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Research paper

A cost and outcomes analysis of alternative models of care for young children with severe disabilities in Ireland[☆]

Analyse du coût et des qualités de modèles alternatifs de soin adressés à de jeunes enfants nés avec des handicaps sévères en Irlande

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ABSTRACT

Young children born with severe disabilities in Ireland may receive either continuous hospital inpatient care or homecare services in their family environment. In practice, a charitable body – the Jack and Jill Foundation (JJF) – is the predominant provider of homecare. This non-statutory homecare service is often supplemented by statutory homecare services, through Primary Community and Continuing Care teams. The purposes of this exploratory study are twofold: firstly, we compare costs (both direct and indirect) associated with hospital inpatient care and JJF homecare; secondly, we compare levels of family satisfaction for recipients of continuous hospital inpatient care, JJF homecare and statutory homecare services. Direct costs appear to be substantially greater for the hospital inpatient model than for JJF homecare, from the perspective of both the health service (€156,282 versus €16,267) and of families (€22,261 versus €2,620). Indirect productivity costs are more closely matched at €27,728 for the hospital inpatient model and €22,941 for JJF homecare. Satisfaction ratings were greatest for JJF, with a mean rating of 4.89 out of 5, compared to 3.28 for inpatient

[☆] In memory of Daniel John Revill (1983–2010) – a wonderful brother.

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hospital care, and just 2.86 for statutory homecare services. Findings support previous research that the homecare model is likely to be cost-effective, with lower costs falling on both providers and on families. In addition, families expressed a clear preference for care to be provided at home.

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R É S U M É

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En Irlande, les enfants nés avec des handicaps sévères, susceptibles de recevoir des soins de longue durée, sont pris en charge soit en milieu hospitalier soit par des services de soins à domicile, dans leur environnement familial. L'organisation caritative Jack and Jill Foundation (JJF) est, dans les faits, le principal prestataire de soins à domicile. Les services de soins à domicile statutaires dispensés par les équipes communautaires de soins primaires de longue durée (*primary community and continuing care teams*) complètent souvent ce service de soin à domicile non-statutaire. L'objectif de l'étude exploratoire présentée ici est double : il s'agit, d'une part, de comparer les coûts (tant directs qu'indirects) associés aux soins en milieu hospitalier et aux soins à domicile dispensés par JJF ; d'autre part, il s'agit de comparer les niveaux de satisfaction des familles dont les enfants sont destinataires de soins de longue durée en milieu hospitalier et à domicile, dispensés par JJF, d'une part, et par des services de soins à domicile statutaires, d'autre part. La comparaison des coûts directs du modèle hospitalier et de celui du soin à domicile proposé par JJF fait apparaître un coût considérablement plus élevé du modèle hospitalier, tant du point de vue des coûts pour les services de santé (156 282 € versus 16 267 €) que pour les familles (22 261 € versus 2620 €). Les coûts de productivité indirects des deux modèles sont beaucoup plus proches, c'est-à-dire 27 728 € pour le modèle hospitalier et 22 941 € pour des soins à domicile dispensés par JJF. Le taux de satisfaction des familles est plus élevé à l'égard des prestations de JJF, avec une évaluation moyenne de 4,89 sur 5 versus 3,28 en ce qui concerne le modèle hospitalisé et 2,86 pour des services de soins à domicile statutaires. Ces résultats corroborent les conclusions de recherches antérieures, montrant également que le rapport coût-efficacité du modèle des soins à domicile est selon toute probabilité supérieur, avec un moindre coût supporté par le prestataire des soins et par les familles. S'ajoute à cela, une préférence clairement exprimée par les familles pour les prestations de soins à domicile.

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Introduction

A young child with severe disabilities generally requires substantial and often complex healthcare attention. Normally the child will remain in hospital for a number of weeks after the birth. After that the choice is between the child remaining in hospital or receiving appropriate care in a family setting, or in a residential care centre if this is available.

In Ireland, a child with severe disabilities receives care based on one of the following models:

- the child may receive continuous care in an acute children's ward of a state-run hospital financed by the public health service;

- the child may be discharged to the family home and receive homecare services. This can be provided and financed either through:
 - statutory services – in particular Health Service Executive (HSE) Primary Community and Continuing Care (PCCC) services (currently being merged with the National Hospitals Office to form the new Directorate of Integrated Services),
 - or the Jack and Jill Foundation (often supplemented by PCCC services). This organisation receives 17% of total annual costs (€2.4 million total costs) in funding from the government and raises the rest through voluntary work and donations.

