Foreword

I want to dedicate this Report to my son Jack Irwin who was born 29th February 1996 and died 13th December 1997, a short but influential life, touching the hearts of everyone he met. Jack was born a healthy baby but following some invasive trauma, his brain was damaged and he could not swallow, was blind and deaf and needed a mix of drugs, physio, postural drainage, reflux operations, gastrostomy and suctioning. At that time 14 years ago, there were no services for Jack beyond the walls of the maternity hospital and we were advised to pack his little bag and abandon our son at one of the children's hospitals in Dublin. We said no. Instead we brought Jack home where he was cared for and loved by his family and friends and it's true to say that there's no place like home, especially for a sick child. Sadly, Jack died 22 months later. He had taught us a great deal and we vowed that no other parents should have to face this nightmare alone and that's why we set up the Jack & Jill Children's Foundation in 1997.

Today, the Jack & Jill model of home nursing care works and empowers parents to care for their sick children at home – children like Jack who are born with or develop brain damage and who suffer from severe intellectual and physical developmental delay. Many of the 1,200 families we have supported over the years refer to our service as "the gift of time" - time to do those normal things that others take for granted, like sleeping, shopping, spending time with the other siblings, with the peace of mind that their sick child is being well cared for. Now I ask you the reader to give us the gift of your time – time to read this Report and to engage with us on its findings and recommendations.

We are currently funded by the Government to the tune of 19% and we raise most of the €3 million we need annually through the recycling of old mobile phones which is not sustainable long term. This Report makes a strong economic argument for Jack & Jill by proving the efficiency and cost effectiveness of our frontline home nursing care model and the high satisfaction ratings from our families. It shows that a hospital stay for our children is nine times more expensive than home care and it recommends an increase in our level of State funding to make our service more sustainable and to save the tax payer money. It also recommends the expansion of our service to support children up to the age of 6 – something our families are calling for – and a positive development that would provide a substantial net saving to the HSE.

Lastly, I would like to thank our patron, Eddie Hobbs, for encouraging me to undertake this study; Professor Charles Normand and Paul Revill for all the hard work that went into this Report and my staff, nurses, families, fundraisers, trustees and supporters for all the effort that has gone into making Jack & Jill the success it is today. Jack Irwin would be proud.

Thank you.

Jonathan Irwin

Jonathan Irwin
Founder & CEO
Jack & Jill Foundation

Contents

Executive Summary

1. **A young child born with severe disabilities in Ireland requires substantial and often complex health care attention.** The early years of life are a stressful time, not only for the child, but also for his or her parents. Successful models of care must therefore support not only the well-being of the child, but also the well-being and functioning of the broader family.

2. **For the past 13 years, the Jack and Jill Children's Foundation (JJF) has provided frontline homecare and respite services to the families of children who are born with or develop brain damage and who suffer from severe intellectual and physical developmental delay as a result.** JJF has supported over 1,200 families to date by providing home visits, practical advice, emotional support, information and guidance to access the range of additional assistance available, bereavement support and funding for up to 80 hours of home nursing care per month for children up to the age of 4 years old. JJF provision is based upon the strong belief that homecare, within a supportive community, is the best model for both children and their families.

3. **There are three possible models of care for a child with severe disabilities in Ireland:**
   a) The child may receive continuous care in an acute children's ward of a hospital;
   b) The child may be discharged to the family home and receive services through the Jack and Jill Foundation (JJF); or
   c) The child may be discharged to the family and receive homecare from statutory authorities – in particular Health Service Executive (HSE) Primary Community and Continuing Care (PCCC) services.

4. **To date there has been little published literature in the Irish context on the costs and outcomes of the three models of care.** This report therefore fills a gap in the evidence base and aims to assess each of the models in terms of (a) the costs of care falling on the State; (b) the (direct and indirect) economic costs falling on families; and (c) the satisfaction of families with the alternative models of care.

5. **A systematic search was undertaken of the literature in Western European countries, with similar healthcare systems to Ireland, to inform the report.** Studies consistently show that the costs falling on the State are far greater for hospital care than for homecare models. Financial costs do not appear to be pushed onto families with homecare, and may in fact be reduced. The well-being of families is greatly enhanced with homecare; and the health of children does not appear to be compromised and may even be improved when homecare is an appropriate option.

6. **The average annual costs falling on the State to deliver acute hospital care for a severely disabled child are estimated to be €147,365.** This was estimated using ESRI-Hospital Inpatient Enquiry (HIPE) system data and HSE-Casemix Cost data. A random sample of children currently receiving care with the JJF was selected and the average costs for hospital care based on their prognoses were estimated.

7. **The average annual costs of JJF homecare provision are estimated to be much lower at €16,422 per child.** This was estimated based on both the variable and overhead costs incurred by the JJF for the care of a child. It also includes the costs of supplementary nursing care received by the HSE.

8. **Statutory homecare, provided by the State, for severely disabled children in Ireland is highly variable according to local healthcare authorities.** There is therefore no basis for a uniform costing of statutory home-based care. For this reason the report focuses on the cost differences between hospital-based care and JJF-provided homecare.

9. **The annual direct costs per child falling on families are estimated to be €22,261 for hospital care and €2,620 for JJF-provided homecare.** Direct costs are out-of-pocket expenses incurred for the care of their child. The main cost-drivers behind the large difference are family accommodation, parking and additional food requirements when a child is in hospital.

10. **The annual indirect costs falling on families are estimated to be €27,728 for hospital care and €22,941 for JJF-provided homecare.** Indirect costs represent lost income generating opportunities through the care of a disabled child. Indirect costs are clearly an enormous financial burden on families irrespective of the model of service delivery.

11. **Families report much greater satisfaction for JJF care than for the other service models.** On a rating scale of 0-5 (in which 0 is 'very dissatisfied' and 5 is 'very satisfied') families report their satisfaction with the JJF care at 4.93 for 'Supporting the health and well-being of the disabled child', and 4.85 for 'Supporting the functioning and well-being of the broader family'. These far exceed the ratings for inpatient hospital care, of 3.71 and 3.14 respectively; and the much lower ratings for HSE PCCC care, of 3.09 and 2.64. However, families supported by JJF worry about what happens to their support structure once their child reaches the age of 4 years old and beyond and have asked JJF to extend the age group it supports.

