



Nick Hopkins Consulting

Evaluation Fieldwork for
Royal Hospital for Sick Kids (RHSC)
Hospital
Financial Inclusion Service

Nick Hopkins Consulting
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Executive Summary

Background

In August 2014, Nick Hopkins Consulting was commissioned by NHS Greater Glasgow and Clyde to carry out fieldwork to support an evaluation of the Royal Hospital for Sick Kids (RHSC) Hospital Financial Inclusion Service.

The service has been delivered to parents and carers of children attending Royal Hospital for Sick Kids (RHSC) Hospital since August 2012, building outwards from an initial focus on children involved with particular specialities.

The future of the service is uncertain beyond March 2015, and this report is intended to make a contribution to the consideration of how and whether the service is funded beyond that point.

This report is based on:

- A review of key documentation.
- 13 interviews with clients of the service selected at random.
- 8 interviews with staff who were involved in the project.

Parents whose children become seriously ill enter a situation with a potential shattering impact on their finances as well as their own wellbeing. They do so in a context in which many of them will already be financially stretched due to trends in the labour market, cost of living and wider economy, and which welfare reform has made worse, and may continue to make worse.

The Royal Hospital for Sick Kids (RHSC) Financial Inclusion Service.

The service was set up following a carer's needs assessment carried out in 2011, which found that parents attending the hospital identified support around money worries and financial advice as their top priority.

The service fits with key areas of developing NHSGGC policy, set out within the Policy Framework Statements 2013/16. In particular it fits with NHSGGC commitments under its 'Employability, Financial Inclusion, and Responding to the Recession' theme.

The service began in August 2012. The project advice worker was employed by Glasgow Central CAB, working out of the hospital 4 days a week, and based with colleagues at the employing CAB 1 day a week to allow for management and peer support.

The first year of the service limited referrals to being made by clinical nurse specialists working in the following areas, and building on the role of those specialists in providing case management support to parents:

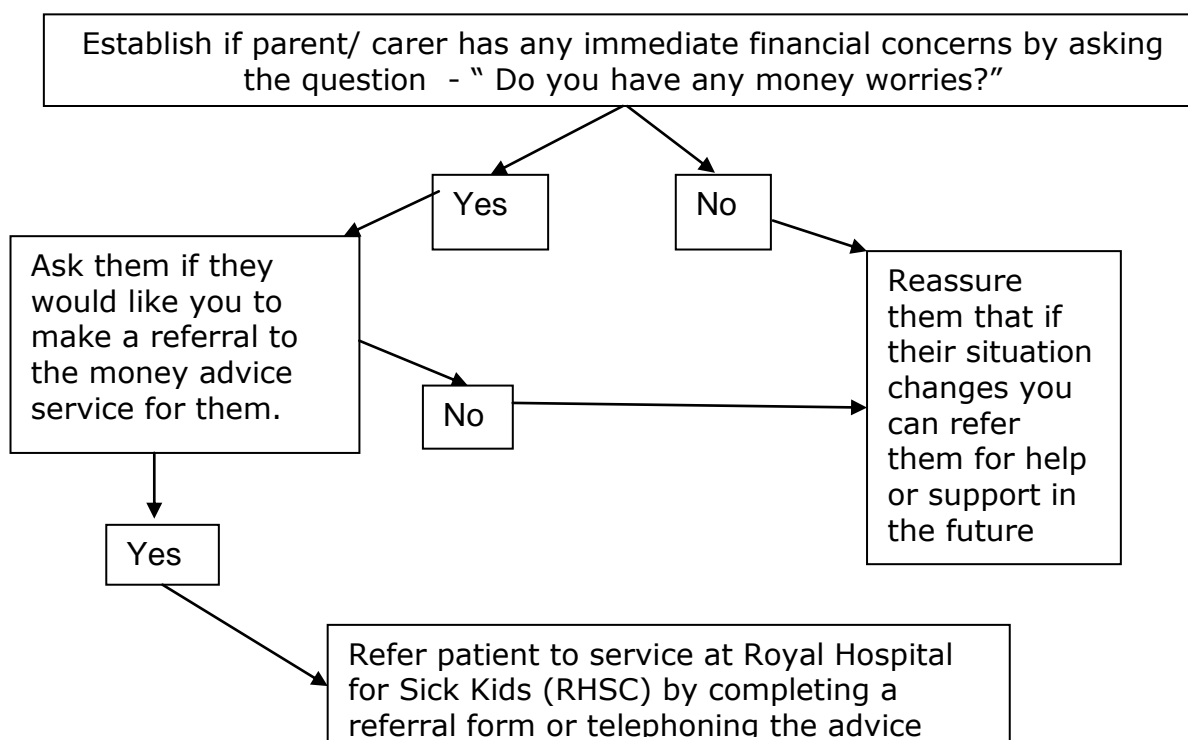
- Neurology.
- Cardiology.
- Renal.
- Diabetes.

In year 2, the pilot was extended to enable referrals from Clinical Nurse Specialists in complex airways and Schiehallion wards.

The service operates in a way that builds on the specific expertise and role of clinical staff and their ability to identify parents potentially in need of support through the asking of simple questions, then refer them to the service with their consent.

Referrals for appropriate support are made in accordance with a clear pathway without clinical staff becoming involved too deeply in resolving financial problems for parents in a way that exceeds their experience and capacity.

This flow chart sets out how referral to the service is intended to operate in practice.



Findings from Parent Interviews

Impact of Child's Illness

- A child's serious illness has a huge impact psychologically on parents, siblings and, when they have insight into their situation, on children themselves.
- Parents may feel that their life has utterly changed, with life understood in terms of 'before' and 'after', and that the 'natural order of things' has been overturned by their child being ill before them.
- That impact can be compounded by concurrent events, or by further life changes triggered by the illness and the response of those in the household to it.
- Caring for a seriously ill child requiring hospital treatment is exhausting, emotionally and physically.
- Parents may find that they have to give up work to care for their child. In couples, it appears to be the mother who does so more often.
- This will generally trigger a significant loss of income for the family.
- Parents may find their buffers against financial problems reduced in these circumstances.
- No evidence was gathered of employers proving difficult in the context of parents taking unpaid leave, in fact the opposite appeared to be the case.

- Parents may face a care burden such that they have little opportunity to do anything else. This appears to be true for the primary care giver in a couple, as much as for single parents.
- Part of the increase in care burden results from time spent supporting their child with treatment, part in response to everyday parenting tasks becoming more time consuming.
- A minority of parents experience considerable struggles to secure the quality of care for their child that they feel is acceptable.
- Single parents appear to be more at risk of financial problems than those with partners:
 - The majority of those facing debt issues were single parents, and in one case debt problems were clearly triggered by relationship breakdown.
 - Single parents appear to be in a situation in which they have less financial resilience/ smaller or no financial buffers.
- For parents with a partner, the most serious financial problems after a child falls ill may result from compounding problems such as the loss of the secondary carer's job to occur.
- Single parents also appear to be more at risk of exhaustion than parents sharing the care of their child.

Experience of Referral/ of Other Advice Services.

- A clear majority of clients were using advice services for the first time when they accessed support from the Royal Hospital for Sick Kids (RHSC) service.
- There was universal comfort with the method of referral from clinical or other support staff to the service.
- The service appears to make an attractive offer to parents who have used other advice services in the past, even though they were happy with the support those services offered.
- Parents had sometimes been referred in response to discussions about specific money issues.
- Discussion of money issues followed by referral felt to parents like natural elements of the clinical services they were provided with.

Financial and Psychological Impact of the Service

- Support to parents is critical in terms of helping them deal with a benefit system and financial problems of which they may previously have had no knowledge or experience.
- Such support is also useful for parents who are migrants to the UK.
- The service provides critical support to parents who might otherwise not have been able to deal with the financial challenges they were facing, on the grounds of carer burden causing exhaustion and lack of time.
- The service helps some people overcome attitudinal and emotional barriers to claiming benefits.
- Disability Living Allowance:
 - Helps supplement reduced family incomes, particularly in conjunction with Carers Allowance.
 - Can help parents meet extra costs associated with having a sick child such as extra or different food, nappies, and heating.
 - Enables families to engage in normal social and leisure activities, and brings a sense of brightness and freedom into lives that can feel constrained.
 - Helps parents purchase equipment for their child.
 - May meet parents' additional travel costs, including the use of taxis.

- Through Motability, enables people to be more flexible in their transport options.
- May help parents save against future needs.
- Extra resources may help parents feel more relaxed about taking time off work without pay, or enable them to take longer off work. For one interviewee, this meant extra time spent with her terminally ill son.
- Money and the financial inclusion service cannot solve all the problems facing a family, but:
 - The service may have a major positive impact on clients' wellbeing, to the point of preventing a breakdown.
 - Less dramatically, it may ensure that clients have one less thing to worry about/ feel less stressed.
 - It may improve dynamics within the family, including between parent and child.
 - It may support the child to maintain former activities and some of their previous degree of confidence.

Perception of Added Value:

- The personal qualities of the project worker have been key to the impact it has achieved for parents, and the added value it has delivered.
- Parents believe that key aspects of the service are that:
 - It is based within the hospital, facilitating their easy access, and on occasion being able to chase clinicians for them.
 - Has a close working relationship with clinical staff reducing their need to explain over and over again the details of their child's condition.
 - The project worker has developed an in depth understanding of the needs of parents in their situation.

Future Use of Service and Future of Service

- A significant minority of parents expect to use the service again in the future. The majority of parents expecting to claim DLA again on behalf of their child expect to use the service again.
- There is a clear preference amongst parents to use the Royal Hospital for Sick Kids (RHSC) Service as opposed to other advice services.
- This is due to the relationship and trust established with the project worker.
- Sometimes interviewees reported a clear reluctance to use another service, and not wishing to open up to anyone else.
- Parents would recommend the service to others in their situation, and some have already done so.
- There are few recommendations for service improvement, other than that the service is more widely advertised to catch more people sooner.

Findings from Staff Interviews:

- Delivering the service challenges the project worker to support parents facing a wide range of issues at a very emotional time. One of the service's key functions is as a listening ear for parents.
- There are issues around balancing continuity of care for parents and the requirement to refer them on to other local services. It is not clear how robust referral links to other services are.
- Clinical staff demonstrated a clear understanding of the financial issues facing parents of the children they care for.
- Different groups of parents may have particular needs; those with more experience claiming benefits and lower incomes may require support to think through their income and expenditure; those with less experience with the benefit system may require support to navigate it.
- Previously referrals had been made to a number of other services to deal with such issues, with Social Work provision in the hospital being identified as the main one. Such provision and referral was seen as ad hoc and patchy.
- Clinical staff have previously been involved, though to different levels, in the completion of DLA forms. The project worker suggested that this was poor practice.
- CNSs clearly understand that they are responsible for opening up discussion with parents on money issues, though some parents will raise concerns themselves.
- They have developed ways of opening up such discussions, and some feel more confident doing so now that they have a clear service to refer to.
- Clinical staff may make a general offer of the service, or seek to identify parents who are in particular need of its support.
- The slow build up of referrals to the service had the positive effect of allowing the service to identify problems at an unpressured time.
- Observed variations in referral from different clinical specialist areas and across time are seen by the project worker as resulting from variations in practice, not fluctuations in need.
- Staff report a very positive relationship with the project worker, based around her commitment, accessibility and flexibility.
- The project worker makes continued efforts to develop and maintain relationships with referring staff. That these staff do not always report being engaged by these efforts probably reflects the challenges of engagement with staff who are constantly pulled into other work and often away from their base.
- The service is greatly valued by staff as a part of the support they can offer parents.
- They believe it is critical that the service is provided on site, delivered by someone identified to them, with the expertise developed by the project worker.
- Staff believe that the service has an impact on the health and well being of parents and possibly on their ability to care for their child, but cannot provide extensive evidence for that belief.
- The project worker believes that
 - The service is getting to people who would not otherwise access advice, and is getting to them earlier.
 - It delivers added value by being based in the hospital and working alongside the CNSs, which benefits the service both in terms of accessibility and in the quality of work delivered
- Staff are clear that the service should continue.

Summary Key Messages

- This service, like any service looking to working with parents with seriously ill children must take into account the broader context of the emotional and practical challenges facing parents
- The service is very positively regarded by parents, who are deeply appreciative of the way that it is delivered.
- The primary direct impact of the service is on reducing the various financial stresses faced by parents, in particular through supporting claims for Disability Living Allowance.
- The service often enables households to feel more comfortable about decisions that they planned/ were forced to take, such as reducing hours in work.
- The service often has a major impact on parents' well being by reducing one aspect of the psychological stress they face.
- Added value provided by the service stems from its hospital location, the timing and route of the offer of support, and the manner in which it is delivered.
- The service reaches people who have not, and would not, access other services.
- Parents experience the service as seamless, and are appreciative of the barriers they face to resolving their financial issues themselves.
- The service should continue to offer holistic support to parents, and good care and practice dictates there should be a degree of acceptance that a minority of parents will use the service for counselling as well as financial inclusion purposes, or will continue to seek continued financial inclusion support from this service rather than others.
- The service builds referrals naturally on the experience, knowledge and understanding of parents' lives amongst clinical staff.
- It marks a clear improvement from previous patchy practice.
- An inherent part of the service is ongoing work from the project worker to promote effective referral relationships.