Since 1997, the Jack and Jill Foundation (JJF) has provided home nursing care and respite services to over 1,200 young children in Ireland, and currently serves around 286 children according to JJF nurses. These children are born with or develop brain damage and suffer from conditions such as cerebral palsy, and as a result suffer severe neurological and developmental delay. This service is provided from birth to the age of 4 years. In total, it is estimated that there are approximately 1,369 children in Ireland under the age of 18 who are affected by conditions such as these, with the majority cared for by the two statutory services models (DOHC/IHF, 2005).

The JJF allocates a monthly care budget to families based on their child's individual care needs, which the parents can then utilize to employ nurses and skilled carers. The JJF seeks to emphasize continuity of care by assigning a single team of nurses to each child for the duration of their JJF care, and also provides a liaison service in which they advise parents on services potentially available to them from other organisations.

Due to advances in technology, children with complex disabilities are surviving longer than before (Wang & Barnard, 2003) and consequently the numbers of children needing care are rising. Although the patient population is relatively small in the Irish context, providing care to this specialised group is costly. Prior to the development of the JJF voluntary homecare model, care was provided in a largely ad hoc manner with State provision of homecare to a particular child decided by the local PCCC. The JJF homecare model was developed in an effort to fill gaps in the provision of care. Yet responsibility for managing this group of children is still somewhat ill-defined and there is still no statutory budget dedicated to their care. Making decisions on the appropriate choice of alternative models of service provision requires an assessment of their associated costs and benefits. There is a lack of evidence internationally and this is therefore seen as a central objective of the current research agenda (Emond & Eaton, 2004). Due to limited data availability, in particular from randomized subjects, this study adopts an exploratory comparative approach. It aims to inform policy within Ireland and contribute to the international evidence base.

The key objective of this study was to analyse the costs and benefits of alternative models of care for severely disabled young children in the Irish context. Direct costs may fall on the funding bodies or on families, while indirect economic costs fall only on families.

We examine costs and outcomes in the following settings:

- acute hospital stay: costs falling on the third party public payer;
- charitable body homecare: costs falling on the JJF and other agencies.

The study has the secondary objectives of gathering evidence on subjective preferences of parents as a measure of health outcome, and whether the models have different impacts on the wellbeing and functioning of families.

To meet these objectives, a literature review was first undertaken to obtain the best international knowledge on the costs and outcomes of alternative models of care for children with severe disabilities. The literature review had the following objectives:

- to ensure that all models of care have been captured in the study;
- to obtain data on costs of care, associated with the alternative models, falling on public health systems similar to Ireland (i.e. in Western Europe);

- to obtain data on the direct and indirect economic costs falling on families from the alternative models;
- to identify whether the international literature highlights any difference in outcomes for children, or for families, from the alternative models of care.

A systematic search was undertaken of the PubMed and Science Direct databases using the search terms ‘costs’, ‘children’, ‘disabilities’ and ‘care’; and the search was confined to works published in English after 1997. In addition, bibliographies were searched for further useful works, and an informal search of the grey literature was also undertaken.

The abstracts of retrieved references were reviewed and assessed according to their relevance for the present study. The literature search was restricted to costing studies undertaken in Western Europe, since health systems within this region are most similar to the Irish context. The inclusion criteria were works that provided information of any of the following:

- models of care for severely disabled young children in the European context;
- comparative evaluations of service provision for severely disabled young children;
- assessments of costs falling on families of disabled children in the European context.

In total, 246 works were retrieved from the PubMed database, of which 27 were selected, and a further 67 were retrieved from Science Direct, of which six were selected. A further five works were retrieved from reviewing bibliographies and the informal search. Each of these works was read in full. Ten were found not to be relevant, but the other 22 are summarized in [Table 1](#) below, where “III” signifies highly relevant, and “I” least relevant ([Table 1](#)).

Literature review findings

Costs falling on the state of alternative models of care

The literature around the costs and effectiveness of alternative models of care for severely disabled children is small and substantial gaps exist in knowledge. The most robust recent comparative study on the costs of provision to the state is by [Noyes, Godfrey & Beecham \(2006\)](#). The authors follow a sample of 34 technology-dependent children in the UK for a period of one year; and estimate costs falling on the National Health System (NHS), social services, education authorities, and the voluntary sector. However, family costs, both direct (i.e. purchases) and indirect (lost hours of work), are excluded. It is worth noting that technology-dependent is usually defined as being dependent on one of the following technologies on a regular basis: medical ventilation, parenteral nutrition, tracheotomy, oxygen therapy, suction machines, tube feeding.

Seven of the children in the [Noyes et al. \(2006\)](#) study received hospital care throughout the year, and had an average cost of care of £428,000 pa. Twenty-four children received home-based care, with a much lower average cost of £104,000 p.a.

It is possible that children in hospital had greater care needs. Therefore, useful information was obtained on four children who started the year in hospital but were later discharged to home. Even within this cohort, home-based care costs were estimated to be 44% lower than when in hospital.

