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ORIGINAL ARTICLE

Referrals to a learning disability social work team 1996 to 2005

Aine Morrison*, **David Bickerstaff†** and **Brian J. Taylor‡** *Belfast Health and Social Care Trust, Northern Ireland, UK. †Health and Social Care Board, Northern Ireland, UK. ‡Department of Social Work, University of Ulster, Northern Ireland, UK. (E-mail: bj.taylor@ulster.ac.uk)

Accessible summary

- This research is about people with learning disabilities who were referred to the North Belfast social work team.
- There were 252 referrals between 1995 and 2005 but only 127 cases were closed.
- Over a third of the people being referred had behaviour problems.
- There were more people with autism referred in the second half of the 10 years.
- A fifth of the people who were referred only found out they had a learning disability when they were aged 16 or over.
- People with learning disabilities often have health problems but these were often not mentioned when people were referred.
- This research matters to people with learning disabilities because it is important to know what problems people have and what help they need.

Summary

In order to understand better the needs of clients and to inform the delivery of services, referrals to the North Belfast Learning Disability Social Work Team between 1 January 1996 and 31 December 2005 were studied. The documentary analysis of all 252 referrals during the 10-year period included referral books, social work files and the electronic client-based system Soscare. There were increases in referrals with recorded autism and in those aged 18–25, and high levels of recorded behavioural difficulties. There were low levels of recorded visual impairment, hearing impairment and mental health problems. Twenty-one per cent of referrals were likely to have been diagnosed with a learning disability at age 16 or over. Child referrals showed a broad spectrum of identified need whereas adult referrals were predominantly identified as needing daytime occupation. There was an increase in the team caseload from 364 to 489 over the period caused by the number of referrals exceeding the number of closures every year except 1997. We recommend a greater focus on health status in social work assessments, a review of case management practice and greater inclusion of ‘newly diagnosed’ adolescents and adults in service planning.

Keywords Assessed need, people with learning disabilities, referral, social work

Context

This study examines referrals to the learning disability social work team in North Belfast. There was concern

amongst managers at the increasing workload of the team and interest in the types of referrals and the services provided. In order to make informed decisions about service improvement and the priority training needs of

staff an audit was undertaken of referrals over a 10-year period.

The functions of the social work team include promoting the welfare of children (Monteith & Cousins 1999; Malone *et al.* 2000), aspects of child protection (Moore 2004), supporting the transition on leaving school (McConkey & Smyth 2001) and developing opportunities for vocational education and employment (Taylor *et al.* 2004a,b). They also include facilitating access to, and discharge from publicly funded services such as respite, domiciliary care, day care (McConkey & Mezza 2001) and long-term care (Parahoo & Barr 1996) including hospital (McGilloway & Donnelly 1999) and secure provision (Fernando & Sockalingum 2001; Selby & Alexander 2004). Much of this work is carried out increasingly in a multi-professional context (Taylor 1999; McCray 2003; Concannon 2006).

To be eligible for the team's services a person must be deemed to have a learning disability. This is defined as an IQ score of <70 and a concurrent significant impairment in social functioning (British Psychological Society, 2001). Eligibility is assessed both formally and informally. The application of eligibility criteria, informed by current norms of definition and measurement, largely conforms to an individual model of disability that believes that disability can be objectively assessed and diagnosed. However the social model of disability criticises this perspective for not taking into account the social aspects of disability, arguing that societal attitudes to impairment are the primary disabling factor. Goodley (2000) argues that any understanding of learning disability as an impairment must include the socio-cultural and political nature of diagnosing and thus constructing learning disability. The understanding of what a learning disability involves is of importance in determining who reaches referral point. Community tolerance, self-perception, family dynamics as well as the availability and adaptability of other services are all liable to impact on who is referred for specialist learning disability provision, particularly for those with milder disabilities.

The team acts as gatekeeper for the learning disability programme's other services including daytime activity, supported living, respite care and domiciliary care services. This structure means that referrals to the team reflect new demands on the whole programme of care.

The general experience is that available resources have fallen behind ever increasing demands. Reasons for increased demands are less clear with prevalence rates, demographic changes and legislative and policy requirements all having a potential impact. The literature highlights difficulties in establishing prevalence because of differences in definitions, diagnostic criteria, record keeping, record availability, service delivery criteria and service availability (Yeargin-Allsopp *et al.* 1992; McDonald & MacKay 1996; Roeleveld *et al.* 1997; Leonard & Wen 2002; McConkey *et al.* 2003; Prasher 2003). The WHO (1986)

suggests a figure of 3% for prevalence of learning disability in industrialised countries. McConkey *et al.* (2003) reported the administrative prevalence (i.e. those recorded in health and social care records) in Northern Ireland as 0.97%.

