What are the risk factors in the abuse and maltreatment of children with disabilities?

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Attestation of Authorship

"I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except when explicitly defined in the acknowledgments), nor material which to be substantial extent has been submitted for the awarding of any other degree or diploma of a university or other institution of higher learning."

Signed:_____

Date:_____

Acknowledgements

There are a number of people who have influenced my journey in researching and writing this study. First, I would like to thank my supervisor, Keith Tudor, for his guidance, ongoing support, and encouragement of me to maintain focus during a challenging 12 months.

I would like to thank the many colleagues and peers who have supported me and guided my growth and development in the challenging field of care and protection. Finally I would like to thank the children and families/whanau that I have worked with over the years. The children are truly inspiring and are my greatest teachers.

Thank you to the child psychotherapy programme. The programme gave me the knowledge and understanding on the impact of trauma for children. This knowledge has been the base for me to develop into a role of child advocate and the foundation to continue to learn from the children I have the opportunity to work alongside.

Finally, I would like to thank CCS Disability Action[1] and my family. CCS Disability Action for the support, resources and commitment to supporting children and their families. My family for their emotional support and understanding they have offered me during the process of researching and writing this study. Many thanks, to Sheryll, my wonderful partner, for supporting me through the process of this dissertation, and for walking alongside me in my journey.

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[1] CCS Disability Action. CCS is an acronym. Historically CCS stood for Cripple Children Society, however as society and disability rights developed this was no longer acceptable. CCS Disability Action keeps the acronym CCS, however, as it is a well know "brand".

Abstract

This study explores the risk factors in the abuse and maltreatment of children with disabilities. From the study the best practices to support children with disabilities, who experience abuse and maltreatment, are identified. A modified systematic literature review was employed due to the appropriateness of qualitative research for the study.

Introduction

Included in this study are the interactions between parents and children with a disability and the impact of that interaction on the parent-child attachment; including the additional challenges for parents when their child is born with a disability. The link between a parent's ability to cope with stressors and the child's disability, characteristics and behaviour, was explored to consider if this link increased the risk of abuse and maltreatment. Social workers' experiences in supporting children with disabilities are discussed as is the lack of knowledge and training in this field, which highlights the increased risk to children with disabilities for abuse and maltreatment. Finally, the study discusses where to next in New Zealand, and makes recommendations that will support children with disabilities who experience abuse and maltreatment.

Chapter one defines attachment theory, disabilities, models of disabilities, child abuse and maltreatment, along with the statistics of child abuse and maltreatment, this provides clarity on the terminology through the dissertation.

Following on from chapter one, chapter two clearly outlines the methodology and method used to conduct this dissertation.

The next chapter (three) explores the risks of abuse and maltreatment along with models of abuse. This chapter provides the reader with the theoretical models of abuse and neglect and the additional risks of abuse for children with disabilities. Chapter three identifies the disruption in the formation of infant-caregiver attachment and the prolonged stress associated with raising some children with disabilities. Chapters four and five explore attachment more indepth and chapter five links parental stress and abuse and maltreatment.

Chapter six discusses fostering children with disabilities, the additional challenges fostering children with disabilities. It investigates family-based foster care in Finland and how this model may benefit fostering children with disabilities in New Zealand.

Finally chapter seven makes possible suggestions on 'where to next' in New Zealand, identifying learnings from research used throughout this dissertation.

Chapter One: Definitions of Attachment Theory, Disability, Models of Disability, Child Abuse and Maltreatment, and Statistics of Child Abuse and Maltreatment

The aim of this research is to identify the risk factors in the abuse and maltreatment of children with disabilities, along with the best practices to support children with disabilities who experience maltreatment. In this chapter, attachment, disability, models of disability, child abuse and maltreatment are defined, and the statistics of child abuse maltreatment are reported.

For the purpose of this study, three key risk factors are identified and discussed: 1) the impact of a child's disability on the mother-infant attachment, 2) the link of parental stress and abuse and maltreatment, and 3) the external environment. Finally, best practices for supporting children with disabilities who experience abuse and maltreatment will be discussed.

Attachment

Bowlby (1977) described attachment theory as a "way of conceptualizing the propensity of human beings to make strong affectional bonds to particular others and of explaining the many forms of emotional distress and personality disturbance ... to which unwilling separation and loss give rise" (p. 201). In formulating his theory of how attachment relationships form, Bowlby incorporated knowledge from a variety of disciplines, viewpoints, and research paradigms, including: psychoanalysis, object relations theory, social experimental, developmental psychology, evolutionary theory, and ethology; all of which impacted on Bowlby's hypotheses regarding secure and insecure attachment relationships.

Bowlby (1977) explained that it is just as necessary for analysts to study the way a child is "really treated by his parents as it is to study the internal representation he has of them" (p. 103). The primary form of studies should be the interaction of the one with the other, of the internal with the external.

As Bowlby (1977) noted, attachment researchers focus on interpreting attachment processes in infancy and on the development of secure and insecure infant-caregiver attachment. Ainsworth's "Strange Situation" is the predominant measure to assess the quality of attachment in infancy (Ainsworth & Wittig, 1969). The strange situation is a 21 minute, structured laboratory procedure designed by Ainsworth to produce low-level stress of sufficient magnitude to activate the infant's attachment behaviour

system. From this experiment, Ainsworth and her colleagues identified three major attachment categories: insecure-avoidant, insecure-ambivalent, and secure. Later, a fourth major pattern was identified as disorganised (Ainsworth, Blehar, Waters, & Wall, 1978). The quality of an infant's attachment relationship to his/her caregiver is believed to be a function of the history of the infant's interactions with that particular caregiver during the first year of life.

Insecure-avoidant.

A child with an insecure-avoidant attachment will independently explore his or her environment, easily separate from his or her primary caregiver and show little affection, sharing or affiliation to strangers. The child will actively avoid his or her primary caregiver on reunion, for example turning away or ignoring. (Ainsworth et al., 1978).

Insecure-ambivalent.

A child with an insecure-ambivalent attachment will struggle with exploring his or her environment, for example a child may have difficulty separating from the primary caregiver to explore and can be wary of new situations and people. On reunion with their primary caregiver children may have difficulties settling. For example, the child may mix contact seeking with contact resistance such as hitting and kicking, may continue to cry and fuss, or may show noticeable passivity (Ainsworth et al., 1978).

Cicchetti, Sheere, Toth, and Lynch (1995) examined how insecure children, tend to have mothers who found holding and physical contact difficult, who were unresponsive to their infant's needs and not well attuned to their rhythms. As they grow up insecure children tend to be socially isolated, show a lack of self-awareness and are unable to tell a coherent story about themselves.

Secure attachment.

A child with secure attachment will use the caregiver as a secure base to explore the environment, for example can readily separate to explore toys, share and play with peers, show affection and acknowledge strangers in his or her caregiver's presence, and is readily comforted when distressed. The child can actively seek contact on reunion and if distressed seek and maintain contact with his or her caregiver until comforted (Ainsworth et al., 1978).

Cicchetti, Sheree, Toth, and Lynch (1995) examined how children who are securely attached, have mothers that are responsive and attuned to their babies and provide them with a secure base for exploration. The mothers are able to hold their babies, delight in them and cope with the discontent and aggression in a satisfactory way. Their secure infant grows up to be well adjusted socially and have a realistic self-appraisal. Secure mothers and secure children have a well-developed capacity for self-reflection and narrative ability, and convey a sense of coherence in their lives.

Disorganised attachment.

A child with a disorganised attachment may show sequential and/or simultaneous displays of contradictory behaviour patterns, undirected and incomplete movements and expressions. They may freeze on reunion or show apprehension towards their caregiver (Ainsworth et al., 1978).

