Young adults with learning disabilities: a study of psychosocial functioning at transition to adult services

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A study of the psychosocial functioning of young adults with a history of learning disability* (LD) in childhood is reported. The design was a non-clinic community follow-up investigation of a cohort of children who had received special education, the sample frame for which was a birth-period cohort survey. Participants were 149 young adults (89 males and 60 females derived from a survey of the 33,800 children born in the Cambridge Health District between 1967 and 1973) at the stage of transition to adult services (age 18–22y), whose measured IQ scores in childhood were <80, and who had received special education during school years. Most of the young adults were living at home (n=108) and many were in full-time employment (independently employed n=41, sheltered employment n=90), this survey having been carried out in an area of high employment. A strong correlation was found between the child IQ score and subsequent adult Vineland Scale Score. Greater efforts should be made to detect and assess LD and its attendant problems in children in order to plan future care and transition to adulthood, especially for those with more severe disabilities.

What are the long-term consequences of learning disability (LD) in childhood? To what extent do the disabilities we see in children enable us to anticipate subsequent problems of psychosocial adjustment in later adult life? Given the myriad influences at play here, it is not for the clinician to attempt to predict outcomes in individual cases, but to be aware of what might reasonably be anticipated in individuals who display certain characteristics. These include such factors as the cause and severity of LD, any additional physical or sensory disabilities, and any other major neurological problems such as epilepsy. All these should be considered in the context of other crucial determinants of developmental outcome, especially the child’s experience in educational and specialist health services (O’Brien 2001a). Any approach to study in this area requires careful consideration of both the study population and the outcomes to be measured.

Various methods are employed to identify and diagnose LD, such as general cognitive development, academic attainment, and service contact. The three most common approaches used to define childhood LD (CLD) are: (1) definition by IQ alone; (2) the World Health Organization (WHO) ICD-10 Classification of Mental and Behavioural Disorders (WHO 1992) approach using IQ combined with social functioning and age at onset; and (3) definition by service contact, the so-called ‘administrative definition’ (Richardson et al. 1986). These methods give some indication of the presence and severity of CLD, but each method has its shortcomings, especially if used in isolation. The strengths and shortcomings of these different approaches have been reviewed elsewhere (O’Brien 2001b).

Reviewers of the transition to adult services for children with LDs have long emphasized the importance of careful planning, especially for children with multiple disabilities (Basset and Smith 1996). Such planning needs to be comprehensive, taking account of all evidence of the child’s skills, attainments, progress, disabilities, health, and social functioning. It is well-recognized that the assessments required in this process need to focus on a wide range of domains, including both the actual identifiable deficits in skills in the young person, in addition to those assessments which are more prediction-related (Agran and Morgan 1991). These assessments, considered in the personal, family, and social context, aim to facilitate the shift to adult services for the young people concerned.

For most young people in the general population, the transition to adult life is characterized by a diminution of parental control and involvement in the child’s life. But for many young people with LD, ‘reality suggests a greater reliance on parental resources’ (Thorin et al. 1996, p 117) rather than any reduction in dependence on their parents. Furthermore, for most people in the general population, the transition period from education onwards is not so much a shift from child to adult services, as it is a move from school to the workplace. Most studies of the extent to which this is true for young people with LDs have yielded disappointing results in that the employment levels among young people with LDs are not high (O’Brien 2001a). This is unfortunate, given the clear association which has been found between a successful employment placement and a better quality of life for young people with LD (Kraemer et al. 2003).

Studies in a wide variety of countries and of various services have highlighted similar themes and challenges in the transition to adult life for all young people with LD. These were

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*US usage: mental retardation.

See end of paper for list of abbreviations.
admirably summarized by Matsuya (2000) who emphasized certain constituent features of contemporary services for maximizing psychosocial adaptation in young people with LD, namely: (1) a shift in emphasis from a medical to a social model; (2) early diagnosis and intervention; (3) close attention to medical care for children with multiple disabilities; (4) family support and engagement; (5) career education and preparation for the young person; (6) multi-agency transition planning; and (7) empowerment for the young person.

These studies give the following guidance to the study of adult outcome of CLD. First, careful definition of the population to be studied is crucial. Here, an approach which combines the best features of all three approaches – assessment by intelligence testing, the WHO approach, and the administrative/service definition – would be optimal. Given that children with LD are no longer admitted to long-stay hospitals, the focus should be on those who have received special education for reasons of LD. In studies of psychosocial outcomes, a measure of the capacity for independence is required, as is a detailed account of living circumstances and employment/daycare, in order to gain a picture of the outcome of the transition from child to adult life. All of these need to be considered in the light of any lifelong major physical disabilities, which interact with all of these factors.

