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Ollscoil na hÉireann, Gaillimh

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**Diploma in Health Services Research**

**Paper 2**

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Time allowed for each section is 45 minutes

Answer one question in each section  
Use a separate answer book for each section

**Section A: Quality Assurance in Health Care**

- Q. 1. What is quality? Outline what you consider to be the key elements of a Quality System for the health care service of your choice.
- Q. 2. Internal audits, statistical techniques and FMEA's (Failure Mode Effect Analysis) are powerful quality tools. Select one of these tools and describe how it can be applied in the health care context.

**Section B: Health Services Research**

- Q. 3. Read the accompanying journal article and critically evaluate it in terms of:
- (a) methodology
  - (b) relevance
  - and
  - (c) importance for health policy and planning.

# Caring for people with intellectual disability: The need for residential care

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## Abstract

When the needs of a person with intellectual disability exceed the resources available to the family, including home support services, residential care may be necessary. The objective of this study was to identify factors other than the degree of disability (ID) that precipitated the need for such care. An observational survey with a case control study design was carried out by means of a structured interviewer administered questionnaire. Fifty children and adults with ID from the region who were admitted to residential care in the South Eastern Health Board area between 1988-1993 formed the cases, while 50 with ID living at home in the region between 1988-1993 formed the study population for the controls. Residential care was significantly more likely for those with behavioural or physical dependency problems. Admission was precipitated by increasingly difficult behaviour in 32% of cases, and increasing age and infirmity of the parents in 26%. A significant degree of social gain for the families was found following admission of the child to care. Approximately 70% of parents found that the special school or local workshop was the most useful day facility. Higher dependency needs and difficult behaviour are indicators of priority need for residential care.

## Introduction

Many changes have occurred in the services provided for people with intellectual disability (ID) throughout the centuries. Prior to the mid 1800s individuals with ID were referred to as "cretins" and "idiots" and were cared for in psychiatric hospitals. In 1869 Stewart's Hospital was founded. This institution was the only state facility available at that time, catering exclusively for those with intellectual disability.<sup>1</sup> This was followed by the setting up of voluntary run institutions, i.e. Daughters of Charity, Navan Road (1926), Brothers of Charity, Lota, Cork (1939) and many others until the 1950s to 1960s when local community based special schools were started to serve those with special needs who lived with their families in the community.<sup>2</sup> Improved services have enhanced the quality of life for people with intellectual disability and have eased the burden of caring experienced by their families.<sup>3</sup> This study was undertaken to identify factors, other than degree of ID, which precipitated admission to residential care, and which could be useful as indicators for the prioritisation of applicants for residential care facilities and for planning the development of future services.

## Methods

The sampling frame used for the selection of individuals in residential care was the manual register of individuals in residence with ID which was maintained by each residential unit. The South Eastern Health Board's computerised database was the sampling frame used to select individuals with ID living at home. Inclusion criteria for the cases were as follows: their home address was in the South Eastern Health Board region (SEHB) at the time of admission to residential care; that they were living at home prior to admission, not transferred from another residential setting; and they were resident for either five or seven days weekly in residential care. Inclusion criteria for the controls were: that their home address was in the SEHB region; their name was on the computerised database; and that they were living at home between 1988-1993. Controls were selected by matching each one to the case for age, sex, county of residence and degree of ID. If more than one control matched a case a random method of selection was used to select the control. Exclusion criteria for cases and controls were: no fixed abode for their home address and those whose mother had died.

The mother of each subject was interviewed at home by means of a structured questionnaire between August and October 1993. This questionnaire consisted of two parts, the first examined accessibility to services used, independence regarding daily living tasks, behaviour profile, home facilities and family support network. Part two studied the stress involved in caring for a child with ID, use of and usefulness of services and mothers' views on residential care. Validated instruments were used where appropriate, as well as some open questions with closed questions making up the majority of the 100 questions in the questionnaire. An explanatory letter was sent to each subject to arrange the interview at a suitable time and to invite their

participation by drawing on their experience to study certain aspects of mental handicap. Two refused to be interviewed and one could not be contacted at their home despite repeated efforts. One family of a control initially selected refused to be interviewed and two families did not fulfil the inclusion criteria. All were successfully replaced by the next randomly selected control. The overall response rate was 94%. Data analysis was carried out by using the Epi Info Software package, version 5.01b (Dean USD Incorporated, Stonemountain, Georgia) and the Statistical Package for the Social Sciences (SPSS).<sup>4</sup> The Chi-square test was used where appropriate. Probability values less than 0.05 were considered statistically significant.

## Results

Of the fifty cases in the study population admitted to residential care, 30% had mild, 30% moderate, 24% severe and 16% profound intellectual disability. Fifty per cent resided in the town and 50% in a rural setting. The age range was 4-42 years with 64% in the 10-30 age group. The controls had a similar profile with 82% matched to within 3 years, and 98% to within 6 years, of the case.

A comparison between mother's perception of the degree of ID of her child and the degree of ID which was recorded showed that 70% concurred, 25% of mothers overestimated their son's/daughter's degree of ability and 5% underestimated their son's/daughter's degree of ability. As shown in Table 1, the individual's use of their hands, as well as feeding and dressing independently were significantly less among the cases compared to the controls. Displays of established difficult behaviour patterns as well as temper tantrums, over active behaviour, inappropriate sexual behaviour and urinary incontinence were significantly more evident among the cases compared to the controls. Significantly more families of cases lived in their home for 16 years and longer. Mothers of cases indicated that they got less physical help from family members, and were more dissatisfied with the overall help given by family, relatives, neighbours and friends compared to mothers of controls. However, overall subjects considered that the family provided a high degree of support.

