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Measuring the Parental, Service and Cost Impacts of Children with Autistic Spectrum Disorder: A Pilot Study

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Key words: Autism; cost; burden of illness; informal care

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ABSTRACT

The aim of this study was to carry out a preliminary examination of a research instrument developed specifically to collect cost information for individuals with autistic spectrum disorder. There is very little cost information on children or adults with autism or autism-related disorder, and no study appears to have carried out a specific cost collection in this area. Although some global cost estimates can be made, little is known about the cost implications of parental burden. By using different techniques to collect indirect costs, the study outlines a functional methodology. Results from this small pilot study point to considerable economic burden for parents and give some indication of the associated costs of autistic spectrum disorder.

KEY WORDS: Autism; cost; burden of illness, informal care.

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INTRODUCTION

The development of resource-intensive behavioural therapies for children with autistic spectrum disorder has focused attention on the need to understand the costs of supporting people with autism and also on the need for studies of the cost-effectiveness of different interventions. The response from the research community has been quite muted. Jacobson, Mulick & Green (1998) developed a cost-benefit analysis model of early intensive behavioural intervention (EIBI) based on reported clinical outcomes, but the model was criticised for focusing only on EIBI and for assumptions that were said to be speculative (Marcus *et al*, 2000). Economic descriptions of the cost consequences of autism and economic evaluations such as cost-effectiveness comparisons between different therapies or educational interventions which are based on observational cost data appear to be almost completely absent.

How might such observational studies proceed? In some health, education and other service systems routine data holdings are quite well developed, perhaps for the purposes of billing, perhaps for accountability purposes or resource management, perhaps for performance monitoring. This routinely collected statistical information will usually be able to chart which individuals use which services, how often and how intensively. It might also make it possible to compute the associated costs. But the availability of such useful data is not characteristic of many such systems - and certainly not across most of Europe - so that economic studies usually cannot be built on data that are already available. Moreover, autism spectrum disorders have (potentially) such wide impacts across many different services and agencies that it is unlikely that all the necessary resource use information would be readily accessible in such a way.

Consequently, economic studies are going to have to be built, in part if not in full, on specifically tailored data collections. This will require instrumentation to gather service utilisation and related data for individual children and families. The wide severity range within the spectrum and the broad range of therapies now in use (Howlin, 1998) make demands on such an instrument. One requirement for any such instrument would be that it could collect the necessary cost information across the potentially many domains of relevance. It would also be necessary to develop a functional methodology for the collection of costs associated with ‘informal care’ by families.

It is well known that autistic spectrum disorder has a major impact on parental and family life. Family costs might include lost employment and income, lost leisure time and out-of-pocket expenses. There are reasons to believe that these informal care costs represent a major part of the total cost due to the disorder. Fujiura et al. (1994) noted that most of the care for people with learning disability is provided by families, and Dobson & Middleton (1998) estimated that the cost of bringing up a child with a severe disability is three times more than for a child without disability. However, the size of the impact on families has not been assessed in economic terms, and so has not featured in evaluations or discussions of therapies or other interventions. For example, lack of information meant that we ourselves were unable to estimate the family impact in economic terms in an exploratory study of the costs of autistic spectrum disorder in the UK (Järbrink & Knapp, 2001).

The objective of this paper is therefore to outline the elements to be included in a cost study in the autistic spectrum disorder field and, in particular, to describe how to approach the collection of cost information concerning informal care. The application of the instrument in a small pilot study offers some tentative evidence on the parental economic burden and the costs of informal care from a societal perspective.

METHOD

Measures

A questionnaire was developed from the Client Service Receipt Inventory (CSRI) which, since 1986, has been used in more than 200 evaluations of interventions for people with needs related to mental health, learning disability, physical disability, old age, and child and family problems (Beecham & Knapp, 1992, 2001). The purpose of the CSRI is to collect detailed information on the client’s service use and family support in order to estimate component and total costs. The broad structure of the schedule has tended to remain the same from one evaluation to another, although differences in service context, user focus and study location have generated a need for different emphases and different service coverage.