Mental health and childcare legislation and policy both govern learning disability services, requiring for example; regular social work visits to children in state care (referred to as 'looked after children' in the UK) and to a person subject to guardianship, planning for care leavers and child and vulnerable adult protection investigations. Community care reforms have also impacted on learning disability services. In the early 1990s, a major reform of social welfare services for adults was implemented in Great Britain (The National Health Service and Community Care Act 1990) and in Northern Ireland (DHSS, 1990). This included significantly increased funding, the creation of homecare services and the option for professionals to use public funds to purchase private, voluntary and statutory care. Adults with complex needs are 'care managed' meaning that an identified health or social care professional is responsible for co-ordinating the contributions to assessment and care delivery of the other professionals (Taylor 1998). Community care reforms specific to learning disability services include the resettlement of long stay hospital patients and moves towards more inclusive accommodation and daytime service options (DHSS 1995: Review of Policy for People with a Learning Disability).

Methodology

A documentary analysis of the administrative and social work records of the learning disability social work team in North Belfast examined all those referred between 1/1/1996 and 31/12/2005.

Three documentary sources were used in the study: (i) hard-bound referral books gave a complete record of all referrals including date of birth, age, gender, ethnic origin, date of referral and referral source; (ii) case numbers and reasons for closures were taken from the electronic client database SOS CARE which is used in most Health and Social Care Trusts in Northern Ireland and (iii) social work files provided all other data, largely taken from eligibility assessment details, referral letters and first assessment forms.

Particular attention was paid to defining precise data categories to aid replication and comparisons (Dudley *et al.* 1999). Information was gathered in three categories: personal details, identified need and social services' duties. An initial list was augmented following piloting with 10 files to include epilepsy as a category under personal details as this was an issue in four of the 10 files. Age-related exclusions were added to the categories of autism and behavioural difficulties as it became evident that these were not

applicable to very young children. A further option was also added under the category of referral source.

Reliability was enhanced by selecting measures likely to be stable over time. This was generally straightforward but changing sensibilities about language use over time caused some potential difficulties. For example, the earlier records were more likely to have used 'mental handicap' than 'learning disability' or 'behavioural problems' than 'challenging behaviour'. The first author's knowledge of the field of learning disability allowed for increased accuracy in interpretation of the meanings of terms.

Data collection – personal details

An 18–25 age band was decided upon to allow for a grouping of those who could be called 'young adults'. Children were grouped to allow for comparison with educational provision. A wide definition of autism was adopted, as many people with learning disability would be understood as having autism without a formal diagnosis. Behavioural problems were recorded if a professional with experience of learning disability used the terms behavioural problems, behavioural difficulties or challenging behaviour. Self-injurious behaviour was included under mental health issues rather than as a behavioural difficulty.

To ensure consistent categories for data gathering, WHO (ICD 10 Guidelines; WHO, 1994) definitions of mild, moderate and severe were used, although we are aware that the definition of learning disability includes a concurrent significant impairment in social functioning (British Psychological Society, 2001; McConkey *et al.* 2004).

For the categories of hearing impairment, visual impairment, mobility difficulties, mental health issues, drug or alcohol misuse, autism, adjudicated offending history, non-adjudicated offending history, technology dependence and behavioural difficulties, options of a 'no' or a 'not recorded' were used. A 'no' was used if someone was recorded as definitely not having the condition. 'Not recorded' was used where the issue had not been reported. The likelihood is that most of the 'not recorded' did not present with the issue. The distinction was made to allow for the fact that this was not certain. A 'not applicable' option was made available for a number of categories, mostly age-related. For example it was deemed to be 'not applicable' to consider drug and alcohol issues for a child under 10 or an adjudicated offending history for a child below the age of criminal responsibility, again 10.

Data collection – categories of need

Any agreed need was recorded. Where a professional suggested a particular need but the client or carer did not agree, these professional suggestions were not included. No distinction was made between client and carer need except

where it was evident from the category title. It was recognised that identified need may not be a wholly valid measure of actual need with assessment skills, recording practice and the complexities of client and professional interaction all likely to impact on this.

