

SERVICE EVALUATION

# An evaluation of the Health Equalities Framework for people with a learning disability

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None declared

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## Abstract

There is increasing evidence that the Health Equalities Framework (HEF) benefits people with learning disabilities, but there is little information about service users' and carers' views of it. This article reports on an evaluation of the HEF tool and the views of service users and carers, collected through a questionnaire. Findings suggest that service users benefit in many ways, based on the 29 indicator scales of the five domains of the HEF assessment: social, genetic-biological, communication, behaviour/lifestyle and service quality. The article outlines how HEF assessments reduced health inequalities, and includes examples of feedback about the outcomes.

## Keywords

health equalities framework, health inequalities, learning disabilities, service users' perceptions

THE HEALTH Equalities Framework (HEF) (Atkinson et al 2014, 2015, Thomas 2014) developed parallel to, and as a result of, the premature deaths and health inequalities of people with learning disabilities (Mencap 2012, Heslop et al 2013) and is now in its sixth year. The framework measures how reducing exposure to the determinants of health inequality and delivering services that mitigate their effects influences healthy life expectancy among people with learning disabilities (Atkinson et al 2014).

Emerson and Baines (2010) suggested that people with learning disabilities experience health inequalities in five groups of determinants:

- » Social determinants, such as poverty, poor housing, unemployment, discrimination and isolation.
- » Genetic, biological and environmental causes of learning disability.
- » Communication difficulties and reduced understanding of health issues.
- » Personal behaviours, such as poor diet and lack of exercise.
- » Lack of access to high-quality healthcare services.

These five determinants were further divided into 29 health inequalities indicators by Atkinson et al 2014 (Table 1).

Healthcare practitioners who use the HEF tool rate the effects of exposure to these 29 indicators on a five-point Likert scale, through

an electronic data capture programme, in which a rating of one TO indicates little exposure and five indicates a great deal of exposure. The resulting macro-enabled spreadsheet HEF tool creates an overall HEF rating for each of the five determinants, and generates a visual image-pentagon or spider diagram (Figures 1a, 1b).

There is increasing evidence of the effectiveness of using the HEF with people with learning disabilities in several areas. Atkinson et al (2014) demonstrated its effectiveness at four NHS trusts in the first pilot, while Hebron et al (2014) showed the outcomes and benefits of this approach in Gloucestershire Together NHS Foundation Trust's outreach team's services. A comparison between methods for assessing indicators for the healthcare of people with Down's syndrome (van den Driessen Mareeuw et al 2017), found the HEF was favourable compared to 12 other measures. Using an Appraisal of Indicators through Research and Evaluation (AIRE) instrument – a manual and checklist of healthcare indicators – the HEF scored highest and the World Health Organization's (WHO) measure of quality (WHO 2006) was evident in five out of six quality dimensions. Duff (2016) collected practitioners' views of the HEF in Scotland and found that it was received well overall. Further implementation across four regional boards was planned.

The HEF is also an effective assessor of innovative interventions (V-connect 2017), in that using it can transform care and service delivery, as well as aspects of staff performance.

The framework is being rolled out across many trusts in the UK, for use by learning disability nurses, as well as allied health professionals and social workers in integrated teams. It is also being developed for use with children and young people, those at risk of homelessness, people with autism who do not have learning disabilities and people with mental distress (Atkinson D, personal communication 2017).

Service users' and carers' views are important, and they were consulted at the start of the HEF initiative (Atkinson et al 2014). Beresford (2007) stressed the importance of service user involvement in research, while Rooney et al (2016) and Unwin et al (2017) suggested that service user and carer involvement in the delivery of higher education at an English university was beneficial to them and to learners.

During 2015-2016 Worcestershire Health and Care NHS Trust community learning disability teams started to use the original version of the HEF tool, and has now been updated, as part of a commissioning for quality and innovation service improvement initiative, which has continued funding implications.

### Aim

The aim was to evaluate the HEF tool and identify the views of stakeholders, including service users, family carers, paid support staff and Worcestershire Health and Care NHS Trust and Worcestershire County Council staff, who carried out the assessments.