Method
The overall aim of the study was to examine the psychosocial adjustment of young adults with a history of CLD. This was done by close consideration of young adults who had been identified as having low intellectual functioning by mid-childhood and who had received special education.

CASE IDENTIFICATION
Systematic scrutiny of the community child health records (CCHR) of the 33,800 children born in the Cambridge Health District over a 7-year period (1967 to 1973) identified 326 individuals who had been found to have an IQ<80 and had received special education.

All children growing up in Cambridgeshire at that time were screened using the British Picture Vocabulary Scale (Dunn et al. 1982) at age 8 to 9 years. This is not an IQ test, but is the most widely used standardized test of receptive language development in the UK, being an Anglicized version of the (American) Peabody Picture Vocabulary Test (Dunn and Dunn 1997). All children identified as significantly language delayed were then assessed in more detail as part of the educational system in place. Assessment instruments comprised the Wechsler Intelligence Scale for Children (WISC and WISC-IV; Wechsler 1949, 2003) for most of the children, or determination of developmental quotient for children with very severe disabilities who could not be tested by WISC. The CCHR, therefore, yielded an IQ score or equivalent, in addition to details of any known aetiology of LD and major disabling condition; basic demographic data were also available.

This cohort satisfied all three approaches to the definition of LD, in that it included IQ or equivalent assessment, was administratively determined, and only focused on those who were not functioning in mainstream services (here represented by school placement), thus meeting the WHO definition.

For each of the 326 potential participants, a letter was sent to their general practitioner to exclude those who had moved from the local area or who might be deemed unsuitable for the study. A letter was then sent to the parent or guardian, inviting participation in the study. Those young people who were capable of giving informed consent did so, or declined participation. The local Research Ethics Committee approved the study.

For the present study, assessment took place in early adulthood (age 18–22y), some 10 years after the recorded intellectual/developmental assessment. By the time of study, nine individuals had died and 78 had left the area. Of those still living locally (n=239), 111 declined (or their families declined) to be involved in the study. Consequently, 128 individuals had developmental assessment, carried out by the author. Data on personal, family, and service history – including details of health history, residence, daycare, employment, and further education in early adulthood – were collected by parental interview by a research assistant within 2 weeks of the developmental assessment; the two assessors were mutually blind to the results. In an additional 21 cases, the parents agreed to the interview but the young adults themselves did not. Data on family and service history are available, therefore, on 149 participants.

MEASUREMENTS
Developmental assessment of the young adults was carried out by the author, using the MRC-Handicap Behaviour and Skills schedule (Wing 1980), and resulting Vineland Scale Score (VSS; Sparrow et al. 1984). The VSS is the most robust measure of the capacity for independent social functioning and everyday living (the higher the score, the greater the capacity for independence; Sparrow et al. 1984 and O’Brien et al. 2001) applicable to people with LD. These data were taken from examination of the young adults in their homes.

Results
SEVERITY OF LEARNING DISABILITY AND OTHER CLINICAL DATA FROM CHILDHOOD – VALIDITY OF SCREENING AND ATTRITION RATES
Of the 326 potential participants, 84 (25.8%) fell into the moderate/severe LD in childhood range (IQ<50), 121 (37.1%) in the mild LD range (IQ 50–69), and 121 (37.1%) in the borderline (IQ 70–79) range.

The medical records search identified an index sample of 326 young adults. The most robust test of validity of the sample is the comparison between the known rates of moderate to severe LD (IQ<50), and the proportion detected in the study. Given that 0.3% of the population are of IQ<50, the expected index sample derived from the sample frame would be about 100 (0.3% of 33,800). Eighty-four were identified, which suggests that the screen was effective, at least for the children with more severe learning disabilities in that almost all children in this IQ range were identified because they had been placed in special education.

Clinical indices extracted from the CCHR included information on causal syndrome or aetiology of disability – notably of cerebral palsy (CP) and a history of childhood epilepsy. Data such as these are liable to understate and under-record some clinical problems. However, at the parental interview (see above), where data were collected on participants’ health history, the clinical record data on childhood epilepsy history and CP were corroborated in all individuals.
CURRENT SUPPORT SERVICES (149 PARTICIPANTS): PARENTAL INTERVIEW

Residence

The young adults’ residential placements were categorized according to one of the following: family home; hospital; community residential care; residential school/adult education; and others. Results are summarized in Figure 1.