The 'Advice and Information' category was wide-ranging covering, for instance, onward referral and liaison with other services. A need for Emotional Support was likely to form part of the work with many of the referrals but was only recorded when it was explicitly stated as a need.

Daytime Occupation included any referral for day-care, further education or work opportunities. It was considered to be 'not applicable' for anyone under 16. Support with Household Management was considered only applicable for those aged 18 and over and living on their own. For those in residential placements, residential respite care and domiciliary personal care were considered 'not applicable'. Residential Respite Care included family based respite care. Domiciliary Respite Care was defined as a carer coming to someone's home and either providing care for them there or taking them out to an activity.

Ethical and good practice issues

Ethical approval for the study was granted by North and West Belfast Health and Social Services Trust under the arrangements for governance of multi-professional audit and all appropriate steps with regard to access, informed consent, confidentiality and anonymity were taken.

Analysis

The first author (an experienced service manager with detailed knowledge of this field of work) undertook the detailed analysis. The second author (an experienced researcher in health and social care) provided supervision of the process of data categorisation and analysis. *SPSS* was used for data management.

Results

There were 252 referrals during the 10-year period, 144 (57.1%) male and 108 (42.9%) female. Information on causative diagnosis was available for 34 (13.5%) cases, including most commonly Down's syndrome (7.1%) and Microcephaly (1.6%). Information on level of disability was available for only 39 (15.5%) cases, including mild (12.3%), moderate (1.2%), severe (0) and profound (2%). The lack of availability of information on level of disability indicates that eligibility for services is frequently assessed informally. There were 44 (35.5%) adult referrals living with family carers, 19 (15.3%) living on their own or with a partner and 43 (34.7%) living in a residential or nursing home.

Thirty-three (13.5%) of the 245 applicable referrals were recorded as having autism; 20 (60.6%) were under 9 and 27 (75.8%) were under 18. Of those recorded as having autism, 23 (69.7%) were male and 10 (30.3%) were female. There was an increase in referrals with recorded autism over the 10-year period (70% were made in the last 5 years). Twenty-six (78.8%) of the 33 referrals recorded as having autism were also recorded as having behavioural difficulties. This compares to 93 (37%) of the total referrals recorded as having behavioural difficulties. Over half (53.4%) of those recorded as having behavioural difficulties were under 16. Fifty-six (63.6%) of those recorded as having behavioural difficulties were male and 32 (36.4%) were female.

Thirty (18%) of the 167 applicable referrals were recorded as having a mental health difficulty, of whom 14 had a psychotic illness or schizophrenia, eight had self-injurious behaviour, seven had anxiety problems and one had a diagnosis of schizophrenia and depression. Of the 14 recorded as having a psychotic illness or schizophrenia, seven (50%) were male and seven (50%) were female. Of the eight recorded as having self-injurious behaviour, four (50%) were male and four (50%) were female. All seven (100%) of those recorded as having anxiety were male.

Six (2.4%) referrals were recorded as having a visual impairment. Ten (4%) of referrals were recorded as having a hearing impairment. Thirty-two (13.4%) of the 238 applicable referrals were recorded as having mobility difficulties. Nine (5.4%) of the 167 applicable referrals were recorded as misusing drugs or alcohol [eight alcohol (six male, two female), one solvents (male)].

Seven [4.2% (all male)] of the 167 applicable referrals were recorded as having committed criminal offences (three sexual, two physical violence and two other). Four of the seven were recorded as having a mild learning disability.

Four [2.4% (three male, one female)] of the 167 applicable referrals were recorded as having allegedly committed an offence (two sexual, one physical violence and one other). Two of these four were recorded as having a mild learning disability but numbers are too small for comparison with figures elsewhere (Simpson & Hogg 2001).

A need for advice or information either for client or carer was identified in 86 cases, predominantly for referrals in younger age bands [62 (72.1%) under 16, 36 (41.9%) under 3]. This was similar to the need for emotional support either for client or carer. Eighteen out of 25 (72%) were under 16; nine (36%) were under 3. Social Outlets was identified as a need in 28 (11.1%) of the 252 cases.

Twenty-seven (13.4%) of the 201 applicable referrals were identified as needing residential respite care of whom, 22 (81.4%) were under 16, with nine (33.3%) aged 0–3, six (22.2%) aged 4–8 and seven (25.9%) aged 9–15. Fifteen (6.1%) cases (all under 16, five under 3-year old) were identified as needing domiciliary respite care.