The findings of [Noyes et al. \(2006\)](#) are supported by [Glendinning, Giuffrida & Lawton \(2001\)](#), who estimate the home-care costs associated with supporting four exemplar “case study” children over a year. Costs vary significantly depending upon the types of technologies involved and local patterns of service, but often were seen to exceed £100,000 per year. The authors estimate there are around 6,000 such technology-dependent children in the UK.

The official UK record on hospital and community costs of caring for disabled children is maintained by the Personal Social Services Research Unit (PSSRU) at the University of Kent ([Beecham et al., 2007](#)). Their unit cost information on general care is based on the works of [Noyes et al. \(2006\)](#) and [Glendinning et al. \(2001\)](#). They do not have unit cost information on more specialist and/or expensive services, such as respite care or particular interventions. This confirms there is no more costing information in the UK context.

Table 1
Summary of literature review findings.

| Retrieved Reference | Models of care provision | Evaluations of service provision | Costs falling on families | Relevance | Summary |
|---|--------------------------|----------------------------------|---------------------------|-----------|--|
| Bagust et al. (2002) | | X | X | III | Economic evaluation of a paediatric hospital at home versus traditional hospital care. Estimates direct costs falling on parents, but not indirect costs |
| Beecham et al. (2007) | | X | | II | Costs key worker support for disabled children and their families |
| Bumbalo et al. (2005) | | | X | I | Economic impact on families of caring for disabled children. Useful but US focused |
| Clarke and Quin (2007) | | | | II | Investigation into professional carers experiences of providing paediatric palliative care in Ireland. Not exactly relevant for this patient group |
| Corden et al. (2002) | | | X | II | Investigates the financial impacts on families after the death of a child |
| Curran et al. (2001) | | | X | I | Compares the time costs of caring for children with disabilities and without disabilities. Doesn't cover economic costs |
| Fisher (2001) | X | | | II | Reviews the literature on the needs of parents with disabled children. Mostly qualitative |
| Fitzgerald (2004) | | | X | III | Estimates the financial costs of having a child in hospital in Ireland. Parts of the paper are missing |
| Glendinning et al. (2001) | X | | | III | Estimates the numbers of technology-dependent children living at home in the UK and their associated costs |
| Gormley (2003) | X | X | | III | A Master's thesis, primarily qualitative. Examines the needs of families of disabled children in the Irish context |
| Heitmueller and Inglis (2007) | | | X | I | Investigates the wage differentials of informal carers. Focused more on methodology than results and doesn't differentiate parent carers from, for example, carers for the old |

Table 1 (Continued)

| Retrieved Reference | Models of care provision | Evaluations of service provision | Costs falling on families | Relevance | Summary |
|------------------------------------|--------------------------|----------------------------------|---------------------------|-----------|---|
| Joseph Rowntree Foundation (1999a) | | | X | III | Survey of the financial situation of families of disabled children – shows they are more likely to be in poverty |
| Joseph Rowntree Foundation (1999b) | X | | X | III | Examines government efforts in the UK to support disabled children and their families |
| Joseph Rowntree Foundation (2002) | X | | | I | Response to UK Carers and Childrens Act. Country specific |
| Joseph Rowntree Foundation (2003) | | X | X | II | Outlines the support needs of children with complex disabilities over extended periods |
| McConachie (1998) | X | | X | II | Presents a number of conceptual frameworks with which to evaluate services for children with disabilities |
| Noyes et al. (2006) | X | | X | | Examines resource use and service costs for ventilator-dependent children and young people in the UK |
| Parker et al. (2002) | X | X | X | III | A systematic review of the costs and effectiveness of different models of paediatric homecare |
| Roberts (2001) | X | X | | I | Reviews the costs and effects of different services to children with complex health needs, although concentrated more on older children |
| Stabile et al. (2006) | X | X | X | II | Examines household workplace responses to changes in public homecare programs |
| Sloper (1999) | X | X | | III | Key paper – reviews the needs of parents of disabled children and evaluates the features of successful service models |
| Yantzi et al. (2001) | | | X | I | The cost impacts of distance to hospital on families with a child with a chronic condition – interesting methodology, but US focused |
| Young et al. (2008) | X | X | | I | The impact of early support on children with disabilities aged 0–3 – clinically focused, and doesn't differentiate homecare and hospital care |

Therefore, based on the best available international information, there is strong evidence that hospital-based care for a severely disabled child is much more expensive than a model of care provided at home. These findings are, however, based on a very limited number of studies.

Costs falling on families of alternative models of care

There is a limited number of studies on the direct costs borne by families of severely disabled children. However, these studies are generally now slightly dated.

