RESILIENCE IN THE PRESENCE OF FRAGILE X SYNDROME – A MULTIPLE CASE STUDY

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Promoter: Prof. L.C. Theron

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DECLARATION

I declare that the thesis entitled: **RESILIENCE IN THE PRESENCE OF FRAGILE X SYNDROME – A MULTIPLE CASE STUDY** is my own work. It is submitted for the PHILOSOPHIAE DOCTOR degree to the North-West University, Vanderbijlpark. It has not been submitted before for any degree or examination at any other university.

_____ _____

Name Date

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ABSTRACT

RESILIENCE IN THE PRESENCE OF FRAGILE X SYNDROME – A MULTIPLE CASE STUDY

Promoter: Prof. L.C. Theron

Department: Educational Psychology

Degree: PhD (Educational Psychology)

The purpose of this study was to explore what contributes to resilience in females diagnosed with Fragile X Syndrome. Fragile X Syndrome can be defined as an inherited (genetic) condition that causes mental impairment, attention deficit and hyperactivity, anxiety and unstable mood, autistic behaviours, hyper-extensible joints, and seizures. I became aware of Fragile X Syndrome during my time as a live-in caretaker to an adolescent female who was diagnosed with Fragile X Syndrome. Because she coped with her disability so resiliently, I was encouraged to explore what contributes to resilience in females diagnosed with Fragile X Syndrome.

I followed a qualitative approach, anchored in the interpretivist paradigm. This means that I tried to understand the resilience of females diagnosed with Fragile X Syndrome through the meanings that the participants in my study assigned to them. Furthermore, I worked from a transformative paradigm, which meant that I was interested in changing the traditionally negative ways in which females diagnosed with Fragile X Syndrome are seen. I followed a multiple case study approach, which included four case studies. I conveniently selected the first participant, but realised that convenience sampling was not very credible for a qualitative case study. An Advisory Panel was then used to purposefully recruit three more participants. In order to explore what contributed to their resilience, I made use of interviews, observations, and visual data collection. I also interviewed adults (e.g. parents, teachers and consulting psychologists) who were significantly involved in the lives of my participants.

My findings suggest that resilience in females with Fragile X Syndrome is rooted in protective processes within the individual as well as within her family and environment. Because my findings do not point to one specific resource, my study underscores newer understandings of resilience as an ecosystemic transaction. Most of the resilience-promoting resources noted by the participants in my study as contributing to their resilience have been identified as resilience-promoting in previous studies. Although the themes that emerged in my study have been reported in resilience previously, I make a contribution to theory because I link traditional resilience-promoting resources to resilience in females diagnosed with Fragile X Syndrome.

Peer support was previously reported as a resilience-promoting resource, but in my study I noticed that the main source of peer support came from peers who were also disabled. Furthermore, my study transforms how we see females diagnosed with Fragile X Syndrome. This transformation encourages communities and families to work together towards resilience in females diagnosed with Fragile X Syndrome.

LIST OF KEY WORDS

- Resilience
- Protective resources
- Fragile X Syndrome
- Ecosystemic
- Qualitative research

OPSOMMING

VEERKRAGTIGHEID IN DIE TEENWOORDIGHEID VAN FRAGIEL X- SINDROOM – ‘n VEELVOUDIGE GEVALLESTUDIE

Promotor: Prof. L.C. Theron

Departement: Skool vir Opvoedkundige Wetenskappe

Graad: PhD (Opvoedkindige Sielkunde)

Die doel van hierdie studie was om vas te stel watter faktore bydra tot veerkragtigheid in vrouens met Fragiel X-Sindroom. Fragiel X-Sindroom kan gedefinieer word as ‘n oorerflike (genetiese) toestand, wat verstandelike verswakking, aandagafleibaarheid en hiperaktiwiteit, angs, wisselende buie, outistiese gedrag, hiper-verlengde gewrigte, en toevalle veroorsaak. Ek het van Fragiel X-Sindroom bewus geword gedurende my tydperk as oppasser van ‘n jong meisie met Fragiel X-Sindroom. Die feit dat sy so goed kon aanpas ten spyte van haar ongeskiktheid, het my aangemoedig om navorsing te doen oor watter faktore bydra tot veerkragtigheid in vrouens met Fragiel X-Sindroom .

Ek het ‘n kwalitatiewe benadering gevolg, geanker in die interprevistiese paradigma. Dit beteken dat ek probeer het om die veerkragtigheid van vrouens wat met Fragiel X-Sindroom gediagnoseer is, te verstaan deur middel van die betekenis wat die deelnemers in my studie daaraan verleen het. Voorts het ek vanaf ‘n transformatiewe paradigma gewerk, wat beteken dat ek die tradisionele negatiewe wyse waarop vrouens met Fragiel X-Sindroom gesien word, wou verander. Ek het ‘n veelvoudige gevallestudiebenadering gevolg wat vier gevallestudies ingesluit het. Ek het geriefshalwe die eerste deelnemer gekies, maar het besef dat geriefsmonsterneming nie baie geloofwaardig vir ‘n kwalitatiewe gevallestudie sou wees nie. ‘n Adviserende Paneel is gebruik om nog drie deelnemers te werf. Ek het gebruik gemaak

van onderhoude, waarnemings en visuele dataversameling om te bepaal watter faktore tot hul veerkragtigheid bydra. Ek het ook onderhoude gevoer met volwassenes (bv. ouers, onderwysers en raadgewende sielkundiges) wat beduidend by die deelnemers se lewens betrokke was.

My bevindings dui daarop dat veerkragtigheid in vrouens met Fragiel X-Sindroom in beskermende prosesse in die individu self, asook in haar familie en omgewing gesetel is. Omdat my bevindings nie net op een spesifieke hulpbron dui nie, onderstreep my studie ‘n nuwere verstaan van veerkragtigheid as ‘n ekosistemiese transaksie. Die meeste van die hulpmiddels om veerkragtigheid te bevorder - wat deur die deelnemers in my studie as bydraend tot hul veerkragtigheid aangedui is - is al in vorige studies as sodanig geïdentifiseer. Alhoewel die temas wat in my studie te voorskyn gekom het al voorheen in studies oor veerkragtigheid aangedui is, lewer ek ‘n bydrae tot teorie omdat ek tradisionele hulpmiddels wat veerkragtigheid bevorder, verbind met veerkragtigheid in vrouens met Fragiel X-Sindroom.

Portuurondersteuning is al voorheen as ‘n hulpbron tot die bevordering van veerkragtigheid aangeteken, maar in my studie het ek waargeneem dat die hoofbron van portuur-ondersteuning kom van eweknieë kom wat ook gestremd is. Verder transformeer my studie die wyse waarop vrouens met Fragiel X-Sindroom gesien word. Hierdie transformasie kan gemeenskappe en gesinne/families aanmoedig om saam te werk om veerkragtigheid in vrouens met Fragiel X-Sindroom te bevorder.

LYS VAN SLEUTELWOORDE

- Veerkragtigheid
- Beskermingshulpmiddels
- Fragiel X-Sindroom
- Ekosistemiese
- Kwalitatiewe navorsing

