g. Identifying people at risk of not having health checks/serious health problems being unnoticed – so that no-one presents with late stage life threatening conditions. e.g. Identifying people at risk through: • Epilepsy • Dysphagia • Body shape distortion so that no-one known to services dies of these conditions.	e.g. Ensure registers are up-to-date and links made with other QOF registers. Support the implementation of health checks e.g. Acute liaison to mitigate risks in hospital e.g. Specialist skills in epilepsy, dysphagia and postural care to: • Co-work with primary/ secondary care. • Support families/ providers • Provide direct interventions.	**Numbers** Number of people with learning disabilities registered with GPs, and cross referencing between registers. Number of people with health checks. Number of people who have accessed health screening **Objective outcome indicators** SAF A1-A8, A10 Audits **Subjective outcome indicators** PROMS **Individual stories** Case studies

The eHEF User Manual

eHEF User Manual

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Introduction

eHEF has been designed to support the Health Equality Framework. It is a Microsoft Excel-based tool that has been designed to be portable and run on most systems. eHEF runs on Excel versions 2003 and above and Excel for MAC.

System Requirements

- Hardware: PC or MAC
- Software: Microsoft Excel 2003 or later
- Screen Resolution: 1280 pixels wide or higher

Security

You must be aware of your organisation's data security, data protection and other relevant policies that might relate to your use of eHEF. In particular, you should be aware that it is not advisable to email eHEF to anyone without due consideration for the security of the data contained within it.

Note: you should remember to SAVE eHEF after adding or editing any data. Depending on you Excel version/settings it may AutoSave. You are advised to check this or just SAVE as you go to be sure.

Support

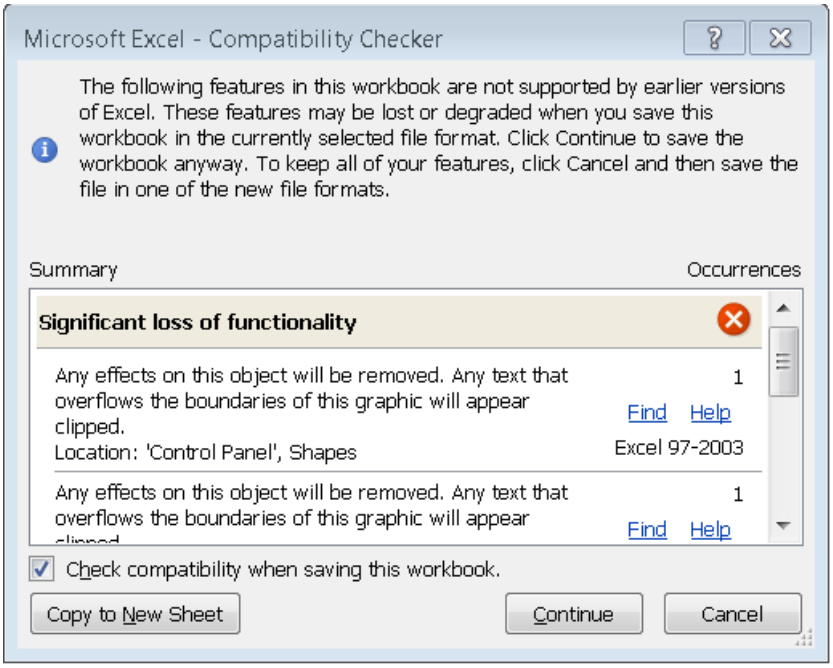
eHEF is designed to be simple to use. However, if you need support and the answer to your question isn't in this manual then please email ehef.assistant@gmail.com.

Storage/Saving

Single User: If you are working alone then you should simply store eHEF in a convenient location on your computer. The default file name is just eHEF.xls. You are free to change this if you wish but it is recommended you keep the first part of the filename intact. So, you may choose to name yours eHEF – Jane.xls (if you are called Jane)

Multi User: If you work within a team where others are also running eHEF then it is recommended you store all copies on the same shared network location. This is to facilitate data aggregation which is managed by eHEF Manager, a separate tool. eHEF Manager has its own user manual. In this scenario it will be essential that file names are unique and that you can easily identify your copy of eHEF in the shared folder. A suggested convention might be the use of your first and last initials with the date of your birthday. Example, if your name is Simon Hughes and your birthday is on 5th September, you would call your file eHEF – SH0509.xls. It is essential that you keep the first part of the file name intact for eHEF Manager to be able to identify it and capture data from it for analysis.

Compatibility Warning: Because eHEF is designed to run on most versions of Excel you will sometimes (depending on your version) get a compatibility warning when saving. You can simply click 'Continue' and you may wish to clear the 'Check Compatibility' box for this file so you shouldn't be bothered by the warning again. None of eHEF's features will be compromised by keeping the file in its original format/version



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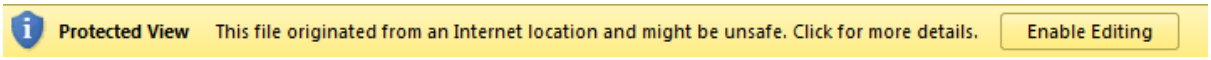
Opening eHEF:

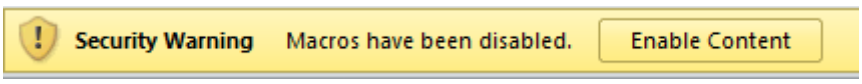
Once you have received your copy of eHEF and stored it with an appropriate name you will want to go ahead and start using it! Open eHEF as you'd open any other file (usually a double-click).

You *may* receive a message prompting you to 'Enable Editing' to which you should agree.

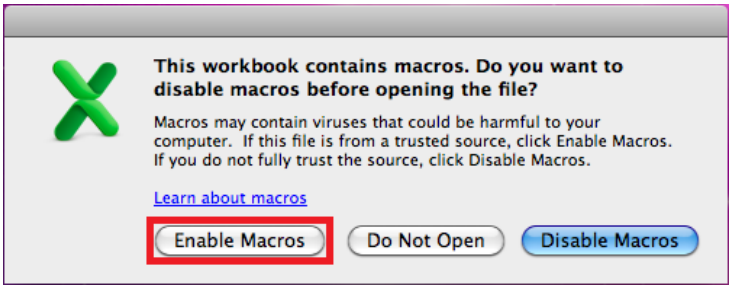


If you've stored eHEF as recommended above you shouldn't receive this message.

Next you'll need to 'Enable Macros'. The prompt for this action looks different according to your version of Excel and your security settings. Here is the Excel 2010 version of the prompt.

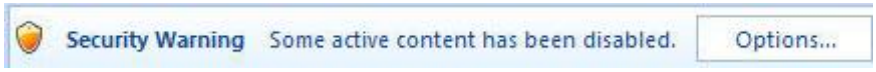


If you are using a mac version of Excel, you will see this prompt and simply click 'Enable Macros'.



If you are using Excel 2003, you will see this prompt and need to click ‘Enable Macros’.

If you have a copy of Excel 2007, you will see this message and you will need to click ‘Options…’ then ‘Enable This Content’ and then click OK.



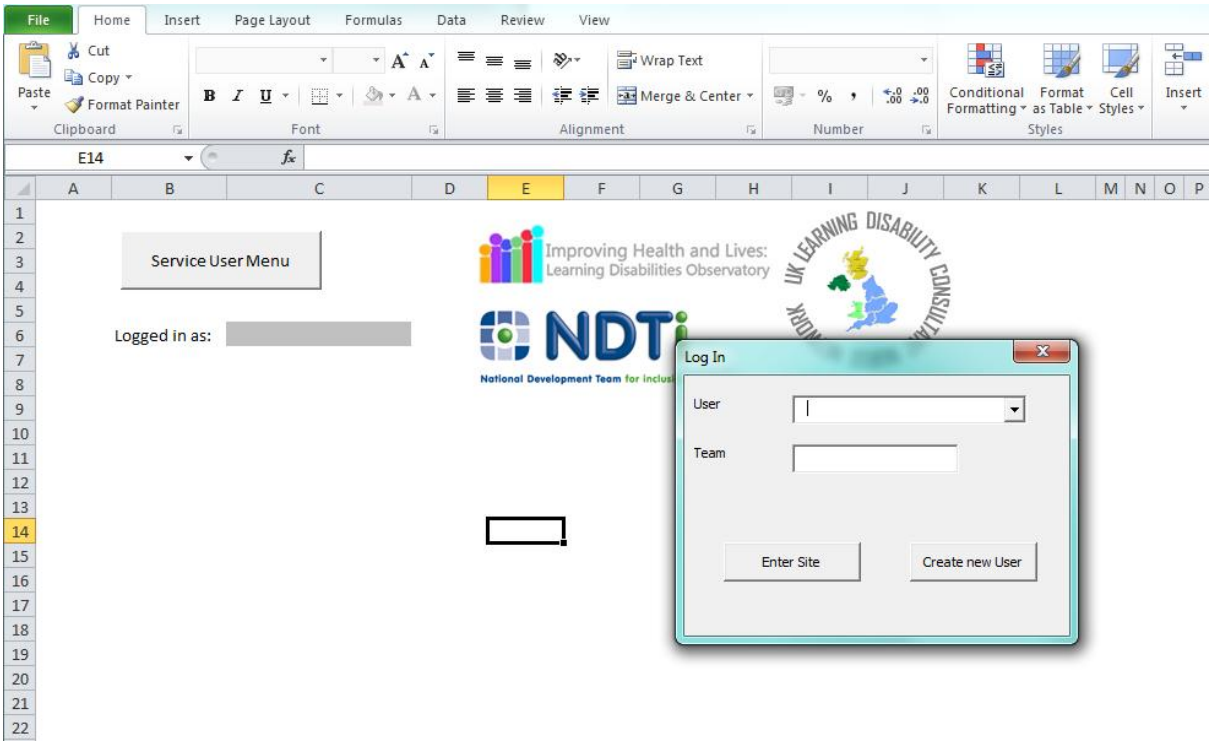
If you see this message instead, click ‘Enable Macros’

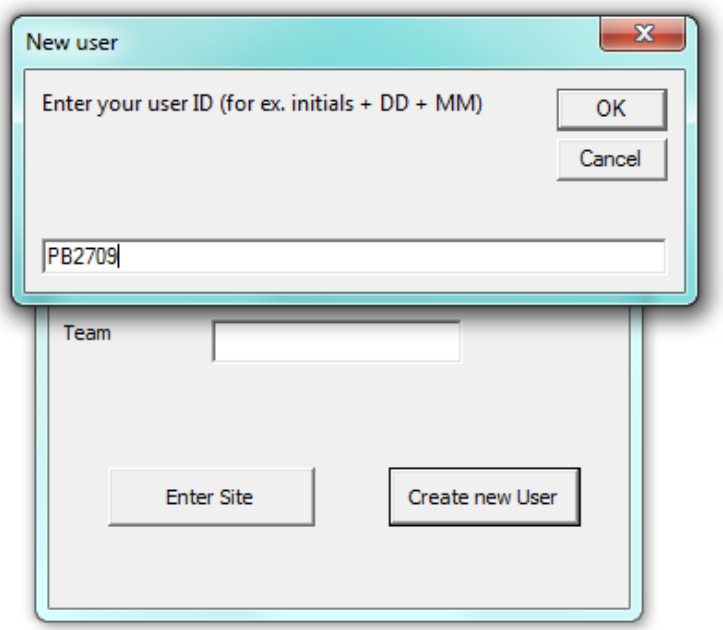
Microsoft Office Excel Security Notice
Microsoft Office has identified a potential security concern.
Warning: It is not possible to determine that this content came from a trustworthy source. You should leave this content disabled unless the content provides critical functionality and you trust its source.
File Path: D:\...ts\A.Net\ExcelMeetManager\NewEMM\Cross-Country\27.xls
Macros have been disabled. Macros might contain viruses or other security hazards. Do not enable this content unless you trust the source of this file.
More information
Enable Macros
Disable Macros