Four [1.7%, (three male, one female)] of the 238 applicable referrals were identified as needing psychotherapeutic input. Thirty [12.6% (20 male, 10 female)] of the 238 applicable referrals were identified as needing behavioural support, the majority of whom were younger [23 (77%) under 16, 17 (57%) under 9].

Fifty (36%) of the 139 applicable referrals had an identified need for daytime occupation, 24 (48%) of whom were in the 18–25 age band. This is 80% of all the referrals in that age band. A further seven (14%) of those identified as needing daytime occupation were in the 16–17 age band.

There were 41 referrals where there was a requirement for placement monitoring under care management arrangements. Seventeen (41.5%) of the 41 were referred from a learning disability hospital; 16 (39%) were 'preserved rights' referrals (nursing or residential home placements previously financed by social security and not monitored by social services transferred to Health and Social Care Trusts in 2003 and are known as preserved rights placements); five (12.2%) were referred from Care Management for Learning Disability; two (4.9%) were referred from a Consultant Psychiatrist for Learning Disability and one (2.4%) from the Probation Service.

Of the 11 'Looked After Children' (children in public care) who were referred, 3, all aged 9–15 years, were identified as needing placement monitoring. There were eight referrals for care leaving planning, three of whom were aged 9–15 and five of whom were aged 16–17.

Two (1.6%) of the 128 applicable cases were referred with concerns that required a child protection investigation. Six (4.8%) of the 124 applicable cases were referred with concerns that required an adult protection investigation. All six were female.

The study shows that during the 10-year period referral levels have remained fairly constant. Total cases have increased by 125 (34%): 364 open cases on 31/12/95, 489 on 31/12/05 because referrals have exceeded closures in every year except 1997.

Discussion

Legislation and government policy have both reflected and promoted changing attitudes to people with a learning disability over the years. Both policy and attitudinal change are likely to be reflected in the numbers and types of referrals to the team. In particular, needs are likely to be influenced by the expectations of the time and people involved. Attitudinal change largely began with the normalisation and social role valorisation principles (Wolfensberger, 1972). The development of a social model of disability has further aided the reconceptualisation of disability. The relatively new concept of person-centred planning (Sanderson 2000) has continued the attitudinal progression, founded as it is on the principle of

self-determination. Legislation and policy for people with a learning disability have also progressively embraced an ideology of inclusion. This is most recently seen in England and Wales in *Valuing People* (DoH 2001), *Valuing People Now* (DoH 2009) and in the *Bamford Review* in Northern Ireland (Bamford 2005, 2007), which stresses the need for social inclusion, citizenship and empowerment. The policy for resettling long stay hospital patients is detailed in the earlier *Review of Policy for People with a Learning Disability* (DHSS, 1995) and will have had a substantial impact on referrals to community teams. Trends towards inclusion could also potentially be seen in requests for more independent and less congregated living settings or in requests for less traditional daytime services.

Legislation and policy which impose a duty to provide services also have the potential to influence referrals. The *Children (Northern Ireland) Order 1995* places a duty on Health and Social Care Trusts (providing equivalent services to local authority social services departments in England and Wales, and social work departments in Scotland) to provide services to 'children in need'. This term 'children in need' is not tightly defined but includes children with disabilities. The *Children (Leaving Care) Act (Northern Ireland) (2002)* highlights the need for services for care leavers, which in turn could prompt referrals for care leavers with a disability. The *Carers and Direct Payments Act (Northern Ireland) (2002)* has highlighted the need for provision for carers. It is also possible that government promotion of direct payments could lead to a change in the nature of service requests. The government decision [through the *Personal Social Services (Preserved Rights) Act (Northern Ireland) 2002*] to transfer the responsibility for 'preserved rights' residents in residential and nursing placements to Trust care management systems also had an impact.

The definitions used for this study were made as precise as possible given the constraints of the records being used. Below we draw comparison with other countries, but possible differences in definitions should be borne in mind. The study used data gathered by busy professionals and administrative staff and may have contained errors. The first author was a manager of the service and had personal knowledge of many of the cases which provided a check on any major errors in the organisation's records. The average yearly increase in this study is 3.4%. The literature reports a 1% per annum increase in numbers of people with learning disability in England (McGrother *et al.* 2001). Given that the numbers of new referrals including children and ethnic minorities in this study have remained relatively constant, it would appear likely that two population factors have influenced prevalence rates and consequently increased caseloads: increased life expectancy and the numbers of children with learning disability born in the 1950s and 1960s.