For the purposes of the present pilot exercise, the format of the CSRI was adapted so that it could eventually be used in a postal survey and be completed by family carers of children with autism spectrum disorder. Three techniques were used to collect information about time spent on informal care, two questions in the questionnaire and a diary survey. Informal care was defined as care or support provided by relatives and friends who are not paid for these activities. The input of informal carers has usually been conceptualised in terms of time spent (frequency and duration) and tasks undertaken (such as personal care, shopping, domestic tasks and social visits). One approach to measuring the costs of informal care would therefore be to ask family members about such time inputs and tasks. Another approach would be to ask specifically about time lost from paid work, unpaid work and leisure. Out-of-pocket expenses due to the disorder were measured by asking parents to estimate their weekly average expenses over the last six months in each of a number of categories.

A schedule for a diary survey was also developed to get benchmarks for the answers in the CSRI regarding time spent on informal care and out-of-pocket expenses. This diary was to be completed by the carer on a daily basis for fourteen days. (Copies of both the CSRI and the diary can be obtained from the authors.)

Children with autistic spectrum disorder potentially use a wide range of services. We asked about service frequency and duration of use for all possible health, social care, education and related services.

Ethical Approval

We developed a study information sheet and a consent form to inform and recruit respondents. Ethical approval for the study was given by the Bethlem and Maudsley NHS Trust and the Institute of Psychiatry Ethical Committee.

Subjects

In order to pilot the schedule, a small sample of respondents was recruited from Greater London, Surrey and Sussex with the help of PACE (Parents' Autism Campaign for Education), a parental organisation. Twenty parents known to PACE were sent letters, together with the study information sheet and consent form, inviting them to join the study. Sample selection was made by representatives from PACE; it was not random nor could the sample generated by PACE be seen as representative of all parents of a child with autism spectrum disorder in the UK. We nevertheless worked with this ‘convenience sample’ - expected to be using a wide range of services - in order to help the early development of a research instrument that we hoped would be of wider application in due course. If parents were interested, they were asked to sign and return the consent form and were then telephoned by the researcher in order to fix the time and place to meet.

Procedure for Data Collection

As one of the study aims was to examine the schedule’s appropriateness for use in a postal survey, each parent was asked to read and answer the questions on their own while the researcher was sitting nearby. However, the parent was also asked to note any uncertainties and ask questions if something was not understood. All expressed uncertainties and questions were systematically recorded. When the questionnaire was completed, the parent was asked about the schedule's appropriateness and ease of completion, with the researcher following a semi-structured questionnaire to gauge their views. These answers were also recorded.

Finally, the diary schedule was handed over to the parent to be completed over a fourteen day period and to be mailed back to the research centre. One week after the interview, a letter was sent to each parent expressing appreciation that they had participated in the study and inviting them to contact the research team if they had any questions. If the diary schedule had not been received a month after the meeting, a reminder letter was sent.

Coding and Statistical Analysis

Information on service utilisation was costed by applying unit cost figures either from the annual UK compilation by the Personal Social Service Research Unit (Netten & Dennett, 1999), or from earlier studies (Järbrink & Knapp, 2001, Beecham et al, 2000) or as reported by the parents. All costs were converted to 1999-2000 price levels using the UK national pay and prices index for hospital and community health services and the retail price index (Netten et al, 1999). London costs were applied when a choice needed to be made, as some price and wage levels are higher in the capital. All figures were calculated so as to be additional costs due to the autistic spectrum disorder. Thus, for instance, the costs of mainstream education were excluded when calculating the cost for special education.

RESULTS

Sample Characteristics

Sixteen parents responded to our invitation to participate in this pilot exercise and returned the consent form. It was not possible to arrange a meeting with one of the parents, and so 15 were included in the study. Information was collected for 17 children as two families had more than one child with autistic spectrum disorder. Eleven of these children were living in London, three were girls, 16 were Caucasian and one was African-Caribbean. The children were aged between 4 and 10 with a mean of 7.8 years.

All children had been diagnosed according to ICD-10 which is the classification used in most centres in the UK. There was a wide range in the severity of the disorder. Six of eleven children diagnosed with autism had some degree of mental retardation (learning or intellectual disability). Three children were diagnosed with atypical autism and one of those had a mental retardation. Two children had Asperger syndrome and one child was diagnosed with semantic pragmatic disorder. In addition to the autistic spectrum disorder, two had chronic bowel syndrome, one had epilepsy and one suffered from gluten intolerance.

Informal Care

The estimates obtained from the three ways of measuring informal care time are presented in Table I. Several parents thought it was a little difficult to answer the first question asking for the average time spent in different caring activities as a result of their child’s disorder, and six were not able to answer it at all. The following reasons were given: some parents could not separate time between the activities, some could not distinguish the hours that were due to the disorder and some felt that their child took *all* their available time. We are not, of course, the first to encounter such reactions, nor are they peculiar to autism (Smith & Wright, 1994; McDaid, 2001). They illustrate some of the inherent problems in measuring informal care. The eleven parents that answered this question said they spent on average nearly 60 hours per week in caring and supporting their child due to the disorder.