TABLE OF CONTENTS

DECLARATION ..... **ii**

ACKNOWLEDGMENTS ..... **iii**

ABSTRACT ..... **iv**

OPSOMMING ..... **vi**

TABLE OF CONTENTS ..... **viii**

LIST OF TABLES ..... **xiv**

LIST OF FIGURES ..... **xv**

LIST OF PHOTOS ..... **xvi**

CHAPTER ONE **1**

OVERVIEW AND RATIONALE **1**

1.1 INTRODUCTION **2**

1.2 RESEARCH FOCUS **3**

1.3 RESEARCH QUESTIONS **4**

1.4 RESEARCH AIM **4**

1.5 RESEARCH PARADIGM **5**

1.6 SYNOPSIS OF METHODOLOGY **7**

1.6.1 Literature study **7**

1.6.2 Research design **9**

1.6.2.1 Qualitative research 9

1.6.2.2 Participants 10

1.6.2.3 Data collection 10

1.6.2.4 Data analysis 11

1.6.2.5 Rigour of the study 12

1.6.2.6 Ethical aspects 12

1.7 PREVIEW OF CHAPTERS 13

1.8 CONCEPT CLARIFICATION 13

1.9 CONCLUSION 15

CHAPTER TWO 16

THE NATURE OF RESILIENCE 16

2.1 INTRODUCTION 16

2.2 RESILIENCE DEFINED: OUTCOME AND PROCESS 18

2.3 THE PROCESS OF RESILIENCE 22

2.3.1 Risks threatening resilience 25

2.3.2 Protective resources 28

2.3.2.1 Individual 29

2.3.2.2 Family 33

2.3.2.3 Community 35

2.3.2.4 Culture 37

2.4 CONCLUSION 39

CHAPTER THREE 40

THE PHENOMENON OF FEMALES WITH FULL MUTATION FRAGILE X SYNDROME 40

3.1 INTRODUCTION 41

3.2 DEFINING FRAGILE X SYNDROME 41

3.3 THE CHARACTERISTICS OF FRAGILE X SYNDROME 43

3.3.1 Physical characteristics 43

3.3.2 Behavioural and emotional Issues 47

3.3.3 Speech and language development 51

3.3.4 Sensory integration 53

3.3.5 Cognitive Development 56

3.4 ACCOMMODATING INDIVIDUALS WITH FRAGILE X SYNDROME 60

3.5 CONCLUSION 62

CHAPTER FOUR 63

RESEARCH DESIGN AND METHOD 63

4.1 INTRODUCTION 64

4.2 RESEARCH AIM 64

4.3 PARADIGMATIC APPROACH REVISITED 64

4.4 RESEARCH DESIGN AND METHOD 65

4.4.1 Literature study 65

4.4.2 Research design 66

4.4.2.1 Case study research 70

4.4.2.2 Participants 74

4.4.2.2.1 Background of primary participants 78

4.4.2.2.2 Background of secondary participants 81

4.4.2.3 Data collection 82

4.4.2.3.1 Interviews 85

4.4.2.3.2 Observations documented as field notes 89

4.4.2.3.3 Research Journal 92

4.4.2.3.4 Visual data collection 92

4.4.2.3.5 Data collection process 93

4.4.2.4 Data analysis 96

4.4.2.5 Rigour of the study 100

4.4.2.6 Ethical aspects 102

4.5 CONCLUSION 105

CHAPTER FIVE 106

RESULTS OF EMPIRICAL RESEARCH 106

5.1 INTRODUCTION 107

5.2 INTRAPERSONAL ANTECEDENTS 107

5.2.1 Self-determination 107

5.2.2 Ability to ask for help 109

5.2.3 Tenacity 110

5.2.4 Social inclination 112

5.2.5 Self-knowledge 115

5.2.6 Academic progress 117

5.2.7 Humour 119

5.2.8 Sunny temperament 121

5.2.9 Empathy for others 122

5.2.10 Role-play/fantasy 125

5.2.11 Peacefulness and privacy 127

5.2.12 Imperviousness 128

5.3 INTERPERSONAL ANTECEDENTS 130

5.3.1 Familial protective resources 130

5.3.1.1 Supportive family members 130

5.3.1.2 Parental encouragement and high expectations 136

5.3.1.3 Parental understanding 138

5.3.1.4 Love and acceptance 142

5.3.1.5 Family quality time and shared activities 144

5.3.2 Community Resources 146
5.3.2.1 Supportive school 147
5.3.2.2 Peer support 159
5.3.2.3 Professional community 163
5.3.2.4 Enlightened, well-resourced community 167
5.3.3 Cultural Resources 175
5.3.3.1 Religious activities 175
5.4 DISCUSSION OF FINDINGS 180
5.5 RECOMMENDATIONS 186
5.5.1 Recommendations for families 186
5.5.2 Recommendations for communities 187
5.5.3 Interactivity of resources 189
5.6 CONCLUSION 190

CHAPTER SIX 192
CONCLUSION AND RECOMMENDATION 192
6.1 INTRODUCTION 193
6.2 AIMS REVISITED 193
6.3 CONCLUSIONS FROM THE LITERATURE STUDY 196
6.3.1 The nature of resilience 196
6.3.2 Fragile X Syndrome from a risk perspective 199
6.4 CONCLUSIONS FROM THE EMPIRICAL STUDY 199
6.5 LIMITATIONS OF THE STUDY 205
6.6 CONTRIBUTIONS MADE BY THE STUDY 206
6.7 RECOMMENDATIONS FOR FURTHER STUDY 207
6.8 CONCLUSION 208

REFERENCES 212

ADDENDUM A 241

ADDENDUM B 254

ADDENDUM C 279

ADDENDUM D 283

ADDENDUM E.....289

LIST OF TABLES

Table 1.1: Overview of relevant literature sources 7

Table 2.1: Summary of risk factors 27

Table 3.1: Example of a typical conversation with an individual diagnosed with Fragile X Syndrome 52

Table 3.2: Example of a typical conversation with an individual diagnosed with Fragile X Syndrome 53

Table 4.1: A summary of the different types of qualitative research designs 69

Table 4.2: Summary of the strengths and limitations of case studies 71

Table 4.3: Steps in conducting a case study 72

Table 4.4: Advisory Panel members' definitions of resilience 75

Table 4.5: Summary of barreirs 80

Table 4.6: Summary of the advantages and limitations of interviews 87

Table 4.7: Summary of the advantages and limitations of observations 91

Table 4.8: Summary of the process of data collected 93

Table 4.9: Steps in data analysis 96

Table 6.1: Aims governing this study 193

Table 6.2: Summary individual protective processes of empirical study 200

Table 6.3: Summary of familial protective resources of empirical study 202

Table 6.4: Summary of community protective resources of empirical study 203

Table 6.5: Summary of cultural protective resources of empirical study 204

LIST OF FIGURES

Figure 1.1: Overview of chapter one 1

Figure 2.1: Overview of chapter two 16

Figure 2.2: The process of resilience 24

Figure 3.1: Overview of chapter three 40

Figure 3.2: Summary of physical characteristics 47

Figure 3.3: Summary of emotional and behavioural issues 51

Figure 3.4: Summary of sensory integration issues 56

Figure 3.5: Summary of cognitive development difficulties 60

Figure 4.1: Overview of Chapter Four 63

Figure 4.2: Research process 67

Figure 4.3: Summary of the primary participants and data collection techniques used 84

Figure 5.1: Overview of Chapter Five 106

Figure 5.2: Summary of findings 180

Figure 6.1: Overview of Chapter Six 192

Figure 6.2: Resilience depends on interaction between inter- and intrapersonal resources 198

LIST OF PHOTOS

Photo 5.1: Walking down the stairs independently, with determination 108

Photo 5.2: Lucy socializing with friends before her prom 113

Photo 5.3: Melissa, Cindy, and Lucy interacting with my sister and I ... 114

Photo 5.4: Lucy and friends imitating 'Goofy', showing her sense of humour 121

Photo 5.5: Lucy helping out a friend, showing empathy 123

Photo 5.6: Lucy and a friend role-playing 126

Photo 5.7: Lucy at occupational therapy 132

Photo 5.8: Lucy showing that she has overcome her fear of dogs, thanks to her mother's continuous encouragement and high expectations for her to overcome her fear. 138

Photo 5.9: Lucy with her family and extended family spending quality time together as a family during a trip to Israel 146

Photo 5.10: Lucy's school offering occupational therapy 150

Photo 5.11: Lucy with her favourite teacher after their school play 156

Photo 5.12: Lucy tying her own shoe laces 160

Photo 5.13: Lucy and her four friends shopping together 161

Photo 5.14: Lucy, Melissa, and Cindy together with their consulting psychologist, my sister and I 166

Photo 5.15: Lucy taking part in the Independence Day Parade 169

Photo 5.16: Lucy with her camp counsellors 171

Photo 5.17: Lucy working on her balance with her personal trainer 172

Photo 5.18: Lucy together with some of the leading researchers in Fragile X Syndrome Movement 173

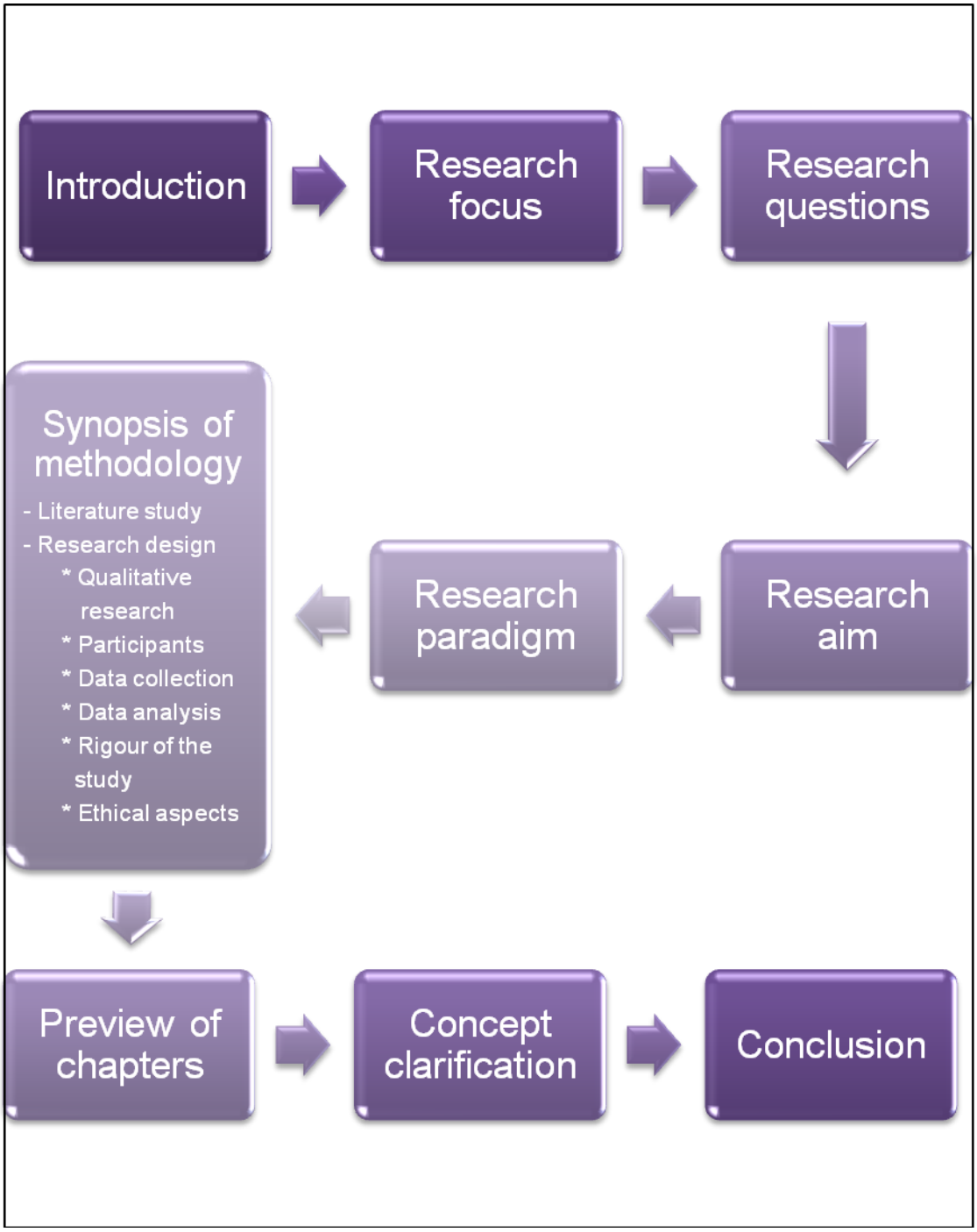
Photo 5.19: Lucy at her confirmation ceremony 178

Photo 5.20: Lucy lighting a candle during a Hanukah ceremony 179

CHAPTER ONE

OVERVIEW AND RATIONALE

Figure 1.1: Overview of chapter one



2.1 INTRODUCTION

According to Theron (2006:199), life can be an awkward experience for individuals who have to cope with disabilities. They are constantly faced with struggles (Segal, 1986:4). Because many individuals faced with disabilities have difficulty coping with their circumstances, they often develop dysfunctional behavioural patterns (Theron, 2006:199). One such disability is Fragile X Syndrome (Braden, 1996:3; Hagerman & Hagerman, 2002:30; Reiss & Hall, 2007:663).

