

Thesis

Exploring key working: Parents' perceptions of key workers in Clare Early Intervention Service (CEIS)

By

Brigid Mullins

Thesis for Masters in Health Science (Primary Care)

Supervisor: Dr. Brian Buckley.

Head of Department: Professor Andrew Murphy

**Department of General Practice,
National University of Galway, Ireland**

2008

Acknowledgements

Many thanks to Dr. Brian Buckley, Dr. Mary Byrne, Dr. Peter Cantillon, Dr. Ann McFarlane and Dr. Eleanor McCarrick at NUI Galway.

Thanks to Ms. Margaret Hennessey, Director of Public Health Nursing, HSE West PCCC for supporting my participation in the masters.

Thanks to Ms. Patricia Dillon, Disability Manager, HSE West and all the staff in the Disability Service for their continued encouragement and support during the year.

Thank you to the staff at the Clare Children's Service and particularly Ms. Irene O'Loughlin for her assistance in sending out the questionnaires.

Many thanks to all the parents of children with disabilities in CEIS for taking the time to respond to the questionnaires, which enabled me to conduct this piece of research.

Finally thanks to my understanding and supportive family for their patience and encouragement during the year.

Declaration I, Brigid Mullins, declare that this thesis is entirely my own and that I have acknowledged the writings, ideas and work of others. Furthermore, this work has not been submitted by me in the pursuance of another degree.

.....

Table of contents	Page
Acknowledgements	ii
Declaration	iii
Abstract	2
Chapter 1	3
1.1 Introduction	3
1.2 Background	3
1.2.1 Clare Early Intervention Service	4
1.2.2 Family Centred Practice	6
1.2.3 Transdisciplinary working	6
1.2.4 The key worker	7
1.3 The research	7
1.4 Why parents perspective	8
Chapter 2 Literature search strategy	9
2.1 Literature search	9
2.2 Search results	9
2.3 Inclusion criteria	10
Chapter 3 Literature Review	11
3.1 Introduction	11
3.2 The role of the key worker	11
3.2.1 Designated key workers	12
3.3 Legislation and policy	13
3.4 Effectiveness of key working	15
3.4.1 Transdisciplinary working	15
3.4.2 Multi agency working	16
3.5 Parents views of key workers	17
3.5.1 Access to services	18
3.5.2 Service coordination	18
3.5.3 Frequency and regularity of contact	19
3.5.4 Family centred practice	19
3.5.5 Relationships with services	20

3.6 Conclusion	21
Chapter 4 Methodology	22
4.1 Introduction	22
4.2 Aim of study	22
4.2.1 Objectives	22
4.3 Design of study	23
4.4 Ethical considerations	24
4.4.1 General	24
4.4.2 Assessment of ethical risks	24
4.4.3 Data management	24
4.4.4 Help and support available	25
4.5 Location of research	25
4.6 Research phase	25
4.7 Study population	26
4.8 Sampling and recruitment	26
4.8.1 Sample size	26
4.9 Data – key worker questionnaire	26
4.9.1 Socio economic questions	27
4.9.2 Questions about contact with key worker	27
4.9.3 Types of disability	27
4.9.4 Satisfaction with the key worker service	27
4.9.5 Aspects of key working	28
4.9.6 Open ended questions	28
4.9.7 Questionnaire for parents	28
4.10 Pilot study	29
4.10.1 Survey conduct and confidentiality	29
4.11 Response rates	30
4.12 Data preparation	31
4.12.1 Data analysis	31
Chapter 5 Results	33
5.1 Response rate	33
5.2 Contingency methodology	35
5.3 Descriptive statistics	36
5.3.1 Characteristics of sample	36

5.3.2 Family profile	36
5.3.3 Marital status of respondents	37
5.3.4 Area of residence	38
5.3.5 Diagnosis	38
5.4 Types and level of disability	39
5.4.1 School	40
5.4.2 Effects on employment	40
5.5 Objective 1	42
5.5.1 Aspects of key working	42
5.5.2 Satisfaction with key worker service	43
5.5.3 Correlations –satisfaction – aspects of support	44
5.5.4 Correlation –length of service – satisfaction	45
5.5.5 Satisfaction levels and child's difficulties	45
5.6 Objective 2	46
5.6.1 Families contact with key workers	46
5.6.2 Telephone contact with families	47
5.6.3 Type of contact with the key worker	48
5.6.4 Open ended questions	48
5.6.5 Aspects valued most	49
5.7 Objective 3	50
5.7.1 Consistency and reliability	50
5.7.2 A sportive open relationship	51
5.7.3 Access and referral to other services	51
5.7.4 Information gathering	52
5.8 Constraints identified	53
5.8.1 Lack of therapy staff	54
5.8.2 Therapy staff too busy for role of key worker	54
5.8.3 Staff turnover	54
5.8.4 Communication	55
5.8.5 Part time workers	55
5.8.6 Clarity of the role	55
5.8.7 Key workers for children over 6 years	56
5.8.8 Family centred approach	56
5.8.9 Key worker independence	56

5.9 Objective 4	57
5.9.1 Child's difficulties – having /not having a key worker	57
5.9.2 Areas of support needed	57
5.9.3 Comments from respondents	58
5.9.4 Summary	59
Chapter 6 Discussion	60
6.1 Main findings	61
6.2 Response rate	61
6.3. Characteristics of respondents	61
6.3.1 Area of residence	62
6.3.2 Diagnosis of the children	62
6.3.2 Influence on employment	63
6.4 Key worker provision	64
6.4.1 Aspects of key worker provided	64
6.5 Satisfaction levels	65
6.6 Features which improve service coordination	66
6.7 Factors which inform good practice	66
6.7.1 Consistency and reliability	67
6.7.2 Proactive contact	68
6.7.3 Supportive open relationship	68
6.7.4 Access and referral to other service	69
6.7.5 Information gathering	69
6.8 Constraints	70
6.8.1 Resources	70
6.8.2 Time for role	71
6.8.2 Communication	72
6.9 Comparisons	73
6.10 Comments from respondents who did not have a key worker	72
6.11 Strengths and limitations	73

Chapter 7 Conclusions	75
7.1 Summary of main findings	75
7.2 Implications for the organisation	76
7.3 Implications for future research	77
7.4 Dissemination of the results	77
References	78
Appendices	81
Appendix 1	81
Appendix 2	88
Appendix 3	93
Appendix 4	96

Abstract

Research has shown that parents of disabled children face a constant battle to negotiate access to services across different agencies. In order to overcome their difficulties key workers have provided a single point of contact service in the form of a named person. The key worker helps the family navigate through the maze of agencies from therapy services to counselling, family support to respite services.

This study aims to explore parents' perceptions of key workers in Clare Early Intervention Service (CEIS), in order to inform decisions taken on the development of a key worker service for school age children and young people aged 6 to 18 years.

A review of the literature was conducted and issues identified for exploration. A primarily quantitative postal questionnaire was sent to 100 parents of children with a disability on the CEIS data base who were identified as having a key worker. A second shorter version of the questionnaire was sent to 60 other parents of children who were identified as not having a key worker from the data base. A 65% response rate was achieved.

The results in general support previous studies. The level of provision of key workers was higher than that of other studies (72%). Levels of satisfaction with the key worker service were high (88.4%) and the role was valued greatly by the parents for whom key working was going well. However, the open ended qualitative questions revealed issues of importance to parents such as isolation, confusion and at times lack of consistency in relation to the role of a key worker. The study concluded that key working is a worthwhile service to provide to parents of children with a disability. However, if key working is to be successful it should be a clearly defined role not just an 'add on' role to the other professional job. The key worker role needs to be incorporated into the job description, with time allocated for the role and with agreed protocols/standards. A service manager is required to ensure best practice is achieved and sustained, and to provide training for the role.

Chapter 1

Exploring key working: Parents' perspectives of the key worker system in Clare Early Intervention Service (CEIS)

1.1 Introduction

Research on the needs of families of disabled children in Britain and talking to families of children with disability in Ireland finds that families report a consistent set of difficulties. They describe a “constant battle” to find out what services are available and about the roles of different agencies and different professionals; to get professionals to understand their situation and their needs; to obtain recognition of their own knowledge of the child; to tackle delays and bureaucracy.¹

The main reason for the problems the families face appears to be because of the multiplicity of agencies and professionals involved. There is often a lack of communication between agencies, and families have to make several contacts before they receive the information they need. One of the consistent recommendations from the research is that families need a named person or key worker.²

The value of key workers in providing a named person support for disabled children has long been seen as worthwhile.² The named person is the person the family can approach for practical help with any problem related to the disabled child. Until now, research has shown that less than a third of families with severely disabled children have a key worker, or named person. However comparative studies have shown that families who have a key worker, show evidence of in terms of relationships with and access to services and overall quality of life.² In the UK different models of key working services and models of practice have proliferated. However, in Ireland and in Clare Early Intervention

Service in particular, key worker services are limited to non-designated key workers i.e. professionals who work with a few families in addition to their normal professional role. Even when families do have someone they see as a key worker it tends to be on an ad hoc basis, undertaken at the initiative of an individual professional. As a result, if the professional leaves the service the role does not continue. Times of great stress for families and children for example transition from pre -school to primary school, primary school to secondary school, transition to adult services are identified as times when key workers are invaluable. Also families have to work with many agencies as part of inter agency working and partnerships within the Health Service. However, they are rarely supported by a key worker service.

1.2 Background

1.2.1 Clare Early Intervention Service (CEIS)

A Regional Child Development Centre (RCDC) was established in the Mid West in 2003. The service was spearheaded by a manager who had experience of such a service in New Zealand. Transdisciplinary working, which is regarded as a strong community based model of service delivery was developed which offers assessment, intervention and support for families of children with developmental needs in an integrated and coordinated way. Included in the model is the key worker role. The key worker approach is dependent on the family's needs and therefore, the key worker is required to work across a continuum of care and remain flexible to the ever changing needs of families. Because key working is about communication, every member of the clinical team is expected to carry out the functions of a key worker, regardless of their professional background or agency affiliation.

The RCDC was to be the single point of referral for children with two or more areas of need. The plan was to establish family focused and coordinated services in the region – Clare, Limerick and Tipperary. Initially six teams based

on population statistics were established, four teams in Limerick, one team in Tipperary and one team in Clare for children up to 6 years of age. The teams involve partnership working, including the Health Service Executive (HSE) with Voluntary agencies, Enable Ireland and the Brothers of Charity. A link worker service was also established as part of the service to enable parents of newly born disabled children find their way around the maze of services and professionals. The link worker meets the parents of a newborn baby with a disability while they are in the hospital and provides the support between the hospital and the community. She would typically refer the child to the RCDC for assessment and possibly provide onward referral to other agencies. When the child is embedded in the services, the link worker withdraws and closes the case. It is left up to the family to re-open the case. The RCDC then refers the child out to the local early intervention service for example, CEIS, where a key worker is identified. The second part of the plan was to establish a School Age Team (this is still in process). Both teams are managed by the Clare Children's Service Manager.

The early intervention services in the Health Services Executive (HSE) and in particular Clare Early Intervention Service strives to realise the essential ethos of the United Nations (UN) Convention on the rights of the Child and the principles of the National Children's strategy which states that services should be;

- Child centred;
- Family orientated;
- Equitable;
- Inclusive;
- Action orientated;
- Integrated;

The 'whole-child' perspective aim is at the centre of policy development and service delivery.³ The central principle underpinning the whole child perspective is that the service is family orientated.

1.2.2 Family Centred practice

Family centred practice involves working with families as partners and active participants in the early childhood intervention programme.⁴ It is a method of service delivery for the whole family where there is a partnership between parents and professionals. The focus is 'on the family's role in the decision making about their child and recognises parents as experts on their child's status and needs.'⁵ CEIS recognises that parents have firsthand knowledge of their child and their own strengths and needs. The most important component in the intervention process is the family because it is within this unit the child spends most of their time. The above perspectives are further underpinned by the guiding principles of the National Health Strategy 2001 which states that every child with a disability would have access to a key worker. The key worker is the vital link in responding to family priorities, empowering family members, employing a holistic approach to the family and demonstrates insight and sensitivity to families.^{4 6}

1.2.3 Transdisciplinary working.

The transdisciplinary team approach is an approach used by an early intervention team whereby the child is viewed and understood only within the context of the family, that is that the child's development – physical, cognitive and social domains are interdependent and complex.⁷

Transdisciplinary team working has been described as a "deliberate pooling and exchange of information, knowledge and skills and the crossing and re-crossing of traditional disciplinary boundaries by various team members."⁸ (p274) The key worker is an essential part of transdisciplinary team working.

Team members make a commitment to teach, learn and work together across disciplinary boundaries to implement coordinated services by what is described as role release. Flexibility is an important aspect of transdisciplinary working as team members accept responsibility within their own discipline and also take on responsibility not usually associated with their role. In transdisciplinary working roles are not fixed. The most important aspect of transdisciplinary working is

that it is a flexible approach that can be adapted for individual families and that the family is considered part of the team.⁴

1.2.4 The key worker

A key worker is a named person who is available as a contact /link for a family of a child with a disability to the services. The key worker provides information on resources and entitlements and links the family to community services such as respite, family support, education and early intervention therapy.

A designated key worker is one whose full time primary role is key working. A non designated key worker is one who provides a key working role in addition to their primary professional role. The key worker can be any professional already working with the family and plays a lead role for the family in guiding them, through the maze of professionals and services.

A number of different terms are used to describe the role, for example key worker, care coordinator, link worker and family support worker. For the purpose of this study key worker is the term used.

1.3 The Research

The author is employed as a Public Health Nurse in the area of disability, co-ordinating and facilitating children and their families with regard to the disability services and to their entitlements and case managing complex cases. This includes being a member of various teams including the Clare School Age Team (6 to 18 years). Currently there is a debate as to whether or not a key worker system should be developed for the team. The key worker system is used by the Clare Early Intervention team (CEIS) for children 0 to 6 years, but little research has been carried out in Ireland to date as to the effectiveness of the system. The aim of this research is to explore the key worker service as used by the Clare Early Intervention Service in Ennis, Co. Clare from parent's perspectives in order to inform decisions taken on the development of a key worker service for school age children and young people (6 to 18 years).

1.4 Why parents perspectives

‘Together from the start’ in Britain, reminds us that ‘Parents have a unique knowledge of their child’ and that families have important information to contribute and a key role to play in determining how effectively the services provided have met their and their children’s needs.⁹ Generally in the UK there has been a move towards engaging ‘parents as partners’ as well as active players in the development and education of their child. Parents can now access the web and are better informed and able to be more critical and aspirational with regard to the type of support needed for their child. Listening to parents views is a very important aspect in the development of the services.

There is evidence in the literature that considers parents as experts in disability research.^{4 5 10} Studies have shown that parents want to work in conjunction with services to get the best outcomes for their child. They wish to be part of the decision making process and be part of the management and governance structure of services.¹¹

Carpenter holds the view we have to let go as professionals if we are to truly empower parents.¹⁰

Hence the focus of this study is to explore the parent’s perspectives on key working in Clare Early Intervention Service to enable decisions to be made about key working for older children and young people aged 6 to 18 years.

Chapter 2

Literature search strategy

2.1

The literature searches were carried out to identify and retrieve materials pertaining to key workers and parents perceptions of key workers in the context of early intervention for children with disability less than 6 years of age.

A search was conducted, including electronic bibliographic databases from Nursing, (CINAL), Medical, (Medline) psychological, sociological and disability. The papers were sourced mainly from the UK with some from Australia, USA, Canada and Ireland.

Terminology key words used were: Key worker; key working, children, disability, early intervention, link worker, care coordinator, case worker and transdisciplinary working in early intervention, using Boolean terms as necessary in order to improve the relevance of articles.

A general search was conducted using the search engine Google Scholar with the same search terms.

2.2 Search results

The search terms generated 92 papers and 47 were relevant to this study.

The majority of articles were freely available electronically in abstract form or were accessed in full form from specific journals or university departments on request.