12. **JJF service provision therefore offers a less costly alternative for both the State and families, and is the preferred model of service delivery for families.** The case for an expansion of a good quality and comprehensive package of homecare is straightforward – it offers a net saving and is the preferred model of care. Although homecare can in theory be provided by either the JJF or through state homecare services, this study shows the JJF should be preferred based on its successful track record of providing quality services at reasonable costs.

13. **The report recommends the State increases its financial contribution to the JJF to ensure the sustainability of services and to achieve a net saving for the public purse.** At present, the Foundation receives around 19% of its income from the State with the remaining coming primarily from JJF's recycling campaign and private contributions, which can be highly volatile. A greater State contribution would help ensure the sustainability of quality services and could be achieved at a net saving for the State through easing the burden on the hospital system.

14. **The total financing gap of increasing the upper age limit for JJF care from 4 to 6 years of age is estimated to be €1,970,640 per annum.** The JJF can be expected to continue its success if and when providing services to the higher age group, and similar per capita net savings attributable to homecare compared to hospital care should also be achievable. It is therefore recommended that the HSE fill this financing gap to enable the expansion of JJF provision to the higher age group.

15. **The report also highlights the enormous strains on the families of severely disabled children.** The most obvious strain is the worry and distress of having a child in serious ill health. This is compounded by massive financial losses – including, not only the direct costs, but even more significantly the indirect costs of lost income generating opportunities. It is recommended that the State acts to mitigate these strains.

1. Introduction

A young child with severe disabilities generally requires substantial and often complex healthcare attention. It is a stressful time, not only for the child, but also for the broader family. 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.

Since 1997 the Jack and Jill Foundation (JJF) has provided home nursing care and respite services for young children who are born with or develop brain damage and who suffer severe intellectual and physical developmental delay as a result from birth to the age of four. JJF provision is based upon the strong belief that homecare is the best model to enhance the health, comfort and well-being of severely disabled children and facilitates effective functioning of the broader family. It enables child and family to live, not within the confines of a hospital, but within a supportive community setting. Since its creation, the JJF has assisted over 1,200 families across Ireland. This has primarily been through the provision of financial assistance with which families can then employ nurses and skilled carers to meet their children's needs.

Over the years it has become clear to the management of the JJF, however, that families also require more general support and guidance in addition to the provision of healthcare services to their children. The Foundation has therefore increasingly taken on an advocacy and lobbying role on behalf of families. This is (1) to ensure that families can access available services currently provided by the State and other bodies, and (2) to inform State policy so that it better meets the needs of severely disabled children and their families.

It is in this context that the JJF has commissioned this study from the Centre for Health Policy and Management, at the School of Medicine, Trinity College Dublin. The study analyses the costs and benefits of alternative models of care for severely disabled young children in the Irish context. The study will enable the JJF management to contribute more effectively to policy debates about the future direction of disability care services. It also provides information on how to provide better services to current JJF families and to determine the Foundation's future scope of coverage – a particular consideration is whether JJF services should be extended to children up to the age of six – the age at which children begin to receive care through expanded government programmes.

Three possible models of care have been identified for a child with severe disabilities in Ireland:

1) The child may receive continuous care in an acute children's ward of a hospital;
2) The child may be discharged to the family home and receive services through the Jack and Jill Foundation; or
3) The child may be discharged to the family home and receive homecare from statutory services - in particular Health Services Executive (HSE) Primary Community and Continuing Care (PCCC) services[1] .

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[1] PCCC is currently being merged with the National Hospitals Office to form the new Directorate of Integrated Services.

The study therefore had the following objectives

- To determine costs for the State, and other funding bodies, associated with the three models of care previously outlined ;
- To determine (direct and indirect) economic costs falling on families associated with the three models of care;
- To obtain evidence on differences in health outcomes for disabled children; and whether the models have different impacts on the well-being and functioning of families;
- To provide information to the management of the JJF on how to improve further the services provided by the Foundation.

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.

2. Review of the Evidence

To determine the evidence base around the three models of care, a literature review was undertaken. The literature review had the following objectives:

1. To ensure all models of care have been captured in the study.
2. 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)
3. To obtain data on the direct and indirect economic costs falling on families from the alternative models.
4. 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’ (unpublished and non-peer reviewed) literature was also undertaken.

The abstracts of retrieved references were reviewed and assessed according to their relevance for the present study. The inclusion criteria were works that provided information on any of the following: (i) Models of care for severely disabled young children in the European context; (ii) comparative evaluations of service provision for severely disabled young children; or (iii) 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 6 were selected. A further 5 unpublished works were retrieved from reviewing bibliographies and the informal search. Each of these works was read in full. 10 were found not to be relevant, but the remaining 22 published papers are summarized in the table in Appendix 1.

2.1 Costs Falling on the State of Alternative Models of Care

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 most robust recent comparative study on the costs of provision to the state is by Noyes et al (2006). The authors follow a sample of 34 technology dependent children in the UK for a period of 1 year[2] ; 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.

7 of the children in the Noyes et al study received hospital care throughout the year, and had an average cost of care of £428,000 pa. 24 children received home based care, with a much lower average cost of £104,000 p.a.

It is possible that children in hospital had more serious prognoses. Therefore, useful information was obtained on 4 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 are supported by Glendinning et al (2001), who estimate the homecare costs associated with supporting 4 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, 2001). Their unit cost information on general care is based on the works of Noyes et al and Glendinning et al. 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.

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 small number of studies.

2.2 Costs Falling on Families of Alternative Models of Care

There are some studies on the direct costs borne by families of severely disabled children, but these studies are generally now slightly dated.

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[2] Technology dependent is usually defined as being dependent on one of the following technologies on a regular basis: medical ventilation, parental nutrition, tracheotomy, oxygen therapy, suction machines, tube feeding.

The Joseph Rowntree Foundation report on Paying to Care, by Dobson and Middleton (1998), is probably the most comprehensive. This estimates that it costs three times as much to raise a disabled child as it does 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, referenced in the Joseph Rowntree report Counting the Costs, 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 Baghurst et al (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 lower 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 this present study addresses. 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.

2.3 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 the subjective preference of children and parents for home care. For instance, Baghurst et al (2009) report that in a satisfaction survey of 40 families 90% expressed a clear preference for home care. This can be interpreted as 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 (e.g. Richman, Stevenson and Graham, 1982; Wallender and Varney, 1998; referenced in Sloper, 1998: 87). Therefore models of care associated better parental and family outcomes can also be expected to be beneficial to the disabled child.