The second way of questioning - in which they were asked to categorise the time-loss due to their child's disorder in terms of opportunities forgone as either paid work, unpaid work or leisure - was found easier. On average they estimated that there were 40 hours per week (SD = 22 hours) that they would have spent in other activities if their child had not had autistic spectrum disorder. They estimated that 22 hours (SD = 16 hours) could have been spent in paid work. Unpaid work corresponded to a small share but there was a large standard deviation (17 hours), partly because several parents gave a *negative* answer of hours: they said they would have spent *less* time in unpaid work if it had not been for their child's disorder. Several were now actively engaged in voluntary organisations, which would not have been the case if their child had not had the disorder. Finally, parents estimated that they lost 17 hours (SD = 11 hours) of leisure activities per week because of their child's disorder.

The answers gleaned from this second question gave approximately the same responses as the diary survey, which was based on a prospectively-gathered, daily judgement of time spent in different activities over a two week period. A diary helps obtain detailed records and eliminates recall problems typical with retrospective questionnaires. However, a diary cannot handle seasonal changes, and research has shown under-reporting by people with lower educational attainment (Bruijnzeels et al., 1998). Diaries are also more time-consuming for parents. With an average hourly cost of £15 for paid work and £4 for unpaid work and leisure, and taking a human capital approach to costing these inputs (which may not necessarily be appropriate; for example, see Gold et al., 1996), the mean cost for informal care would have been £397 per week.

Out-of-Pocket Expenses

The reported out-of-pocket expenses are presented in Table II. Parent-borne costs for education, early intervention therapy, health services and medication are not included as these are collected elsewhere in the CSRI.

The estimates collected in the diary survey are higher compared to those collected in the questionnaire. One explanation for the difference might be that some outlays are forgotten when a six-month period is reviewed retrospectively. This is supported by the fact that estimates for more regular expenses, such as travelling and extra help (often au-pair or similar support), are more similar between the two methods than are estimates for food, damages and additional costs for therapy/education that might more easily be forgotten. Additional costs for therapy/education in the diary survey included costs such as computer games, toys, and food for the therapist. The category 'other' includes a few high costs for adaptations and assessments. Both additional costs for therapy/education and 'other' include cost categories that were rarely remembered when the schedule was answered. The two assessed weeks might not be representative for a whole year, of course, but the size of the difference between the methods and the categories of costs that are under-represented in the schedule suggest that out-of-pocket expenses might be underestimated when collected by a retrospective schedule, particularly one covering as long a period as six months.

Service Use

Eight out of seventeen children had special support in mainstream schools, two were in boarding schools, two in special day schools and two in small private schools with special support. The remaining three children were attending a special unit in a mainstream school, an independent special day school and a nursery. The costs calculated for education include additional school fees, costs for classroom assistance, educational psychologist and early intervention programmes. The school fees also include special therapy for some children, such as language therapy given within the school.

Ten children were involved in early intervention programmes. The therapists were also often involved as school assistants, and the therapist costs can therefore be separated into classroom assistance and early intervention programme elements. Early intervention therapy is the service where the parental cost contribution is greatest - on average 33 per cent was paid by parents.

The costs for health and social services - the most common being for in-patient hospital care, social services respite care and clinical psychologist appointments - are small compared to the costs for education.

Income Losses

All parents reported that their child's disorder had negatively affected their career and/or income. However, only eleven parents – generally those who had experienced a clear reduction in income - were able to estimate the associated income losses. The weekly losses quoted by parents (and averaged per autistic child in the family) had a mean of £231 and median of £250. Two estimates were below £100 and two reached over £800, with seven of the eleven estimates in the range £200-£450 per week.

Total Cost

The combined cost estimates are presented in Table III. The total societal cost for a child with autistic spectrum disorder in this small, selected study sample is £689 per week when the only time cost included is the average reported income loss of £231. If we instead apply the human capital principle and calculate a cost based on the figures from the second question regarding informal care and presented in Table I (£397), the total weekly cost rises to £855.