The [Joseph Rowntree Foundation \(1998\)](#) on paying to care is probably the most comprehensive. This estimates that it costs three times as much to raise a disabled child as it does for a non-disabled child. This is due to additional direct costs that are incurred such as aids, adaptations to home, transport, heating, and childcare. These costs leave families of disabled children at greater risk of living in poverty (Department of Work and Pensions figures 2006/07, in the [Joseph Rowntree Foundation, 2008](#)). This study, however, excludes indirect costs.

A key concern is whether home-based care shifts the financial burden onto families from the State, relative to hospital care. This was the focus of a study by [Bagust, Haycox, Sartain, Maxwell & Todd \(2002\)](#) who present an economic evaluation of a paediatric hospital at home versus traditional hospital inpatient care trial, again in the UK. Children in the trial generally suffered from relatively milder conditions (such as breathing difficulties, diarrhoea/vomiting, and fever), so caution should be retained for interpreting the results for the present purposes. Nevertheless, they find costs borne by families were reduced by an average of 44% for homecare patients.

There were no studies found on the opportunity or indirect costs incurred by families with severely disabled children. These include time off work to care and transport time. This is clearly a significant gap in the literature, and is one important aspect addressed by this present study. Despite relatively sparse evidence it does appear that direct costs for families are somewhat reduced when the child is at home – with the important proviso that the State is also supportive of a home-based care model.

Outcomes of the models of care

There is little clinical evidence that health outcomes for severely disabled children differ depending on whether care is received in a hospital setting or at home. In the most comprehensive systematic review of costs and effectiveness of models of paediatric home care, [Parker et al. \(2002\)](#) find few controlled studies or studies that used clinical outcomes in the assessment of care to technology-dependent children. No further contributions to the literature were found since 2002.

Although there is an absence of differential clinical evidence, there is reasonably strong evidence on a subjective preference of children and parents for home care. For instance, [Bagust et al. \(2002\)](#) report that in a satisfaction survey of 40 families, 90% expressed a clear preference for home care. This can be regarded as subjective evidence on quality of care.

The literature does show that the management of parental distress and effective family functioning impacts positively on the cognitive, behaviour and social development of children (Richman et al., 1982 in [Sloper, 1999](#); Wallender and Varney, 1998 in [Sloper, 1999](#)). Therefore models of care associated with better parental and family outcomes can also be expected to be beneficial to the disabled child.

[Sloper \(1999\)](#) investigated the literature on factors related to parental wellbeing. Families vary in how they appraise the situation of having a disabled child, but it has been shown this variation is not greatly explained by the severity of illness. Instead, important factors that increase parental distress include:

- problems with the child's behaviour or sleeping;
- adverse life events, such as family illness, or separation and divorce;
- material and financial difficulties;
- parents' lack of a sense of control. Models of care should therefore act to mitigate these problems.

The factors that cause distress can be linked to the particular unmet needs of parent carers. [Sloper \(1999\)](#) identifies the most common of these as being information and advice about services, financial

and material support with transport and housing, and practical help with breaks from care. In contrast, models of care that have been evaluated as being 'successful' generally include the following aspects:

- a 'key worker' that helps to navigate parents through the myriad of available assistance;
- the availability of parental counselling;
- an element of parental partnership in the supply of services.

To conclude, it is not possible to state with certainty that clinical outcomes to children or families are better with home based rather than hospital care. However, it is likely that family functioning and wellbeing is improved with home-based care that meets the needs of parents; and this is likely to have a positive effect on children.

Methods

Acute hospital stay costing: costs falling on the third party public payer

For children cared for in the hospital setting, the cost of the hospital stay falls on the third party public payer. The mean cost per year was estimated based on nationally collected Diagnosis Related Groups (DRG) cost data, based on the frequently replicated Australian Classification System.

The expert judgment of JJF workers was used to match children currently receiving JJF care to hospital DRG based on their prognosis. The annual cost of hospital care for these children was then calculated based on Ireland-specific DRG cost weights. For this component of the costing, a random sample of 30 children was taken from the case lists of JJF nurses. Seven children were matched to the "cerebral palsy" DRG (B65Z), four to "respiratory signs and symptoms with severe or catastrophic complications" (E67A), one to "respiratory signs and symptoms minus severe or catastrophic complications" (E67B), five to "respiratory infection/inflammatory-CC" (E62B), one to "congenital heart disease" (F68A), 11 to "seizure without complication or co-morbidity" and one to "other digestive system or procedures with catastrophic complications" (G12A). Crucially, these DRGs are representative of the overall JJF casemix, enhancing the validity of the cost comparison between JJF children and hospital inpatients.