Fragile X Syndrome is a hereditary condition that often leads to learning problems in both males and females. It is the most common known cause of inherited mental impairment (Dyer-Friedman, Glaser, Hessl, Johnston, Huffman, Taylor, Wisbeck & Reiss, 2002:237; Finucane, McConkie-Rosell & Cronister, 2002:5; Kesler, Lightbody & Reiss, 2008:403). Symptoms that can be associated with Fragile X Syndrome are mental impairment, attention deficit and hyperactivity, anxiety and unstable moods, autistic behaviour, hyper-extensible joints, and seizures (Braden, 1996:10; Clapp & Tranfaglia, 2007:1; Hagerman & Hagerman, 2002:3; Hessl, Dyer-Friedman, Glaser, Wisbeck, Barajas, Taylor & Reiss, 2001:1; Heyman, 2003:1). I could find very few studies that suggested that individuals with Fragile X Syndrome lead full or satisfying lives. Because I prefer to look for the positives and because I am aware that many adolescents who are challenged by difficult lives bounce back and demonstrate resilience (Masten, 2001:227), I became aware of the need for a research study that changed how Fragile X Syndrome is understood.

In order for an individual with Fragile X Syndrome to be resilient she has to be characterised by good outcomes in spite of threats to her development (Luthar, Cicchietti & Becker, 2000:543; Masten, 2001:228; Masten & Reed, 2005:77; Schoon & Bynner, 2003:22). The resilient individual with Fragile X Syndrome is able to bounce back from the adversities she faces due to Fragile X Syndrome.

2.2 RESEARCH FOCUS

It has been found that in the United States of America, approximately 1 in every 4000 males and 1 in every 6000 to 8000 females are affected by Fragile X Syndrome (Jewell, 2008:2; Quercia, 2002:1366). Other researchers state that Fragile X Syndrome occurs in one out of every 2000 to 5000 live births (Dyer-Friedman *et al.,* 2002:237; Glaser, Hessl, Dyer-Friedman, Johnston, Wisbeck, Taylor & Reiss*,* 2003:21; Hessl *et al.,* 2001:1). Although this is not a high incidence, Fragile X Syndrome is associated with multiple, rigorous challenges (Ashley-Koch, 2003:39; Dyer-Friedman *et al*., 2002:237; Jewell, 2008:3; Orloff, 2008:67; Quercia, 2002:1366-1367), as mentioned above.

The context of my study is somewhat unique: During the study I was employed as a live-in caretaker to an adolescent female (Lucy) who had been diagnosed with full mutation Fragile X Syndrome. Before I met Lucy I had never heard of Fragile X Syndrome. In order to prepare for my time as live-in carer to a female with Fragile X Syndrome, I began to read up on Fragile X Syndrome.

I did some extensive reading on Fragile X Syndrome and came to the conclusion that a great deal of the literature often concentrated on males diagnosed with Fragile X Syndrome due to fact that males are more severely affected than females (Saunders, 2000:114). I also did not find much research on what helps females diagnosed with Fragile X Syndrome to cope resiliently with their disabilities. I began to believe that this opportunity provided me with a unique opportunity to gather data on females with Fragile X Syndrome and to explore what might empower females to cope resiliently with Fragile X Syndrome.

When I met Lucy and came to know her, I was impressed with how resiliently she coped with the many challenges of her disability. Her example did not match what I had read because even though she struggled, she bounced back and coped well with her life. What I read emphasised the negative aspects of Fragile X Syndrome.

Literature in general and more especially on Fragile X Syndrome has often focused on deficits. This is at odds with a positive psychology approach

(Seligman, 2005:3-8). Mertens (2009:25) states that “positive psychology as a theoretical framework changes the focus from one of mental illness to one of mental health”. I chose to adopt a positive psychology framework for my study, with specific emphasis on resilience theory.

Resilience refers to individuals demonstrating positive adaptation even though they might face significant risks or adversity (Masten & Reed, 2005:75). In order for individuals to be seen as resilient, they must have experienced some kind of risk or threat, overcome the risk and demonstrate positive outcomes (Masten, 2001:228; Masten & Reed, 2005:77). Given that Fragile X Syndrome is a complex syndrome that typically places individuals diagnosed with this syndrome at risk for negative outcomes, I began to wonder what would helped individuals like Lucy to be resilient despite their living with Fragile X Syndrome. I wanted the focus of this study to be on finding positive features within their challenging experience (Mertens, 2009:25). In so doing, I hoped to transform how researchers, medical practitioners, therapists and teachers conceptualise living with Fragile X Syndrome (Mertens, 2009:10). Even though the females diagnosed with Fragile X Syndrome may have many difficulties, I wanted to determine what factors enable them to cope resiliently.

2.3 RESEARCH QUESTIONS

The above led to the following research questions:

- What is resilience?
- What is the impact on a female diagnosed with Fragile X Syndrome?
- What might encourage resilience in females diagnosed with Fragile X Syndrome?

2.4 RESEARCH AIM

The aim of this study was to explore what contributes to resilience in females diagnosed with Fragile X Syndrome.

The aim was then further sub-divided into sub-aims, namely:

- To conduct a literature study on resilience;
- to conduct a literature study on Fragile X Syndrome;
- to conduct an empirical study to determine what might encourage resilience in females diagnosed with Fragile X Syndrome;
- to provide recommendations for parents and communities to encourage resilient functioning among females diagnosed with Fragile X Syndrome.

2.5 RESEARCH PARADIGM

Paradigm refers to the way a world view is described (Maree & Van der Westhuizen, 2007:33; Mertens, 2009:44). In other words, it refers to the way in which we formulate our beliefs and assumptions about the world. There are various frameworks from which researchers can work. Within the transformative paradigm (Mertens, 2009) (as mentioned in my research focus) I approached my study from an interpretivist perspective (Nieuwenhuis, 2007a:58-60).

The interpretivist perspective attempts to understand a phenomenon through the meanings that people assign to them (Nieuwenhuis, 2007a:59). Knowledge arises from conclusions about observable phenomena, but also from people describing their intentions, belief systems, values and reasons, meaning-making and self-insight (Henning, Van Rensburg & Smit, 2004:20). Within an interpretivist perspective, the aim is to generate a perspective of a situation, to examine the situation (to look for the way in which people find meaning in their lives), and to comment meaningfully on the ways in which a particular group of people make sense of their situation (Henning *et al.,* 2004:20; Nieuwenhuis, 2007a:60). In other words, interpretivist paradigm means that I am interpreting what they tell me, but I also understand that what they tell me is their interpretation of reality. This perspective located my work in the post-modern realm (Nieuwenhuis, 2007a:63-64).

In qualitative research I am the researcher, the instrument through which the data are collected and analysed (Nieuwenhuis, 2007a:60). Henning *et al.* (2004:19) state that the researcher is a “co-creator of meaning” in research.

Therefore it is inevitable that the researcher will influence the interpretation of the data to some extent (Leedy & Ormrod, 2005:151; Nieuwenhuis, 2007a:56). The question then arises: “How do we know that I am not biased?” The interpretive researcher realises that observations are fallible and have error and that all theory is revisable (Henning *et al.,* 2004:19-20). It is not possible to eliminate biases completely, but a way in which I could lessen it, was to state my assumptions upfront. Therefore I would make my assumptions about the topic known so that others can evaluate if my conclusion were influenced by my assumptions (Leedy & Ormrod, 2005:5).

My assumptions were as follows:

I believed that individuals can be resilient because of:

- their internal locus of control; optimism; and self-determination to succeed;
- their desire to be supported and accepted by others (family, peers, community);
- having set high standards for themselves, but also by their family, school, community;
- their participation in their family, school, community, and culture;
- attachments and processes that could protect them from vulnerability and promote resilient functioning.

In my interpretation I wanted to transform how we conceptualise females living with Fragile X Syndrome. Strength is often overlooked (Mertens, 2009:18). A situation commonly believed to be “difficult” is transformed by understanding the phenomenon and then to concentrate on the positives (Mertens, 2009:25). The victim is not blamed, and the participants are not powerless to change (Mertens, 2009:10). I chose to focus on finding positive features within the challenging experience of females living with Fragile X Syndrome (Mertens, 2009:25). Based on this framework, I focused on the positives or the protective resources that encouraged resilience, rather than on the risk that the participants faced. This meant that I had to be doubly careful not to overlook evidence that contradicted my transformative, positive approach.

2.6 SYNOPSIS OF METHODOLOGY

This study contains both a literature overview and a qualitative research design. These are summarised below and will be discussed in detail in Chapter Four.

2.6.1 Literature study

Relevant literature was surveyed and an overview of the literature sources used is tabulated below:

Table 1.1: Overview of relevant literature sources

Resilience	Ahern *et al.*, 2008 Anderson, 2008 Armstrong *et al.*, 2005 Atkinson *et al.*, 2009 Besthorn, 2005 Berger, 2008 Benard, 1999 Bottrell, 2007 Boyden & Mann, 2005 Brooks & Goldstein, 2005 Cameron *et al.*, 2007 Cicchetti, 2003 Donnon & Hammond, 2007 Evans & Prilleltensky, 2005 Fergus & Zimmerman, 2005 Fergusson & Hammond, 2003	Ginsburg & Jablow, 2006 Goldman, 2004 Heath *et al*., 2008 Hjemdal, 2007 Kaplan, 2005 Kim-Cohen, 2007 Koller & Lisboa, 2007 Kumpfer, 1999 Lee & Tay-Koay, 2008 Lewis & Frydenberg, 2002 Luthar, 2005 Luthar *et al*., 2000 Mampane, 2005 Masten, 2001 Masten & Powell, 2003 Masten & Reed, 2005 McMurray *et al*., 2008 Naglieri & LeBuffe, 2005 Newman, 2005	Oliver *et al.,* 2006 Oswald *et al.,* 2003 Perkins & Borden, 2003 Place *et al*., 2002 Schoon, 2006 Schoon & Bynner, 2003 Schroeder, 2008 Segal, 1986 Siqueira & Diaz, 2004 Taub & Pearrow, 2005 Ungar, 2004; 2005; 2006; 2007; 2008a; 2008b Ungar *et al*., 2008 Ungar & Liebenberg, 2005 Vaillant, 1993 Vanderbijl-Adriance & Shaw, 2008 Winslow *et al.*, 2005 Yates *et al*., 2003 Yates & Masten, 2004