A number of papers and publications were identified opportunistically in the reference lists of other articles and through specialist web sites in the UK for example, Interconnections. Books were identified from specialist websites were

purchased over the internet and provided very useful information in the relevant chapters contained therein.

Publications accessed via organisations were received electronically and in paper form and stored accordingly.

The relevant Government and statutory documents were obtained both from Ireland and the UK.

Finally contact with CCN UK proved to be a valuable source of information combined with useful links for references.

The literature search took place between September 2007 and March 2008.

2.3 Inclusion criteria

Assembled articles were read for relevance to the study's aims and objectives. These were retained if they were judged to be relevant to the issues addressed by the research. They were arranged numerically under various headings for example, the role of key worker, key working in policy and legislation, parent perceptions of key working, key working as family centred practice, key working in transdisciplinary practice in disability concerning children and key working in early intervention.

Relevant materials identified by searches of other sources were judged to be reliable if they were included in government documents or recognised university sites and were linked or referred to by such sites.

.

Chapter 3

Literature Review

3.1 Introduction

The concept of key working is implemented and used by different health or related services, for example in services for people with mental health difficulties and in child protection services. In this study key working is explored as pertaining to early intervention services

The purpose of this chapter is to give an overview of the literature surrounding key working in early intervention and to review national and international literature about key working in the context of

- The role of the key worker.
- The key worker in legislation and policy.
- Evidence of the effectiveness of key working.
- Parental views of key worker services.

The chapter examines relevant literature and other documentary sources in order to provide a context for the research findings.

3.2 The role of the key worker

Key workers and key working has been mentioned in the literature more frequently in recent years. However, the role of the key worker referred to is not always the same. In fact there are various definitions depending on who is describing the role. A number of studies have commonalities in relation describing the role.^{4 12-14} The most comprehensive research into key working was conducted by Greco, Sloper et al of the Social Policy Department at the University of York. In their study 'An exploration of different models of multi agency partnerships in key worker services for disabled children effectiveness and costs,' they used a five part mixed methods approach to the evaluation of models of key worker services.¹⁵ Their research describes the role of key worker as

- providing information and advice about services
- providing emotional support
- identifying and addressing needs of all family members
- coordinating care
- improving access to services
- speaking on behalf of the family when dealing with services
- support in a crisis

Other studies report that it is the role of the key worker to plan meetings, write the report and family service plan and set dates for review.²⁰

The McKenzie Centre in New Zealand defines Key workers by the tasks and responsibilities. Their approach is flexible to meet changing needs, it facilitates family learning opportunities, and it creates empowerment not dependency.²¹

3.2.1 Designated key working

The Team around the Child (TAC) is an approach to early intervention which is in keeping with Every Child Matters (UK 2000). The key worker in this model is a designated person who is central to what they call “joined up” support within a multi agency service for children with disability.¹⁶ Limbrick who is the main proponent of TAC describes key workers being supported to develop a helping relationship, to offer emotional support, to be available when needed, but also be confident in saying “I don’t know, but’, and seeking further help for family such as counselling, advocacy and family therapy if it is required.¹⁷

In Ireland the literature on the role of the key worker appears to be relatively new and scarce. The most comprehensive description of a key worker is in a report (Synergy) by Cederman which was a study commissioned by the Centre for Early Development and Education.⁷ Synergy is a 9 month qualitative and quantitative exploration of quality early intervention for children with special needs in diverse settings in North Tipperary. Cederman describes the role of the key worker as the primary contact providing ongoing information from the team so that the family can focus on one primary professional relationship. In her study, which espouses the transdisciplinary model, the key worker also consults with the child’s teachers, mediates interest-based activities and routines for the

child, integrates learning targets for the child across the domains, and trains others to embed therapy into the child's daily routines. Key workers help plan what comes next for the child in terms of their provision, education and care. Where needed, they provide information on resources linking families and community services. This is an all encompassing description which would appear idealistic in practical terms, but possibly one that can be aspired to in the Irish setting. It is not clear if Cederman is referring to designated or non designated key workers in her study.

3.3 Legislation and policy

The culture of key working has been identified in much of the policy pertaining to children with disability in the last few years in Britain.^{18 19 20 21}

The Every Child Matters campaign has transformed the way the Government looks at children and families. The aim is to promote seamless, joined up services for children. The Every Child Matters agenda is a good example of a philosophy of progressive thinking – help for all and extra help for those who need it most.¹⁸ The guidance “Together from the start” 2003 recommends all children with complex needs have a key worker.⁹

The Labour government introduced an office for disability issues which advocates for the needs of disabled people. In his speech at the Rachel Squire Memorial lecture, Ed Balls, M.P in 2005, acknowledged the need for more services and support, including short break provisions, key workers and therapists, so that more families can be supported and more children helped to achieve best outcomes. He recommended early contact with such ‘key worker’ professions to help parents feel less isolated and to be in control of their lives. He recommends that every family should have the early practical and emotional support they need, connected to a full range of services through a key worker or a team, focussed on seamless support designed around the child.²²

The British Government has continued to lead in the area of disabled children's issues giving them priority both nationally and locally, a commitment confirmed in the NHS Framework.²³ In May 2007 it launched ‘Aiming High for Disabled

Children' (AHDC)' supported by substantial new funding and measures designed to make the system work better. Mr. Ed Balls now Secretary of State for Children recently announced "Together for Disabled Children" as the national support body for the AHDC programme.^{18 22}

Other countries such as Australia and Canada have followed the example of Britain with regard to the key worker modal of service in their policy documents.²⁴

²⁵ In Australia, the Early Childhood Invest to Grow Program was developed in response to findings from extensive consultations around Australia as part of the development of the National Agenda for Early Childhood. Invest to Grow is only one component of the Australian Government commitment to early childhood intervention for children with disabilities as part of the Stronger Families and Communities Strategy.²⁶

In Ireland the concept of key working is a relatively recent addition to policy and legislative documents. The National Health Strategy 2001 identifies the lack of integration of care between and within some services as a problem in existing health service provision, with some clients having to access the system several times to have all their needs addressed. The Strategy proposes that a holistic approach is taken to planning and delivering care, which should include the appointment of key workers in the context of care planning, in particular for children with disabilities.²⁷ This has been strengthened by the provisions of the Disability Act 2005 and the EPSEN Act 2004, Citizens Information Act, 2006, and the Equal status Act 2000.^{28 29 30 31} Under the Disability Act the child gets comprehensive assessment of need which will provide the family with an assessment report which will inform the service for the child. Where the services of an Early Intervention Team are to be provided, the statement will reference the Individual Development Plan, the drawing up of which will be the responsibility of the key worker in association with the parents.²⁸

A National Health Service Executive (HSE) discussion document 'Proposal for the development of a national framework for service delivery for children 0 to 5 years with complex developmental needs' strengthens the case for key workers in early intervention in Ireland.²⁰ It states that the HSE aims to provide 'dynamic, progressive and high quality services for children and families which will be child

and family centred, easily accessed, seamless, quality driven and delivered in an equitable manner.’(p6) The document acknowledges that children with complex needs be supported by a dedicated child development service i.e. an early intervention team. According to the document each child will be assigned a key worker within the team whose additional responsibilities will include providing a named link for the child and family to enable consistent communication, support and monitoring of the Individual Development Plan (IDP).

On a more local level, the HSE West in its service specification document commits to as vision of key worker who by performing a coordination, access and supportive role, strives to enable children and their families negotiate their way through the complex landscape of the multi-disciplinary services in order to achieve a holistic, seamless experience of service delivery for service users.³²

3.4 Effectiveness of key working

The research by Greco et al at the Social Policy research unit of York University was a UK - wide survey of Care coordination schemes which identified that not all care coordination schemes have a key worker system. Only 30 services were providing key workers for disabled children.¹⁵ Greco’s research shows that key workers provide a valuable service and had positive impacts for families. Key workers coordinated services between agencies and schools which facilitated access to appropriate support for disabled children and their families. However, outcomes varied between areas. Factors identified were definition of the key worker role, supervision and training for the role and management of the service. For both the designated and non designated key worker the core components of the role must be clear and well understood.¹¹ Their research identified that matching the job description and the person specification to be vital and more important than the nature of the primary professional role.

3.4.1 Transdisciplinary team working

An Australian team in Kurrajong found in their service that key working within a Transdisciplinary model of working was more effective due to the role release

kind of support. The team there adapted transdisciplinary best practice and 'team around the child' approaches to suit the needs of families.⁴ In their services the key worker is seen as essential in the provision of coordinated, integrated services for families, but also recognises the need for flexibility in the application of the model so that it is responsive to the needs of families and children.

The Transdisciplinary model is especially effective in the context of providing reassurance and empathetic support if need quickly in the short term.³³ It requires building of trust and respect between team members and being able to let go of their specific role when appropriate.³⁴ However, it is admitted that role release is a challenging and controversial sharing of expertise for therapy staff used to more traditional approaches.³⁴

Transdisciplinary working is seen as a cost effective way of delivery of services. Team members become multi skilled and are able to role release enabling less disciplines and staff to be involved with a family at the one time. Transdisciplinary working is a very useful method of working particularly when there is a shortage of therapists.³⁴

3.4.2 Multi agency working

Multi agency working is of paramount importance in order to provide coordinated services to children with disabilities and their families. Cooperation has to take place between with statutory agencies: Departments of Health, Social Services and Education and also involving housing authorities, respite providers and counselling services^{14 35 36} The multi agency working model must be well developed in order for this to happen.

One of the problems with the key worker role working in a multi agency partnership is that the key worker role has no real status.² There can be a lack of trust between agencies especially if there are not clear, well thought out guidelines for planning and implementing plans.

Lack of partnership working is also borne out in Townsley's research which looked in detail at 6 services, four of which provided key worker services. She identified the importance of inter agency work and in particular the Education

Department was mentioned as the agency with whom it was most difficult to work.¹⁴ However, Greco et al showed that there were many examples of good working relationships between key workers and schools.¹⁵ The key workers in Greco's study fulfilled an extremely important role as information brokers, including information for parents about school procedures and Individual Education Plans (IEP). They helped schools understand factors affecting children's behaviours, by explaining the nature and implications of particular conditions and suggesting coping strategies. The key worker mediated between schools and families to tackle problems and to diffuse potential confrontations.¹⁵

Earlier studies by Greco et al found that key workers need to have protected time as key working was acknowledged as very involving and a time consuming task.² They recommend that a 'non designated key worker should work with 3 families and a designated key worker on about 30 families.² Greco's study recommended supervision and training are as vital for the success of the service. Having a clear and understood job description, development of team spirit and the promotion of good communication and information is the key to success according to the study.

A study by Barton found that team working is extremely important and change management strategies, training and funding all have an impact on multi agency key working.¹¹

3.5 Parents views of key workers

Research shows that parents want to work in partnership with services to achieve the best for their child. Parents also want to have their expertise as parents and carers of their child recognised and valued and to be involved in decision making.^{12 35} One study established that families want to be part of the decision making process as well as being part of the management and governance of service.¹¹

Choosing a key worker was found to be important in Greco's study. In their non designated services parents/families choose the key worker from the professionals they work with. Families were introduced to professionals who later became their key worker. Families were generally happy with the key

worker as they already had a good relationship with the key worker. Conversely, the key worker knew the family. However, families choices can be limited because only few professionals can take on another family to their caseload.¹²

Key workers are usually assigned a family in designated services. Designated key workers are usually satisfactory for families as they have more specialised training and have more time to carry out the role.¹⁵

3.5.1 Access to services

A study conducted at the Norah Fry Research Centre of Bristol asked families in their research if they found it easier or more difficult to get access to services if they had a key worker.¹⁴ Townsley's research was a three part project – an exploratory phase, personal visits to services and case study visits which included interviewing families and disabled children. There was a small body of evidence to suggest that access was better as a result of having a key worker though it was not statistically significant it was in the two sites that were identified as having a key worker system. Families in the two areas also felt that when access wasn't given to services it wasn't the fault of the key worker but that enough funding wasn't provided to deliver that service.

3.5.2 Service coordination

With regard to service coordination in Townsley's study the research found there was a lack of clarity around the role of the key worker in relation to service coordination.¹⁴ From twenty five families interviewed in relation to this only six felt that the key worker did actually coordinate services and two said the effectiveness was variable. Problems highlighted were issues such as waiting lists and funding.

For the families who did have a key worker there were issues such as staff turnover – the key worker not replaced if she left the service. Some families in their study felt let down by key workers and that the key worker was ineffective. However, many families appreciated the time and effort that went in to coordinating services and were pleased that some of the burden was lifted from them.

Families felt empowered, had increased coordination of service delivery, and were more aware of their entitlements in Barton's research.¹¹

Help with meetings was an aspect that families found helpful and guiding the families to how the service worked.¹⁴ Greco's study concurs with this view. Parents felt supported when the key worker was available to plan, organise and spoke on behalf of the family if necessary. It was especially helpful when the parents were asked if they had any issues for the agenda and if they wanted to have particular professionals involved in the meeting.¹⁵

3.5.3 Frequency and regularity of contact

Regular contact with families was seen as very important in many studies.^{2 8 11 14} Most families in Greco's study said that key working had reduced their stress considerably, due to having access to respite care, spending less time looking for information, writing letters and telephoning, especially if the key worker was proactive and not waiting for the family to get in contact.² In a follow up study by Greco, being proactive was one of two main themes arising in the problems expressed by parents.¹⁵

The single point of contact was appreciated by several families in Townsley's study as they had a named person to contact if they had a query. However, there was no consistency about frequency of contact and the question was raised by the researcher about whether the key workers were in proactive, regular contact.¹⁴

A study conducted in Ireland in relation to services for children with learning disabilities notes that 'Ireland tends to be characterised traditionally, by strong societal and particularly religious norms, which may lead to a misplaced stoicism and lower levels of parental help seeking.'³⁷(p227)

3.5.4 Family centred practice

A consistent theme in all of the research literature into key working is that of family centred practice.^{4 10 11 14 15} Greco claims that a family focus is highly prized by parents and the whole family approach is much appreciated.¹⁴

However, not all key workers in Greco's study viewed the family holistically, i.e. enquired about the rest of the family. This tended to be in situations where the key workers were not coordinating care appropriately on the whole and parents were dissatisfied with the service.¹⁵

Having a flexible approach is recommended by Davies as family's needs change over time.⁴

Edwards emphasises that key workers work for the family and not the agency and should work with the family strengths and ways of coping.⁵¹ This point is reiterated in a study by Mukherjee who emphasises further that key working is for families and not just for the disabled children.³⁵

3.5.5 Relationship with the services

Barton in her evaluative study of key workers in Warwickshire reiterates the reduction of stress and lessening of the number of times families had to explain themselves particularly if the parents had the same key worker for a significant amount of time.¹¹

Research carried out by Liabo and others has shown that families with a key worker have better relationships with the services, better morale, fewer unmet needs and higher parent satisfaction partnership working than families who do not have a key worker.^{13 54} However, Liabo warns that the focus in the literature is on parental needs and that we cannot assume that the needs of the children will in all cases be similar to these.

Harrison rightly states that there is ample research evidence that a family who have a child with developmental delay or disability may be at increased risk of intra-familial conflict, depression and increased levels of stress.^{33 10 38} He observes that a family of a child may be coping fine with protective factors at their disposal such as secure housing, adequate income, high quality social supports and actively involved family members within a predictable stable lifestyle. He astutely observes that services must seek to support families not because they are dysfunctional but because they are the child's most meaningful asset. However, he cautions that a child with a disability within a family with

other risk factors such as economic, social or psychological issue, may have a devastating effect on a on the family.

