

## Healthcare for people with disabilities

December 2009

### Executive summary

This paper is the final report on the commissioned CHRE policy project on the health professional regulators' role in healthcare for people with disabilities. Reports from Mencap and a Department of Health-commissioned review of access to healthcare for people with learning disabilities have highlighted the problems and impact of substandard care.<sup>1</sup> A Disability Rights Commission report in 2006 found that people with learning disabilities and/or mental health problems were more likely than other citizens 'to experience major [physical] illness, to develop them younger, and die from them sooner.'<sup>2</sup>

Our focus in this work is the role of the health professional regulators. Regulators are only one of a number of influences on the quality of care provided by a health professional to individual patients and service users. Making changes to regulatory activities can help to address problems experienced in healthcare, but we should not assume it is always the most appropriate response. Alongside the regulators, others such as employers, educators, individual professionals and their peer groups, and patients themselves have particular roles and responsibilities to fulfil. This perspective guides our analysis and recommendations through this report.

Health professional regulation can influence the standards of care delivered to people with disabilities through core regulatory activities such as standards and codes of practice, and in education and training. In their responses to us, regulators also discussed other initiatives such as established involvement with groups of disabled people, supplementary guidance for registrants, training fitness to practise panellists in equality and diversity issues, and the opportunity offered by revalidation in delivering improved standards of care in the future.

Reports from patient surveys and disability groups indicate that there is the potential for considerable improvement in healthcare provided to people with disabilities. Problems with access, communication, consent and confidentiality, and making reasonable adjustments to care were reported. Whether disabled or not, patients share common expectations of healthcare and yet the experiences of disabled people are less positive than those of people without disabilities. This is in spite of a duty of disability equality. In the future we expect the numbers of people with a disability to grow. These results leave us concerned

---

<sup>1</sup> Mencap, 2007. *Death by indifference*. Available at <http://www.mencap.org.uk/case.asp?id=52&menuId=53> [Accessed 27 August 2009]; Michael, J, 2008. *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*.

<sup>2</sup> Disability Rights Commission, 2006. *Equal treatment: closing the gap, a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. Available at: [http://83.137.212.42/sitearchive/drc/library/policy/health\\_and\\_independent\\_living/equal\\_treatment\\_closing\\_the\\_g.html](http://83.137.212.42/sitearchive/drc/library/policy/health_and_independent_living/equal_treatment_closing_the_g.html) [Accessed 27 August 2009]

that without additional effort the detriment and substandard care currently experienced by people with disabilities could be more widespread in the future.

It is a cause for concern when patients report the absence of some of the core values of all health professionals such as consent, confidentiality and dignity. As well as undermining care and treatment of individuals, this situation could damage public confidence in the health professions. It suggests action is necessary by the regulators, among others, to promote high quality care and help achieve wider duties of disability equality.

Based on our analysis we recommend that:

- The Government<sup>3</sup> takes action to subject all regulators to the same duties and expectations under disability discrimination legislation. The current Equality Bill would provide a good opportunity to achieve this
- Regulators' disability equality schemes and action plans in the future should consider the regulators' indirect impact on the healthcare received by people with disabilities, and where possible this impact should be monitored and evaluated. Guidance from the Equality and Human Rights Commission would be helpful in meeting this recommendation
- The Government acts to subject all regulators to legislation that clearly states their role in protection of the public and ensuring that registrants adhere to standards necessary for safe and effective practice. This will enhance public confidence in professional regulation
- As regulators review their standards and codes of conduct and competence, they should address issues raised by patients, service users and carers, through surveys and other research, as well as new statutory developments. Supplementary guidance should focus on the ways and means of practising in a safe and effective manner for groups of people with different disabilities as this may be the most effective way of improving care
- Regulators make certain that education and training programmes throughout a registrant's professional life provides skills and competencies necessary for meeting the healthcare needs of people with disabilities
- Regulators work towards meeting the recommendation in *Healthcare for all* and this approach should be reflected in their standards for education and training and through their quality assurance work
- Regulators' plans for revalidation should consider risks of poor care from patients' perspectives. This could inform a targeted approach, and help to remedy the threat of failing to meet the healthcare needs of people with disabilities
- Government departments, service providers, regulators and professional leadership bodies should work with organisations representing the interests of disabled people to facilitate the sharing of good practice in the delivery of healthcare to people with disabilities, through training and service improvements.

We have been encouraged by the responses given to us by some regulatory bodies during the course of this project. Our recommendations aim to build on good practice and they focus on delivering a consistent statutory framework that is allied to responsive, proportionate and agile encouragement of high quality care by regulators. The scale and nature of the response needed from each regulator will be determined in part by the risks

---

<sup>3</sup> Throughout this report, Government refers to the appropriate authority overseeing each regulator. As responsibility for equality legislation has been devolved to the Northern Ireland Assembly, they are the government overseeing the Pharmaceutical Society of Northern Ireland.

posed to people with disabilities of the delivery of substandard healthcare. However, the task of maintaining public confidence in the health professions is common to all regulators.

## Introduction

- 1.1 The Council for Healthcare Regulatory Excellence is an independent body accountable to Parliament. Our primary purpose is to promote the health, safety and well-being of patients and other members of the public. We scrutinise and oversee the health professional regulators<sup>4</sup>, work with them to identify and promote good practice in regulation, carry out research, develop policy and give advice.
- 1.2 This paper is the final report on the commissioned CHRE policy project on the regulators' role in healthcare for people with disabilities. It reports on the responses we have received from the regulatory bodies, feedback and material supplied by disability organisations and our analysis and recommendations.

## 2. Background

- 2.1 This project was commissioned by the Department of Health under section 26(7) of the NHS Reform and Health Care Professions Act 2002. The commission came in two stages. The first stage drew on the outcomes and recommendations of Sir Jonathan Michael's review<sup>5</sup> into access to healthcare for people with learning disabilities, specifically its recommendations around education and training of health professionals. This formed part of the Department of Health's learning disabilities strategy, Valuing People Now.<sup>6</sup> The second stage of the commission arose following discussions between CHRE, DH, officials in the devolved administrations and the Equality and Human Rights Commission. This extended the scope of the project in the light of subsequent reports, such as *Six lives: provision of public services to people with learning disabilities*<sup>7</sup>, and built on CHRE's experience of providing advice to ministers on health professional regulation. This led to a scope that took a wider view of the functions of health professional regulators and to consider the range of regulators' contributions to addressing the problems highlighted in these report for people with disabilities. The two commissioning letters can be found in Annex 1.
- 2.2 Health outcomes for people with disabilities are often found to be less good than those who do not have a disability. A Disability Rights Commission report in 2006 found that people with learning disabilities and/or mental health problems were more likely than other citizens 'to experience major [physical] illness, to develop them younger, and die from them sooner.'<sup>8</sup> Sir Jonathan Michael's report described the range of actions necessary to ensure people with learning disabilities receive the 'services they are entitled to expect'. This review was prompted by Mencap's 2007

---

<sup>4</sup> General Chiropractic Council, General Dental Council, General Medical Council, General Optical Council, General Osteopathic Council, Health Professions Council, Nursing and Midwifery Council, Pharmaceutical Society of Northern Ireland, Royal Pharmaceutical Society of Great Britain

<sup>5</sup> Michael, J, 2008. *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*.

