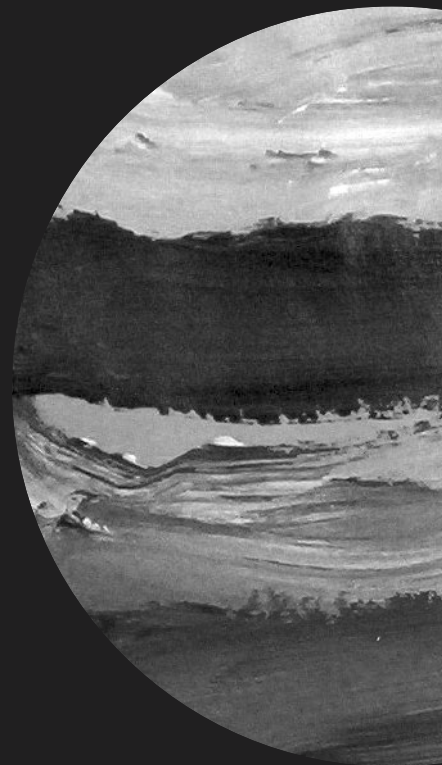


# Learning disabilities registers: Who should we register and why?

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## Abstract

The paper considers the advantages and disadvantages of setting up a register of people with learning disabilities. It is noted that one major problem in setting up such a register is that we do not know who the majority of people with a learning disability are. It is suggested that any register needs to define clearly who is being registered, have all or nearly all the people who fit that definition registered and have an appropriate update system for the register.

**Key Words:** Learning Disability, Registers, Prevalence

## Introduction

In the 1990s I administered the Huddersfield register of people with a learning disability, and, in part because of this, I was recently asked by South West Yorkshire Mental Health NHS Trust to look at the use of registers in the region and the possible advantages and pitfalls of setting up such a register. This paper is based on this work and on current ideas about the nature and prevalence of learning disabilities.

There are numerous examples of computerised registers of people with learning disabilities both in this country (Farmer, Rohde and Sacks 1993) and abroad (Jacobson 1990). Within the South West Yorkshire area there are at least five registers which wholly or partly contain people with learning disabilities and there is currently a debate as to whether there should be an area wide register developed.

There are a number of advantages of holding a computerised register of people with learning disabilities in a particular location. It is able to store information on clients in such a way that it can be accessed easily. Information on a given individual could be obtained by simply typing a name into a computer. In this sense the register is a little like an electronic filing cabinet. However, the real advantage of computerised registers is their ability to provide detailed statistical information on the entire group of people on the register, or on specific sub sections, very quickly. This clearly has advantages for the planning and monitoring services. For example, a register of people with learning disabilities could be used to monitor compliance with the requirements of the White Paper Valuing People (Department of Health 2001), for example telling managers how many people had a Health Action Plan or had had a Person Centred Plan in the last six months. Similarly it could be used to aid planning by giving demographic information such as the number of people living with parents aged 70 or older. This would allow the service to run more efficiently and so hopefully have a beneficial effect on the people who are on the register.

There are, however, a number of ethical, practical and cost benefit considerations that should be taken into account before setting up such a register.

## Ethical Issues

Setting up a register of people with learning disabilities is not without its ethical considerations. With any register there is the issue as to whether it is right to hold private information on individuals that could be potentially accessed by people they may not wish to have it, or could potentially be used against them for instance to withhold a service if they did not meet a criterion. These problems are greater for people with learning disabilities who may not understand the implications of

agreeing to go on such a register, or providing information for the register. Ethical considerations are complex and it is not the primary aim of this paper to consider them. However, before setting up such a register, there needs to be consideration as to whether the clients on the register would benefit from being on it. If not the register must be ethically questionable.

## Cost Benefit Considerations

In addition to considering if a register would have advantages for the individuals who are on it, one should also ask if the financial cost of setting up and operating a register would be recouped by the financial savings of having the register and/or the improvement in the service. Clearly if the benefits do not outweigh the costs then there is little point in having a register. This assessment may not be easy to undertake as it goes beyond simply looking at finances but should also include possible improvements to services that cannot be quantified. However, one factor that should be considered is whether the register can do what it is required to do. There are a number of potential problems with registers in general and with learning disabilities registers in particular, which could lead to them not being able to do what they have been set up to do. It is these that this paper will focus on.

## The Need for Registers to be Inclusive

If a register does not have records of all the people, or nearly all the people, from a defined population, or a random sample of that population, then it will not be able to give accurate statistical information about that population. For example, as we are more likely to know of children with learning disabilities than adults due to their obvious failure at school, then a register could be biased to younger people. Such a register would not be able to provide information on elderly people with learning disabilities, or to provide an age distribution of people with learning disabilities. The need for a register to be inclusive, however, raises the issue as to whether people should be given a choice as to whether they should go on the register. Clearly it is ethically more sound to allow people choice, but if too many people do not wish to go on the register then the statistical information it provides will not be accurate.