On average parents pay £72 weekly for education and at least £66 for food, damage repairs, extra help and transport. Together with the income losses, these outlays imply that more than 50 per cent of the total societal cost fall (directly or indirectly) to parents. This can be compared with the 2.3 per cent that was estimated in our earlier study in which we were considerably hampered by the complete absence of information about the economic consequences for the parents (Järbrink & Knapp, 2001). However, it is important to distinguish the societal costs related *to* parents and the actual costs *for* parents. In our sample the parents received on average £59 per week in social security allowances as a result of their child's disorder. In addition, the income losses from a societal perspective are expressed as gross income before deduction for taxes.

The weekly societal cost for a child with a learning disability (mental retardation) appears to be higher than for a child without (£855 compared to £573), as does the education cost (£441 compared to £71). On the other hand, parental income losses appear to be higher for the more able children (£275 compared to £169). Further comparisons are not meaningful because of the sample size.

Quality of the Schedule

After parents had completed the schedule, a short structured interview was held about its appropriateness and manageability. Only two parents (out of 15) thought that the questions in the schedule were difficult to answer, whilst some who found it easy to answer said this was due to the researcher's presence.

Parents found it difficult to separate services given in the school or outside. For many parents there were also great differences in service use and impacts for their own responsibilities between school term time and school holidays. This was successfully sorted out in the interview and would need careful wording in a postal survey. No parent thought the questions were too personal or sensitive. All respondents also felt that it was appropriate for the schedule to be completed by parents of children with autistic spectrum disorder, but only five parents thought a similar version of the schedule could be answered directly by adults with high-functioning autistic spectrum disorder. Worries were expressed about the exactitude. Seven parents did not think that there were questions missing; others asked for questions about the effects on siblings, insurance, retrospective costs and expenditure not due to the disorder. The 'interviews' took between 20 and 74 minutes with an average of 48 minutes, but this duration of course included discussion of the research method and instrument.

DISCUSSION

The schedule developed for collecting cost-related data appeared to work well. Parental input in time and outlays can be collected in a postal survey, preferably by asking separately about time losses in relation to paid work, unpaid work and leisure. This technique is also attractive from a health economic perspective as it simplifies the costing when time is expressed in terms of opportunities forgone. Asking for time spent in specific care tasks posed more difficulties for respondents and complicated the separation of time that was due to the disorder. This might also lead to overestimates among stressed parents who are experiencing a heavy burden. Whether a questionnaire or a diary is the more reliable method cannot be answered by this study because of the small and unrepresentative sample. Findings suggest, however, that for routine items the diary captures smaller expenses better than the interview, whereas less frequent and more salient expenses are picked up better by the interview (Silberstein & Scott, 1991).

Information would also be needed about current or last salary for the purposes of costing. The question about extra expenses slightly underestimated costs compared to the diary survey and would need a few adjustments to help respondents remember costs that arise only infrequently. It would also be sensible to ask about average use and costs for an annual period to pick up differences between school term time and school holidays, or to use questions that ask for information on each of these periods separately. Employing a retrospective period as long as six months may be too demanding, and future research could perhaps experiment with shorter periods.

Relying on parental estimates of lost income is clearly subjective, and a more objective estimate would come from - for example – comparing income from employment before and after a child develops autism. Of course, one would also need a control group of families with a similar aged child *without* autism in order to control for a number of external factors. Such a study would be informative but difficult to conduct, as it would need to be built on an ongoing, large-sample cohort design. In fact, most of our respondents explicitly calculated their household incomes before and after their child developed autism, but in so doing they were not controlling for factors such as career development, the birth of further children, changes in the national/local economy with implications for employment or other extraneous influences.

The schedule did not include questions about savings that might result from the disorder, such as reduced expenditure on fashion clothes, sports equipment, restaurant visits and holidays. Earlier research has shown that the family costs for a child with autistic spectrum disorder are positively related to family finances (Birenbaum & Cohen 1993). In the present study information about family finances was not collected but examples were given that supported this relationship. Some parents said that they could not go on holidays, or just short ones, because of their child's disability. Other families said that they had to pay an assistant to go with them when they were on holiday, but that they were able to afford these extra costs. Many of these items - whether incurred costs or saved expenditures - will be income-related: other things being equal, they will be more important for higher-income families.