Risks and protective processes	Armstrong *et al*., 2005 Boyden & Mann, 2005 Brooks, 2005 Brooks & Goldstein, 2004 Crawford *et al*., 2005 Cunningham & Glenn, 1985 Donnon & Hammond, 2007 Fergusson & Horwood, 2003 Fergusson & Lynskey, 1996 Ginsburg, 2006 Glicken, 2006 Greene & Conrad, 2002 Hamill, 2007 Hauser-Cram & Krauss, 2004 Hjemdal, 2007 Johnson & Lazarus, 2008	Kaplan & Owens, 2004 Kim-Cohen, 2007 Kim-Cohen *et al.,* 2004 Lachiewicz & Mirrett, 2000 Lantieri, 2008 Masten & Reed, 2005 McMurray *et al*., 2008 Mills & Dombeck, 2007 Morales, 2008 Murray, 2003 Naglieri & Lebuffe, 2005 O'Dougherty Wright & Masten, 2005 Oliver *et al*., 2006 Owens & Shaw, 2003 Peres *et al*., 2007 Richardson, 2002 Rodger & Ziviani, 2006	Schoon, 2006 Scott, 2008 Siquiera & Diaz, 2004 Smith & Drawer, 2008 Spender *et al.*, 2001 Theron, 2004 Ungar 2005 Ungar, 2008a Ungar, 2008b Ungar & Liebenberg, 2005 Ungar *et al.*, 2008 Vanderbilt-Adriance & Shaw, 2008 Willoughby *et al*., 2003 Winslow *et al*., 2005 Yates *et al.*, 2003 Zimmerman & Arunkumar, 1994
Fragile X Syndrome	Anon, 2007a Ashley-Koch, 2003 Barry, 2007 Finucane *et al*., 2002 Fraxa, 2008 Genetixs Home Reference, 2007	Hagerman, 2000 Hagerman & Hagerman, 2002 Harris-Schmidt & Fast, 2004 Jewell, 2004; 2008 National Fragile X Foundation, 2007	Orloff, 2008 Quercia, 2002 Reiss & Hall, 2007 Roley, 2004 Saunders, 2000 Sherman, 2003 Wallis, 2008
The impacts of Fragile X Syndrome	Anon, 2007a Biavati, 2006 Braden, 1996; 2000; 2004a; 2004b	Hagerman, 2002 Harris-Schmidt & Fast, 2004 Helgoe *et al*., 2005	Rachman, 2004 Reiss & Hall, 2007 Stackhouse, 2004 Tyrer, 1999

	Gerzon, 1997 Hagerman, 2000	Jewell, 2008 Merrell, 2008	
Accommo-dating Fragile X Syndrome	Hagerman & Hagerman, 2002	Harris-Schmidt & Fast, 2004	

Clearly, the above summary of sources illustrate that no study referred specifically to the resilience being present in females with Fragile X Syndrome. This is the gap my study addressed.

2.6.2 Research design

After having clarified the research question, a method needs to be selected that will help answer the question being researched (Fade, 2003:139). Trochim (2002:1) explains that research design holds the research project together. It organises facts, gathers data, and therefore structures the research project, so that all the major parts of the research are clearly shown. It provides a plan to address the central research question. The design used in this study was a qualitative research design. I describe the design in detail in Chapter Four and so I only overview the most salient parts below:

2.6.2.1 Qualitative research

Qualitative research can be defined as an in-depth study that enables the researcher to understand human beings, how they view and understand the world, and to construct meaning out of their world (Leedy & Ormrod, 2005:95; Nieuwenhuis, 2007a:51; Merriam, 1998:5). In other words, it refers to the researcher "seeing through the eyes of the participants" (Nieuwenhuis, 2007a:51).

In this study, I followed a multiple case study approach (Merriam, 1998:40). Case studies can be defined as a descriptive, in-depth approach aimed at gaining greater understanding of and insight into the dynamics of a specific situation over a defined period of time (Leedy & Ormrod, 2005:165; Nieuwenhuis, 2007b:75-76; Merriam, 1998:19; Mertens, 2009:174). A multiple case study approach concentrates on more than one case study (Leedy &

Ormrod, 2005:135). As stated previously, to the best of my knowledge there are no current studies on what might empower a female individual diagnosed with Fragile X Syndrome to cope resiliently.

2.6.2.2 Participants

I include four case studies. The participants were all American, Caucasian females, between the ages of 16 and 29, who had been diagnosed with full mutation Fragile X Syndrome, and were seen as resilient. Convenience sampling took place with the first primary participant (Lucy) as I was a live-in carer for her. The other three primary participants (Melissa, Cindy and Kelly) were identified as resilient by an Advisory Panel (AP). The AP consisted of three members (a parent and two professionals), and they were all members of the Fragile X community. Thus purposeful sampling (Maree & Pietersen, 2007:178) was used with the other three primary participants. I then approached the identified additional participants (primary participants) and also their involved adults (secondary participants) to participate in my study. The AP also knew Lucy and confirmed that they experienced her as resilient.

2.6.2.3 Data collection

Merriam (1998:91) states that in qualitative research, interviewing is often a major source for understanding the phenomenon that is under study.

I interviewed the three primary participants (as chosen by the AP) and made use of semi-structured interviews (Merriam, 1998:75). The interview questions were based on open-ended questions (Merriam, 1998:74). Much like a conversation, they were flexible and exploratory. The basic questions asked during the interviews were as follows:

- How does FXS impact on your life?
- What mitigates/buffers/softens these impacts (protective factors)?
- What in you personally helps to buffer the impacts of FXS?
- What in your family helps to buffer the impacts of FXS?
- What in your school helps to buffer the impacts of FXS?
- What in your friends helps to buffer the impacts of FXS?

- What in your community helps to buffer the impacts of FXS?
- What in your culture helps to buffer the impacts of FXS?

I also observed the three primary participants and was able to collect visual data such as photographs and video clips.

I observed Lucy continuously, as I lived with her. I recorded my observations in a reflection journal (Henning *et al.,* 2004:81-100; Merriam, 1998:94-111). I also interviewed Lucy, and once again made use of semi-structured interviews, based on open-ended questions. The basic questions that were used were the same as those used with the other three primary participants (as stated above).

I also interviewed the involved adults (i.e. parents, teacher, tutor and consulting psychologist) of the four primary participants. I also made use of semi-structured interviews with the involved adults. The basic questions were as follows:

- How does FXS impact on her life?
- What mitigates/buffers/softens these impacts (protective factors)?
- What in her personally helps to buffer the impacts of FXS?
- What in her family helps to buffer the impacts of FXS?
- What in her school helps to buffer the impacts of FXS?
- What in her friends helps to buffer the impacts of FXS?
- What in her community helps to buffer the impacts of FXS?
- What in her culture helps to buffer the impacts of FXS?

A copy of an interview with a primary and also secondary participant is included in Addendum B and the rest of the interviews are available upon request.

2.6.2.4 Data analysis

Inductive qualitative analysis was primarily used to organise, code and categorise the data which had been collected in the study (Henning *et al.,* 2004:104-109; Leedy & Ormrod, 2005:32; Lincoln & Guba, 1985:202; Maree

& Van der Westhuizen, 2007:37; Nieuwenhuis, 2007c:99 & 107). Firstly, the interviews that were conducted were transcribed (Henning *et al.,* 2004:104). I then read through all the interviews in order to get a global impression of the content (Henning *et al.*, 2004:104; Nieuwenhuis, 2007c:105). The interviews were then coded (Henning *et al.*, 2004:104; Nieuwenhuis, 2007c:105). The codes that were selected were influenced by what I understood about resilience (*Cf*. Chapter Two), the impact of Fragile X Syndrome on females (*Cf.* Chapter Three), and also my experience as a live-in caretaker for a female individual who had been diagnosed with Fragile X Syndrome. This means that although my primary approach was inductive (I looked for issues within the data that shed light on how females with FXS coped resiliently), there was also some deductive coding. Merriam (2008) comments that coding is often inductive and deductive. The related codes were then grouped, using axial coding (*Cf*. Addendum B), into themes that explain how protective resources encourage resilience among the participant (Henning *et al.*, 2004:104). I did the same (i.e. conducted primarily inductive coding) with my observations, research journal and visual data.

2.6.2.5 Rigour of the study

In qualitative research trustworthiness is considered of the utmost importance (Nieuwenhuis, 2007c:113; Merriam, 1998:198). According to Lincoln and Guba (1985:991), credibility, applicability, dependability and confirmability are considered the key criteria for trustworthiness. In addition I triangulated multiple sources of data. I pursued trustworthiness rigorously in my study (as documented in 4.4.2.5).

2.6.2.6 Ethical aspects

Research should be conducted ethically. These ethical aspects should include standard ethical respect for participants, these being (at the very least) protection from harm, informed consent, privacy, and honesty (De Vos, Strydom, Fouche & Delport, 2005:58; Leedy & Ormrod, 2005:101). I discuss these in detail in 4.4.2.6.

2.7 PREVIEW OF CHAPTERS

Chapter One: Overview and rationale. This chapter consists of a general summary of the study.

Chapter Two: The nature of resilience. This chapter will focus on the nature of resilience and it will focus on the protective processes that influence an individual's ability to function resiliently.

Chapter Three: The phenomenon of girls with Fragile X Syndrome. This chapter will focus on the phenomena of females diagnosed with Fragile X Syndrome and what the impact is of this syndrome on the individual's life.

Chapter Four: Research design and method. The aims, objectives and methods of research are outlined.

Chapter Five: Results of empirical research. In this chapter I present the research results in an effort to answer my research questions.

Chapter Six: Conclusion and recommendation. A conclusion regarding the empirical and literature study is given in this chapter. I also state my limitations and recommendations for further study.

