

A 5-YEAR DEVELOPMENTAL STUDY OF SEVERELY MENTALLY HANDICAPPED CHILDREN

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INTRODUCTION

There are few developmental studies of mentally handicapped children because of the problems of identifying and tracing cohorts over long periods of time through the diverse range of services provided for them. Nevertheless, such studies are potentially of great value to planners, managers and direct-care staff in describing the types of progress and changes made both for and by mentally handicapped children over long periods of time. As the number of case registers increase and their potential in this area is realised (see Martindale, 1976 and 1980), it may be that such developmental studies will be forthcoming.

This paper describes the first such developmental study undertaken by the Sheffield Case Register (Martindale, *op. cit.*). It follows up a complete cohort of severely mentally handicapped children aged between 7 and 16 years from a large city (Sheffield) over a 5-year interval between 1975 and 1980.

METHOD

For the purpose of this study, severely mentally handicapped children were defined as those who either used services for the severely mentally handicapped such as E.S.N.(S) schools, subnormality hospitals etc. or with latest I.Q.s ascertained as under 50. To avoid confusion, all other Down's syndrome children were included even if they did not satisfy these criteria. A cohort of all children satisfying these criteria from Sheffield Metropolitan District (pop.=530,000) who were aged between 7 and 16 years of age on 31st July, 1975 were selected using the generalised sample selection programme in the 'menu' of functions which can be carried out on the Case Register's mini-computer. For each person selected, a history of services, benefits, aids, activities, diagnosis and medical complications were printed out together with details of social and physical incapacities (SPI) and speech, self-help and literacy (SSL) skills (Kushlick, Blunden & Cox, 1973) pertaining to two dates — 31st July, 1975 and 31st July, 1980. In this connection it should be noted that SPI and SSL information is updated for each person on the Sheffield Register at the following ages for each child — 3, 6 and then every two years to 18 years (see Martindale, 1982).

The bottom age of the sample (7) was chosen because it was believed that by this age all severely mentally retarded handicapped children (including even the majority of acquired cases) would have been identified. The cohort, spanning 10 years of births in the city, was divided into two samples aged between 7 and 11 and between 12 and 16 years respectively on 31st July, 1975. By 31st July, 1980, the younger sample corresponded with the older sample 5 years later on whereas the older sample were now over 16 years of age.

Comparisons were made both between the two samples and between the two dates in terms of the information described above.

RESULTS

The size of the two samples in the cohort were very similar as shown in table 1 which categorises the major groups within the samples.

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Table 1

Main groups in 1975:	Age of sample on 31st July, 1975 (years):	
	7-11	12-16
Long-term residential care	20	34
Attending E.S.N.(S) school — I.Q. < 50	113	122
— I.Q. \geq 50	13	18
Others I.Q. < 50	37	25
Other Down's syndrome children with I.Q. \geq 50	9	5
Total	192	204

The table reflects the fact that a greater number of Down's syndrome children and others with I.Q.s <50 in the younger sample were in schools for those with moderate learning difficulties. Moreover, fewer of the younger group were in long-term residential care. The overall age-specific rates of I.Q. <50 were 4.0/1000 in the 7-11 years age-group and 4.3/1000 in the 12-16 years age group. Between 1975 and 1980, 7 of the younger sample (including 3 in long-term care) either died or left the area.

Looking in more detail at those in *long-term residential care*, there are some interesting differences between the younger and older samples at the beginning and end of the 5-year survey period. Between 1975 and 1980, 1 of the younger sample and 1 of the older sample returned to live at home but a further 7 of the younger sample and 15 of the older sample went into long-term care for the first time. This mirrors the fact that rates of entry to long-term care increase until after school-leaving age. Of those in long-term care at the end of the period (1980), 8 of the 25 in the younger sample and 13 of the 60 in the older sample were in hostels, children's homes or voluntary homes and the remainder were in hospital units. However, of these 17 younger children and 37 older children remaining in hospital units at the later date, only 4 younger children and 17 older children were not in purpose built units provided under the Sheffield Development Project (MO(MS) 46, 1971).

Looking now at the whole samples, almost exactly half of both the younger and older samples used *short-term care facilities* at least once in the 5 years of the survey. However, whereas over three-quarters of the older sample had been or were currently on social workers caseloads in 1980, only about half of the younger sample were similarly described.

The great increases between 1975 and 1980 in *therapy, aids and benefits* available to the children and their families are shown by comparing the younger sample in 1980 with the older sample in 1975 (*i.e.* at equivalent ages but with five years between them).