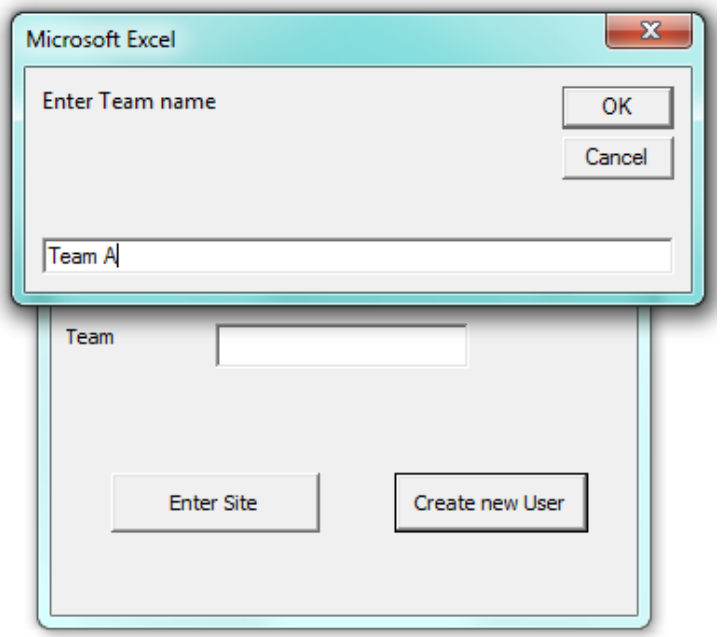
Creating a User ID:

First time you use eHEF you will need to create your username. To do this:

1) Click 'Create new User'
2) Enter your chosen user ID. It is recommended you follow the convention (mentioned in the Storage section above) of using your first and last initials with the date of your birthday. For example, if your name is Peter Brown and your birthday is on 27th of September, your username would be PB2709.
3) Click 'Ok'
4) Next you are prompted for your Team Name. If you are a single user you can leave this blank. In a multi user environment please consult with colleagues to agree a suitable (short) team name. This will be important for the eHEF Manager tool which has the ability to group data by team name.

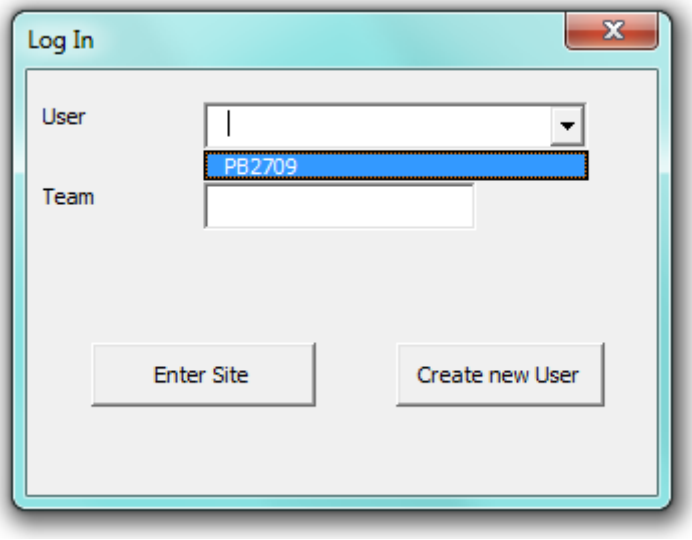


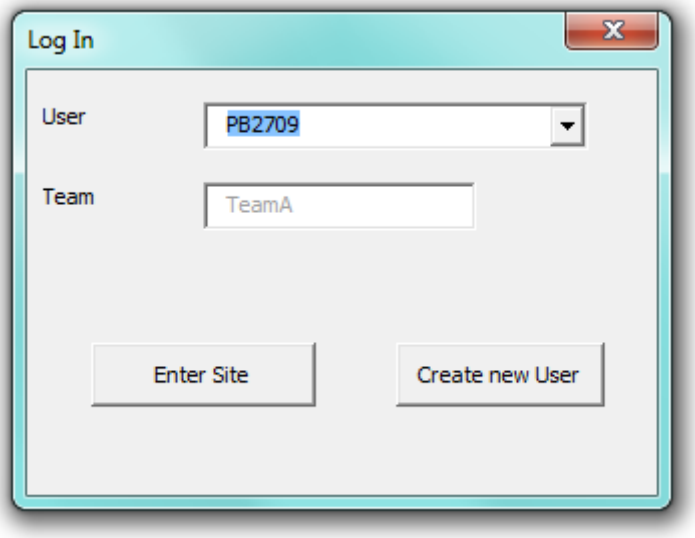

New user
Enter your user ID (for ex. initials + DD + MM)
OK
Cancel
PB2709
Team
Enter Site
Create new User


Microsoft Excel
Enter Team name
OK
Cancel
Team A
Team
Enter Site
Create new User

Logging in with as an existing User ID:

Once you've created your username in eHEF you can log in simply by selecting the appropriate name from the drop-down list. Usually there'll only be one name here but in some scenarios users may wish to share a copy of eHEF with colleagues.





Note about activity logging:

eHEF has a simple logging feature that keeps track of any significant activity. The following actions are logged:

1) New individual added
2) Individual's details edited
3) New HEF score added
4) HEF score edited

Adding a new individual:

To add a new individual to eHEF follow these steps.

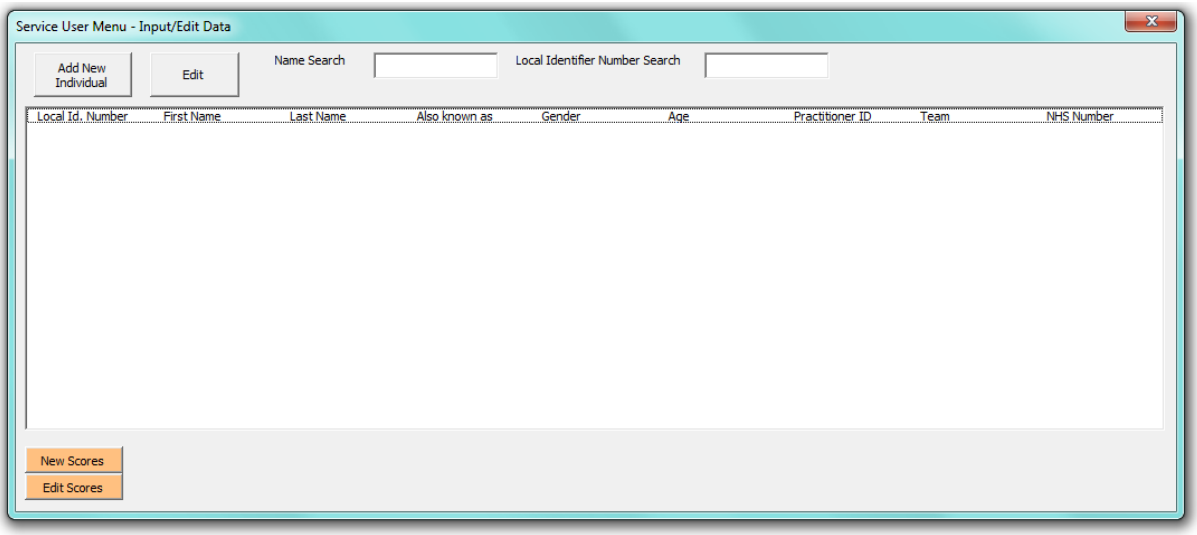
1) Click the 'Input/Edit Data' button on the home screen.
2) Click 'Add New Individual'
3) Complete the individual's details
4) Click 'Save' and then confirm submission. You'll receive a prompt that the record has been saved

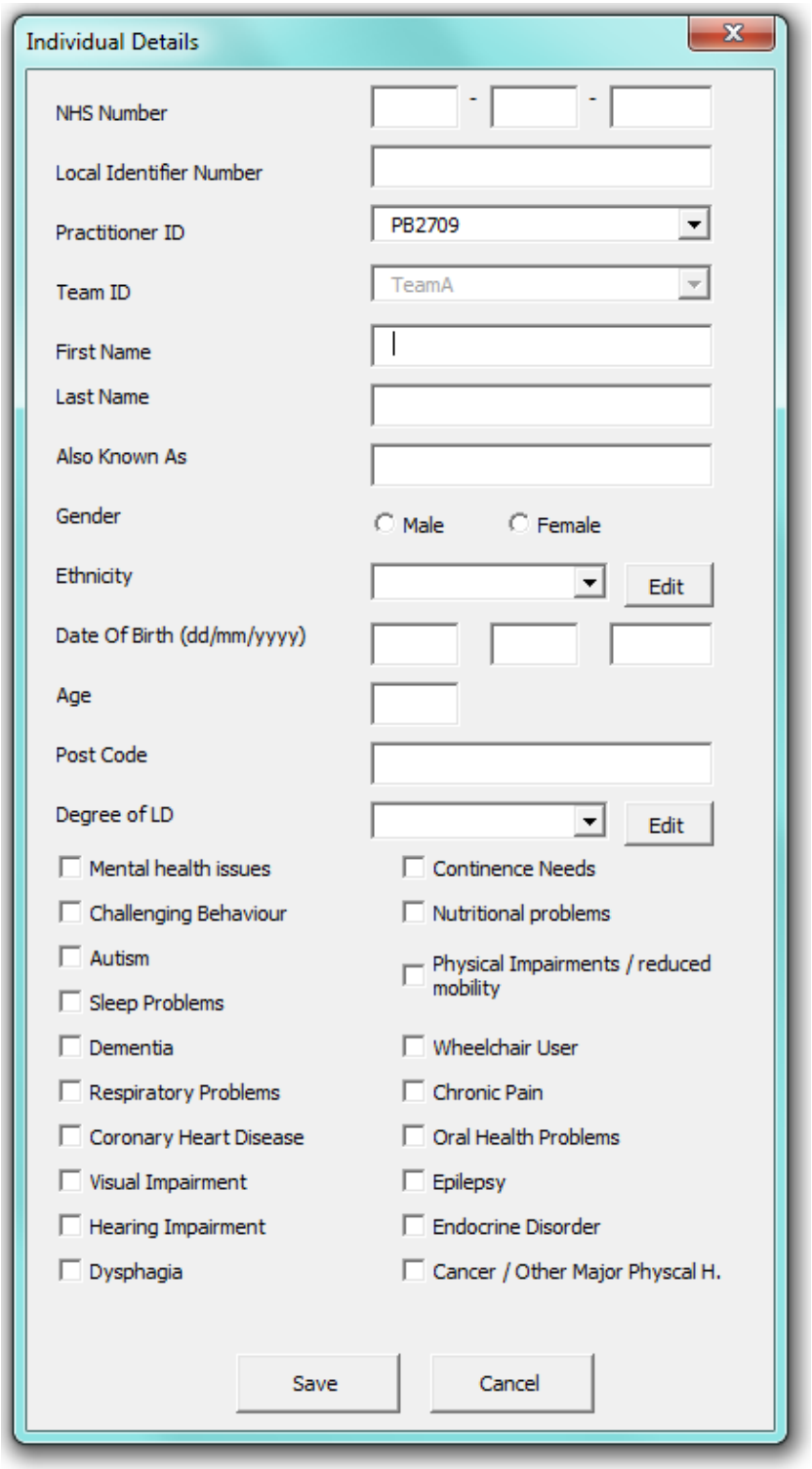
Required Fields: The fields in the table below are required fields.