<sup>6</sup> HM Government, 2009. *Valuing people now: a new three-year strategy for people with learning disabilities*. Available at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093377](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377) [Accessed 27 August 2009]

<sup>7</sup> Health Service Ombudsman, 2009. *Six lives: the provision of public services to people with learning disabilities*. Available at:

[http://www.ombudsman.org.uk/improving\\_services/special\\_reports/hsc/six\\_lives/index.html](http://www.ombudsman.org.uk/improving_services/special_reports/hsc/six_lives/index.html) [Accessed 27 August 2009]

<sup>8</sup> Disability Rights Commission, 2006. *Equal treatment: closing the gap, a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*. Available at:

[http://83.137.212.42/sitearchive/drc/library/policy/health\\_and\\_independent\\_living/equal\\_treatment\\_closing\\_the\\_g.html](http://83.137.212.42/sitearchive/drc/library/policy/health_and_independent_living/equal_treatment_closing_the_g.html) [Accessed 27 August 2009]

report into the deaths of six people with learning disabilities<sup>9</sup> in health and social care settings. The particular details of each of these cases were investigated by the Health Service Ombudsman, who reported in March 2009.<sup>10</sup>

- 2.3 Health professional regulators must meet obligations under disability discrimination legislation to promote disability equality actively. In England, Scotland and Wales, this is articulated in the Disability Discrimination Act 1995 as the Disability Equality Duty:

*The basic requirement for a public authority when carrying out their functions is to have due regard to do the following:*

- *promote equality of opportunity between disabled people and other people*
- *eliminate discrimination that is unlawful under the Disability Discrimination Act*
- *eliminate harassment of disabled people that is related to their disability*
- *promote positive attitudes towards disabled people*
- *encourage participation by disabled people in public life*
- *take steps to meet disabled people's needs, even if this requires more favourable treatment*<sup>11</sup>

Similar legislation applies to organisations in Northern Ireland. Certain public authorities, including some but not all of the regulators we oversee, also must meet additional specific duties that are designed to support the achievement of the general duty.

### 3. Our approach

- 3.1 In addressing the questions and spirit of the project, we have taken a broad view which considers the actions being taken by health professional regulators to ensure that people with disabilities receive high quality and personalised healthcare from their registrants. We asked the regulators two questions:
- i. What actions have you taken, and are you planning to take in the future, to enable people with disabilities to access and receive high quality healthcare from your registrants?
  - ii. What is your response to the recommendation arising from Sir Jonathan Michael's inquiry into access for healthcare for people with learning disabilities?
- 3.2 The reports highlighted above, in paragraph 2.2, describe the disproportionate detriment experienced by certain groups. During this project we have discussed the issues with organisations representing the interests of people with disabilities and reflected on other research data to understand in greater detail the nature of concerns about the provision of healthcare.

---

<sup>9</sup> Mencap, 2007. *Death by indifference*. Available at <http://www.mencap.org.uk/case.asp?id=52&menuId=53> [Accessed 27 August 2009]

<sup>10</sup> Health Service Ombudsman, 2009. *Six lives: the provision of public services to people with learning disabilities*. Available at: [http://www.ombudsman.org.uk/improving\\_services/special\\_reports/hsc/six\\_lives/index.html](http://www.ombudsman.org.uk/improving_services/special_reports/hsc/six_lives/index.html) [Accessed 27 August 2009]

<sup>11</sup> Disability Rights Commission, 2006. *Doing the duty: an overview of the Disability Equality Duty for the public sector*. Available at: <http://www.dotheduty.org/> [Accessed 27 August 2009]

## 4. Views from the regulators

4.1 We consider the replies to the questions we posed the regulators in four parts:

- Standards and guidance
- Education and training
- Other functions and activities
- Specific response to *Healthcare for all* recommendation

### *Standards and guidance*

4.2 Regulators responded highlighted key aspects or elements of their core standards in their responses to our first question. Standards and codes of conduct, with associated guidance materials are the foundation stone of professional regulation. They inform not only the day to day practice of health professionals, but also education and training before and after registration, issues of fitness to practise, and through these functions, standards also impact on registration. Different regulators take different approaches to this function. Some produce core standards, with supplementary codes and guidance available for particular roles or situations. Others work closely with professional organisations to deliver the balance of principles and detailed guidance that is necessary for the practice of healthcare. Specific guidance is not always issued to address the delivery of healthcare to people with disabilities. In those instances, regulators highlighted aspects of their generic standards and guidance that outline their expectations around the provision of patient-centred care, demonstrating respect for patients' dignity and observing anti-discrimination legislation, including that specifically focused on disabilities.

4.3 The General Chiropractic Council highlighted their recent review of the Code of Practice and Standard of Proficiency, effective from mid-2010. Standard A3 states the legal duty of chiropractors to promote equality and to tackle discrimination when it occurs. As part of meeting this standard, chiropractors must make sure their own beliefs and values do not prejudice patient care.

4.4 The General Dental Council told us they expect their registrants to adhere to their standards and to be aware of and observe the laws and regulations that impact on their practice, such as the Disability Discrimination Act. They referred to those aspects of their guidance that emphasise dignity, patient-centred care and the duty to treat patients fairly and not to discriminate.

4.5 The General Medical Council informed us about their work in 2007 with the Disability Rights Commission to help doctors understand how to apply *Good Medical Practice* when working with people with disabilities. They referred to an online 'GMP in Action' case study, developed with advice from Mencap, which seeks to specifically address issues raised in *Death by indifference*. Doctors can access a series of resource guides through the GMC website to help with issues that may arise around diversity and equal opportunities.

4.6 The General Optical Council explained that their competencies had recently been reviewed and that they were satisfied that they covered the need for their registrants to communicate effectively with all patients, including those with disabilities.

4.7 The General Osteopathic Council's standards and code of practice highlights the need to make reasonable adjustments for disabled people and that osteopaths must be sensitive to the 'special needs and requirements of disabled patients.'

4.8 Common standards of conduct, performance and ethics apply across the 14 different professions regulated by the Health Professions Council. These include acting in the best interests of service users, and communicating properly and effectively with

service users. The HPC issue generic and profession-specific standards of proficiency that describe the standards of knowledge and skills needed for safe and effective practice. The generic standards include practising in a non-discriminatory manner. Some profession-specific standards of proficiency, for example in physiotherapy, set more detailed expectations around providing care that takes account of the physical, psychological, social and cultural needs of individuals.