Sloper (1998) 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 explained by the severity of illness. Instead, important factors that increase parental distress include: (i) problems with the child's behaviour or sleeping; (ii) adverse life events, such as family illness, or separation and divorce; (iii) material and financial difficulties; and (iv) 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 (1998: 90-92) 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: (i) a 'key worker' that helps to navigate parents through the myriad of available assistance; (ii) the availability of parental counselling; and (iii) 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 JJF-style home based rather than hospital care. However, it is likely that family functioning and well-being is improved with home based care that meets the needs of parents; and this is likely to have a positive effect on children.

In summary, the literature around the costs and effectiveness of alternative models of care for severely disabled children is limited and substantial gaps exist in knowledge.

The evidence is quite strong that the costs facing the state are lower, in some cases substantially, through the provision of adequate packages to support homecare rather than relying solely on hospital care. It does not appear that costs shift onto parents with home care, although no studies were found on the indirect costs facing parents. It is clear, however, that in all service models the financial burden facing parents even from direct costs can be substantial.

There is a lack of clinical evidence on comparative endpoints from the alternative models of care, although the search found a strong subjective preference for home care in the literature. However, none of the key studies were carried out in Ireland, so there is need to build an evidence base in the Irish context.

3. Methods

The key objective of this study is to obtain evidence on the public costs, facing the State and voluntary organizations, and the direct and indirect private costs associated with the 3 models identified for the care for a severely disabled child:

1) The child may receive continuous care in an acute children's ward of a hospital;
2) The child may be discharged to the family home and receive services through the Jack and Jill Foundation; or
3) The child may be discharged to the family home and receive homecare from statutory authorities - in particular Health Services Executive (HSE) Primary Community and Continuing Care (PCCC) services.

The study has the secondary objectives of obtaining some information on subjective preferences of parents as a measure of health outcome, and information to guide the JJF management on service improvement – this includes determining a cost estimate to expand services to children up to age six.

3.1 Acute Hospital Stay Costing

The average cost per year of hospital stay was estimated based on the ESRI-HIPE data and the HSE Casemix Cost data.

The Hospital Inpatient Enquiry (HIPE) system is an information system that collects data on discharges from 62 acute public hospitals in Ireland. It is administered by the Economic and Social Research Institute (ESRI) and provides a standard dataset on inpatient morbidity and mortality. One of the most important uses of HIPE is that it provides a basis for the Casemix Cost estimations for adjustments in acute hospital budgets.

The most up-to-date Casemix Costs relate to 2007 activities, and are held in the Ready Reckoner 2009[3] . This was kindly released by the HSE Casemix/HIPE Unit for the purposes of this study. Cases are broken down into 23 Medical Diagnostic Categories (MDCs)[4] . The MDCs are broken down further into 665 Diagnosis Related Groups (DRGs); which are split by medical, surgical and other cases, and by four severity levels. The DRGs are based on the frequently replicated Australian Classification System.

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 €272 for extended stays. The estimated annual cost of stay is therefore €3,935 + (365-27)* €272 = €95,871. As shown below children cared for at home with support from JJF have on average complex problems that have higher annual costs for hospital stays.

A random sample of 10 children currently receiving JJF care was selected and these were assigned to the relevant DRGs based on their prognosis. The sample was taken from the case list of a JJF nurse – starting from a random number and then taking every third child until the sample was complete. Costs were inflated to 2008 prices to match the period of recall of the parents' questionnaire. An annual inflation rate of 3% was assumed. Full details of the sample can be found in Appendix 2.

3.2 JJF Care Costing

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. 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. The detailed cost calculations can be found in Appendix 3.

It was necessary to base per case cost estimates on the total costs incurred by the Foundation, so that both variable and overhead costs were accounted for. It is assumed that if the JJF were to upscale operations they would still incur the same ratio of fixed to variable costs.

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[3] Casemix Cost estimates relate to 37 hospitals that participate in the Irish National Casemix Programme, although activities are based on all 62 HIPE hospitals.

[4] These include, for example, MDC-01: Diseases and Disorders of the Nervous System; and MCD-04: Diseases of the Respiratory System.

In addition to receiving care from the JJF, families often receive supplementary hours of assistance from qualified nurses, carers and home-helps, which is funded by the HSE. In order to establish the typical level of supplementary State assistance a family receives, a survey of 20 families was undertaken. 17 responses were received and are summarized in Appendix 4. 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.

3.3 Statutory Authorities Homecare Costing

It was very difficult to obtain costing information on JJF-type statutory care. In practice, no uniform package of statutory homecare is available in Ireland – instead, whenever such care is available, it is highly variable according to local health authorities. Therefore, a common cost estimate would be speculative and is virtually impossible.

Approaches were made to obtain costing information from local health authorities, but those did not prove fruitful. This was not surprising since the literature search revealed very little community costing information even in the international context. In the end, the conclusion had to be made that there is no basis to differentiate costs of statutory homecare and JJF provision. Evaluation between these service models must therefore be based on alternative means.

3.4 Direct and Indirect Family Costs Associated with the Alternative Models

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.

The questionnaire was delivered by JJF nurses 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.

The questionnaires were delivered by all 9 nurses employed by the Foundation, as of July 2009. One nurse delivered 2 questionnaires due to an upcoming holiday, and the other eight nurses delivered 3 or 4 questionnaires each. The nurses were told to deliver the questionnaires to the first families on their weekly visits that (1) had been receiving JJF care for at least 6 months, so that they had basis to make an accurate evaluation; and (2) had not recently been bereaved.

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

Summary results of the questionnaire can be found in Appendices 5 and 6. Data were obtained on all direct and indirect costs incurred by families with the current JJF model of care, scaled to 1 year. Direct costs include costs of specialist equipment, transport to health centre and hospital appointments, and additional costs of care. Indirect costs were obtained through asking parents the change in their working hours compared to their desired level to care for their child at home and their income generating power. Data were also collected on additional care received by families from other channels.

Data on the direct and indirect costs associated with hospital care was obtained by asking parents to recall periods when their child was in hospital. Direct costs associated with hospital care include accommodation for parents in or near the hospital, parking, and additional purchases of food. Indirect costs were obtained based on the parent's average hours of work when the child is in hospital, compared to their preferred levels, and their income generating power.