Our aim was to develop a research instrument that could collect data on service use and (particularly) informal care and other family inputs for children with autistic spectrum disorder as the basis for calculating the costs of support. The study sample showed a wide variation in relation to needs in the spectrum. Because the focus was children, the sample was suitable for developing a schedule that collects information about education, service use and family support. However, consequently we do not know how well the schedule would work in collecting cost-related information for adults in paid work. Certainly it would be necessary to cover a different range of services and life opportunities, and to identify a slightly different set of informal care tasks. The instrument is also context-specific: it would need some adaptation not only to different age groups but to different countries and cultures. We know from some of our own and related work in quite a different area – care for adults with schizophrenia – that service utilisation patterns, costs and family support can vary markedly even between countries with similar financing mechanisms and similar policy environments (Knapp et al., 2002; Magliano et al., 1998). We are not aware of any equivalent evidence in the autism field, but would expect similar patterns of inter-country distinctiveness.

Respondents were recruited from the membership of an active parental organisation and were all enthusiastic about participating. This implies that all children were diagnosed and that, by virtue of their membership, these parents are quite likely to be more active in pressing for improved services for people with autism and better informed than a general population of parents of children with autistic spectrum disorder. As an illustration of this, ten of the seventeen children were attending some form of early intervention programme - a higher proportion than would generally be expected in the UK today. The costs for education are therefore also probably higher than would generally be the case. Of the total estimated societal cost, more than 50 per cent could be linked to the parents. Even if the sample is not representative, it is fairly clear that the costs for informal care, income losses and outlays exceed the 2.3 per cent estimated in a previous exploratory ‘cost-of-disorder’study (Järbrink & Knapp, 2001). In addition, we have also shown that more able children with autistic spectrum disorder generate substantial societal costs.

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Table I

Time spent in informal care per child per week, by three ways of measuring

	No of children	Mean weekly hours	Standard deviation, hours	Median weekly hours
Question 1. Informal care in different activities, n=11				
Personal care, e.g. dressing, toileting, meals	9	21.97	29.91	11.67
Providing transport	5	2.65	4.52	0.00
General housework and shopping	6	3.55	4.64	2.00
Supervision/companionship/emotional support	7	28.11	33.99	20.00
Other	4	3.64	6.64	0.00
Total 1	9	59.92	40.51	58.00
Question 2. Categorising informal care in alternative time, n=17				
Paid work	15	21.77	15.54	20.00
Unpaid work	13	0.37	16.88	0.00
Other such as leisure	14	17.22	11.46	18.00
Total 2	16	39.36	22.35	39.00
Diary, n=16				
Personal care, e.g. dressing, toileting, meals	13	8.89	8.54	6.58
Providing transport	12	2.15	2.24	1.29
General housework and shopping	12	3.00	4.39	1.38
Supervision/companionship/emotional support	15	23.84	23.57	19.38
Other	8	5.27	6.47	2.63
Total	15	43.15	30.62	43.01

Table II

Families' average weekly out-of-pocket expenses per child for other items and services than education, early intervention therapy, health services and medications, by two ways of measusring, £

Items/services	Questionnaire (n = 17)				Diary (n = 16)			
	Number of children	Mean cost, £	SD, £	Median cost, £	Number of children	Mean cost, £	SD, £	Median cost, £
Damages, certain food, clothes, extra laundry	13	14.26	15.98	10.00	12	33.17	32.15	23.50
Extra help	8	26.88	48.98	0.00	9	22.52	28.92	5.00
Transport	8	9.02	15.72	0.00	8	9.34	13.02	0.25
Special activities	10	6.52	7.03	5.00	3	2.48	6.02	0.00
Additional costs for therapy/education	6	4.69	7.73	0.00	4	12.03	28.99	0.00
Extra costs for siblings	1	1.47	6.06	0.00	0	0.00	0.00	0.00
Court cases/solicitor	2	3.07	12.11	0.00	2	1.43	5.30	0.00
Other	0	0.00	0.00	0.00	6	19.22	64.46	0.00
Total out-of-pocket expenses	**16**	**65.91**	**54.24**	**56.38**	**15**	**100.15**	**83.91**	**73.10**

Table III

Total costs per average week, £

	No of children	Mean weekly cost, £	Standard deviation, £	Median £
Education	16	223.82	304.92	84.08
Early interventional therapy	10	144.38	173.83	100.00
Health and Social services	17	20.12	21.92	12.53
Voluntary support	7	2.14	3.89	0.00
Medication	11	1.67	1.89	1.04
Other costs paid by parents	16	65.91	54.24	56.38
Income losses	11	231.18	292.32	200.00
Total	17	689.21	406.87	649.53