The largest group of young adults ($n=108$) lived with their parents. The group in residential education ($n=10$, 7%) were placed in special adult education facilities out of county. The small group of ‘others’ included those people who were homeless (i.e. either living on the streets or sleeping on friends’ floors). There was a strong association between severity of CLD and type of adult residential placement, which was a reflection of the greater dependency and care needs of those who had more severe CLD. Most of the young adults in residential care (14 out of 23) were in the moderate to severe LD categories. However, almost half of the moderate to severe group (16 out of 37) was living with their families as young adults.

It was enquired whether carers were aware of other support services which were not being accessed. Most (63%) reported no knowledge of other possibilities; 15% said they would like to receive residential respite care but that this was not available; 14% felt that further education would be appropriate; and 6% said they lacked daycare. In this study, only 1% mentioned employment as a local shortcoming, which is consistent with the findings on the employment and occupation of these young adults.

DAYTIME OCCUPATION

Carers were asked how the young adults spent their day. Replies were coded into the following categories: (1) education; (2) day centre attendance; (3) spends day at residential care placement; (4) employment; and (5) unemployed/no daycare arranged. These results were analyzed according to the severity of CLD, categorized here into mild/borderline and moderate/severe groups. Results are summarized in Figure 2.

A close association was found between a more independent pattern of daytime occupation, and a lesser degree of CLD. $\chi^2 = 45.7$, degrees of freedom (df)=4, $p<0.001$: one-way analysis of variance (ANOVA) of child IQ by adult day occupation corroborates this ($F=17.429$; df=5, $p<0.001$). The low rate of unemployment/no care, and especially the high rate of employment for a cohort of young adults with intellectual disability, is striking (Fig. 2). Of the 61 young people in employment, two-thirds (41) were in independent, open, non-sheltered employment.

There was no significant difference with respect to sex of participants, in either this parental dataset nor in the developmental assessment dataset.

DEVELOPMENTAL ASSESSMENT (128 PARTICIPANTS)

The VSS of the 128 participants assessed are summarized in Figure 3.

The VSS was analyzed by key variables in child history: history of epilepsy, demographic situation, diagnosis of CP, and severity of CLD. Analysis was by ANOVA, simple factorial, taking VSS as a dependent variable and the four child clinical history variables as factors. The severity, or degree of CLD was the one factor in child history which was closely associated with adult VSS, a measure of the capacity for independent functioning, or conversely, social disability. The effect of CLD on subsequent adult VSS was so powerful as to account for the bulk (19826/57884=34%) of the explained variance (33019/57884=57%; Table I, Fig. 3).

The other factor in child history which showed a relationship with adult VSS was a diagnosis of CP. The significance of this effect on the whole group was small, but this is merely a reflection of the fact that only a minority ($n=23$) had this condition.
diagnosis, while by definition, a degree of CLD operated across the group.

Neither childhood epilepsy nor demographic situation was found to be significantly associated with adult VSS, although there was a non-significant trend towards a lower VSS in those with a history of epilepsy. As with CP, only 40 (27%) of the group had a history of epilepsy, of whom 15 (12%) had active epilepsy as young adults, which has, therefore, had little effect on the whole group results. Almost half of the variance is unexplained (Fig. 3), emphasizing that other factors not considered in this analysis, such as education and other developmental influences, are important determinants of adult capacity for independence.

Discussion

One hundred and seventy-seven participants lost in parental interview is clearly a major issue. Given that all 326 had been identified by the same means (i.e. from CCHR), it is possible to test the extent to which those interviewed were representative of the total sample. This was, therefore, carried out according to the principal criteria on which data were available: age/date of birth, sex, history of epilepsy, presence of a major medical problem or aetiology/syndrome (this was recorded in 48% of participants), demographic situation, and severity of LD. Results were not significant in any of these indices, except severity of CLD, where attrition was lower in the borderline IQ group (29%), but the same for the mild and moderate/severe groups (46%). The finding of an identifiable aetiology in 48% of participants corresponds with levels reported elsewhere (Daily et al. 2000).

School health records were a useful and reliable source of crucial historical information for some of the indices explored. Most notably, in all cases the IQ level of developmental functioning was recorded, as were basic demographic data. When interviewing the young people in the presence of their parents it was clarified that the data recorded on epilepsy and CP diagnosis were also accurate.