In addition to the costing data, parents were also asked to rank their satisfaction with the alternative models of care in terms of: (i) the service models supporting the health and wellbeing of their child; and (ii) the service models supporting the functioning and wellbeing of the broader family.

To assist the JJF to further improve standards of care, parents were also asked open-ended qualitative questions on the benefits of JJF care and areas for further improvement.

4. Results

The costing results of the alternative models are outlined in the following sub-sections.

4.1 Acute Hospital Stay Costing

The Costs Facing the State
Based on the sample of 10 typical children currently receiving care from the JJF, the mean cost incurred by the State when a severely disabled child receives care in a hospital setting can be seen below. Costs have been inflated to 2008 prices to match the period of recall for household expenditures.

Average Annual Cost of Hospital Care for Severely Disabled Children	€147,365

The children that receive care from the JJF have a broad range of often complex disabilities, and this is reflected in the relatively large standard deviation in costs of €42,540.

The Costs Facing Families
The family questionnaire revealed that the mean family incomes and total additional financial assistance from the State from those surveyed was as follows:

Mean Primary Income of Families	€48,029
Mean Additional Financial Assistance Received From the State	€11,219
Mean Total Income of Families	**€59,248**

*It should be noted that the average incomes reported by families are those currently received when in the provision of JJF care.

The families of disabled children incur significant costs for the care and support of their children.

The direct costs facing families when their child is in hospital are

Mean Costs of Family Travel to Hospitals Per Year	€5,439
Mean Out of Pocket Direct Costs Incurred When Child in Hospital	€16,822
Total Direct Costs	**€22,261**

It is clear that these direct costs significantly eat into the income of families.

The indirect costs associated with reduced working hours when the child was in hospital are as follows

Mean Indirect Costs of Reduced Working Hours When the Child is in Hospital	€27,758

Family Satisfaction with Hospital Care Services
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. The satisfaction results of the hospital model of care are as follows

Average Satisfaction with Supporting the Health and Wellbeing of the Disabled Child	3.71
Average Satisfaction with Supporting the Functioning and Wellbeing of the Broader Family	3.14

4.2 JJF Care Costing

The Costs of JJF-Led Care
The average costs of care per child faced by the JJF over the last 3 years are shown below. The 2006 and 2007 costs have been adjusted to 2008 prices.

	2006	**2007**	**2008**
Average Costs per Child for Receipt of JJF Care	8,198	9,965	9,369

These are total costs, including both fixed and variable costs, which must be incurred for a JJF package of care.

It can be seen that the average JJF costs are relatively stable although there was a jump in average costs between 2006 and 2007. The average cost per child over the three years was €9,177.

The annual accounts show that for the years 2007 and 2008 administrative costs represented 29% of total costs, whereas the remaining was spent directly on nursing and carer time (there are no disaggregated figures available for 2006). 30% for administrative costs is often taken as a marker of efficiency for firms operating in competitive environments. This is therefore indicative of the general efficiency of JJF provision.

A survey of 20 families was undertaken to reveal that the average amount of additional assistance received from the HSE. 17 questionnaires were returned and can be summarized as follows

	Weekly Hours of Care Received from HSE Nurses	Weekly Hours of Care Received from HSE Financed Carers	Weekly Hours of Home-Help Financed by the HSE
Average	4.2	3.6	1.5

The supplementary care received by the HSE is highly variable – with 41% of families receiving no supplementary care at all, and 24% receiving more than 20 hours supplementary care per week. It is not clear whether supplementary care correlates with the severity of illness.

The JJF currently donates €16 per hour to a family to engage a nurse and €8 per hour for a carer. The costs of an average package of HSE supplementary care if this were to be provided by the JJF can be estimated at €139.32 weekly per child (inclusive of the 29% overhead). This translates to additional annual cost of €7,245 per child.

When the costs of the supplementary care are added to the €9,177 core costs of JJF care, this comes to an estimated total annual cost of JJF-led homecare per child of €16,422.

Total Annual Costs for Child for a JJF Package of Care	**€16,422**

The costs of JJF-led care are clearly much lower than the costs falling on the State when children are in hospital.

The Costs Facing Families

Children that receive JJF homecare provision visit medical facilities, on average, 6 times per month. The range of required medical visits is broad, however, with 20% of children requiring more than 10 visits per month.

The time and travel costs facing families are less than 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 in hospital are accommodation for parents and additional food requirements – therefore out of pocket costs associated with JJF homecare are also substantially lower.

Mean Costs of Family Travel to Health Facilities Per Year	€1,328
Mean Out of Pocket Direct Costs Incurred When Child Receives JJF Homecare	€1,292
Total Direct Costs	**€2,620**

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 lower indirect costs relative to those incurred with hospital care

Mean Indirect Costs of Reduced Working Hours When the Child Receives JJF Home Care	€22,941

Family Satisfaction with JJF Home Care Services
Families report very high satisfaction with JJF homecare services. In fact, only 3 families report satisfaction less than 5 against either of the two questions (two of these provide a rating of 4 and one of 3).

Mean Satisfaction with Supporting the Health and Wellbeing of the Disabled Child	4.93
Mean Satisfaction with Supporting the Functioning and Wellbeing of the Broader Family	4.85

4.3 Statutory Homecare Costing

It was not possible to obtain any reliable costing information on statutory homecare provision. There is therefore no basis on which to differentiate costs of homecare between when they are provided by the JJF and when they are provided by State authorities. It should be noted this does not mean they are subject to the same costs – simply that the scarcity and variability of State homecare services makes a standard costing virtually impossible.

It is illuminating, however, to see the reported satisfaction of families with homecare services provided by the HSE PCCC. These are as follows

Mean Satisfaction with Supporting the Health and Wellbeing of the Disabled Child	3.09
Mean Satisfaction with Supporting the Functioning and Wellbeing of the Broader Family	2.64

These are low average ratings, in comparison to both the JJF homecare and State hospital care models, indicating there are clearly shortcomings 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.