In final summary, the fieldwork suggests that:

- The Royal Hospital for Sick Kids (RHSC) Financial Service is the right service, located in the right place, referred to at the right time by the right people, and delivered in the right way by the right person, to have a real impact on people in genuine need of support.
- There is strong evidence for the theoretical basis on which the service has been built.
- Both parents and staff are clear that the service should continue, and that it should do so in close to its current form.

Section 1: Introduction.

In August 2014, Nick Hopkins Consulting was commissioned by NHS Greater Glasgow and Clyde to carry out fieldwork to support the evaluation of the Royal Hospital for Sick Kids (RHSC) Hospital Financial Inclusion Service.

The service has been delivered to parents and carers of children attending Royal Hospital for Sick Kids (RHSC) Hospital since August 2012, building outwards from an initial focus on children involved with particular specialities.

The service has broken new ground. It is understood to be the first and only dedicated financial advice service located within a children's hospital setting.

The future of the service is uncertain beyond March 2015, and this report is intended to make a contribution to the consideration of how and whether the service is continued beyond that point.

The report is based largely on a series of interviews carried out with parents who have used the service since its inception, and of staff who have made referrals to the service.

The consultant would like to put on record his thanks to all those staff and clients who generously gave their time to be interviewed, particularly to clients who were prepared to respond very honestly to personal questions about emotionally charged issues.

The structure of the report is as follows:

- Section 2 describes the methodology for the delivery of the report, and sets out the characteristics of those interviewed.
- Section 3 sets out the context for parents in which the service is delivered, looking at the financial challenges facing parents, and the links between caring responsibilities, financial challenges and mental health.
- Section 4 provides a description of the service as it is delivered.
- Section 5 explains the structure of the two chapters that follow.
- Section 6 sets out the findings of the interviews with parents.
- Section 7 sets out the findings from the interviews with referring staff.
- Section 8 sets out a number of conclusions and reflections.

Section 2: Methodology.

The research on which this report was based was delivered in the following stages:

- A review was carried out of key documentation allowing the consultant to familiarise himself with the project.
- 13 interviews were carried out with clients of the service selected at random.
- 8 interviews were carried out with clinical staff who were involved in the project,

Interviews with Clients.

13 semi structured interviews were carried out with clients of the Royal Hospital for Sick Kids (RHSC) service, using an aide memoire on which the client had the opportunity to comment. All but one of the interviews were carried out over the phone, the remaining interview was carried out at Royal Hospital for Sick Kids (RHSC) hospital.

All the clients were a parent with primary/ shared primary care responsibilities for a child in receipt of care from Royal Hospital for Sick Kids (RHSC) Hospital.

In terms of age:

- 1 interviewee was aged between 25 and 29.
- 2 interviewees were aged between 30 and 34.
- 2 interviewees were aged between 35 and 39.
- 5 interviewees were aged between 40 and 44.
- 3 interviewees were aged between 45 and 49.

11 interviewees were the mother of a child in receipt of care from Royal Hospital for Sick Kids (RHSC) Hospital, 2 interviewees were the father.

7 interviews were living with a partner, 6 were single parents.

In terms of the clinical specialist area caring for children of interviewees:

- 5 interviewees' children were being cared for by cardiology.
- 1 interviewees' child was being cared for by the diabetes department.
- 4 interviewees' children were being cared for by neurology.
- 3 interviewees' children were being cared for in renology.

In the second year of the service, referrals have also made by staff from Schiehallion (non malignant tumours) and complex airways, but no parents with children from these wards/ areas were interviewed.

One interviewee was the mother of a child diagnosed with a terminal heart condition.

Interviews with Staff.

Eight semi structured interviews were carried out with staff.

Five were carried out with clinical nurse specialists from cardiology, complex airways, neurology, renal and diabetes departments respectively, using an aide memoire on which the client had the opportunity to comment.

The remaining three interviews were carried out with:

- The project advice worker.
- The manager for the CAB 'hosting' the advice service.
- The Head of Nursing at Royal Hospital for Sick Kids (RHSC) hospital.

Section 3: Context for Parents*.

This section focuses on:

- Providing a very brief overview of the broader financial pressures that may be impacting on parents coming to use the service resulting from policy change, in particular welfare reform, and the broader socio economic context.
- Setting out some of the specific pressures that parents may be facing when they access the service, based on key lessons from the literature relating to the links between wellbeing, money worries, carer responsibilities.
- Giving a sense of the potential impact of advice services on the wellbeing of parents and children.

Financial Context.

The financial context facing parents on low to middle incomes is currently particularly difficult as a result of:

- Welfare reforms.
- The ongoing squeeze on household incomes, and the consequences in terms of debt and reduced resilience to financial shocks.

Welfare Reform.

The UK Government may be seen as being at the 'end of the beginning' of a very long period of welfare reform that began under the previous administration.

The key elements are:

- Three major transitions from existing benefits to newly created benefits.
- The 'salami slicing' of incomes of people reliant on benefits.

Transitions

Parents caring for a sick child may be affected by any one of the three transitions:

- From existing income based benefits and tax credits to Universal Credit.
- The creation of Employment and Support Allowance to replace Incapacity Benefit.
- The creation of Personal Independence Payment to replace Disability Living Allowance for people of working age.

Universal Credit currently remains a future risk rather than a current problem for low to middle income families due to delays in its roll out. The Government claims that the new benefit will be simpler and will reward people for working, including those only able to take up part time jobs.

There are a huge number of concerns about Universal Credit over and above widespread scepticism about whether it will prove to be technically feasible. These include that:

- The benefit will not incentivise work for all families.
- Extending the payment period to monthly will put huge pressure on claimants' financial capability.
- Direct payment of Housing Benefit for social renting tenants will increase the likelihood of arrears, and bring an enhanced risk of homelessness.
- The emphasis on online application will disadvantage those who are digitally excluded.

* The term parents is used in the report as shorthand for people with parental responsibility for children attending Royal Hospital for Sick Kids (RHSC) Hospital

- The sanctions regime may be applied to people in part time work unable to increase hours in work.
- The sanctions regime inherited from current Job Seekers Allowance regulations is too inflexible, and the conditions on which it is based are too inflexible.
- The increased use of sanctions under JSA and Universal Credit carries the risk of increased destitution.
- Problems that may result from payment to a single member of the household, particularly in the context of abusive relationships.

There is also a specific change under the UC regulations that will make the benefit less generous for families with caring responsibilities. Under the current tax credit system, families with disabled children in receipt of Disability Living Allowance are entitled to additional support through the disability related element of child tax credit. Unless a child is registered blind or is on a high rate of DLA, that entitlement will halve under Universal Credit.

Employment and Support Allowance (ESA) replaced Incapacity Benefit for new claimants in 2008, and existing Incapacity Benefit claimants began the transfer to ESA in 2011, a process that is now nearing conclusion. Parents with their own health problems who are unable to work may apply for ESA.

To access ESA, applicants have to pass through the Work Capability Assessment. This is seen as delivering inappropriate outcomes through a variety of failings including; failing to take proper account of the variability in people's conditions, the impact of pain and fatigue and medication and effect of compounding conditions; failing to consider people's mental health problems properly; not taking full account of the social model of disability; being based on inaccurate assumptions, inaccurate recordings and use of unsophisticated tools; and too often involving unprofessional conduct by staff carrying out assessments.

Applicants may find the process of passing through the WCA very stressful, with potential longer term impacts on mental health. Those receiving inappropriate decisions will receive lower income than they are due, and may be required to undertake inappropriate work related activity.

Like Universal Credit, **Personal Independence Payment (PIP)** belongs largely in the category of future rather than current threats. New applicants have been applying for PIP rather than DLA since last Summer, the process of transferring existing DLA claimants to the new benefit is just getting going.

PIP has been set up specifically with the purpose of limiting the growth in the level of spending on disability related benefits. Whilst there will be some who gain in the transition from DLA to PIP, it is estimated an equal number of applicants will lose some entitlement, and a further smaller number will lose all entitlement to benefit.

Current focus of concern around PIP has been on its shift to a less generous interpretation of the applicant's ability to undertake certain mobility tasks, and most critically on the long wait that many claimants are experiencing for assessment. In the longer term it is feared that the assessment process for PIP may reflect some of the flaws of the WCA.

Salami Slicing

Parents may also be experiencing the effects of the 'salami slicing' of benefits. Whilst the Bedroom tax is now fully mitigated in Scotland, tenants living in private rented accommodation may face reductions in the financial support they can claim to meet rental costs.

Furthermore, savings from changes to tax credits which will be carried forward into Universal Credit are greatest from families with children.

The other significant change has been the year on year erosion of the value of job and income related benefits and tax credits. The rise in the value of these benefits was limited to 1% in 2013/14, 2014/2015 and 2015/16. This is another area of future risk, with the current chancellor indicating his intention to freeze the value of these benefits over the first three full financial years of the next parliament.

Squeezed Incomes.

A number of trends in the wider economy, resulting in part from the recession, but also predating it, may mean that parents face the situation of having a sick child with more stretched financial resources.

These trends include:

- Continuing problems of unemployment and economic activity in the labour market, particularly in West Central Scotland.
- An economic recovery in which headline reductions in unemployment hide:
 - The growth of 'odd job' style self employment.
 - The growth of part time work, including based on zero hours contracts.
 - The growth of underemployment (over 3 million people in the UK being in this situation)¹.
 - High levels of 'churn' in the labour market with people moving between employment on a number of occasions over any given period.
- A number of negative trends in relation to wages and incomes²:
 - A squeeze on family living standards, despite economic growth, from the early 2000s onwards with the recession greatly intensifying this effect. Between 2008/09 and 2011/12 median household income fell by 3.8%, taking it back to the level of 2004/05.
 - The median wage of UK employees fell from £23,800 to £21,900 between 2007/08 and 2011/12. It will not reach the pre recession level until mid 2017.
 - The median household income of *working age* households falling by more than the figure for all households, back to where it was in 2001 and £1,500 lower in real terms than it was in 2008/09.
- Low pay and in-work poverty remain endemic:
 - 1 in 5 workers in the UK are earning beneath £7.50 per hour.
 - 26% of women are in low paid work, 16% of men.
 - 43% of part time workers are low paid, a group overwhelmingly female³.
- Rising prices:
 - Household essentials have risen in price significantly more than other items; in particular housing, fuel, food and transport. This is of greater significance for low to middle income households for whom such expenditures take up a greater proportion of their income.

¹ <http://www.ons.gov.uk/ons/rel/lmac/underemployed-workers-in-the-uk/2012/sty-underemployed-workers-in-the-uk.html>

² J Plunkett, A Hurrell, M Whittaker 'The State of Living Standards' Resolution Foundation 2014

³ J Plunkett, A Hurrell, M Whittaker *ibid*

- Household energy bills have risen particularly fast, between 2006 and 2013; gas prices rose by 106%, electricity prices rose by 53% and dual fuel prices rose by 88%⁴.
- This means that 29% of Scotland's population are in fuel poverty, with significant numbers of households rationing their consumption of fuel, defaulting on their energy bills, rationing food to pay their energy bills⁵.
- The cost of basic foodstuffs is now 30% higher than it was 5 years ago⁶.
- Low to middle income households have seen the share of their household income devoted to household essentials increase.
- The cost of bringing up children is rising at above the more general rate of inflation⁷.

Consequences of the Squeeze.

One of the key consequences of this squeeze has been an increase in the proportion of households experiencing debt. The Money Advice Service's recent UK wide baseline survey on financial capability presented a picture of a country that it described as 'working hard to manage'⁸.

According to the Survey, over half of all UK households (52%) are now struggling to keep up with household bills and credit card repayments, an increase since 2006, when around a third were in this position. Around 10m adults are estimated to live in households which may be described as being 'on the edge' of experiencing financial problems, 9m adults to live in households in 'urgent need of help' with managing money.

The most common debts that people on low to middle income have related to what debt advisers call 'core debts', debts connected with household essentials including; rent, Council tax, utilities and water rates⁹.

The potential for already stretched households to be tipped into debt problems because of the onset of their child's illness appears to be clear. Significantly, around one in ten low to middle income households identify injury or illness in their household as the trigger for debt.

A further consequence of the squeeze is households having lower levels of savings, reducing their resilience to financial shocks. Amongst low to middle income households:

- 51% have no savings at all.
- 67% hold less than one month's savings.
- 84% of those reliant on benefits have savings of less than £1,500¹⁰.