## The Need for Register to be Up to Date

If the information on any register is out of date then any statistical or individual information will also be out of date. In my experience simply relying on staff working with people on the register to provide information when circumstances change is not effective. There needs to be a mechanism whereby the client is contacted personally or a person familiar with them is contacted to confirm that the information is correct or to provide the updated information. To some extent, this can be done by asking service providers, such as day care or residential services, to do this for the people who are receiving such a service; however, one cannot do this with the people who, although known to services, are not currently receiving a service. When I managed the Huddersfield register I found that approximately half the people on it were currently not involved with services and required an annual visit from a member of the community team. There is therefore a requirement for these people to be visited and if necessary located on an annual basis, which clearly will have a cost implication.

## Who Should be Registered?

Further problems specific to the registers of people with learning disabilities are inherent in the current definition of learning disabilities. Although there are a number of definitions of learning disability (British Psychological Society 2001; Department of Health 2001; American Association on Mental Retardation (AAMR) 1992; World Health Organisation 1985) all of them, including the White Paper Valuing People (Department of Health 2001), require the following three elements:

- Having an IQ below a critical point, usually 70.
- Having a deficit in adaptive skills or social function.
- That these deficits are present during the developmental period, usually taken to be before the age of 18.

One concern is whether we can actually assess IQ accurately enough for it to be used as a defining attribute of learning disability. I have proposed elsewhere (Whitaker 2003; Whitaker unpublished), that we cannot and that we should change our definition of learning disability so that it not longer specifies an IQ figure. However, I recognise that this is not likely to happen in the next few years and will be assumed that IQ will remain a key defining feature of learning disability.

The major problem for registering people who meet this definition is that we do not know who most of them are and there is no easy way of finding out. The White Paper Valuing People (Department of Health 2001) suggests that the prevalence of learning disability is about three percent of the population as a whole, a figure that agrees with a number of other estimates. Emerson et al (2001) suggested that the prevalence of mild learning disparity is between 2.5% and 3%. The World Health Organisation (1985) also put the figure of mild learning disability for children in industrialised countries at 2% to 3%. However, these estimates cannot be accepted uncritically. The IQ level below which someone can be regarded as having a learning disability is usually taken to be 70 (or 2 standard deviations below the norm). Assuming a mean IQ of 100 and a standard deviation of 15, about 2.3% of the population would meet the IQ criteria of learning disability. However, as the definition requires the individual to have both an IQ below 70 and a deficit in adaptive function it is likely that less than 2.3% of the population would meet the definition. Studies that have looked at the prevalence of learning disabilities in the population as a whole have produced a range of estimates but tend to support this. Those studies that only used IQ as the criterion have tended to come up with figures similar to 2.3%. For example, Birch et al (1970) found that 2.74% of eight to ten year old children in Aberdeen had an IQ below 75, and Rutter et al (1970) found that 2.53% of 10 year olds living on the Isle of Wight had intelligence levels that fell within the learning disabilities range when compared against their peers. In reviewing the literature Roeleveld et al (1997) found that the prevalence for children of school age with IQ less than 70 was about three percent. I have only been able to find one study that surveyed a whole population assessing people on both IQ and adaptive behaviour. Mercer (1973) surveyed 2661 households to assess coping abilities and then gave IQ tests to those that were screened as having low coping ability. She found that 2.17% had IQs below 70, but only 0.97% met the dual AAMR criteria for learning disabilities.

It seems to me that, although it is very difficult to come up with a precise figure for the prevalence of learning disability, it is probably between 1% and 3%, depending on the definition that is used (c.f., Whitaker 2004). If only IQ is used in the definition then the rate may be nearer 3%, whereas if the criterion of deficits in adaptive behaviour is also used then the rate may be nearer 1%.

Irrespective of definition, the number of people who meet the criterion for having a learning disability will probably be greater than the number who have been labelled. If this difference were small it would not matter a great deal; however, the evidence suggests that it is quite large. Whitaker and Porter (2002) surveyed learning disability services in West Yorkshire and found that they know of a number corresponding to 0.29% of the population as a whole. Although this study only covered a few districts in West Yorkshire, the finding is consistent with other studies. Farmer et al (1993) report on the register of people with learning disability held by NW Thames Regional Health Authority. This region had a total population of 2.69 million (about 5.3% of the population of England and Wales) yet had only 6625 people on the register or 0.23% of the population as a whole. In the US, the number of people registered as having a learning disability is similarly low. In California, Borthwick-Duffy and Eyman (1990) report that 78,603 people are registered as having a learning disability, which

is 0.23% of the 33,871,648 people living in California (based on the 2000 census). Jacobson (1990) reports similar figures in New York State; the Developmental Disabilities Information System (DDIS), effectively a register of people with learning disabilities, had 42,479 people on it, which is 0.24% of the whole population of New York State of 18,976,457. The figures are considerably lower than the estimate of between 1% and 3% suggested as the true prevalence. It is therefore likely that we only know about between 10% and 25% of the people who could be considered to have a learning disability. The implication of this finding for registers of people with learning disabilities is that we cannot register everyone who meets the current definition of learning disability, as we do not know who they are. We therefore need to consider carefully who should be on a learning disability register. I would suggest that there are the following options:

The first option would be to register everyone labelled as having a learning disability, without acknowledging that this is only a small proportion of people who meet the current criterion for having a learning disability. This has several problems, not the least of which is that it is dishonest and therefore unethical. Not only would such a register not include the majority of people who fit the definition of learning disability, it would include a lot of people who, although known to services, do not currently require a service. The information from such a register would be both inaccurate and misleading. Any statistics produced from it would appear to relate to people with learning disability as a whole when in fact they only related to those that have been labelled. For example, if the register was to be used to monitor compliance with the recommendations of the White Paper, which are for “all people with learning disabilities”, it would only be able to give figures for those that are known about, but give the impression that the figures were for people with learning disability as a whole. Whereas this would produce much better figures for compliance with the White Paper’s recommendations than if all people with leaning disabilities were being considered, it is somewhat disingenuous to quote them as actual estimates of compliance with these recommendations. In addition, such a register could be difficult to maintain, as many of the people on it would not be in contact with services and have to be located and contacted on a regular basis in order to update their records. In short this option would be costly, ethically dubious, and have no clear benefits for people with learning disabilities.

Secondly, we could just register people who have a severe or profound degree of learning disability; that is people with IQs less than 40. This could have a number of advantages: All the people in this group would be in need of support in order to cope, so we would not be registering people who do not potentially need a service. It would also be easier to maintain a full and up to date register, as we know far more accurately who these people are and the majority of people will be in regular contact with services that could provide the information to update their records. However, there would still be problems deciding who fits the criterion of having an IQ below 40 as most IQ tests do not measure that low and there is still a substantial error of measurement. Also such a register would not include people with moderate and mild learning disabilities who, according to the White Paper, should be entitled to services such as Health Action Plans. If this approach were followed then there would have to be mechanisms in place to ensure that these other people with learning disabilities got the services they were entitled to.

Thirdly, only those people with a learning disability label who are currently in receipt of a service could be registered. This would include some people with moderate and mild learning disabilities, so these people would not be explicitly excluded. The register would be relatively easy to maintain as the services could provide the information for updating. However, it would not include those people, who were not able to cope without help not currently in receipt of a service, either because relatives were caring for them, or they were refusing to accept a service or a service was not available to meet their specific needs. It seems to me that to exclude people who are in need but not receiving a service is not only against what Valuing People says but also against the spirit of what it means.

A fourth option would be to register those people who have a learning disability label and currently need help in order to cope. These would be people who, without assistance, would not be able to provide a reasonable quality of life for themselves or their dependents. This would include all those people who were being provided with help by relatives instead of statutory services, all those who were refusing a service, and all those for whom a service could not be provided, as well as those who were currently in receipt of a service. It also includes people, such as parents with learning disabilities who may be able to meet their own needs but may be challenged in providing for their own dependents. However, it would not include people who do not currently need a service. As with the other options it does not include all the people who have a learning disability as defined in the White Paper, though to do this is not realistic. However, as the White Paper is about making sure that people with learning disabilities get the services they need, including people who are in need, this seems to be the best compromise. One disadvantage of this option is that as not all the people on the register would be in contact with services, the updating system would require those people not in contact with services to be contacted on a regular basis to ensure that the information on the register about them is correct, and so there would be a cost.

## Conclusions

Setting up a register of people with learning disability is not a straightforward matter. If such a register is to be able to perform a useful function, the following steps should be taken. Planners and managers need to outline what they require from the register, which will determine what information should be kept on the register and to some extent how often the information will require updating. However, in deciding what the register will be required to do, it is clearly important to be realistic in terms of what it is possible for a register to do: it is not possible for it to have information on everybody who has a learning disability. After it has been specified what information the register should provide a decision can be made as to which people are going to be registered and what information is to be recorded about them. I have suggested above that the group that should be registered are those that have a learning disability label and are currently in need of a service; however, this is only one of several options. What is important is that it is made explicit exactly which group is being registered so that statistics produced from the register can be clearly stated as relating to this group and not people with a learning disability as a whole. Once this has been carried out then a suitable updating system should be designed so that the information on the register is sufficiently in date to be useful. If this process is not thoroughly carried out when setting up the register then it is likely that the register will contain little useful up to date information and in effect will be an expensive white elephant. It may also be the case that once this planning process has been completed that it is felt that a register either could not fulfil the purposes required of it, or that it could only do this at an unacceptable cost, in which case there is the option of not having a register.

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