The finding that almost half of the young people with the most severe disabilities were living in the family home supports a study by Farmer et al. (1993), who found that one-third of adults with the most severe disabilities who were on a regional LD register were living with their families, and the more recent findings of Kraemer and Blacher (2001) who found that most young people of this age with more severe LD live at home with their parents. The parents in the present study, who were in most cases the principle carers, were not aware of any additional support services or opportunities which might have been available locally. The two types of service opportunity of which there was some substantial knowledge – both reported by around 15% of carers – were education and residential respite care. These findings should be compared with those in respect of the small proportion of participants who did receive such services (Fig. 2). It is likely that such services were highly sought after, and the carers who here reported that there were such additional opportunities available, included many individuals who wished their daughter/son to be receiving such services, where places are limited and constantly under competitive pressure. It is also of interest to note that in only two participants did their parents/carers report that employment opportunities were lacking. While almost all of those who were deemed by parents/carers to be fit for employment were indeed in employment, there appears to be a substantial proportion who might have benefited from either ongoing education or residential care, but who were not receiving such services. A smaller proportion was deemed to be 'missing' appropriate day care. The very low rate of hospitalization (3%, n=5) is as expected, in line with current care policies.

Rates of employment were very high. Two factors are particularly important here: (1) the long history of availability of manual work in the Cambridge colleges and local farming industry; and (2) the affluence and high employment rate in the area at the time of the study. In their long-term follow-up of young adults growing up in the Aberdeen area of Scotland, Richardson and Koller (1997) noted that times of high employment in that locality – when the oil industry was at its peak – resulted in high employment rates for young men with LD. Few areas within the UK, or indeed possibly elsewhere, would be likely to reveal such high levels of employment for such a population.

The close correlation between child IQ and adult VSS is very striking. Here, within the population of people identified in childhood as having IQ<80 and who received special

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Demog., demographic.

Figure 3: Vineland Scale Score results of young adults aged 18 to 22 years (n=128).
educational attention, child IQ was strongly associated with the VSS in early adulthood. Physical disability (diagnosis of CP) also exerts an influence, although not to the same extent as CLD. However, almost half of the variance is unexplained. This emphasizes that the capacity for independent functioning in the young adult is a result of both constitutional factors in the child, especially IQ, and any physical disability, and of a host of environmental influences, including close attention to medical care, appropriate styles of family support and engagement, and careful multi-agency transition planning.

One issue highlighted by the study is the lack of long-term multi-agency and interdisciplinary coordination and follow-up for these young people, despite the high value placed on such coordination by the transition studies reviewed above. Such coordination can only be effectively implemented in the long term by the use of a regularly updated register or similar system. No such system is in widespread use in the UK, and this has resulted in the problems encountered in case ascertainment in the present study. On the other hand, of those individuals and families still living locally, most were interested and motivated to participate in the study. Their responses have yielded important messages, with good news – especially concerning employment in this affluent area – and some not so good news. Perhaps most striking was their complaint that they were not kept informed of services and options available locally, which is another reflection on the lack of cross-service collaboration in the lives of these young people and their families.

All of the young people in the present study had received some form of special education due to their LD. In some cases, this comprised removal into a separate school, whereas in others, education was given in special classrooms within a mainstream school, or similar arrangement. These data were collected around 1990. The young participants in the study had, therefore, grown up at a time when there was less emphasis on integrated education, and more opportunity for separation into special classes. The present study does not give any clear indication of the merits or demerits of the current emphasis on integrated and inclusive education; the study was not designed to explore this issue. However, the favourable findings regarding employment especially, suggest that the system in place at the time of the present study had its strengths, in terms of preparing young people for adult life.

Finally, the present study was only possible because educational attainment-based screening had been in place when the young people had been in mid-childhood. Definition of the cohort studied relied on the widespread application of intelligence testing, or equivalent developmental assessment in the case of children with more severe disabilities. At different phases in the evolution of education and other services for children with LD, such screening and assessment policies have had their supporters and critics. The present study has emphasized the relevance of the child’s IQ to her/his subsequent development and capacity for adjustment – while also emphasizing that other factors are more important. Educational and specialist support services for these children need to be geared towards the child’s assessed abilities and potential, while giving highest emphasis to maximizing the child’s social development. Does this mean that we should be re-emphasizing the value of intelligence testing as one element of the child’s assessment? Perhaps future research on the outcome of children in current educational contexts will yield the answer to that question.

References

List of abbreviations

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<td>CCHR</td>
<td>Community child health records</td>
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