- 4.9 The Nursing and Midwifery Council revised their code of conduct in 2008 and included specific clauses around equality and diversity, reasonable adjustments and relevant legislation such as the Mental Capacity Act and the Disability Discrimination Act. They have provided detailed advice and guidance to registrants on learning disabilities. The July 2008 issue of NMC news focused on learning disabilities and developing good practice.
- 4.10 The Pharmaceutical Society of Northern Ireland identified three of the eight core principles in their recently revised *Code of Ethics*: Respect and protect confidential information; show respect for others; encourage patients to participate in decisions about their care. The code is supported by guidance, outlining how a pharmacist can deliver high quality care. The revision of the code of ethics involved a number of disability groups. Alongside these standards and guidance, the PSNI are publishing new Community Pharmacy Premises Standards in 2009 to ensure access to a pharmacy for people with disabilities, including wheelchair users.
- 4.11 The Royal Pharmaceutical Society of Great Britain sets out the principles that their registrants must follow in the Code of Ethics for Pharmacists and Pharmacy Technicians: principle 1 requires registrants to make the care of patients their first concern; principle 3 requires registrants to show respect for others; principle 4 requires registrants to encourage patients to participate in decisions about their care. They also highlighted their supplementary guidance on patient consent.

### *Education and training*

- 4.12 Standards and codes describing regulators' expectations around conduct, performance and ethics in turn influence the education and training given to health professionals and would-be health professionals. However, as the regulators are focused on the outputs from a programme of study that are required for registration, they generally have limited involvement in the details of curriculum design. Post-registration training is recognised through continuing professional development programmes and through specialist registers, once particular qualifications have been achieved.
- 4.13 The GCC reported that the criteria for recognition of chiropractic degrees are being reviewed following the publication of their revised Code of Practice and Standard of Proficiency. This will identify any necessary changes to pre-registration training that the new standard A3 will demand.
- 4.14 The GDC said that they have always specified that aspiring dentists and dental care professionals must have 'experience and competence in treating patients with a range of disabilities including learning disabilities.' The outcomes that the GDC specify for registration are currently under review, and they have commissioned research on patients' needs and expectations about their dental treatment. This will target groups with additional needs, such as people with disabilities. With post-registration education and training, the GDC have recently introduced a new specialist list in Special Care Dentistry, aimed at the treatment of adult and adolescent special needs patients including those with disabilities and learning disabilities. This is complemented by their specialist list in Paediatric Dentistry with

specific learning outcomes relating to children with disabilities and learning disabilities.

- 4.15 The GMC have recently revised their standards for undergraduate training, *Tomorrow's Doctors*. This stresses the importance of competencies that cover the delivery of good medical practice to all patients, including those with a disability. *Tomorrow's Doctors* outlines standards for delivery of undergraduate medical education. Paragraph 20(f) states that medical graduates should be able to 'understand and accept the legal, moral and ethical responsibilities involved in protecting and promoting the health of individual patients, their dependants and the public – including vulnerable groups such as children, older people, people with learning disabilities and people with mental illnesses.' Paragraph 104 states that 'From the start, students must have opportunities to interact with people from a range of social, cultural, and ethnic backgrounds and with a range of disabilities, illnesses or conditions. Such contact with patients encourages students to gain confidence in communicating with a wide range of people, and can help develop their ability to take patients' histories and examine patients.' The Foundation Programme Curriculum for new doctors, jointly approved by the GMC and the Postgraduate Medical Education and Training Board, includes specific reference to patients with disabilities, including learning disabilities, in competencies that cover history taking, communication skills, and treating people with dignity and respect. This curriculum is currently under review and will be completed by the end of 2009.
- 4.16 The GOC reported that current curriculums for optics and optometry demanded that students could demonstrate that they could identify patients' communication needs and adapt their style accordingly. In addition, as part of its quality assurance checks the GOC must be satisfied that approved training institutions and pre-registration scheme providers are meeting the requirements of Equality and Diversity legislation, specifically including the Disability Discrimination Act and Mental Capacity Act.
- 4.17 The GOsC's standards for education derive from their standard of proficiency (see paragraph 4.7). The quality assurance process, through Annual Reports, seeks information about compliance with equality duties including disability equality.
- 4.18 The HPC assess education and training programmes against their standards for education and training with the aim of ensuring that students completing programmes will meet the current standards of proficiency for a particular profession, as outlined above. The standards of education and training refer to the curriculum guidance that is developed by other professional bodies.
- 4.19 The NMC noted that midwifery education already has a standard relating to the care of disabled women and families including those with learning disabilities. HEIs are encouraged to involve disabled people in education as best practice. The NMC is aware of good practice where HEIs involve people with learning disabilities in the delivery of education.
- 4.20 The PSNI administers the pre-registration training year for pharmacy graduates in Northern Ireland. The end of year exam includes disability issues, for example, how to conduct an interview with a person with a disability who is seeking advice. Performance standards are assessed by workplace tutors, and these include respecting confidentiality, appropriate questioning, and responding to spoken and unspoken needs.
- 4.21 The RPSGB has developed a Code of Conduct for Pharmacy Students that will be implemented from 2009/10. It is based on the principles in the Society's Code of Ethics for Pharmacists and Pharmacy Technicians and is designed help students to



develop an understanding of what is required of a pharmacist from the start of their training, including their responsibilities with respect to people with disabilities. Consequently, principles 1, 3 and 4 highlighted above (paragraph 4.11) will be similarly applicable to students. In the pre-registration year, trainees must adhere to the standards in the Code of Ethics. The pre-registration year includes performance standards which must be met including the requirement to act appropriately in response to spoken and unspoken needs of others. Training for pharmacy technicians includes a mandatory requirement for knowledge of disability discrimination legislation and responsibilities under this legislation. There is a requirement for competence in communication, the importance of collecting information about the needs of individuals and the importance of showing empathy. The RPSGB has introduced a Code of Conduct for Pre-registration Trainee Pharmacy Technicians. This mirrors the pharmacy student code. The Society sets minimum requirements for other staff working under the direction, guidance or supervision of a pharmacist, including pharmacy/dispensing assistants and medicines counter assistants. Assistants are required to have an understanding of the needs of different types of customers and the procedures for dealing with clients who have special needs.

- 4.22 The RPSGB highlighted work on new standards for education that is being undertaken by the DH on behalf of the General Pharmaceutical Council, the new regulatory body for pharmacy in Great Britain that begins work in 2010. The standards are based on nine domains, one of which is 'equality, diversity and opportunity'. Under this domain there is a requirement that 'equality, diversity and opportunity awareness pervades the other domains and all activities' placing equality and diversity at the centre of pharmacy education.