Disability

One in five New Zealanders has a long-term impairment. Many are unable to reach their potential or participate fully in the community because of barriers they face doing things that most New Zealanders take for granted. The barriers range from the purely physical, such as access to facilities, to the attitudinal, due to poor awareness of disability issues. (Ministry of Health, 2001, p. iii)

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have. (Ministry of Health 2001, p. 1)

The World Health Organisation (2012) defined disabilities as:

an umbrella term, covering impairments, activity limitations, and participation restrictions. An Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. (p. 1)

When discussing children with disabilities, parents, families and professionals want a clear-cut definition, so the child can be put into a category and services can be planned. However, agreeing on a definition is challenging. "The number of disabled children is not known with any accuracy, partly because of lack of comprehensive

registers and partly because of a lack of agreement about what constitutes a disability, as well as which definition is used" (Middleton, 1992, p. 75).

Cousins (2006) described how a child's circumstance, and an organisation's perception and requirements, determine whether a child is defined as disabled. Due to the elusiveness of a definition, and the potential number of children who might qualify as having disabilities, organisations have had to develop criteria in order to manage their services and the limited resources from immeasurable demands.

Models of disability.

Cousins (2006) explained there are two primary ways of viewing disability: "the medical or individual model, and the social model" (p. 8).

Medical model.

The medical or individual model of disability is approached by medical or clinical teams in an attempt to cure or improve the impairment through intervention. A diagnosis names the impairment, providing the medical or clinical team with a pathway to some form of solution. The disabled child is, however, often the passive recipient of treatment and rehabilitation. There is a place for the medical model, especially when children are ill, however children with a disability, like typically developing children, are not always "ill".

Oliver (1990) pointed to the fragility of this perspective, the aim of which, he argues, is to work towards getting disabled people to become "normal". This is both culturally questionable and, in the light of necessary clinical procedures, may not be personally desirable; it also suggests that the problems belong to the disabled person themselves.

Morris (1995) discussed how the medical model results in people becoming objects to be "treated, changed, improved, and made more normal" (p. 9). Human beings are seen as flexible and alterable, while society is inflexible.

Social model.

Cousins (2006) explained how the social model of disability challenges the medical model. It identifies the problem not within the individual but in the wider society. In essence, people may have impairments, however they are not so much disabled by their impairment but by the way society creates barriers to full participation and opportunity. Disabilities are then a society-defined term rather than a

condition inherent to the individual, a perspective which "radically challenges the medical or health definition of disability" (Cousins, 2006, p. 9).

Morris' (1995) research in England gave an account of disability by disabled people themselves:

> Disabled people's own view of the situation is that – while we may have medical conditions which hamper us and which may or may not need medical treatment – human knowledge, technical knowledge and collective resources are already such that our physical or mental impairments need not prevent us from being able to live perfectly good lives. It is society's unwillingness to employ these means to altering itself rather than us, which causes our disabilities. This is what we call the Social Model of Disability. It puts the problem outside of ourselves, back onto the collective responsibility of society as a whole. (p. 32)

It is important to acknowledge the value of medical intervention where appropriate, however the social model moves away from biological pathology towards a holistic view of human functioning which is recognised as being affected by a variety of social (not just clinical) factors. A combination of the medical model and social model based around the needs of the child with a disability and their family encourages a holistic approach to supporting the child and their family.

Child Abuse and Maltreatment

The World Health Organisation (1999) noted that child abuse or maltreatment constitutes all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child's health, survival, development or dignity in the context of a relationship of responsibility, trust or power. New Zealand's *Children, Young Persons and their Families Amendment Act* (1989) defined child abuse as "the harming (whether physically, emotionally, sexually), ill-treatment, abuse, neglect or deprivation of any child or young person" (p.23).

Statistics of Abuse and Maltreatment

Morris (1998a, 1998b) documented that, in the United Kingdom, there is no requirement to collect and collate statistical information on the abuse of children with disabilities. As a result, children with disabilities can remain invisible, even when they are placed on child protection registers. Similarly, New Zealand does not require authorities or agencies to collect statistical information on the abuse of children with disabilities. It was hoped that this study would give some idea of the number of

children with disabilities in New Zealand experiencing abuse, but lack of statistical information on children with disabilities has prevented this.

By not collecting statistical information on the abuse of children with disabilities, New Zealand can be seen as failing children with disabilities. By not collecting statistics, authorities and agencies struggle to direct resources and funding that will meet the needs of children with disabilities who have experienced maltreatment or abuse.

In 1988, the American Human Association (cited in Benedict et al., 1992) data revealed over half of the reports for child abuse or maltreatment were for physical abuse. The common forms of abuse included cuts, bruises, fractures, and burns. Neglect included medical neglect, lack of proper supervision, inadequate housing and poor hygiene. Other reporting reasons included failure to thrive, child behavioural problems, parental unwillingness to assume care, and sexual maltreatment.

Crosse, Kaye, and Ratnofsky (1993) conducted a study of children involved with child protection service agencies in the United States. The study found children with disabilities were over-represented. In comparison to abused and maltreated children without disabilities, children with disabilities were:

> 2.8 times more likely to be emotionally neglected, 2.1 times more likely to be physically abused, 1.8 times more likely to be sexually abused, and 1.6 times more likely to physically neglected. In 47% of cases, case workers believed the characteristics associated with disability contributed to the maltreatment. (Crosse et al., 1993, p. 234)

Ammerman, Hersen, Van Hasselt, Lubetsky, and Sieck's (1994) American study, interviewed 138 families of children and adolescents with disabilities who were psychiatrically hospitalised. A total of 61% of children and adolescents with disabilities were found to have experienced "a severe form of abuse or neglect at some point in their lifetime" (p.2 34).

The Ministry of Social Development's (2011) statistical report, noted that in 2009/2010, Child Youth and Family received 124,921 reports of concern of which 49,541 reports required further action; 12,535 were for emotional abuse, 2,855 for physical abuse, 1,201 for sexual abuse, 4,403 for behavioural/relationship difficulties, and 5,007 for self-harming/suicide. The report did not distinguish between children with or without disabilities, or children who acquired a disability due to experiencing abuse and maltreatment. I would hypothesis that, due to the lack of statistics on children with disabilities who experience abuse and maltreatment, authorities are

unaware of the requirements/needs for the population of children, and this limits the resources and research required to ensure New Zealand protects children with disabilities from abuse and maltreatment.

Summary

In this chapter attachment theory was defined primarily focusing on John Bowlby and Mary Ainsworth's research on attachment. Disability, as defined by the New Zealand Disability Strategy and World Health Organisation, was discussed and Cousin's (2006) explanations on the medical model and social model of disabilities explored. New Zealand's Children, Young Persons and their Families Amendment Act (1994) and the World Health Organisation's definitions of child abuse and maltreatment were noted. Finally in this chapter the lack of statistics of child abuse and maltreatment was examined and the potential risk of not collecting statistics in New Zealand identified. In the next chapter I will discuss the methodology and methods I have used to conduct this dissertation.

Chapter Two: Methodology and Methods

Introduction

The purpose of this dissertation is to explore the following research question: "What are the risk factors in the abuse and maltreatment of children with disabilities?" From this question a second question falls out, i.e. "what are the best practices to support a child with disabilities who has experienced abuse and maltreatment?" In this chapter, concepts of qualitative research and systematic literature review will be discussed and related to the aim and purpose of this study.