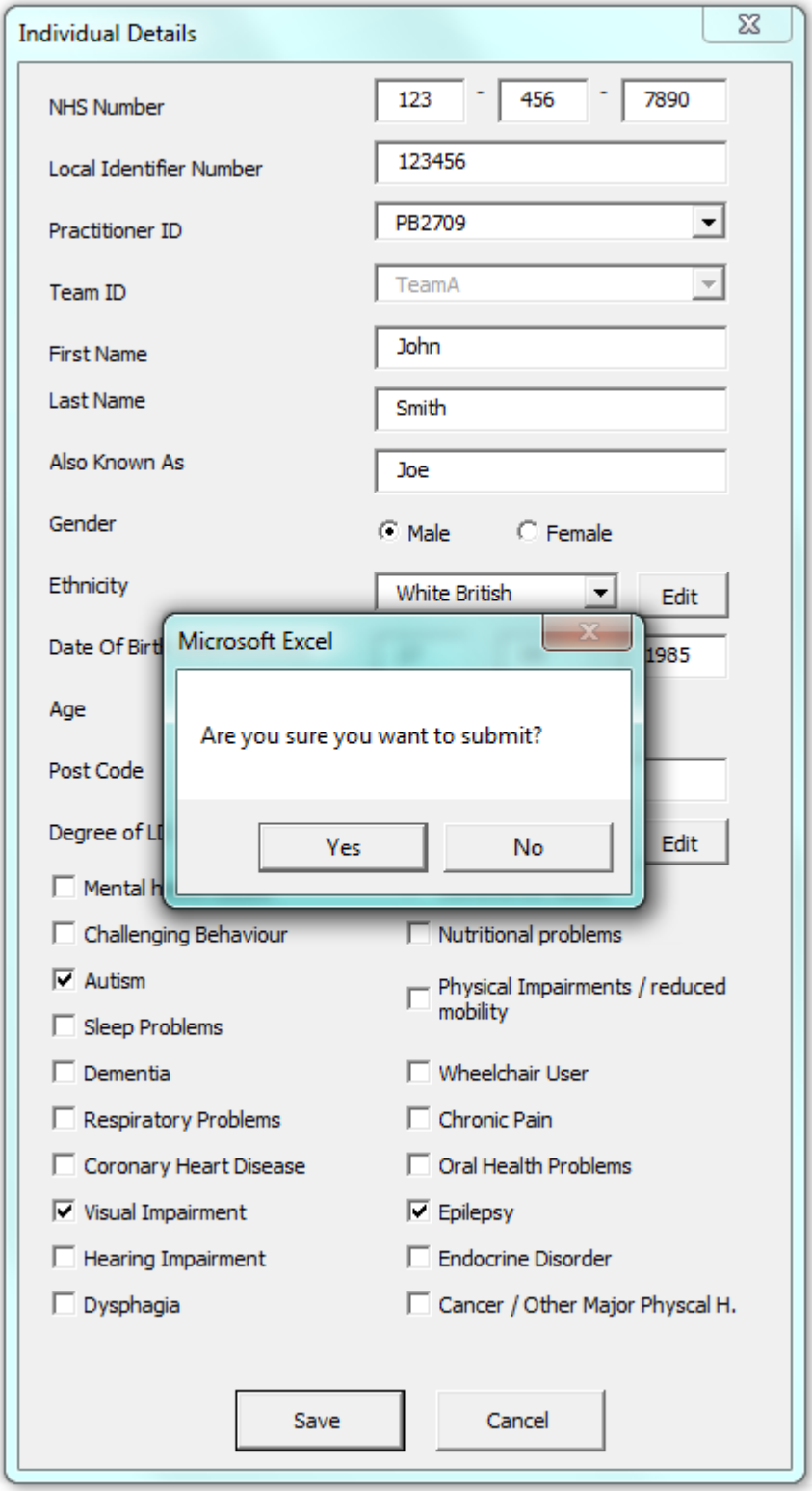
Practitioner ID & Team ID	**Ethnicity**
First Name	**Date of Birth & Age**
Last Name	**Post Code**
Gender	**Degree of LD**

Tick boxes: The tick-boxes in the lower half of the form (mental health issues, challenging behaviour etc) will record a 'no' value if not ticked so although they're not required fields they do generate a value if left un-checked.

Local Identifier: The Local Identifier field (not a required field) is available for you to capture a reference number, or similar, that you would use within your organisation.



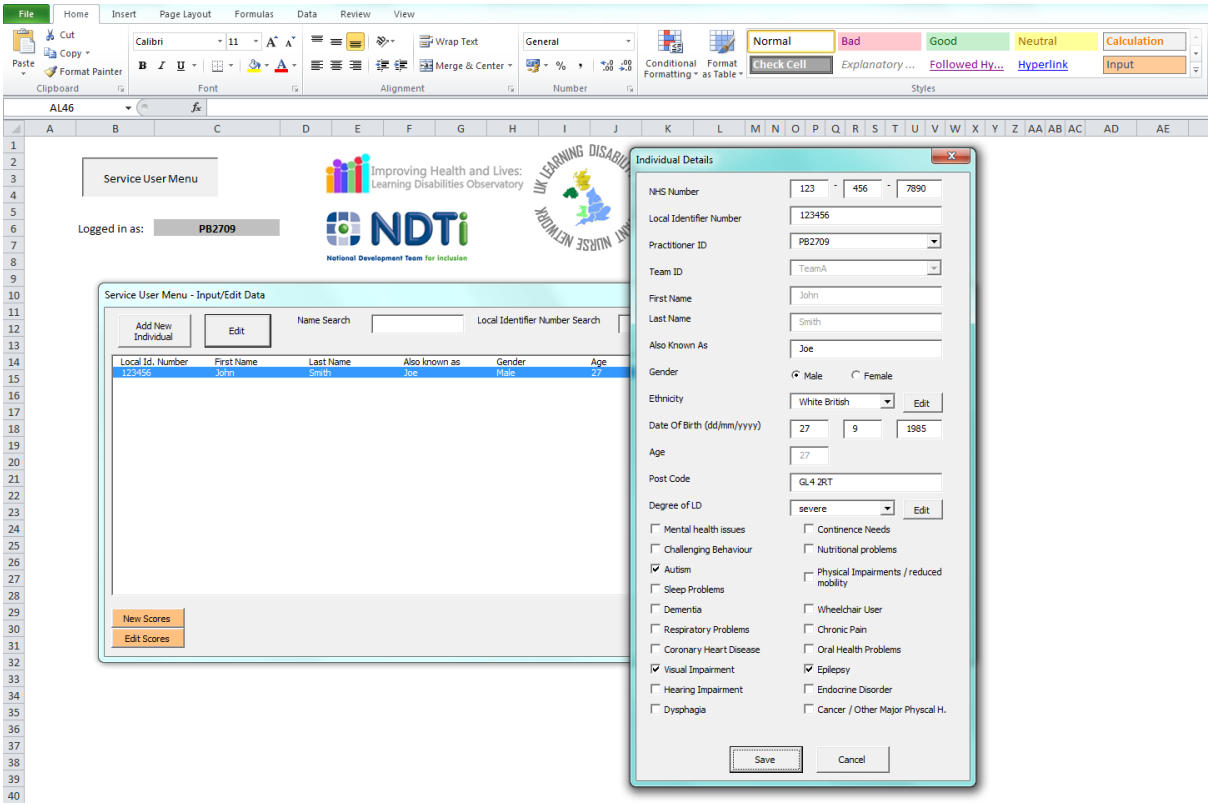

Individual Details
NHS Number
Local Identifier Number
Practitioner ID
PB2709
Team ID
TeamA
First Name
Last Name
Also Known As
Gender
Male
Female
Ethnicity
Edit
Date Of Birth (dd/mm/yyyy)
Age
Post Code
Degree of LD
Edit
Mental health issues
Challenging Behaviour
Autism
Sleep Problems
Dementia
Respiratory Problems
Coronary Heart Disease
Visual Impairment
Hearing Impairment
Dysphagia
Continence Needs
Nutritional problems
Physical Impairments / reduced mobility
Wheelchair User
Chronic Pain
Oral Health Problems
Epilepsy
Endocrine Disorder
Cancer / Other Major Physcal H.
Save
Cancel


Individual Details
NHS Number
123
456
7890
Local Identifier Number
123456
Practitioner ID
PB2709
Team ID
TeamA
First Name
John
Last Name
Smith
Also Known As
Joe
Gender
Male
Female
Ethnicity
White British
Edit
Date Of Birt
1985
Age
Post Code
Degree of LI
Edit
Microsoft Excel
Are you sure you want to submit?
Yes
No
Mental h
Challenging Behaviour
Autism
Sleep Problems
Dementia
Respiratory Problems
Coronary Heart Disease
Visual Impairment
Hearing Impairment
Dysphagia
Nutritional problems
Physical Impairments / reduced mobility
Wheelchair User
Chronic Pain
Oral Health Problems
Epilepsy
Endocrine Disorder
Cancer / Other Major Physcal H.
Save
Cancel

Editing an individual's details:

1) Click Add/Edit Data
2) Select the individual whose details you wish to edit
3) Click 'Edit' and off you go..
4) Click 'Save' and confirm

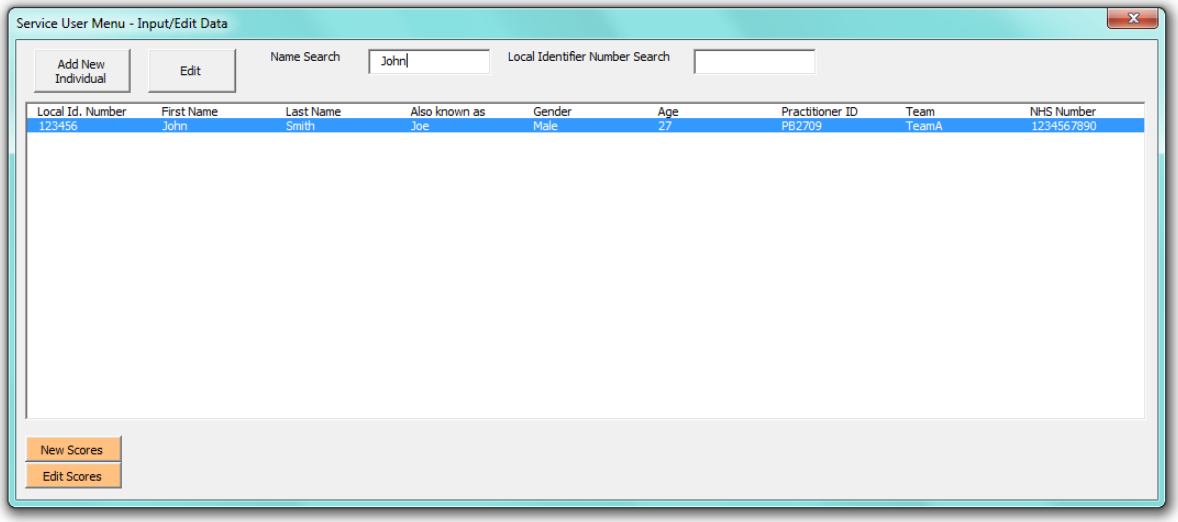
Note: you cannot edit an individual's name. This is to ensure consistency of data and prevent users from inadvertently over-writing a name.