4.4 The Annual Costs of Increasing the Upper Age Limit for JJF Care from Four to Six Years of Age

A secondary objective of the study is to investigate the cost implications of increasing the upper age limit for children in receipt of JJF care from 4 to 6 years of age. The average number of children, from birth to age 4, receiving care from the JJF over the past 3 years is as follows

2006	**2007**	**2008**
250	256	288

There is then a slight upward trend, and a conservative estimate of the number requiring care in the coming years, if the current age range were retained, can be estimated to be 300. Increasing the age coverage from four to six years would therefore be approximately a 40% increase in the average number of children requiring JJF care, or 120 additional children receiving care on a full year equivalent basis.

If it is assumed the same average cost of care applies to children of the higher age group this results in an additional financing requirement of 120 x €16,422 = €1,970,640 per year; of which €1,101,240 would be related to services currently provided by the JJF and €869,400 would be related to supplementary services provided by the HSE.

Two provisos, however, must be noted. Firstly, it is likely that some children will unfortunately not survive up until age six. Secondly, it is possible that the JJF will receive new referrals of children aged older than 3 that have not previously received homecare. There is not a sound basis of evidence to estimate either of these factors; however, they work in opposite directions and may balance out.

The total estimated costs of increasing the upper age limit for care are then as follows

Estimated costs of increasing the upper age limit for JJF provision from 4 to 6 years of age	**€1,970,640**
- Of which relate to services currently provided by the JJF	€1,101,240
- Of which relate to services currently provided by the HSE	€869,400

5. Discussion

The costs of caring for severely disabled children have been shown to be far greater in hospital than with the provision of a decent package of homecare. This is clear from the international evidence, which unequivocally shows hospital care is the most expensive service model, and from 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 €147,365 whereas JJF provision enables a child to be cared for in a home environment for an average cost of €16,422 per child per year.

The direct and indirect costs of care facing families are also substantially reduced with the provision of JJF homecare relative to hospital services. The results of this study reveal that the average direct costs facing families when a child is in hospital are €22,261 compared to €2,620 per child per year with JJF care. 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 – being €27,758 with hospital care and €22,941 with JJF care.

The JJF provide a package of care efficiently with administrative expenses being very reasonable at 29% of total costs. In principle it is a package that could be provided fully by statutory authorities. However, in practice, the HSE, which has responsibility for providing home based care for severely disabled children delivers only sporadic services that vary by geographic area. There is a significant lack of costing information to estimate a standard cost for HSE PCCC homecare. The HSE has limited experience in providing homecare for this patient group, and may not currently have the capacity to do so even if it were adequately financed.

It is likely that there are also substantive reasons, aside from cost alone, that should make JJF the preferred provider to expand homecare services to severely disabled children. The review by Sloper (1998) provides useful information in this regard. It highlights common unmet needs of parents being financial and material support and breaks from care; and that successful service models tend to have a key worker to relay information to parents, are based upon parental networks, and provide some element of counselling support. Since its inception the JJF has been led by parents, and these elements continue to be integral to its model of care. It is unlikely that a public model could offer the same level of parental understanding and stability of care around a key worker.

The success of the JJF model is 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 ratings for HSE PCCC care, of 3.09 and 2.64. It is clear 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.

The total costs of expanding JJF care to children up to age six were estimated at €1,970,640 per year. From this total amount, €1,101,240 relates to expanding the current level of service provided by the JJF and €869,400 is a cost estimate of the supplementary care that is currently provided by the HSE but could be provided in part or in full by the JJF. The details of an expanded service should though be informed by the relative success of the alternative providers in delivering care to the younger age group.

A striking aspect to emerge from this study is the evidence on 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 very high 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 per family direct and indirect costs associated with hospital care of €22,261 and €27,758 respectively; and with JJF care of €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 JJF care.

It is clear that if the strains placed on families are to become at least manageable, these high 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.

5.1 Insights on JJF Service Provision

A secondary objective of this study was to provide information to the management of the JJF on what further improvements can be made in their service delivery. As noted, the family satisfaction ratings for JJF services were extremely high, but as for any organization further improvements are always possible.

The family questionnaire contained two qualitative questions to guide the management of the Foundation:

(i) What are the main benefits your disabled child and family receive from JJF care?; and
(ii) What are the areas for possible improvement?

The majority of comments were overwhelmingly positive. They included: ‘The service gives us a chance to go out and do our day to day chores’; ‘It enables us to have a full night’s sleep’; ‘The nurse has helped me by giving advice and information about benefits and entitlements … she has acted as an advocate for me and my family’; and ‘Without the JJF my child would not have survived the first years of life; and I fear neither I nor my spouse would have coped mentally, physically or psychologically’. Out of the 28 returned questionnaires, 22 provided positive feedback to the first qualitative question.

No comments were particularly negative about JJF care, but rather provided advice on how the service could be further improved. Four of the families commented that they would like JJF care to be extended to children beyond four years of age. Two families said they would benefit from getting to know other families in a similar situation to their own. Suggestions on how this could be done included the establishment of regional networks or a buddy system; whereby parents of newly born disabled children receive one-to-one support through the difficult early stages from parents that are more experienced in providing for a disabled child.

In summary, the JJF model is evidently effective but there is strong demand from parents for the services to be extended beyond the age of four. Also, the expansion of psychological and emotional support to parents would likely be beneficial, and the management of the Foundation may consider how this may be done.

6. Conclusion

The case for an expansion of a good quality and comprehensive package of homecare support for severely disabled young children and their families in Ireland is straightforward. It offers significant cost reductions to the State and is the preferred mode of service delivery for children and their parents. It should therefore be a priority for the public health system.

The State has two choices as regards how to expand homecare services to this patient group: (1) Utilize the organization with the experience and a positive track record of service delivery in this area - the Jack and Jill Foundation; or (2) Expand the role and financing of statutory authorities, in particular the HSE PCCC, to provide a standardised JJF-type package of care to all patients in this group across Ireland.

There are good reasons why the former of these choices should be preferred. Firstly, it is the low risk option – the HSE PCCC have not shown they have the capacity nor experience to implement a large scale and standardised package of care to this patient group, whereas the JJF have a successful track record for over 12 years. Secondly, the literature and this study are clear that service models based on key workers and parental networks are most successful in assisting families to provide effective care to their children. Thirdly, this study has revealed that the JJF is cost-efficient and effective in delivering successful outcomes.

In conclusion, this report offers the following recommendations to the HSE and State authorities:

- To prioritize the provision of homecare services as a substitute for hospital care for young children with severe disabilities
- To increase finance to the JJF to spearhead homecare services to this patient group, to make the JJF model sustainable and enable the JJF to increase the upper age limit of their services from four to six years of age.
- To investigate means to mitigate the financial burden on parents of disabled children.