At the earlier date 4, 3, 2 and 1 children received physiotherapy, hydrotherapy, speech therapy and psychotherapy respectively whereas at the later date the equivalent figures were 20, 11, 10 and 2 respectively for children at the same age 5-years later. The same picture was apparent when aids are considered: 1, 7, 10, 14 and 1 children respectively had manipulation, walking, house adaptation, incontinence and nursing aids respectively compared with 6, 33, 24, 27 and 18 equivalent children at the later date. Moreover, whereas 29 families at the earlier date were not receiving any financial benefits, in 1980 there were no such families. (Nevertheless it was often unclear what the rationale behind the receipt of certain allowances had been).

Only about one third of the samples of both dates used *voluntary clubs, societies* etc. organised specifically for the mentally handicapped.

Turning now to *education and training* received by the samples, the younger sample were all under 16 on both dates and attended schools (even if they were in long-term

care). Only 12 children in the younger sample who lived in hospitals in 1980 did not attend schools outside their place of residence. However, in the older age-group when at the same 'stage' in 1975, 27 children living in hospitals remained in hospital during the day (albeit on hospital school registers). In 1980, all the older sample were over 16 years of age but 37 remained at special schools. Of those (83) who had left, the majority (67) had entered A.T.C.s, 2 had found work and 5 attended hospital day-care units. No less than 9 received no education or training and did not work and, of these, 5 had refused or not taken up A.T.C. places offered to them whereas 4 had been excluded because of the severity of their problems for which alternative services had not been found (even in hospital day-care units!).

The principal *diagnostic groups* in the two samples were very similar in size with roughly 25-30% Down's syndrome, 5-15% brain injuries or damage, 25-35% not known and the rest scattered across many different types of conditions and causes. About 15-20% had associated physical handicaps associated with cerebral palsy and about one quarter of each sample had some degree of epilepsy.

The rest of this section is devoted to a consideration of *changes in SPI and SSL assessments* in the 5 years of the survey. Because the Register only began collecting this information for those in schools other than E.S.N.(S) schools in 1978, the figures relate only to those in residential care or E.S.N.(S) schools in 1975 and 1980. The possible influence of this upon findings is discussed later in the paper. Martindale (1982) draws attention to the fact that assessments of SPI and SSL problems can be different depending on whether the information is collected from a school or A.T.C. or from the place of residence (whether this be a residential unit or home). Because of this, comparisons in this paper relate to those collected in the day placement (school or A.T.C.). It must be remembered that this may not therefore represent in all cases the position accurately as far as residential staff or parents are concerned but is in fact how teachers and A.T.C. staff saw the 'childrens' problems.

Table 2 compares the SPI and SSL assessments for the two samples when each sample was aged 12-16 years (*i.e.* in 1975, for the older sample and in 1980 for the younger sample).

Table 2

<i>SPI/SSL Rating</i>	<i>Sample:</i>	
	<i>1975</i>	<i>1980</i>
Severe walking, behaviour or incontinence problems	77	54
Mild walking, behaviour or incontinence problems	32	25
None of above but self-help problems	48	35
None of above but speech problems	3	3
Literacy problems only	21	26
Not known	—	3
Total	181	146

Table 2 shows that similar proportions of each sample had different types of problems when compared at the same age. This is also true if those who were in residential care and those who were living at home are considered separately. However, 72% of the younger sample and 76% of the older sample in residential care when at the same age had severe problems with walking, incontinence or behaviour compared with 30% and 33% of the younger and older samples respectively who were living at home *i.e.* older children in residential care on both dates were not typical of the whole group of mentally handicapped children from which they came in that a far greater proportion had severe social and physical incapacities.

The rest of the results section is devoted to a consideration of the *improvements and deterioration in SPI/SSL assessments*. 18% of the comparisons for the older sample and 9% for the younger sample were not known either through deaths or transfers to other areas or because some children were not followed-up between 1975 and 1980 as the up-dating policy (see Method section) only began in 1978.

Improvements and deteriorations were classified as to whether they were *major* (i.e. between non-adjacent ratings e.g. speaks nothing — speaks sentences) or *minor* (i.e. between adjacent ratings e.g. severe incontinence — mild incontinence) in the manner recommended by Kushlick *et al.* (*op. cit.*) and used previously by Martindale (1982 *op. cit.*). Three types of information are considered separately: social and physical incapacities (walking, behaviour and incontinence), self-help (feeding, washing, dressing) skills and speech and literacy (reading, writing, counting) skills.

Table 3 below shows improvements and deteriorations in *social and physical incapacities* made by the two samples between 1975 and 1980.