Following admission of the child to residential care (Table 2), mothers reported a significant decrease in all indicators of stress within the family. Mothers of control subjects reported more disruption of household routines, interference with sleep patterns, and felt more in need of a "break." Significantly more mothers of cases blamed themselves for their child's condition and thought their family coped less well than mothers of the controls. Over 75% of mothers of both groups said they would turn to their husband and family first for support when a crisis arose. The most common sources of financial strain experienced by families caring for a child with ID were costs incurred involving transport to medical specialists followed by damage and breakages to household equipment and furniture resulting from the individuals antisocial behaviour.

The services which were found most useful were similar for both groups i.e. special pre-schools, schools and workshops (74%) as well as the support mothers got from their families and from professionals 27%.

When mothers were asked which services required further development the following were mentioned: special schools and workshops adequately staffed with paramedical professionals (38%), expansion of respite care (25%), counselling for families to help them come to terms with their grief (21%) and help to be provided in the home during a crisis (19%).

The following factors were described as precipitating admission of the child into residential care: disimproved and antisocial behaviour in (36%), advancing age of the parents (26%), and planning ahead for their child's future (22%).

Table 1. Subject's social competence

Independence/Behaviour		Cases		Controls	
		No.	%	No.	%
Feeding	Independently	28	56	30	60
	Verbal prompt	3	6	4	8
	Physical help	15	30	5	10
	Need to be fed	4	8	11	22
$p=0.037$					
Temper tantrums	Usually	10	20	3	6
	Sometimes/never	40	80	47	94
$p=0.037$					
Difficult to manage	Usually	11	22	2	4
	Sometimes/never	39	78	48	96
$p=0.007$					

Table 2. Indicators of maternal stress prior to and after admission of the child into residential care.

Stress indicators		Cases		Controls	
		before admission		after admission	
		No.	%	No.	%
Unable to cope	Never/sometimes	31	62	47	94
	Always	19	38	3	6
Felt need for a break	Never/sometimes	36	72	49	98
	Always	14	28	1	2
Household routine altered	Never/sometimes	35	70	50	100
	Always	15	30	0	0
Sleep interrupted	Never/sometimes	37	74	50	100
	Always	13	26	0	0
$p=0.001$ for all the above					

## Discussion

In 1995 there were 26,000 persons with intellectual disability (ID) registered in the Republic of Ireland.<sup>4</sup> Approximately 50% of the 12,308 individuals in the moderate to profound categories were in residential care according to the 1981 census information.<sup>5</sup> The objectives of this study were to determine what factors caused parents to opt for residential care, apart from the degree of ID. Despite the development of community services, waiting lists for residential placements exist and admissions often arise because of a crisis situation. Hence, for families finding it too stressful to care for their child at home, some mechanism to plan for and prioritise admissions is needed.

The study found that the main differences between people with similar degrees of intellectual disability who are admitted to residential care compared to those living at home are the lack of independence in daily living skills and the presence of more difficult and antisocial behaviour patterns. The literature supports the necessity of a high staff ratio to client for those with such needs, as well as the selection of staff

from those who wish to and who would be trained appropriately to work with such individuals.<sup>6,7</sup> However, such a high level of support is clearly necessary if the needs of these individuals are to be fully met. A good family support network is well recognised as playing an important role in caring for a child with ID.<sup>8,9</sup> A high degree of support was generally present among both groups in the study, although mother's of those admitted to residential care felt that they got less physical support from family and friends rather than those living at home. Indeed, this may have influenced the decision to opt for residential care for their child. Families experienced a significant social gain following the admission of their child to residential care.

Meeting the special needs of individuals with ID in the home environment for as long as possible requires further development of community services. In turn these should be integrated with the availability of appropriate residential services when parents are no longer able to cope.

The study found that there are hidden costs in caring for a child with ID at home including the repair of household damage resulting from antisocial behaviour. Days off work for the parents to care for a child with ID are not always recognised by the workplace and represent loss of earnings which Baldwin<sup>10</sup> found were not always made up by receipt of state allowances. As there are few data available on the topic, further research of this issue is indicated.

Residential places are in short supply and prioritisation of waiting lists remains a problem. The principal reason given by mothers for opting for residential care was the increasingly difficult behaviour pattern of their growing child in conjunction with ageing parents. The main conclusion from this study is that those who are highly dependent on others for daily living tasks and those with challenging and antisocial behaviour are in increased need of residential care. A further reason given by parents for opting for residential care was to plan for their child's long term future. The information routinely recorded on the ID database should include a simple grading system for the individual's level of dependence, behaviour profile and an assessment of the family's coping skills. Such data would be helpful in planning the future expansion of services on the basis of local need, taking into consideration the level of community support services, i.e. schools, workshops and home support and in line with the principle of equity underpinning the National Strategy.<sup>11</sup> In the context of ID, priority for residential care should be given to families caring for a child with increased physical dependency and with challenging behaviour.

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