NHS
London

Benchmark of Best Practice

Healthcare for Vulnerable People

BENCHMARK STATEMENT

Vulnerable people receive NHS funded care
which is safe, effective and person-centred

SEPTEMBER 2010

Contents

Foreword

In March 2007 Mencap published a national report, Death by Indifference, which set out case studies relating to six people with learning disabilities. Mencap believe that they died unnecessarily as a result of receiving worse healthcare than people without learning disabilities.

The Report of the NHS and Local Government Ombudsmen into these six cases (Six Lives: the provision of public services to people who have learning disabilities) found significant and distressing failures in service across health and social care.

These reports show the impact of organisational behaviour which does not adapt to individual needs, or even consistently follow procedures designed to maintain a basic quality of service for everyone. They identified a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights. This led to situations in which people with learning disabilities were treated less favourably than others, resulting in prolonged suffering and inappropriate care.

The policy framework in this area includes, in particular, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Valuing People) issued in 2001 (and *Valuing People Now 2008*), which requires public services to treat people with learning disabilities as individuals, with respect for their dignity. Other general guidance, in particular the professional standards set out by the General Medical Council and the Nursing and Midwifery Council, stresses the importance of looking at the individual, of personal accountability, the interests of patients and the need for co-operative working.

There are now in place a number of recommendations for public services. These include;

That all NHS and social care organisations in England should review urgently:

- the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas;
- the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities.

This tool was created by bringing together interested learning disability clinicians and clinical leaders, and self advocates and their supporters and enabling them to analyse information from a number of sources.

This energetic and lively group then spent a day working together to devise the following benchmarks.

NHS London is pleased to make this contribution to the Mencap campaign ‘Getting It Right’. As a Strategic Health Authority it is not possible to deliver all the pledges of the campaign, but by providing organisations with tools with which to measure their performance and upon which to build future development, we can show our support for the aspirations expressed in the campaign.

We commend this approach to all organisations keen to measure and develop their services, and to contribute in the longer term to the body of evidence for healthcare for vulnerable people.

Trish Morris Thompson
Chief Nurse
NHS London

BENCHMARK STATEMENT

Vulnerable people receive NHS funded care which is safe, effective and person-centred

The Benchmarks

The benchmarks avoid solely referring to people who have learning disabilities; often refering to vulnerable people generally. This reflects the adage that 'if you get it right for people with learning disabilities, you get it right for everyone', certainly in the opinion of the development group.

Where there are specific references to people who have learning disabilities, this is due to clear evidence that this issue or risk applies to this group of people and therefore action is required.

This is most evident in Factors such as *Knowledge Skills and Values*. Evidence heard at the Michaels Enquiry confirmed research findings; that mainstream practitioners lack understanding of the impact of learning disability on a persons health, and can sometimes bring value judgments to the decision-making process based on perceptions of a persons quality of life. This can no longer be unchallenged.

Similarly, in *Factor: Outcomes*, an indicator is expressed in terms of post-mortems routinely sought, and other references to diagnostic overshadowing. A significant number of deaths of people with learning disabilities are not investigated post-mortem sometimes due to the low expectations of those involved in treating them: the death is an acceptable outcome, no matter what the age or condition of the person. In many cases, learning disability or a similar condition (e.g. Down Syndrome) listed as the cause of death.

These benchmarks give organisations explicit indicators which can be used to challenge, or at least question some of these decision-making processes.

In one respect, this document veers from the principle of the benchmarks being 'Patient-focussed'.

The group chose to include a Factor and Indicators which reflect the attributes, skills and supports of staff in 'new' specialist roles such as Acute Liaison Nurse or Strategic Health Facilitator.

Some organisations have chosen to invest in these roles as a 'reasonable adjustment' of their services. However, evidence suggests that these posts often lack the links into organisational clinical governance, and professional advisory and leadership processes, leading in some cases to isolation and difficulty in influencing services and workforce.

It is hoped that those designing or managing these roles will use the benchmark to provide quality assurance for those who are using services.

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Introduction

This document contains the toolkit for benchmarking NHS funded services approach to vulnerable people.