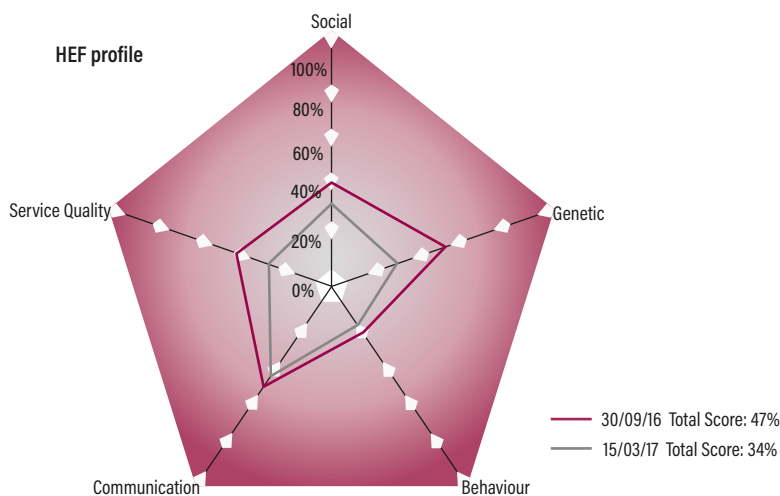
### Methods including ethical considerations

HEF and HEF+ tools were used in 2015-2016 and 2016-2017 to record assessments and generate pentagon or spider diagrams. HEF+ is a version which includes more refined descriptors and piloting suggested improved reliability. In addition, spreadsheet analysis of individual assessment values was undertaken to calculate mean and percentage positive difference:

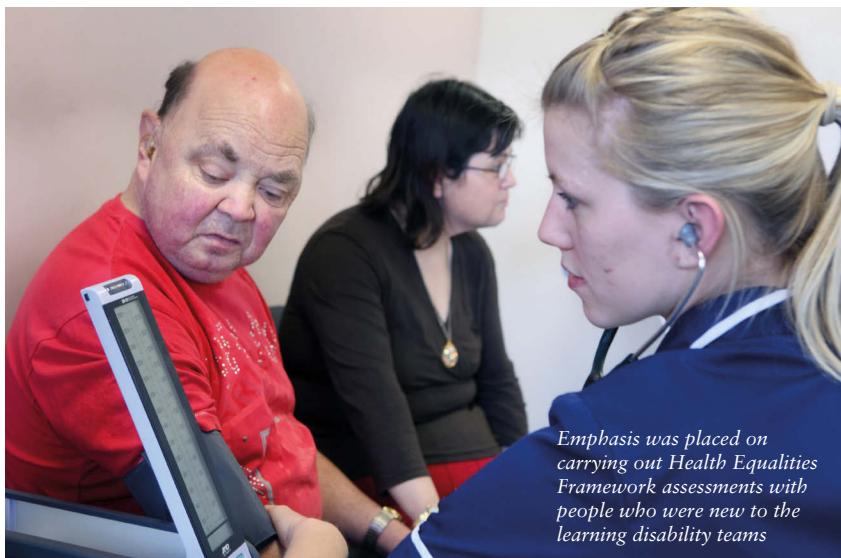
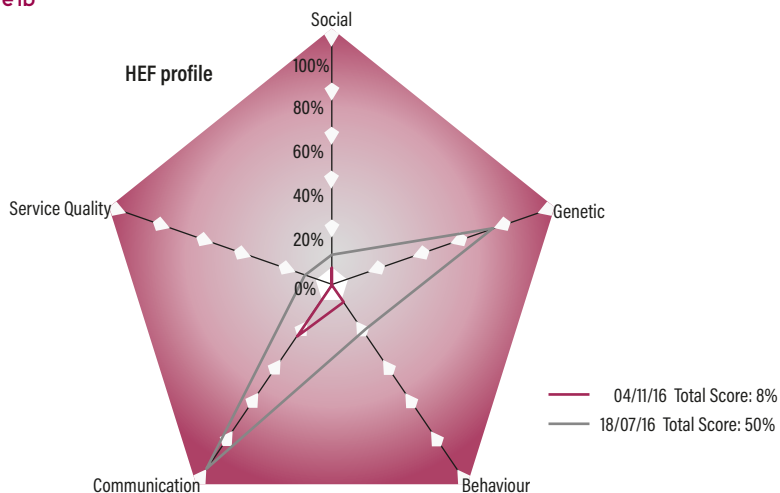
$$\frac{(\text{initial mean HEF value}) - (\text{final mean HEF value})}{\text{initial HEF value}} \times 100.$$

An evaluation tool in the form of an easy-read questionnaire was developed. Practitioners undertaking HEF visits asked

**Figure 1a.** Two examples of anonymised pentagon or spider diagrams created by the Health Equalities Framework (HEF+) tool



**Figure 1b**



service users and their families to complete these anonymously following, or during, the second assessment. Staff were invited to complete a similar evaluation tool anonymously. Service users and carers were assured that their views would not affect their healthcare. Completed questionnaires were given to learning disability administrators, who passed them to the senior author. The senior author ensured the confidentiality of these anonymous questionnaires by keeping them under lock and key.