#### *Other regulatory functions and activities*

- 4.23 Beyond the implicit link to standards, a few regulators remarked on particular opportunities to influence the delivery of care through their fitness to practise procedures. The GCC told us that 'if there is a finding against the chiropractor, we will report the outcome and the key learning points in the relevant Fitness to Practise report. These annual reports are distributed direct to every registrant.' The GMC discussed their work to pilot a specialist support scheme for vulnerable witnesses involved in their fitness to practise cases. This includes guidance for staff and panellists highlighting issues such as the need to ask questions that are capable of being understood and making reasonable adjustments to accommodate anyone who may have a disability. There are plans to develop a Virtual Reality hearing room to enable witnesses to become familiar with the venue ahead of the hearing itself. The GMC are developing an easy read leaflet for people with learning disabilities on how to complain about doctors.
- 4.24 Continuing professional development and revalidation processes were highlighted as potential levers for change by some regulators. Referring to their continuing education and training scheme, the GOC said they saw 'a potential opportunity to consider introducing a specific requirement in respect of dealing with patients with disabilities' as part of reforms leading to revalidation. The results of the GDC's research project, discussed above, will feed into their work on revalidation.
- 4.25 The HPC discussed the indirect influence other work could have on the delivery of healthcare to people with disabilities. They have produced 'A disabled person's guide to becoming a health professional', which includes a chapter for admissions staff, outlining the duties of education providers under the Disability Discrimination Act, including making reasonable adjustments for disabled students. With the help of an

expert advisory group that brought together a wide range of organisations with expertise in disability issues, the GMC has also published guidance on encouraging people with disabilities into medicine: *Gateways to the professions*.

4.26 The NMC has formed an expert panel of disabled people – half registrants and half people with an interest in policy to inform their work and specifically the development of their equality scheme. The GOsC are planning involvement activities in late 2009 with registrants and patients as part of work around their equality scheme. The NMC are members of the Learning Disability Action for Health Group and were involved in the production of *Getting it right*, a leaflet providing practical advice to health professional on working with people with disabilities. The NMC have developed an Easy Read section in their new website, and are examining how they can improve their systems for communicating with disabled people as part of their Fitness to Practice processes.

#### *Response to Healthcare for all recommendation*

4.27 Sir Jonathan Michael's report *Healthcare for all* was published in July 2008 and recommended that:

*Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.*<sup>12</sup>

4.28 Some regulators described activities already underway to meet the recommendation:

- The GCC reported that two of the three institutions that offer chiropractic training will be involving people with learning disabilities and their carers in programme delivery from 2009/10. All three institutions agreed that this issue should be considered in this year's review of the criteria for recognition of programmes
- The GDC highlighted the steps they are already taking to ensure that the needs of people with learning disabilities are taken account of in undergraduate and specialist education and training (see above, paragraph 4.14)
- The HPC have recently revised their guidance to education providers to provide further support on service user involvement in programmes
- The NMC wholeheartedly supported the recommendation and will use it to influence their ongoing review of pre-registration nursing education that includes the development of competencies for learning disability nurses.

4.29 Some regulators' support for the review and the conclusions it reached was more general. The GOC said they 'support the need to ensure education and training are subject to ongoing review and development leading to an improved healthcare service to all patients including those with disabilities.' The RPSGB said:

*We agree that pharmacists and pharmacy technicians must be trained to work with people with different needs ... Where students get exposure to patients we agree that they should be exposed to as wide a group as possible which ideally should include people with learning disabilities.*

4.30 However, some responses expressed notes of caution. Changes to education and training programmes can take time to introduce, involving wide consultation with education providers. In response to the *Healthcare for all* recommendation, the GOC said they 'would be reluctant to single out learning disabilities over any other

---

<sup>12</sup> Michael, J, 2008. *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*.

disabilities. The GOC would expect that all types of disability, and all persons with disabilities, be treated fairly.’ The HPC advised that the focus of their interest in education is not the detail of the curriculum but the outcome from the programme. They also suggested that training in learning disabilities may be highly appropriate for some professions such as occupational therapy, while it would be less relevant for others where a profession’s involvement with service users is quite different, for example, the clinical scientists.

## 5. Views and experiences of patients

5.1 To complement the views expressed by the regulatory bodies, we have sought to understand more about disabled people’s experiences of healthcare and the issues that can arise.

5.2 Healthcare Commission analysis of national patient survey data in England revealed that people with disabilities had a more negative experience of healthcare in surveys of accident and emergency units, primary care trusts and outpatients than people without disabilities.<sup>13</sup> This is not due to differing priorities. Preparatory work for a national patient survey in Scotland has found that disability has little effect on the ranking of issues key to a good inpatient experience: ‘The top ten items for patients who reported limited day-to-day activities were almost identical to those of patients who reported no limitations’.<sup>14</sup>

5.3 Mencap’s report *Death by indifference*<sup>15</sup> threw a clear spotlight on the poor health and social care that led up to the deaths of six people with learning disabilities. Through the testimonies of friends and family, Mencap describe the following issues:

- Ignorance among healthcare services towards people with learning disabilities
- Poor communication with and involvement of patients and carers in treatment decisions
- Failure to attend to basic needs, such as food and pain relief
- Poor continuity of care and communication between teams of professionals

5.4 Following *Death by indifference*, Sir Jonathan Michael’s report<sup>16</sup> in 2008 outlined the factors underlying the unmet health needs of people with learning disabilities, which contribute to the failure to deliver safe, effective and personalised healthcare. These included:

- Difficulties in navigating the healthcare system and accessing appointments
- Difficulties in communicating with health professionals about symptoms and treatment options
- Poorer access to health screening and other health promotion initiatives
- Low levels of staff awareness about the needs of people with learning disabilities

---

<sup>13</sup> Healthcare Commission, 2006. *Variations in the experiences of patients using the NHS services in England. Analysis of the Healthcare Commission’s 2004/2005 surveys of patients.* Available at: [http://www.cqc.org.uk/db/documents/Surveys\\_Variations\\_Report1.pdf](http://www.cqc.org.uk/db/documents/Surveys_Variations_Report1.pdf) [Accessed 7 October 2009]

<sup>14</sup> Reeves R, Bruster S, 2009. *Better together: Scotland’s Patient experience programme. Patient priorities for inpatient care.* Available at: <http://www.scotland.gov.uk/Publications/2009/07/08114927/0> [Accessed 7 October 2009]

<sup>15</sup> Mencap, 2007. *Death by indifference.* Available at <http://www.mencap.org.uk/case.asp?id=52&menuId=53> [Accessed 27 August 2009]

<sup>16</sup> Michael, J, 2008. *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities.*

- Diagnostic overshadowing, the ‘tendency to attribute symptoms and behaviour associated with illness to the learning disability, and for illness to be overlooked’.

5.5 RNID have reported the following experience for people with hearing loss:<sup>17</sup>

- Difficulties in communicating with GP and nurses, and hospital staff
- Difficulties in making an appointment
- Unsure about instructions for medication
- Missed appointments in noisy clinics because name not heard when called out
- Lack of British Sign Language interpreters in Accident & Emergency.

This leads to lack of clarity about health conditions, a greater risk of medication errors, breaches of confidentiality through reliance on family for interpretation, and avoiding consulting because of communication difficulties.

5.6 Recent work by RNIB has contrasted the experience of blind and partially sighted people with views of health professionals.<sup>18</sup> The study surveyed 600 blind and partially sighted people and 500 health professionals in primary and secondary care.