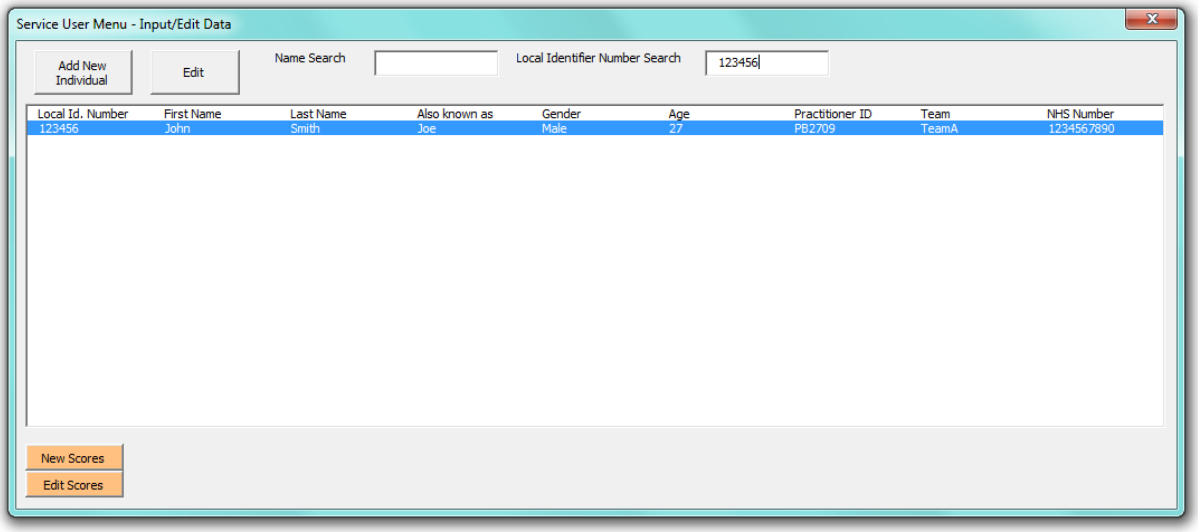


Finding an individual:

There are three ways to find an individual:

a) You can simply scroll down your list until you find the person you're looking for. This will be fine if you only have a small number of individual's records.
b) Start typing the first name in the *Name Search* box. The nearest match will then be highlighted/selected
c) Use the *Local Identifier Number Search* box in the same way as above, simply start typing the reference/number in the search box and the nearest match will be highlighted



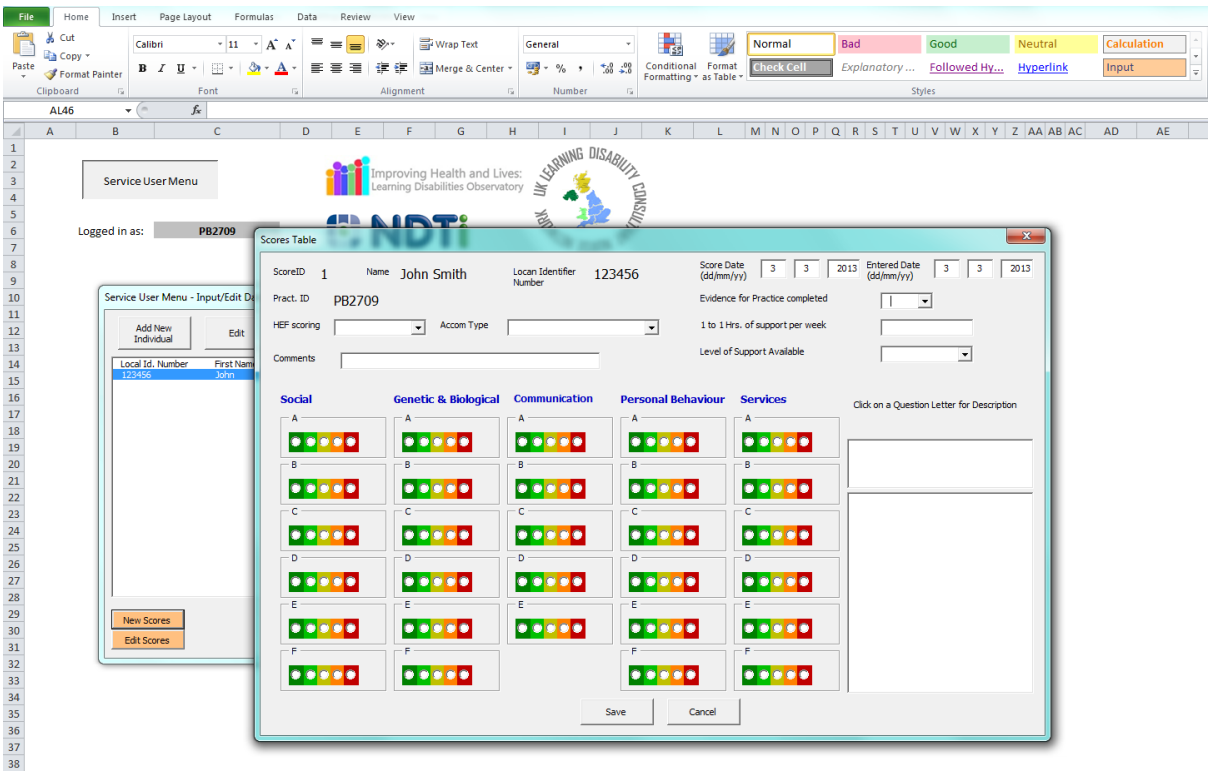


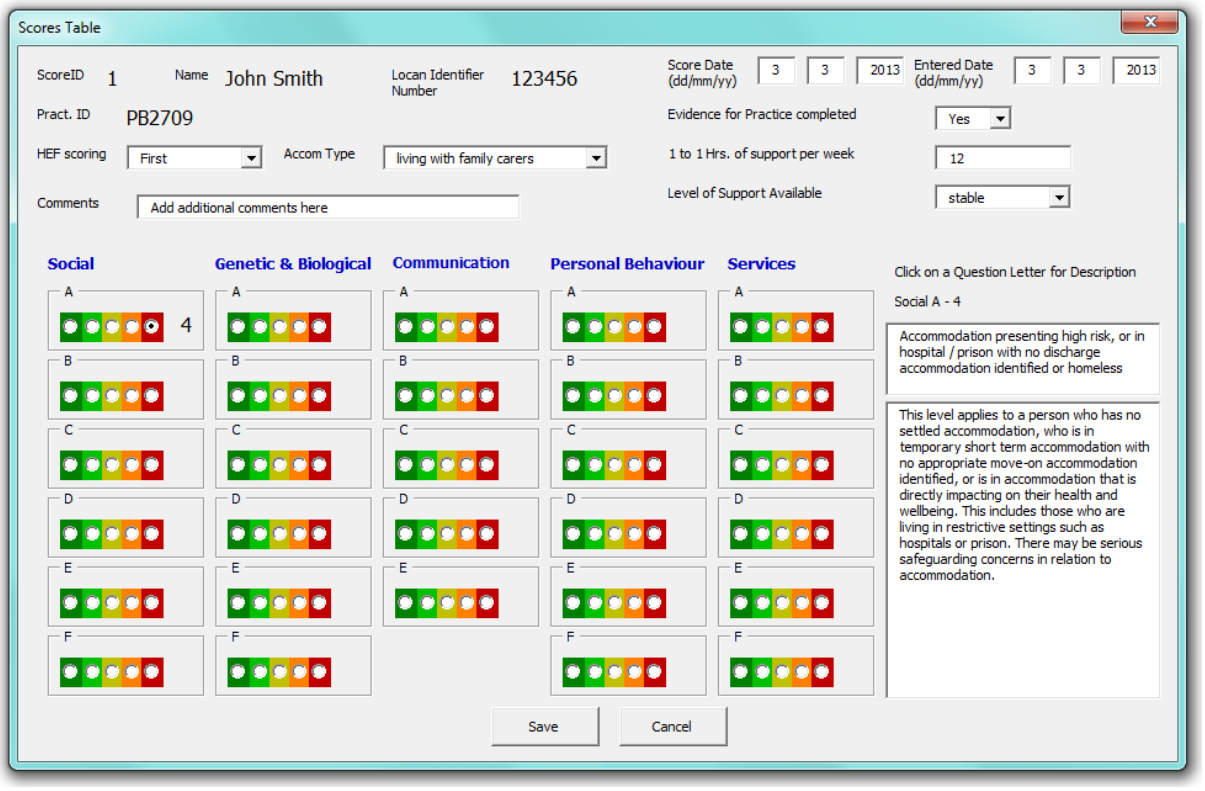
Adding a set of new scores:

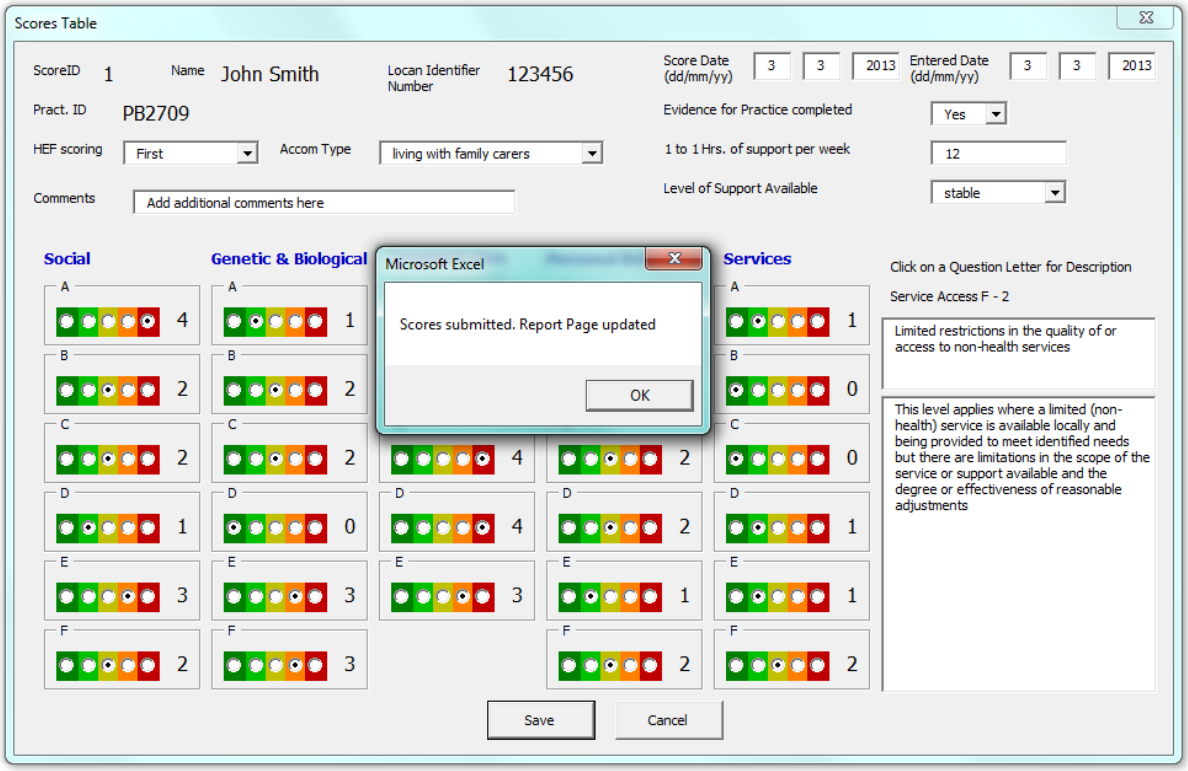
Once you've added the details of one or more individuals to eHEF you can go ahead and start recording HEF assessment information.