The report also offers the following recommendations to the management of the JJF on how to further develop their service model:

- Given availability of finance in the form of increased State funding, to expand the upper age limit on services to six years of age.
- To investigate means to improve psychological and emotional support to parents: this may involve establishing regional parental networks or a buddy system.
- To lobby for increased state financial support to parents to compensate for the direct costs and lost income generation opportunities associated with care.

Young children with severe disabilities are one of the most vulnerable patient groups in Ireland. 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. In cases when it is feasible, this report shows clearly that the best model to meet both cost and outcomes objectives is homecare.

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Appendix 1: Works of Greatests Relevance to the Present Study

Retrieved Reference	**Models of Care Provision**	**Evaluations of Service Provision**	**Costs Falling on Families**	**Relevance**	**Summary**
Bagust, A., A. Haycox, 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, J., P. Sloper, et al. (2007)		X	X	II	Costs key worker support for disabled children and their families.
Bumbalo, J., L. Ustinich, et al. (2005)		X	X	I	Economic impact on families of caring for disabled children. Useful but US focused.
Clarke, J. and S. Quin (2007)		X		II	Investigation into professional carers experiences of providing paediatric palliative care in Ireland. Not exactly relevant for this patient group.
Corden, A., P. Sloper, et al. (2002)			X	II	Investigates the financial impacts on families after the death of a child.
Curran, A. L., P. M. Sharples, et al. (2001)			X	I	Compares the time costs of caring for children with disabilities and without disabilities. Doesn't cover economic costs.
Fisher, H. R. (2001)	X			II	Reviews the literature on the needs of parents with disabled children. Mostly qualitative.
Fitzgerald, E. (2004)			X	III	Estimates the financial costs of having a child in hospital in Ireland. Parts of the paper are missing.
Heitmueller, A. and K. 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.

Gorley (2003)	X	X		III	A Master’s thesis, primarily qualitative. Examines the needs of families of disabled children in the Irish context.
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		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, H.R. (1998)	X		X	II	Presents a number of conceptual frameworks with which to evaluate services for children with disabilities.
Parker, G., P. Bhakta, et al. (2002)	X	X	X	III	A systematic review of the costs and effectiveness of different models of paediatric homecare.
Richardson, J. and J. McKie (2007)	X	X		II	An economic evaluation of services for NHS, presenting a case for fairness in dealing with severe disabilities.
Roberts, G. (2001)		X		I	Reviews the costs and effects of different services to children with complex health needs, although concentrated more on older children.
Stabile, M., A. Laporte, et al. (2006)	X	X	X	II	Examines household workplace responses to changes in public homecare programs.
Sloper, P. (1998)	X	X		III	Key paper – reviews the needs of parents of disabled children and evaluates the features of successful service models.
Yantzi, N., M. W. Rosenberg, 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, A., B. Temple, 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.

Appendix 2: Hospital Cost Calculations

The average costs of hospital stays were estimated based on expected DRG groups of a sample of 10 children currently receiving JJF care.

	MDC	**DRG**	**Description**	**Casemix Cost per Case (Euro)**	**Relative Value**	**Average Length of Stay**	**Low**	**High**	**Per Diem (Euro)**	**Cost Per Year of Inpatient Stay**
#2	01	B65Z	Cerebral Palsy	3,935	0.78	9.79	1	27	272	95,871
#5	04	E67A	Respiratory signs and symptoms +CSCC	4,864	0.97	6.77	1	24	528	184,912
#8	01	B65Z	Cerebral Palsy	3,935	0.78	9.79	1	27	272	95,871
#11	01	B65Z	Cerebral Palsy	3,935	0.78	9.79	1	27	272	95,871
#14	04	E67A	Respiratory signs and symptoms +CSCC	4,864	0.97	6.77	1	24	528	184,912
#17	04	E67A	Respiratory signs and symptoms +CSCC	4,864	0.97	6.77	1	24	528	184,912
#20	01	B65Z	Cerebral Palsy	3,935	0.78	9.79	1	27	272	95,871
#23	04	E67A	Respiratory signs and symptoms +CSCC	4,864	0.97	6.77	1	24	528	184,912
#26	04	E67B	Respiratory signs and symptoms -CSCC	1,677	0.33	2.44	0	9	451	162,233
#1		G12A	Other digest sys or PR +CSCC	13,369	2.66	18.15	2	35	400	145369
			Average (2007 prices)							**143,073**

The Casemix costs are estimated for an average length of stay, and up to the high length of stay. For additional inpatient days a per diem level is charged. The Casemix costs are estimated at 2007 prices. For 2008 prices a 3% inflation rate is levied so that the average cost per year of inpatient stay is **€147,365**.

Appendix 3: JJF Cost Calculations

The average costs per child for a year of JJF care were taken from the JJF Management Accounts. Total costs include both the variable costs associated with the care of a child and the overhead costs. These were divided by the average number of children supported through each of the years to determine an average cost per child supported – these were then averaged across the 3 years.

	2006	**2007**	**2008**
1. Average number of children supported through the year	250	259	288
2. Total cost of services provision	1,931,791	2,505,836	2,698,203
Of which Direct Charitable Expenditure	-	1,791,703	1,922,785
Of which Administrative Expenses	-	714,133	775,418
3. Average cost per child supported (2/1)	8,198**	9,965**	9,369

* Disaggregated figures for direct charitable expenditure and administrative expenses are not available for 2006.

** Inflated to 2008 prices using an inflation rate of 3%.

Average annual cost of care per child	€9,177

Appendix 4: Supplementary Care Received from the HSE When a Child Receives JJF Homecare

Observation	Average Weekly Hours of Care Received from HSE Financed Nurses	Average Weekly Hours of Care Received from HSE Financed Carers	Average Weekly Hours of Home-Help Financed by the HSE
1	20	0	0
2	0	0	0
3	0	0	0
4	8	15	6
5	0	0	0
6	7	0	0
7	0	12	3
8	0	0	0
9	16	0	0
10	0	0	0
11	12	12	6
12	0	0	0
13	9	9	0
14	0	0	0
15	0	0	3
16	0	2	0
17	0	12	8
Average	**4.2**	**3.6**	**1.5**

JJF does not provide home-help today and does not intend expanding its service into home-help.