- 95 percent of blind and partially sighted people feel it is important to have health information in a format they can read, but 8 out of 10 blind and partially sighted people said they did not get medicines information in a format they could read
- 1 percent of blind and partially sighted people want information through a carer or relative, while 28 per cent of healthcare professionals thought this was what all blind and partially sighted people wanted
- Two out of 10 blind and partially sighted people said they had missed an appointment because the letter was not in an accessible format
- 7 out of 10 healthcare professionals said they lacked sufficient training to make necessary adjustments; 6 out of 10 lacked resources to provide accessible information.

The impact for blind and partially sighted people includes:

- a loss of privacy and independence
- compromised confidentiality
- safety issues with medicines
- missed appointments
- lack of available and accessible public health and general health information.

5.7 The campaign group Every Disabled Child Matters highlighted some examples of poor basic care in a recent report:<sup>19</sup>

*Accessing basic dental care for my daughter is a nightmare. Because of her physical disability she can't get in to a dentist's surgery, and there is no understanding of her complex needs which mean she doesn't lose her teeth as other children do because she is fed through a tube – so doesn't chew. We had a dentist visit her at home once and he just stuck his hand in her mouth without even washing it first – she was extremely frightened. He didn't stay long after that!*

<sup>17</sup> RNID, 2004. *A simple cure*. Available at: <http://www.rnid.org.uk/VirtualContent/84923/asimplecure.pdf> [Accessed 12 October 2009]

<sup>18</sup> RNIB and Dr Foster, 2009. *Towards and inclusive health service: a report into the availability of health information for blind and partially sighted people*. Available at: <http://www.rnib.org.uk/aboutus/Research/reports/accessibility/Pages/access.aspx> [Accessed 12 October 2009]

<sup>19</sup> Every Disabled Child Matters, 2009. *Disabled children and health*. Available at: <http://www.edcm.org.uk/health> [Accessed 12 October 2009]

5.8 A formal investigation by the Equality Commission for Northern Ireland into the provision of health information for people with learning disabilities concluded that 'much needs to be done to ensure that [health] services are accessible for people with a learning disability.'<sup>20</sup>

## 6. Analysis

6.1 Issues such as confidentiality, consent and good communication are at the heart of healthcare and of regulators' standards, and are fundamental to the delivery of safe, personalised healthcare. It is a cause for concern when patients report the absence of these core values when they are being treated by health professionals. Whether disabled or not, patients share common expectations of healthcare and yet the experiences of disabled people are less positive than those of people without disabilities. In the future we expect the numbers of people with a disability to grow. There is evidence of some good practice by the regulators. However, the reports from patients and carers described in section 5 indicate to us that additional effort is necessary to avoid continuing detriment and substandard care.

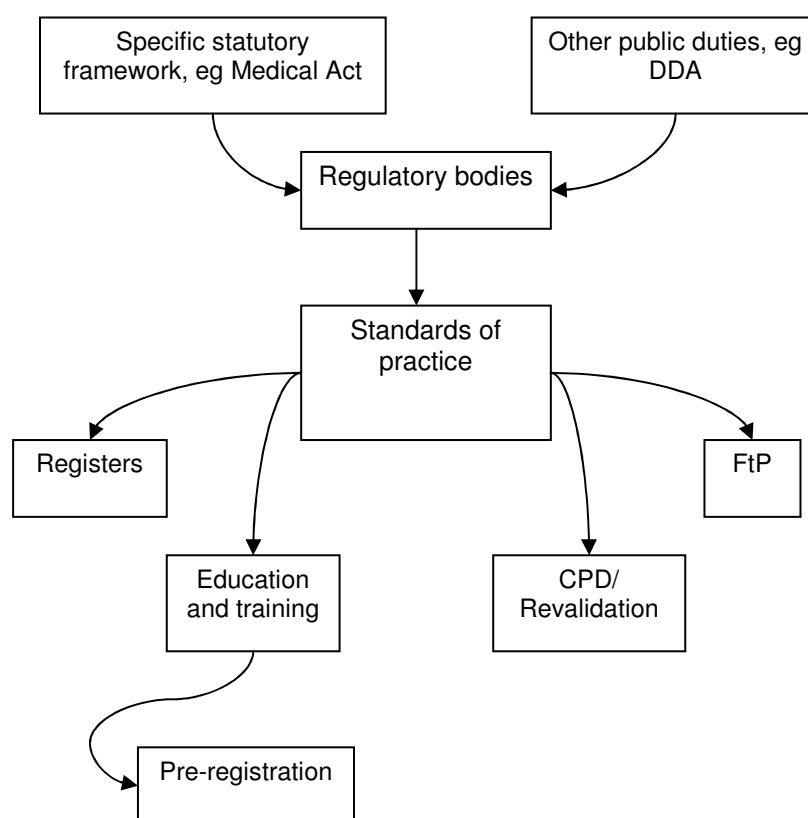
6.2 Our focus in this analysis is on the role of the health professional regulators. Regulators are only one of a number of influences on the quality of care provided by a health professional to individual patients and service users. Making changes to regulatory activities can help to address problems, but we should not assume it is always the most appropriate or proportionate response. Alongside the regulators, employers, educators, individual professionals and their peer groups, and patients themselves have particular roles and responsibilities to fulfil. This perspective guides our analysis and recommendations.

6.3 The figure below outlines the influences working on regulators and those regulators can in turn use in directing the practice of healthcare. The figure also helps to illustrate where action may be taken in the future if improvements are to be made. The recommendations we make below are made in this spirit, as a means of building on current practice to ultimately contribute to improvements in healthcare for people with disabilities.

---

<sup>20</sup> Equality Commission for Northern Ireland, 2008. *The accessibility of health information in Northern Ireland for people with a learning disability*. Available at: [http://www.equalityni.org/sections/default.asp?cms=Publications\\_Disability\\_investigation%20reports&cmsid=7\\_33\\_574&id=574&secid=8](http://www.equalityni.org/sections/default.asp?cms=Publications_Disability_investigation%20reports&cmsid=7_33_574&id=574&secid=8) [Accessed 7 October 2009]

**Figure 1**



- 6.4 Taken together, the regulators' responses have highlighted activity in all the boxes that flow from standards of practice. Standards are at the heart of regulatory activity as they determine registration, practice, education and considerations of fitness to practise. They are essential to maintaining public confidence in the profession. They are reviewed on a regular basis, to ensure they are relevant and up-to-date descriptions of expectations of the practice that is essential for public protection and patient safety. Once revised, changes to other dependent areas of regulatory activity follow.
- 6.5 Influencing the development of standards, among other things, are the specific and generic statutory obligations that may be placed on the regulators. These include the acts and orders that established the individual regulators, any subsequent amendments, plus legislation such as the Disability Discrimination Act.
- 6.6 Some regulators expressed a view that their roles in influencing the delivery of care were limited. We take a more positive view. The regulators set the baseline or threshold of acceptable practice by professionals, and by virtue of this, they are in a position to influence the quality of care that is delivered to patients and service users. Other organisations play important roles, but health professional regulators are the constant influence throughout all healthcare settings and throughout a professional's career. They have the responsibility to protect public confidence in the professions and perhaps to date have been overlooked as potential levers in efforts to maintain an acceptable standard of healthcare for people with disabilities.
- 6.7 Good practice by regulators in promoting disability equality has been highlighted by others. The 2007 DRC report, *Equal treatment: closing the gap – one year on*, commended the GMC on the production of disability equality supplement to *Good Medical Practice*. The progress that the NMC have made in involvement and

engagement of disabled people in their work was highlighted in a 2009 report from Radar.<sup>21</sup>