According to Giacomini and Cook (2000), qualitative research is a method where data is summarised and interpreted to gain theoretical insights that describe and explain social phenomena such as people's experiences and roles. Leininger (1985) has suggested that qualitative research is concerned with documenting and interpreting, as closely as possible, the entirety of what is being studied, particularly focusing on the subject's viewpoint or frame of reference, in an attempt to understand her or his internal and external worlds.

I used the modified systematic review process while completing my literature review. A modified systematic review involves incorporating strategies in ways that limit bias, to the assembly, critical appraisal and synthesis of all relevant studies to address the dissertations questions. I have chosen this method to ensure my own bias and thoughts on the abuse and maltreatment of children with disabilities is addressed. Dickson (2005).

The modified systematic review I conducted involved searches of academic databases, official websites and the CCS Disability Action library.

It is important to acknowledge the difference between methodology and method. Wilson (2011) discussed how method and methodology are sometimes used as though they were synonyms. They are not. Methodology is the study of methods and deals with the philosophical assumptions underlying the research process, while a method is a specific technique for data collection under those philosophical assumptions. The method of the modified systematic review provided me with the foundation to be systematic, explicit and comprehensive whilst conducting the review of literature.

Systematic Review Process

This dissertation follows the six key components of the systematic review process as described by Dickson (2005).

1. Define the research question

The first step is to define the research question. The original research question was "What are the outcomes for children with disabilities in family based foster care?" The focus of the systematic search of the literature for this question was on material related to children with disabilities in family-based foster care, with care and protection concerns. Failure to define a clear question can result in wasted time for the researcher (Dickson, 2005).

According to Dickson (2005), the process of developing the question may require discussions with other colleagues who understand the clinical area. From my own experience in the field, including discussions with colleagues over some years before I began this research, I had the sense that there was little research in this particular field. As I started my systematic review of literature, it became apparent that there was very little research on the outcomes for children with disabilities in family based foster care.

After conversations with my supervisor and the results of the systematic literature review, it became apparent that there was a need to redefine the research question to: "Do the attachment styles of children with disabilities affect their long term outcomes in family-based foster care due to care and protection concerns?" As I continued the systematic review of literature, the searches identified research on disabilities and attachment, parental stress and the external environment and how this impacts the support for children with disabilities. However there was limited research on family-based foster. At this time, I stopped and reflected on the purpose of my first and second question. It became apparent that question one and two were driven by external factors, such as, my work within the care and protection field at CCS Disability Action, and wanting to find research that supports my experiences.

In supervision I was able to redefine the question to: "What are the risk factors in the abuse and maltreatment of children with disabilities?" From this question a second question follows: "what are the best practices to support a child with disabilities who has experience abuse and maltreatment?"

2. Search the literature

The second step comprises a thorough search of literature. This included in-depth searches of the following databases: PsychInfo, Proquest Dissertation and Theses, Psychoanalytic Electronic Publishing (PEP), Google Scholar, PubMed, ERIC, Psych Articles, and AEducation. The databases were searched until relevant articles were repeated. A summary of database searches is detailed in Table 1 on page 17. A summary of search words used is detailed in Tables 2 to 9 (pp.17-19).

In addition to the databases, an in-depth hand search from relevant journals, articles and books from the CCS Disability Action's library was searched. Summaries of these searches are detailed in Table 1 (p. 17).

On the initial searches for the original research question the results were limited. An overview of the broader search questions; "children with disabilities in foster care" and "disabled children in foster care," received either no results, or over 1000 results with no relevant articles. The following searches: "psychosocial impact on children with disabilities in foster care," "emotional development for children with disabilities," "physical development for children with disabilities in family based foster care," "long term outcomes for children with disabilities in foster care," and "developmental issues for young children with disabilities in foster care," received a high number of results; however only a low number of relevant articles. To extend the search on the relevant articles I checked the bibliography of each article to identify other research that may have been relevant.

The searches for the second question produced articles that provided me with enough research to continue with the dissertation. An overview of the broader search questions: attachment theories, secure attachment, impact of disabilities on attachment, infant disabilities and attachment, children with disabilities and the risk of child abuse and maltreatment, child abuse and maltreatment and insecure attachment, parent attachment and child abuse and maltreatment, received high numbers of results. For the final question, I redefined the searches and included risk factors for abuse and maltreatment, parental stress and children with disabilities, professional experiences when supporting children with disabilities, social workers and disabilities. I received appropriate articles to complete the dissertation. I also checked the bibliography of each article to identify other research that resulted in more relevant articles.

Table 1 Summary of Document Search

Search Strategy	Number of relevant publications located
Database (Original Question)	
PsychInfo	0
Psychoanalytic Electronic Publishing (PEP)	1
Google scholar	4
Proquest Dissertations and Thesis	1
ERIC	1
Database (Second Question and Final Question)	
Proquest Social Science Journals	2
PsycInfo	0
Proquest Education Journals	0
Eric via Ovid	3
PsychArticles	1
CINAHL via EBSCO	3
Journals (Original Question)	
Infants and Young Children	1
Child Welfare	0
Child Psychology & Psychiatry	1
British Association for Adoption and foster care	0
Fostering Network (London)	1
Journals (Second Question and the Final Question)	
Child Abuse & Neglect (The International Journal)	3
Journal of Early Intervention	1
Child Welfare Journal	1
Infant Mental Health Journal	1
Journal of Developmental and Behavioural Paediatric	1
Journal of Clinical Child Psychology	3
Infant Behavior and Development	2
Child Health and Development	2
Books/Articles/Documents	
Ministry of Health	1
World Health Organisation	1
Research Register for Social Care	1
Welfare Reform on the Web – British Library	0
Australian Institute of Family Studies	1
Human Services Research Institute	1
Social Care Online	0
Child Welfare Information Gateway	

Table 2: Details of Database Search - PsychInfo

Search words	Combination word (s)	Results	Relevant articles
Children with disabilities in foster care		0	0 refined search
Disabled children in foster care		1090	0 refined search
Foster care	Disabilities	0	0
SECOND QUESTION AND FINAL QUESTION			
Attachment theory		1105	0 refined search
John Bowlby attachment theory	Childhood	1105	0
Mother-Infant attachment	Impact if disability	27	2
Children with disabilities	Attachment	0	0

Table 3: Details of Database Search - Psychoanalytic Electronic Publishing (PEP)

Search words	Combination word (s)	Results	Relevant articles
Children with disabilities in foster care		0	0 refined search
Disabled children in foster care		1090	0 refined search
Foster care	Disabilities	0	0
Psychosocial impact on children with disabilities in foster care		7	0 refined search
Emotional development for children with disabilities in family based foster care		44	1
Long term outcomes for children with disabilities in foster care		0	0
Physically development for children with disabilities in family based foster care		0	0 Refined search
Physically development for children	Foster care	0	0

Table 4: Details of Database Search - Google Scholar

Search words	Combination word (s)	Results	Relevant articles
Children with disabilities in foster care		86,400	Refined search
Children with disabilities in foster care dated between 2005 – 2011		16,400	2
Developmental issues for young children with disabilities in foster care		46,400	0
Long term outcomes for children with disabilities in foster care		2051	1

Table 5: Details of Database Search - Proquest Dissertations and Thesis

Search words	Combination word (s)	Results	Relevant articles
Children with disabilities in family based foster care 2005 – 2011		2029	0 refined search
Abused disabled children in foster care		1	1
Disabled children in family based foster care	Family based	1090	0
Parental Stress	Children with disabilities	11	2
Statutory agencies	Children with disabilities	48	3

Table 6: Details of Database Search - ERIC

Search words	Combination word (s)	Results	Relevant articles
Children with disabilities in family based foster care 2005 – 2011		1020	0
Long term outcomes for children with disabilities in family based foster care		2090	1
Disabled children in foster care	Family based	42	0
SECOND QUESTION AND FINAL QUESTION			
Parent Attachment	Child Abuse	2	0
Child Abuse	Insecure Attachment	4	0
Increased risk of child abuse	Children with disabilities	0	0
Disability	Child abuse	131	3