Mukherjee reports in her analytical and evaluative study, that the well being of children is inextricably linked to parental well-being. She says that this is point is not always recognised in organisational structures of statutory agencies that support families with disabled children Therefore, she argues that directing resources via a key worker is a legitimate way of helping to achieve better relationships with services which in turn leads to positive outcomes for the child.³⁵

3.6 Conclusion

The vast majority of the literature in relation to key working emanates from the U.K to the extent that most studies from other countries refer back to that body of literature. The literature on key working in early intervention services is limited in Ireland. It is hoped that this study will begin the process of addressing that deficit and will add to the general body of study on key working with specific reference to consideration of parents' perceptions of key working in early intervention services in Ireland. It is hoped that the report will inform the development of key worker services for children and young people 6 to 18 years of age in the Clare Children's Services in particular.

Chapter 4

Methodology

4.1 Introduction

The focus of this study is to elicit parents' views of key workers in Clare Early Intervention Services (CEIS) on issues of importance to the parents.

This chapter initially outlines the aims and objectives of the study including the methodology/design of the study. The next section addresses the ethical considerations followed by location, population, sampling and data issues. A description of the two questionnaires is provided. The pilot study is then discussed. Finally, survey conduct and confidentiality is addressed with regard to response rates, data preparation and data analysis.

4.2 Aim of the study.

The aim of the study is to assess parents' views of the Clare Early Intervention Key Worker Service in order to inform the development of a key worker service for the school age team.

4.2.1 Objectives

- To assess parents' views of the CEIS key worker service in terms of a variety of outcomes of importance to parents and children.
- To identify features of key working which contribute to improved service coordination for disabled children and their families.
- To highlight factors which can inform good practice in the development and delivery of key worker services for disabled children and their families.
- To compare the responses of parents who do not have a key worker service to those who do.

4.3 Design of the study

The study design was quantitative research in the form of a postal questionnaire which was administered to all parents of children on the CEIS database. Choice of design is influenced by the research questions and the aims and objectives of the study. Information gathered from questionnaires is similar to that of an interview but the questions tend to have less depth. However, postal questionnaires tend to be more anonymous than direct interviews and less threatening especially where a 'delicate' issue is being explored, for example aspects of service provision.⁴³ A questionnaire was chosen for a number of reasons. Firstly it was considered an appropriate method of obtaining parents views of key working as they experience key working at firsthand.³⁹ Secondly a wide range of data could be obtained from a relatively large representative sample that was geographically distant from the researcher. As the questions are consistent for each respondent there is less likelihood of bias. Moreover mail questionnaires are considered as a relatively economic and expedient method of collecting data from large groups.⁴⁰ These advantageous aspects proved invaluable, given that the researcher is in fulltime employment.

Despite the many advantages it is important to acknowledge a number of drawbacks associated with questionnaires particularly postal questionnaires – poor response rates; inability to confirm accuracy of responses; and difficulty of making valid generalizations if the response rate is low.⁴⁰

In this study a questionnaire survey was conducted to produce quantitative data relating to issues in the literature review. The questionnaire was adapted from one developed and used by the Social Policy Department of York University¹⁵, modified to ensure that the language used is culturally suitable to an Irish setting. Modification of the questionnaire was developed with the guidance of a supervisor from the Department of General Practice, National University Galway. The questionnaire collected data on demographic variables and on factors and outcomes relating to aims and delivery of the key worker service.

4.4 Ethical considerations

4.4.1 General

- Participants were informed of the study's aims, methods and assured of confidentiality.
- Participants were free to not take part in the survey.
- No questionnaire data were supplied to Clare Early Intervention Service.
- The identity of those to whom the questionnaire was sent was not disclosed by HSE staff to the researcher.

4.4.2 Assessment of ethical risks.

- Where issues were raised relating to key workers these were in general terms
- Where an issue was raised which had not hitherto been considered and which was considered to be of concern by a participant, it was conceivable that this may have caused of anxiety.
- There were no physical risks to the participants.
- The questionnaire focused more on what is working well or not working well in relation to key working and therefore did not cause anxiety or change the way they perceived the service they have.

Ethical approval was sought and approved by the Irish College of General Practitioners (ICGP) in November 2007.

4.4.3 Data management

- Responsibility for management of research data rested with the researcher.
- Data from recipients were anonymous.
- Workstations which had access to confidential data were not left unattended and computers turned off when not in use. Data could only be accessed by a password known only to the researcher.
- Data were not stored on laptops or memory sticks unless absolutely necessary due to risk of theft or loss. The data if stored in this way were

transferred to a secure computer as soon as possible and deleted from the mobile unit.

- The number of duplicate files was kept to a minimum.
- Access rights were clearly defined and controlled. (In this study only the manager had access to identifiable data.)
- Computers used to store data were password protected which were not written down or shared with unauthorised users.

4.4.4 Help and support available to participants in this study.

- The researcher's contact details were made available to all participants should they wish to discuss any concerns they may had.
- Literature was provided about key workers in the information leaflet included in the questionnaire package.

The Department of General Practice provided an ongoing supportive environment, with research, statistical facilities and resources.

4.5 Location of the project

The research is situated in Clare, a coastal county located in the Mid-West region of Ireland. It is a predominately rural county with a capital town of Ennis and an industrial computer belt town in Shannon which has an International Airport. Ennis is one of the fastest growing towns in Ireland with a population of 20,234 in the immediate town area. However, including the rural surrounding suburbs of Ennis there is a total population of 38,000 people, while the population for the whole county is in the region of 110,970.⁴¹

4.6 Research Phase

The research took place between October 2007 and June 2008. The parent questionnaire was developed and ethical approval sought and achieved in Nov/Dec 2007. The questionnaire was first administered to parents in early January 2008. A follow up reminder letter was posted two weeks later. The questionnaire

was re administered to all parents on the database at CEIS in mid February except to the parents who signed their name to be interviewed at the later date.

4.7 Study population

The study population are the parents of children who have at least two areas of developmental delay who are currently on the CEIS data base. These children range in age from birth to six years. This group was chosen as they were easily identified group of children who had been referred to CEIS via the Regional Child Development Centre which is the recognised single point of entry for children with a disability.

4.8 Sampling and recruitment

The sample was identified by the manager of the Clare Children's service who is data controller of the service's records. The service has a specific database for CEIS. All parents of children who had a disability who were on the database were sent a questionnaire.

4.8.1 Sample size

At the time of the research, the Clare Early Intervention Service had 160 children on their database.⁴² It was originally proposed to send the questionnaire to 100 parents of the children who had a key worker. It was later decided to send a shorter version of the original questionnaire to parents of children who did not have a key worker. This was to enable comment on the success of the key worker service against the identified needs of those who did not have a key worker.

4.9 Data

The questionnaire was employed to produce quantitative data relating to issues in the literature review. The topics included data related to;

- Demographics of the parents.

- The extent of the child's disability.
- Difficulties experienced by the child.
- Parents needs in relation to caring for the child.
- Parent's perceptions of the key worker service they receive.
- Parents relationships with key worker staff.

Parent Questionnaire for parents who had a Key Worker

Both questionnaires were modified and adapted from the questionnaire developed and used by Greco.¹⁵

4.9.1 Socio demographic questions

Participants were asked questions regarding identity of the respondent, age of the child, marital status, urban or rural location, employment a number of other children, ages of other children, diagnosis, child's schooling, child's individual education plan and effects of having a disabled child on employment.

4.9.2 Questions about contacts with the key worker

Participants were how often they saw the key worker in the last 3 months, how long these visits last, would they like to see the key worker more often, how often they have spoken to the key worker on the telephone in the last 3 months, how long these contacts last and if they would like to talk more often, about the same or less often. They were also asked if the key worker was proactive in making contact or whether it was left up to the parent to make contact.

4.9.3 Types of disability

A nine item list was used, measuring the type and level of difficulty experienced by the child. These items were – communication, behaviour, learning, mobility, health, vision, hearing, continence and social skills. Respondents were asked to rate whether the child had difficulties in each of the areas, either 'Not at all', 'Moderately so', or 'Very much so'

4.9.4 Satisfaction with the key worker service

Respondents were asked how satisfied they were with the key worker service, 'Overall how satisfied are you with the key worker service you receive?' – 'Very satisfied, Satisfied, Not satisfied, Not at all satisfied'.

4.9.5 Aspects of key working

An 11 item scale was used to measure how much the key worker performed various aspects of the key worker role. Examples are, emotional support, information about the child's condition, information about services, advice, identifying needs of other family members, advocacy, crises support. Participants rated the items 'Not at all, some, and Very much'.

4.9.6 Open ended questions

Four open ended questions were asked:

1. Which is the aspect of your key worker service you value **MOST**?
2. Which is the aspect of your key worker service you value **LEAST**?
3. Do you have any specific comments on the key worker's role in relation to the different services your family receives from: Education, social services, and Health.
4. Any other comments.

4.9.7 Questionnaire for parents with no key worker

A shorter modified version of the original questionnaire was used for the parents of children on the database who had no key worker. (See appendix 2) The questionnaire otherwise is similar to the original questionnaire until the section C; Question 15 respondents were asked to choose in order of preference from a list of 11 areas of support from 1 to 4. The areas of support were; Emotional support, information about the child's condition, information about services, advice, identifying needs of other family members, advocacy, crises support.

4.9.8 Open ended questions

Two open ended questions were asked:

- 1 Do you have any specific comments on the key worker's role in relation to the different services your family receives from: education, social services and health.
- 2 Any other comments.

4.10 Pilot study

Pilot testing is considered necessary to refine questionnaires so that they are easily understood and completed by the respondents. It also enables the researcher to obtain some assessment of the questions' validity and the likely reliability of the data that will be collected.⁴³

Because of the limited numbers of families available to participate in the research the questionnaire was initially piloted with 10 families who had a key worker and 10 families who did not have a key worker (20 families in total) (12.5%) to ensure quality of design. Data were collected during the pilot phase on respondent's views of the questionnaire. While the response rate to the pilot was poor, 30% (n= 6), no major changes were required to the questionnaires as they were judged to be clear and easily completed. It was considered that the time of arrival of the questionnaire (before the Christmas break) may have been a factor in the low response rate. However, a question was added asking the respondents if they would be willing to be interviewed in person at a later date in relation to their views of key working in CEIS. A consent form to facilitate this was added to the end of the questionnaire. This was a strategy designed to afford the researcher an opportunity of conducting interviews where needed to further clarify issues raised by the questionnaire responses. Qualitative interviews could be undertaken if the response rate to the questionnaire was not acceptable as the poor response rate in the pilot was worrying.

These parents' data were included in the final database.

4.10.1 Survey conduct and confidentiality

Following the pilot phase, questionnaires were sent to the remaining parents on the CEIS database. Included with the questionnaire were a leaflet and a covering letter from the researcher. (See appendices 3 and 4)

The identity of the families was not disclosed to the researcher. The questionnaire and the accompanying documents were sent by the manager of the Clare Children's Services, who is also the manager of the 6 to 18 team. A pre-paid addressed envelope was provided to enable the responses to be returned to the researcher.

Questionnaires were returned anonymously unless respondents voluntarily completed the section agreeing to participation in further follow up qualitative interviews. (Interviews were only being conducted if it was necessary in order to clarify information emerging from the postal survey or if the response rate was less than 30%)

The information leaflet (See appendix 3) for participants contained information about the methods and aims of the research and assurances relating to the following issues:

- that participation is entirely voluntary
- that their decision to participate or not to participate will not affect their children's care
- that any information or views they give in the questionnaire will be in the strictest confidence
- that no information given in the questionnaire will be reported to the Clare Early Intervention service
- that their anonymity will remain unknown to the researcher (unless they complete the voluntary section relating to interviews)

Approximately two weeks later a reminder letter was sent out to all the parents. The plan was that if the response rate at that stage was poor that the questionnaire was to be sent to everyone except the parents who signed their name to be interviewed at a later date.

4.11 Response rates.

Strategies were adopted which were thought to help to maximise the response rate. The cover letter to recipients made clear that the results of the survey will be used to improve existing service and to develop the service for parents of older children. A pre paid white envelope for return of the questionnaire and each package included a pen to encourage response.⁴⁴ Assurances were given in the accompanying letter that parents' responses would not affect the services they receive and that no data will be reported to HSE services.

Packages were sent in early January 2008 to all the parents of children with a disability who were on the CEIS database at that time.

Each package contained,

- a cover letter,
- an information sheet,
- a key worker parent questionnaire,
- a prepaid return address envelope and
- a pen.

4.12 Data preparation

The questionnaires were assessed for variables which were inputted to the SPSS database for analysing. Fifty eight variables were identified. Numerical coding was used when inputting the data for statistical analysis to ensure confidentiality of the participants. Data will be stored for a period of two years following the completion of the research, when electronic files will be deleted and hard copy data will be shredded.

3.12.1 Data analysis

Data were analysed using SPSS15.00 for Windows.

Descriptive statistics were used to summarise the results from the questionnaires and to describe the characteristics of the respondents.

Spearman's RHO tests were used to examine differences between ordinal variables or between ordinal and scale variables.

Chi Square was used to look for differences in nominal variables between groups.

Mann Whitney was used to examine differences between groups of two variables.

The open ended questions, of which there were four in the first questionnaire and two in the second questionnaire, were transcribed manually and arranged in themes for analysis.

Chapter 5

Results

In sections 5.1 and 5.2 the response rate and contingency methodology is outlined.

Section 5.3 presents descriptive analysis on characteristics of the parents and children. Section 5.4 presents the types and levels of disability of the children of the respondents.

The remainder of the chapter will examine the results in terms of the objectives of the study, which were:

- To assess parents' views of the CEIS key worker service in terms of a variety of outcomes of importance to parents and children.
- To identify features of key working which contribute to improved service coordination for disabled children and their families.
- To highlight factors which can inform good practice in the development and delivery of key worker services for disabled children and their families.
- To compare the responses of parents who do not have a key worker service to those who do.

5.1 Response Rate.

The initial overall response was 32% (n= 53). A reminder letter was sent two weeks following the first mailing which increased the response rate to 42% (n= 67). As 42% is generally well below the reported representative acceptable level it was decided to re-send a full package to all the parents except those who had given their name to be interviewed at a later date. This method improved the response rate to 102 (63.7%). A final reminder letter brought the response rate up to 104 (65%). (Table 1)

Table 1 Response Rate.

Date sent out	Response number (%)
2008-01-02 Full package	53 (32%)
2008-01-16 Reminder letter	67 (42%)
2008-02-25 Full package	102 (63.7%)
2008-03-05 Final reminder letter	104 (65%)

Three responses were not included in the final analysis as they were not completed appropriately which reduced the available responses for analysis to 63%.

64% (n=64) responded to receipt of the first questionnaire (for families who had a key worker) of the 100 sent out. Five respondents to this questionnaire for those who had a key worker responded indicating that they did not actually have a key worker.

The second questionnaire was sent out to parents who did not have a key worker as indicated on the CEIS database. Of the 60 recipients 61.66% (n=37) responded. Again, there were some (n=14) who received the 2nd questionnaire for parents who do not have a key worker, who reported that they did have a key worker. (Table 1a)

1 st questionnaire to parents with key worker	100
2 nd questionnaire to parents with no key worker	60
Total questionnaires sent	160
Total responses received	104
Valid responses	101
Responses from 1 st questionnaire	64
Of these had no key worker	5
Responses from 2 nd questionnaire	37
Of these had a key worker	14

(Table 1a)

The original intention of having two questionnaires was to compare the responses of the recipients who had a key worker to those who did not. However, during examination of the responses it was found that there were only 23 valid non key worker responses for comparison key worker responses which limited the amount of analysis possible.

The non key worker questionnaire was a shorter, less detailed questionnaire, so therefore the data obtained from the other 14 respondents from that questionnaire was not as rich as would have been expected had they received the key worker questionnaire. Conversely, the data obtained from the 5 respondents who received the key worker questionnaire who did not have a key worker was not as rich as would have been expected if they had received the non key worker questionnaire. The reason for such discrepancies was because of inaccuracies on the database due to administrative staff shortage for database maintenance at the time of delivery of the questionnaire.

At the time the study was conducted 72.2 %(n=73) of parents involved with CEIS indicated that they had a key worker.