Table 3
Changes between 1975 and 1980:

	Age group (1975)	Improvement:		No Change	Deterioration:		Not known
		Major	Minor		Minor	Major	
Ambulance	7-11	—	9	97	26	1	13
	12-16	—	7	140	1	1	32
Behaviour	7-11	6	10	89	15	13	13
	12-16	4	21	98	15	11	32
Incontinence	7-11	37	12	57	26	1	13
	12-16	4	21	116	8	—	32

The majority of children in both samples had shown no changes in these assessments between 1975 and 1980. However, both minor and major improvements and deteriorations were detected for some residents. In the case of ambulance (walking), only the unexpectedly large number of minor deteriorations amongst the younger sample is worth noting. For behaviour, there were more deteriorations (both major and minor) than improvements amongst the younger sample but in the older sample there were more minor improvements than minor deteriorations but more major deteriorations than major improvements to offset these gains. Turning to incontinence, in the younger age-group, despite a considerable proportion of minor deteriorations, improvements (major in most cases) vastly outnumbered deteriorations. This was also true of the older age-group except that improvements tended to be minor in extent.

Table 4 overleaf shows improvements and deteriorations in *self-help skills* between 1975 and 1980 for the two samples.

All changes in both samples tended to be minor in extent. In the younger sample improvements in all aspects of self-help skill tended to outnumber deteriorations especially in dressing skills. In the older sample, deteriorations in feeding outnumbered improvements, but improvements in washing and dressing skills outnumbered deteriorations especially in the case of dressing in which no less than 38% of the sample for whom information was known improved in the five-year period.

Table 4
Changes between 1975 and 1980:

	<i>Age group (1975)</i>	<i>Improvement:</i>		<i>No Change</i>	<i>Deterioration:</i>		<i>Not known</i>
		<i>Major</i>	<i>Minor</i>		<i>Minor</i>	<i>Major</i>	
Feeding	7-11	—	23	91	19	—	13
	12-16	—	4	133	12	—	32
Washing	7-11	2	24	92	14	2	13
	12-16	1	18	114	14	2	32
Dressing	7-11	—	38	86	8	1	13
	12-16	—	57	90	10	2	32

Table 5 below is the equivalent of tables 3 and 4 but for speech and literacy skills.

Table 5
Changes between 1975 and 1980:

	<i>Age group (1975)</i>	<i>Improvement:</i>		<i>No Change</i>	<i>Deterioration:</i>		<i>Not known</i>
		<i>Major</i>	<i>Minor</i>		<i>Minor</i>	<i>Major</i>	
Speech	7-11	1	16	106	10	—	13
	12-16	—	22	114	13	—	32
Reading	7-11	6	14	91	19	2	13
	12-16	3	17	97	31	1	32
Writing	7-11	3	9	112	5	3	13
	12-16	2	6	129	9	3	32
Counting	7-11	—	17	100	15	—	13
	12-16	—	13	110	25	1	32

Again, changes tended to be minor in extent except perhaps in the case of reading where 6 major improvements in reading were observed. In both samples, improvements in speech outnumbered deteriorations but the reverse was the case in the older sample as far as reading, writing and counting was concerned. In the younger sample, improvements and deteriorations in reading and counting were similar in number but slightly more children's writing improved than deteriorated.

DISCUSSION

In the age-group 12-16 years, the age-specific prevalence rates of children with IQ <50 from Sheffield Metropolitan District were similar — 4.3/1000 in 1975 and 4.0/1000 in 1980. All the children in the survey were born before the national (and local) decline in the birth-rate began in 1969. It will therefore be most interesting to study the effect of the decline in the birth-rate upon future prevalence rates.

Despite the similar prevalence rates which were reflected in the diagnostic data, the smaller proportion of the later sample who were in long-term residential care and E.S.N.(S) schools when samples are compared at the same age reflects both national trends and local policies. These trends are likely to continue in the future. It will therefore be very important for registers of the mentally handicapped to extend their service coverage to other special schools if they are to continue to obtain complete identification of severely mentally handicapped children in future.

Between 1975 and 1980, a proportion of children from the older sample of the cohort were admitted to A.T.C.s. It has been shown that not all such children entered A.T.C.s, some being excluded (a few of whom received other day services), some being offered places but not accepting them and others remaining at school. In fact, those who did enter A.T.C.s comprised only 54% of school leavers who entered A.T.C.s in Sheffield between 1975 and 1980. The remaining 46% were admitted from other (principally E.S.N.(M)) schools. This is a surprisingly high proportion which is probably not typical of both the period prior to 1975 (when the equivalent figure was about 30%) and the future (when E.S.N.(S) leavers who have begun to stay on longer at school eventually leave at 19). Nevertheless, we are alerted to the fact that figures for severely mentally handicapped children alone *cannot* be used to predict uptake of A.T.C. places in future planning. This is another reason why mental handicap registers ideally need to cover other special schools and services in addition to E.S.N.(S) schools. In fact in Sheffield between 1975 and 1980, E.S.N.(S) leavers accounted for only about a third of the full increase in A.T.C. numbers because of a further group of adults leaving hospitals to hostels who began to attend A.T.C.s for the first time.