People would like to save, but find themselves unable to do so. Families with younger children also tend to look to pay down debts rather than build up savings.

⁴ Quarterly Energy Prices March 2013' DECC, 2013.

⁵ 'Scottish Fuel Poverty Forum: Review of the Scottish Government's Fuel Poverty Strategy' Scottish Government, 2012

⁶ Walking the Breadline The Scandal of Food Poverty in 21st Century Britain' Oxfam and Church Action on Poverty, 2013.

⁷ Hirsch A, Sutton L, Beckhilling J, 'The Cost of a Child in the 21st Century' CPAG 2012

⁸ 'The Financial Capability of the UK' The Money Advice Service, 2013

⁹ Whittaker M 'Squeezed Britain the Annual Audit of Low to Middle Income Households' Resolution Foundation 2012

¹⁰ Whittaker M *ibid*

Budgeting

People may be facing this squeeze without the financial capability to cope. Some parents may not budget effectively, less than half the population regularly draws up a budget, and one in five of those doing so report struggling to stick to it. Some parents may also lack knowledge/ expertise in some areas of financial management, the MAS Baseline Survey suggested that one in six respondents could not identify a balance on a bank account¹¹.

However, it is essential to understand that for some people, incomes may be so low as to overwhelm their capacity to manage money effectively, no matter what level of financial capability they possess.

Financial Problems, Advice and the Health of Parent and Child

This section briefly sets out key aspects of the relationship between financial problems, the health of parents and children, and advice services. It both gives a sense of the context in which the service is delivered, and the research and theory that underpin it¹².

Relationship between Financial Problems and Health

- Carers often experience financial problems because they find themselves unable to continue to work to, or have to reduce hours in work, due to their new caring responsibilities.
- Adjusting to loss of income is one of the most difficult and stressful challenges faced upon the onset of a long term condition in the family.
- There is a clear moderate association between debt and mental health problems.
 - Greater levels of debt and number of debts means increased risk of mental health problems.
 - Debt can be associated with postnatal depression, conflict based family relationships, and potential mental health problems amongst children.
 - Debt has negative impacts on personal identity.
 - Debt repayment difficulties have an association with thoughts about suicide.
- People with less experience of problem debt may find their mental health particularly badly affected, to the point of worrying about debts that are, objectively, manageable.
- Financial capability and feeling in control financially also have a clear association with levels of mental health.
- There may be physical impacts on health of reduced income if it impacts on increased fuel poverty, or access to healthy food/ appropriate diets.

Relationship between Caring Responsibilities and Mental Health

- The potential impact of financial difficulties on their well being will be experienced at the same time as parents are dealing with the challenges to identity, adjustment to new role, upset and practical challenges of being a carer for their child.
- Levels of psychiatric morbidity relating to stress, anxiety and depression for carers are only slightly less than for people in the general population affected by depression.
- Higher levels of carer burden result in lower levels of mental health.

¹¹ 'The Financial Capability of the UK' The Money Advice Service, 2013

¹² The findings stated in this subsection are taken from an unpublished report- 'The Case for Advice' written by the consultant for the Health and Social Care Alliance Scotland. A longer list of references is given in an appendix.

- Lower income carers are at greater risk of experiencing psychological difficulties.
- Restrictions on finances may mean carers cutting back on social activities essential for their quality of life/ well being.
- The mental health of the carer is a central determinant of the mental health of the cared for person.
- The suffering of the cared for person in turn has a major impact on the mental health of carers.
- Fatigue and sleep deprivation also have a major impact on carer mental health.

Relationship between Advice and Health Outcomes.

- Co-location of advice and health services is an effective way of building links between advice and health services.
- This appears to be partly based on the trust that exists between health professionals and patients, which seems to transfer from health to advice workers, playing a legitimating/ permissive role for the patient.
- Identification and referral of people in need of advice also appears to be a natural development of the work of clinical staff, and the issues they discuss with patients.
- There is a clear impact of the receipt of financial inclusion related advice on mental health. The impact on physical health is less well established in the literature and may be partly mediated through impact on mental health, including carer mental health.
- The opportunity to talk through problems appears to have an impact on mental health, particularly on decreasing anxiety, independent of any impact on income, particularly where it leads to an increase in control over their situation.
- People in receipt of advice services may experience:
 - Stabilisation of their mental health.
 - Greater calm and peace of mind.
 - Reduced depression, anxiety and stress.
 - Improved marital relationships.
 - Reduced destructive coping behaviour.
 - Lower reliance on medication and health service contact to resolve their own problems.

Section 4: The Royal Hospital for Sick Kids (RHSC) Hospital Financial Inclusion Service

This section:

- Identifies the drivers behind the setting up of the service.
- Describes how the service has been delivered, and how delivery has developed over time.

Identification of Need.

The need for the service was initially identified by NHS Greater Glasgow and Clyde in a carer's needs assessment carried out in 2011. This found that parents attending the hospital identified support around money worries and financial advice as their top priority. A further needs assessment in 2013 as part of the 'On the Move' programme saw parents identify money worries as being a key issue for them.

Key elements of the financial challenges facing parents have been identified as being:

- Travel costs in respect of accessing treatment, potentially over a long period of time.
- Impact on employment due to taking up caring responsibilities.
- Changes to the benefit system under the UK Government's welfare reform programme.
- The impact of the recession.

The expectation was that the service would demonstrate additional value over existing community based advice services in terms of:

- Location on the hospital site.
- Alignment with the existing Family Support and Information Service.
- The potential for flexible delivery of service by the welfare advice worker.
- The use of the relationship of parents with clinical nurse specialists as the basis for referral to the service.

Policy Drivers.

Delivery of the service fits with key areas of developing NHSGGC policy, set out within the Policy Framework Statements 2013/16.

In particular it fits with NHSGGC commitments under its 'Employability, Financial Inclusion, and Responding to the Recession' theme.

This includes commitments to work to:

- Identify patients at risk of poverty and refer them to appropriate advice.
- Mitigate the impact of welfare reform on patients.
- Involve staff in routinely asking questions about money worries and other social circumstances affecting their health.
- Build clear pathways between health services and financial inclusion support organisations.

In addition it fits with, supports commitments or echoes ways of thinking under a number of other themes:

- Commitments under the Health Improvement theme to:
 - Maximise opportunistic interventions.
 - Facilitate and enable access to services that improve health and well being and reduce key risk factors.
 - Tackle early years poverty, and issues such as infant nutrition.
 - Tackle issues around financial inclusion and poverty for disabled people.
- Commitments under the Unpaid Care theme to:
 - Ensure that carers are not disadvantaged or discriminated against by virtue of being a carer.
 - Provide financial inclusion support for carers.
 - Provide advice and information to carers in a timely way.
 - Provide support for carers for children and young adults with significant health needs/ disability.
 - Support carers to be economically and socially active.

Format of the Service.

The service began in August 2012. The project advice worker was employed by Glasgow Central CAB, working out of the hospital 4 days a week, and based with colleagues at the employing CAB 1 day a week to allow for management and peer support.

The first year of the service limited referrals to being made by clinical nurse specialists working in the following specialist areas, and building on the role of those specialists in providing case management support to parents:

- Neurology.
- Cardiology.
- Renal.
- Diabetes.

In year 2, the pilot was extended to enable referrals from Clinical Nurse Specialists in complex airways and Schiehallion wards.

The service has now been opened up to referrals from any staff including those admitting patients to wards, with a view to extending to clinical staff, dietetics, physiotherapy, occupational therapy and psychological therapy.

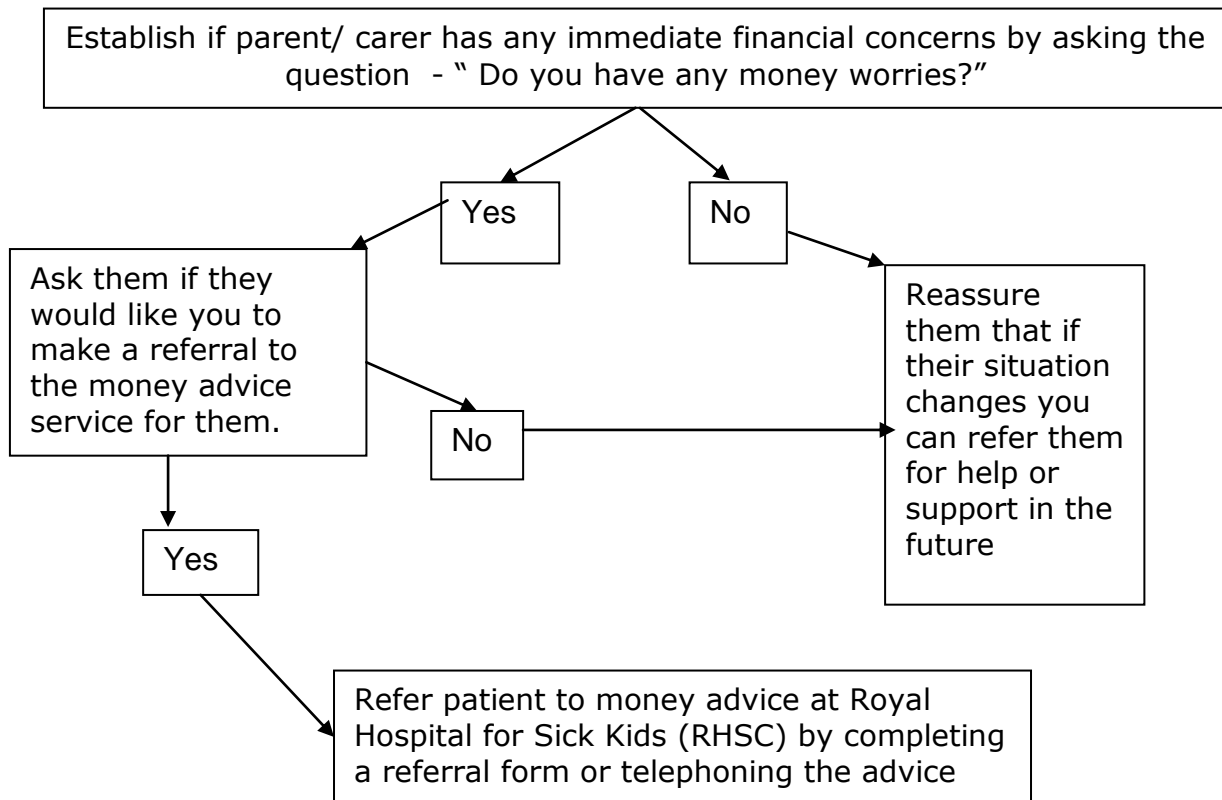
The flow chart on the following page sets out how referral to the service is intended to operate in practice.

The service operates in a way that builds on the specific expertise and role of clinical staff and the project advice worker, including:

- The ability of staff to identify parents potentially in need of support through the asking of simple questions, then referring them to the service with their consent.
- The ability of the project worker to deal with the range of potential money issues from entitlement to benefits to debt management, money management, and fuel costs.

The service allows clinical staff to make a referral for appropriate support in accordance with a clear pathway without becoming involved too deeply in resolving financial problems for parents in a way that exceeds their experience and capacity.

Referral Route Map



Section 5: Structure of the Main Research Sections.

The two main sections of the report look in turn at the feedback from clients of the service, and from the staff involved.

Interviews with Clients.

The tender brief set the following key research objectives for the consultant to explore in respect of service clients:

- To find out:
 - How parents experience the service.
 - whether they would have been likely to go to a community based financial advice service.
 - how they would feel about using a community based financial service in the future.
- To assess the impact on parents (esp. around stress, health, self efficacy).
- To assess any impact on parent/carers' skills around budgeting and managing money.
- To assess whether there was any knock-on effect on managing their child's condition at home through using the financial advice service.
- To assess how using the financial services fed into related decision-making around domestic circumstances (e.g. change in employment hours, remaining or giving up employment, housing, etc.).
- To assess the value of the service location (i.e. within the hospital setting as opposed to being community based).

In meeting these objectives this section of the report explores in turn:

- The psychological, financial and practical impact of clients' children's illness on parents to set out a clear patient context in which the service is delivered.
- The extent to which clients had used other advice services in the past.
- Clients' experience of referral to the Royal Hospital for Sick Kids (RHSC) service.
- The financial impact of clients' accessing the service, exploring:
 - The direct impact of the service on benefit claiming and debt resolution.
 - What extra benefit income and reduced debt have meant in terms of families' incomes and spending behaviour.
- The psychological impact of receiving support from the service on parents, children and the family more broadly, including the impact on relationships.
- Clients' direct views on the added value provided by the service, looking at both manner of service delivery, and the location of the service.
- Clients views on their future use of the service, willingness to recommend it to others, and ideas for its improvement.

To preserve appropriate emphasis on the personal characteristics of the project worker, and the relationship she established with parents, her name has been remained recorded within parents' quotes rather than her being anonymised, as elsewhere in the report, as 'project worker'.