Table 7: Details of Database Search - Proquest Social Science Journals

Search words	Combination word (s)	Results	Relevant articles
Child disability	Foster care Attachment Last three years	779 182	2 refined search 1
Attachment disorders	Disabled children Foster care Last three years	150 29	0 refine search 1

SECOND QUESTION AND Final Question				
Attachment theories		17266	Refined search
Attachment theories	Types of attachment	1197	Refined search
Attachment theories	Types of attachment/John Bowlby	131	2
Children with disabilities in child welfare	Family care	9	1
Children with developmental disabilities	Foster care	127	2

Table 8: Details of Database Search - Psych Articles

Search words	Combination word (s)	Results	Relevant articles
Insecure Attachment	Child Abuse	83	Refined Search
Disable children with insecure attachment	Risk of child abuse	0	0
Impact of disabilities on attachment	Caregiver	0	0
Infant disabilities	Attachment styles	0	0
Disabled infant	Attachment styles	1	1

Table 9: Details of Database Search - CINAHL via EBSCO

Search words	Combination word (s)	Results	Relevant articles
Foster care	Children with disabilities	23	3

3. Inclusion and exclusion criteria

The third step involves selecting studies on the basis of inclusion and exclusion on criteria.

Inclusion

Dickson (2005) explained the importance of defining what research will be included before beginning the literature research. Doing so helps to ensure the "criteria are not based on the research results that you know are available" (Dickson, 2005, p. 51). The inclusion criteria should directly reflect the research question, and what type of studies will be included.

The original research question inclusion criteria included literature with a focus on children (defined as aged 0-17 years) with disabilities. I discussed definitions of disability in chapter one and used the criteria outlined. Initially the search focused on research from 2005 – 2011, however this needed to be expanded to include older articles, due to the limited relevant articles found during 2005 – 2011 period. While focusing on articles from 2005 – 2011, I began to realise the limited research available for this group of children and young people.

Also included was literature on emotional, physical growth, development, care and protection and family-based foster care. Literature from a social work perspective on this topic was also included. On searching databases with the search words "emotional

development for children with disabilities in family-based foster care," common themes were found between literature on emotional development and attachment for children in foster care.

The second and final research question inclusion criteria included literature with a focus on children (defined as aged 0-17 years) with disabilities, attachment in typical and atypical development, attachment disorder, attachment theories, impact of disabilities on attachment with caregivers, infants with disabilities and attachment styles, foster care, disabilities and child abuse and maltreatment, parent attachment and child abuse and maltreatment, parental stress, social workers experiences. The search focused on research from 1990 – 2011.

Exclusion

The original question resulted in a high proportion of the literature that discussed adoption and/or did not include experiences for children with disabilities. These studies were not included within this study. An extensive amount of information was found when the search words "children with disabilities in foster care" were searched within the databases. In reviewing the literature the common themes were learning and developmental disabilities, with limited literature on physical and sensory disabilities. Thus, due to the limited literature, physical and sensory disabilities were excluded from this study. Publications not in English were also excluded.

Within the final question, studies related to adoption or that did not include experiences for a child with disabilities, childhood mental health, any articles older than 1980, (apart from articles on attachment theory as this is still relevant today) were excluded. Again, publications not in English were also excluded.

Finally I excluded studies related to children with acquired disabilities resulting from abuse, maltreatment or accidents, for example, falls and car accidents. The exclusion was in part due to the fact that the dissertation focuses on the interactions between parents and child born with a disability, the disruption of infant-caregiver attachment, and early supports for parents of a child with disabilities.

4. Quality approval of studies

The fourth key component of the systematic review process is the quality approval of studies included (Dickson, 2005). Dickson (2005) explained that for a systematic review to be useful, it is dependent on the quality of the research included. It is important to acknowledge that not all research is conducted using the best methods;

hence each study reviewed must be assessed for the quality of its research methods. Throughout the dissertation I used Greenhalgh & Taylor's (1997) questions for critiquing the dissertation, as follows:

Is the question concise?

Does the title clearly indicate the content?

Do/does the authors(s) have recognised qualifications and/or experience?

Is a rationale for the study stated?

Is the literature up to date?

Does the literature clearly identify the need for the research proposed?

Are all terms used, clearly defined?

Does the methodology clearly state the research approach?

Is the method appropriate to the research problem?

Are the subjects clearly identified?

Are any data collection procedures adequately described?

Are results/outcomes clearly presented?

Is the discussion balanced?

Are conclusions supported by the results obtained?

Do the recommendations suggest further areas for research?

5. Extraction of data

The fifth component of the systematic process includes extraction of data (Dickson, 2005). It is important that the data extracted from the included studies be as accurate as possible, which will make it easy to use when the researcher begins to analyse the data. To assist in extracting data, I incorporated the assistance of my supervisor and colleagues in the disability sector who had an understanding of attachment and its impact on children. Together with my supervisor and colleagues I discussed the articles and data, assessed the articles and the significance of the data in term of my research questions and checked the data against inclusion and exclusion criteria.

For the final question the literature gathered was divided into: information on children with disabilities in family based foster care; and that which showed the importance of attachment for children and attachment disorders, the impact of attachment in foster care for disabled children, the impact of disabilities on attachment, the risk of maltreatment/abuse for children with disabilities, and parent attachment.

6. Synthesis of data

The sixth component of the systematic process includes synthesis of the information (Dickson, 2005). The analysis of the data will be presented in a narrative summary of findings. This provided some challenges around the need to ensure my bias was not included in the review. To ensure my bias was not included, the assistance of my supervisor and a colleague in the extraction of data became extremely important, along with the questions asked when ascertaining the quality of research and studies.

Summary

This chapter discussed the aim of the study and the concepts of qualitative research and systematic reviews. The systemic review process has been explained as it relates to this study. The reason for using a modified systematic literature review has been discussed and the process, as it relates to this study, has been explained. The next chapter will focus on the risk of abuse and maltreatment for children with disabilities and will explore theoretical models of abuse and neglect.

Chapter Three: Risk of Abuse and Maltreatment. Models of Abuse

This chapter will explore the risk of abuse for children with disabilities. Discussion will focus on the theoretical models of abuse and neglect, and social workers' experiences when supporting children with disabilities both in New Zealand and overseas.

Child abuse and maltreatment impacts more than only the child and his or her family. The cost to society such as police involvement, hospital admittance and Accident Compensation Corporation (ACC), highlights the importance for New Zealand as a society to recognise and acknowledge that child abuse and maltreatment occurs to children with or without disabilities. If, as a society, we refuse to acknowledge the existence of child abuse and maltreatment society sabotages any possibility of taking action, as well as any possibility of recognising the greater risk of abuse and maltreatment of children with disabilities.

Theoretical Models of Abuse and Neglect

There are various theoretical models of abuse and neglect. Ammerman and Galvin's (1998) description of their theoretical models of child abuse and neglect includes the contribution of certain child characteristics to the aetiology of abuse and maltreatment. Common factors include severe behavioural problems such as opposition, aggression and defiance, or other variables that elicit negative reactions from caregivers such as prolonged crying. The link between disabilities and abuse and maltreatment is based on the similarity between hypothesised "abuse- provoking" behaviours of some maltreated children and those exhibited by children with disabilities.