The most up-to-date casemix costs relate to 2007 activities. Costs were inflated to 2008 prices to match the period of recall of the parents' questionnaire. The average costs related to each DRG are based upon average length of inpatient stay for each classification. These were then extrapolated to an annual length of stay based on a per diem charge. For example, for 'DRG B65Z-cerebral palsy' the casemix cost per case is €3,935 and there is an upper average length of stay of 27 days, with an additional per diem charge of € 282 for extended stays. The estimated annual cost of stay is therefore $€ 3,935 + (365 - 27) \times € 282 = € 99,251$. The drawbacks of this methodology are outlined in the concluding section.

JJF home care: costs falling on the JJF and other agencies

The costs of a typical JJF package of care were estimated based on the average annual costs incurred by the Foundation over the past 3 years, rather than for a sampled subpopulation of children in the JJF model. These total annual costs were then divided by the average number of children receiving care per month for each of the 3 years, inflated to 2008 prices. An annual inflation rate of 3% was assumed. Cost per case estimation was based on the total costs incurred by the Foundation to account for both variable and overhead costs.

In addition to receiving care from the JJF, families often receive supplementary hours of assistance from qualified nurses, carers and home help funded by the HSE. Cost data could not be obtained for support provided by other statutory and voluntary agencies including local early intervention services, social work support, physiotherapy and occupational therapy. We surveyed 30 families to establish the typical level of supplementary State assistance a family receives, of whom 26 families responded. The estimated costs of these additional services were then factored in to provide a total cost for JJF-led homecare, including contributions from both the JJF and State authorities.

The costs of the HSE-financed supplementary care received by a child in receipt of JJF homecare were, for the purposes of this study, estimated based on the nursing and carer costs associated with the JJF. In reality these may differ from the costs incurred by the State for the provision of these services. However, since the objective of the study is to assess the efficiency of JJF provision this was appropriate. It enables a fair assessment to be made of JJF homecare provision as an alternative to State-led care.

Statutory authorities homecare costing

In practice, no uniform package of statutory homecare is available in Ireland. Attempts to obtain costing information were unsuccessful, perhaps unsurprisingly as the literature search revealed scant community costing information in the international context. The conclusion was made that there is insufficient basis to differentiate costs of statutory domiciliary care and JJF provision in this study.

Direct and indirect costs falling on families for each model

The direct and indirect costs falling on families with the alternative models of care were estimated based on a questionnaire sent to 30 families currently receiving care from the JJF (this differs from the sample used to estimate statutory costs for JJF families). JJF nurses delivered the questionnaire on their weekly visits, and families were provided with stamped addressed envelopes to anonymously return the questionnaire after completion. It is therefore believed that families completed the questionnaires truthfully.

All nine nurses employed by the Foundation, as of July 2009, delivered the 30 questionnaires. One nurse delivered two questionnaires, and the other eight nurses delivered three or four questionnaires each. The nurses were told to deliver the questionnaires to the first families on their weekly visits that:

- had been receiving JJF care for at least 6 months, so that they had basis to make an accurate evaluation;
- had not recently been bereaved.

The sample covered all geographic areas of Ireland, the range of disabilities for which the Foundation provides care, and all socioeconomic groups. The sample should therefore be representative, and there is no reason to suspect selection bias. In total, 28 questionnaires were returned, a response rate of 93%.

Data were obtained on all direct and indirect costs incurred by families with the current JJF model of care, scaled to one year. Direct costs include costs of specialist equipment, transport to health centres and hospital appointments, and additional costs of care. As many parents have had to adjust their working hours due to caring for their child (in both the hospital and home care setting), we used the “opportunity cost” method to estimate indirect costs falling on families (Van Den Berg et al., 2006). Using this method we elicited parents change of work hours due to caring for their child at home, and used their income generating power (approximate market wage rates) to estimate the opportunity cost of caring for a child at home. Data were also collected on families’ additional care from other channels.

Data on the direct and indirect costs associated with hospital care were obtained by asking parents to recall periods when their child was in hospital, as we were unable to collect data directly from a sample of the families of children receiving the hospital inpatient model of care. Direct costs associated with hospital care include accommodation for parents in or near the hospital, parking, and additional purchases of food. Data on costs of inpatient stays for JJF group lacked detail on the specific causes of admissions, hence was included as sensitivity analysis rather than in the base case.

In addition to the costing data, the sample of 30 parents was asked to rank their satisfaction with the alternative models of care in terms of:

- the service models supporting the health and wellbeing of their child;
- the service models supporting the functioning and wellbeing of the broader family.

The satisfaction outcome measure involved giving the service models a rating of 1–5, in which 1 was extremely dissatisfied and 5 was extremely satisfied. A single sample of parents rated all three-care models, as the parents had experience of each model (on an intermittent basis for the hospital and supplementary statutory services) and it was unfeasible to send the questionnaires to families outside of the JJF cohort.