### *Promoting disability equality*

- 6.8 Regulators' obligations under disability equality legislation were briefly discussed above. Many public authorities will also have to meet a set of specific duties which contribute to meeting the general duty. These organisations are listed in regulations, and the specific duties focus on the production of a disability equality scheme and action plan outlining the steps each organisation is intending to take to meet the general duty. It should focus on making practical improvements to equality for disabled people.
- 6.9 Of the nine regulators we oversee the following have been listed as required to meet the specific duty outlined in the Disability Discrimination Act:
- General Chiropractic Council
  - General Dental Council
  - General Medical Council
  - General Optical Council
  - General Osteopathic Council
  - Nursing and Midwifery Council
- 6.10 The DDA covers England, Scotland and Wales. Different, but similar, legislation covers Northern Ireland. In their Equality and Diversity Policy, the PSNI note that they are not a public authority and therefore not subject to Section 75 of the Northern Ireland Act 1998 which covers equality matters and they are not subject to the Disability Discrimination Act Regulations 2006 Northern Ireland. Having said that, they seek to maintain high standards in the 'application of equality and diversity to all its functions' through recruitment and employment practice, through registration, education and FTP procedures. They consider the policy in terms of registrants and the public.
- 6.11 The presence or absence of the need to meet the specific duty under the DDA (or equivalent legislation) must not be viewed as a verdict on a regulator's competence in this area. Rather, we are highlighting this as a possible area for improvement across professional regulation because of the potential that meeting the specific duty could have on improving disability equality. Work by Radar and the DRC has emphasised the value and contribution that formally meeting the involvement, monitoring and evaluation aspects of disability equality schemes. We recommend a more consistent approach across the regulators on the basis of this, alongside the public demonstration it gives to the prominence of this important issue.
- 6.12 Respecting devolved arrangements, we can find no reasonable rationale for different expectations on regulators to meet the specific duty and the current inconsistencies in the details of disability discrimination legislation could usefully be ironed out. The Equality Bill currently before Parliament will create a new public sector duty and replace the disability equality duty that currently exists. Again, a number of public bodies will be identified and expected to demonstrate how these duties will be met. This would represent a useful opportunity to ensure a consistent expectation of regulators.

---

<sup>21</sup> RADAR, 2009. *Lights, camera, action: promoting disability equality in the public sector*. Available at: <http://www.radar.org.uk/radarwebsite/RadarFiles/Documents/lightscameraaction.pdf> [Accessed 12 October 2009]

- 6.13 **Recommendation** – We recommend that the government takes action to subject all regulators to the same duties and expectations under disability discrimination legislation. The current Equality Bill would provide a good opportunity to achieve this.
- 6.14 Current schemes developed by regulators focus, understandably, on areas of direct influence such as employment, facilities, fitness to practice processes and arrangements, admission to courses. Other healthcare organisations working at arms-length from the point of care such as the National Institute for Health and Clinical Excellence<sup>22</sup> have highlighted in their schemes the indirect impact that their work can have on disability equality for patients. We do not suggest that this is straightforward, but in considering this, regulators would be reflecting on the influence they have on the delivery of care.
- 6.15 **Recommendation** – We recommend that regulators’ disability equality schemes and action plans in the future should consider the regulators’ indirect impact on the healthcare received by people with disabilities, and where possible this impact should be monitored and evaluated by regulators and the Equality and Human Rights Commission. We believe that guidance from the Equality and Human Rights Commission would be helpful in meeting this recommendation.

#### *Regulators’ statutory framework*

- 6.16 In spite of the variety of phrasing, we commonly describe the regulators as working to a main objective of public protection, through their standard-setting, registration and fitness to practise activities. Advice to the Government following the publication of *Trust, Assurance and Safety* indicated that how regulators are constituted helps to enhance confidence in both regulation and the professions.<sup>23</sup> Conversely, anything that allows a perception that professional regulation is not solely and wholly focused on public protection works against the current programme of reforms, undermining public confidence in these organisations and their important work. The governance reforms that were launched by the White Paper are not yet complete.
- 6.17 In recent DH consultations<sup>24</sup> there was strong public support for the ‘principle of giving greater emphasis to the need and importance of public protection’ in regulators’ legislation. An example of this would be the proposed objective for the forthcoming General Pharmaceutical Council:

*The main objective of the Council ... is to protect, promote and maintain the health, safety and well-being of members of the public, and in particular of those members of the public who use or need the services of registrants, or those provided at a registered pharmacy, by ensuring that registrants, and those persons carrying on a retail pharmacy business at registered pharmacies, adhere to such standards as the Council considers necessary for the safe and effective practice of pharmacy*<sup>25</sup>

<sup>22</sup> NICE, 2007. *NICE Equality Scheme*. Available at:

<http://www.nice.org.uk/media/FBC/FC/NICEEqualityScheme.pdf> [accessed 27 October 2009]

<sup>23</sup> Dickson, N, 2007. *Implementing the White Paper Trust, Assurance and Safety: enhancing confidence in healthcare professional regulators - final report and DH response to recommendations*. Available at:

<http://www.dh.gov.uk/en/Managingyourorganisation/Humanresourcesandtraining/Modernisingprofessionalregulation/ProfessionalRegulationandPatientSafetyProgramme/EnhancingConfidenceinHealthcareProfessionalRegulators/index.htm> [Accessed 12 October 2009]

<sup>24</sup> Department of Health, 2009. *Health Care and Associated Professions (Miscellaneous Amendments and Practitioner Psychologists) Order 2009. Consultation Report*. Available at:

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_095920.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_095920.pdf) [Accessed 12 October 2009]

<sup>25</sup> Draft Pharmacy Order 2009. Available at:

[http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH\\_091681](http://www.dh.gov.uk/en/Consultations/Closedconsultations/DH_091681) [Accessed 12 October 2009]



We welcome this for the clarity and detail it provides in this respect but note that the changes necessary to existing regulators' legislation have yet to be made.

- 6.18 **Recommendation** – We recommend that the government acts to subject all regulators to legislation that clearly states their role in protection of the public and ensuring that registrants adhere to standards necessary for safe and effective practice. This will enhance public confidence in professional regulation.