Ammerman, Van Hasselt, and Hersen (1988) have discussed three processes whereby children with disabilities are at a higher risk of abuse and maltreatment:
(1) disruption in the formation of infant-caregiver attachment,
(2) prolonged stress associated with raising children with disabilities,
(3) increased vulnerability to certain types of maltreatment. (p. 232)

(1) Disruption in the formation of infant-caregiver attachment

Cicchetti (1987) has suggested that there is a link between insecure attachment and abused and maltreated children and their parents/caregivers. Attachment is discussed in chapter five which also talks about the impact of disabilities on the formation of an attachment between mother and infant.

(2) Prolonged stress associated with raising some children with disabilities

Stress is discussed in chapter four as an additional risk factor in families of children with disabilities. Ammerman et al. (1988) debated that some of these children display challenging attitudes such as self injurious behaviours, aggression, hyperactivity, crying and screaming, that are resistant to intervention. The additional stress and frustration provoked by these difficulties may contribute to subsequent stress.

(3) Increased vulnerability to certain types of maltreatment

Ammerman et al. (1988) have suggested that the final risk factor associated with abuse and maltreatment in children with disabilities is vulnerability. Primarily, many children with disabilities are more vulnerable to abuse and maltreatment in that cognitive and/or communicative deficit can impact their ability to disclose information to others of the abuse and maltreatment. The greater need for personal care, special education or medical intervention may provide specific opportunities for abuse and maltreatment. For example, the reliance on others for personal cares, such as showering, dressing and toileting care.

It needs to be acknowledged that Ammerman et al.'s (1988) theoretical model of abuse and neglect is not the only one. Belsky (2002), for example, suggested three different basic theoretical models to account for abuse:

1. a psychiatric model which emphasises the role of the individual abuser;

2. a sociological model that highlights the role of social factors in abuse; and

3. a personal model which emphasises the effect of the child on the caregiver pointing toward the role the child plays in stimulating his own maltreatment.

For the purpose of this dissertation, however, Ammerman et al.'s (1988) theoretical model of abuse and neglect best captures the needs of children with disabilities who experience abuse and maltreatment and neglect. Ammerman et al.'s model identifies attachment, stress and the child's vulnerability. As this dissertation identifies, these three areas increase the risk factors of abuse and maltreatment for all children; however are more relevant for children with disabilities.

Social Workers' Experiences

In 2001 Cooke and Standen (2002) sent out a questionnaire to 121 Chairpersons of Area Child Protection Committees in the United Kingdom, to gain an understanding of

practices in recording/documenting the abuse of children with disabilities. Of the 121 questionnaires sent, 73 were returned. Over 50% claimed to identify the disability of an abused child, but only 10% could give an actual figure. The lack of statistical evidence made it impossible to calculate anything except an approximation of the rate of abuse of children with disabilities.

"Semi-structured interviews with eight of the key workers for disabled children revealed that they were concerned there was a tendency 'not to see' the abuse of disabled children, and they did not feel there was sufficient training regarding the interface between abuse and disabilities" (Cooke & Standen, 2002, p. 1).

There are a number of reasons for key workers "not to see", both consciously and subconsciously, relating to the lack of knowledge and support, but also due to potential complications that may arise such as cost, in terms of time and resources.

The eight key workers all felt that children with disabilities were likely to be at a disadvantage in relation to abuse issues. One worker stated, "the fact that they have a disability is seen first" (Cooke & Standen, 2002, p. 8) and this appears to be crucial in the recognition, or possible lack of recognition, of abuse. Bruising, for example, may be seen as a result of clumsiness or "thrashing around", while sexualised behaviour may be seen as associated with a learning disability: "They tend to do that, don't they" (Cooke & Standen, 2002, p.9) was quoted in a case of excessive masturbation, with little consideration of what might lie behind such behaviour, or the age and understanding of the child concerned.

Cooke and Standen's (2002) study lent support to the comments made by keyworkers who were interviewed: that "they did not believe children with disabilities had equal opportunities with regard to services compared with non-disabled children" (p. 8). Orelove, Hollahan, and Myles (2000) interviewed the key workers who also expressed anxiety about the lack of knowledge and training, in relation to the abuse of children with disabilities.

Summary

This chapter discussed three aspects of abuse and maltreatment. The first section discussed Ammerman et al.'s (1988) theoretical model of abuse. This model acknowledged the specific risk of abuse and maltreatment for children with disabilities. It does, however, need to be acknowledged that the model can also be relevant for any child who experiences abuse and maltreatment. The second section discussed the experiences of social workers supporting children with disabilities. It highlighted the lack of training on disabilities, needs and issues, how social workers

saw the disability first and not the child, and how abuse and maltreatment of children with disabilities can be invisible, and not seen by social workers.

This chapter also highlights the limited amount of research conducted directly with social workers on their experiences supporting and working with children with disabilities who have experienced abuse and maltreatment. It discussed the experience of a small number of social workers who shared their concerns of not seeing abuse or maltreatment due to seeing the disability first and insufficient training regarding the interface between disability and abuse. These issues highlight the need for urgent in-depth research and training for social workers involved in care and protection of children with disabilities.

In the next chapter, I will investigate the impact of a child's disability on the mother-infant attachment.

Chapter Four: Children with Disabilities and Attachment

This chapter examines the impact of a child's disability on the mother-infant attachment. Attachment has been defined in chapter one. The key themes in this chapter are parent-disabled child interactions, and parental unresolved feelings and disability.

Interactions Between Parents and Disabled Children

Howe (2006) explored the early premise of attachment theory as the child's pattern of attachment being determined by the characteristics of their caregiver, and that the child's factors did not play a significant part in their classification. However, over the past two decades this view has been modified. For example, a study by Belsky and Rovine, cited by Colin (1996) found that although "caregiver factors determined whether an infant developed a secure or insecure attachment, the child's temperament did appear to affect the manner in which the security or insecurity was expressed" (p. 95).

Ainsworth (1980) suggested there was a number of factors that may hinder a secure attachment for children with disabilities; these include frequent mother-infant separations secondary to illness and deficits in specific attachment-promoting behaviours (e.g., gaze, responsiveness) in physically and sensory-disabled children.

Studies by Susman-Stillman, Kalkoske, Egeland, and Waldman (1996) suggested that parental sensitivity might be affected by the child's temperament, for example, reactivity, temperamental difficulties, arousability and ability to self regulate. The study found that irritable infants were more likely to be classified insecurely attached, especially in disadvantaged environments, such as, when parent's economic, social and/or psychological resources are strained. Howe (2006) stated that, if disability is substituted with child's temperament, then attachments and the relationship between parent-child interactions, in the case of children with disabilities, could be explored. It could be hypothesised that the behavioural, interactional and communication characteristics of some children with certain disabilities are likely to affect the level of parental stress, quality of caregiving and therefore security of attachment.

Research and theorists such as Bowlby and Ainsworth agreed that caregivers that are sensitive and responsive to their children's communicative signals tend to have securely attached children. For children with disabilities there is evidence of increased

risk of parental stress, often based on problems of communication, understanding and interpretation (Johnston, Hessl, Blasey, Eliez, Erba, & Dyer-Friedman, 2003). Children who feel their needs are not being met by their caregivers become distressed. The child's distress can then increase the caregiver's frustration and stress. Stress associated with caregiving can activate the caregiver's own attachment-based defences, including any unresolved attachment issues (Mitchell & Sloper, 2002). The cycle of parental stress due to problems of communication and the child's distress, when their needs are not met, impacts on the security of attachment between caregiver and infant.