Appendix 5: Summary Statistics from Parental Questionnaire

Response Rate	28/30 = 93%

FINANCIAL INFORMATION	
Mean annual primary incomes of households	€49,695
Mean additional annual income assistance	€11,219
Proportion receiving available financial assistance	0.43

Mean annual financial assistance from extended family	€714
Proportion receiving financial assistance from extended family	0.11
Mean annual care hours received from extended family	227
Proportion receiving regular care assistance from extended family	0.39

Mean annual financial assistance from neighbours	€0
Proportion receiving financial assistance from extended family	0.00
Mean annual care hours received from extended family	85
Proportion receiving regular care assistance from extended family	0.14

Mean reported annual assistance from the JJF	€6,622

WHEN RECEIVING JJF CARE	
Mean visits to health facilities per month	6
Mean annual travel costs to health facilities	€1,328
Mean annual other direct out of pocket costs associated with care of child	€1,342

Mean weekly reduced hours of work in household to care for child	32 hours
Proportion reporting reduced hours of work associated with caring	0.82
Proportion reporting increased hours of work for income generation	0.11
Mean annual reduced income due to lost hours of work	€22,941

WHEN RECEIVING HOSPITAL INPATIENT CARE	
Proportion with previous extended periods of hospital care	0.79
Mean annual travel costs to hospitals	5,439
Mean annual other direct out of pocket costs associated with hospital care	16,822
Mean annual reduced income due to lost hours of work	27,758

OTHER SERVICES	
Proportion reporting receipt of care at out of house respite centres	0.21
Mean annual nights at out of home respite centres	31.21 nights
Proportion reporting receipt of HSE PCCC community care	0.75
Proportion reporting receipt of other non-public community care services	0.79

SATISFACTION RATINGS	
Mean satisfaction with JJF services in supporting the health and wellbeing of the child	4.93
Mean satisfaction with JJF services in supporting the functioning and wellbeing of the broader family	4.85

Mean satisfaction with hospital inpatient care in supporting the health and wellbeing of the child	3.71
Mean satisfaction with hospital inpatient care in supporting the functioning and wellbeing of the broader family	3.14

Mean satisfaction with HSE PCCC community care in supporting the health and wellbeing of the child	3.09
Mean satisfaction with HSE PCCC community care in supporting the functioning and wellbeing of the broader family	2.64

Mean satisfaction with community care from other non-public organizations in supporting the health and wellbeing of the child	3.35
Mean satisfaction with community care from other non-public organizations in supporting the functioning and wellbeing of the broader family	2.85

Appendix 6: Qualitative Response from Parents

#	Benefits of JJF Assistance	Ways JJF Services Can be Improved
1	1. The assistance has allowed us to have more time on our own 2. It enables the child to be looked after 3. The financial strain is taken away for a few hours per week	1. I think they are excellent in all ways and do a great job.
2	1. Without the JJF my child would not have survived the first years of life; and I fear neither I nor my spouse would have coped either mentally, physically or psychologically. 2. The financial support provided enables us to have a nurse care for our daughter – this was invaluable – having someone competent caring for her, giving us a chance to rest one/two nights a week. 3. The well-being of the family has been greatly enhanced by the continuous support, back-up, ease of contact. The general caring, understanding attitude displayed to us helped all the family get through the ordeal.	1. Jack and Jill are an excellent organization that I find no fault with and really couldn't think of anything else to say.
3	1. J&J are providing financial help towards homecare costs. 2. My baby is getting better attention and care on a one-to-one basis. 3. It frees up my time so I can give more attention to the other kids. 4. It also means I get out of the house and can go to pay bills or do banking or get my hair done. 5. Helps me to keep my sanity knowing I get out a day a week so my well-being has improved.	1. I suppose extra funding would never go amiss. 2. More home help would be wonderful – I don't get any help from family or friends so we are reliant on J&J hours.
4	1. The JJF were the first organization to help us get our son home after 9months in hospital. 2. They immediately offered their full services of 20hrs per week which we in turn used as 2 night nurses.	1. I don't know how they could improve things much more. They are doing what they can to help with the resources they have. 2. Maybe a national database of nurses would be good

	3. It was fantastic to feel that our son was going to get home and that he would be well looked after while we sleep.	because in our area I had to find the nurses myself.
5	1. Gives me a break from my child. 2. The nurse comes and takes her off to her own house allowing me time with the other kids.	1. None.
6	1. Provides 2 nights nursing a week for child. 2. J&J care but the others don't! 3. Provided some quality time with other child. 4. Advice and support on entitlements and benefits 5. Advocacy 6. J&J hours are flexible and longer shifts than HSE nights so much more beneficial for us as a family.	1. If J&J could continue funding us until the child is 6 years old. 2. If our J&J liaison nurse lived near us that would be a great benefit/support us both.
7	1. Time available to spend with our other child. 2. Time available to spend with spouse/family 3. Financial worries ease, especially now. 4. Our child getting used to other people and places outside of our home.	1. It's difficult for us to think of any ways to improve your services as even the smallest amount of help is so much appreciated by all. 2. The improvements need to be made in the HSE!
8	1. Mum has a chance to go out on every 2nd Saturday which helps her dealing with coping with our child. 2. A qualified nurse looks after him, and grandmother gets peace of mind that he is well cared for as he is prone top unpredictable and very serious seizures requiring hospitalization.	1. Happy with the present services. 2. However, it should be extended past 4 years of age.
9	1. Child X is a special needs child and is a twin. The JJF has helped so much in the past year – helping with hospital visits, physio, speech and language, CRC. 2. Also to help with the care of her twin sister to let me attend appointments with our disabled child.	1. Because our disabled child is a twin it is hard to manage her sister, when she is in hospital. I can't spend time with her sister when she is in hospital because the JJF hours are stopped. This prevents me going to hospital since I've nobody to mind her sister – if the hours were maintained I could spend time with Child X in hospital as she is in a lot.
10	1. The service gives us a chance to have some free time to go out and do our day to day chores.	1. I have no way to think to improve their service.