1) Using one of the methods described in 'Finding an Individual', locate the person for whom you wish to capture a score set
2) Click 'New Scores'
3) The scores form opens up ready for your data
4) Once you've completed all required fields click 'Save' and confirm
5) You receive a prompt letting you know that the scores have been saved and the report page updated – see the *Reports* section later in this document for details of reports.

Required fields: Everything on this form is required to be completed except *Comments* and *1 to 1 Hrs. of support*. If you miss anything out eHEF will prompt you after you click save.


Service User Menu
Logged in as:
PB2709
Improving Health and Lives: Learning Disabilities Observatory
Scores Table
ScoreID 1
Name John Smith
Locan Identifier Number 123456
Pract. ID PB2709
Score Date (dd/mm/yy) 3 3 2013
Entered Date (dd/mm/yy) 3 3 2013
Evidence for Practice completed
HEF scoring
Accom Type
1 to 1 Hrs. of support per week
Level of Support Available
Comments
Social
Genetic & Biological
Communication
Personal Behaviour
Services
Click on a Question Letter for Description
Save
Cancel
New Scores
Edit Scores


Scores Table
ScoreID 1
Name John Smith
Locan Identifier Number 123456
Score Date (dd/mm/yy) 3 3 2013
Entered Date (dd/mm/yy) 3 3 2013
Pract. ID PB2709
Evidence for Practice completed Yes
HEF scoring First
Accom Type living with family carers
1 to 1 Hrs. of support per week 12
Comments Add additional comments here
Level of Support Available stable
Social
Genetic & Biological
Communication
Personal Behaviour
Services
Click on a Question Letter for Description
Social A - 4
Accommodation presenting high risk, or in hospital / prison with no discharge accommodation identified or homeless
This level applies to a person who has no settled accommodation, who is in temporary short term accommodation with no appropriate move-on accommodation identified, or is in accommodation that is directly impacting on their health and wellbeing. This includes those who are living in restrictive settings such as hospitals or prison. There may be serious safeguarding concerns in relation to accommodation.
Save
Cancel

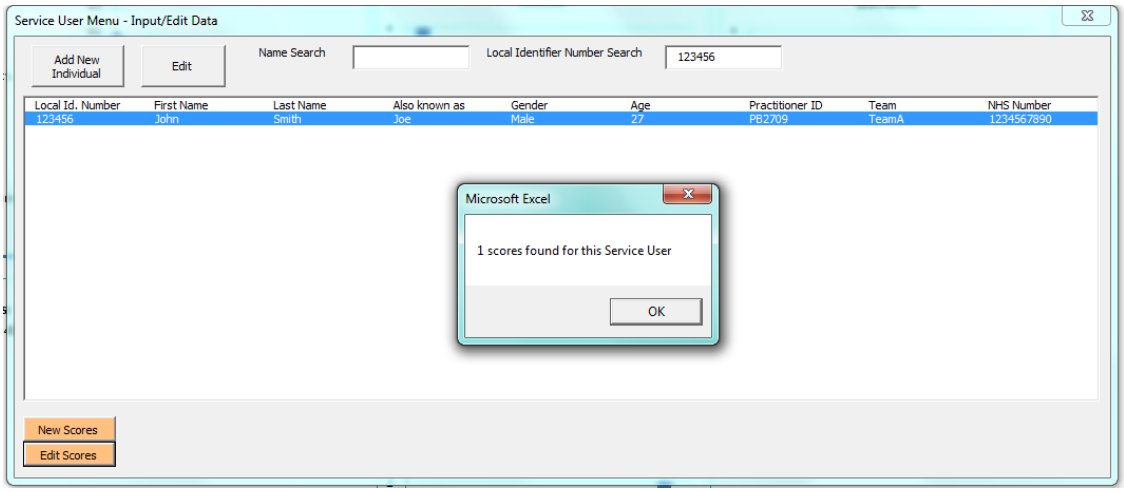


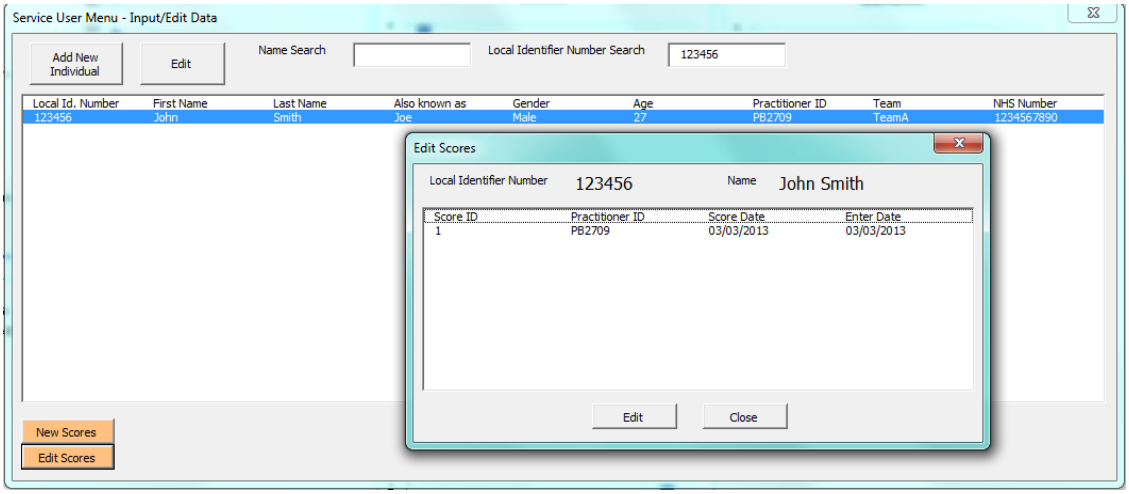
Editing a set of scores:

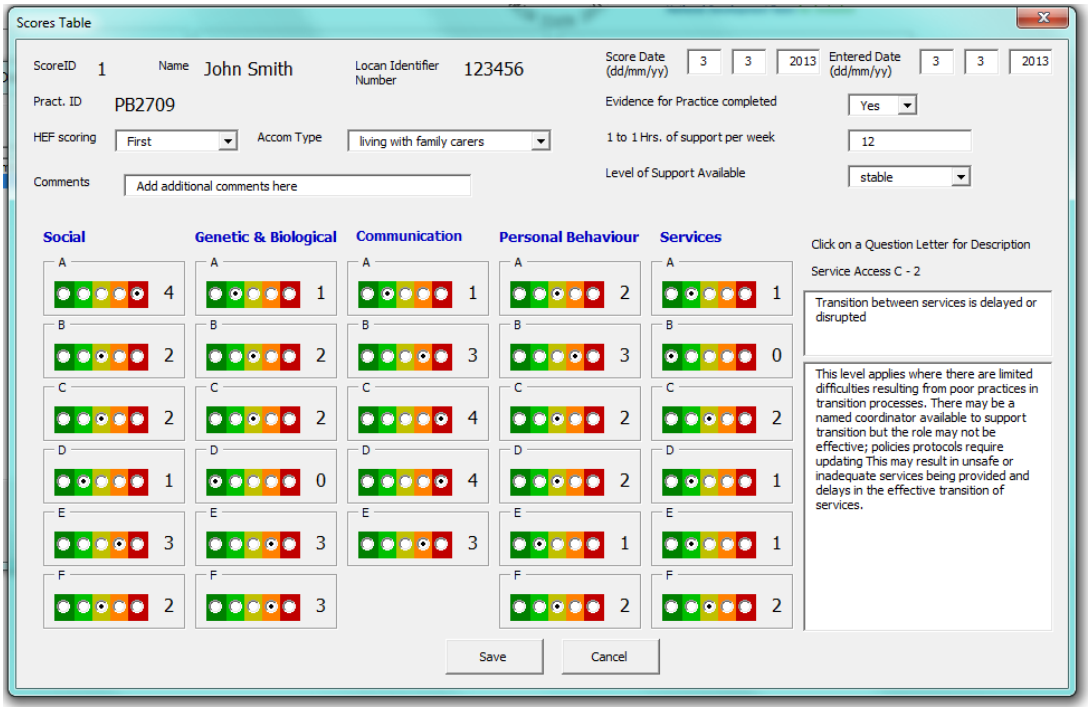
Whilst it is recommended you aim to record data accurately it is also recognised that you may occasionally have the need to make corrections or changes. So, the *Edit Scores* feature is available for this purpose. To use it:

1) Locate the individual whose scores you need to edit – see section above for a reminder of the options for searching
2) Click 'Edit Scores' – you'll then be prompted with the number of score sets for the individual
3) Click 'Ok' and in the next dialog box choose the score set you want to edit
4) The dates on which the scores were taken and logged are available to assist you find the right one
5) Select the score set you want to edit and click 'Edit'
6) Make your necessary changes and click 'Save'

Note: Remember you must complete the majority of fields in the scores form. If you leave any required fields blank eHEF will prompt you to complete them when you save.

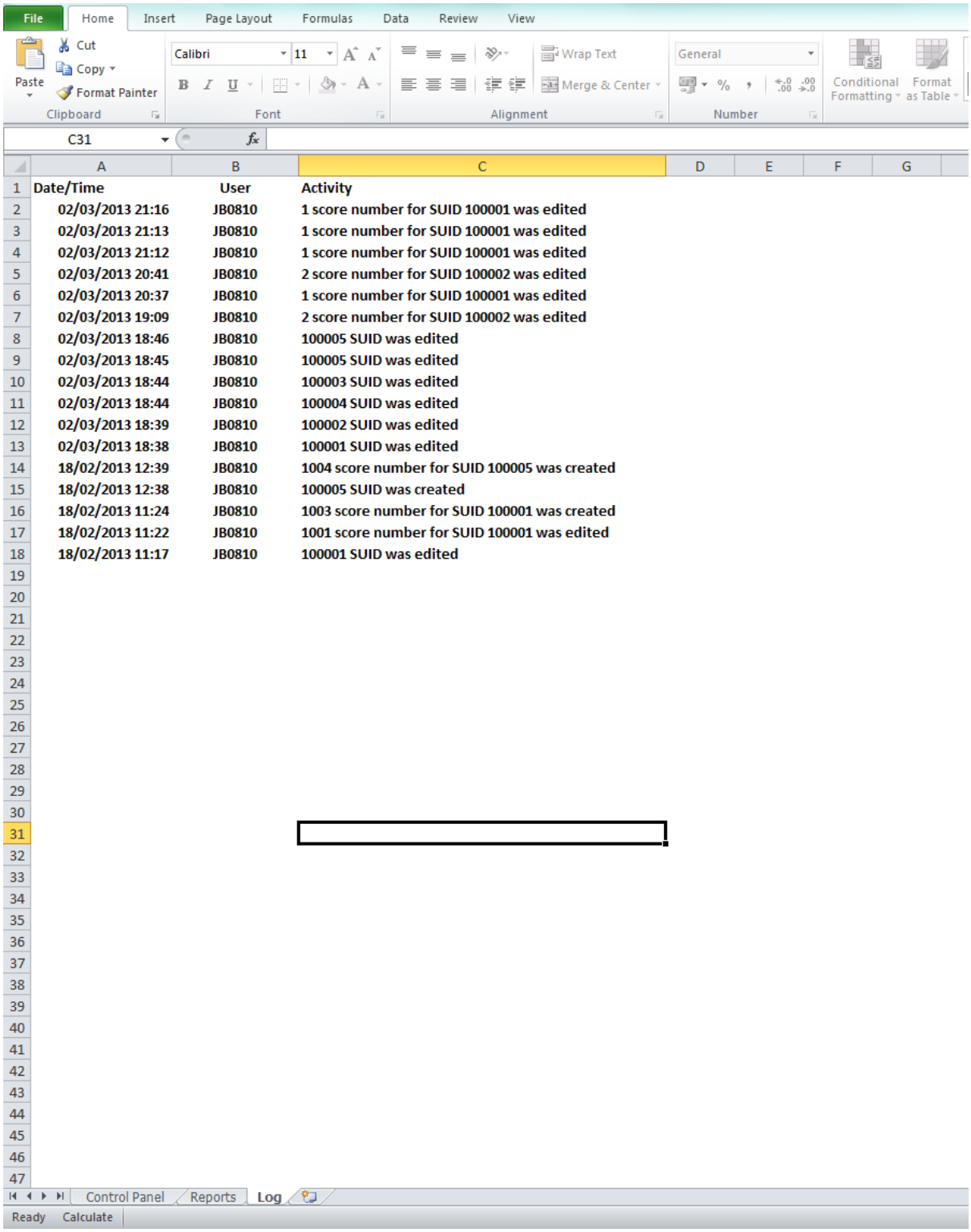

Service User Menu - Input/Edit Data
Add New Individual
Edit
Name Search
Local Identifier Number Search
123456
Local Id. Number
First Name
Last Name
Also known as
Gender
Age
Practitioner ID
Team
NHS Number
123456
John
Smith
Joe
Male
27
PB2709
TeamA
1234567890
Microsoft Excel
1 scores found for this Service User
OK
New Scores
Edit Scores