Looking now at the question of facilities for school leavers with special needs, it was found that up to 30% of children living at home had severe problems with either mobility, behaviour or incontinence and may therefore require facilities not always at present provided in A.T.C.s on leaving school. Whilst a small number (6) of this group of 77 children in the older sample were after all admitted to A.T.C.s between 1975 and 1980, 4 died, 3 went into long-term residential care and only 5 went into special day units. Of the remainder, 4 left school and now receive no day services whereas the rest stayed at school. These figures typify what appears to have been a 'make do and mend approach' between 1975 and 1980 on behalf of this needy group of school leavers. Co-ordinated services for the group seem to be difficult to plan and implement not just in Sheffield but elsewhere. It is believed that figures from case registers can give very detailed information for this group of school-leavers and there seems to be no good reason why the state of affairs should not be eliminated in the next 5 years.

The figures in this paper show the magnitude of the increases which have occurred in the short period of 5 years in therapy, aids and benefits received by groups of severely mentally handicapped children and their families in Sheffield when compared at the same age. This does not imply that no further problems exist but rather shows how poor such facilities were only 5 years ago. There is still a long way to go before all needs are being catered for in all aspects. We look to the recent setting up of community teams in Sheffield to improve the position still further. By contrast, there is no evidence that the proportions of the samples using voluntary services or short-term care facilities has increased in the same way. Whereas each of these services have seen increases in usage between 1975 and 1980, it tends to have been the same people using the facilities more often. The task of widening the net for such services will be a continuing challenge for the future to which attention is being directed as a result of the work reported here.

It is believed that cohort studies of mentally handicapped people from Case Register data are extremely important in following-up the progress of real change over long periods of time rather than inferring change from cross-sectional studies of samples at different times --- a hazardous exercise because of all the possible correlated variables which can have an influence. For example, the figures show how factors other than sheer level of handicap play a part in admissions to long-term residential care, admissions between 1975 and 1980 not all being amongst the group with severe problems despite the overall fall in numbers of those in long-term care. It is hoped that such factors can be studied in more detail in a future paper.

Turning finally to the changes observed in social and physical incapacities (SPI), speech, self-help and literacy (SSL) skills of the cohort, it can first of all be said that, at equivalent ages the two samples in the cohort had very similar distributions of problems. It is interesting

to find, however, that SPI and SSL assessments *can* reveal progress made by groups over a long period of time. The scales were not devised for this purpose (Kushlick *et al.*, *op. cit.*) and the study has therefore discovered an extension of their utility. However, many children even in the youngest sample in 1975 had already achieved the top level of skill on many items and could not therefore show improvements. Conversely, some profoundly handicapped children assessed at the lowest level of skill on most items could not therefore show deteriorations. Such limitations on the method mean that *not all changes* in performance can be identified by such an approach. Nevertheless, some overall improvements and deteriorations in the groups were found. These demonstrate particularly the success of toileting programmes in reducing incontinence and the fact that children gradually improve throughout the whole school age-range 7-16 years in their speech and self-help skills (but especially at the earlier ages except in the case of dressing in which most improvements occurred between 12 and 16 years). It is of concern that whereas literacy skills showed more improvements than deteriorations in the younger sample, the reverse was the case in the older sample. This may be explained by the fact that when children leave schools at least some A.T.C.s in Sheffield give less attention to literacy in favour of work skills etc. so that some children unfortunately lose previously acquired expertise through lack of practice. A more balanced approach may avoid this effect.

The decrement in mobility amongst some of the younger sample is difficult to explain except in terms of the inherent unreliability of the method (see Martindale, 1982) in view of the fact that physical deterioration only occurred in a couple of instances.

SUMMARY

A cohort of severely mentally handicapped children from Sheffield aged 7-16 years were followed up for 5 years. The paper compares developments to and within two samples aged 7-11 and 12-16 years from the cohort. Main services, handicaps, diagnoses, aids, benefits and activities are studied. The results are used in connection with aspects of take-up of adult services and investigate development in the problems exhibited by the groups.

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