The Benchmarks should be used in the spirit of *ESSENCE OF CARE* benchmarking tools and it is intended that NHS funded organisations use this document to measure their effectiveness and address issues of concerns within their organisations.

CONTENT OF BENCHMARKING TOOL

The benchmarking toolkit comprises of:

- an **overall patient-focused** outcome that expresses what patients and or carers want from care in a particular area of practice
- a number of **factors** that need to be considered in order to achieve the overall patient-focused outcome

Each factor consists of:

- a patient-focused **benchmark of best practice** which is placed at the extreme right of the continuum
- a **continuum** between poor and best practice. The benchmark for each factor guides users towards best practice
- **indicators** for best practice identified by self advocates and professionals that support the attainment of best practice
- information on how to use the benchmarks
- accompanying forms to facilitate documentation

Benchmarking Process

STAGE ACTIVITY

One

- Consider the patients' or carers' experiences and outcomes, and how current care is delivered. The clinical governance questions and general indicators (see appendix one and two) may provide useful guidance at this step
- Establish a comparison group *
- Consider the overall outcome and the benchmarks of best practice
- Using the general indicators and specific indicators agree the evidence that the comparison group consider necessary to be provided in order to achieve the benchmarks of best practice

Two

- Obtain baseline information by observing against best practice, using audit and involving patients in the clinical area
- Consider the indicators and provide evidence that represents current achievement towards best practice
- Consider barriers which prevent achievement of best practice
- Compare and share best practice so that good practice is not wasted. Some comparison groups find considering their positions on an E (poor practice) to A (best practice) continuum useful to stimulate discussion
- General indicators are common to all sets of benchmarks. Specific indicators are particularly relevant to the factor with which they are identified.

Three

- Produce an action plan detailing:
  - the changes that need to be made
  - who is responsible for leading the changes
  - the time scale in which these should occur
- Actions should be realistic, achievable and measurable
- Carry out the action plan

Four

- Document activities, any improvement, problems and or unexpected observations
- Analyse data and evaluate actions - did the patients' or carers' experiences or outcomes improve? Did service delivery benefit from changes made?
- If there is no improvement review activities in action plan
- Share with comparison group

Five

- If improvements are identified, disseminate improvements and good practice and implement change as widely or review action plan as appropriate through comparison group and other organisational systems
- Include in organisation's business planning cycle, clinical governance plan and quality report via relevant managers, and clinical governance and quality leads

Six

- Agree best practice as stage one.

Data Collection

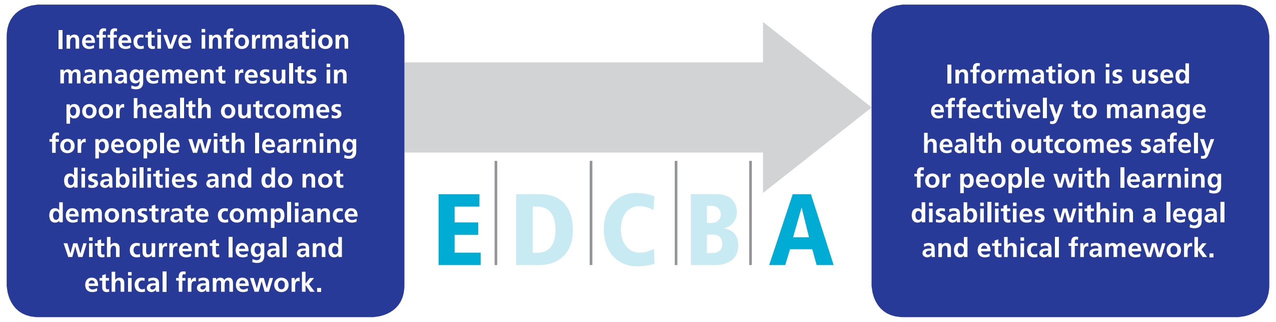
In order to support the review and updating of this document, NHS London appreciates your support with data collection.