2.8 CONCEPT CLARIFICATION

For the purpose of this study the following concepts are clarified:

- ***Resilience***

Resilience refers to a dynamic process that is characterised by good outcomes in spite of serious threats to development (Luthar *et al.,* 2000:543; Masten, 2001:228; Masten & Reed, 2005:77; Schoon & Bynner, 2003:22). It is a dynamic, positive developmental process between individuals, their environment, culture, psychological and physiological processes (Benard, 1999:270; Boyden & Mann, 2005:9; Cameron, Ungar & Liebenberg, 2007:285; Evans and Prilleltensky, 2005:407; Hjemdal, 2007:306; Kim-Cohen, 2007:272; Koller & Lisboa, 2007:342; Lee & Tay-Koay, 2008:241; Schoon, 2006:6; Siqueira & Diaz, 2004:150; Ungar, 2005:xxviii). In other words, it is

seen as both a process and an outcome, a dynamic give and take that helps individuals to bounce back from challenging circumstances.

- ***Protective resources***

Protective resources are seen as variables that buffer the impact of risk on an individual's life to reduce the potential for negative outcomes (Fergus & Zimmerman, 2005:399; Kim-Cohen, 2007:272; Murray, 2003:18; Seidman & Pedersen, 2003:319; Ungar, 2004:348; Winslow, Sandler & Wolchik, 2005:338).

- ***Risks***

Risks can be defined as characteristics, traits and experiences that increase the likelihood that individuals will manifest negative developmental outcomes (Armstrong, Birnie-Lefcovitch & Ungar, 2005:276; Boyden & Mann, 2005:6; Mash & Wolfe, 2005:17; Masten & Powell, 2003:7; Murray, 2008:21; Schoon, 2006:5; Seidman & Pedersen, 2003:318; Theron, 2006:201; Theron, 2008:216).

- ***Fragile X Syndrome***

Fragile X Syndrome is an inherited (genetic) condition. It is seen as the most common inherited cause of mental impairment. This condition leads to a wide range of mental impairment, from mild learning disabilities to severe mental retardation (Anon, 2007a:1; Finucane *et al*., 2002:5; FRAXA, 2008:1; Hagerman, 2000:9; Hagerman, 2002:7; Hagerman & Hagerman, 2002:30; Harris-Schmidt & Fast, 2004:9; Jewell, 2008:2 of 10; National Fragile X Foundation, 2007:1; Orloff, 2008:67; Reiss & Hall, 2007:663; Sherman, 2003:55; Wallis, 2008:47).

- ***Full mutation***

Everyone has an FMR1 gene and there should be approximately 5 to 50 CGG repeats. However, the number of CGG repeats in individuals with Fragile X Syndrome is 200 or more. This is called full mutation (Anon, 2007a:1; Hagerman, 2000:9; Hagerman & Hagerman, 2002:3, Harris-Schmidt & Fast, 2004:12 & 118; Quercia, 2002:1366).

2.9 CONCLUSION

In this chapter a general overview of the study was provided. The focus and aim of the study were explained. My study worked from the transformative paradigm (Mertens, 2009:10-21), which means that I concentrated on the positives rather than the deficits. Even though females diagnosed with Fragile X Syndrome face various difficulties, this does not mean that they cannot be resilient in the face of these difficulties. Therefore, by working from the transformative paradigm, this study would try to find out which processes were involved in making these young women more resilient. The following chapter will discuss the process of resilience in detail.

CHAPTER TWO

THE NATURE OF RESILIENCE

Figure 2.1: Overview of chapter two

3.1 INTRODUCTION

All human beings experience difficulties. No-one is exempt. Every life has its drama, crisis or tragedy (Grotberg, 1995:6; Segal, 1986:4). When life is hard, adolescents often demonstrate negative outcomes from being exposed to

stressful and harmful environments (Garbarino, 2005:xi). Environments are potentially harmful when they are characterised by adversity. Adversity comes in various forms. Boyden and Mann (2005:3) state that adversity can be a result of “social or political strife, environmental tragedy, individual omission or commission or many other causes”. According to Boyden and Mann (2005:3) and Theron (2006:199), under such circumstances life can be a demanding and difficult experience for adolescents, often characterised by continuous hardship.

One form of adversity that makes it difficult for adolescents to cope, is disability. Murray (2003:16) states that several studies have shown that adolescents with high-incidence disabilities (i.e. emotional-behavioural disorders, learning disabilities, and mild intellectual disabilities) have been found to experience poor outcomes. It has been found that adolescents with high-incidence disabilities tend to have lower rates of employment, earnings, rates of postsecondary school attendance, and rates of independent living status, than do adolescents without disabilities. Adolescents with emotional and behavioural disorders also tend to have high rates of school dropout, high imprisonment rates, low rates of employment and post-secondary school attendance (Murray, 2003:23). Adolescents with mild mental retardation experience many similar problems after high school. However, several investigations suggest that adolescents with mild mental retardation are even more likely than adolescents with learning disabilities and emotional and behavioural disorders to experience poor outcomes (Murray, 2003:17).

However, even adolescents exposed to the most extreme and harsh conditions can overcome adversity and have healthy adult outcomes (Murray, 2003:18). When adolescents are exposed to adversity and respond adaptively or achieve healthy outcomes, they are thought to be resilient (Ahern, Ark & Byers, 2008:32; Anderson, 2008:63; Berger, 2008:94; Bottrell, 2007:600; Donnon & Hammond, 2007:450; Masten & Reed, 2005:3; Murray, 2003:18; Newman, 2005:227; Oliver, Collin, Burns & Nicholas, 2006:1; Schoon, 2006:6; Ungar, 2008b:218). Those individuals who are able to conquer adversity or distress and move on and establish fruitful and productive lives are seen as resilient (Ungar, 2005:xxviii).

What intrigues many researchers is why some individuals adapt positively to life's challenges (Hurd, 2004:339; Luthar *et al*., 2000:573; Murray, 2003:18; Place, Reynolds, Cousins & O'Neill, 2002:162). This chapter will focus on defining resilience, explaining resilience as a process, specify certain risks threatening resilience and describe and discuss possible resources to ensure positive outcomes despite facing diversity. It will try to help create an understanding of what makes adolescents healthy when growing up facing various risks.

3.2 RESILIENCE DEFINED: OUTCOME AND PROCESS

In essence, resilience refers to positive development in children and youth (and even adults) when faced with adversity (Ungar, 2008b:218). Nevertheless, literature lacks a single operational definition of resilience (Davidson, 2006:26).

According to Goldman (2004:1); Place *et al.* (2002:162); and Vaillant (1993:284), resilience means to be able to "spring back" after being impacted by stress, adversity, trauma or tragedy. In other words, it can be seen as the ability to recover from negative experiences.

Resilience is a person's ability to keep going during hard times, to overcome adversity and therefore continue along a path of normal development (Ginsburg & Jablow, 2006:4; Goldman, 2004:1; Naglieri & LeBuffe, 2005:108; Oswald, Johnson & Howard, 2003:50; Schroeder, 2008:1; Taub & Pearrow, 2005:358; Ungar, 2007:3; Winslow *et al.,* 2005:337).

According to Barton (2005:135); Berger (2008:94); Besthorn (2005:122); Masten (2004:7-8); and Ungar (2004:347), resilience is considered to be a multidimensional construct which typically manifests in the form of the following dimensions:

- Overcoming odds: This refers to the way in which an individual achieves positive outcomes even though she[1] might be living within a high-risk environment. For example, a child living in poverty is exposed to family violence and has little available resources to enable her to overcome these stressors and lead a satisfying life.
- Sustained competence under stress: This refers to the coping skills that an individual obtains when facing adversity. For example, some adolescents exposed to violence within their families are able to cope with the risks and still continue to maintain internal and external equilibrium.
- Recovery from trauma: This refers to an individual following a healthy development pathway even though she experienced trauma. For example, an individual that survived a natural disaster is scarred by the experience but not devastated, and is capable of continuing a meaningful life after the tragedy.

Resilience can therefore only occur in the presence of difficult life circumstances and is manifested when a young person 'does well' (Ungar, 2010) despite these difficulties. The definitions above make it clear that resilience is evident in positive outcomes, despite contexts of adversity. The focus is more on strengths than deficits. Resilience therefore refers to an individual's ability to not just deal with but to conquer unfortunate drawbacks, or significant threats and maintain healthy adjustments (Atkinson, Martin & Rankin, 2009:138; Fergus & Zimmerman, 2005:399; Kaplan, 2005:42; Kim-Cohen, 2007:271).

Nevertheless, resilience is not seen as a fixed concept. Luthar *et al.* (2000:543) and Schoon and Bynner (2003:22) define resilience as a dynamic process, rather than a single outcome. It is a dynamic, positive developmental process between individuals, their environment, culture, and psychological and physiological processes (Benard, 1999:270; Boyden & Mann, 2005:9;

[1] I will refer to the female gender in this study. However, this is for stylistic purposes only and unless explicitly stated to the contrary, also refers to male adolescents.

Cameron *et al.*, 2007:285; Evans & Prilleltensky, 2005:407; Hjemdal, 2007:306; Kim-Cohen, 2007:272; Koller & Lisboa, 2007:342; Lee & Tay-Koay, 2008:241; Schoon, 2006:6; Siqueira & Diaz, 2004:150; Ungar, 2005:xxviii). Resilience is therefore considered as changeable in nature (Berger, 2008:4; Luthar, 2005:3). In other words, individuals might be resilient in certain situations, but not resilient in others, depending on the situation. For example, a child might have strong academic skills but experience difficulty with interpersonal skills. Luthar (2005:3) explains that this scenario might be commonly found amongst at-risk individuals. Due to the fact that the individual might experience success in one area, but simultaneously experience hardship in another, the individual might not experience any success without the mediation of protective resources (Winfield, 1991:41).

The idea that resilience is a process encouraged by protective resources was not part of how resilience was initially understood. Masten (2001:227) states that the study of resilience has undergone many changes. She concludes that some of the original assumptions were wrong or at least misleading, especially the idea that resilience related to only individual strengths. Resilience was once thought of as a special characteristic of an individual (Brooks & Goldstein, 2005:4; Kim-Cohen, 2007:272; Luthar *et al.,* 2000:544; McMurray, Connolly, Preston-Shoot & Wigley, 2008:300). For example, Benard (quoted by Grotberg, 1995:2) thought resiliency to be an innate capability, a human capacity. Researchers stated that every human being is capable of acquiring a resilient mind-set. They suggested that developing a resilient mind-set would enable the individual to deal with and cope with stressor in her life (Brooks & Goldstein, 2005:4). For example if the individual was optimistic and assertive she was seen as possessing the necessary intrinsic strength to be resilient. The concern that has occurred in considering resilience as an individual trait is that it places blame on any individual who fails to overcome adversity or risk (Fergus & Zimmerman, 2005:405).