Each quote from a parent is followed by identification of whether they were a mother or father, whether they were a single parent or living with a partner, their age, and the clinical specialist area caring for their child.

Interviews with Staff.

The second set of research objectives set out in the tender brief related to the experience and views of hospital staff:

- To find out what staff understand about the impact of having a sick child in the family.
- To examine staff's understanding of the referral process and what motivates them to refer to the FI service.
- To find out how staff responded to parent/carers' financial concerns before the FI service was in place.
- To find out whether referring staff respond to parent/carers' financial concerns any differently now than before the FI service was in place.
- To gather staff views on any impact of the service on the health of the child or the family's ability to support the child while in hospital/at home.

This section of the report explores in turn the views of clinical nurse specialists on:

- Their knowledge of financial issues impacting on families with children receiving care from Royal Hospital for Sick Kids (RHSC) Hospital.
- Their previous practice working with parents on financial inclusion issues.
- How they currently play their referral role, how they have developed it, and the impact on their practice of being able to refer parents to the service.
- Their relationship with the service.
- The strengths and value of the service.
- The service's future.

Throughout this section, the feedback of clinical nurse specialists is explored alongside that of key stakeholders and project staff.

Section 6: Client Experience of the Service

Impact of Child's Illness.

Psychological Impact.

Across the board, it was difficult to overstate the impact of their child's illness on parents:

'The diagnosis changed everything. Everything was blown apart..' (Mother, Partner, 40-44, Neurology)

'I felt everything getting on top of me. Just knowing that this is him for life, he'll always have it.' (Mother, Single, 45-49, Diabetes).

The dividing line between life before their child's illness, and life after was very clear:

'It was a different life, nothing else mattered apart from her health. It was a different world' (Mother, Single, 45-49, Renal)

'I've been at her side for 8 years, never going out or anything.' (Mother, Partner, 45-49, Neurology)

'It thrust me into the world of disability. It's been frustrating, I can't work now and I've worked all my life' (Mother, Single, 40-44, Renal)

The 'unnaturalness' of the situation was described by one interviewee:

'There was a lot of strain on me. You just don't expect your child to be ill like that. That's not supposed to happen' (Mother, Single, 40-44, Cardiology).

That impact extended across families, including to siblings. Sometimes the impact on siblings was felt in terms of stress, on other occasions in terms of lack of attention:

'It was traumatic for her brother and sister. They couldn't bear to see their little sister in that state' (Mother, Partner, 40-44, Neurology).

'There's a lot of stress on my other son too, he's only 4 and he's been crying a lot, he picks up on it.' (Mother, Single, 30-34, Neurology)

'It's been hard for my daughter with us being away so much [her son recently underwent an operation in London]' (Mother, Single, 40-44, Cardiology).

For some mothers, the illness of their child exacerbated or triggered other mental health problems, in particular for one client, post natal depression:

'Yes, it had a big impact on me. I had PND and everything was painted so black at the start, it just made it worse.' (Mother, Partner, 40-44, Cardiology)

Some had managed to come to terms with their situation:

'We have been very worried about our son. But I am a religious person. I have faith. It's beyond the scope of man to change these things.' (Father, Partner, 35-39, Renal).

For some clients, the illness of the their child had come at a time of other traumatic or difficult events, the combined effect leaving them feeling under pressure or even putting their mental health at risk:

'It was really stressful [when her son became ill with a heart condition]. It was just after the other one had nearly choked. I didn't want to be by myself, I was too nervous' (Mother, Partner, 35-39, Cardiology).

'A lot of things happened at once. The same day my daughter took ill, my father died. Her condition came out of the blue.....

They put me on tablets for my nerves. I couldn't cope with it all- I'm not sure how I managed. Just couldn't cope with life... I was panicking all the time and couldn't explain all the feelings I had' (Mother, Single, 45-49, Renal)

The relentlessness of the effort involved in caring for their child left a number of interviewees reporting exhaustion:

'I have to stay awake for him, I can't go to sleep until I get so tired.' (Mother, Single, 30-34, Neurology)

'I don't sleep well, she's often ill during the night' (Mother, Single, 40-44, Neurology).

'I'm fine, that is apart from the exhaustion and the stress' (Mother, Single, 40-44, Renal).

Interviewees with older children who had become ill identified that their children themselves experienced a psychological impact as a result of their illness:

'It had a big impact on him when he was diagnosed. He's been anxious, and he's been wetting the bed a lot. He's kind of at that age when you're starting to be a bit macho, when you get embarrassed in front of your pals. That whole thing knocked his confidence.' (Mother, Single, 30-34, Neurology).

Financial Challenges.

Significant Negative Impact on Income.

Some interviewees had experienced a significant negative impact on their income as a result of their child's illness.

This was generally as a result of having to give up or take time away from work because of the need to care for their child:

'I had a pretty well paid job [working for a major retailer in a role with national responsibilities]. I had to give that up. Everything has to revolve around my daughter now.....

I found myself getting behind, running up debts, and I couldn't get access to credit any more' (Mother, Single, 40-44, Neurology).

In one case the financial impact resulted from a more complex impact on the interviewee's personal situation, mediated through the impact of her child's illness on the interviewee's marriage:

'I was with my daughter, at her side for 8 months. I slept in a chair by her bed, I never left her.....

I didn't realise my husband had left me, I was just really confused by what was happening. The letters kept coming, I'd never been in that sort of debt before.'
(Mother, Single, 45-49, Renal).

For some interviewees the difference between before and after was particularly striking, in one case exacerbated by other financial troubles:

'I didn't used to worry about money. I've always been good at keeping an eye on things, what's going out, what's coming in.....

We have had less money. We were heading for a problem I think, I'd thought we'd be OK, but stuff was mounting up' (Mother, Single, 45-49, Diabetes).

'It was life changing. Giving up work, well I'd never not worked before... Money felt really tight. We really felt it [the loss of her salary]. I'd been very highly paid....

Then my husband's business went under....It took a long time to get us back onto our feet' (Mother, Partner, 45-49, Neurology).

Only one interviewee explicitly suggested that there had been very little real financial impact as a result of her child's illness:

'I didn't want to be left by myself, so he [her husband] had to take a bit of extra time off work. But we'd budgeted for having less money, and we weren't going out much anyway.' (Mother, Partner, 35-39, Cardiology).

Impact on Financial Resilience/ Plans

Interviewees were sometimes very aware of the thin line that separated them from financial problems:

'I can manage. It's OK. I can't pay for an extra care, but I can manage. But to be honest, without the money from his dad, I think we'd be really struggling'
(Mother, Single, 40-44, Renal).

Others had seen their cushion against financial problems disappear:

'Money is OK, perhaps a little tight. I had to take extra time off, more than just my paternity leave. We were living in [Ronald MacDonald House]. I was travelling back and forwards [a two hour round trip], picking my mother in law up and taking her to the hospital to see her daughter. We did use up our savings' (Father, Partner, 30-34, Cardiology).

The impact could also be felt in terms of aspirations for the future:

'There was a bit of a financial shock when he was born [scans had diagnosed a health condition whilst he was in the womb]. As much as anything because you realised that we weren't going to be this normal family with 2.4 kids.' (Mother, Partner, 40-44, Cardiology).

Impact on Employment

Interviewees did report having understanding employers. Whilst inevitably that could not always wholly protect them from the impact of the loss of income, it made a big difference to their view of their situation:

'I've been with the company about 8 years, so they've been OK about it. They appreciate that my son comes first. I think they value me as a worker, it feels a little bit more like a relationship than a business. That's meant it's been much less of a worry than it might have been.' (Mother, Single, 30-34, Neurology).

Additional Costs

A number of interviewees identified additional costs that they had faced/ were facing as a result of the situation:

'The travelling expenses were quite a lot on top' (Mother, Single, 45-49, Renal).

'We had a lot of expenses when we were down in London [for her son's operation]. There was the transport, and I had to get extra food, he didn't like what he was getting in the hospital' (Mother, Single, 40-44, Cardiology).

There is further discussion of the issue of additional costs in the section below which discusses how the Disability Living Allowance claimed by many parents is spent.

Practical Challenges

Interviewees' caring responsibilities are often very extensive, leaving little space for anything else in their lives:

'I can get 10 or more calls a day from my daughter's school, asking me to come up and deal with issues' (Mother, Single, 40-44, Neurology).

'Life is really exhausting. He needs a very high level of care. I've constantly to be aware of his needs. I can't do anything in terms of leisure, work is impossible and sleep is hard enough' (Mother, Single, 40-44, Renal)

Everyday tasks often became more complex and time consuming:

'He can't just head off to football anymore. I've got to make sure he's got everything with him. I've always got to chase after him with his tablets. Shopping takes longer, something simple like that, I've got to look at food labels more' (Mother, Single, 45-49, Diabetes)

One of the practical challenges reported by interviewees was in coming to understand their child's new needs:

'Everyday was a school day. There was always something new to learn about his condition.' (Mother, Partner, 40-44, Cardiology).

One interviewee felt that she faced a constant struggle to access the support that she and her son needed:

'I've had to fight all the time. My son doesn't fit any of the boxes. No-one seems to want to pay properly for his care.' (Mother, Single, 40-44, Renal).

Key Points: Impact of Child's Illness

- A child's serious illness has a huge impact psychologically on parents, siblings and, when they have insight into their situation, on children themselves.
- Parents may feel that their life has utterly changed, with life understood in terms of 'before' and 'after', and that the 'natural order of things' has been overturned by their child being ill before them.
- That impact can be compounded by concurrent events, or by further life changes triggered by the illness and the response of those in the household to it.
- Caring for a seriously ill child requiring hospital treatment is exhausting, emotionally and physically.
- Parents may find that they have to give up work to care for their child. In couples, it appears to be the mother who does so more often.
- This will generally trigger a significant loss of income for the family.
- Parents may find their buffers against financial problems reduced in these circumstances.
- No evidence was gathered of employers proving difficult in the context of parents taking unpaid leave, in fact the opposite appeared to be the case.
- Parents may face a care burden such that they have little opportunity to do anything else. This appears to be true for the primary care giver in a couple, as much as for single parents.
- Part of the increase in care burden results from time spent supporting their child with treatment, part in response to everyday parenting tasks becoming more time consuming.
- A minority of parents experience considerable struggles to secure the quality of care for their child that they feel is acceptable.
- Single parents appear to be more at risk of financial problems than those with partners:
 - The majority of those facing debt issues were single parents, and in one case debt problems were clearly triggered by relationship breakdown.
 - Single parents appear to be in a situation in which they have less financial resilience/ smaller or no financial buffers.
- For parents with a partner, the most serious financial problems after a child falls ill may result from compounding problems such as the loss of the secondary carer's job to occur.
- Single parents also appear to be more at risk of exhaustion than parents sharing the care of their child.

Experience of Referral/ with Other Advice Services.

Engagement with Other Advice Services.

For a clear majority of interviewees, engagement with the Royal Hospital for Sick Kids (RHSC) Financial Inclusion Service was their only engagement hitherto with the advice sector.

Many reported that they felt they had never had cause to use an advice service before:

'I'd never had a reason to go [to an advice service] before. I've always worked and never claimed for anything' (Mother, Partner, 40-44, Cardiology).

A small number of participants had potentially had cause to go to services before, but had not done so. The interviewee quoted below had not sought advice in the past when making a DLA claim, though she had felt the need to do so this time:

'I'd always claimed DLA for my son. But this time [the benefit was up for review] I felt I needed a lot of help. I mentioned it to them [the clinical nurse specialists] and they told me about Kate' (Mother, Single, 40-44, Cardiology).

Others had used other services in the past. The second interviewee quoted below had unsuccessfully tried to resolve a difficult financial situation by herself, and then sought help from another advice agency who had dealt with her situation appropriately:

'I was already getting DLA. I got some help from a service in the East End [of Glasgow]. I've used them in the past, they've been fine.....

I got onto a debt management scheme. I was paying £300 a month. That was too much, when I went to GEMAP [advice agency in East End of Glasgow] they told me that the scheme was counting my daughter's disability benefits as income, and they shouldn't have been.....

GEMAP sorted it for me, they stopped me paying for a while as tactics, and then we got the amount down to £100 a month.' (Mother, Single, 40-44, Neurology)

That interviewee had sorted the DLA claim for her child out for herself, but was still grateful for the support that she had received from the Royal Hospital for Sick Kids (RHSC) service:

'I wish I'd been able to get the help from Kate years ago.'

Experience of Referral

Clients had been referred through four main sources:

- Most commonly through the clinical nurse specialists.
- For one client, by a ward sister.
- Through social workers within the hospital.
- Through staff working for the Royal Hospital for Sick Kids (RHSC) Hospital Family Fund.

Not a single interviewee reported that they had been in any way uncomfortable about being told about the service, and offered the support that it provides.