Four additional scenarios were examined in a sensitivity analysis. First, an estimation of hospital inpatient costs was included for the JJF homecare group. Second, the least costly DRG was used to calculate the costs of the hospital-based model of care, rather than an average of each DRG. Third, indirect costs were excluded. And finally, the first three scenarios were combined.

Results

Costing

The costs associated with each model of care are outlined in Fig. 1 (2008 prices).

There is a marked difference between the two models of care. Costs falling on the healthcare provider are almost nine times larger for inpatient care than homecare. The variability of the former is demonstrated by the large standard deviation (€ 34,037), while the variability of the latter is unknown as we calculated only a mean cost per child. Costs falling on families (the right hand column in each case), in particular direct family costs, are also substantially greater for the inpatient model.

Breakdown of JJF care costing

The average cost per child over the 3 years was calculated at €9,177 (2008 prices) based on data for the 3-year period 2006–2008. These are total costs, including both fixed and variable costs, which must be incurred for a JJF package of care.

The average amount of additional assistance received from the HSE was calculated using questionnaire data. Results are illustrated in Table 2.

The supplementary care received from the HSE is though highly variable, with some families receiving no supplementary care at all and other families receiving more than 20 hours per week. It is not clear whether supplementary care correlates with the severity of illness.

The cost of a JJF nurse is € 16 per hour, and a JJF carer receives €8 per hour. If we assume home help is also provided at € 8 per hour, the costs of an average package of HSE supplementary care if this were to be provided by the JJF can be estimated at € 136.34 weekly per child (inclusive of the 29% overhead). This translates to additional annual cost of € 7,090 per child.

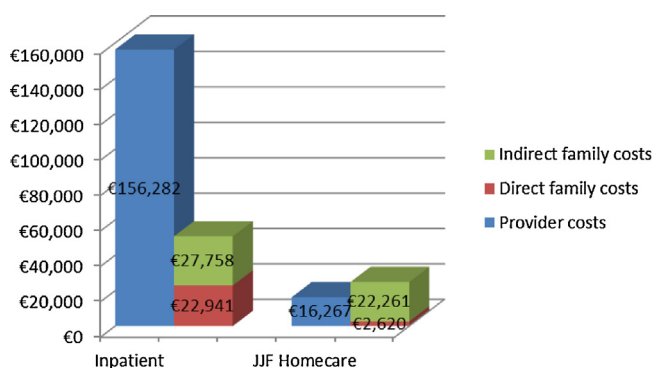


Fig. 1. Inpatient and homecare costs.

Table 2
Additional state-provided assistance for JJF. Results (breakdown of JJF care costing) section.

| | Weekly hours of care received from HSE nurses | Weekly hours of care received from HSE-financed carers | Weekly hours of home help funded by the HSE |
|---------|---|--|---|
| Average | 4.4 | 3.0 | 1.3 |

JJF: Jack and Jill Foundation; HSE: Health Service Executive.

When the costs of the supplementary care are added to the costs €9,177 core costs of JJF care, this comes to an estimated total annual cost of JJF-led homecare per child of € 16,267.

Costs facing families

A breakdown of the costs facing families with each model of care is provided in [Table 3](#).

Costs facing families are almost twice as large for the hospital inpatient model as for JJF care. The bulk of this difference is accounted for by direct costs. Indirect costs, which can be interpreted as the additional income that could be earned if the family didn't provide care to the child, are more similar.

Children that receive JJF homecare provision visit medical facilities, on average, six times per month. The range of required medical visits varies widely, however, with 20% of children requiring more than ten visits per month.

The time and travel costs facing families are less when children are in hospital due to the simple fact that medical facilities tend to be closer to the family home. Similarly, the main cost drivers when a child is at hospital are accommodation for parents and additional food requirements – therefore out of pocket costs associated with JJF homecare are also substantially reduced.

Families indicated that they are able to work slightly more hours per week when the child receives home care relative to when they are in hospital. This is associated with reduced indirect costs relative to those incurred with hospital care.

Family satisfaction

The satisfaction results for each model of care are in [Fig. 2](#).

Families report very high satisfaction with JJF homecare services. In fact, only three out of 28 families report satisfaction less than 5 against either of the two questions (two of these provide a rating of 4 and one of 3). Hospital inpatient services were rated somewhat lower. Interestingly, for state-provided homecare services very low average ratings were reported in comparison to both the JJF homecare and State hospital care models, indicating there are clearly serious problems in the provision of HSE PCCC homecare services. The range of responses was also very broad, with ratings ranging from 1–5 for both of the questions. This may be related to the high variability of HSE PCCC provision, as indicated in the survey of JJF families. If so it raises important questions over the equity of delivery in statutory homecare services.