Later on, resilience was seen as an individual's ability to cope with adversity, stressors or trauma because of the mitigating protective factors within the family and environment. Even though protective factors from outside the individual were now taken into consideration as impacting on the development

of resilience, it was still seen as the individual's responsibility to ensure resilience (Luthar *et al.,* 2000:544; McMurray *et al.*, 2008:300-301; Richardson, 2002:308).

More recently it has been suggested that resilience is not a trait of an individual, even though individuals demonstrate resilience in their behaviour and life patterns (Masten & Powell, 2003:4; Schoon & Bynner, 2003:22). According to Cicchetti (2003:xix), more recently researchers have not only been interested in determining who develops well in the midst of adversity, but they also aim to understand how resilient individuals cope. The focus has shifted to explaining in detail the processes that resilience involves, both in adolescents and their communities (Ungar, Brown, Liebenberg, Cheung & Levine, 2008:2).

In line with this more recent understanding of resilience as a process, it has come to be defined as a "process of navigation and negotiation" (Ungar *et al*., 2008:2). Ungar *et al*. (2008:2) explain that resilience involves the individual as well as the individual's environment. It does not involve the one or the other, but both simultaneously. This means that young people should aspire towards (navigate towards) health resources that might protect them against the potential negative impacts of the adversities they are facing. For example, when an adolescent growing up in extreme poverty navigates towards resources that might strengthen her to cope with her difficult circumstances, she might approach service providers in her neighbourhood or ask to be part of a support group at school. However, the adolescent cannot navigate towards resources if they are not there. It is therefore also up to the families, communities, and governments to provide or negotiate for appropriate protective resources (Ungar, 2010; Ungar *et al.*, 2008:1). Internal resources (within the adolescent; e.g. the willingness to ask for help) and external resources (within the adolescent's ecology; e.g. support groups) are therefore necessary to encourage resilience (Donnon & Hammond, 2007:451; Heath, Toste & Zinck, 2008:40). A resilient individual is the one who therefore, when under stress, is able to access health resources, including the attachments necessary to growth, and one who makes the most of accessible health

resources (Cameron *et al*., 2007:288). As such, resilience is an ecologically embedded bi-directional process (Lerner, 2006:40).

After having presented the history of defining resilience, I chose the framework of my study to be based on this latest definition of resilience, which refers to resilience as a process and an outcome that needs individual input, as well as culturally appropriate inputs from the individual's family, community and culture (Ungar, 2008a:22-23) towards encouraging resilience. The child must be able to navigate towards health enhancing resources, but the individual's family, community and culture must also be able to provide health sustaining resources. Ungar (2008a:22-23) suggests that resilience can only occur if these resources (be it individual and/or ecological) are within reach of the individual.

3.3 THE PROCESS OF RESILIENCE

As stated above, resilience can no longer be viewed as a fixed concept or a personality trait. Resilience now refers to both a process and an outcome. According to Masten and Obradovic (quoted by Atkinson, Martin & Rankin, 2009:139) the development of resilience involves a variety of attributes, not only a fixed concept or process but also a "complex family of concepts". Kumpfer (as quoted by Perkins & Borden, 2003:386) formed a resilience framework that integrated the work of Bronfenbrenner (1983) and Rutter (1987) in order to explain the process of resilience. According to Kumpfer (1999:183-215) this resilience framework includes the following steps:

An individual experiences stress or trauma. The risk factor then threatens the well-being of the individual and initiates the resilience process (Kumpfer, 1999:183; Theron, 2008:218). Before the individual has experienced any stress or trauma, she is considered as being in an equilibrium or homeostatic state. The process begins, once the individual experiences stress or trauma, disturbing the homeostatic state, and therefore creating disequilibrium in the individual (Mampane, 2005:21-22). When an individual experiences a great amount of anxiety, she no longer feels "fine" or "OK". She experiences an imbalance and the process of resilience has started. It is important to note that

what one individual might experience as a minor stressor might be a major stressor to another. This all depends on the level of protective resources that are available in the environment, which leads us to the next step, but also the individual's perceptions and cognitive evaluation of the problem, which will be discussed later (Boekaerts, 2002:403; Kumpfer, 1999:185; Lewis & Frydenberg, 2002:420).

The environment plays a role in the resilience process as it provides protective resources that can soften the individual's experiences. Risk factors occur within a context and within this context the risk and protective resources found in the individual's external environment (i.e. family, community, culture, school, peer group) interact. The interaction between the risk and protective resources is adaptable and changes over time and is specific to culture, geographic location, and historical period (Kumpfer, 1999:183; Theron, 2008:218). For example, a child experiences a high amount of anxiety. Resources that could possibly help decrease the individual's anxiety are available in her environment. These resources could refer to therapists or psychologists.

The third step refers to the individual now interacting with her environment (Kumpfer, 1999:184: Theron, 2008:219). "The individual or caring others passively or actively attempt to perceive, interpret and surmount threats, challenges or difficult environments to construct more protective environments" (Kumpfer, 1999:184). For example, the individual experiences a high level of anxiety. Therapy to help deal with the anxiety is available within her environment. The individual navigates towards these resources that might help her to cope with the anxiety by either approaching a parent or asking to receive therapy. This implies that the resources to which the individual navigates are available and accessible.

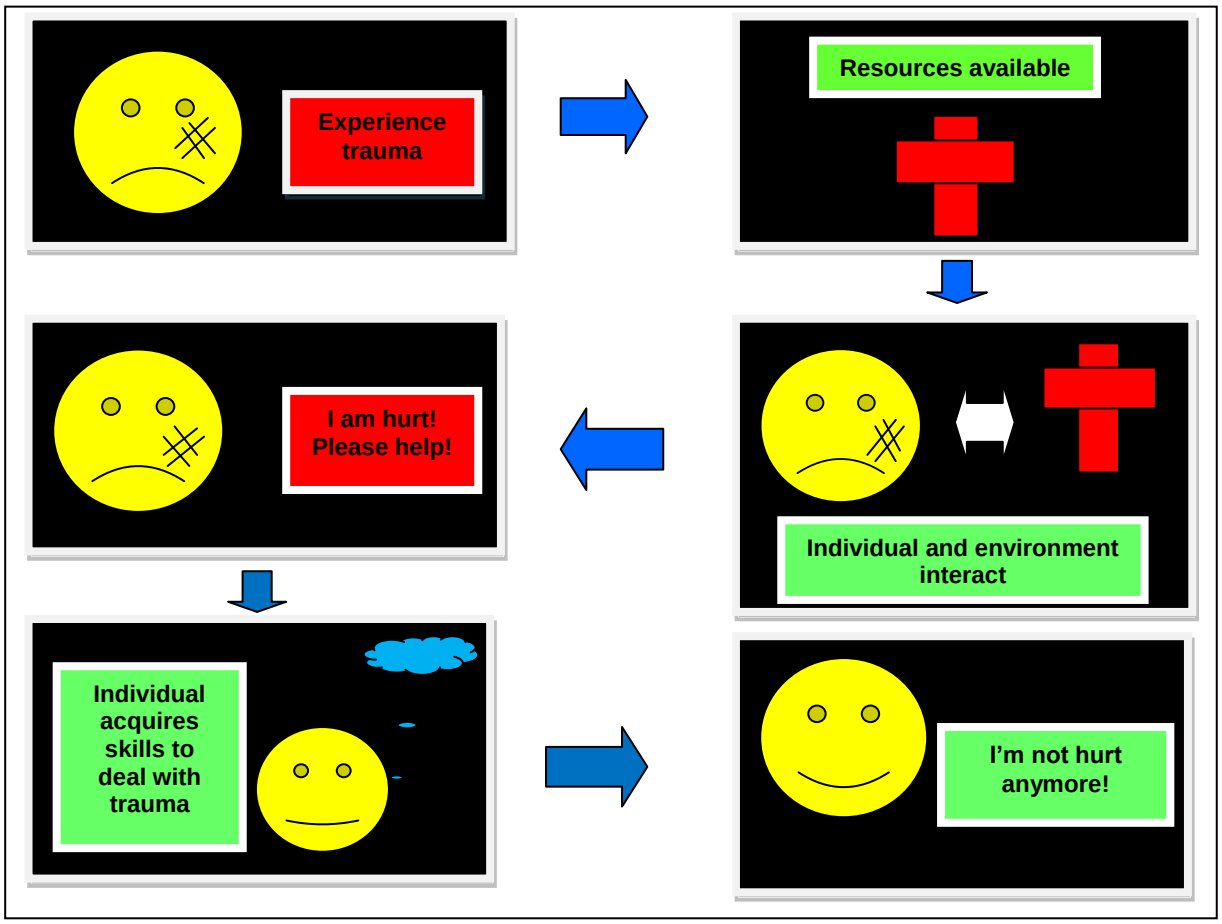
The fourth step refers to the individual's internal resources buffering against the risk. These include internal individual spiritual, cognitive, social or behavioural, physical, and emotional competencies or strengths needed to be successful in different developmental tasks, different cultures and different personal environments (Kumpfer, 1999:184). For example, the individual is

willing to ask for help and is capable of expressing her feelings to the therapist or psychologist.

The fifth step refers to the individual acquiring the necessary coping skills over time to cope with the challenges she may experience (Kumpfer, 1999:184). These skills or processes help the individual to successfully cope and deal with the challenges she faces and to continue functioning positively despite the risks (Kumpfer, 1999:210). For example, the therapists or psychologists teach her skills to be able to cope with the anxiety (i.e. breathing skills or mental exercises) and she makes the most of these skills to cope resiliently with the challenges facing her.

Lastly, a positive outcome which allows the individual to cope is achieved (Kumpfer, 1999:184; Mampane, 2005:22; Theron, 2008:219). A positive outcome suggests that resilience is also predictive of later resilient integration after stress or trauma (Kumpfer, 1999:184).