It was clear that many interviewees would not have considered seeking advice or help on financial issues had it not been for the referral that had been made:

'I found out about it [the service] when I went down the front. I wasn't really thinking about money at all. I'd been in hospital for ages and I hadn't asked for anything.' (Mother, Single, 45-49, Renal).

Others had been looking to deal with issues themselves but had been struggling, had sought out help and then been directed towards the Financial Inclusion Service.

'Social Work said to me 'You don't have to deal with all of this yourself' (Father, Partner, 35-39, Renal).

'I had a form to complete, and the nurse said, go and speak to Kate' (Mother, Partner, 45-49, Neurology).

Referral had occurred over the natural course of discussions between parents and staff, sometimes in response to parents raising particular issues that they had not realised would be directly relevant to money issues such as benefit entitlement:

'The cardiac nurse said, we understand this is a difficult time for you. If you do need more help there is someone who can do that for you' (Father, Partner, 30-34, Cardiology)

'The neurology nurse told me about it. We were talking about all sorts of things, and she said that if I needed to talk about anything to do with benefits or money there is a service that could help me. Actually, she didn't mention benefits, it was more if there's anything bothering you about money' (Mother, Partner, 40-44, Neurology)

'One of the charge nurses told me about it. We'd been chatting about things and I said that my daughter was going through a pair of shoes in about 8 days because she was dragging her feet. So we were talking about that, and he also mentioned about travel expenses and was I getting everything I was entitled to?' (Mother, Single, 40-44, Neurology)

One interviewee reported that the referral had been made specifically because of the impact of ill health on her son:

'The nurse said, because he's terminally ill, he will be entitled to that [DLA]. She said this lady will help you.' (Mother, Partner, 25-29, Cardiology)

One interviewee reported being referred by the family fund, where the conversation had been very directly focused on money:

'They were helping us with some of our costs, and suggested that the service could check up on benefits for us.' (Mother, Partner, 40-44, Cardiology).

One referral from clinical nurse specialists seemed to have been made on a slightly looser basis:

'The nurse gave us this number and said to call it. We didn't really think about it, but I think they told the service about it as well. A while later, I got this call, from Kate. She said we might be entitled to DLA, and did we want help getting it. I was really glad she made the call.' (Mother, Partner, 35-39, Cardiology).

Key Points: Experience of Referral/ of Other Advice Services.

- A clear majority of clients were using advice services for the first time when they accessed support from the Royal Hospital for Sick Kids (RHSC) service.
- There was universal comfort with the method of referral from clinical or other support staff to the service.
- The service appears to make an attractive offer to parents who have used other advice services in the past, even though they were happy with the support those services offered.
- Parents had sometimes been referred in response to discussions about specific money issues.
- Discussion of money issues followed by referral felt to parents like natural elements of the clinical services they were provided with.

Impact of the Service- Increased Benefit Claims and Reduced Debts.

Dealing with Unfamiliarity

Time and again, interviewees referred to the fact that they would have struggled to navigate the benefit system without support, many suggesting that their own lack of experience with the benefit system would have made this task particularly difficult:

'I knew I needed help with the DLA form. I was worried about filling it in wrongly. I've worked all my life, the benefits stuff is all new to me.' (Mother, Single, 30-34, Neurology)

'Kate's really helped where I would have struggled. She made sure everything went through smoother and quicker.' (Mother, Partner, 25-29, Cardiology)

'I'd never have managed the system myself. I know some other people who have had real problems dealing with the system, but I'm OK, I never had any problems.' (Mother, Partner, 40-44, Neurology)

'Kate helped me when I got stuck [with the questions on the DLA form]. She came back and asked the questions, broke them down for me.....

She'd ask me about the situations that were happening, and get me to see things differently. She'd ask me about my son playing football, would he just go? I'd say 'Yes', then I'd think again, and I'd think 'No, he can't. Everything needs to get sorted for him beforehand.' (Mother, Single, 45-49, Diabetes).

One interviewee was facing an entirely alien set of debt problems that the project worker had helped her resolve:

'It all hit me then [after her husband had left]. She sat down and sorted it all out, all the Council Tax, the tax Credits. She dealt with all the letters [from creditors] that I was getting.' (Mother, Single, 45-49, Renal)

Support for Migrant Parents

Two of the interviewees were migrants to the UK. Both concluded that the support of the service had been critical in dealing with an unfamiliar system, for one interviewee a system operating in a foreign language, whilst managing all the other challenges they were facing:

'I wasn't familiar with anything.....I was getting behind schedule and feeling tired all the time' (Father, Partner, 35-39, Renal).

'I'm not 100% that I would have managed the English on the forms. Usually if I don't understand something I can check websites to make sure I'm getting it right. I don't know if that would have been possible here, or if I would have had the time to do it.' (Father, Partner, 30-34, Cardiology).

Some had tried to resolve their financial situations themselves and been unable to do so:

'I am the sort of person who is independent and tries to do things myself, but this was hard, Sometimes you can't do everything yourself. You try, but it's good to know someone is there for you.' (Father, Partner, 35-39, Renal)

Help with Burdens

One of the most consistent themes in feedback from interviewees was the sense that resolving financial problems was a burdensome task that could simply prove too much at a time when their attention was focussed on the illness of their child and they were potentially exhausted:

'It was that she didn't just pass on the phone details [of the utilities companies] and leave me to do it. Sometimes you get all these numbers to phone and you just think 'Oh God'. That took a weight off my shoulders.....

Just having someone professional to do that for you at a time when you are facing all that stress makes all the difference' (Mother, Single, 40-44, Neurology)

'I think it would have taken me a couple of days to do the form if I'd tried myself. Those forms are so frustrating and time consuming if you don't know how to do them' (Mother, Single, 30-34, Neurology).

'I'd have taken months to do the form. I just never get the chance to sit down for a couple of hours to do it. I was spending 15 hour days up there [at the hospital] I was never going to do one of those forms, I was just too exhausted' (Mother, Single, 40-44, Renal).

For some interviewees, there was relief that difficult experiences with other aspects of the support they had been receiving were not being replicated in connection with the benefit system:

'I knew the application was going to go through, and I wasn't going to have to end up in front of some board talking about it. I couldn't have coped with having to fight about this.' (Mother, Partner, 25-29, Cardiology)

Overcoming Barriers

Some interviewees were clear that the service had been critical in their overcoming of attitudinal barriers to applying for benefits:

'I felt uncomfortable applying for Carers Allowance. I brought my daughter into the world, I didn't want to be paid to look after her.....

Kate said 'No, you've paid your tax, you are entitled to it'. I didn't want to claim,

in some ways I still don't, but Kate made me feel OK about it' (Mother, Partner, 40-44, Neurology)

Emotion about their child's condition was another barrier to applying for benefits that people experienced:

'Questions about your child can make you feel really awkward. You don't want to have to answer over and over again.....

It's partly about embarrassment and partly because you have to tell the truth and that means looking at the negative side. It can be quite horrendous' (Mother, Partner, 45-49, Neurology)

'I don't think I would have got things sorted. I think it would all have been a bit too close to home and I'd have struggled with the form' (Mother, Partner, 40-44, Cardiology)

Some interviewees felt that they would ultimately have been successful in their benefit application, but that this could not have been guaranteed.

'I think I'd probably have managed. She [her daughter] has one of those conditions that should mean that you automatically qualify [for DLA] but you just can't know that' (Mother, Partner, 45-49, Neurology)

Impact of the Service- Increased Spending Power and Financial Resilience, Reduced Debt.

Considerable discussion in the interviews focused on the gains that resulted from additional benefits claimed, in particular the impact of DLA.

Two interviewees identified that the additional money had stood between them, financial problems and difficult decisions within the family:

'It had got to the point when I was having to say no to the other boys.....

I think it would all have mounted up, and I'd be relying on my overdraft' (Mother, Single, 45-49, Diabetes).

'Without the money I'd have big debts to pay. I'd have had to do without and we'd have had to borrow. Letting her do without would not be an option.' (Mother, Partner, 45-49, Neurology)

However, some were left feeling that they were still short of the money that they needed:

'It doesn't go too far, I can't afford to buy extra care, I need the money I get from my son's father' (Mother, Single, 40-44, Renal)

Disability Living Allowance had made a huge difference to people's ability to meet some of the extra costs that they faced:

'I do things like buy extra nappies with the money.' (Mother, Single, 40-44, Renal).

'I have to buy more food, lots of perishable stuff, lots of healthy stuff, to make sure that he's got it there if he needs it.' (Mother, Single, 45-49, Diabetes).

One interviewee focused in on the extra transport costs that they were facing, some in the context of accessing treatment:

'It makes a real difference. My son isn't very good at breathing when it's cold or windy. He can struggle in the Winter. That means public transport isn't an option for us, hanging around at stops, we need to use taxis.....

Being able to afford taxis, that means we're not stuck in, not going straight from hospital to home. We can get straight into hospital by taxi, otherwise it's two buses and two hours each way' (Mother, Single, 40-44, Cardiology).

As much as dealing with extra costs, DLA appeared to maintain applicants' ability to engage in social/ leisure activities:

'It's made a fantastic difference. No, we weren't on the breadline, but we can spend more on our daughter now, everything is for her.....

We've been able to make life better for her, I can take her out to places, get her hair done, get her nails done' (Mother, Partner, 40-44, Neurology).

'It's helped us cope with the loss of earnings a bit. A lot of what we are left with goes on those extra costs. A lot of it goes on everyday things, and it goes on trips out, things like that' (Mother, Partner, 45-49, Neurology)

Two interviewees very clearly identified that DLA was used to provide 'extras' and planning for the future:

'I make sure it's his money, I'm conscious of that. I want to provide for him myself. So I get the clothes, things like that, I pay for those.....

We can go on trips, I've bought a small portable machine so that we can keep an eye on his breathing....We don't know what the future holds for him, how his health may be. I'm keeping aside some of the money for a wheelchair, he might need that in the future.....

The money gives us a bit of extra peace of mind, I'm putting aside as much as I can.' (Mother, Partner, 40-44, Cardiology)

'I've been buying clothes and things, and he does need the heating on more, so it's been helpful with that. But I'm putting a lot of money in the savings account ready for the future' (Mother, Partner, 35-39, Cardiology).

The latter of those interviewees reported that her son's DLA claim was ending shortly, but that this wasn't of concern to her:

'I don't think he'll be getting it for much longer. That's fine, not a problem, it was nice while we had it and I don't mind that we are not due anymore.'
(Mother, Partner, 35-39, Cardiology).

Motability support to which DLA is a passport was also identified as a real gain:

'The Motability car has really helped. It's much appreciated because we don't have to rely on taxis all the time.....

It's much easier to get to hospital than it used to be. We used to have to rely on the patient transport all the time. Even if we weren't due until 1, we'd get picked up at 9, and then you'd have long wait at the end of the day. You'd be doing that 4 or 5 times a week.' (Father, Partner, 35-39, Renal)

Interviewees did acknowledge that there were limits to what the advice provided by the service could achieve in terms of dealing with their financial situation:

'We don't have the money we had. It does feel as if we're in poverty, but that's life. Saying that, we are coping, we are getting by'. (Mother, Single, 45-49, Renal).

Impact on Household Decisions

Three interviewees spoke about the impact the service had on household decisions in relation to reducing working.

For two of those interviewees, the impact was felt predominantly in terms of helping clients feel comfortable with decision they had already reached rather than actually determining their decision:

'I have to take unpaid leave as well as holiday. My company has been understanding but obviously they can't pay me when I'm not in work. It's about 3-4 days a month at the moment that I have to be off, to look after my son and my wife.....

The extra money [from Carers Allowance and Disability Living Allowance] it helps. It means I don't have to worry so much, I know that I can cope OK.' (Father, Partner, 30-34, Cardiology)

'The money's helped with the extra time I've been taking off as well.' (Mother, Partner, 35-39, Cardiology).

One interviewee had a son with a terminal condition. She had changed her return to work plans as a result, and was clear that the financial support she had been able to access as a result of the advice she had received was critical to her being able to do this:

'I've been able to stay off work for three more months, I was going back at the end of November and I'm not now.....

It's important for me to have time with him, nothing is as important as that. Practically too, not everyone wants to look after a terminally ill child.....

I'm going back to see her and see if I can get Carers Allowance once I've done my maternity leave, help me stay off work for longer.' (Mother, Partner, 25-29, Cardiology)

Impact of the Service- Psychological.

Reductions in Stress

Support provided by the service had had a very significant impact on the mental health of some of the interviewees:

'I wasn't coping. I genuinely think that I would have had breakdown if I hadn't had the help [from the service].....

This [her money problems which included substantial debts] was something else to deal with' (Mother, Single, 45-49, Renal).

The impact may have been less dramatic on other interviewees, but it was still significant:

'I have more energy, less worry, less stress' (Father, Partner, 35-39, Renal)

'As much as anything it [the rebate I received] took a weight off my mind, it dealt with something that had been bothering me. I was very grateful for that' (Mother, Single, 40-44, Neurology).