The gender balance in referrals, 57.1% male and 42.9% female is in keeping with the higher prevalence of males

with learning disability reported in the literature (Richardson *et al.* 1986; Roeleveld *et al.* 1997).

Information on ethnic origin was only available for 26 (10.3%) of the 252 cases. Only three were recorded as being of an ethnic origin other than white. Although recording is poor, the researchers are confident based on personal knowledge of the cases that these are the only non-white referrals made over the 10-year period. This would suggest that the reported increase in N. Ireland's ethnic minority population (Bamford 2005) is not, as yet, reflected in an increase in reported cases of learning disabilities, a feature worthy of comparison with elsewhere (Emerson *et al.* 1997; Emerson & Hatton 1999; Morton *et al.* 2002). This may reflect an earlier stage of immigration where those who have come to N. Ireland are primarily younger, work-seeking individuals who have not as yet had families.

Although the numbers are small, the study does show a small increase in referrals with recorded autism, which is in line with the increase in reported autism (Wing & Potter 2002; Morgan *et al.* 2002). Thirteen per cent of the total referrals, predominantly children, were recorded as having autism, which is lower than reported prevalence of autism in the learning disabled population (Deb & Prasad 1994; Morgan *et al.* 2002; Wing & Potter 2002).

The study shows a small increase in the numbers of referrals aged 18–25. Analysis of referral source shows that 66.7% of these referrals were likely to be newly diagnosed.

Fifty-two (20.6%) of the referrals were likely to have been for people whose learning disability was diagnosed aged 16 or over. The study did not specifically examine the factors that led to late identification. However, as 32 (61.5%) of these referrals are aged 16–25, this suggests that it is the transition to adult life that has led to the identification of a learning disability. The referral sources that are most likely to refer newly diagnosed 16+ year olds made 32 (64%) of the 50 referrals for daytime occupation. This suggests that in particular, it is leaving school and an inability to cope with mainstream training, work or further education that prompts the referrals. None of these referrals came from the education system which would suggest that current transition arrangements are failing to identify all those who would be eligible for a service.

The results show very low rates of recorded visual and hearing impairment in line with the reported tendency for under-diagnosis of these conditions (McConkey *et al.* 2004; Timehin & Timehin 2004). Mental health problems at a rate of 13% are at the lower end of the reported range (Cooper & Bailey 2001; Taylor *et al.* 2004a,b; Borthwick-Duffy & Eyman 1990). Under diagnosis may be particularly evident in the newly referred. Recorded levels of behavioural difficulties at 37% are high in comparison with other studies (Emerson *et al.* 2000; McGrother *et al.* 2001) though the definition used was wide.

The identified need for children shows a broader range of needs whereas the need for adults is concentrated in one area, daytime occupation. The identified need for children supports research showing a need for advice, information and emotional support particularly at a younger age (Kiernan & Alborz 1995; McKeever & Griffiths 2001; McConkey 2003) and for a range of supports including respite care and social outlets (Monteith *et al.* 2002; McConkey & Adams 2000).

More detail in the categories: advice and information, behavioural difficulties and daytime occupation would have been useful. Further research should be undertaken to clarify the sensitivity of referral and assessment processes.

A number of issues were highlighted by the study that should be addressed to improve services, including a greater focus on health status in first social work assessments (Jansen *et al.* 2004), a review of case management practice in terms of case closure, and greater inclusion of 'newly diagnosed' adolescents and adults in service planning (Smyth & McConkey 2003). The increase in recorded autism and reported behavioural difficulties (Moss *et al.* 1997) needs to be included in service planning (Dixon 2003).

This study was completed in 2005. Since then learning disability services in N. Ireland have been delivering services in line with the vision of Bamford's (2005) Equal Lives with a continued emphasis on citizenship, empowerment, participation and community integration. However, funding for the full implementation of the recommendations of the Bamford review remains an issue particularly in the current financial climate. Services are also awaiting the shape of future legislative reform following a consultation on Bamford's (2007) recommendations of a single legislative approach to all capacity and mental health issues based on four fundamental principles; autonomy, justice, benefit and least harm.

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