	2. It also gives my son something different by meeting and spending time with the nurses. 3. It also gives us time to rest a little and recharge our batteries and be able to think straight for a short time.	
11	1. Having a nurse gives the family a chance to get out and have peace of mind that all will be ok. 2. Child receives full one to one attention allowing extended time for physio, OT, play and speech and language exercises to be carried out.	1. The service is working well for our family so I don't see any need for change in our case.
12	1. Full night's sleep for parents 2. Enabled me to spend time outside the home with my other children 3. Due to his special medical needs, only a nurse could provide adequate care apart from ourselves 4. Peace of mind when I'm not with my child 5. Gives me OCC morning to do something for myself!	1. Nothing – excellent care!
13	1. Relief for the mother and child. 2. Mother and father can give more time to another child. 3. Mother and father can spend some time together. 4. Nurses take good care of the child and follow the programme of the day	1. Nurses might be training for physiotherapy.
14	1. Caring for a child with disabilities is a full time hob, it can be very stressful, strenuous, worrying – J&J nurses I have are on hand to help out at any time, to take over from me, even if just for an hour, to give me a well deserved break. Otherwise I think I would just crack up. 2. They treat our child just like their own. Without the funding from J&J we would not be able to afford them. They help make life for us a little bit less stressful and more normal.	
15	1. Respite hours: 5 hours a week with carer 2. Nurse hours: 6 hours a week with renal nurse – we cannot have a regular babysitter our son is on analysis, hence the renal nurse who know how to do dialysis so we can get out for a couple of hours	1. Our respite and carer hours will end when our son is 4 and we don't know when we will get these hours from then. They are vital for my husband and my well-being. 2. We will really miss the respite hours and would like them extended to age 5.

16	1. Peace of mind that our child is being suitably looked after by a trained nurse. 2. Gives parents some time to themselves to relax or catch-up on things which cannot get done due to looking after the disabled child. 3. Get sleep. 4. Advice.	1. Increased communication 2. Supply nurses to cover time during hospital stays 3. Extend service beyond age 4 4. Buddy system – whereby people with newly born children with disability get support and knowledge from another family who have gone through similar experiences. 5. Greater explanation of nursing requirements – do's and don'ts.
17	1. It has given me a break from the 24 hour caring for my daughter to allow me to relax. 2. The nurse has helped me by giving me advice/information about benefits and entitlements and she has acted as an advocate for me and my family especially in our battle to get a council house.	1. If J&J could be supported by the Government they may be able to offer us more respite.
18	1. In home respite, providing a break from the constant caring, allowing us to spend quality time with each other and the other children. 2. Keeping us sane. 3. Advice and support for benefits and entitlements.	1. If JJF has more staff to allow the nurses to come even more often to provide more hands on care and helpful advice.
19	1. Financial assistance to provide for respite care.	1. None – good service.
20	1. By providing funds for our child I am not as tied to the house as a sole-carer. 2. I am not relying on my husband to take time off work to help me. 3. This is the only time I get to walk out of home and not have to explain what I am doing – it's the only time to myself. 4. Give's all the family breathing space.	1. For my needs as I am not ill, I would not ask for additional help. 2. I would like them to receive additional funding so not dependent on their own funds.
21	1. Our child's carer comes once a week for 5 hours so we can have a social life or if I needed to go somewhere, i.e. meeting, to get hair done, go for a coffee with a friend. 2. This has greatly benefitted us as a family and as a result our (carer/nurse) is going to be our child's S.N.A. at school as she is trained in peg feeding – my/our family do not care for our son in any means.	1. I do not believe JJF can be improved to provide a better service as we think they are doing an excellent service for us as a family and for other families. 2. We have not received any home-help or support for our son since he was born other than through JJF.

22	1. J&J has allowed us to realize things are not as bad as they may seem. If I have bad moments I can call and hear a kind understanding voice of reason. 2. It has allowed us some valuable time with our other kids that otherwise we could not afford. 3. It has allowed us to meet other people in similar circumstances. 4. We don't know how we will manage without it (JJF) when our son becomes over the age. It is a bridge we will cross when we get to it.	1. It would be nice to meet other J&J families more often. We love the annual day out and would be great if smaller, more localized versions could be arranged. It is only families with disabled children who really understand and can support each other.
23	1. The JJF has benefited us by providing the finances so that we have a nurse to come to come to our home and look after our child, which is so important to us because we can do everyday things while she minds our child.	
24	1. Financial assistance to pay for child care. 2. Visits from J&J staff. 3. Invitations to parties/chance to meet other parents.	1. More funding from the Government.
25	1. The support from J&J has allowed our family to have more freedom during our week – we can give our carer a half day, get some groceries done or my husband and I can get out for a date as a couple or occasionally get away for a night for a wedding or break. 2. It has also been positive for our child to have other people who are now trained in provider her with care.	1. Support groups in the region or other regional family days could be helpful. 2. Support with training of new nurses – perhaps if nurses who care for a particular child could give feedback and tips to J&J or to parents in written form (?) using a standard form, it would be of benefit to subsequent nurses and carers.
26	1. The assistance has paid for a paediatric nurse to come in one/two nights a week. This has been a life saver and allowed me (the mother) to get one/two nights good sleep every week without which I could not have managed.	1. I am more than happy.
27	1. The break from the caring is invaluable. 2. It in hospital will allow me to go home for a night. 3. Gives peace of mind he is being looked after and enjoys the break himself.	1. Extend until they are 5 years (school going age?) 2. More regional meetings or newsletters.
28	1. Jack and Jill provide ongoing funding for my daughter to have someone to look after her in order for us to get out, and have a break and a rest from the ongoing care required for her.	1. Jack and Jill provide a fantastic service that can only be improved by more funding.

Appendix 7: JJF Families County Breakdown

County	Number of Children per County
Co. Carlow	4
Co. Cavan	11
Co. Clare	11
Co. Cork	35
Co. Donegal	6
Co. Galway	19
Co. Kerry	6
Co. Kildare	8
Co. Kilkenny	8
Co. Laois	4
Co. Leitrim	2
Co. Limerick	11
Co. Longford	3
Co. Louth	6
Co. Mayo	10
Co. Meath	9
Co. Monaghan	6
Co. Offaly	3
Co. Roscommon	5
Co. Sligo	4
Co. Tipperary	6
Co. Waterford	12
Co. Westmeath	6
Co. Wexford	18
Co. Wicklow	5
Dublin & Co. Dublin	73
TOTALS	291

* Figures in Appendix 7 are as of the 20th January 2010.

NOTES