'Kate's definitely helped me, definitely reduced my stress' (Mother, Single, 40-44, Renal).

Interviewees felt that the service had had a positive impact on their experience of stress, even in an overall context in which the major health issues facing their child remained unsolved:

'It gives you a boost as far as it can' (Mother, Partner, 40-44, Neurology).

'[Her daughter]'s illness was the big thing, but money was still impacting on everything, so of course it was impacting on my health....It was a difficult period for a few years.....

It took the edge off, even if nothing can help with the big thing' (Mother, Partner, 45-49, Neurology).

Impact on Caring Responsibilities/ Family Dynamics/ Activities

A number of interviewees identified reductions in the stress they were experiencing as having a knock on effect on their engagement with their child, as well as on broader family dynamics:

'I was starting to worry about cash....Of course there's an impact if I'm stressed. It impacts on my son, and my other boy starts to think his brother gets special treatment all the time' (Mother, Single, 45-49, Diabetes).

'I've coped with my daughter better, I'm a completely different woman.' (Mother, Single, 45-49, Renal).

The ability to engage in leisure activities was seen as having a definite impact both on the wellbeing of parents, and of their children:

'The money's had a huge impact on my son. He's been able to go to clubs etc,

We've been able to go on trips, that extra bit of money has made the difference.....

It's helped build his confidence again. We aren't stuck in the house so much.....I'm definitely coping with things better, and there's a smile on my boy's face because of that' (Mother, Single, 30-34, Neurology).

A note on 'Sacrifice'

A phrase commonly used about parents is that they would sacrifice anything for their children. Few parents used the actual word sacrifice during interviews.

However, the idea of sacrifice was implicit in many of the interviews. In addition to the parents above who felt that the service did not determine their decision to take time off work, but made them feel more comfortable with it, the following quotes, some used elsewhere in this report, identify the way in which the needs of the sick child are put first, financially and in other ways, and priorities for parents changed:

'Everything is for her' (Mother, Partner, 40-44, Neurology).

'I'm really conscious of it being his money. I want to provide for him myself, clothes things like that. The extra money is for him' (Mother, Partner, 40-44, Cardiology).

'Work's nothing in comparison to being able to spend time with my son. I was really shaken up when this happened. It made me think again' (Mother, Partner, 25-29, Cardiology)

'I would have been forced to rely on my overdraft to stop him going short' (Mother, Single, 45-49, Diabetes).

Key Points: Financial and Psychological Impact of the Service

- Support to parents is critical in terms of helping them deal with a benefit system and financial problems of which they may previously have had no knowledge or experience.
- Such support is also useful for parents who are migrants to the UK.
- The service provides critical support to parents who might otherwise not have been able to deal with the financial challenges they were facing, on the grounds of carer burden causing exhaustion and lack of time.
- The service helps some people overcome attitudinal and emotional barriers to claiming benefits.
- Disability Living Allowance:
 - Helps supplement reduced family incomes, particularly in conjunction with Carers Allowance.
 - Can help parents meet extra costs associated with having a sick child such as extra or different food, nappies, and heating.
 - Enables families to engage in normal social and leisure activities, and brings a sense of brightness and freedom into lives that can feel constrained.
 - Helps parents purchase equipment for their child.
 - May meet parents' additional travel costs, including the use of taxis.
 - Through Motability, enables people to be more flexible in their transport options.
 - May help parents save against future needs.

- Extra resources may help parents feel more relaxed about taking time off work without pay, or enable them to take longer off work. For one interviewee, this meant extra time spent with her terminally ill son.
- Money and the financial inclusion service cannot solve all the problems facing a family, but:
 - The service may have a major positive impact on clients' wellbeing, to the extent of preventing a breakdown.
 - Less dramatically, it may ensure that clients have one less thing to worry about/ feel less stressed.
 - It may improve dynamics within the family, including between parent and child.
 - It may support the child to maintain former activities and some of their previous degree of confidence.

Perception of Added Value.

Manner of Service Delivery.

Universally interviewees were full of praise for the way in which the service was delivered by the project advice worker.

Empathy, engagement and compassion were all identified as qualities she possessed that were appreciated by interviewees:

'She is very empathetic, I like her very much' (Father, Partner, 35-39, Renal)

'I could trust Kate. I could tell her about money things that I couldn't talk about with my friends. I mean I must have trusted her to tell her the things I told her' (Mother, Single, 45-49, Diabetes).

Others also identified the extent to which the worker avoided making them feel negatively about seeking help:

'She's not patronising at all, you get help without being patronised, or someone feeling sorry for you.' (Mother, Partner, 40-44, Neurology).

'She was really easy to talk to, I never felt like I was being judged' (Mother, Partner, 45-49, Neurology).

Interviewees saw the project worker as being very committed to the support that she was providing:

'She goes above and beyond' (Mother, Single, 30-34, Neurology).

'You never had a sense that she was clock watching. She was really professional at all times..... there was never a brush off ' (Mother, Single, 45-49, Diabetes).

The project worker was seen as being approachable, reliable and prepared to engage with people and make time for them:

'I never once called and didn't get the help I wanted straight away, she was just really approachable. (Mother, Single, 45-49, Renal)

'Kate never once said that she didn't have the time to help. She always answered my phone calls and emails' (Father, Partner, 30-34, Cardiology)

The project worker's style was seen as supporting open discussion rather than simply telling people what they should do in response to their situation:

'She's an advocate more than an adviser. She asks you the right questions to make sure that you get the answers that suit you.' (Mother, Partner, 40-44, Cardiology).

What was clear from interviewees was that the manner in which the project worker delivered the service mattered not only in terms of how the service felt to clients, but in terms of the actual outcomes for them.

Part of this was connected to the very substantial benefit that interviewees derived from simply being able to talk about the issues they were experiencing:

'Just talking made a difference. I'm nervous about talking to people I don't know, I don't talk easily. You can talk to Kate about anything, and she will listen to you.' (Mother, Single, 45-49, Renal)

'It's not just about the form filling, it's the way she engages generally' (Mother, Single, 30-34, Neurology)

Interviewees positively compared and contrasted their experience of engaging with the project worker with that of engaging with other professionals:

'Lots of the professionals I've worked with, I don't have a positive word to say about them. Kate's been very different, she stands out against all the others....

I can talk to her honestly, it's not like having a counsellor, it's better than that' (Mother, Single, 40-44, Renal)

'The medical teams, they've had thousands of cases. They do treat you as individuals, I wouldn't say otherwise, but it's not in the same way as with Kate...they don't have the time in the same way....

It's not about being better than the nurses, they just have a different role.' (Mother, Single, 45-49, Diabetes).

Location, Expertise and Relationships

Interviewees were aware of the particular advantages that the specific nature of the service brought.

The experience and expertise of the project worker were highlighted by a number of interviewees as being of critical value in the delivery of the service.

The project worker was seen as having developed real expertise in the issues faced by parents of children who are ill, and in terms of the benefit system as it affects children:

'She knows what's going on in people's lives, she knows what you're going through' (Mother, Single, 30-34, Neurology).

'She knew how to get it through for him quickly [her son is terminally ill]. She sorted it out so there will be no problem on benefits in the future' (Mother, Single, 30-34, Neurology)

'She's there it means that I think she understands the problems in families.'
(Mother, Partner, 35-39, Cardiology).

This expertise, understanding and experience was seen as connecting to the project worker's personal characteristics to help overcome some of the psychological barriers to seeking support that parents were experiencing:

'We could have claimed before when he lost his job. But we didn't want to start giving information to people.....

It felt good to have someone there. You don't always want to have to answer questions. Talking about things, about your sick child can be horrendous, Kate was clear that we had to and helped us see that.....

She understood about the situation, that we didn't want to betray our child, that we didn't want to really say how bad things were.' (Mother, Partner, 45-49, Neurology)

The fact that the project is based in the hospital with good links into the consultants was seen as benefitting clients in a number of ways; through speeding up the process of dealing with their problems, ensuring that parents do not have to repeat over and again the situation with their child, reducing the effort and emotion involved:

'She's there and that helps, she's in contact with the consultants, that gets things done quicker.' (Mother, Single, 30-34, Neurology)

'She knows your circumstances and understands things better. Kate can go and get the information from the nurse. That saves me. To be honest, I don't really understand what's wrong with him, I don't fully get it, it's too complex. And she can just go and speak to the nurse and write it on the form and I don't need to try and explain it to another person' (Mother, Partner, 25-29, Cardiology)

'She's up to speed with what's happening with you' (Mother, Partner, 45-49, Neurology).

Interviewees also identified the location of the service as a central strength and key part of its offer:

'The fact that you can drop in, drop by. That's really important. I could go to her with something that I'd been worrying about, something I'd been thinking about when I couldn't sleep. She's been a real sounding board.....

Having her on site is important. A quick chat or even a phone call can make a difference.' (Mother, Single, 40-44, Renal)

One interviewee reported that the project's location in the hospital had enabled the project worker to resolve an ongoing situation connected with the treatment of her child:

'We weren't happy with the medication he was getting. But we were really struggling to get hold of the consultant. She made sure she pinned him down for us.....

That made such a difference, it made sure we got it sorted, made sure he got the care we wanted.’ (Mother, Single, 30-34, Neurology).

Key Points Perception of Added Value:

- The personal qualities of the project worker have been key to the impact it has achieved for parents, and the added value it has delivered.
- Parents believe that key aspects of the service are that
 - It is based within the hospital, facilitating their easy access, and on occasion being able to chase clinicians for them.
 - Has a close working relationship with clinical staff reducing their need to explain over and over again the details of their child’s condition.
 - The project worker has developed an in depth understanding of the needs of parents in their situation.

Future Engagement and Future Service.

Willingness to Engage with Other Services in the Future.

The almost universal view of interviewees was that they would prefer to use the service based at Royal Hospital for Sick Kids (RHSC) when facing an issue on which they needed advice.

That view was often expressed very strongly. It was also noticeable throughout the interviews how many interviewees referred repeatedly to dealing with ‘Kate’ rather than ‘the service’:

‘A hundred percent I’d go back to Kate in the future. I wouldn’t think about going anywhere else.’ (Mother, Partner, 40-44, Neurology).

‘I’d only deal with Royal Hospital for Sick Kids (RHSC) on these issues. I’ve never been to another advice service.’ (Mother, Partner, 25-29, Cardiology).

Interviewees often clearly anticipated having to use the service in the future, for example to assist with reapplication for DLA when it came up for review:

‘I’d go back to Kate when we need to reapply. It will be good to have help with that’ (Mother, Partner, 45-49, Neurology)

Another anticipated using the service for another reason:

‘I’m going to go in there in January, with a big box of chocolates and a big bunch of flowers and just say ‘thank you’ (Mother, Single, 30-34, Neurology)

A number of interviewees picked up on specific aspects of the service at Royal Hospital for Sick Kids (RHSC), and their relationship with the project advice worker when they spoke about why they would choose to use this service in the future:

‘I’d go back to Kate. There is a relationship of trust that develops over time. I’ve had to prove again and again that we need support, people judging us on our situation, and there is none of that with her’ (Mother, Single, 40-44, Renal)

‘I’d go back to her. She’s just one of those people that you can talk openly to about things you wouldn’t speak about to anyone else.’ (Mother, Single, 45-49, Diabetes).

'I'd go back to Kate because I feel like I know her. You can get to see her easily, and she understands the problems facing families' (Mother, Partner, 35-39, Cardiology).

One interviewee explicitly stated that they would use the Royal Hospital for Sick Kids (RHSC) service rather than another local advice agency, and explained why:

'I'd go back to Kate. Not to my local CAB, no. I don't want to talk to anyone else in depth about my situation' (Mother, Single, 45-49, Renal)

One interviewee, whilst anticipating needing to reapply for DLA again in the future, felt reasonably confident that she would be able to deal with this by herself in the future:

'If there's an issue I might go back. But I think I'm OK with the forms now. I've got used to them' (Mother, Partner, 40-44, Cardiology).

Recommending the Service.

Not a single interviewee disputed the idea that they would recommend the service to others in their position.

Many expressed strongly the view that they would recommend the service to others, some had already begun to do so:

'I'd absolutely say to anyone to go and see Kate. It's essential that people go and see her' (Mother, Partner, 40-44, Neurology).

'She goes above and beyond. I'd definitely recommend it. I've been telling people all about it, trying to get some word of mouth going' (Mother, Single, 30-34, Neurology).