A loose leaf data collection sheet is inserted into this document. This can be scanned in and emailed to mariska.barnett@london.nhs.uk or Stephan.brusch@london.nhs.uk, or posted to Mariska Barnett or Stephan Brusch, NHS London, Southside, 105 Victoria Street, London SW1E 6QT.

**The aim of the comparison group is to compare and share practice likely to contribute to attaining the benchmarks. This is in order that members can support each other in progressing towards best practice. A comparison group may consist of individual health care personnel, members representing a team, members representing an organisation and so on. The group should include individuals who have an interest in achieving best practice as well as individuals who can represent patient and or carer involvement in the process.*

FACTORS

Factor:
Information Systems



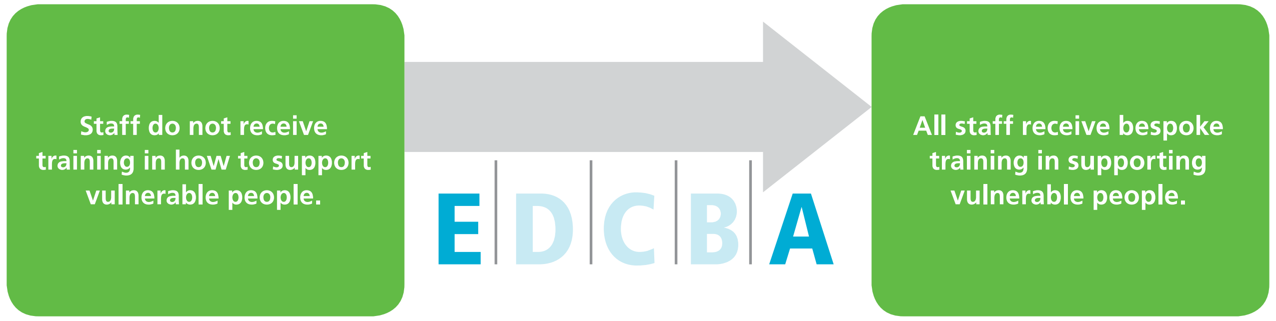
Ineffective information management results in poor health outcomes for people with learning disabilities and do not demonstrate compliance with current legal and ethical framework.

Information is used effectively to manage health outcomes safely for people with learning disabilities within a legal and ethical framework.

INDICATORS OF BEST PRACTICE

- Systems are used to identify people who require adjustments to be made for healthcare to be safe and effective.
- Systems support the use of person-centred records including passports and health plans.
- Systems support the use of, and direct clinicians to use the Mental Capacity Act to support consent and decision-making.
- Systems support the production of materials in a range of formats.
- Systems provide information on learning disability healthcare, legal considerations and provide links into Learning Disability Specialist Services.
- Systems support data-gathering and audit activity including identifying learning disability as a factor in patient safety incidents, complaints and compliments and litigation activity.
- The Data Protection Act is used to support best practice in information sharing to support Safeguarding Adults
- IM&T strategies are explicitly Equality Impact Assessed for their impact upon and accessibility to people with learning disabilities.