5.2 Contingency methodology

Following discussions with the supervisor and the head of the Department it was decided not to conduct interviews during this phase of the research. This decision took into consideration time limitations for completion of a master's degree in one calendar year of a part time study and the fact that a 63% response rate had been achieved. This research is considered a minor thesis and as such is concerned with the practical management which emphasises the importance of the report making viable recommendations, which are the result of clear conclusions based on a set of findings which in turn are based on a sound research design.

A letter was sent to all the parents who had agreed to be interviewed, thanking them for their contribution and informing them that interviews would now not take place. These parents were afforded an opportunity to make contact with the

researcher should they wish to discuss any issues which arose as a result of the questionnaire.

5.3 Descriptive Statistics

5.3.1 Characteristics of sample

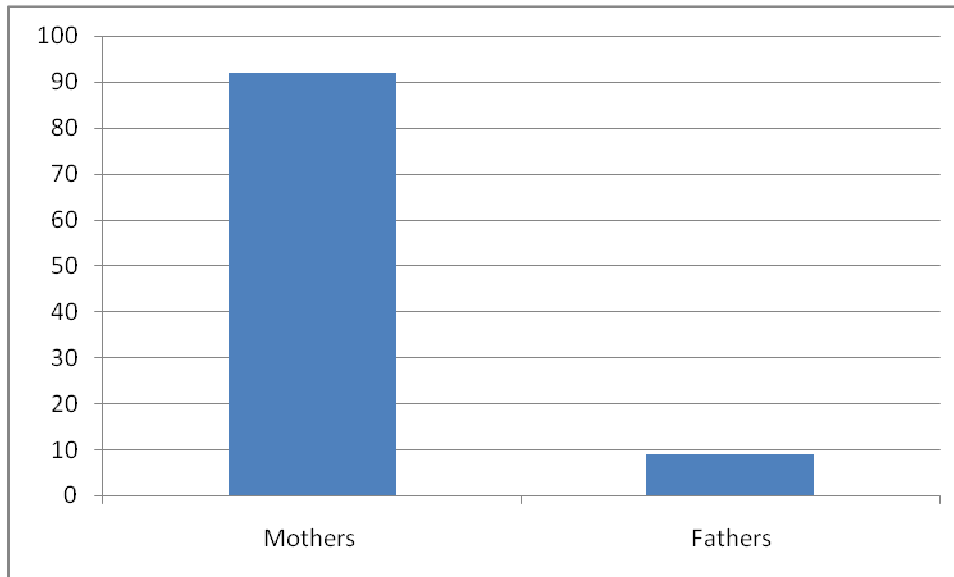


Table 2

Respondents were predominantly birth mothers. (n=92, 91.9%). Nine respondents were fathers (8.9%). (Table 2)

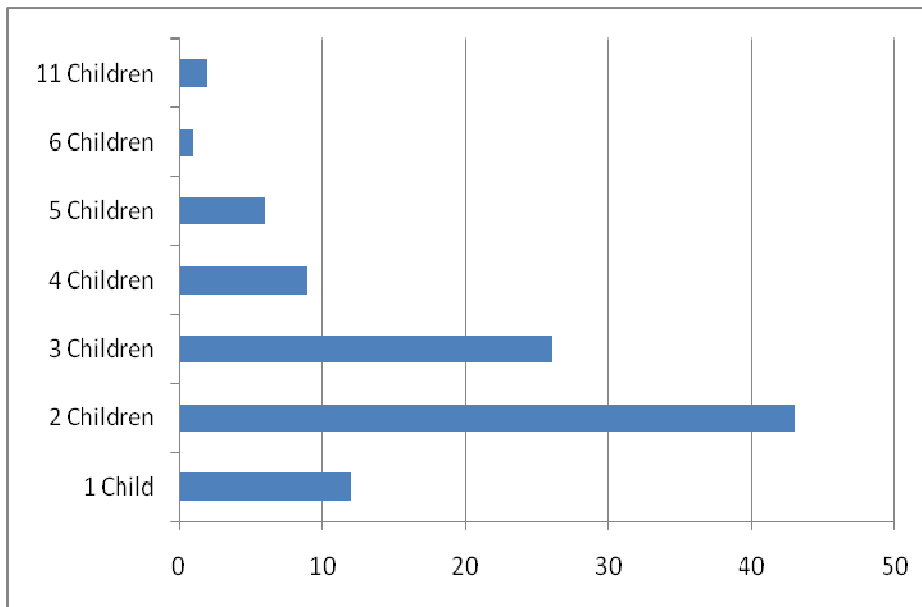
5.3.2 Family profile.

The respondents had between one and eleven children each, including the child with a disability. Mean 2.73 and SD 1.1.609.

Twelve respondents had one child and two had eleven. In one family of eleven, the children were made up 5 children from the father's previous relationship and 6 children from the mothers previous and current relationships. (Table 3)

The age range of the children with a disability ranged from birth to 6 years. Mean age was 3.71, SD 1.535

Table 3 Numbers of children



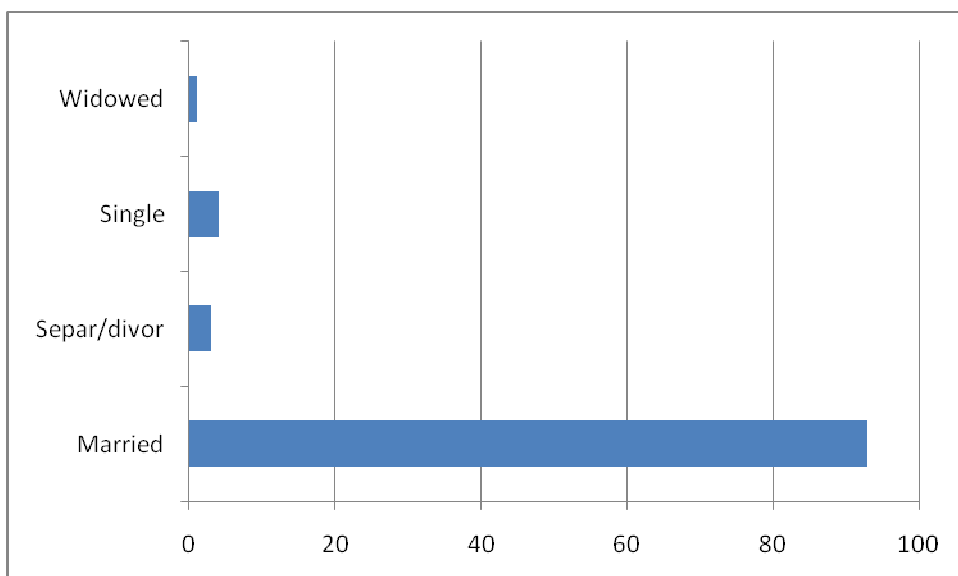
5.3.3 Marital status of respondents

Ninety three respondents were married or living as married (92.1%), three were separated or divorced (3%), four said they were single (4%), and one was widowed (1%). (Table 4)

Eight respondents (7.9%) said they were parenting alone.

Eighty eight said their partner was living at home (87.1%), Ten respondents (9.9%) said their partner was not living at home.

Table 4

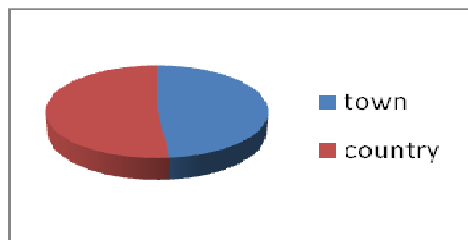


5.3.4 Area of residence

The families in the study came from different geographical areas of County Clare were caring for children with a disability aged fro birth to 6 years.

Of the sixty four who were asked if they lived in a town or rural area, 48.4% (n= 31) said they lived in a town, 33 or 51.3% said they lived in rural area. (Table 5)

Table 5



5.3.5 Diagnosis

The most common diagnoses are given in Table 6. In addition, the sample included children with a range of rare conditions which each occurred in only one case, for example Klinefelter syndrome, Williams syndrome, Spina bifida, Beckwith-Wiedemann syndrome, Rett syndrome, Chromosomal detusion 13 q, and Rubinstein-Taybi syndrome.

Autistic spectrum	28
Down syndrome	16
Developmental delay	18
Cerebral palsy.	7
Developmental coordination disorder (DCD)	4
Speech & language disorder	4
Muscular dystrophy	2

Diagnosis. Table 6

5.4 Types and level of disability

A nine item scale measuring the type and level of difficulty experienced by the child in communication, behaviour, learning, mobility, health, vision, hearing, continence and social skills, was used. Respondents rated whether their child experienced difficulties in each area, either 'not at all', 'moderately so', or 'very much so'.

The results show that the highest area of difficulty was in the area of communication (45.6%) The second highest area of difficulty was in the area of learning (37.1%) followed by social skills as the third highest area of difficulty.

Between 75 and 76.1% percent had no difficulty in the areas of hearing and vision. (Table 7)

Table 7

Difficulty	Not at all	Moderately so	Very much so
Communication	13.3%	41.1%	45.6%
Behaviour	23.9%	51.1%	25%
Learning	15.7%	47.2%	37.1%
Mobility	47.3%	28.6%	24.2%
Health	49.5%	38.5%	12.1%
Vision	76.1%	19.6%	4.3%
Hearing	75%	17%	8%
Continence	45%	28.8%	26.3%
Social skills	24.7%	47.2%	28.1%

5.4.1 School

Eighteen children were in mainstream school (25%), Twelve were in a special school (16.7%), and forty two were in a preschool (58.3%) and 27 were too young to go to school. (Table 8)

49.2% of the children in school had an Individual Education Plan (IEP)

Table 8

Mainstream school	Special school	Pre-school	Too young for school
18 (25%)	12 (16.7%)	42 (58.3%)	27 (42.9%)

5.4.2 Influence of the child's disability on employment

Parents were asked if having a disabled child had affected their employment.

Twenty six respondents (26.8%) said that having a disabled child did not affect their employment. Thirteen respondents (13.4%) were not able to return to work following the birth of a child with a disability and nineteen (19.6%) had to leave work to care for the disabled child. Of these, 2 stated that they did not progress in their job and thirty seven (38.1%) said they cannot work as many hours as they would like. (Table 9)

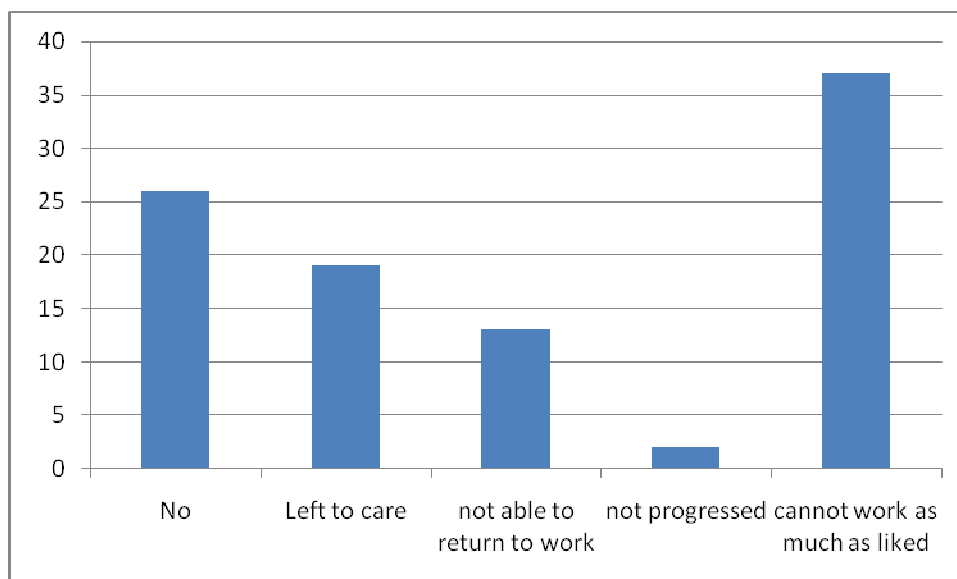


Table 9

Parents were also asked if having a disabled child affected their partner's employment.

Here the majority of respondents, 64 (66.7%) reported that there was no effect on their partner's employment. Four respondents (4.2%) said they had to give up working to care for the child, three (3.1%) were unable to return to work, three (3.1%) felt they had not progressed in their work and twenty two (22.9) cannot work as much as they would like. (Table 10)

Partner's employment

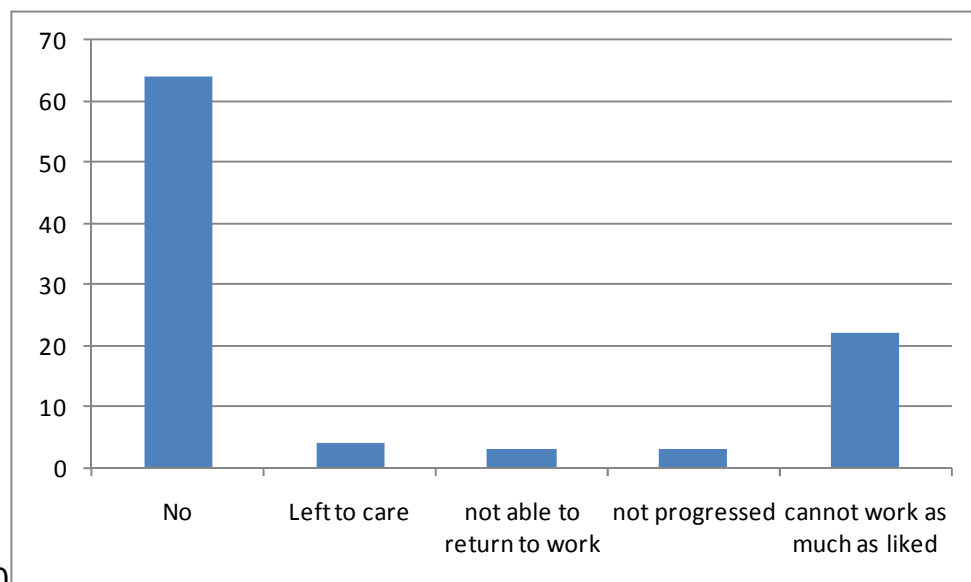


Table 10

Table 10 (A) shows the percentage difference between the two groups

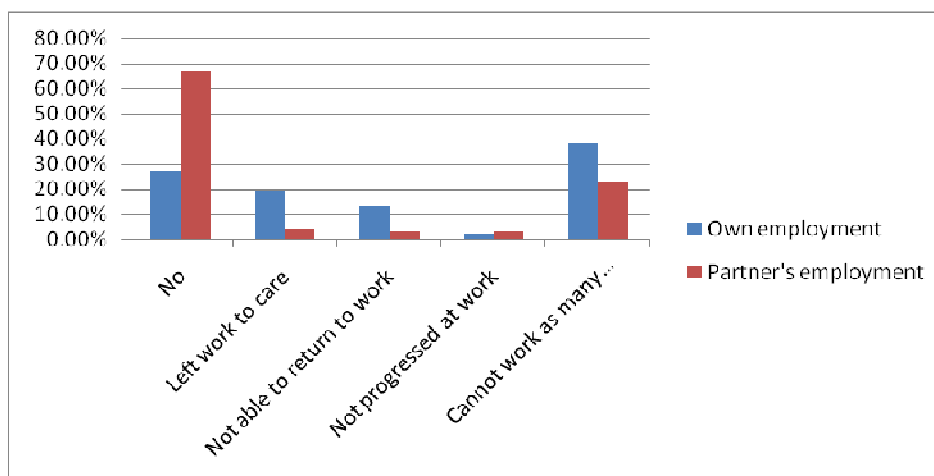


Table 10a

5.5 Objective 1 – to assess parents’ views of the Clare Early Intervention services (CEIS) key worker service in terms of outcomes of importance to parents.

This section firstly identifies aspects of key working in terms of importance of direct impact of key worker provision. Secondly it reports the satisfaction level of parents with the key worker service they receive.

5.5.1 Aspects of key working.

Families were asked to rate how much the service provided them with ten different aspects of key working, on a scale from one (not at all), to three (very much).