Figure 2.2: The process of resilience



This model by Kumpfer (1999) clearly indicates that resilience no longer only depends on innate characteristics of an individual. Assets and resources are used to overcome risks and this demonstrates resilience as a process (Fergus & Zimmerman, 2005:400). The model aligns well with the latest understanding of resilience as an ecologically embedded bi-directional process (Lerner, 2006:40). For resilience to result, families, communities and cultures need to collaborate with young people to support them towards resources that might make resilience possible (Ungar, 2010; Ungar *et al*., 2008:2). So, within situations of risk, resilience is encouraged when young people navigate towards available resources while their ecologies support this navigation actively (Ungar, 2010; Ungar *et al*., 2008:2).

3.3.1 Risks threatening resilience

As noted in the introduction to this chapter, resilience is only possible in the presence of risk. Risks can be defined as characteristics, traits and experiences that increase the likelihood that individuals will manifest negative developmental outcomes (Armstrong *et al.,* 2005:276; Boyden & Mann, 2005:6; Mash & Wolfe, 2005:17; Masten & Powell, 2003:7; Murray, 2003:21; Schoon, 2006:5; Seidman & Pedersen, 2003:318; Theron, 2006:201; Theron, 2008:216). Risks can be present not only in individuals, but also in families and their environments (Boyden & Mann, 2005:6; Mash & Wolfe, 2005:17). In other words, some risks are internal and some external. According to Boyden and Mann (2005); Place *et al*. (2002:163); and Siqueira and Diaz (2004:150), internal risks refer to unique combinations of characteristics that make up an individual, whereas external risks can be found within the family, the neighbourhood, and in societal structures (Armstrong *et al*., 2005:276). Therefore risks can be seen to function within a triad of personal, familial, and environmental factors.

For the purpose of my study, I chose to focus on the risks incumbent to Fragile X Syndrome, but for the sake of completeness I summarised the risks that place individuals at risk for non-resilient outcomes (see Table 2.1). I discuss the risks of Fragile X Syndrome in detail in Chapter Three.

The following summary of risk factors was adapted from Helping America's Youth (2007:1); Kim-Cohen (2007:272); Siquiera and Diaz (2006:150); Thomilson (2004; 384-387):

Table 2.1: Summary of risk factors

Intrapersonal		Interpersonal		
Individual	Family	School	Peer	Community
• Antisocial behaviour • Aggression/ violence • Intellectual disabilities • Developmental disabilities • Lack of assertiveness • Stressful life events • Poor mental health • Low self-esteem • Hyper-activity	• Discipline issues • Erratic routine • Poor attachment or low bonding • Child victimisation • Neglect and abuse • Regular family conflict • Family violence • Divorce • Antisocial siblings • Disrupted family life	• Poor academic achievement • Low motivation • Negative attitude • Bunking • Regular absences • Unsatisfactory school climate • Inadequately functioning school • Labeled as learning disabled • Regular school transitions	• Mixing with antisocial/ aggressive peers • Peer rejection	• Criminal/violent neighbourhood • Unstable community • Low sense of belonging • Poor community • Unsafe neighbourhood • Social and physical disorder/ disorganised neighbourhood

According to Masten and Powell (2003:7), earlier studies often focused on only one risk factor. A risk factor does not result in a single stressful event, but a sequence of stressful experiences. In other words, risk factors do not occur one at a time, but typically occur with other risk factors that often pile up in the lives of individuals over time. Such an accumulation of risk factors and stressors creates even more harmful effects on the individual's functioning (Place *et al.*, 2002:162; Seidman & Pedersen, 2003:318). As a result, many investigators shifted their attention to cumulative risk, studied either by aggregating information about stressful life experiences or by aggregating risk indicators. Risks factors can therefore stem from either multiple stressful life events, one single traumatic event or the accumulation of stress from various sources.

3.3.2 Protective resources

Protective resources are seen as variables that buffer and prevent the impact of risk on an individual's life to reduce the potential for negative outcomes (Fergus & Zimmerman, 2005:399; Kim-Cohen, 2007:272; Murray, 2003:18; Seidman & Pedersen, 2003:319; Ungar, 2004:348; Winslow *et al.,* 2005:338). Protective resources do not only help reduce risks, but also facilitate and encourage positive behaviour and social development. Protective factors are not one-dimensional. They correlate and complement one another and also interact with the setting in which they appear (Boyden & Mann, 2005:6; Schoon & Bynner, 2003:26; Ungar, 2007:xxv). Protective processes operate at different levels and through different mechanisms – individual, family, community, and culture (Boyden & Mann, 2005:6; Ross & Deverell, 2004:18; Schoon & Bynner, 2003:24; Theron, 2004:317; Ungar, 2010). For example, an adolescent with learning difficulties who navigates towards resources that might strengthen her to cope academically, can approach teachers in her school environment or ask her parents or therapist for help. However, in order for the adolescent to navigate towards these resources (teachers, parents and therapists), she needs to negotiate, which includes personal characteristics like the ability to solve problems, and the ability to ask for help. She also needs an ecology that offers accessible protective resources. If she lived in a very poor, uncaring community

she might ask for help but there would be neither the resources (therapists; well-trained teachers) nor the inclination (in uncaring or ignorant communities she might be pushed aside as “retarded”) to help her. To be resilient, she needs her negotiation for support to be reciprocated. So it can be seen that familial and environmental processes as well as individual processes are working together to navigate towards resilience (Ungar *et al*., 2008:2).

Examples of these protective resources will be discussed next in order to try and create an understanding of what the resources are and how they play a role in the process of resilience. Although I discuss each one individually, I am aware that the process of resilience involves the dynamic interaction of these resources (as discussed at length in preceding sections).

3.3.2.1 Individual

Resilient adolescents possess certain qualities and ways of viewing themselves and the world around them. The skills and behaviours that they have developed and the assumptions they have made about themselves and the world around them, influence the process of resilience (Brooks, 2005:300).

Intelligence has been widely documented as an attribute that protects against adversity (McMurray *et al.,* 2008:302). Intelligent individuals learn social skills more easily and typically benefit from the socialisation lessons of their parents and other prosocial adults. This makes it easier for them to follow rules and live up to social expectations (Owens & Shaw, 2003:272). It is further possible that more intelligent children can reason with themselves in order to self-soothe and in so doing regulate negative emotion, and/or reason with others to resolve conflict (Owens & Shaw, 2003:272). Robust academic and intellectual skills have regularly been correlated with positive adjustment in the long term, and intelligent adolescents are therefore more likely to experience more positive outcomes following high school than other adolescents (Murray, 2003:23; Oliver *et al.,* 2006:4). P**roblem-solving**, **decisions making, planning and goal setting skills** are associated with cognitive competence and are therefore thought to encourage positive adolescent development (Brooks & Goldstein, 2004a:251;

Fergusson & Horwood, 2003:132; Masten & Reed, 2005:83; O'Dougherty Wright & Masten, 2005:24; Oliver *et al.,* 2006:4; Theron, 2004:319).

An **easy, outgoing temperament** helps mitigate the effects of stress on an individual's behavioural problems (Boyden & Mann, 2005:6; Kim Cohen, Moffit, Caspi & Taylor*,* 2004:653; Masten & Reed, 2005:83; McMurray *et al.,* 2008:302; Schoon, 2006:79). Temperament can be defined as the 'how' of behaviour, for example how an individual handles a situation or having a sunny disposition (Spender, Salt, Dawkins, Kendrick & Hill*,* 2001:50). An individual with an easy, outgoing temperament is capable of fitting into routine and is flexible. This means she can adopt to change with ease (Kaplan & Owens, 2004:81).

Having a **positive outlook** on life and remaining cheerful and optimistic can also help to mitigate the potentially negative impacts of adverse circumstances (Armstrong *et al.*, 2005:227; Boyden & Mann, 2005:6; Masten & Reed, 2005:83; McMurray *et al.,* 2008:302; Richardson, 2002:310; Schoon, 2006:79; Theron, 2004:319; Ungar, 2008b:227). An individual who is optimistic and has a positive outlook, **believes in a bright future**, has **healthy expectancies**, and is **success-oriented** (Donnnon & Hammond, 2007:24).

Imperviousness is also closely related to resilience as it is seen as the ability to withstand and rebound from adversities (Luthar *et al.,* 2000:544). Imperviousness refers to a state of mind of an individual where she is often not affected by negative experiences, for example negative remarks from peers.

According to Murray (2003:23), one of the most promising abilities that can affect the outcome of resilience is related to the concept of **self-determination**. Self-determination refers to an individual's ability to make independent decisions, set goals, independently attempt to accomplish goals, independently evaluate her performance, and make adjustments based on goal progress (Murray, 2003:23). In other words, the individual has the ability and the capacity to **act independently**, and to **exert some control over the environment**.

Self-awareness is another potential protective resource (McMurray *et al.,* 2008:302; Smith & Drower, 2008:159; Ungar, 2008b:227). An individual who

possesses self-awareness is able to **recognise feelings** while they are happening, is **aware of her strengths, talents, and limitations**, and has **empathy for others** (McMurray *et al.,* 2008:302; Mills & Dombeck, 2007:1). Having empathy for others refers to having a desire to be of assistance to others and to consider situations from another's perspective. An individual who has empathy for others often connects with them emotionally (Brooks & Goldstein, 2004:12; Donnon & Hammond, 2007:452; Mills & Dombeck, 2007:1; Ungar, 2008b:227).

Peacefulness as an individual characteristic has also been found to be a potential protective resource. It has been reported that individuals who are peaceful and calm, treat others with kindness and are able to find good and positive things in their everyday lives (Raatma & Murphy, 2000:5).

Attractiveness to others is another resilience resource (Masten & Reed, 2005:83; O'Dougherty Wright & Masten, 2005:24). A child who is loved and accepted by others develops confidence and a positive self-esteem (McMurray *et al.,* 2008:302; Schoon, 2006:79). It has also been found that **self-esteem** as well as **self-efficacy** can mitigate difficulty and is therefore seen as a protective resource (Boyden & Mann, 2005:6; Donnon & Hammond, 2007:452; Masten & Reed, 2005: 83; McMurray *et al.,* 2008:302; Richardson, 2002:309). Self-efficacy refers to an individual being confident in her ability to identify and implement coping and problem-solving skills, to carry out appropriate behaviour, and having a sense of control over her world (McMurray *et al.,* 2008:300; Ungar, 2008b:227; Willoughby, Brown, King, Specht & Smith, 2003:93-94).