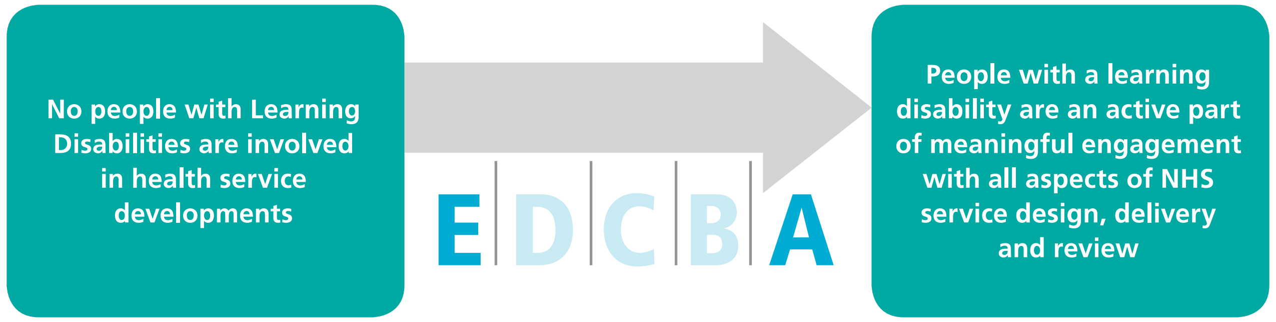
Factor:
Knowledge, skills & values



INDICATORS OF BEST PRACTICE

- All staff receive Learning Disability focussed training
- All clinical staff receive training in capacity and consent, and the law as it relates to consent, rights and discrimination.
- Learning Disability focussed training is developed and delivered in partnership with self-advocates and family carers
- Training covers:
  - Diagnostic overshadowing
  - Health issues for people with Learning Disabilities
  - Risk assessment and management
  - Where to find help, Communication
  - Using Personal Health Records
  - Including Learning Disability Issues in Equality
  - Impact Assessments.
- Training statistics are reviewed by the Clinical Governance and Risk Committee, or similar sub-group of the Trust Board.
- Training content reflects learning from national and local incidents, serious case reviews and reports, including Safeguarding Adults Incidents.
- Training incorporates examples of national and local good practice.

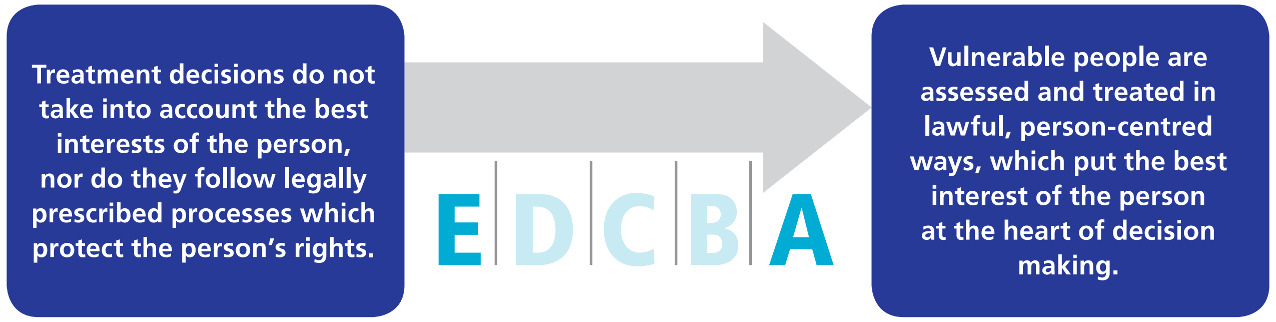
Factor:
Involving People



INDICATORS OF BEST PRACTICE

- People with a learning disability are active in patient and public involvement groups, Foundation Trust Boards (governors and members), Healthwatch and CQC
- All information provided for public domain has an agreed accessible version designed in partnership with self advocates and Speech and Language Therapists.
- An adjustable range of support is available for participation
- Organisational leads reach-out to local groups for views and feedback, with documented outcomes, accountability and follow-up.
- Carer's stories and voices are also heard through feedback mechanisms.
- A range of engagement options are available which are not reliant on the written word, complaints processes or annual surveys including;
  - Random qualitative audit
  - Repeated visits
  - Web-based options for post-episode anonymous comment.
  - Mystery Patient and Carer
  - PALS seeking regular patient stories which are heard by Board members and used to inform service changes.
  - Participation in staff recruitment
- Self advocates and carers receive regular training and support to contribute to the business of the Organisation.

Factor:
Assessment & Treatment



Treatment decisions do not take into account the best interests of the person, nor do they follow legally prescribed processes which protect the person's rights.

Vulnerable people are assessed and treated in lawful, person-centred ways, which put the best interest of the person at the heart of decision making.