Permission for the evaluation was obtained from the Worcestershire Health and Care NHS Trust’s research and audit manager.

**Findings**

A total of 186 HEF assessments were completed in 2015-2016 (Table 1) and 86 in 2016-2017. Different cohorts of service users were used between the two years, because those on practitioners’ active caseloads – and subject to HEF assessments in the first year – were already undergoing interventions before the first assessment and the demonstration of health benefits was small. In the second year, therefore, emphasis was placed on carrying out HEF assessments with people who were new to the community learning disability teams or who had new episodes of need (Table 2). However, some people on the complex needs pathway, on existing caseloads, in replacement care service and those who were admitted to one of the two acute hospitals for treatment, were also considered.

There were increased positive percentages in all domains between the first and second HEF assessments – following interventions – in both years, demonstrating a beneficial effect on health and well-being. The intervention with the greatest effect in both years was for the health or ‘genetic/ biological’ domain of the HEF assessment, while the intervention with the least effect was for behavioural/lifestyle, or ‘personal’, although there was a lower initial mean value for personal (Tables 1 and 2).

There were 41 responses to the questionnaire, from service users, family carers, paid care support workers, NHS trust staff and Worcestershire County Council staff (Tables 3a-e), although not all respondents completed every questionnaire field, so there are some missing values.

All but one trust staff member believed HEF assessment had assisted the service user. This staff member found other measures were more appropriate (Table 3a). Most stakeholders believed that the help was from the answers to the questionnaire - ‘looked at me as a person’, and ‘looked at my health’. There were also many responses around ‘helped me to access services’ (Table 3a), while ‘helped me make a new plan’, and ‘made me think what I want’, gained positive responses (Table 3b). A total of 93% of respondents said the questions were ‘very easy’ to ‘okay’ (Table 3c).

Most stakeholders liked the diagram of healthcare (73%), and reasons for not liking it included the level of understanding required by service users with learning disabilities; people

**TABLE 1. 2015-2016 Mean and positive percentage difference between all first and second Health Equality Framework assessments following interventions (n=186)**

Identifier	Initial social	Final social	Initial biological	Final biological	Initial communication	Final communication	Initial personal	Final personal	Initial services	Final services
Mean	7.5	5.7	8.8	5.8	7.6	6.1	5.6	4.5	4.7	3.3
Positive % difference		23.8		34.2		18.7		17.9		30.1

**TABLE 2. 2016-2017 Mean and positive percentage difference between first and second Health Equality Framework assessments for new cases/new episodes following interventions (n=22)**

Identifier	Initial social	Final social	Initial biological	Final biological	Initial communication	Final communication	Initial personal	Final personal	Initial services	Final services
Mean	9.4	6.6	9.6	6.4	7.5	5.7	7.3	5.7	6.1	4.3
Positive % difference		29.9		33.1		23.7		22.0		29.5

on the community learning disability teams' active caseload usually have severe to profound learning disabilities. In most cases there was an attempt to help service users understand the diagram (Table 3d).

There were eight categories of possible help the community learning disability teams could give to service users (Table 3e). Those most notable were related to health and activities, but housing and money also had large responses. The five categories of stakeholder did not differ in their beliefs about the merits of the eight possible interventions (help) provided for this sample size.

Other categories included courts, police and bereavement issues, as well as autism and complex health needs. Some feedback comments are shown in Box 1.

### Discussion

This is the first evaluation of service users' and carers' views of HEF assessments and demonstrates that stakeholders – including service users, family carers, paid support staff, Worcestershire Health and Care NHS Trust staff and Worcestershire County Council staff – believe it helped service users and carers, and reduced healthcare inequalities. The questions

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**TABLE 3a. 2016-2017 Evaluation of stakeholders' views of Health Equality Framework (HEF) assessments: 'the HEF has helped me?' (n=41)**

Stakeholder	Yes	No	Looked at me as a person	Helped me to access services	Looked at my health
Service users	7	0	4	4	6
Family carers	7	0	2	2	4
Paid support workers	7	0	1	2	3
NHS trust staff	14	1	9	3	9
Worcester County Council staff	5	0	5	2	4

**TABLE 3b. 2016-2017 Evaluation of stakeholders' views of Health Equality Framework (HEF) assessments: 'I like the HEF because it?' (n=41)**

Stakeholder	Helped me make a new plan	Made me think about what I wanted	Other
Service users	4	1	3
Family carers	3	1	1
Paid support workers	3	0	1
NHS trust staff	5	7	1
Worcester County Council staff	3	2	2

**TABLE 3c. 2016-2017 Evaluation of stakeholders' views of Health Equality Framework assessments: 'I found the questions...?' (n=41)**

Stakeholder	Very easy	Easy	Okay	Difficult	Very difficult	Not sure
Service users	0	1	3	1	0	1
Family carers	3	1	1	0	0	
Paid support workers	2	1	1	0	0	
NHS trust staff	5	3	7	0	0	
Worcester County Council staff	0	1	3	1	0	

were understood by service users and carers and easy for healthcare staff to ask. However, the pentagon or spider diagram, that describes outcomes for service users, was not universally approved of, although 73% of stakeholders liked it, most often following explanation.