Table 3
Costs facing families.

| | Acute hospital model | JJF homecare |
|--|----------------------|--------------|
| Mean costs of family travel to hospitals per year (€) | 5,439 | 1,328 |
| Mean out of pocket direct costs incurred when child in hospital (€) | 16,822 | 1,292 |
| Mean total direct costs (€) | 22,261 | 2,620 |
| Mean total indirect costs of reduced working hours when the child is in hospital (€) | 27,758 | 22,941 |
| Total direct plus indirect costs (€) | 50,019 | 25,561 |

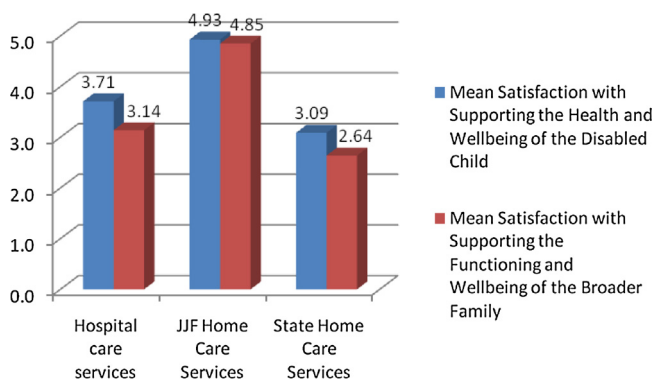


Fig. 2. Satisfaction ratings.

Sensitivity analysis

To explore the robustness of the results, four additional scenarios were examined in a sensitivity analysis. These are outlined in Table 4.

The effects of including an estimation of hospital inpatient costs for the JJF homecare group are shown in Table 5.

It can be seen in Table 5 that total costs for JJF homecare remain far less than for the hospital model of care.

In scenario 2, provider costs for the inpatient model are reduced to €99,251 due to using the least costly DRG in place of the average DRG value. Total costs remain much larger for the inpatient model than for JJF homecare, at €149,240 and €41,148 respectively.

In scenario 3, when indirect costs are excluded, costs for the inpatient hospital model (€178,543) remain far larger than for JJF homecare (€18,887). The impact of combining scenarios 1, 2 and 3 is illustrated in the chart below (scenario 4) (Fig. 3).

It can be seen from the chart below that when all three scenarios are examined collectively, the magnitude of the difference between each model of care is reduced, but JJF remains substantially less costly than the hospital model of care at €33,985 versus €121,196 respectively.

Table 4
Sensitivity analysis.

| | |
|------------|--|
| Scenario 1 | Including hospital inpatient costs for the JJF care group |
| Scenario 2 | Costs for the hospital model of care based on the least costly DRG, rather than average of all DRG |
| Scenario 3 | Indirect costs excluded |
| Scenario 4 | Scenarios 1, 2, and 3 combined |

JJF: Jack and Jill Foundation; DRG: Diagnosis Related Groups.

Table 5
Scenario 1; including hospital inpatient costs for the JJF care group.

| | Inpatient | JJF Homecare |
|-------------------------|-----------|--------------|
| Provider costs (€) | 156,282 | 31,365 |
| Direct family costs (€) | 22,261 | 2,620 |
| Indirect costs (€) | 27,758 | 22,941 |
| Total costs (€) | 206,301 | 56,926 |

JJF: Jack and Jill Foundation.

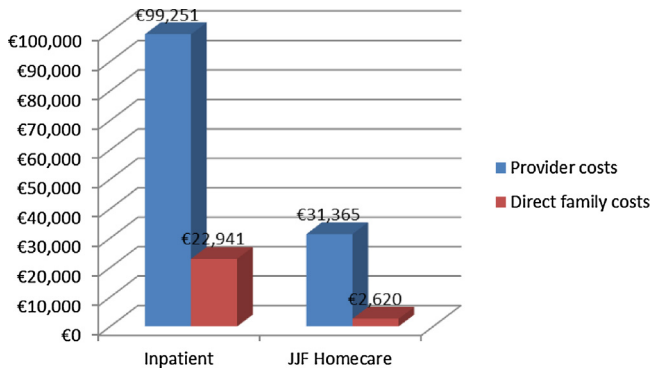


Fig. 3. Scenario 4; combination of scenarios 1, 2 and 3.

Discussion and conclusion

Evidence indicates that the costs of caring for severely disabled children are far greater in hospital than with the provision of a satisfactory package of homecare. This is demonstrated by the international evidence, which shows hospital care is the most expensive service model, and by the results of this study in the Irish context. It is estimated that the average costs on the State of keeping a child in hospital are € 156,282 whereas homecare provision enables a child to be cared for in a home environment for an average cost of € 16,267 per child per year. When an estimation of hospital inpatient costs associated with the JJF homecare model was explored in a sensitivity analysis the latter increases to € 31,520.