INDICATORS OF BEST PRACTICE

- Consent is sought for assessment, examination and treatment, using recognised methods for determining capacity and following principles of best practice where capacity is found to be absent.
- Decision processes reflect the dignity expected for a vulnerable adult
- Personal Health Records both inform, and are informed by, treatment and the processes leading to, and arising from, treatment.
- Reasonable adjustments are made which are designed to give a safe and effective experience of healthcare.
- Behaviour which is described as challenging is not seen as an automatic bar to assessment and treatments, rather the beginning of a process to support the person appropriately.
- The views of people who know the person well are sought and taken into consideration
- Advice and support is sought from partners in all agencies and disciplines to assist the person in their assessment and treatment.
- The care environment is flexible enough to be adapted to meet the needs of individuals, including the needs of their carers for overnight stays or breaks form caring responsibilities.
- Applications made to use Deprivation of Liberty Safeguards are reasonable and proportionate

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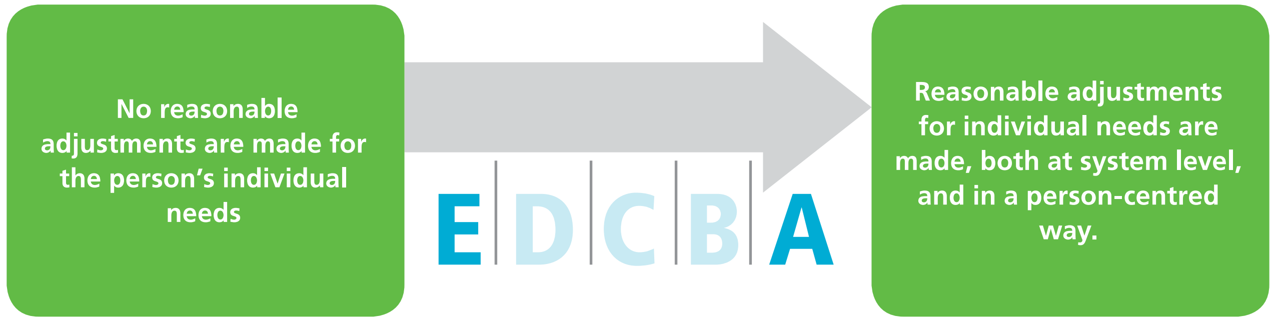
Factor:
Reasonable Adjustments



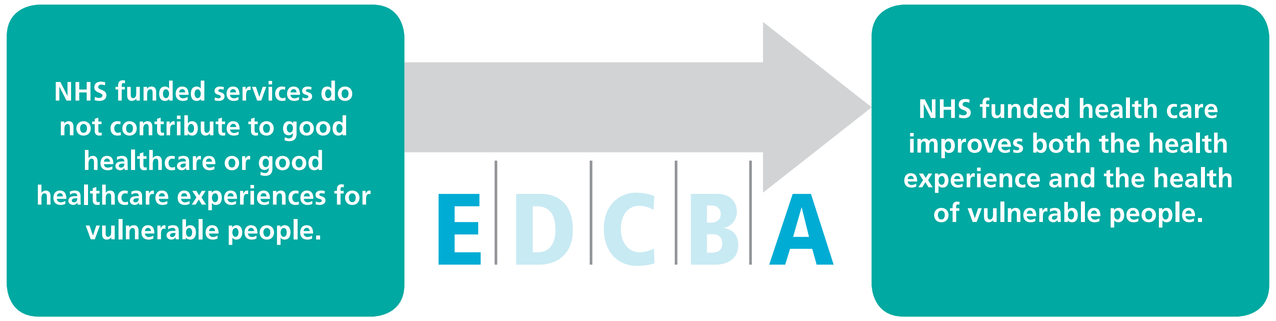
No reasonable adjustments are made for the person's individual needs

Reasonable adjustments for individual needs are made, both at system level, and in a person-centred way.

INDICATORS OF BEST PRACTICE

- Healthcare environmental signage is clear and unambiguous, and the views of vulnerable people are sought in the design and review of the healthcare environment.
- Flexible appointment systems allow for early morning appointments to reduce waiting and longer appointments to facilitate thorough assessment.
- Quiet waiting areas are available for those who need them.
- People are encouraged to use personal health records
- Clinical staff support the completion of personal health records for those who attend without one.
- Clinical staff use the information supplied in personal health records to deliver safe, effective and person-centred care.
- Communication aids, guidelines etc are available and used by all staff.
- Carers need for rest, food and drink and breaks are assessed and accommodated
- Pre-admission visits are routinely offered to minimise admission stress.
- Pain assessments specific to people with learning disability are used and management plans are implemented and regularly reviewed with expert input from those who know the person well.
- Particular attention is paid to screening for dysphagia and nutrition support plans are implemented and closely monitored.
- Particular attention is paid to assessing the support needs for eating and drinking and care plans are implemented and closely monitored.