Table 11 shows the mean scores on each item on the scale. These means indicate the aspects of the role that key workers performed the most were advice, giving information about the services, coordinating care, and improving access to services. The aspects the key workers performed least were identifying the needs of the family, addressing the needs of the family and giving emotional support.

Table 11 Mean scores on aspects of key working

Item	M (SD)
Advice	2.40 (.593)
Giving information about the services	3.37 (.635)
Coordinating care	2.25 (.720)
Improving access to the services	2.19 (.709)
Other	2.18 (.982)
Giving information about the child's condition	2.02 (.767)
Speaking on behalf of the family when dealing with services	2.00 (.809)
Emotional support	1.91 (.745)
Identifying the needs of the family	1.67 (.787)
Addressing the needs of the family	1.64 (.724)

5.5.2 Satisfaction with Key Worker service

Parents were asked how satisfied they were with the key worker service they receive. Satisfaction was rated on a 4 point scale from 'very satisfied' to 'not satisfied at all'. 88.4% said they were satisfied or very satisfied and 11.6% were not satisfied. (Table 12)

Table 12

Very satisfied	Satisfied	Not satisfied	Not at all satisfied
41.70%	46.70%	8.30%	3.30%

Various statistical tests were performed to assess the relationship or difference between satisfaction and other variables.

Spearman's Rank Order Correlation (Rho) tests were performed to examine differences between satisfaction levels of the respondents and variables such as -

Age of the child

Frequency of visits in previous 3 months

Length of visits in those visits

Frequency of telephone contact

Length of telephone contact

However, very weak to weak correlations were found in these variables.

(range $r = -.139$ to $-.400$)

5.5.3 Correlations between satisfaction and aspects of support provided

The relationship between the satisfaction level of the respondents and the aspects of support given by the key worker was examined using the Spearman's Rho correlation coefficient test. There were weak to moderately strong negative correlations found between all the aspects of support provided and satisfaction, with high levels of support provided associated with lower levels of satisfaction.(Table 13)

<i>How satisfied</i>	<i>r</i>	<i>p</i>	<i>n</i>
Emotional support	- 0.376	0.005	55
Information about your child's condition	-.0.351	0.008	56
Information about services	-.0.534	<.001	56
Advice	-.0.425	0.001	56
Identifying needs of all the family	-.0.4	0.002	56
Addressing needs of all the family	-.0.39	0.003	55
Speaking on behalf of family when dealing with services	-.0.605	< .001	55
Coordinating care	-.0.686	<.001	55
Improving access to services	-.0.639	<.001	52
Help/support in crisis	-.0.53	<.001	51

Table 13

5.5.4 Correlation between how long respondents had a key worker and satisfaction with the service

A Spearman's Rho correlation coefficient test was conducted to investigate the relationship between the length of time the respondents had a key worker and their satisfaction with the key worker service. There was a weak inverse relationship which was significant ($p=.026$ and $r=-.303$), which may indicate that the longer the respondents had a key worker the less happy they were.

5.5.5 Satisfaction levels and child's difficulties

Mann-Whitney U tests were carried out to find out whether satisfaction levels were linked to difficulties the child was experiencing. Each difficulty was examined separately and statistically significant differences were found in one area of difficulty – Vision ($p=.026$) Frequencies are shown in table 14

Table 14

Vision	Satisfaction	Percentage	Number
No problem	Satisfied	92.9%	39
No problem	Not satisfied	7.1%	3
Moderate problem	Satisfied	83.3%	10
Moderate problem	Not satisfied	16.7%	2
Severe problem	Satisfied	33.1%	1
Severe problem	Not satisfied	66.7%	2

This indicates that those with children with severe vision difficulties were less likely to be satisfied (33%) than those with no vision difficulties. (93%)

This result would have to be viewed with caution as the number of children who had vision problems was low. ($n=14$)

The p value in the other areas of difficulties ranged from $p=.058$ for continence to $p=.612$ for behaviour.

5.6 Objective 2 – to identify aspects of key working which contribute to improved service coordination for disabled children and their families.

That listening to the family needs and ensuring those needs are met, is an important aspect of key working highlighted by some of the responses to the question which asked what aspect of key working families valued most.

5.6.1 Families’ contact with key workers

In this study families were asked how often they had seen their key worker in the previous three months and how long these visits last. The responses varied from some families not seeing a key worker at all in the previous three months to others seeing her 20 times in the same three months. (Mean 2.49, SD 3.61, N = 53)

The duration of the visit for those who got a visit ranged from ½ an hour to 2 hours. (Mean .96, SD .372, N=40)

The respondents were asked if they wanted to see the key worker “more often’, ‘the same’, or ‘less often’

50% said they would like to see their key worker more often, 44.4% would like to see them about the same, and 5.6% would like to see them less often. (Table 15)

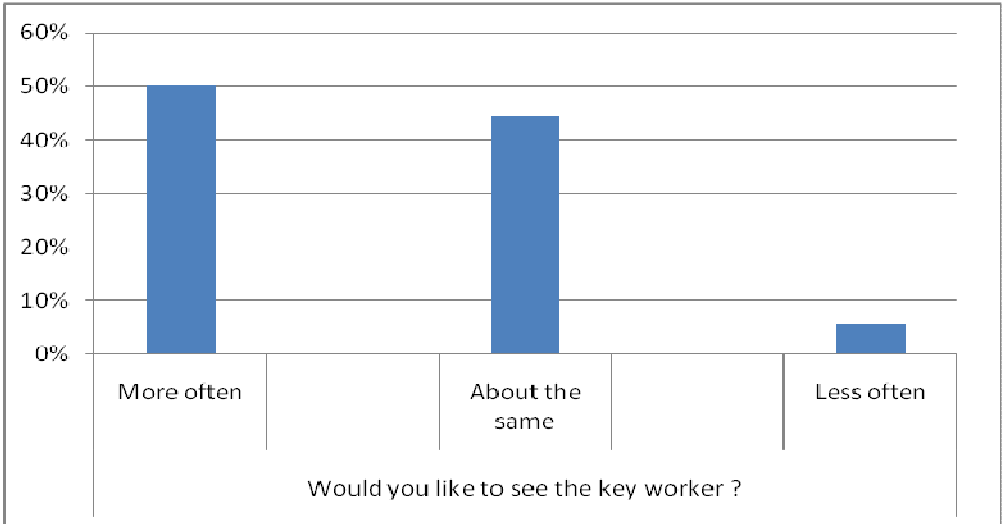


Table 15

The results of Spearman's Rho test in relation to satisfaction levels with contact were presented in section 5.5.2

5.6.1 Telephone contact with families.

Parents were asked how often they had spoken to their key worker on the telephone in the last three months. The mean number of telephone calls over three months were 2.61, (SD 3.73, range 0- 20, N= 49)

The mean duration of telephone calls was 13.14 minutes, SD , N=38)

Respondents were asked if they wanted to talk to their key workers more often, the same or less often: 42.1% said they would like to speak to their key worker more often, 54.4% would like to talk to them about the same and 3.5% would like to talk to the key worker less often. (Table 16)

How often would you like to talk to the key worker?

<i>More often</i>	<i>About the same</i>	<i>Less often</i>
<i>24 (42.1%)</i>	<i>31 (54.4%)</i>	<i>2 (3.5%)</i>

Table 16

Parents stated that some key workers sent texts or emails as a method of contact.

The results of Spearman's Rho test in relation to satisfaction levels of the respondents with telephone contact are given section given in section 5.5.2

5.6.2 Type of contact with the key worker.

Parents were asked whether the key worker contacted them or if it was left up to them to contact the key worker:

50% reported that they key worker generally contacted them and 50% said that it was usually left up to themselves to make contact with the key worker.

5.6.3 Satisfaction level and the type of contact (proactive or not proactive)

A Chi square test was performed to examine the difference between the satisfaction level of respondents and the type of contact they received from the key worker. Fisher's exact test showed $p=.010$ which is statistically significant, indicating that respondents are more likely to be satisfied with proactive contact.

5.6.3 Open ended questions

As outlined in the previous section 42.1% of respondents said they would like more telephone contact and 50% said they would like to see the key worker more often. In the open ended questions three respondents referred to their desire for key workers to be proactive.

'Key workers need to be more proactive and independent and act as family advocates.'

'As a family we would like a key worker to contact us in relation to our son's needs and to see if we have any problems.'

'When she contacted you on the phone to let you know how he is getting on.'

'If I could be able to meet with her more often, as she helps me with the difficult situations that arise.'

'Would like more contact with the service.'

5.6.4 Aspects of key working valued most.

Parents were also asked what aspects of the key working service they valued most.

The overriding theme was being able to contact the key worker and having a named person at the end of a phone should they need to speak to someone. There was a confidence in the knowledge that the key worker was contactable should the need arise, with respondents making reference to -

"Not being passed from A to B to C"

'That when phoned she returns the call with an answer to a query I have';

'If you need help with something and don't know who to ask, your key worker would find out for you fairly fast.'

'In the early days it was a great help to speak to 'one person' who could inform me about other professionals involved in our child's care'.

'It's way better to have one person to deal with rather than be passed from pillar to post by everybody.'

Many parents referred to the key worker being a good listener

'Having someone to talk to re services available'

'Having someone to listen to you that understands your moans about the child and takes time to listen to you.'

'That when you pick up the phone and the person on the other end understands no matter what I ask'.

Conversely there were some parents for whom having a key worker did not have the desired effect.

'Support, advice, and practical assistance. Intermediary role. This happened in a very limited on off manner.'

5.7 Objective 3 - to highlight factors which can inform good practice in the development and delivery of key worker services for disabled children and their families.

5.7.1 Consistency and reliability

Consistency and reliability emerged as a theme as important for parents in the question which asked them 'what aspects of key working they valued most'

'Knowing someone can be contacted by myself or the school at any time'

'She is on hand right away if you need help with something you are not sure about.'

'She will always email back/text as soon as she has information or if you need to speak to her. She is a very valuable member of the multi- d team at CEIS.'

'Having the same key worker who knows my child well'

'Contact with the same individual consistently over years'.

'Consistency'

'That when phoned she returns the call and provides information on what is happening'.

Continuity became an issue if the key worker left or went on maternity leave.

'The close relationship we developed was invaluable. When she left the service there was a massive difference in care/treatment – we were left in a sea of waiting lists'.

'When I had a key worker I felt supported, but since she left I have had very little contact'.

5.7.2 Having a supportive open relationship.

Many respondents referred to having a supportive relationship with the key worker. Some of the comments included the following.

'Friendly and approachable. Always willing to help. Knowing they are there'.

'I like my key worker very much and appreciate her input into our lives'.

'I am watching the progress my child has had so far as a result of the support I got from my key worker. I wish all key workers were like her'.

'It's very difficult dealing with your child's diagnosis especially when you haven't been prepared or have never dealt with anything like this. So the key worker is very important for me and my family.'

However not all parents felt the key worker provided emotional support;

'It was interesting to see the list of items on your question 16. Is the key worker supposed to provide emotional support? I feel alone as a mum with a baby with special needs that works full time.'

5.7.3 Access and referrals to other services

Parents were asked; - In general, do you think having a key worker positively affects the way you are treated by the service, on a scale from one, (never), two, (sometimes), three (often), and four, (always).

Of the 64 valid responses received 56 people answered the question. (Table 17) Eight respondents said having a key worker always positively affects the way they are treated by the services and sixteen said this happens often and twenty one said it happens sometimes. Eleven said that having a key worker never positively affects the way they are treated by the services.

Table 17

Never	Sometimes	Often	Always
11(19.6%)	21(37.5%)	16(28.6%)	8(14.3%)

The responses below are a sample of comments from parents to the open ended questions in relation to access and referrals to other services.

'When I needed to see any of the therapists she would arrange that. When I needed them to come to the playschool if there was a problem she would arrange that meeting. Anytime I rang her she would always ring me back and do what she could for me.'

'Key worker helpful in organising and making you aware of what services are available. Good to have one person to contact if help is required and who is a link between the various services required.'

'Ensuring Joe's (not his real name) name was on the books waiting lists when Occupational Therapists and physiotherapists take up their positions'

'We have never known anything about Autistic children. We depend greatly on our key worker to educate us and assist us in accessing his care and educational needs.'

'Her ability to set up speech and language and physiotherapy appointments. General advice and support.'

'Our key worker initiated contact with CEIS, made us aware of its' existence, helped with application for domiciliary care allowance, gave information on other entitlements, initiated appointments in eye clinic.'

However there were a few parents who felt let down by the service.

'I feel very let down, disenfranchised and upset by the system and the Irish Health Service to the most vulnerable in society.'

5.7.4 Information gathering.

The open ended questions clearly indicated that parents in this study were actively engaged in gathering information and that the key worker played a vital part in the process. The following are a sample of parent comments in relation to information gathering.

'Based on the information she gave us we were more informed before asking other healthcare workers for treatments that Joe (not his real name) was entitled to and should have received.'

'Everything regarding the service was explained to me and my questions answered'

'My key worker advises on any benefits and other things I am entitled to and tells me where to go and who to talk to for the various things.'

'I found my key worker very informative and helpful. It was a stressful time in the planning stage when our child was coming home from hospital, as she had spend 7 months there. All the services were put in place and it has made things easier.'

Not all parents were satisfied that the key worker provided that information with at least two referring to parent support groups, carers organisations, and disease specific organisations such as the Down Syndrome association for their information.

'She usually obtains the information for me but it can be quicker to contact 'Caring for Carers' as they have more resources.'

'Key workers should have more knowledge of health related illness i.e. nursing background particularly for kids with complex needs.'

'Should be well informed on how the HSE and CEIS work. I am aware some positions are filled by professionals from abroad. We were ill informed by one of

these. Luckily another professional we were involved with was able to rectify the situation for us.'

'Any service I may be entitled to I have found out through friends or a support groups etc. However I did great help from my key worker when my child was to start school'

One parent commented –

'I would prefer if the key worker took more of a 'lead' e.g. - recently commenced home tuition – hardly any guidance was given to us to set this up. I don't know what this teacher should do with my son.'

5.8 Constraints identified

Some parents identified what they felt were constraints within the service as evidenced by the comments on issues as outlined below.

5.8.1 Lack of therapy staff.

At least eight respondents felt the need to comment on the lack of therapy services for example,

'My key worker is too busy doing speech and language therapy (SLT) to be a key worker'

'The lack of therapies in CEIS – key worker is being used as a substitute for other therapies.'

'Therapy staff should not be assigned as key workers. Admin (sic) staff or trainee therapy staff should take on the role in an effort to deliver results faster.'

'Being told Jack (not his real name) was going on a list. Not the key workers fault because the positions for SLT and Occupational therapy (OT) weren't filled at the time. As parents we found this frustrating as our son needed early intervention.'

'To be honest my key worker is doing her best but CEIS does not have staff level to meet my/our needs – e.g. on waiting list for SLT assessment for 2 years.'

'This service at CEIS is under resourced and hinders the development of our child and other children in Clare.'

'As a parent you have to follow up a lot yourself – services are under resourced.'

5.8.2 Therapy staff too busy for role of key worker.

Other respondents felt that their key worker was too busy for the role of the key worker.

'The idea of a key worker is good, but in real life the job of a key worker is side-tracked as they are too busy with doing their other job.'

'I am lucky my key worker is very approachable and helpful but always seems to be very busy and under pressure.'

5.8.3 Staff turnover

A few respondents had experience of staff turnover and lack of continuity.

'I was really happy when my key worker was contacting me on a regular basis, but I feel a bit isolated since she left, not sure who to contact about issues/advice/problems.'

'My experience was that the main key worker built up a very good relationship/understanding of my child. However, when this key worker went on maternity leave, the service completely collapsed.'

'People are constantly leaving just when you've build up a rapport with them. Staffing is a serious problem.'

'The continuity of care was poor. Since my key worker left the service I do not know who my key worker is.'