The caseload in Worcestershire is made up of people with severe to profound learning disabilities, so this is to be expected. However, Ward et al (2016) cautions practitioners not to be a barrier to people with severe and profound learning disabilities who can participate if given enough support.

All eight of the ways that HEF assessments and community team interventions assist people with learning disabilities were regarded as important by stakeholders, with health and activities scoring most highly, although housing and money were also frequently scored as positive.

The HEF (Atkinson et al 2013, 2015) is beginning to reduce the high number of premature deaths and health inequalities in people with learning disabilities (Mencap

2012, Helsop et al 2013). It is the first outcomes-based assessment tool that considers the healthcare of people with learning disabilities holistically and its use is spreading across the UK (Hebron et al 2014, Duff 2016, V-connect 2017). Evaluation against other measures is positive, for example for Down's syndrome (van den Driessen Mareeuw et al 2017) and it is being piloted for use with other groups of vulnerable people.

Service users' and carers' views are increasingly important in the design, development and assessment of new healthcare initiatives and Atkinson et al (2013) consulted with service users and carers on the design and development of the HEF. However, there is little literature on learning disability service users' participation in this field, apart from in higher education (Bollard et al 2012, Ward et al 2016) and wider service users' and carers' involvement through participation in selection, teaching and learning, curriculum design, research and quality for students (Rooney et al 2016).

**TABLE 3d. 2016-2017 Evaluation of stakeholders' views of Health Equality Framework assessments: 'diagram of my health care' (n=41)**

Stakeholders	Liked?			Someone helped me to understand the diagram?	
	Yes	No*	Not sure	Yes	No*
Service users	5	1	1	3	2
Family carers	4	3		2	1
Paid support workers	3	1		3	0
NHS trust staff	8	1		3	1
Worcester County Council staff	2	0	1	2	0

\*The service user, and other stakeholders, felt that it was not possible for service users to understand the diagram due to the severity of the learning disability

**TABLE 3e. 2016-2017 Evaluation of stakeholders' views of Health Equality Framework assessments: 'The learning disability team has helped me with...' (n=41)**

Stakeholders	Better health	Health eating	Activities	Housing	Health action plan	Money	Feelings about my health	Other
Service users	7	3	2	1	5	3	3	3
Family carers	4	1	2	1	4	0	3	1
Paid support workers	2	1	1	1	3	1	0	2
NHS trust staff	8	3	4	3	5	2	6	1
Worcester County Council staff	4	4	3	3	1	3	2	3

## Conclusion

Over the two-year evaluation period, the HEF assessments, before and after interventions, improved the health and well-being of people with learning disabilities in Worcestershire. This small-scale evaluation demonstrates that service users and carers appreciate the significance of the framework in terms of transforming their lives, enabling them to live longer and lead self-determined lives, with choice and control.

### BOX 1. Feedback and comments from stakeholders

- » Service user: 'The outcomes of the Health Equalities Framework 'Helped me feel happy'.
- » Paid support worker: 'Initiated a real change in support plan, new carer support, new activities - improvement in health.'
- » NHS trust staff member: 'A useful tool, helping to take a fresh look at individuals' health and impact on life choices.'
- » Worcestershire County Council staff member: 'Helped to access mental health services for ongoing support.'



### Implications for practice

- » It should not be assumed that service users with learning disabilities cannot understand the Health Equalities Framework (HEF) assessment process or its significance in improving their health and well-being.
- » Practitioners need to help service users understand the pentagon or spider diagram generated by the electronic HEF assessment tool.
- » Families who are carers and paid support workers should also be helped to understand the significance of the HEF and the resulting pentagon or spider diagram.
- » This evaluation gave health practitioners and social workers information about, and confidence in, adopting the HEF in general practice.
- » A large-scale study of stakeholders, using the easy-to-read evaluation tool, could confirm or refute the outcomes of this evaluation.
- » Such evaluations with stakeholders could be carried out with other vulnerable groups, for whom the HEF is being designed and piloted.

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