'I've already told some of the parents with younger children about it, that they can get DLA, and the service is there to help them with it'

There were very few recommendations made for improving the service, though one interviewee suggested that self referral should be possible. Another made the comment that:

'Perhaps the service should be at the heart of things, in the main body of the hospital. It's a little bit hidden away at the moment.' (Mother, Single, 45-49, Diabetes)

Key Points: Future Use of Service and Future of Service

- A significant minority of parents expect to use the service again in the future. The majority of parents expecting to claim DLA again on behalf of their child expect to use the service again.
- There is a clear preference amongst parents to use the Royal Hospital for Sick Kids (RHSC) Service as opposed to other advice services.
- This is due to the relationship and trust established with the project worker.
- Sometimes interviewees reported a clear reluctance to use another service, and not wishing to open up to anyone else.
- Parents would recommend the service to others in their situation, and some have already done so.
- There are few recommendations for service improvement, other than that the service is more widely advertised to catch more people sooner.

Section 7: Staff Perceptions of the Service.

Format of Service

The project worker gave more detailed feedback on the format of the service:

- Initial meetings are always about the assessment of the client's situation.
- The worker estimates that 50% of her work on benefits focuses on DLA applications, though many parents, particularly those whose children have been ill for longer, have already claimed that benefit on their behalf.
- DLA form filling is hugely time consuming, and is rarely completed in one session, regularly taking three meetings, with forms being subject to alteration as circumstances change.
- The worker does not carry out complex benefits work, although she supports people to submit Mandatory Reconsiderations, the step before appealing. She does not represent at tribunal.
- The worker also engages with clients on housing, homelessness, care package issues and fuel poverty, the latter through making referrals to G-Heat.
- Some work is done on financial capability, through looking at income and expenditure for people who are struggling, and doing 'What if' calculations looking at someone's financial future. The worker also suggests that where possible she likes to look creatively at people's financial circumstances to see where savings can be made, particularly where they are not entitled to additional benefit support. This element of her work is limited by the time available.
- The worker provides some debt advice. This often focuses on working through debt packs, aiming to show clients that creditors will be understanding, and putting them into a position in which they can deal more fully with their debt situation when time is less pressured.
- Some of the role is about simply allowing her clients to unpack their problems to her.
- This, and the general context in which the job is delivered, make it emotionally exhausting.

The worker reports that she is only meant to deal with people for as long as they are attending Royal Hospital for Sick Kids (RHSC). Her focus beyond this is on making referrals/ signposting to other local services. This is a matter of frustration for her; sometimes people are referred to her shortly before discharge, restricting what she can do for them; sometimes she feels as if people slip through the net at this stage; and more generally she feels that this way of working cuts against the continuity of care that is an important part of advice delivery, particularly given advice clients' propensity to become attached to services.

The worker sees some of the key challenges involved in delivering the service as resulting not so much from the complexity of the issues she deals with, but from the way in which they face more than one issue. There are also practical challenges resulting from the cancellation of appointments as parents get pulled into other things, and in travelling around the hospital delivering ward based appointments.

Staff at a strategic level felt that the work had proved to be more intensive than had been expected. They felt that there might be the potential to expand the financial capability/ forward planning aspects of the service.

Awareness of Financial Issues.

Each of the clinical nurse specialists (CNSs) interviewed indicated that they were aware of the financial issues facing parents of their patients.

For most this awareness arose out of their having played their current role, or something similar over the course of a number of years, for one interviewee a previous role as a health visitor had given her considerable insight.

Interviewees not only reported that they were aware of relevant financial issues, but were able to demonstrate such an understanding during the course of the interviews.

Amongst the issues identified by staff as impacting on parents were:

- Travelling expenses.
- Financial pressure for those unable to work.
- Interruptions to income causing problems in terms of maintaining mortgage payments or falling into rent arrears.
- Resulting housing problems in some cases creating risk of homelessness.
- Extra costs resulting from the condition of the child, for example diabetic children requiring extra expenditure on appropriate healthy food.
- The costs of eating away from home whilst staying with children.

One interviewee described a child's illness as having a huge financial impact on families, as turning their whole world, including their finances, upside down.

Perhaps unsurprisingly, the most extensive discussion of the financial impact of a child's illness was carried out with a member of staff who had worked in her current/similar role for over 20 years.

The project worker confirmed this picture of the challenges facing parents, and made a couple of key additional points, highlighting that:

- Parents will do almost anything to continue to visit their child when they are ill, to the point of landing themselves in financial trouble. A small number of parents find themselves in situations when this becomes impossible without additional financial help, for example through the hospital's Family Fund.
- Parents who have long term experience with the benefit system are often clued up on the benefits they should be getting, those with less experience of the system are more likely to be unaware of the support available to them.
- Parents whose child has been ill for a long time are generally claiming their entitlement, although there remain a significant number of parents in these circumstances who are not.

Previous Engagement in the Issues.

Each of the interviewees had been involved in supporting people to deal with their financial challenges before the Financial Inclusion Service had been set up.

Each had been involved in making referrals to a variety of other organisations. Social Work staff within the hospital were most commonly identified as the previous destination of referrals, but interviewees also mentioned CABx, and the Department for Work and Pensions (though the interviewee made reference to the DSS) and Job Centre Plus. One interviewee reported that she and her colleagues had made referrals to people's local social work services, or to the service based within the hospital, based on whether people were in or outpatients.

Four of the interviewees identified that they or colleagues had been involved in form filling for parents, though involvement had been at different levels in their respective specialities, and in each case was limited to supporting DLA applications on behalf of the child:

- One interviewee referred to completing the specific medical sections of the DLA form, then referring parents on to someone else for support.
- Another referred to being aware that her colleagues had previously completed DLA forms, i.e. before the service had been created, but had moved away from this as it wasn't proving to be sustainable.
- A third interviewee, working with diabetic children, reported more intensive involvement in the completion of DLA forms. This included production by her team of a sample form of words that parents could use on particular sections of the form, based on information on the Diabetes UK website.

One interviewee reported that her involvement in supporting parents had included giving advice on housing issues.

Social Work's support of parents with financial issues was viewed as mixed, or fragmented by some of the interviewees. One identified their input as being useful on issues such as food vouchers, but as being patchy beyond that.

One interviewee explicitly suggested that community based provision did not work for parents attending the hospital, feeling that there was often a lack of follow through in support, and that the huge pressure on people would crowd out financial issues from amongst their priorities.

The project worker identified that previous form filling work from nurses had sometimes been problematic. She described it as being common for nurses to 'dabble' in the work, advising parents how to complete forms, and difficulties resulting from people not fully understanding criteria. In the early stages of the project she had looked to get across the idea to nurses that 'dabbling' and filling out forms themselves was not good practice.

Experience of Referral.

In each of the interviews a considerable amount of discussion focused on how clinical nurse specialists went about identifying parents in potential need of support from the financial inclusion service.

Requirement and Opportunity to Raise Discussion

CNSs reported that generally they had to open up the discussion, parents did not usually volunteer information about financial problems that they were having. It was suggested that many parents did not wish to moan, or be seen to moan about their situation, most wanted to get on with things. This was seen as firmly placing the onus on CNSs to steer the conversation/ open it up to discussion about money issues.

CNSs were clear about the way in which their role gives them the opportunity to develop a wide ranging discussion with parents about their social situation, and the pressures acting upon them. They felt it was a natural part of their work to touch on money issues.

One of the key elements within that relationship is the trust that develops between nurses and parents. The relationship becomes quite an intimate one over time, based on conversations about all sorts of personal issues. As one interviewee indicated 'In my job, I couldn't be shy about talking about anything'.

Some interviewees did indicate that it was important to let the relationship with parents develop before they began to discuss these issues. It was not something that they dived in to pick up at the first meeting. This was contradicted by the diabetes CNS, who indicated that questions asked of families at diagnosis gave a good indication of people's financial situation.

Where parents do volunteer information about their financial circumstances, that was seen as being based on their trust in the CNSs, and the way that they had come to feel comfortable sharing all sorts of information with them.

Confidence in Referring

For two of the CNSs, the existence of the new financial inclusion service had increased their confidence in raising financial issues with parents. They now felt that they could offer solid support to parents with the problems they were facing, rather than avoiding in depth discussions on financial issues because they were not certain about their own capacity to direct people towards appropriate help.

Others felt that they had no inhibitions in this regard, having been involved in making such referrals over such a long period of time. For one interviewee, the fact that they could couch discussion in the most general of terms meant that she felt no concern about raising the issue. She suggested that she didn't have to tread into difficult areas because she was not looking for detailed information on people's lives.

One of the bases for this general confidence was that parents very rarely seemed to be unhappy in any way about being asked if they wanted support on money issues, even those feeling they were not in need of support responding positively to the offer. Some CNSs located the positivity of this response in the voluntary nature of the service, there is absolutely no pressure on parents to take up the service.

General Offers and Specific Identification

CNSs seemed to try to strike a balance between identifying people at specific risk of financial difficulties and making a general offer of the service. Some did initially mention the service to all their families, others focused on offering the support on those who appeared to need particular help.

CNSs felt that they had developed a certain amount of skill and confidence in identifying parents who were facing difficulties. Some talked about particular ways they had developed of doing so, one would use general questions about whether people had been buying new bedding to open up a conversation. CNSs also talked about deliberately keeping an eye on some parents, or for particular events. This could mean focusing on new parents, seen as more likely not to be getting the support that they need, and on spotting changes in circumstances such as parents losing or giving up their jobs.

Those who made a more general offer felt that they were happy to come back and raise the issue again with parents if they thought that the service could be of use to them.

One CNS had a role that took her into the homes of parents. She felt that this gave her the opportunity to identify people who may be struggling financially. This could sometimes be in quite a roundabout way, for example identifying a lack of kitchen utensils within the home.

One CNS highlighted that identifying people in potential need of the service should not, in any way, be seen as making a judgement on them.

Non Referral

One CNS, who had discussed how she and her colleagues did some more intensive work on DLA claims, reported that they did not always refer people on to the service, particularly where parents appeared to be competent and confident in dealing with issues themselves.

Experience from the Advice Side

The project worker and CAB manager identified that there had been a slow build up of referrals, with initial targets not being met.

This had in part been a function of the deliberate decision to pilot the service, and only expand it slowly, but also reflected the challenge of coming to understand and respect the way in which the hospital operates.

This slow start may have assisted the service in settling down and identifying challenges without being under immediate delivery pressure.

The project worker identified some ongoing issues with referrals:

- Most positively, about 99% of referrals made are appropriate.
- The number of referrals fluctuates causing challenges for workload management.
- There are variations between the number of referrals coming from different clinical specialist areas that she does not consider justified in terms of the demand that parents in those areas will experience. She suggests that some of the biggest referring specialist areas should actually be referring still more.
- Referrals from specific areas tend to fall when there is pressure on staff in those areas.
- Some staff appear to get out of the habit of making referrals.
- She does not get referrals from the wards, she believes ward staff have too much on their plate to refer to her.
- She sometimes receives referrals too late, when there is little time before someone leaves hospital, when there is a reduced amount that she can do for them.

Significantly, the project worker suggests that if as many referrals were being generated as demand would dictate, she would not have the capacity to cope.

The project worker believes that it should be possible for Family Support Workers to make referrals to the service, believing that some CNSs feel frustrated at having to make two sets of referrals, to Family Support Workers and the service, and that this is a barrier to referral to her service.

Relationship with the Service.

Preparatory work had been done with each of the departments involved in making referrals to the service, focused on generating an understanding of the referral pathway; who was to be referred, how they were to be identified and the route through which referral was to be made.

- Two CNSs reported that they and colleagues had met with the project advice worker prior to the service beginning. This meeting had talked about the worker's role in supporting parents, and had discussed examples of circumstances when referrals would appropriately be made.

- One of these CNSs reported that discussions had also taken place about the specific types of question that they might ask parents in relation to their finances.
- For one CNS this meeting had been part of her induction training.
- Another CNS reported more restricted discussions in her initial discussion with the project worker, which had talked about the worker's role, but not covered situations in which referrals might be made.
- Another CNS reported that it had been her colleague that had met with the project advice worker initially, and had then been involved in cascading information about the service down to her colleagues.

Interviewees all indicated that:

- Their working relationships with the project advice worker were positive.
- This positivity was often identified as being the result of the accessibility and visibility of the project worker being out and about on the wards.
- The referral system, which could involve paper, e mail or phone call according to preference, was simple and effective.

One interviewee identified a minor issue with the referral system, that it was not always clear that a referral had been received by the project advice worker.

The project worker provided a sense of the work h she had undertaken to build relationships with CNSs:

- Initial engagement at team meetings highlighting the pathway to the service.
- Ongoing attending of team meetings, focusing on highlighting service successes in terms of financial gains.
- Keeping an eye on where referrals come from, and dropping by to engage with staff who have not been making a referral.
- Keeping plugging away, considering relationship building an essential ongoing part of her work.

Strengths/ Value of the New Service.

Interviews focused on the particular strengths and value of the new service, often in direct comparison to the former situation.

At a strategic level the service is seen as:

- Fitting naturally with the role of CNSs to refer people to appropriate support, and enabling them to pass on issues requiring appropriate expertise to tackle.
- Provide a clear illustration of value of work done by CNSs.