### *Standards of practice*

- 6.19 In their responses, many of the regulators identified the expectation they place on registrants to deliver care centred on the needs of the individual patient. We believe that regulation exists to support and encourage good professionals, providing a framework that outlines expectations and identifies when behaviour falls outside these boundaries of accepted norms. However, reflecting on the healthcare experiences of people with disabilities (paragraph 2.2), it is clear that essential values and standards of healthcare, such as consent, communication and confidentiality cannot be guaranteed. A reliance on calls for patient-centred healthcare in standards in itself may therefore not be sufficient to ensure reasonable adjustments in care and communication, as well as access and treatment, are available for people with disabilities. We acknowledge that the extent of direct influence may be limited, but we believe that the ultimate test of the regulators' performance is the health, safety and well-being of those people being treated by registrants. Standards of practice should represent a reality for patients, not a theoretical aspiration.
- 6.20 Previous reports have highlighted the clear gap between the law, policy and the delivery of services. Some have described this as 'rhetoric without reach'.<sup>26</sup> Through work of other organisations, in the voluntary sector, in academia, in the wider healthcare sector, much is known about patients' experiences and issues with care. This can, we believe, help to inform how regulators can bring standards to life through guidance and good practice notes and communications with their registrants.
- 6.21 Standards should help to raise awareness of appropriate and acceptable behaviour, and specifically in this context they should clearly articulate what a right to equal treatment entails. Evidence suggests this is not always the case. *Healthcare for all* commented that '[Health professionals] commonly fail to understand that a right to equal treatment does not mean treatment should be the same'.<sup>27</sup> The Joint Committee on Human Rights drew attention to the finding from investigations into learning disability services in Cornwall and in Sutton and Merton that 'staff did not believe and understand that they were doing anything wrong'.<sup>28</sup> A 'one size fits all' approach to healthcare does not meet the spirit of equality legislation, and this should be reflected in regulators' standards.
- 6.22 **Recommendation** – We recommend that as regulators review their standards and codes of conduct and competence, they should address issues raised by patients, service users and carers, through surveys and other research, as well as new statutory developments. Supplementary guidance should focus on the ways and

---

<sup>26</sup> Joint Committee on Human Rights, 2008. *A life like any other? Human Rights of Adults with Learning Disabilities*. Available at: <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/jtrights.htm> [Accessed 12 October 2009]

<sup>27</sup> Michael, J, 2008. *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*.

<sup>28</sup> Joint Committee on Human Rights, 2008. *A life like any other? Human Rights of Adults with Learning Disabilities*. Available at: <http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/jtrights.htm> [Accessed 12 October 2009]

means of practising in a safe and effective manner for groups of people with different disabilities as this may be the most effective way of improving care.

### *Education, training and revalidation*

- 6.23 The detailed structure of pre-registration training is the result of a combination of influences: education providers, commissioners and regulators, and other professional bodies. If we are to provide education that delivers professionals who can meet the current and likely future needs of patients, individually and collectively, action is necessary on all sides. We would expect to see that commissioners of education ensure training that equips new cohorts of staff with the technical and non-technical skills to fulfil their duties without breaching the law. Similarly we would expect that regulators, through standards and quality assurance are in a strong position to ensure that new registrants enter the profession capable of delivering care in line with legal duties and expected standards of care.
- 6.24 **Recommendation** – We recommend that regulators’ make certain that education and training programmes throughout a registrant’s professional life provides skills and competencies necessary for meeting the healthcare needs of people with disabilities.
- 6.25 **Recommendation** – We recommend that regulators work towards meeting the recommendation in *Healthcare for all* and this approach should be reflected in their standards for education and training and through their quality assurance work.
- 6.26 Getting education and training right for those about to enter the professions is important, but for those already in practising ongoing professional training and development is of equal value. *Healthcare for all* identified that ‘Pre-registration training is unlikely to be sufficient by itself in the long term and in-service training or continuing professional development are also very important’.<sup>29</sup>
- 6.27 We note that some regulators, such as the GDC, have developed specialist post-registration training to meet the complex healthcare needs of some people with disabilities. While specialist services should not seek to replace the concerted effort to mainstream healthcare services for people with disabilities, we recommend that, in time, the value of further accredited training to meet very complex health needs should be evaluated as it may be an approach worthy of further consideration by other regulators.
- 6.28 Reforms outlined in the White Paper, *Trust, Assurance and Safety*, paved the way for the introduction of revalidation across all the regulated health professions. This is a welcome development and represents a step-change in the nature of the relationship between regulators and their registrants.
- 6.29 The purpose of revalidation has been described as ensuring ‘that health professionals remain up to date and continue to demonstrate that they continue to meet the requirements of their professional regulator. The professional standard against which each is judged is the contemporary standard required to be on the register, not the standard at the point at which the individual may have first registered.’<sup>30</sup> The GMC describe revalidation as ‘one of several mechanisms

---

<sup>29</sup> Michael, J, 2008. *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*.

<sup>30</sup> Working group for non-medical revalidation, 2008. *Principles for revalidation*. Department of Health, London. Available at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_091111](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091111)  
[Accessed 12 October 2009]

intended to contribute to improvements in the quality of care by giving focus to doctors' efforts to keep up to date and improve their practice.<sup>31</sup>

- 6.30 We view revalidation as a new and timely opportunity to try to address some of the issues highlighted in section 5. Through the emphasis on contemporary standards of practice, revalidation will be able to reflect prevailing social and cultural expectations of health professionals and ensure they are meeting wider statutory duties as well as demands specific to an individual profession. Different models are in development across the nine regulators.
- 6.31 The eight non-medical regulators have agreed common aims and principles to ensure consistency across their plans and to have the 'confidence of the public that it is appropriate, relevant and fit for purpose'. It should be risk-based and proportionate and based around the principle of continuing professional development. The views and experiences of patients and the public are intended to have meaningful input: 'Patients and the public have a vital role to play in helping to define what counts as good healthcare, in identifying good professional practice and in drawing attention to unacceptable standards of care'. However, the principles for non-medical revalidation point out that revalidation 'may highlight a poor response to the legislative requirements to "make reasonable adjustments" within practice'.<sup>32</sup>
- 6.32 **Recommendation** – We recommend that regulators' plans for revalidation should consider risks of poor care from patients' perspectives. This could inform a targeted approach, and help to remedy the threat of failing to meet the healthcare needs of people with disabilities.

#### *Wider context*

- 6.33 These recommendations will contribute to improvements in the healthcare delivered to people with disabilities. However, other organisations more closely involved in the day to day delivery of care have important and significant contributions to make to the improvements that are needed. The contribution of the regulator to the provision of safe and high-quality care for people with disabilities is complemented by that of other organisations, not least the NHS.
- 6.34 Regulators have a role in helping to shape and support the professionalism of registrants. Professionalism is the heart of good practice and the most important element in safety and quality and the role of regulation should be to support good professionals and allow them to flourish for the benefit of patients. While fulfilling of their own legal duties with respect to disability discrimination, regulators also have a leadership role in helping to define and describe good professional practice. This can be realised in other areas of activity. For example, regulators' valuable work in providing guidance and identifying good practice in admissions to pre-registration training and education, alongside other activities to involve disabled people in their work. Training in disability equality for staff, council and fitness to practise panellists is also essential.