Factor:
Outcomes



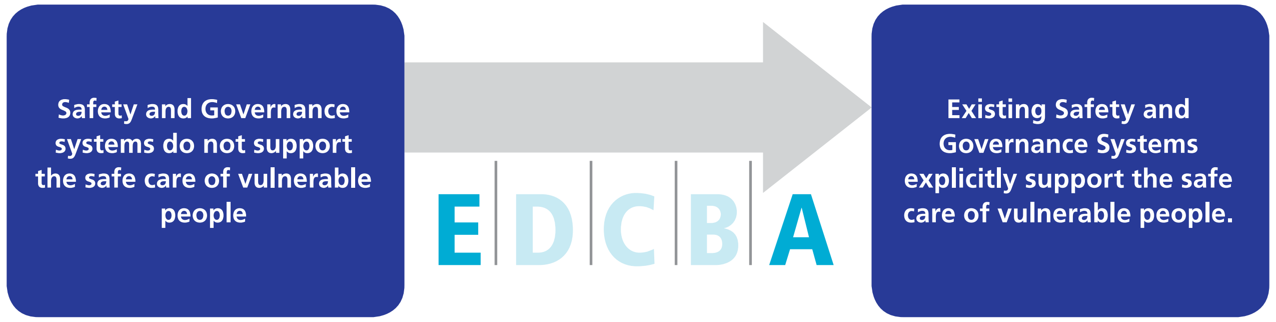
NHS funded services do not contribute to good healthcare or good healthcare experiences for vulnerable people.

NHS funded health care improves both the health experience and the health of vulnerable people.

INDICATORS OF BEST PRACTICE

- Opportunities for greater health impact are explored as part of routine assessment processes. (E.g. where a general anaesthetic is being used, what other investigations can be undertaken opportunistically? Dental or podiatry etc)
- Careful discharge arrangements involve partners across agencies reduce risks relating to premature discharge and medication or follow-up issues.
- Patient Stories are heard at Trust Board level events and used to plan service improvements.
- Human Resources processes are used when evidence suggests discriminatory behaviour.
- People are routinely signposted on to other activity for health improvement and monitoring where assessment reflects current or future needs.
- Post Mortem examinations are actively sought following the death of a vulnerable person.
- Quantitative data is collated to provide information on the care and treatment of vulnerable people and to plan for service improvements. To include data regarding INCA referrals, numbers and types of Best Interest decisions made, length of stay and re-admissions.
- Onward referral and discharge letters include requirements for reasonable adjustments and information pertinent to safe and effective care.

Factor:
Safety



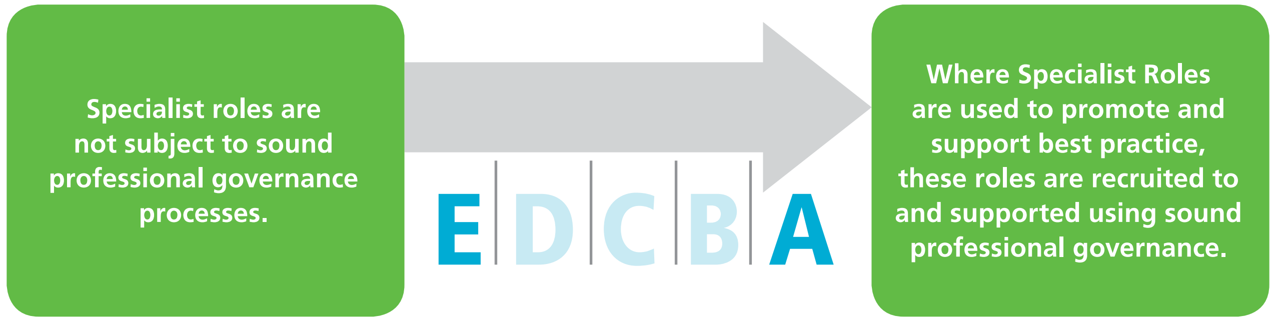
Safety and Governance systems do not support the safe care of vulnerable people

Existing Safety and Governance Systems explicitly support the safe care of vulnerable people.