'Discontinuation of key worker contact as a result of staff turnover at CEIS.'

5.8.4 Communication

Some respondents were not properly informed about a change of staff.

'It would be helpful to families whose key worker was leaving the service to introduce the new key worker prior to leaving. It would give a more seamless service that families felt connected.'

'My key worker has just left CEIS and I found out by accident when phoning about something else. The letter telling me arrived after she left. A key worker plays a major role in both the child and parents life. To lose her with no replacement and not even a call is really hard for parents. It makes you feel irrelevant.'

5.8.5 Part time key workers

Two respondents referred to the disadvantage of having a key worker who worked part time.

'Having a single point of contact that is part time and is rarely in the office serves no purpose whatsoever.'

'She only works part time so is not always available.'

5.8.6 Clarity of the role

One respondent was unclear about what the key worker does.

'For me it was unclear how much does the key worker do. How involved would they be – maybe it is useful to make this clear at the start. I think having a key worker is very important.'

5.8.7 Key workers for children over 6 years

A few respondents expressed a wish for a key worker service in the school age service and appeared anxious about the transition.

'I would like to see key workers put in place for the over 6 children.'

'The key worker has been a great help in getting the right help for our child and is always there when we call her. If only there were key workers for the children over 6 years.'

'I am very happy with the service I have received from CEIS and am only sorry that as my child is reaching age 6 in January that I will have to leave this service.'

'Not happy that at age 6 she is moved to another service and new faces for her to deal with. It's silly really.'

5.8.8 Family centred approach

One respondent felt the key worker should visit more often and be more family orientated.

'I feel the key worker could visit the family more often and give recommendations about problems encountered with my older child in relation to having a sister with special needs'

5.8.9 Key worker independence

A respondent felt the key worker was working on behalf of the HSE rather than the family and that she was acting in the medical model rather than the social model.

'There is a conflict of interest – often parents are being critical HSE services- yet key workers are HSE employees. (Cannot answer on behalf of the HSE (will not).)'

'Discuss more what parents think, - rather than what fits in with HSE professional model.'

5.9 Objective 4 - to compare the responses of parents who do not have a key worker service to those who do.

A second shorter questionnaire was sent to 60 parents whose names were on the data base as not having a key worker. There were 37 appropriate responses (61.6%)

However, 14 respondents from this group indicated that they already had a key worker which left the study with 23 responses for comparison.

The characteristics of the sample were reported as part of the whole sample in a previous section of this chapter, (Section 5.3.1 - 5.3.4), as is the type and level of disability (Section 5.4.1 – 5.4.2), and the effect of the disability of the child on their employment and on their partners employment, (Section 5.4.3 – 5.4.4)

5.9.1 Childs difficulties and having or not having a key worker

Mann Whitney U tests were carried out to find out if having a key worker or not having a key worker was linked to the difficulties experienced by the child. However, no significant differences were found in any of the areas. The p values ranged from .094 for health to .806 for communication. This result would indicate that the difficulties experienced by the child were not linked to whether or not they had a key worker.

5.9.2 Areas of support needed.

Parents were asked if they had a key worker service which area they would like support in order of preference. From a list of eleven areas as outlined below, parents were asked to give their area of highest need from 1 to 4;

- Information about your child's condition.
- Information about the services
- Advice
- Identifying the needs of all family members
- Addressing the needs of all family members
- Speaking on behalf of the family dealing with the services
- Emotional support
- Coordinating care
- Improving access to services
- Help/support in a crisis
- Other

46.9% of respondents said that they would like support in relation to information on the child's condition as a matter of priority. Information about services was the second highest support need identified by 21.9% of the respondents. 16.1% identified advice as the third highest need and fourthly improving access to services was next highest at 6.3 %.(table 18)

Table 18 Areas of highest need in terms of support from a key worker service

			Mean
1	Info on child's condition	46.9%	2.59
2	Info about services	21.9%	4.16
3	Advice	16.1%	5.77
4	Improving access to services	6.3%	6.76

5.9.3 Comments from respondents who had no key worker.

Some respondents were clearly very disappointed.

'We have had meetings with child psychologist, speech therapist and physiotherapist, but we have never met a key worker. We feel let down in this area as we have never received the above mentioned supports. I would have liked someone other than family or friends to talk to and discuss things with. I often felt isolated and unable to cope and even though I have family and friends close by. Same time I would not want to confide these feeling with them. It would have been great to have the back up of a key worker.'

A very striking comment was received from one respondent.

'On speaking to other people with children with special needs they have described their key worker as their rock. I wish I could have had that too.'

'Feeling of isolation in the early stage. Good at present.'

It is interesting to note that there is some confusion among some of the respondents about the service for example,

'We don't know who to contact in CEIS about a key worker'

'We found the system very confusing and have been left to fend pretty much for ourselves. A key worker could have lessened the stress for us and perhaps helped to speed up some of the processes.'

'Key worker could help so that each service is contacted and forms filled out at the right time. In all it was a year before she started to get the help she needed. This needs to be reduced. Key worker could help with this.'

'I think that when a child is 'diagnosed' the parents should be informed of all the 'entitlements' that are available to them. As parents we got this information from other parents of disabled children. We have to fight for everything, including nappies, domiciliary care allowance etc. None of this information was provided to us by the service.'

Summary

The aim of the study was to explore the parent's perceptions of key working at CEIS.

One hundred and sixty questionnaires were sent to parents of children with a disability who were on the CEIS database. The response rate was 65% which is considered reasonable for a postal questionnaire.

The results were presented in terms of the four objectives of the study.

There are a number of very positive findings in this study. 72.27% of the respondents indicated they had a key worker and the satisfaction rate is high at 88.4%. In general the responses support what is seen in the literature. The comments in the open ended questions were positive for the most part. However not everyone was satisfied and some constraints were identified within the service.

Chapter 6

Discussion

Key working for families with a child with a disability has been on the national agenda in countries such as Britain, Canada, Australia and New Zealand for many years and has been enshrined in their national policies for disabled children. Examples such as 'Every Child Matters (ECM)',¹⁸ in Britain has meant that there has been an upsurge in the development of key working services there.¹⁵

In Ireland, while key working has been referred to in several national documents and policy papers, there has not been the same attention given to the development of key worker services for disabled children and consequently the research is scant.

This study contributes to the discussion of key working through exploring parents' perceptions in Clare Early Intervention Service in terms of the four stated objectives. The study has highlighted several perceived strengths and weakness in the CEIS service as reported by families who receive a key worker service.

The first part of this chapter summarises the main findings of this research project.

The second section discusses the results of the study in terms of the objectives in the context of the literature. Some discussion is given to what the author perceives as gaps/constraints of the service as reported by parents in the free text questions.

The strengths and limitations of this research report are discussed. Finally, ideas and recommendations are given for the future of key worker services for CEIS and the Clare School age team (6 to 18 years).

. 6.1 Main findings

- CEIS are providing higher percentage of key worker service (72%) to parents of children with disability than reported in previous studies of services elsewhere.
- 84.4% of respondents were satisfied or very satisfied.
- Advice, getting information, coordinating care and improving access to services identified as most important supports being provided.
- Parents more likely to be satisfied with proactive contact.
- Having a named person to contact who is reliable, consistent and a good listener is highly valued by parents.
- Parents who had no key worker identified what they needed most was information about the child's condition.
- Some parents who had no key worker felt let down and isolated.
- Constraints identified were key workers not having time for the role, lack of clarity about the role and communication difficulties.

6.2 Response rate

A 65% response rate is considered acceptable for a postal questionnaire. Some researchers⁴⁵ suggest that 50% is a good response rate while others suggest anything between 10 and 50% are average for postal surveys.⁴⁶ It has been suggested that where the response rate is lower than 50% the representativeness of the sample may be questioned.³⁹

6.3 Characteristics of sample

The profile of the respondents was similar to profiles from the literature,^{11 14 15} with 92 of the valid responses being from mothers and 9 responses from fathers. There was nothing striking in the profiles of the respondents except that 2 families had 11 children each, which is higher than those reported in the literature in Britain and Australia.

There was a predominance of female participants. The high female response rate probably reflects the reality that it is often the mother who takes the bulk of the responsibility for the caring for a child with a disability in Ireland. It would have been interesting to have received a higher number of replies from fathers in relation to their perceptions in order to compare their perceptions with those of the mothers.

Ninety three were married or living as married with 3 separated/divorced. The separation/divorce rate is surprisingly low as it has been reported anecdotally that having a disabled child is stressful on a relationship, which leads to marriage/relationship break up.

Studies in Britain have reported higher levels of separation/divorce (11.7%) in families with a child with a disability.¹⁵ The point also is made in the literature that a child with a disability within a family with other factors such as economic, social or psychological issue may have a devastating effect on a family.³⁸

However, the low separation/divorce rate in this study may be attributed to the fact that the study was carried out on parents of children less than 6 years. It is conceivable that as the disabled child becomes older the stress to the parents may be increased, leading to further marriage breakdown. Furthermore, Irish divorce arrangements are such that makes it more difficult for people to obtain a divorce than elsewhere.

6.3.1 Area of residence

There were an almost equal number of respondents living in rural areas as in town area. A Chi square independent test revealed no difference in satisfaction between rural or urban respondents which indicates that the service is provided equally between town and country residents as is recommended in the literature.²⁷

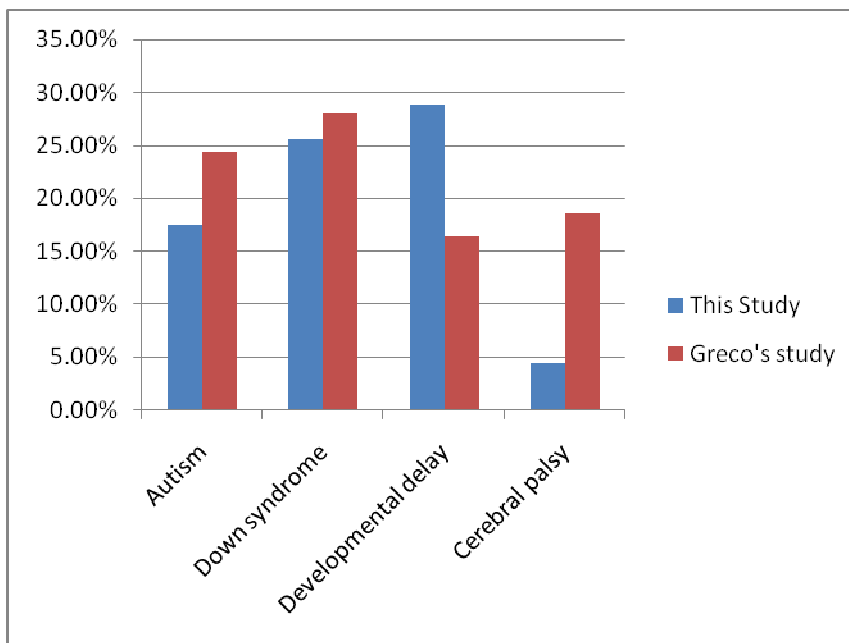
6.3.2 Diagnosis of the child

The most common conditions identified by the respondents as being diagnosed were Autism (17.5), Down syndrome (25.6%), Developmental delay (28.8%),

and Cerebral Palsy (4.33%). In Greco's study where the same question was asked it is interesting to note that Autism was identified at 24.3%, Down syndrome 28%, Cerebral palsy 18.5%, and Developmental delay 16.4%.

Table 19 below illustrates a higher incidence of conditions in Greco's sample than in the current study except for developmental delay. This is an interesting finding given that Greco's study was conducted in Britain where abortion is legally available.

Table 19



However, the current study surveyed parents of children from birth to 6 years of age whereas in Greco's study the children ranged in age from birth to 18 years.¹⁵ The age range surveyed in the current study (0 to 6 years) may not have allowed the true level of incidence of the conditions to be captured.

6.3.3 Influence of the child's disability on employment

73.2% of the respondents indicated that having a disabled child had an influence on their employment with 26.8% reporting that the disability did not affect their

employment. The number is slightly less than in Greco's study which as previously reported surveyed parents of children up to 18 years of age.

66.7% of the respondents stated that the disability of the child had no effect on their partner's employment while 33.3% reported some effect. The figures compare well with Greco's study.¹⁵

6.4 Key worker provision

In this study 72.27% of respondents reported that they had a key worker. Similar studies have previously reported a much lower percentage of key workers working with families who have children with disabilities in their services. For example, in a study of services for autistic children, it was found that 39% of the respondents had a key worker service, which included informal key workers as well as formal ones.⁴⁷ Other studies found that less than one-third of families with a child with a disability have a key worker.^{2 13 15}

It would appear that CEIS are providing a high level of key worker support to families in comparison to other early intervention services as indicated in recent studies. This is a very positive finding considering that key working is relatively new to early intervention services in Ireland.

6.4.1 Aspects of key working provided

There was considerable difference in how parents reported the activities provided by the key workers which reflects individual differences in families' needs and ability to cope. This highlights and confirms the need for key workers to adopt a flexible and individual approach as families' need change over time.³⁵

Respondents placed 'advice' as being the most important service aspect that the key worker provided to them. Getting information regarding the service was the second highest. Number three was coordinating care and fourth was improving access to services. These aspects are in line generally with that of the literature.^{15 37}

Interestingly, emotional support was identified as 8th on parents list of what aspects of key working that were being provided in this study, which is even lower than that found in other studies.^{11 15} It may be that because in general extended family support is often better in Ireland than in locations where other

studies were carried out. It has been suggested in one such study that although parents may want and need emotional support the key workers may be unable or not willing to give emotional support either because they may feel it is not their role, or because parents tend to present more practical problems for solving.¹⁴ Furthermore, asking for emotional support can be a very personal issue and possibly families tend to rely more on family and friends or support groups for this type of support.

When examined statistically, aspects of key working comprising provision of advice, information about the services, information about the child's condition, identifying and addressing the needs of all family members, provision of emotional support, speaking on behalf of the family when dealing with the services coordinating care, improving access to the services and provision of support in a crisis, were not a strong predictor of satisfaction with the service as seen by the test results. The stronger links were coordinating care, improving aspects to services and speaking on behalf of family when dealing with the services. Why this should be the case is unclear, but it is an interesting result which could imply that not the right kinds of supports were always being provided.

6.5 Satisfaction levels

Overall, a high level of satisfaction was recorded with 88.4% being satisfied or very satisfied by parents who had a key worker as in other studies of key worker services.¹³⁻¹⁵ However, the length of time the respondents had a key worker does not necessarily mean that they are more satisfied as demonstrated by the Spearman's Rho correlation coefficient test.

It would appear that the longer the respondents had a key worker the less likely they were satisfied with the service. It is possible that in the beginning respondents were satisfied with the 'honeymoon period' of having a key worker but as time elapsed they either needed more help, different kinds of help or they became disillusioned with the service for one reason or another.

From tests conducted there did not seem to be any difference in satisfaction levels between the mothers and fathers, or between those parenting alone or not alone or between those who live in a rural or town area which indicate that the key worker service is being provided equitably. These results are very positive and are in keeping with that which is advocated by policy documents In relation to equity of provision.²⁷

6.6 Features which improve service coordination

Many of the respondents in the questionnaire referred to having one named person to call on for support and information and mentioned development of the relationship with the key worker as being important in improving service coordination. This is in keeping with many studies.^{11 14 15 48}

The frequency, duration and type of contact indicated a high level of consistency and reliability which was the basis of satisfactory key working is also common to other research.^{11 15}

Being proactive is seen as a way of improving service coordination and is very important aspect of key working for parents in the literature.^{2 15} Having someone to listen to their fears and worries was also seen as helping to improve service coordination as the parent felt they were listened to then they could access the right service in a timely way. However, as seen in other studies, resources were sometimes not available and it was not possible to provide coordination for a service that did not exist.⁴⁸

Having enough time for the role is noted in the literature as important for service coordination.⁴⁹ A few parents felt that key worker did not have enough time for the role or felt that the key worker was under pressure. - *'Key worker too busy with her other job.'*

6.7 Factors which can inform good practice.

If the value of parent participation in the development of services is to be fully realised it is their views and their opinions about the contribution of the key worker which should be explored.¹¹ The outcome from these views can have a

direct impact upon informing the development and delivery of key worker services for disabled children and their families.