Howe (2005) stated it is ironic that children with disabilities who require sensitive caregiving could challenge their parents' ability to provide such care, due to potential challenging care needs and behaviours, limited interactional and communication characteristics. Moran, Pederson, Pettit and Krupka (1992) found that for a group of parents with developmentally delayed children, their ability for maternal sensitivity and security of attachment were low. They speculated that,

> it is likely that these low levels of sensitivity and attachment are related to the developmentally delayed infants' relative inability to provide the stimuli and responses necessary to support sensitive interaction with caregivers . . . The developmentally delayed children in this sample were perceived by their mothers to be difficult and to present more parenting problems that is typical in nondelayed populations. (p. 439)

Stone and Chesney (1978) have suggested that for children with disabilities there is increased risk of reduced parental sensitivity, protection, attunement and availability, resulting in more children with disabilities to be classified as insecurely attached. A growing body of research also concludes that children with a variety of disabilities and congenital medical conditions are more likely to be classified as insecurely attached (Cicchetti & Pogge-Hesse, 1982; Cicchetti & Sroufe, 1978; Clements & Barnett, 2002; Moran et al., 1992).

A review of seven studies on children with disabilities by Barnett, Hunt, Butler, McCaskill, Kaplan-Estrin, and Pipp-Siegel (1999), found that children with neurological problems, classified as insecurely attached, ranged between 20% and 33% compared to 15% of children typically developing. Children with congenital problems consistently averaged less than 50% securely attached compared with a rate of 65% found in typically developing children. Their review, however, also found that the increased severity of a child's disability does not actually predict increased risk of

insecurity. In-fact there is indications that children with more severe disabilities have an increased rate of security. One explanation for this suggests that when a child's disability is unquestionably present, parental recognition, understanding and acceptance increase, and expectations are therefore more realistic.

It would be easy to suggest that the presence of a disability alone can increase the risk of insecure attachment. However, there is evidence that suggests that the presence of a disability on its own does not simply predict an insecure attachment. Parenting quality partially mediates the relation between the child's disability and attachment security (Clements & Barnett, (2002). If parents remain mindful, reflective, available and emotionally attuned to their child, their child is likely to be securely attached.

Parental Unresolved Feelings and Disability

Research conducted on whether parental reactions to their child's diagnosis were affected by whether or not they had resolved their feelings about their child's disability, explored the idea of attachment insecurity among children with disabilities being linked with parental resolution to their child's diagnosis (Barnett et al., 1999). A key finding from Barnett et al.'s (1999) research was that children whose parents were "unresolved" with respect to their child's diagnosis, were nearly three times more likely to be rated more insecure than those whose parents were "resolved". Parents who have unresolved feelings toward their child's disability have decreased levels of sensitivity and emotional attunement, thereby undermining their child's sense of security at times of need.

Howe (2006) examined how an unresolved feeling with respect to trauma and loss can be triggered by a variety of emotionally difficult experiences, such as the birth of a child with a disability. When a parent is unable to resolve the trauma and loss, their unresolved state of mind with respect to attachment will be triggered during routine care-giving interactions with their child. This can result in decreased parental availability and attunement, resulting in an increase risk of the child having an insecure attachment, especially disorganized attachment. For each time the unresolved parent experiences further loss and distress, such as delays in their child meeting developmental milestones, grief is reactivated and with it, the related risk of insensitive caregiving.

The finding from Pianta, Marvin, Britner & Borowitz's (1996) study indicates that parental resolution versus non-resolution was strongly linked with secure versus insecure child-parent attachment. Parents who had worked through their grief, loss

and held realistic mental representation of their child and the implications for their care-giving role were more likely to have securely attached children. However parents who remained unresolved around their child's disability had decreased emotional availability, which increased the risk of insecure or disorganised parent-child interactions.

The study opens up the concept that neither child nor parental factors alone are likely to be fully accountable for the increased risk of abuse and maltreatment faced by children with disabilities. It is likely that vulnerability factors on both sides of the interactional exchange will be present for abuse or maltreatment to occur. Insecure parents with unresolved losses and traumas are at risk of being overwhelmed by their child's attachment needs, resulting in them being unavailable and insensitive to their child's distress. At these times, the child feels even more vulnerable, frightened, alone and hyper-aroused. The attachment system is therefore left in a highly activated state with no immediate prospect of being terminated. The parent and child become locked in a mutual escalation of unregulated arousal. In extreme cases, this leads to out-of-control parental hostility and/or helplessness (Pianta, et al. 1996). Thus, children with disabilities who are cared for by parents with unresolved feelings, with respect to attachment, are likely to be at heightened risk of one or more forms of distressed, out-of-control care-giving, which can result in abuse and maltreatment of the child with a disability.

Howe (2006) has suggested that a critical time to support parents to work through unresolved feelings towards their child's diagnosis is when they are first told of their child's diagnosis. Parents, who receive sensitive supports at this time are more likely to accept their children and as a result are more likely to be less distressed and more attentive and positive toward their child than parents who are not helped through the early days.

Summary

This chapter has discussed the interactions between parent-child with a disability and the impact of that interaction on the parent-child attachment relationship. It explored the difficulties behavioural, interactional and communication characteristics of some children with certain disabilities are likely to have on parental stress, quality of caregiving and therefore security of attachment. Finally it explored the impact on attachment when parents have unresolved feelings with regard to their child's

diagnosis. The following chapter will explore more in-depth the link between parental stress and abuse and maltreatment of children with disabilities.

Chapter Five: The Link between Parental Stress and Abuse and Maltreatment for Children with Disabilities

This chapter examines the link between parental stress and abuse and maltreatment for children with disabilities. The literature revealed three themes: the additional challenges for parents when a child is born with a disability, the crisis of diagnosis when parents are informed, and the link between stress, abuse and maltreatment.

For the purpose of this dissertation, stress is defined as, "a function of the interaction of the subjectively defined demands of a situation, and the capacity of an individual or group to respond to these demands. Stress exists when the subjectively experienced demands are inconsistent with response capabilities" (Straus & Kantor, 1987, p. 46). The definition suggests that some life events, in this case the child's disability, produce a certain but unknown degree of demand on parents. It also implies that the population of children with chronic conditions may invoke a level of stress over a long period of time.

Additional Challenges for Parents when a Child is Born with a Disability

Typically the birth of a child brings joy, excitement, and the end of a period of expectation about the unborn child. It also brings with it new challenges and responsibilities for parents as they adjust to the new family member (Brooks, 1987). For a child born with a disability, there are a host of not only new, but also additional challenges for parents. Featherstone (1980) described how the adjustment period might be more difficult. Additional demands may be placed on the parents due to the need for medical care, developmental or educational services, and basic care-giving needs. The adjustments may not only be more pronounced, but also prolonged, as families accommodate and adjust to the new demands, that arise over the years with the growing child.

Pelchat, Ricard, Bouchard, Perreault, Saucier, Berthiaume and Bission, (2001) have discussed the key questions that parents are likely to continue to revisit as their child matures, and as the child and family undergo transitions in school, and other life experiences. Questions often focus on practical concerns, such as: (1) how to support their child, and provide an environment that maximises his or her development; (2)

how to access and ensure that the child receives the services and supports necessary, to succeed in their school, and life outside of school; (3) how to cope with the various demands and expectations, that come with having a child with a disability; and (4) how to understand the cause and characteristics of the child's condition. Parents also have other questions that perhaps reflect deeper concerns with meaning and purpose in life: (1) how can I make sense out of why this happened to my child? (2) what does it mean for my life and me? and (3) what is its meaning in the larger world?

Although most parents may have similar questions for their child without a disability, for some parents of children with disabilities they may find these questions around demands, supports, and what it means for their own lives more challenging.