INDICATORS OF BEST PRACTICE

- Learning Disability themes are identifiable in incident reports, complaints and compliments, litigation reports and in service changes which arise from these.
- Learning Disability issues are discussed and recorded regularly at Trust Board meetings.
- A range of feedback methods are in place which do not rely on complaints and written processes.
- Workforce Development Plans reflect the Organisations ability to deliver safe, effective and person-centred care to vulnerable groups.
- Job Descriptions and KSF outlines reflect expectations, responsibilities and accountability for supporting vulnerable people.
- Personal Review Processes and Development Plans enable individuals to reflect upon their personal responsibility and professional accountability when working with vulnerable people through explicit reference to Job Description requirements.

Factor:
Specialist Roles



Specialist roles are not subject to sound professional governance processes.

Where Specialist Roles are used to promote and support best practice, these roles are recruited to and supported using sound professional governance.

INDICATORS OF BEST PRACTICE

- Sound values base which is embodied as empathy, patience and kindness and which is applied to all interactions
- Specialist knowledge of and experience of meeting the particular health needs of people with learning disabilities
- Knowledge of NHS and social care organisations and the political context of the time
- Expert teacher who brings gravitas and credibility to the role.
- Sound knowledge of IMT systems and the ability to see opportunities for imaginative use.
- Expert communicator who is able to use plain English to convey ideas both verbally and in writing.
- Expert understanding of Clinical Governance and the mechanisms in place to protect users of services.
- Able to work as a team member of many teams, and to work alone.
- Able to use entrepreneurial skills to seek out opportunities, act on them and make them real
- Excellent interpersonal skills
- Good organisation and time managements skills
- Routinely and regularly uses reflective practice supervision to check on the quality of the work and interactions with all people.
- Routinely and regularly participates in Continuous Professional Development Activities which support the sound on-going delivery of excellent service.
- Routinely and regularly participates in professional networking opportunities both internal to the employing organisation and to the local health and social care community.
- Routinely and regularly avails themselves of professional leadership activities with Head of Profession to ensure sound professional governance processes are maintained.
- Remains registered with professional governing body.

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Presenting the Evidence of Current Practice

NAME:	**CONTACT:**

BENCHMARKS BEING CONSIDERED:

FACTOR(S)	**EVIDENCE REQUIRED** (Use general and specific indicators for guidance)

Presenting the Evidence of Current Practice

	CURRENT ACHIEVEMENT TOWARDS BEST PRACTICE	**BARRIERS THAT PREVENT ACHIEVEMENT OF BEST PRACTICE**

Comparison Group Information

COMPARISON GROUP FOR:
(Insert name of team/ward/unit/area/directorate/group/trust/region)

FACILITATOR:

COMPARISON GROUP MEMBERS:

NAME	REPRESENTING	CONTACT DETAILS

Action Planning

WHAT ACTIONS HAVE TO BE TAKEN ACHIEVE BEST PRACTICE?

FACTOR(S)	CHANGES THAT NEED TO BE MADE TO IMPROVE PRACTICE	WHO IS RESPONSIBLE FOR LEADING THE CHANGES	TIME SCALE	REVIEW DATE

Evaluation of Actions

FACTOR(S)	ACTION	PROGRESS REPORT	I* Y/N	P* Y/N	UO* Y/N

Key to Table:
I = Improvement
P = Problem

Benchmarking into Business Planning Cycle

KEY OBJECTIVES	ACTION	RESPONSIBILITY	TIME SCALE	COST

NHS London
Southside
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www.london.nhs.uk