Service User Menu - Input/Edit Data
Add New Individual
Edit
Name Search
Local Identifier Number Search
123456
Local Id. Number
First Name
Last Name
Also known as
Gender
Age
Practitioner ID
Team
NHS Number
123456
John
Smith
Joe
Male
27
PB2709
TeamA
1234567890
Edit Scores
Local Identifier Number
123456
Name
John Smith
Score ID
Practitioner ID
Score Date
Enter Date
1
PB2709
03/03/2013
03/03/2013
Edit
Close
New Scores
Edit Scores


Scores Table
ScoreID
1
Name
John Smith
Locan Identifier Number
123456
Score Date (dd/mm/yy)
3
3
2013
Entered Date (dd/mm/yy)
3
3
2013
Pract. ID
PB2709
Evidence for Practice completed
Yes
HEF scoring
First
Accom Type
living with family carers
1 to 1 Hrs. of support per week
12
Comments
Add additional comments here
Level of Support Available
stable
Social
Genetic & Biological
Communication
Personal Behaviour
Services
A 4
B 2
C 2
D 1
E 3
F 2
A 1
B 2
C 2
D 0
E 3
F 3
A 1
B 3
C 4
D 4
E 3
A 2
B 3
C 2
D 2
E 1
F 2
A 1
B 0
C 2
D 1
E 1
F 2
Click on a Question Letter for Description
Service Access C - 2
Transition between services is delayed or disrupted
This level applies where there are limited difficulties resulting from poor practices in transition processes. There may be a named coordinator available to support transition but the role may not be effective; policies protocols require updating This may result in unsafe or inadequate services being provided and delays in the effective transition of services.
Save
Cancel

Log:

As mentioned at the beginning of the manual, there's a log feature that captures all significant activities on eHEF. Below is an illustration of the log – not very interesting but potentially very useful in some scenarios.

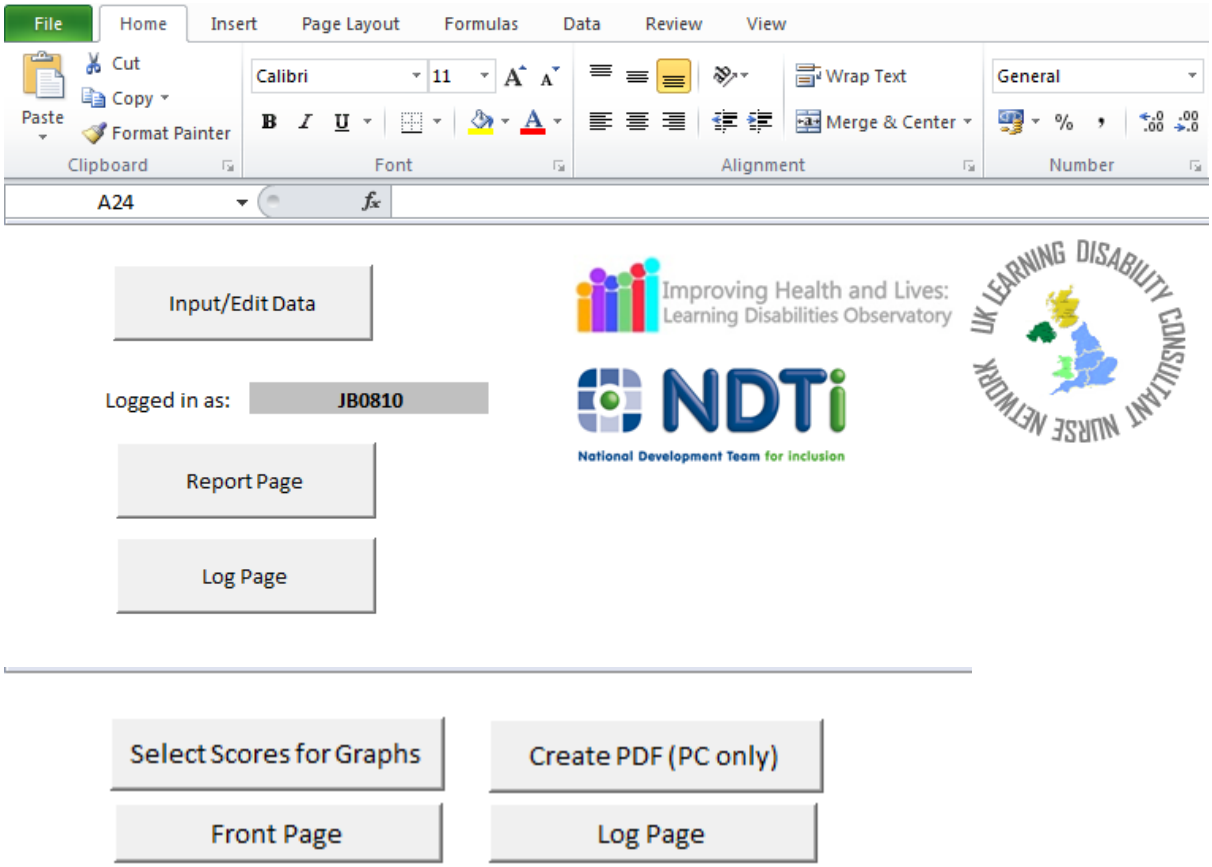


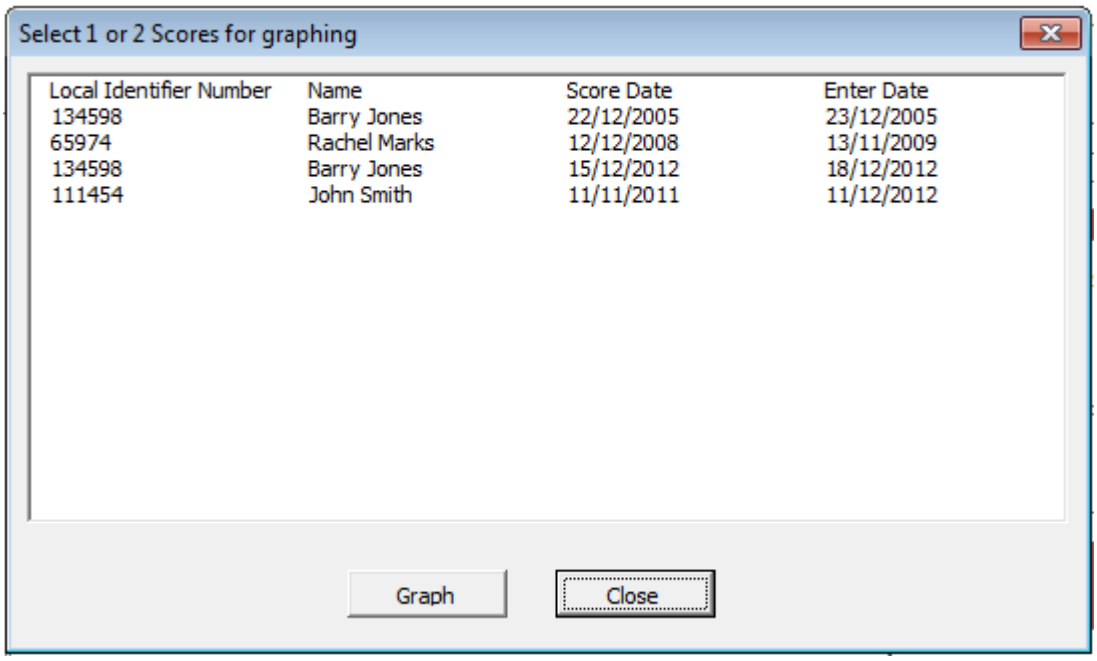
	A	B	C
1	Date/Time	User	Activity
2	02/03/2013 21:16	JB0810	1 score number for SUID 100001 was edited
3	02/03/2013 21:13	JB0810	1 score number for SUID 100001 was edited
4	02/03/2013 21:12	JB0810	1 score number for SUID 100001 was edited
5	02/03/2013 20:41	JB0810	2 score number for SUID 100002 was edited
6	02/03/2013 20:37	JB0810	1 score number for SUID 100001 was edited
7	02/03/2013 19:09	JB0810	2 score number for SUID 100002 was edited
8	02/03/2013 18:46	JB0810	100005 SUID was edited
9	02/03/2013 18:45	JB0810	100005 SUID was edited
10	02/03/2013 18:44	JB0810	100003 SUID was edited
11	02/03/2013 18:44	JB0810	100004 SUID was edited
12	02/03/2013 18:39	JB0810	100002 SUID was edited
13	02/03/2013 18:38	JB0810	100001 SUID was edited
14	18/02/2013 12:39	JB0810	1004 score number for SUID 100005 was created
15	18/02/2013 12:38	JB0810	100005 SUID was created
16	18/02/2013 11:24	JB0810	1003 score number for SUID 100001 was created
17	18/02/2013 11:22	JB0810	1001 score number for SUID 100001 was edited
18	18/02/2013 11:17	JB0810	100001 SUID was edited