CNSs highlighted the value of being freed up to talk about other things, knowing that they could relax in the knowledge that the service was dealing with financial issues affecting parents appropriately. One interviewee described financial issues as previously 'scratching away at her'.

Extra capacity was highlighted by one CNS as a critical part of what the service brings, with the interviewee suggesting that the project advice worker can do a whole range of work in terms of chasing up calls and people that she does not have the time to do herself. In contrast, another CNS felt that the real benefit of the service lay in the expertise involved in its delivery, by a professional wholly up to date on a fast changing benefit system.

One interviewee highlighted the importance of having an identified person to make a referral to, which avoided CNSs having to take considerable time to look up services which might be of potential use to parents.

The separation between the CNS and financial inclusion services was seen as an important part of its success. Parents were seen as finding that separation more comfortable for them, as it prevented them from having to discuss their details with the CNSs, and gave them a degree of confidentiality.

One interviewee highlighted a similar issue around the independence of the service from social work, suggesting that psychological barriers remained to some people accessing social work services, and that an independent service was therefore a much better option to have available to offer.

The presence of the service on site is seen as an important part of what it offers to parents, due to the impact this has on accessibility for people who under severe time and broader pressure, who can then engage with the service at their convenience.

The project advice worker's own way of delivering the service was seen as a particular strength:

- Her flexibility and accommodating nature with families was seen as making her easy for both CNSs and families to engage with. CNSs appreciated her commitment to feed back to them where problems had arisen.
- Her focus on offering families options as well as advice, and her ability to work out what they need.

One interviewee reported a particular task that the project advice worker had carried out on her and her colleagues' behalf. She had reviewed the information handed out to parents thinking about claiming DLA that they could use to guide their own completion of the form, identified areas in which it was out of date, and had rewritten it as appropriate.

The project worker believes that:

- The service gets to people who would not otherwise be reached, particularly parents who may be slightly better off who have less familiarity with the benefit system/ advice world.
- Even where parents would have accessed another advice service at some point in the future, there is value in the way that she can get to them sooner.
- She has had some clients who have been attending Royal Hospital for Sick Kids (RHSC) for years without their need for advice being recognised, who are surprised that financial and advice support are actually available to them.
- The service benefits from her, with the permission of parents, being able to liaise with CNSs and get forms completed appropriately. Some conditions, she suggests, are too complex for parents to understand properly.
- She benefits from being able to make appointments on the ward, making it as easy as possible to access the service she provides, a key issue for parents who often do not want to be away from their children for any length of time.

Perceptions of Impact

Staff believed that the service does have an impact on the health of parents. Some staff reported that they had identified parents who had been less stressed as a result of receiving the service. Others felt that they could not evidence this directly, but assumed that such an impact was delivered. One staff interviewee suggested that the

service has a potential impact on parents' attendance at appointments, including training appointments to learn about caring for their child's condition.

Staff did report some barriers to finding out what impact the intervention of the service had had on parents, although feedback from the project advice worker (with the permission of her clients) did sometimes make clear that the service had delivered positive financial impacts:

- It can be difficult to identify the specific impact of the service amongst a range of other interventions.
- Respect for the privacy of parents means that it is not always appropriate to seek too detailed feedback.
- Staff may prefer simply to trust that financial issues have been dealt with appropriately and focus on their own work.

The project worker echoes these perceptions of impact suggesting that:

- Parents who receive the service can be seen to visibly relax.
- The service allows someone else (her) to deal with complex issues, leaving parents with one less thing to worry about at a time when they can feel as if their world has been turned upside down.
- The ability for parents to unpack their troubles to someone itself has a major impact.

She also suggested that there was a need for Glasgow City Council, as a major funder of the work, to develop a better understanding of the outcomes that it delivers.

This confidence in the impact of the service was echoed by interviewees with strategic oversight of the service, one suggesting that the service has a major impact at 'a hell of a difficult time', another highlighting the way that it removes pressure from parents.

Overall View on Service and Its Future.

CNSs were very supporting of the overall value of the service, and clear that they wished it to continue.

Adjectives used about the service included 'fantastic', 'well used', and 'invaluable'.

CNSs did not want the service to stop, suggesting variously that:

'It's really important to maintain it'

'It's a really important service to have access to, it's a real addition to the support that my colleagues and I can provide.'

'It's got its place alongside all the other interventions. All my colleagues feel the same way. Without question if the service was withdrawn it would really take away from families'

'It's a worthwhile service for money to be spent on. It adds to the ways my colleagues and I can support people'

'Even in difficult times for the NHS, the service should be there....'

'I'd be devastated if the service wasn't there any more. I don't want to send people to another service, particularly those travelling in to us'

One CNS felt that more research might be done on the business case for the service, looking at whether it had an impact on parents/ carers attending appointments.

Key Points: Staff Views

- Delivering the service challenges the project worker to support parents facing a wide range of issues at a very emotional time. One of the service's key functions is as a listening ear for parents.
- There are issues around balancing continuity of care for parents and the requirement to refer them on to other local services. It is not clear how robust referral links to other services are.
- Clinical staff demonstrated a clear understanding of the financial issues facing parents of the children they care for.
- Different groups of parents may have particular needs; those with more experience claiming benefits and lower incomes may require support to think through their income and expenditure; those with less experience with the benefit system may require support to navigate it.
- Previously referrals had been made to a number of other services to deal with such issues, with Social Work provision in the hospital being identified as the main one. Such provision and referral was seen as ad hoc and patchy.
- Clinical staff have previously been involved, though to different levels, in the completion of DLA forms. The project worker suggested that this was poor practice.
- CNSs clearly understand that they are responsible for opening up discussion with parents on money issues, though some parents will raise concerns themselves.
- They have developed ways of opening up such discussions, and some feel more confident doing so now that they have a clear service to refer to.
- Clinical staff may make a general offer of the service, or seek to identify parents who are in particular need of its support.
- The slow build up of referrals to the service had the positive effect of allowing the service to identify problems at an unpressured time.
- Observed variations in referral from different clinical specialist areas and across time are seen by the project worker as resulting from variations in practice, not fluctuations in need.
- Staff report a very positive relationship with the project worker, based around her commitment, accessibility and flexibility.
- The project worker makes continued efforts to develop and maintain relationships with referring staff. That these staff do not always report being engaged by these efforts probably reflects the challenges of engagement with staff who are constantly pulled into other work and often away from their base.
- The service is greatly valued by staff as a part of the support they can offer parents.
- They believe it is critical that the service is provided on site, delivered by someone identified to them, with the expertise developed by the project worker.
- Staff believe that the service has an impact on the health and well being of parents and possibly on their ability to care for their child, but cannot provide extensive evidence for that belief.
- The project worker believes that
 - The service is getting to people who would not otherwise access advice, and is getting to them earlier.
 - It delivers added value by being based in the hospital and working alongside the CNSs, which benefits the service both in terms of accessibility and in the quality of work delivered
- Staff are clear that the service should continue.

Section 8: Conclusions.

The consultant offers the following conclusions and reflections in respect of the key research questions identified in the tender brief, and a small number of additional issues identified over the course of the delivery of commission.

Key Messages

In summary, the fieldwork suggests that the Royal Hospital for Sick Kids (RHSC) Financial Service is the right service, located in the right place, referred to at the right time by the right people, and delivered in the right way by the right person, to have a real impact on people in genuine need of support.

There is evidence from the fieldwork that the theoretical basis for the service; the potential of health linked advice interventions to engage effectively with people and to impact positively on health and wellbeing of parents and children; appears to have been correctly identified.

Both parents and staff are clear that the service should continue, and that it should do so in close to its current form.

Emotional and Practical Challenges

The fieldwork makes clear that parents who become clients face huge emotional and practical challenges in a situation in which their understanding of their life and role are thrown up into the air. Financial challenges are unlikely to be their primary concern at this point, but can be a source of unneeded additional stress. Any service looking to support them must take into account this broader emotionally difficult context.

Impact of Service

It is not clear from the fieldwork that the primary impact of the service is as an anti poverty service, though it does have a positive impact on the poverty faced by some parents.

The fieldwork suggests that primary direct impact of the service should be seen as reducing the financial stress faced by parents in the aftermath of a life changing event, and as a contribution to the development of their coping strategies.

It is clear that support to claim Disability Living Allowance has a major impact on household finances, facilitating the meeting of additional costs, supplementing income and acting as a buffer against problems, but perhaps most significantly in health and wellbeing terms, providing the opportunity to engage in activities raising the child (and thereby parent's) quality of life.

Some impact on household decisions to work was observed. Amongst the relevant small sample, this was more commonly observed to be the service facilitating greater comfort with a decision than determining the decision itself. Similarly, a number of interviewees appeared clear that their child was put first in any spending decisions, with the impact of any additional income gained as a result of the service perhaps likely to be felt by less constrained expenditure elsewhere in the household.

Clients do not generally perceive the service as making a difference to their financial capability/ budgeting skills, though some clients did report discussions around financial planning, and the issue of financial control was picked up in the discussions on debt issues. This is despite it being reported as a focus of activity by the project advice worker.

The fieldwork did not find parents reporting that they have been affected by the range of pressures currently flowing from welfare reform and the wider squeeze on low to middle income families.

The discrepancy and findings recorded above may be the result of the particular sample of clients interviewed. They are more likely perhaps to result from the way in which people view the financial challenges they face as stemming from the shock of their child's illness, not as something as even partly generated by their prior circumstances.

The primary indirect impact of the service is on the psychological stress faced by clients, in some cases a major impact. Whilst for most, the importance of financial issues pale into insignificance compared to the problems faced by their child, the significant relief of getting them resolved appears to have a broader impact on their life.

Added Value of the Service

The hospital location of the service does appear to deliver added value.

The service is experienced very positively by parents, who are receptive to referrals at the point that they are made, and deeply appreciative of the support they receive from the service and the manner in which it is delivered.

The service is reaching people who have not used other advice services in the past, and it may be assumed, would not have used an advice service at this juncture without having been referred to the Royal Hospital for Sick Kids (RHSC) service.

Clients are in no doubt that the service offers added value through:

- Flexibility in delivery, and accessibility on site, for people who may be uncertain from one day to the next where they are going to be.
- Delivery through staff with an in depth understanding of their needs.

The service is also particularly valued for:

- Providing expert support at time when they do not have the energy, capacity, time and in many cases the knowledge and skills to resolve their financial problems themselves.
- Offering a seamless service, giving parents a break from constantly explaining their situation and their child's illness to different professionals.
- Overcoming their emotional and attitudinal barriers to claiming benefit.
- Offering a service without judgement.

The fieldwork has identified some potential issues with the way parents use the service. Concerns might be raised about

- Clients becoming dependent on this specific service rather than moving on to local options.
- Its use as a counselling service.
- Resultant pressures on the service, with ongoing clients/ clients seeking more than financial inclusion advice competing for the service's capacity with new referrals.

However:

- The project worker does seek to move people on to other services, though it is possible links with other services might be improved.
- The service is not working with clients with a 'standard' set of problems. It has a human responsibility to meet the needs of its clients who are facing huge practical and psychological challenges.
- The fieldwork suggests strongly that best practice probably dictates that continuity of support from the Royal Hospital for Sick Kids (RHSC) Service should be possible.
- The fieldwork also suggests that there is real value and therapeutic impact in the simple listening function performed by the project worker for some clients.
- There is no suggestion that the majority of clients keep relying on the counselling element of the service. Whilst some clients may avail themselves of this support a few times over a period, the great majority of inputs remain focused on financial issues.
- It is not clear that majority of clients come back for financial inclusion advice on occasions beyond those it takes to resolve their presenting problems.

Effective Functioning from Staff Point of View.

Referrals are made by clinical staff who have a clear understanding of the issues facing parents with sick children. That understanding, based on the fieldwork with parents, extends to an awareness of the significance of particular situations/ changes in circumstances for parents' benefit entitlement.

All those involved believe that the service has an impact on the health and wellbeing of parents. Clinical staff operate on the reasonable assumption that parents will be better placed to meet some of the challenges that they face as a result of the intervention of the service.

Referrals appear to be motivated by staff's clear commitment to help solve as many of parents' problems as they can in support of their care of their child.

The existence of the service is seen as a clear improvement on the previous situation, and lying behind concerns about the future of the service may be fears about returning to the former, less effective situation.

The service is seen as working because it is based on effective referral relationships with clinical staff, on a natural fit with the roles of referring staff. Staff are now empowered to play their part in dealing effectively with problems that could formerly be less tractable.

Improvement appears to be possible in the number of referrals that are made to the service, but there is no magic recipe for achieving such, beyond the project worker continuing to invest time in relationship building with clinical staff, supported by strategic encouragement from hospital management.

Parents now have the benefit of easy access to a service that is appropriately located, delivered by an expert, who is supported by clinical staff where appropriate.

Appendix: Literature on Relationships Between Financial Problems, Advice and the Health of Parent and Child

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