The methodology adopted in this study to explore parents' perceptions has made it possible to draw from their experiences a number of good practice factors, which could guide the manner by which key worker services would develop in the future.

The following themes were obtained from the open ended questions in the parent questionnaire which are considered good practice factors.

- Consistency and reliability – proactive regular contacts and good listening skills.
- Having a supportive open relationship
- Access and referral to other services.
- Information gathering – empowerment for parents.

6.7.1 Consistency and reliability

The frequency with which the respondents in this study had contact with the key worker service varied widely. Some families had not seen or spoken their key worker in the previous 3 months while others reported seeing her 20 times in the same period. There was no consistency either in the reported duration of contact which ranged from none to ½ an hour to 2 hours for a visit. (Mean .96 minutes.) The mean duration of telephone contact was 13.14 minutes.

In this study, regularity and frequency of contact seemed to be largely dependent on individual circumstances. It is possible that the family, who reported having 20 visits and 15 telephone contacts within the three month time frame, may have had a child with very complex needs, was new to the service or had a crisis during this particular period.

On the other hand it could be argued that a key worker was being flexible and responding to individual needs and abilities which is highlighted in the literature as an important consideration for someone carrying out the role.⁴

Overall, there was considerable evidence in the free text questions of the questionnaire which would indicate that where key working was working well

there was sense that parents were more relaxed knowing they had someone on which to call if needed. *'Knowing she can be contacted if needed.'*

6.7.2 Proactive contact

Proactive contact has been described in the literature as a pre-requisite for good communication between families and professionals.³⁵ In fact some studies have found that the frequency of proactive contact was a measure by which families judged whether or not they were receiving a key worker service.³⁵

Findings from this study, in terms of the analysis of correlations between satisfaction and frequency of contact or the degree to which the key workers were perceived as proactive indicate that respondents were more likely to be satisfied with proactive support which is in line with previous studies.^{2 12 15 13}

However, the question has been asked in the literature if parents always feel confident enough to make contact, and also if some key workers are themselves reluctant to make contact with parents as they are not used to this type of proactive contact in the other aspect of their job.¹¹

Furthermore, a study conducted in Ireland in relation to caring for children with learning difficulties, notes that 'Ireland tends to be characterised traditionally, by strong societal and particularly religious norms, which may lead to a misplaced stoicism and lower levels of parental help seeking.'³⁷(p227)

Findings from the current study showed proactive contact to be at 50% which is worrying, as best practice guidelines recommend proactive regular contact.³⁶ In view of the above findings there is considerable room for improvement in this area and may indicate that there is a lack of awareness and training around the proactive aspect of key working.

6.7.3 A supportive open relationship

Previous research has suggested that the relationship between the family and the key worker is of critical importance from which all other things flow.³⁵ From the richness of several of the comments received stating they felt they could contact their key worker at any time to discuss issues or problems, it could be assumed that in those cases there was a supportive open relationship. For the

parents who felt they had a supportive relationship it was highly valued. For example *'I can say anything I feel like to my key worker and it puts me at ease.'*

Listening to the family needs and ensuring those needs are met is also important as seen by the responses to the question on what aspect of key working they valued most. It makes perfect sense that if key workers are to provide an effective service it would be mandatory requisite/characteristic that they have good listening skills as alluded to in previous studies.^{35 48}

6.7.4 Access and referral to other services.

42.9% of respondents indicated that having a key worker positively affects the way they are treated by the service either often or always. 37.5% stated that this was true sometimes. This finding is in contrast to one study where there was only a small amount of evidence that access was improved by virtue of having a key worker.¹⁴

Moreover, several respondents highlighted the key worker role with getting services such as SLT and also linking them in to other services in health and education. A couple of respondents in the comments section indicated they felt let down by the service.

Similarly, some respondents were aware of inherent difficulties for key workers who were acting as advocates for families while also performing their own professional role as therapist, nurse. However, respondents were quick to defend the key worker stating it was not her fault that the resources were not always available. Similar responses were identified in previous studies.¹¹

One respondent felt that it was difficult for the key worker to act independently as she worked for the agency which provides the service. It is noted in the literature that the key worker should be accountable to the family, not perceived as working for an agency.^{5 50}

6.7.5 Information gathering

Giving information must be designed to empower rather than create dependency.⁵¹

Parents of children with a disability need access to good quality information and accurate advice in order to feel empowered and more informed to make decisions.¹⁴

Previous research has suggested that many families neither get the information they need, nor are satisfied with its quality and quantity.⁵²

Parents in this study seemed to understand that the key workers could not be experts in every area but were happy enough when the key workers were able to find the information and get back to them. Parents referred to personal qualities such as approachability, friendly manner, understanding, listening skills, consistency and reliability.

Parents not alone need information about services available but also need to know the role of the person giving that information. There was evidence from some of the comments received that parents were not well informed about what exactly was the role of the key worker.

Many studies found that the role of the key worker needs to be clearly defined for each service. When some families did not receive an adequate explanation of the role, they had very high expectations of the role which led to disappointment.²

In the Pembrokeshire area they produced a leaflet which they give to the family on the first visit 'What your key worker can do for you' ¹⁶ They recommend key worker role be incorporated into the job description, so that it is not just an add-on role without protected time and training allocated to it.

6.8 Constraints

6.8.1 Resources

There was concern expressed in the open ended answers that resources at CEIS were inadequate to meet the needs/demands of the parents of the children with disability. The philosophy of Transdisciplinary team working would appear

to be a method which could help to overcome perceptions of inadequate resources. Transdisciplinary working is identified in the literature as a very efficient, cost effective way of delivering services to increasing numbers of children requiring early intervention.³⁴ This approach can address the shortage of therapists by reducing the need for face to face contact with a number of therapists due to the role release kind of provision.³⁴

It is conceivable that not every family in CEIS requires the service of a key worker. The fact that a high proportion of families are receiving this service makes one wonder if there are agreed criteria for such provision or if the overall aim is to provide this service to every family. In other jurisdictions a key worker is provided to families of a child with complex needs only.²

6.8.2 Time for the role

More than one respondent referred to the key working not having time for the key worker role due to carrying out her main professional role. Several respondents made reference to the key worker being under pressure or stretched. There may be different reasons for these concerns. Firstly, there may be a genuine shortage of staff to take on the key worker role. Secondly, it is conceivable that key workers at CEIS are expected to key work with more than three families as an add on role as is recommended in a few research studies^{15,36} Furthermore, it would appear that there are no clear guidelines as to how much time a key worker spends on each aspect of their role. Key working has been acknowledged in many studies as time consuming.^{11 15} The need for clear guidelines and clarity of the role of key worker is mentioned in many studies indicating that if there are protocols, and standards are set, it eliminates uncertainty and misunderstanding for both the parents and the key worker.^{11 14 15}

^{35 53} As indicated in the literature the role of the key worker should be drawn up and incorporated into the job description.¹⁵ This would further help to eliminate difficulties for both parents and professionals in relation to having protected time for the role.

Much of the literature in relation to key working identifies the need for key worker services to be managed to enable them to have support, supervision, training

and development.^{2 11 15 36 54} The issues referred to here could be addressed by the management of the service.

6.8.3 Communication

A few respondents referred to discontinuation of key working in CEIS when people left the service, when the key worker went on maternity leave and when people work part time. Others referred to not being informed that the key worker was leaving or were not introduced to the new key worker. In the literature problems such as these are overcome by having agreed protocols for such events and standards for key workers.^{11 15 34 47}

Many studies found that the role of the key worker needs to be clearly defined for each service.^{11 15 34} In the Pembrokeshire area they produced a leaflet which they give to the family on the first visit 'What your key worker can do for you'¹⁶ Overall, it would appear that there is a need for robust management of the service to enable standards to be set and protocols introduced and agreed.

6.9 Respondents who did not have a key worker in terms of supports needed.

It would appear that the support most needed as identified by respondents who had no key worker was that of information about the child's condition. However, the number of valid responses was very small. (n=23)

Information about the child's condition was ranked 6th by those who had a key worker in terms of key worker supports provided. This difference could indicate key workers lack of knowledge of the child's condition, lack of insight on the part of the key worker in addressing that particular issue or perhaps not listening fully to needs of the parents. It could be argued that information about the child's condition is the responsibility of the medical staff and Paediatrician. However, key workers and professionals working with families ought to have a general knowledge of conditions of the children with whom they work.

6.10 Comments from respondents who did not have a key worker

There were fewer comments from respondents who had no key workers as there were fewer respondents. However, despite the limited response, there was a palpable feeling of disappointment and isolation in the comments that were expressed. Some of the respondents expressed a need to have someone besides their family to confide in.

There was confusion about the role of a key worker which caused stress for families. There was a general lack of information available to families about entitlements and services available especially following diagnosis. Some respondents replied with sadness in relation to time lost for their child for example, *'We felt a lot of time has been wasted in these crucial early years'*

6.11 Strengths and limitations of the study

The study employed a principally quantitative methodology in the form of a postal - questionnaire sent to parents of children who have a disability and who are clients of Clare Early Intervention Service. The response rate was 65% which compares well to other studies which used postal questionnaires.

The questionnaire was used to explore the views of parents in relation to key worker services. While there have been quite a few similar studies conducted in the UK and in Australia, this is the first known study that has been conducted in Ireland to obtain the views of parents of children with a disability in relation to key working. The study also enabled comparison to be made between parents who have a key worker and parents who do not have a key worker.

In discussing the findings there is a need to acknowledge the limitations of the project and what they mean in terms of the conclusions that can be drawn from the research. Firstly, the research took place in a very specific context; a relatively new early intervention service for children with a disability under 6 years in County Clare, which provides a non-designated key worker service.

Secondly, the questionnaire to parents produced results of a snapshot in time, and although the response rate was good for a postal questionnaire it clearly does not give the complete picture of key working. The fact that of the 37 responses from the parents who according to the database had no key worker, 14 said they had a key worker meant that there were a limited number of responses with which to compare. Furthermore, two replies were received from the group who were on the database as having key workers, with notes stating that they could not complete the questionnaire as they did not have a child with a disability. These inaccuracies would suggest that there are issues in the service in relation to the inputting and maintenance of the data base. Therefore, any attempts to generalise the results would have to be completed with caution.

Thirdly, the questionnaires proved to be limited in terms of results which could be garnered. They were deliberately kept short in order to try to get a reasonable response rate which meant that there were a limited number of questions asked. This resulted in considerable reliance on the comments in the open ended questions for interpretation.

Upon reflection changes could have been made to include a question on parental need, which may have further added to the data for analysis. It would have been interesting too, to have obtained parents views on the role the key worker plays in facilitating respite care for families of children with disabilities.

Finally, due to the limited time and resources available to the study, it was not possible to include the views of key workers or service managers, which would have allowed a broader exploration of the issues, their affects and potential solutions. Qualitative data from such staff would add corroboration and further illuminate the findings obtained here.

Chapter 7

Conclusions

The aim of this study was to assess parents' views of the Clare Early Intervention key worker service in order to inform the development of a key worker service for the school age team 6 to 18 years.

In general the study supports the issues identified in the literature.

7.1 Summary of the main findings

- CEIS are providing a high percentage (72.2%) of key workers to families in Clare, in comparison to other early intervention services studied in previous research.
- Satisfaction levels were high with 88.4% being satisfied or very satisfied.
- Advice, getting information, coordinating care and improving access to services were identified as the most important supports provided by the key worker.
- Emotional support was rated lower down as being provided by key workers than reported in previous studies.
- Parents were more likely to be satisfied with proactive contact. Frequent proactive contact either by visits or telephone contacts were seen to be features which contributed to improved service coordination.
- Parents were less likely to be satisfied the longer they had a key worker.
- The factors highlighted which inform good practice were - having a named person who was consistent and reliable and who is a good listener.
- The role of key worker needs to be clarified and added to the job description with time allocated to it.
- Constraints were identified in relation to staffing levels, professions too busy for the role, key working not continuing when key worker leaves, goes on maternity leave or works part time.
- The parents who had no key worker identified what they needed most was information about the child's condition. When compared to parents

who had a key worker, information about the child's condition was identified as 6th in the supports provided.

- Some parents who had no key worker felt let down and isolated.
- There is a need for best practice guidelines/standards and agreed protocols to be developed. Training and supervision needs to be addressed by a service manager.
- Transdisciplinary team working should be seriously considered, not only as a model of best practice but also as a method of managing effectiveness and costs.

7.2 Implications for the organisation

In view of the many positive findings concurrent with previous studies in the literature, it would appear that key working is a worthwhile and valuable service to provide to families of children with a disability including children and young people 6 to 18 years of age. However some caveats should be considered.

- That the role is clearly defined and written into the job description with time allocated for the role.
- That agreed protocols and standards are introduced so as to reduce the constraints identified in this study. The protocol could address issues about what happens when the key worker leaves, goes on maternity leave, on holidays, on sick leave or works part time. It could also address what happens when the child moves to the school age service (6 to 18 years). Standards could address issues such as how many families a key worker will take on.
- There is a role for a manager to develop and implement all of the above and to provide training in the area of key working.

7.3 Implications for future research

This study explored parents' perceptions of the key worker service at Clare Early Intervention Service by virtue of a primarily quantitative postal questionnaire. The results compared very well in relation to previous studies. The area of key worker provision was substantially higher in this study (72.2%) than other studies and overall levels of satisfaction were very good (88.4%).

It would be useful to conduct qualitative studies to get the views of key workers themselves and the views of service managers of early intervention services. Such research would further illuminate and add corroboration to the findings obtained in this study.

7.4 Dissemination of the results

The results will be made available to the staff at CEIS and the school age team, 6 to 18 years of age. To this end the report will be summarised and events organised to present the results to the Clare Children's Service and to colleagues in the Public Health Nursing Department.

A summary of the report will be made available to the respondents on request.

An expression of interest in an article based on the report has been received from Peter Limbrick of Interconnections, UK.

An abstract will be forwarded to the National Institute of Health Sciences in Limerick, for inclusion in their research bulletin.