Crisis of Diagnosis

Hanson and Hanline's (1990) research related to the

> effects of the birth of a child with a disability [which] focuses on the crises of diagnosis when parents are informed, the period of adjustment that follows, the behaviour of professionals that either supports or hinders the family, and the child and parents characteristics that may affect the adaptation process. (p. 234)

Hanson and Hanline's research indicated, that a wide variety of factors may contribute to both the adaption and stress experienced by families of disabled children, for example, the child's characteristics such as age, diagnostic category, care giving demands and behavioural characteristics; along with the parent's ability to cope with stressors in general and parental beliefs about the cause of disabilities.

Fortier and Wanlass (1984) explored the crisis following the diagnosis of a child with a disability and how it affects the family on many levels. Immediately, the family may need to provide care for their child, transportation to treatments, altering previous family routines, and having to meet new financial needs. On an affective level, the parents begin to work through feelings of grief, anger, guilt, helplessness and isolation. On a physical or sensory level, psychosomatic symptoms may arise as a result of stress of the crisis experience. On an inter-personal level, family may have to deal with labelling and stereotyping, a sense of isolation from others, handling 'helpfulness' from friends and extended family, and having to provide support to other family members. Finally on a cognitive level, parents are required to assimilate technical information about the disability, and deal with the impact of the diagnosis on established values and expectations.

Link between Stress and Abuse and Maltreatment

Benedict, Wulff and White (1992) have suggested that families of children with disabilities are at higher risks of stress related to the caretaking needs associated with the child's disability. I would hypothesise that this stress may increase the risk of parents abusing or maltreating their child(ren).

Crnic, Friedrich and Greenberg, (1983) argued that parents of children with disabilities, have greater stress than families with nondisabled children. Their levels of stress may vary over time and may be influenced by the type of disability, severity of the disability and the parental coping patterns. Psychosocial stressors, such as parental depression or chronic life events including financial, marital, employment, or housing issues, may influence parents coping mechanisms.

Stress has also been linked to child abuse and maltreatment (Egeland, Breitenbucher, & Rosenberg, 1980; Justice & Calvert, 1985). Theories of the aetiology of child abuse and maltreatment note the role of stress, in terms of the stress of poverty that may be associated with abuse and maltreatment, child abuse as one response to family, and environmental stress and the concept that a child with a disability may be at increased risk for abuse and maltreatment. Camblin (1982) suggested children with disabilities are represented, and perhaps over represented, in abused and maltreated populations. The suggestion from Benedict et al.'s (1992) study indicates that:

> families with a history of maltreatment would be likely to report higher levels of stress associated with the care of their disabled children, as compared to families without a child maltreatment history. In addition, it was hypothesised that abusive families might show higher levels of stress than neglecting families. (p. 156)

Martin (1982) has suggested that severely disabled children are at lower risk for abuse and maltreatment, than children with moderate or mild disabilities. This may be linked to families experiencing less stress levels when the outcome is definite, rather than when the outcome is not clear. Parents of children with moderate or mild disabilities, perhaps expect more of their child, than they would for children who are severely disabled. Such reasoning suggests that parents of children with moderate to mild disabilities may be subject to considerable added frustration when their children do not function up to parental expectation. Parents of severely disabled children may reconcile to the disability, and not expect increased improvement from their child over time.

Summary

In this chapter, three themes were discussed: 1) the additional challenges for parents, when their child is born with a disability, 2) the 'crisis of diagnosis' addressed the impact on the family immediately after the diagnosis, and through life transitions, and 3) the link between stress, abuse and maltreatment. It also addressed the link between the parent's ability to cope with stressors, and the child's disability, their characteristics and behaviours. The next chapter will discuss fostering children with disabilities, the additional challenges, and will explore a model of family-based foster care in Finland, which has a high success rate in fostering children with disabilities.

Chapter Six: Fostering Children with Disabilities

In this chapter I will critically analyse what "supports and challenges" are involved in fostering a child with disabilities, within a family-based foster care environment. I will focus on a model of specialised family care for children with disabilities in Finland, compared to foster care in New Zealand. I am using the model in Finland, as it is a model that demonstrates the high success rate of professional family-based foster care, there are fewer placement breakdowns, resulting in children with disabilities having a secure and safe family environment in which to grow and develop. This model has potential to be adapted and implemented within New Zealand. Finally, in the following chapter, I will discuss "where to next?" in New Zealand.

For the purpose of this dissertation, family-based foster care is described as a residence owned or rented by a family as their home (Hauber, Bruininks, Hill, Lakin, & White, 1984).

Additional Challenges for Children with Disabilities Requiring Foster Care

Waldman, Perlman and Lederman (2007) stated that, "the very systems intended to protect children in crisis were simply not designed to identify, assess, and manage the physical, emotional, and cognitive disabilities of children with special needs" (p. 20). All children and young people in foster care are vulnerable; they are at risk of abuse, maltreatment and permanent separation from birth-parents and have a greater incidence of emotional and behavioural difficulties. This is not surprising, given they have been abused, maltreated and/or abandoned by the very people meant to protect, love and care for them. They are removed from their homes and often placed with strangers in new environments. Children removed from their homes and family, often want to return despite the reasons for removal. Children with disabilities in foster care are as vulnerable, if not more, and at risk due to the additional issues they face, such as disrupted mother-infant attachment, increased vulnerability and higher levels of parental stress resulting from caring for a child with a disability (Waldman, Perlman and Lederman 2007) (as discussed in Chapter 5).

Throughout this dissertation, attempts have been made to clarify the relations between child maltreatment, abuse and children with disabilities; however definitive answers remain elusive. Some researchers, for example, Crosse, Kay and Ratnofsky

(1993) have also attempted to clarify the relationship without sourcing definitive answers. Available data gathered suggests that children with disabilities are at greater risk for abuse and maltreatment than children without disabilities (Hansen, Mawjee, Barton, Metcalf, & Joyce, 2004). Children with disabilities are likely to remain in care longer and experience more placement breakdowns in foster care. They are less likely to experience family reunification than children without disabilities (Rosenberg & Robinson, 2004). I would suggest the higher level of placement breakdowns in foster care and the reduction in family reunification could be linked to the limited training and support given to foster-carers and to biological families when transitioning a child back into the biological family's care.

In New Zealand, it is not common for CYF or non-government foster care agencies to recruit, train, support and focus on the needs of children with disabilities. As a result, the challenges of the required emotional and physical care increase the likelihood of placement breakdowns, resulting in a reduction of a secure and settled placement.

Family-Based Foster Care in Finland

Szymanski and Seppala (1990) described the benefits of family-based foster care such as the inclusion of the foster child into a family life and into the community. Family-based foster care, combined with use of community resources, the provision of a personalised home environment, and improvement in adaptive behaviours provides the child with a secure and safe living environment. However there is potential for negative factors such as "tendency of the foster parents to overprotect the [child] … and to encourage dependency" (Symanski & Seppala, 1990, p. 368).

Szymanski and Seppala (1990) explored family care in Finland. Finland has a tradition of providing extensive social services, chiefly through municipalities or confederations of several municipalities. The central government reimburses the municipalities for up to 60% of the cost of these services. Since the 1980s foster carers caring for children with disabilities were recognised as important, and were conducting a professional task. Caregivers were given professional status, including commensurate salaries and benefits. Quality standards were developed and specific supports, training, and supervision were given to foster carers. Any start up costs may be granted for initial expenses such as purchase of furniture, or remodelling to make the house accessible for children with disabilities. The foster carers receive benefits such as retirement insurance, one free weekend each month, and four weeks of paid

vacation. These entitlements may sound extensive, however the cost of "family care is approximately 60% of the cost of institutional care and 75% of the cost of well-staffed, intensive group home care" (Symanski & Seppala, 1990, p. 371).