Importantly, the direct and indirect costs of care facing families are also substantially reduced with the provision of homecare relative to hospital services. The results of this study estimated the average direct costs facing families when a child is in hospital at € 22,261 compared to € 2,620 per child per year with JJF homecare. The main cost drivers behind this difference are family accommodation, parking, and additional food requirements at hospital. The indirect costs are more similar, but substantial with both service models at € 27,758 for hospital care and € 22,941 for JJF homecare.

The robustness of these findings was explored in a sensitivity analysis. Results were varied in three ways. First, including an estimation of hospital inpatient costs for the JJF homecare group; second, using the least costly DRG to calculate the costs of the hospital-based model of care rather than an average of each DRG; and third, excluding indirect costs. JJF homecare remained substantially less costly in each case. Finally, to examine the most extreme case in favour of the hospital model of care, the changes from each of these scenarios was combined. JJF homecare remained far less costly than hospital care, at € 33,985 and € 121,196 respectively, demonstrating the robustness of the findings.

The merits of the JJF homecare model are also reflected in its parental satisfaction ratings; which are 4.93 for supporting the health and wellbeing of the disabled child, and 4.85 for supporting the functioning and wellbeing of the broader family. These far exceed the ratings for inpatient hospital care, of 3.71 and 3.14 respectively; and the particularly low ratings for HSE PCCC care, of 3.09 and 2.64. The evidence strongly suggests that the JJF is the preferred model of care for parents, that it meets their needs, and should be the favoured option for an expansion of care to disabled children.

One of the most striking aspects to emerge from this study is the clear evidence of the enormous strains placed on the parents of severely disabled children. The most obvious aspects of these strains are the worry and distress of having a child in serious ill-health. These strains are compounded however by financial costs – including, not only the direct costs, but even more significantly the indirect costs of lost income generating opportunities.

The financial costs of bringing up a disabled child are very large with all service models. This study estimates annual direct and indirect costs falling on families in the hospital care model to be € 22,261 and € 27,758 respectively; and with JJF homecare € 2,620 and € 22,941 respectively. These exceed

the average annual Government financial assistance to families, estimated at € 11,219, by a factor of 4.46 for hospital care and 2.28 for JFF care.

It is clear that if the strains placed on families are to become at least somewhat manageable, these large costs must be mitigated. The channels through which this can be done require further investigation. However, it is likely that greater State assistance will be required to mitigate the financial burdens on families.

This study has some limitations. Due to an absence of data, it was not possible to compare the costs of the JFF model versus a statutory home-care model. Hospital costs were calculated using Diagnosis Related Groups, which are based on average costs, rather than the specific costs of the children included in the study. Findings should be interpreted with caution as these cost estimates may differ significantly from more detailed microcosting estimates (Heerey, McGowan, Ryan & Barry, 2002). Data on hospital inpatient admissions for the JFF group lacked detail on the specific cause of admission, hence were included as a sensitivity analysis. Costs falling on families of the hospital inpatient group were assumed to equal those in the JFF group, scaled up to reflect the year-long hospital stay, as it was unfeasible to collect this data directly from the hospital care families.

Judging the effectiveness of JFF care requires a multidimensional approach incorporating clinical data, but this was unavailable for analysis therefore only satisfaction ratings were used. Parents of children receiving JFF care may have felt compelled to give favourable satisfaction ratings due to the involvement of JFF nurses in distributing surveys, although this was offset by ensuring the anonymity of families at all times. Furthermore, the substantial differential in hospital inpatient costs (the main driver of the cost difference between groups) may be partially attributable to casemix differences, and detailed sample descriptive data (e.g. age, diagnosis) required for techniques such as propensity scoring was not collected due to the need for family confidentiality. These concerns are mitigated by the expert (and *ex-ante*) judgement of JFF staff that the selected DRGs are firmly representative of the JFF casemix.

On balance, however, this study has uncovered arguments for expanding the JFF homecare model in place of hospital inpatient care and statutory homecare in Ireland. First, the literature and this study indicate that service models based on key workers and parental networks are most successful in assisting families to provide effective care to their children. Second, this study has found evidence that the JFF reduces costs of care and enhances parents' reported satisfaction levels.

Young children with severe disabilities are one of the most vulnerable patient groups in society. In providing support to their offspring, families are also stretched to the limit – physically, emotionally, psychologically, and financially. An effective model of care must ensure support to both parent and child, and the JFF model seeks to achieve this in the home environment. According to a recent systematic review on the costs and effectiveness of paediatric home care (Parker et al., 2012), there is growing evidence that the home care model can achieve equivalent clinical outcomes for children and in some cases reduce the burden and costs for families. This exploratory study adds to the evidence base suggesting that, in cases where feasible, the more appropriate model of care to meet both costs and outcomes objectives is a homecare model.

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