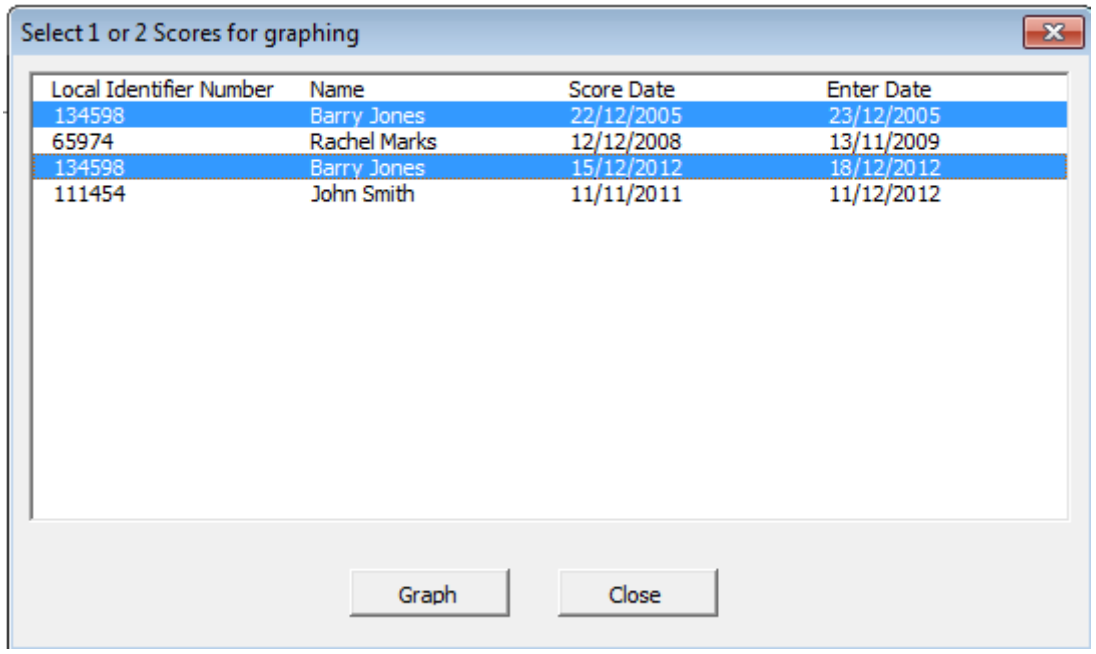
Graphing:

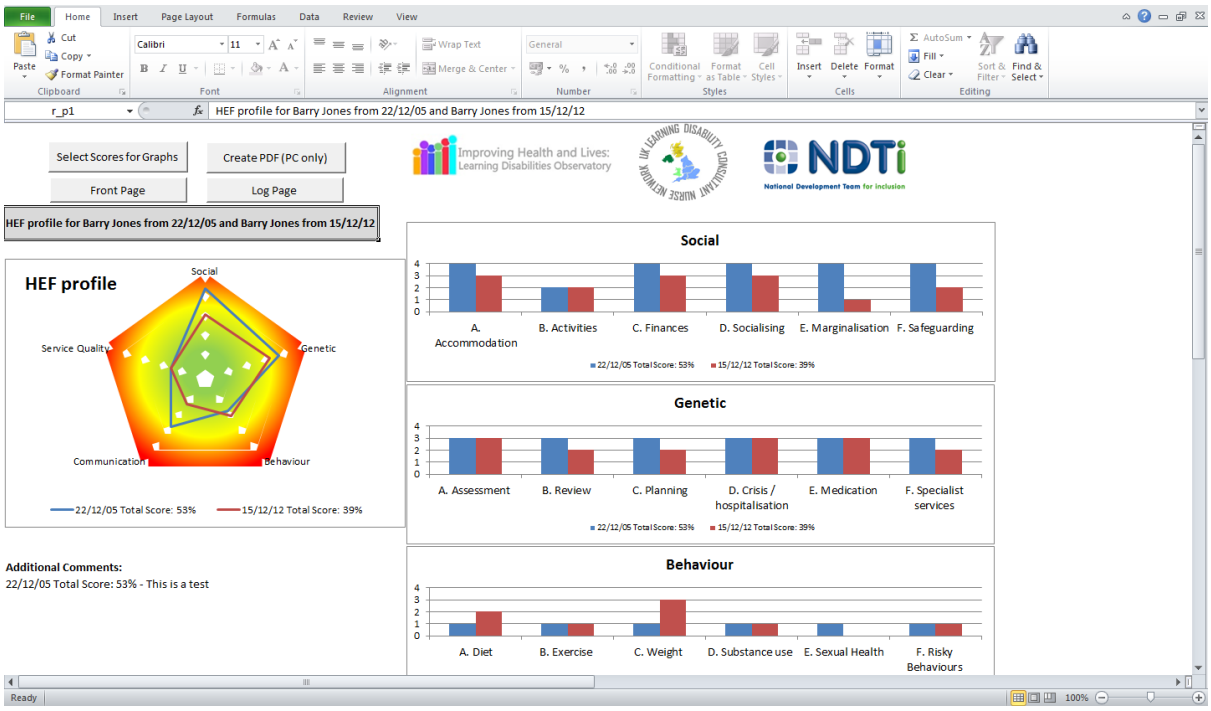
To create graphical reports of individuals, navigate your way to the Front Page and then click on 'Report Page'. This will bring you to where you can create graphs to see one or two sets of data so you can see just one current or past set of scores or choose two to compare change over time. To create graphs, do the following:

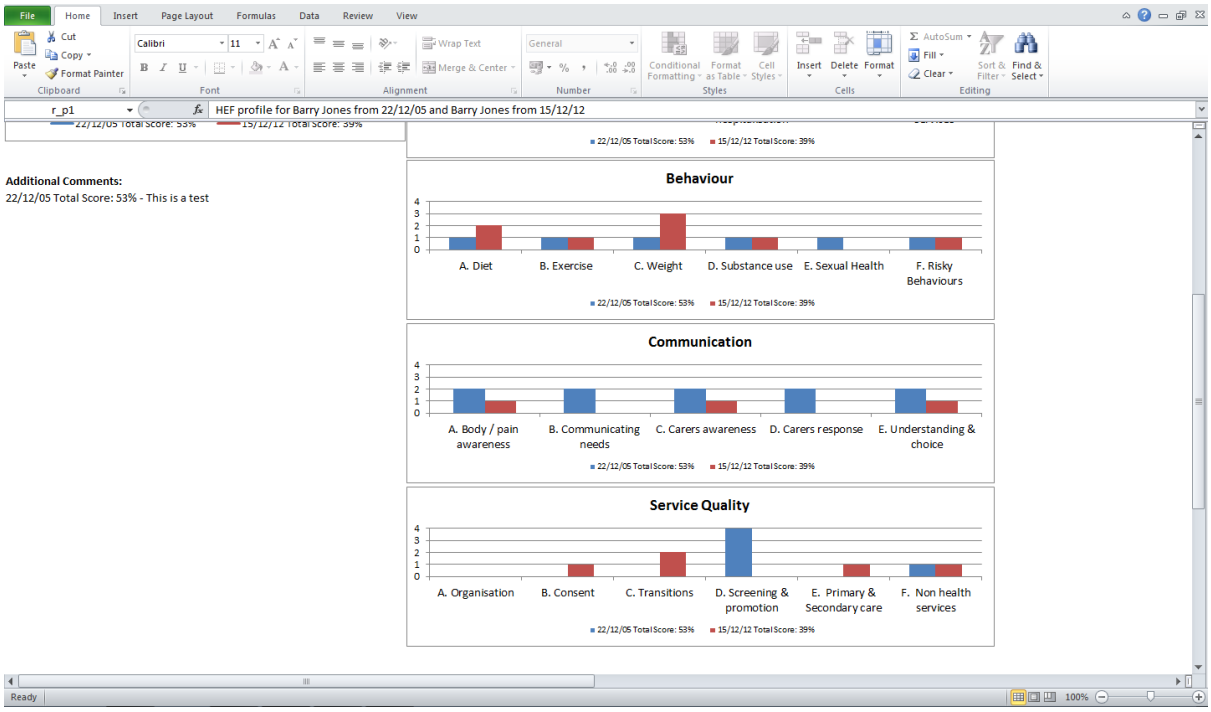
1) Click on 'Select Scores for Graphs
2) Select one or two sets of scores
3) Click Graph and then graphs displaying scores for each of the sections will be created onto the current sheet. You may need to scroll down to see all of the graphs.




Select 1 or 2 Scores for graphing
Local Identifier Number
Name
Score Date
Enter Date
134598
Barry Jones
22/12/2005
23/12/2005
65974
Rachel Marks
12/12/2008
13/11/2009
134598
Barry Jones
15/12/2012
18/12/2012
111454
John Smith
11/11/2011
11/12/2012
Graph
Close


Select 1 or 2 Scores for graphing
Local Identifier Number
Name
Score Date
Enter Date
134598
Barry Jones
22/12/2005
23/12/2005
65974
Rachel Marks
12/12/2008
13/11/2009
134598
Barry Jones
15/12/2012
18/12/2012
111454
John Smith
11/11/2011
11/12/2012
Graph
Close