References

1. Jugnoo S, Manaras I, Toumainen H , Lewando Hundt. G. Meeting the Needs of Parents Around the Time of Diagnosis of Disability Among Their Children: Evaluation of a Novel Program for Information, Support, and Liaison by Key Workers. *Pediatrics* 2004; 114(4):477-482.
2. Greco V, Sloper P. *Care co-ordination and key worker schemes for disabled children: results of a UK-wide survey*. *Child: Care, Health & Development* 2004; 30(1):13-20.
3. Department of Health and Children. The National Children's Strategy Our Children - Their Lives: Stationary Office, Government Publications, 4-8 Harcourt Road, Dublin 2, 2000.
4. Davies S. Team around the Child: Working together in early intervention. Wagga Wagga: Kurra Early Intervention Service. 2007.
5. Law M, Hanna S, King G, Hurley P, Kertoy M, Rosenbaum P. *Factors affecting family-centred service delivery for children with disabilities*. *Child, Care, Health and Development Journal* 2003; 29(5):357- 366.
6. Harbin G, MCWilliams R, Gallagher J. Key working. In: Shonkoff JP MP, editor. *Handbook of early intervention*. New York: Cambridge University Press, 1990:398.
7. Cederman K. Synergy - An Exploration of High Quality Early Intervention for Children with Special needs in Diverse Early Childhood Care and Education Settings. Dublin: CECDE, 2006.
8. Foley GM. 'Portrait of the arena evaluation: assessment in the transdisciplinary approach' In: Gibbs E.D and Teti DM, editors. *Interdisciplinary Assessment for Early Intervention Professionals*. Baltimore: Paul H. Brookes, 1990:274.
9. Department of Health/Department of Education and Skills. Together from the Start: Practical Guidelines for professionals working with disabled children (Birth to third birthday) and their families. Nottingham: DfES Publications. 2003.
10. Carpenter. B. Families in Context Emergent Trends in family Support and Early Intervention. In: Carpenter B, editor. 2nd ed. London: David Fulton Publishers, 1997.
11. Barton L, Clarke L. Altogether Now. An evaluation of the Key Working Process in Warwickshire: Final Report. Professional and Parental Views, Integrated Disability services. Stareton, Warwickshire.2006.
12. Sloper P, Greco V, Webb R. *Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families?* *Child; Care, Health & development*, 2006; 32 (2):147-157.
13. Liabo K, Newman T, Stephens J, Lowe K. A review of key worker systems for children with disabilities and development of information guides for parents, children and professionals-Summary: Welsh Office for Research and Development (WORD), 2001.
14. Townsley R, Abbott D, Watson D. Making a difference? Exploring the impact of multi-agency working on disabled children with complex health care

- needs, their families and the professionals who support them. Bristol: The Policy Press, 2004.
15. Greco V, Sloper P, Webb R, Beecham J. An Exploration of Different models of Multi-Agency Partnerships in Key worker Services for Disabled Children: Effectiveness and Costs. University of York: 2005:206.
 16. Norris H. 'Bromley Early Support - Keyworking and Co-ordinated Services: The journey in Bromley'. Presentation at Conference: Key working without tears. 2007.
 17. Limbrick P. Family-centred Support for Children with Disabilities and Special needs. A collection of essays. Clifford: Interconnections, 2007.
 18. Department of Education and Skills. Every Child Matters. London: DfES The Stationary Office, 2001.
 19. Department of Education and Skills. The Children Act 2004. The Stationary Office, 2004.
 20. Health Services Executive. Proposal for the Development of a National Framework for Service Delivery for Children 0-5 with complex Developmental Needs. HSE. 2007.
 21. Department of Health/Department of Education and Skills. National Service Framework for Children, Young People and Maternity Services: Disabled Children, Young People and Those with Complex Health Needs. Department of Health, 2004.
 22. Balls E. Speech at the Rachel Squire Memorial Lecture, London. Why every child matters, disabled children and their ECM agenda. London, 2007:
 23. Department of Health. Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services. Department of Health Publications. 2004.
 24. Department of Health. (Canada). The Children's Act. Department of Health. 1989.
 25. Department of Health and Social Security. Fit for the future: Committee Court Report on child health services. London. HMSO 1976
 26. Davies S, editor. The Rural Beginnings Project. A Pilot Project for Early Intervention. Kurrajong Waratah. Wagga Wagga. 2007.
 27. Department of Health and Children. "Quality & Fairness - A Health System for You": Department of Health and Children, 2001
 28. Department of Health and Children. The Disability Act: The Stationary Office, Dublin, 2005.
 29. Department of Education and Science. The Education of Persons with Special Educational Needs: The Stationary Office, Dublin, 2004.
 30. Department of Justice and Law Reform. The Citizen's Information Act: The Stationary Office, Dublin, 2006.
 31. Department of Justice and Law Reform. The Equal Status Act: The Stationary Office, Dublin, 2000.
 32. Health Service Executive-West. Service Specification for Early Intervention in the Mid-West Region. 2007.
 33. Harrison J. Individual Family Service Plans as a means to Evaluate Transdisciplinary Practice. In: Davies S, editor. Team Around the Child: Working together in early intervention. Wagga Wagga: Kurrajong Waratah; 2007.

34. Davies S. The transdisciplinary team approach. In: Davies S, editor. Team around the child. Working together in early intervention. Kurrajong Early Intervention Service: Wagga Wagga. 2007.
35. Mukherjee S, Beresford B, Sloper P. Unlocking key working. An analysis and evaluation of key worker services for families with disabled children. Joseph Rowntree Foundation, 1999.
36. Care Co-ordination Network UK. Developing a Key Worker Service for Families with a Disabled Child. A resource pack: York: Publications Office, University of York, 2006.
37. Kenny K McGilloway S. *Caring for children with learning disabilities: an exploratory study of parental strain and coping. British Journal of Learning Disabilities 2007; 35(4):221-228.*
38. Quine L, Pahi J, Stress and Coping in Families Caring for a child with severe Mental Handicap. Kent. Institute of Social and Applied Psychology and Centre for Health Studies. University of Kent, 1989.
39. Burns N, Grove S.K. Understanding Nursing Research 3Rd Ed. Arlington: Saunders, 1999.
40. Cormack FS, editor. The Research Process in Nursing. London: Blackwell Science, 1991
41. Central Statistics Office, Census, Cork. 2006.
42. CEIS Statistics. Ennis. 2007.
43. Saunders M, Lewis P, Thornhill A. Research Methods for Business Students. 3Rd ed. Harlow: FT Prentice Hall. 2003.
44. Edwards P, Roberts I, Clarke M, DiGuseppi G, Prapet S. WentZ, R. et al. *Methods to increase response rates to postal questionnaires. BMJ 2002; 324:1183-1185.*
45. Healey MJ. Obtaining information from businesses. Harlow: Longman, 1991.
46. Neuman W.L. Social research methods. 2nd ed. London: Allyn and Bacon, 2000.
47. McConachie H, Robinson G. *What services do young children with autism spectrum disorder receive? Child: care, health and development. 2006; 32(5):553-557.*
48. Barton L, Clarke L. 'Altogether Now' An Evaluation of the Key Working Process in Warwickshire: First report. Professional and Parental views. Stareton: Integrated Disability Service 2005.
49. Greco V, Sloper P, Webb R, Beecham J. *Key Worker Services for Disabled Children: the views of parents. Children & Society 2007; 21:162-174.*
50. Care Co-ordination Network. Key Worker Standards. York: CCNUK, 2004.
51. Edwards J. Family-centred support: Lessons from a Keyworker Service. In: Family-centred support for children with disabilities and special needs. A collection of essays. Limbrick P. Editor. Clifford: Interconnections, 2007.
52. Mitchell W, Sloper P. User-friendly information for families with disabled children: Guide to good practice. York: Joseph Rowntree Foundation, 2000.
53. Limbrick P, Editor. Keyworking without tears. Interconnections seminar; London. Interconnections, Parks Farm, Clifford. May 2007
54. Sloper P, Greco V, Beecham J, Webb R. *Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families? Child: Care, Health & development, 32, 2, 147-147 2006.*

Appendices

Appendix 1

EXPLORING KEY WORKER SERVICES FOR DISABLED CHILDREN AT CLARE EARLY INTERVENTION FROM PARENTS' PERSPECTIVES

QUESTIONNAIRE

Section A: You and your family

1. Are you...? Child's mother ☐ Child's father ☐

2. Are you...? Married or living as married ☐ Separated or divorced ☐
Single ☐ Widowed ☐

3. Is your partner living at home? Yes ☐ No ☐

4. Do you live in: Town ☐ country area ☐

5. Has having a disabled child affected your partner's employment?

- ☐ No
- ☐ Had to leave work to care for child
- ☐ Has not been able to return to work
- ☐ Has not progressed as far in his/her job
- ☐ Cannot work as many hours as he/she likes

6. Has having a disabled child affected your employment?

- ☐ No
- ☐ I had to leave work to care for child
- ☐ I have not been able to return to work
- ☐ I have not progressed as far in my job
- ☐ I cannot work as many hours as I like

7. What age is your child?

8. Including your disabled child, how many children do you have?

9. How old are your other children (if any)? _____

SECTION B: YOUR CHILD'S DISABILITY

10. Please describe the diagnosis you have been given for your child's condition

11. What kind of school is your disabled child currently attending?

- Pre school ☐
Special school ☐
Ordinary/mainstream school ☐
Special unit in ordinary/mainstream school ☐

12. Does your child have a statement of special educational needs? (IEP)

Yes ☐ No ☐

13 Does your child's disability mean he/she has difficulties in any of the following areas?

	Not at all	Moderately so	Very	much so
a. Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. social skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION C: YOUR NEEDS

14. How long have you had a key worker?

Years Months

15. Overall, how satisfied are you with the key worker service you receive?

Very satisfied ☐ Satisfied ☐ Not satisfied ☐ Not at all satisfied ☐

16. Overall, how much does your key worker service provide you with the following?

	Not at all	Some	Very
a. Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Information about your child's condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Information about services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Identifying the needs of all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Addressing the needs of all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Speaking on behalf of the family when dealing with services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Coordinating care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Improving access to services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Help/support in a crisis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION D: RELATIONSHIPS WITH STAFF

17. In general, do you think having a key worker positively affects the way you are treated by services?

Never ☐ Sometimes ☐ Often ☐ Always ☐

18. Which is the aspect of your key worker service you value MOST?

19. Which is the aspect of your key worker service you value LEAST?

SECTION E: CONTACTS WITH SERVICES

20. In the last 3 months, how often have you seen your key worker? (Please fill in the approximate number of times)

21. Typically, how long do these visits last?.....

22. Would you like to see your key worker:

More often ☐ About the same ☐ Less often ☐

23. In the last 3 months, how often have you spoken to your key worker over the phone? (Please fill in the approximate number of times).....

24. Typically, how long do these contacts last?

25. Would you like to talk to your key worker

More often ☐ About the same ☐ Less often ☐

26. Regarding contact with your key worker (please tick ONLY ONE):

My key worker usually makes contact with me regularly ☐

My key worker usually leaves it up to me to contact them ☐

27. Do you have any specific comments on the key worker's role in relation to the different services your family receives from: Education, Social Services, and Health?

28. Any other comments

Please attach separate sheet if you would like to write more comments

Thank you for taking the time to fill in this questionnaire!

If you are willing to be interviewed at a later date in to discuss further the issues involved in key working, please give your name in the space below.

It is entirely voluntary.

NB. This does not commit you to being interviewed. More information will be sent to you at a later date.

Name.....

Address.....

.....

Phone number

Consent signature for interview at later date;

Date.....

Appendix 2

EXPLORING KEY WORKER SERVICES FOR DISABLED CHILDREN AT CLARE EARLY INTERVENTION FROM PARENTS PERSPECTIVES

QUESTIONNAIRE 2

1. **Are you...?** Child's mother ☐ Child's father ☐

2. **Are you...?** Married or living as married ☐ Separated or divorced ☐
Single ☐ Widowed ☐

3. **Is your partner living at home?** Yes ☐ No ☐

4. **Has having a disabled child affected your partner's employment?**
 - ☐ No
 - ☐ Had to leave work to care for child
 - ☐ Has not been able to return to work
 - ☐ Has not progressed as far in his/her job
 - ☐ Cannot work as many hours as he/she likes

5. **Has having a disabled child affected your employment?**

- ☐ No
- ☐ I had to leave work to care for child
- ☐ I have not been able to return to work
- ☐ I have not progressed as far in my job
- ☐ I cannot work as many hours as I like.

6. **Including your disabled child, how many children do you have?**_____

7. **How old are your other children (if any)?**_____

SECTION C: YOUR CHILD'S DISABILITY

8. Please describe the diagnosis you have been given for your child's condition

9. **What kind of school is your disabled child currently attending?**

Pre school ☐

Special school ☐

Ordinary/mainstream school ☐

Special unit in ordinary/mainstream school ☐

10. Does your child have a statement of special educational needs? (IEP)

Yes ☐

No ☐

11. Does your child's disability mean he/she has difficulties in any of the following areas?

	Not at all	Moderately so	Very much so
a. Communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Learning.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Mobility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Social skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION D: YOUR NEEDS

Some families who have a child with a disability are supported by a key worker who can provide information and support and help to organise services.

12 Have you ever had a key worker? Yes ☐ No ☐

13 If YES, how long have you had a key worker. Years Months

14 If no, why not any longer?

15. If you had a key worker service, which area would you like support in order of preference. Please choose from the list your area of highest need from 1 to 4.

- ☐ Information about your child's condition
- ☐ Information about services
- ☐ Advice
- ☐ Identifying the needs of all family members
- ☐ Addressing the needs of all family members
- ☐ Speaking on behalf of the family when dealing with services
- ☐ Emotional support
- ☐ Coordinating care
- ☐ Improving access to services
- ☐ Help/support in a crisis
- ☐ Other.....

16. Do you have any specific comments on the key worker's role in relation to the different services your family receives from: Education, Social Services, and Health?

17. Any other comments

Please attach separate sheet if you would like to write more comments

Thank you for taking the time to fill in this questionnaire!

✂.....
.....

If you are willing to be interviewed at a later date to discuss further the issues involved in key working, please give your name in the space below.

It is entirely voluntary.

N.B. This does not commit you to being interviewed. More information will be sent to you at a later date.

Name.....

Address.....

.....

Phone Number.....

Consent for interview..... Date.....

Appendix 3



Exploration of the key worker model of service in Clare Early Intervention Service (CEIS)

Information sheet for parents

The purpose of this leaflet is to outline the above study and to explain what will happen if you decide to take part.

What is the study about?

The study is about what parents think about key working in Clare Early Intervention Service. (CEIS).

It is well documented that parents with disabled children express the need for a single point of contact with services by means of an effective, trusted person who will ensure that they receive the help they need. This person is often called a key worker or care coordinator. Findings show that families with key workers have better relationships with services, less isolation and feelings of burden, more information about services, and fewer unmet needs.

This research will generate data relating to how parents view key workers in CEIS. It will provide useful data in relation to service provision and will highlight barriers and difficulties encountered by parents of children with disability. This will enable service providers to make recommendations to improve the service for parents of children with disability.

Aims of the study

- To assess parents' views of the CEIS key worker service in terms of a variety of outcomes of importance to parents and children.
- To identify features of key working which contribute to improved service coordination for disabled children and their families.
- To highlight factors which can inform good practice in the development and delivery of key worker services for disabled children and their families.

Who is doing the study?

My name is Brigid Mullins, Coordinating Public Health Nurse Disability and I am enrolled in a masters degree at the National University of Ireland, Galway. In order to meet the requirements of my study I am conducting a piece of research. The enclosed questionnaire is being carried out to find out how the key worker system is operating at the Clare Early Intervention Service (CEIS).

If I complete this questionnaire what will happen?

The project seeks to explore the ideas of parents of children with disability concerning key worker services. By agreeing to help, the research will be able to draw upon your experience and knowledge of the key worker service as you have experienced it. These results will help us to improve services for children and families in CEIS and older children.

What do I have to do?

Simply complete the questionnaire and return it in the envelope provided.

Do I have to take part?

You have a right not to take part. You have a right to say no! You do not have to give a reason. You will continue to receive your service as usual. Saying no will not affect your future treatment or your relationship with the Clare Children's Service.

If I take part what will happen to the information?

All information will be treated in confidence. Your name and address will not be on the questionnaire so I will not be aware of who is responding.

Are there any risks for me and my family?

There are no risks of any sort to you for responding to the questionnaire.

Who can I contact for further information?

The researcher Brigid Mullins will be happy to answer any queries you may have in relation to issues raised in the questionnaire. She can be contacted at Dept of General Practice NUI Galway, or by calling 087 6184969

What do I get out of it?

You will be helping to identify features of key working which will be very useful for improving existing services and to develop the services for older children.

Appendix 4



25.02.2008

Dear Parent,

You are invited to participate in an important piece of research.

My name is Brigid Mullins and I am enrolled in a masters degree at the National University of Ireland Galway. In order to meet the requirements of my study I am conducting a piece of research. The enclosed questionnaire is being carried out to find out how the key worker system is operating at the Clare Early Intervention Service (CEIS). Please answer the questions freely. You cannot be identified from the information you provide and no information will be given to Clare Children's Service.

All the information you will provide will be treated with the strictest confidence.

Your responses and comments are very important for informing the development of future services for older children.

Please return the completed questionnaire in the envelope provided.

NB. If you have already returned the questionnaire please ignore this letter.

An information leaflet explaining about the research is enclosed.

Many thanks for taking the time to answer the questionnaire.

Yours sincerely.

Brigid Mullins