---

<sup>31</sup> General Medical Council, 2009. *Revalidation: information for doctors and frequently asked questions*. Available at: [http://www.gmc-uk.org/doctors/licensing/docs/GMC\\_Revalidation\\_FAQ%20document\\_02\\_06\\_2009.pdf](http://www.gmc-uk.org/doctors/licensing/docs/GMC_Revalidation_FAQ%20document_02_06_2009.pdf) [Accessed 12 October 2009]

<sup>32</sup> Working group for non-medical revalidation, 2008. *Principles for revalidation*. Department of Health, London. Available at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_091111](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091111) [Accessed 12 October 2009]

6.35 **Recommendation** – We recommend that government departments, service providers, regulators and professional leadership bodies should work with organisations representing the interests of disabled people to facilitate the sharing of good practice in the delivery of healthcare to people with disabilities, through training and service improvements.

## 7. Conclusion

- 7.1 Evidence indicates that healthcare for people with disabilities is less good than that for people without disabilities. While there are a number of underlying factors that may contribute to this situation, the reported absence of some of the core values of all health professionals such as consent, confidentiality and dignity are a cause for concern. As well as undermining care and treatment of individuals, this situation could damage public confidence in the health professions. It suggests action is necessary by the regulators, among others, to promote high quality care that is tailored to the needs of individual patients, and to help achieve wider duties of disability equality.
- 7.2 Ultimately healthcare for people with disabilities is determined by a number of different influences. We have been encouraged by the responses given to us by some regulatory bodies during the course of this project. Our recommendations seek to build on good practice and they focus on delivering a consistent statutory framework that is allied to responsive, proportionate and agile encouragement of high quality care by regulators. The scale and nature of the response needed from each regulator will be determined in part by the risks posed to people with disabilities of the delivery of substandard healthcare. However, the task of maintaining public confidence in the health professions is common to all.

**Annex 1**

Commissioning letters from Department of Health

Mr Harry Cayton  
Chief Executive  
Council for Healthcare Regulatory Excellence  
1<sup>st</sup> Floor  
Kierran Cross  
11 Strand  
London  
WC2N 5HR

07 August 2009

Dear Harry

### **Valuing People Now Unique ID: 22/2008**

In December 2008, the Department of Health commissioned CHRE to consider some aspects of professional regulation arising out of the English learning disability strategy, Valuing People Now. (Annex 1)

Having considered the initial scope of that commission, CHRE felt that a more positive contribution could be made if they took a broader approach, both in policy terms and in geographical spread. Following discussions between CHRE and DH it has been agreed that:

CHRE will provide the advice by taking a broad view that will consider the actions being taken by health professional regulators to ensure that people with disabilities receive high quality and personalised healthcare from their registrants. They will take into account regulators' work on standards and guidance, and fitness to practise, as well as education and training. CHRE will include consideration of those specific aspects of the commission that they are in a position to comment on, given their function, and to cross reference this to other commissions as appropriate.

In providing their advice CHRE will seek to meet the spirit of the recommendation in the Health Service Ombudsman's report, 'Six Lives: provision of public services to people with learning disabilities' (March 2009) that:

'those responsible for the regulation of health and social care services (specifically the Care Quality Commission, Monitor and the Equality and Human Rights Commission) should satisfy themselves, individually and jointly, that the approach taken in their regulatory frameworks and performance monitoring regimes provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements in relation to the provision of services to people with learning

disabilities; and that they should report accordingly to their respective Boards within 12 months of the publication of this report'.

The report will have relevance to the four countries of the UK with country specific matters being reflected within it.

I am copying this letter to Chief Executives of the healthcare regulatory bodies and to the ECHR.

Yours Sincerely

A handwritten signature in black ink that reads "M Fagg". The letters are cursive and slightly slanted.

Matthew Fagg  
Professional Regulation  
Department of Health

Annex 1

Mr Harry Cayton  
Chief Executive  
Council for Healthcare Regulatory Excellence  
1<sup>st</sup> Floor  
Kierran Cross  
11 Strand  
London  
WC2N 5HR

December 2008

Dear Harry

### **Valuing People Now Unique ID: 22/2008**

In accordance with section 26(7) of the NHS Reform and Health Care Professions Act 2002, I am writing on behalf of the Secretary of State to ask the CHRE for advice on the matter outlined below. We would appreciate an interim report by 15/07//2009 and a final report by 30/09/2009. We understand that CHRE has agreed processes for the development of advice. We would request that the work takes into account the differing systems in operation across the UK that impact on regulation of the healthcare professions.

It would assist the Secretary of State, if the Council could (i) take account of the views of the Regulatory bodies referred to in section 25(3) of the 2002 Act, (ii) provide evidential detail and (iii) clearly indicate in the advice the opinions of the regulatory bodies and the Devolved Administrations.

Last year, MENCAP published a report into the tragic deaths of six people with learning disabilities. Following that, an independent inquiry was established, to identify the action needed to ensure that people with learning disabilities receive appropriate treatment. The inquiry, led by Sir Jonathan Michael, identified education and training as key to tackling the inequalities experienced by people with learning disabilities. The report of the inquiry made the following recommendation:

*Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training. Work currently being undertaken to modernise careers in medicine, nursing and in other areas should therefore consider these recommendations in full.*

The Department of Health has accepted this recommendation. In doing so, it is committed to act with all the bodies that influence education and training to ensure that staff are equipped with an understanding of learning disability.



The Secretary of State would therefore welcome advice about what possible changes (if any) in pre or post-registration education and training are required to improve the care of people with learning disabilities. He therefore requests that CHRE initiate work to review whether any changes in education and training for healthcare professionals are required.

In particular, we would be grateful for advice on the following:

- to what extent the curricula contain the necessary material to secure a workforce that is aware of, and can comply with, the Disability Discrimination Act (DDA);
- what general training is offered on issues such as human rights, mental health, learning disabilities, what emphasis is placed upon it and how it is combined with other modules on ethics;
- how the regulators are approaching the modernisation of curricula to reflect changes in practise for their professional groups brought about by changes in society. (Any relevant relationship with the QA of Education project (ID 16/2008), especially the bullet concerning "how the health professions regulators keep pace with changes in professional practice that may influence the structure or content of professional education" would be useful here)
- to what extent higher education institutions are able to deliver the education and training across professional groups on these issues;
- What guidance is available via regulators / education establishments to help staff to understand how to make reasonable adjustments to the way in which they provide care to reflect the needs of people with a learning disability; and
- whether greater (and more immediate) impact on the delivery of care may be possible through targeting changes in areas beyond education as it may not be entirely a regulatory issue.

It would also be helpful if the Council could identify examples of good practice in the approach to human rights, mental health, learning disabilities.

Public protection and patient safety must be the guiding principles throughout this analysis.

I am copying this letter to Chief Executives of the other healthcare regulatory bodies.

Yours Sincerely



Matthew Fagg  
Professional Regulation  
Department of Health

## **Appendix 1: Acknowledgements**

We are grateful to the health professional regulators and the following organisations and stakeholders for their contributions to this work:

Every Disabled Child Matters

Mencap

Radar

RNIB

RNID

Valuing People Now Steering Group