What is the Health Equalities Framework?

- An evidence based outcomes framework for people with learning disabilities
- Systematically developed
- Measures the impact of care and support in reducing / mitigating the impact of, exposure to determinants of health inequalities
- Launched March 2013

Why was it developed?

- Winterbourne
- Death by indifference
- Confidential Inquiry into premature deaths
- Increased focus on outcomes within policy
- Increasing focus on equalities (equalities legislation, public health agenda etc)
- Changing commissioning structures
- Service reconfigurations
- Strengthening the Commitment

What it is not

- Based on a medical model
- A tool for nurses
- An approach that locates the ‘problem’ within the person
- A way of measuring symptoms, illness or conditions
- A way of measuring if people are “getting better”

What does it do?

- Helps practitioners make sense of health issues
- Guides practice
- Influences priorities with health action plans
- Provides information which informs strategic planning re skill mix, training & development
- Informs commissioning decisions
- Informs public health strategy
- Provides performance data

The challenge of demonstrating outcomes in learning disabilities

- Wide variations in service models & structures
- Varied / changing commissioning structures & priorities
- No authoritative comparative national dataset relating to the health of people with learning disabilities
- Lack of gold standards (no valid outcome measures)
- Little research on outcomes in LD (nursing) practice
- Disparate patterns of needs

How was it developed?

- Review of evidence
- Pilot work
  - Census: 233 service users; 20 nurses; 4 localities
  - MDT longitudinal pilot Gloucestershire
- Consultation
  - NDTi commissioning reference group
  - Local partnership boards / health subgroups
  - Self advocacy groups
  - Service quality checkers
  - National Valuing Families Forum
- Delphi technique
  - Full UK Consultant Nurse Network
  - Learning Disability Professional Senate
  - Royal Colleges

Making sense of health inequalities

Five Determinants of Health Inequality

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

How does the HEF work?

- Register the service user and record their needs
- Consider the impact of exposure across 29 indicators to the 5 determinants
- Input ratings for exposure
- View HEF profile and decide what needs to be done differently

All HEF materials including software, manuals and guides for service users & family carers can be downloaded from the NDTi website and used free of charge.
The HEF for people who use services: Meet Ray

Ray was a 64 year old man with a moderate learning disability, he had lived in his own home for a number of years with just a few hours support each week. His workers referred him to the local community team. He had become withdrawn and uncommunicative; he was reclusive, didn’t want to go out or do the things he used to enjoy and seemed generally unhappy. At times he would be verbally abusive towards his support workers who thought he was being awkward and wanted help to manage his ‘challenging behaviour’.

Ray had also started to lose quite a bit of weight but hadn’t seen a doctor for years.

The community nurse helped Ray to see his GP for an annual health check. He was found to have terminal prostate cancer. He was receiving no treatment or pain relief, was thoroughly miserable, had lost contact with former friends and had no family.

The nurse profiled Ray’s exposure to determinants of health inequality using the HEF; he had high levels of exposure across all determinants placing him a high risk of serious health inequalities such as reduced life expectancy and poorer quality of life than someone without a learning disability who had a similar tumour.

The nurse worked with other members of her team. They supported the GP and other health staff to make reasonable adjustments to their care pathways so Ray could be fully assessed, receive an accurate diagnosis and access treatment. They developed a visual pain communication tool so that Ray’s support workers could recognise when he was in pain. Ray moved to a nursing home where he could get the right care and support.

The community team worked with the new staff to help them understand how to communicate effectively with Ray and how best to meet specific needs related to his learning disability.

The team started building a history of Ray’s life to identify things and people that had been important to him. They were able to reconnect him with some old friends and enable a more varied lifestyle with Ray starting to do the things he used to enjoy, when he felt well enough. They also worked with the palliative care team to develop a person centred end of life plan.

As a result of these and other interventions, using the HEF, the team were able to demonstrate that they had reduced Ray’s exposure to the determinants of health inequality. He was still terminally ill but could now have a similar life expectancy and quality of life to anyone else living with similar health problems.

The power of aggregated data

- Analysis of pilot data over a 6 month period showed significant differences across 2 neighbouring community teams:
  - Team A: threefold prevalence of mental health problems; fivefold prevalence of sleep problems; twice as many people with autistic spectrum conditions; 75% more mild learning disability; 33% more moderate learning disability; mean age 33 yrs...
  - Team B: threefold increase in sensory impairments; twice as many people with physical impairments; a fivefold increase in wheelchair users; twice the prevalence of epilepsy; 60% more severe learning disability; mean age 49yrs...
  - Team A demonstrated a 16% mean greater reduction in the impact of exposure to determinants than team B
  - Across both teams:
    - Males showed greater reductions than females
    - People aged 25-54 showed greater reductions than either younger or older groups
    - People with moderate / mild LD showed greater reductions in the impact of exposure to the determinants of health inequality

- The teams were found to be most able to reduce the impact of exposure to the determinants by:
  - Enhancing the ability of carers to respond to signs of ill health
  - Ensuring a current assessment of health status was undertaken
  - Supporting people to access long term conditions pathways

- The teams struggled to mitigate the impact of exposure to:
  - Hazardous sexual health behaviours
  - Poverty
  - Weight problems

Benefits of the HEF

- Profile someone today ✡ Change the way they are supported tomorrow
- Indicators are important & relevant; they establish a consensus around the objectives of care & support
- Indicators are valid: face validity / construct validity
- Data can be gathered in a cost effective manner (free software, minimal training required, 20 minutes to complete a profile)
- Variation in service outcomes can be identified & data disaggregated to aid understanding of variances
- Analysis of performance data supports decision making about improvements to service systems
- Can inform commissioning decisions
- Can inform public health strategy

The Future of the HEF

- eLearning package
- Linked care pathways
- Research
- Large scale Scottish pilot
- Welsh pilot
- Children & young peoples’ version
- Other marginalised populations

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