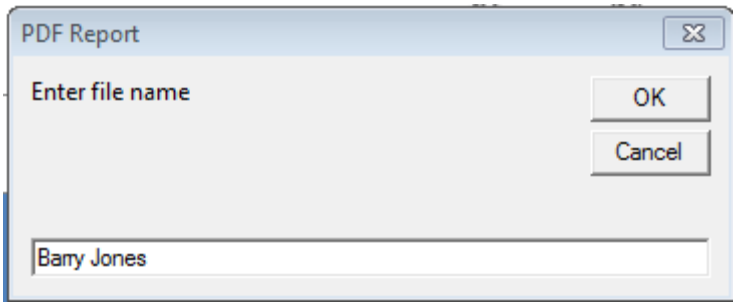


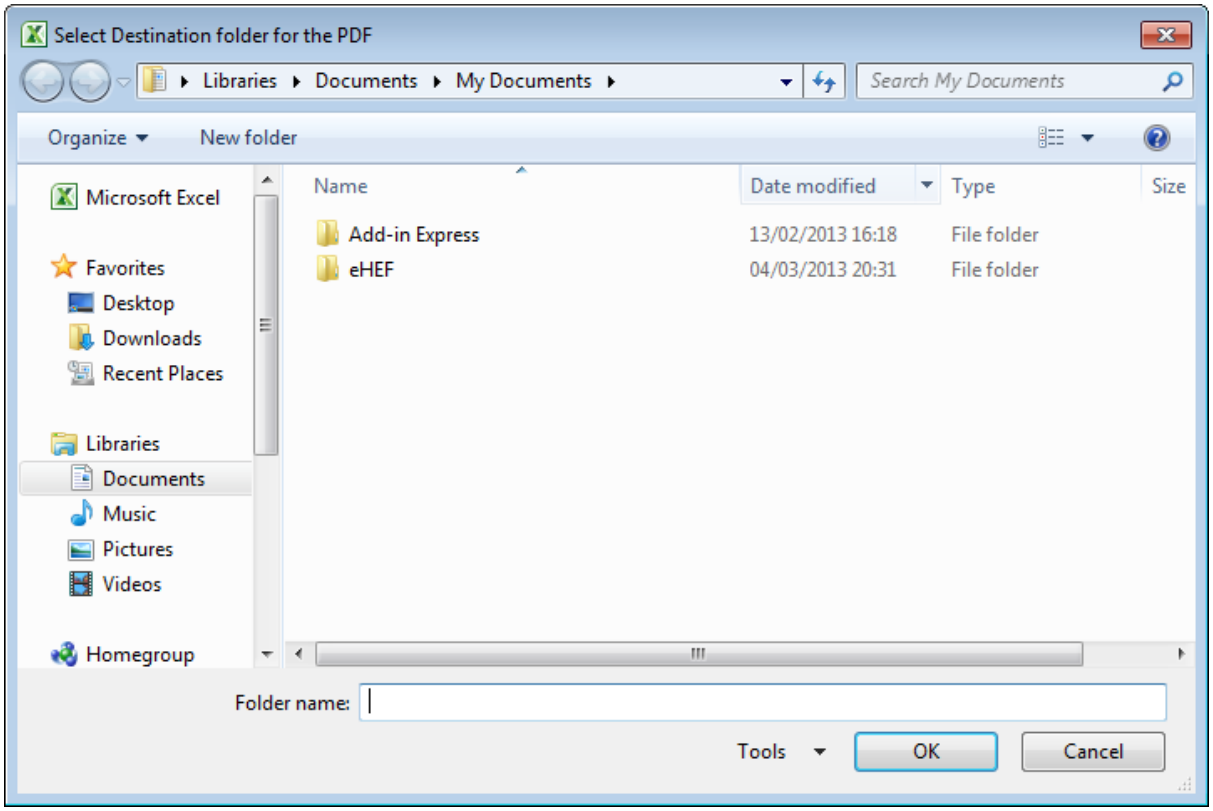


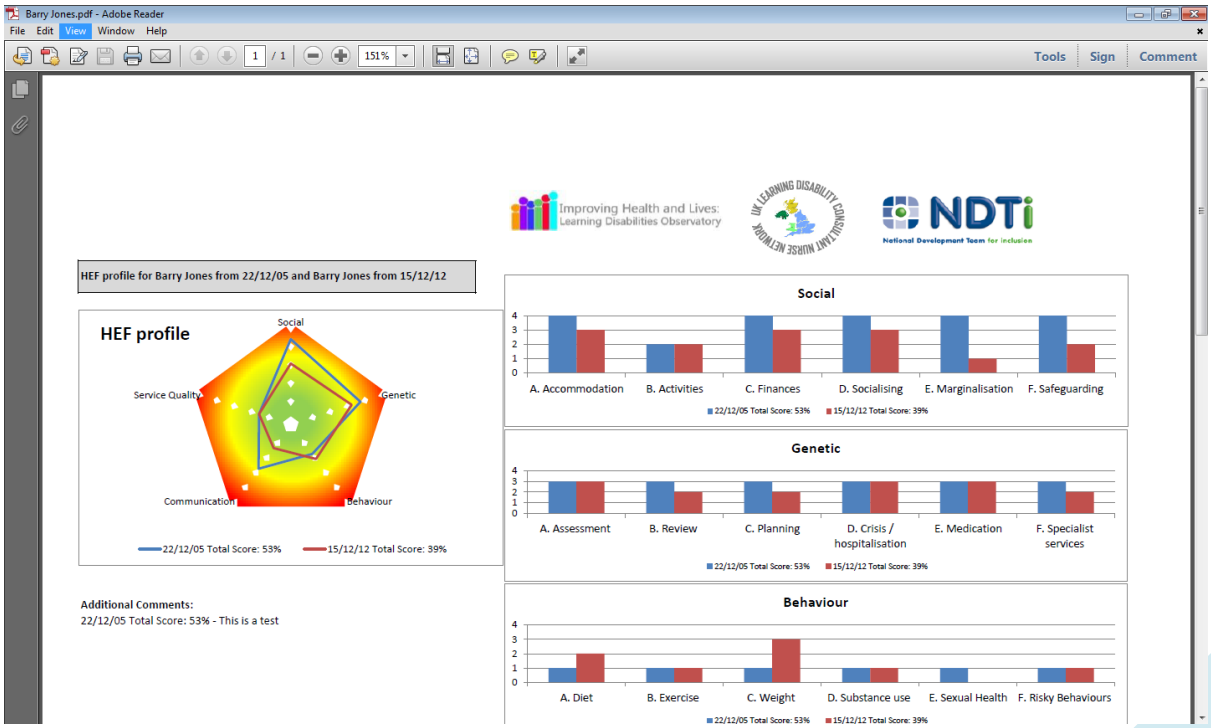
Creating a PDF report for printing

You can then create a PDF file displaying the graphs you have just created by doing the following:

1) Click Create PDF (PC only) on the Report Page
2) Name the file appropriately
3) Find an appropriate place to save the PDF file
4) Click OK and then it will create the file and save it where you specified


PDF Report
Enter file name
OK
Cancel
Barry Jones


Select Destination folder for the PDF
Libraries ▸ Documents ▸ My Documents ▸
Search My Documents
Organize
New folder
Microsoft Excel
Favorites
Desktop
Downloads
Recent Places
Libraries
Documents
Music
Pictures
Videos
Homegroup
Name
Date modified
Type
Size
Add-in Express
13/02/2013 16:18
File folder
eHEF
04/03/2013 20:31
File folder
Folder name:
Tools
OK
Cancel


Barry Jones.pdf - Adobe Reader
File Edit View Window Help
Tools Sign Comment
Improving Health and Lives: Learning Disabilities Observatory
UK Learning Disability Consultant Nurse Network
NDTi
National Development Team for inclusion
HEF profile for Barry Jones from 22/12/05 and Barry Jones from 15/12/12
HEF profile
Social
Genetic
Behaviour
Service Quality
Communication
22/12/05 Total Score: 53%
15/12/12 Total Score: 39%
Social
A. Accommodation
B. Activities
C. Finances
D. Socialising
E. Marginalisation
F. Safeguarding
Genetic
A. Assessment
B. Review
C. Planning
D. Crisis / hospitalisation
E. Medication
F. Specialist services
Behaviour
A. Diet
B. Exercise
C. Weight
D. Substance use
E. Sexual Health
F. Risky Behaviours
Additional Comments:
22/12/05 Total Score: 53% - This is a test

eHEF Manager

This is a separate tool that performs aggregation and analysis of data from one or more eHEF files. eHEF Manager has its own user guide available from the same website where you obtained this manual and your copy of eHEF.

eHEF Manager can produce reports based on many individuals and it analyses HEF scores based on the demographics and categories you entered along with that individual's record. For example, you can compare:

a) scores for all females with scores for all males
b) scores for individuals with challenging behaviour with those who don't
c) scores for people with a first HEF scoring against those with follow-up or final scores
d) HEF scores for those in hospital against those at home

In fact, any data that eHEF captures can be used to filter aggregated records from one or more eHEF files.

The Health Equalities Framework – a guide for family carers

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)[23] 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.

[23] 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	*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*
3	Significant restrictions to healthy eating and drinking	*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.*
2	Limited restrictions to healthy eating and drinking	*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.*
1	Minimal restrictions to healthy eating and drinking	*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*
0	No restrictions to healthy eating and drinking	*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.*

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.

The HEF – an accessible guide for people with learning disabilities

This guide has been produced for people with learning disabilities. A fully accessible version of the full HEF guide has also been produced and can be downloaded from either the IHaL or NDTi websites.

How well are we doing on health?

Easier read guide to the **Health Equalities Framework**

What is in this booklet?

	Page
What is this booklet about?	3
What does the **Health Equalities Framework** measure?	5
How does the **Health Equalities Framework** work?	8
Using the **Health Equalities Framework** for lots of people	11
List of difficult words	12

Some of the words to do with health are a bit difficult. In this booklet we show them like this: **outcomes**.

At the end of the booklet is a list of the difficult words and what they mean.

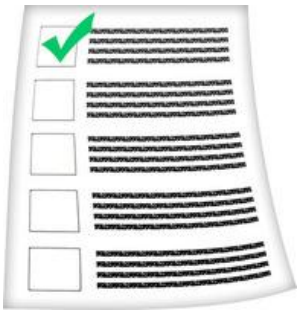
What is this booklet about?

Some people have less good health than other people.
This can be because of poorer health care or other reasons.
This happens for many people with learning disabilities.

We need to know if services are helping people to get better health. When we look to see if services are helping people to get better health, we call this looking for health '**outcomes'**.

The Government has set some **outcomes** for everyone. These are called '**outcome frameworks**'. There are two for health and one for social care.
We have made an **outcome framework** that is especially for people with learning disabilities.

It is called the '**Health Equalities Framework**'. It is all about making the health of people with learning disabilities more equal to the health of other people.



In this booklet we will call it the '**HEF**' for short.

You can use the **HEF** to think about your own health.

You can use it with your family or people who are paid to help you.

You can use it with health staff, like nurses.

What does the HEF measure?

There are 5 big things that affect people's health:

1. Where you live and what you do

2. Health problems you may have

3. Understanding your health and being able to tell people how you feel

4. Things you can do to keep healthy

5. Using health services – and how good they are

Now we will say a bit more about each of these.

1. Where you live and what you do

People with learning disabilities often live in poorer areas.

Lots of people do not have jobs or their own home.

Lots of people experience hate crime.

Some people do not have many friends.

2. Health problems you may have

Some people have health problems that are linked to the cause of their learning disability.

People should have health checks.

People should have Health Action Plans.

3. Understanding your health and being able to tell people how you feel

People with learning disabilities may not understand when something is wrong with their health.

Sometimes people feel ill or in pain, but they cannot tell other people how they are feeling.

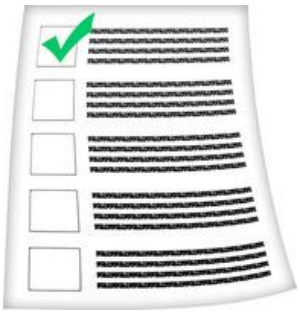
4. Things you can do to keep healthy

People with learning disabilities do not always know how to be healthy. They may not get support to help them be healthy.
Being healthy includes things like what you eat, exercise, and not smoking.

5. Using health services – and how good they are

Health staff do not always change how services are given to people with learning disabilities so they can use them.
For example, longer appointment times or having information in easy read.
People with learning disabilities sometimes get less good services than other people.
Health staff do not always understand the law about when someone can agree to treatment, and what to do if they cannot.

How does the HEF work?



The **HEF** is a way of looking at all the things that might affect your health.

The **HEF** helps you to score all the things that affect your health.
It is good to do the scoring with someone who can help you think about all these different things.

Some people like to start by talking to a member of their family.

Some people prefer to talk to a health person, like a nurse.

You can do both!

Look at the example on the next page.

Example

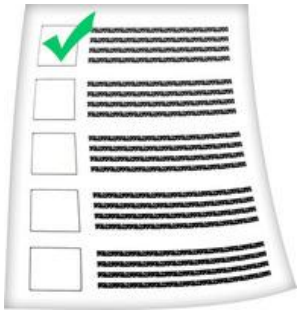
Things you can do to keep healthy: eating and drinking

Score		What this might mean
4	Really big problems about healthy eating and drinking	The person has difficulty swallowing and no help with this. The person hardly eats or drinks anything. The person eats dangerous things.
3	Big problems about healthy eating and drinking	The person has quite a poor **diet** with things that are bad for them or not enough good things to eat. The person eats and drinks too much or too little.
2	Some problems about healthy eating and drinking	The person eats some of the right things, but they eat and drink too much or too little. The person gets some help with their **diet**.
1	Just a few problems with healthy eating and drinking	The person has quite a good **diet**. There might be just a few things that could be better. The person gets any help they need with their **diet**.
0	Healthy eating and drinking	The person has a healthy **diet** with all the right things in it. The person drinks enough water. The person gets advice about healthy eating.

What score would you give yourself?

Using the **HEF**, you can look at each of the scoring sheets in turn.
Or you can just pick the sheets that are most important for you.

Once you have done all the scoring, you can talk about what needs to be done!
It is good to talk to a health person about the action.



You can agree who will do the actions, and when.
You can put all the agreements in your Health Action Plan.

Then you can set a date to look at the scoring sheets again and see if things have got better.

Using the HEF for lots of people

Services can use the **HEF** to look at how well they are doing for lots of people with learning disabilities. It can help them think about what they need to do to support people to get better health.

You can ask your local commissioners and services what they are doing to help people with learning disabilities keep well and get good health care.

List of difficult words

Difficult words	What they mean
Diet	What you eat and drink
Health Equalities Framework	A set of measures to help people and services look at making the health of people with learning disabilities more equal to the health of other people
HEF	This is short for the Health Equalities Framework
Outcomes	Ways of measuring to see if people are getting better health
Outcome framework	A whole set of outcomes

Improving Health and Lives:
Learning Disabilities Observatory

NDTi

National Development Team for inclusion