Currently, in New Zealand, foster carers recruited by CYF are reimbursed for the care of the child. This includes a small board payment to cover living costs such as electricity and food. They are allocated a quarterly allowance for clothing; and medical costs are reimbursed, along with funding for birthday and Christmas presents. The amount funded is dependent on the child's age. CYF social workers are required to visit the foster care family and the child in care once every 90 days.

Szymanski and Seppala (1990) discussed family care placements in Finland as being long-term. A child or young person is placed for a trial period and the professionals make a final decision after two to four months. The foster carers receive the necessary initial and ongoing guidance and training from the social worker in charge of family care and from other professionals, such as psychologists. They also attend specialised courses, such as in psychology training and special education, with the federation covering related expenses, including hiring sitters to care for the child.

Szymanski and Seppala (1990) explained that in the previous five years before they conducted their study, only three or four children were removed from a foster care home: "In one case, the foster parents were abusing alcohol; in another case the family did not have the physical strength to handle an autistic, very restless child" (Symanski & Seppala, 1990, p. 372). The primary objective of Finnish family care is to provide children with supportive and loving homes. "The fostered child is seen as any other child with disabilities in the community living with his or her own families, and receives the same services from the community facilities, such as health care, education in public schools, and specialised therapies" (Symanski & Seppala, 1990, p. 372).

Finally Szymanski and Seppala (1990) broke down the Finland specialised family care into five key features that contribute to the success of the foster care placement. They are as follows:

The agencies.
Agencies do not approve foster care families solely to provide them with a source of income.

Professionalism of the foster care family

Foster parents' training, as well as their own parenting skills and experience, are seen as important if not more important than the training of agency workers. Foster parents are expected to pursue ongoing training and personal development. A significant positive outcome to the professionalism of foster care families is the impact for biological families. Biological families are less likely to see the placement as evidence of their failure as parents. It has produced less hostility between foster and biological families and permits the child to maintain a relationship with his/her biological family.

Economic factor

Well-funded family care may be less expensive than group care and offers financial saving to the society, both directly and indirectly, by preventing placement breakdowns, institutionalisation and hospitalisations.

Lesser restrictions of family care

Compared to group homes or residential schools, children in family-based foster care are more included within their local community and belong to a family.

The potential permanency of this care model

This care model increases the potential for permanency for the child, due to them belonging in a family environment and being included into their local community
The Finland Specialized family care for children with disabilities is a model of foster care that should be investigated more fully, and adapted to meet the needs of children with disabilities in New Zealand. Currently in New Zealand, children with disabilities are at times invisible, over-represented in foster care and experience a high number of placement break downs. Foster carers have limited support and training, which results in burnout of foster carers. Although Finland's model may not fully fit with New Zealand's society and culture, it is a great starting point to address the current issues facing children with disabilities in foster care.

Summary

In this chapter I have discussed what supports and challenges are involved in fostering a child with disabilities within a family-based foster care environment. The findings from the research in Finland captured the high success rate of professional

family-based foster care. It identified the importance of support and training for foster carers to ensure the needs of the child are being met. The final chapter will explore 'where to next' in New Zealand.

Chapter Seven: Where to Next in New Zealand?

In this concluding chapter I will explore possible options for 'where to next' for New Zealand.

New Zealand is currently struggling to meet the needs of children with disabilities in foster care.

Resourcing and educating social workers involved in care and protection needs to be a priority. This includes training, support and supervision around the specific needs of children with disabilities who have experienced abuse or maltreatment, to ensure social workers are able to identify abuse and maltreatment and then implement the best practices to support these children.

In New Zealand, the Ministry of Social Development (2011) statistical report on reports of child abuse and maltreatment did not distinguish between children with or without disabilities. As a result children with disabilities can remain invisible, even when they are placed on the child protection registers. The Ministry of Social Development needs to begin documenting and recording statistics on reports of abuse and maltreatment against children with disabilities. This will contribute towards ensuring appropriate resources are allocated to meet the needs of children with disabilities.

Early supports and interventions are required for families at the time of the birth or time of diagnosis of their child with a disability. Increased parental stress and the impact of an insecure attachment between mother-infant could be minimised if families receive early support and intervention to assist and guide them through the crisis of diagnosis, the additional stress, frustration, grief and uncertainty for the child's future. Reduced parental stress and a secure attachment can reduce the risk of child abuse and maltreatment.

New Zealand needs to acknowledge child abuse and maltreatment occurs for all children. Once this occurs, New Zealand as a society can address the issue of child abuse and maltreatment. No one-government agency, community agency medical profession or school can tackle child abuse and maltreatment. Society as collective needs to address child abuse and maltreatment and care for our most vulnerable citizens, our children.

As a result of this study I have identified the need for further research as this study raises a significant issue for society, government and its agencies of failing to identify, and in doing so, overlooking the basic care needs of a vulnerable population.

Summary

The aim of this dissertation was to answer the question: What are the risk factors in the abuse and maltreatment of children with disabilities? From this question a second question falls out, i.e., "what are the best practices to support children with disabilities who experience abuse and maltreatment?"

The findings from this dissertation are congruent with my 6 years experience of supporting children with disabilities who experience abuse and maltreatment. Children with disabilities are more at risk of abuse or maltreatment, reporting of child abuse or maltreatment is lower for children with disabilities due to the complexities of identifying abuse or maltreatment. Early supports for parents/caregivers are crucial at time of diagnosis to limit parental stress and support them through the crisis of diagnosis. Finally the support for foster carers of children with disabilities, need to be specific for the child and the foster carers to reduce placement breakdowns.

In chapter three models of disabilities were explored to identify the risk of abuse and maltreatment for children with disabilities. The findings from the research highlighted the gap in training of social workers about disability issues and supporting children with disabilities who experience abuse and maltreatment. This gap needs to be addressed immediately in New Zealand, with social workers working in care and protection requiring training around identifying abuse and maltreatment of children with disabilities. Training would include supporting social workers to see the child first, not the disability, would support social workers in communicating with children with disabilities and reduce the fear of the unknown.

In chapter four the impact of a child's disability on the mother-infant attachment was discussed, along with the impact of parents having unresolved feelings towards their child's disability. It was noted that parents who had unresolved feelings were nearly three times more likely to be rated as having a child with insecure attachment. The findings identified the critical need for early supports at the time the family finds out about their child's disability. Parents who receive sensitive supports at this time are more likely to accept their child and are more likely to be less distressed and more attentive and positive toward their child than parents who do not receive early sensitive supports.

In chapter five the link between parental stress and abuse and maltreatment for children with disabilities was examined. Three themes were explored: the additional challenges for parent when a child is born with a disability, the crisis of diagnosis when parents are informed, and the link between stress, abuse and maltreatment.

Chapter six critically analysed what supports and challenges are involved in fostering a child with disabilities within a family-based foster care environment. The findings from the research in Finland captured the high success rate of professional family-based foster care. It identified the importance of support and training for foster carers to ensure the needs of the child are being met. The success rate of the Finland family-based foster care, warrants a review within New Zealand on how foster carers are recruited, supported and reimbursed for the valuable work they do for children who experience child abuse and maltreatment, whether or not they have a disability.

Chapter seven also made possible suggestions on where to next in supporting children with disabilities in New Zealand, including resourcing and training for social workers involved in care and protection, the need for New Zealand gathers data on children with disabilities requiring care and protection to ensure children with disabilities do not remain invisible and so they receive the supports and resources required to meet needs. Finally, New Zealand needs to acknowledge child abuse and maltreatment occurs for all children, and that not one-government agency, community agency, medical profession or school can tackle child abuse and maltreatment. Society as a collective, must address child abuse and maltreatment.

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