Another important individual capacity is related to **social competency** (McMurray *et al.,* 2008:302; Theron, 2004:319). Social competency includes a variety of interpersonal skills that contribute to adolescents being able to achieve social and personal goals in that these skills help them to meaningfully integrate their thoughts, feelings, and actions. When adolescents develop and practice effective communication and conflict resolution skills, their social competency is encouraged. Typically this includes **learning about and recognising relevant**

social cues, correctly **interpreting these cues** and **developing and implementing suitable responses** to interpersonal problems (Oliver *et al.*, 2006:4). Adolescents who are socially competent and who are able to nurture prosocial relationships are more likely to cope well after school (Murray, 2003:23).

A **sense of humour** has also been identified as contributing to resilience (Glicken, 2006:235; Kaplan & Owens, 2004:83; Masten & Reed, 2005:83; O'Dougherty Wright & Masten, 2005:24; Ungar, 2008b:227). A sense of humour has been found to reduce stress that is caused by adversity and provides the individual with relief. It can improve one's mood, promote mental health and allows one to bond with others (Glicken, 2006:235; Scott, 2008:1; Siquiera & Diaz, 2004:151).

It has also been found that individuals that have an **imagination** and are able to **role-play** are capable of dealing with personal problems or negative emotions. Their imagination and fantasies allow them to reassure themselves, be more spontaneous and thus release creative energy (Morales, 2008:8).

Internal locus of control refers to the ability to have some control over what happens to you, and believe that you have influence over your own fate (Theron, 2004:319). It has been found to relate to resilience as it helps one to not feel helpless, and thus the situation becomes less threatening as the individual feels more competent about her ability to cope (Lantieri, 2008:1; McMurray *et al.,* 2008:302).

More individual resources that promote resilient functioning include **assertiveness** (Ungar, 2008b:227). Assertiveness refers to an individual's ability to express her feelings, dreams and ideas, and to balance independence and dependence on others, in other words, being able to **stand up for oneself** and **ask for help** when needed in an appropriate manner. The individual is therefore able to act **autonomously** (Greene & Conrad, 2002:36; Mills & Dombeck, 2007:1; Theron, 2004:319; Ungar, 2008b:227; Yates, Egeland & Stroufe, 2003:252).

It is important to remember that not only individual resources influence the outcomes when faced with adversity. According to Luthar and Cicchetti (quoted by Vanderbilt-Adriance & Shaw, 2008:31), the individual resources discussed above are also often strongly affected by contextual factors, such as the family, which will be discussed next.

3.3.2.2 Family

Research on family characteristics has shown that families are the primary source of **emotional support** promoting resilience (Hjemdal, 2007:307; Murray, 2003:23). Adolescents can be helped to manage stress points in their lives within the family if they are offered **care and support**, have to live up to **high expectations** to succeed and **participation** within the family and community is encouraged (Ungar & Liebenberg, 2005:218; Winslow *et al.*, 2005:338). Murray (2003:20) states that protective familial resources among individuals with high-incidence disabilities could be **family connectedness**, **parental presence**, **parental expectations** and **activities shared with parents**.

Having a **relationship with at least one supportive adult** is seen as a protective resource (Masten & Reed, 2005:83; McMurray *et al.,* 2008:302; Murray, 2003:18; 23). This need not be a parent, which might be difficult in a dysfunctional family. It could be a grandparent, aunt or uncle. Having a supportive family member will make the adolescent feel that she has someone she can trust and who will be there for her. This adult might also be a mentor and role-model for the adolescent by providing an example and reinforcement for problem-solving, motivation, and other coping skills. It is also helpful having a family that provides a **nurturing, caring and loving home environment** (Donnon & Hammond, 2007:452; Ungar & Liebenberg, 2005:218; Winslow *et al.,* 2005:24). Masten and Reed (2005:85); and Ungar and Liebenberg (2005:219) emphasise the fact that an individual should feel welcome and relaxed in all her living surroundings.

When parents expect **high standards of moral behaviour,** adolescents tend to develop resilience and an understanding that even though they might fail, they

can bounce back and try again. The family **encourages the adolescent to set goals** and **do her** best. An example of this might be when children grow up in poverty, but still succeed in school. The reason for this often is parental expectations (Donnon & Hammond, 2007:452; Ungar *et al.,* 2008:1-2; Ungar & Liebenberg, 2005:218; Winslow *et al.,* 2005:338).

Participating in family and social activities and **contributing** to the family and community in meaningful ways are also seen as working towards resilience. **Giving adolescents responsibilities** lets them know that they are trusted, worthy and capable of contributing positively to the family and community. For example, adolescents who are given chores or do part-time work, develop resilience (McMurray *et al.,* 2008:302; O'Dougherty Wright & Masten, 2005:24; Ungar & Liebenberg, 2005:218). It has also been found to be of importance for **families to be consistent** and to **spend quality time together** (Fergusson & Lynskey, 1996:289; Kim-Cohen, 2007:277).

According to Hauser-Cram and Krauss (2004:711), a number of studies have shown that the **relationship between siblings** where one sibling has a disability, seems to be more positive than in the case of typically developing siblings.

It has also been found that **early intervention** in the case of a child with a disability helps parents to not only **understand the implications of the disability**, but also **enables them to find appropriate help** (i.e. professional counselling, therapy, curriculum changes) for their child (Cunningham & Glenn, 1985:347-359). In other words, parents who take action to obtain a diagnosis and/or intervention when a child is disabled, encourage resilience.

Parents typically have responsibilities in planning for the future of their children. However, parents of children with disabilities have a heightened responsibility. By **arranging environments** in which their child's social an economic life can be supported, they are more likely to be accepted in the community more readily and build self-efficacy (Hauser-Cram & Krauss, 2004:711).

Family is therefore seen as a valuable protective resource in the process of resilience. The individual needs an adult to connect with, moral behaviours need

to be demonstrated to her through the family and participation in the family or encouragement is important. However, family is not the only external resource that plays a part in the process of resilience.

3.3.2.3 Community

Not only supportive relationships with family and non-parental adults help to protect adolescents from adversity, but also factors in the community (Boyden & Mann, 2005:7). One of the primary potential protective community resources is the **school** (Johnson & Lazarus, 2008:19-20; Schoon, 2006:14). Murray (2003:24) states that individuals develop the skills and capacities for later success at school. Therefore the protective resources found in school are discussed below.

Care and support are just as important in the school environment as at home. It is important to have **well-trained and well-compensated teachers**. According to Johnson and Lazarus (2008:19), a **variety of teaching methods** can also potentially improve resilience, which can help **teacher and learner form relationships**. Teachers can be **role-models** too, teaching adolescents warmth, caring and compassion for others. A **positive climate** at school and **feeling safe** will create a sense of belonging and enjoyment (Donnon & Hammond, 2007:452; Murray, 2003:24; Ungar & Liebenberg, 2005:218).

Taking part in different **school-based activities** has also been proven to be a potential protective resource (Johnson & Lazarus, 2008:20; McMurray *et al.,* 2008:302). By taking part in school-based activities, the adolescent will have the opportunity to interact with others by sharing ideas, providing help and participating in decision-making (Zimmerman & Arunkumar, 1994:12).

High expectations at school have also shown that adolescents have higher levels of academic success. High expectations help learners set and achieve their goals. Also, giving adolescents responsible roles within the school have been shown to heighten achievement as well as resilience (Schoon, 2006:33).

Research has shown that **high school graduation** and **transition planning** is considered to be important school level variables that can influence the post-school outcomes of individuals with high incidence disabilities (Murray, 2003:24). Johnson and Lazarus (2008:29) have concluded that schools consisting of more **effective resources** have fewer problems with adolescents facing adversities, possibly due to the fact that they can offer support.

Support from peers and **peer acceptance** can also enhance adolescents' resilience. Positive peer relationships enable adolescents to experiment, develop attitudes, skills and values, learn how to share and help others. These then all correlate with individual protective resources such as competence, building relationships with others, empathy, and feeling as though they are part of a group. The adolescent is able to build confidence, which helps build resilience (Boyden & Mann, 2005:8; Wong & Lee, 2005:316).

Having a **caring and friendly neighbourhood**, which is **safe**, with a **low level of violence**, **affordable housing** and access to **recreational centres**, **access to emergency services** (such as police, fire and medical services) and **opportunities for age-appropriate work** are all resources that can help an adolescent navigate towards resilience (Donnon & Hammond, 2007:452; Masten & Reed, 2005:83; Ungar & Liebenberg, 2005:218; Ungar *et al.,* 2008:1-2).

Support from the community also serves as positive protective resources. This can include **receiving advice**, **emotional support**, and **positive reinforcement** (Boyden & Mann, 2005:7). When individuals are supported by their community, they get a sense of belonging. **Role-models** such as teachers, therapists, and counsellors, may form a support system for adolescents (Masten & Reed, 2005:83; McMurray *et al.,* 2008:302). If an individual feels supported and part of the community it is easier to ask for help, guidance and support.

Being **diagnosed** and receiving the **right medication** have also been found to be protective resources. Individuals with learning difficulties often experience failure early in life. However, receiving a diagnosis early on can help these individuals to get the necessary help in order to experience and achieve success.

It also helps the individual with disabilities to **understand what her capabilities are** (Lachiewicz & Mirrett, 2000:236-237; Willoughby *et al.,* 2003:94-95). Roger and Ziviani (2006:105) state that the presence and severity of physical, cognitive or social difficulties may often form barriers which can limit an adolescent's ability to fill certain occupations. It has been therefore found that **therapy,** such as occupational therapy, can help such individuals cope and often overcome these difficulties (Roger & Ziviani, 2006:105-107).

Therefore, seeing that the community plays an important role in the process of resilience (Boyden & Mann, 2005:7), it is necessary for the community to be educated about the influence they have in the development of resilience. The individual needs to know that she is cared for and has the unconditional support of her community (Boyden & Mann, 2005:7). This will enable her to develop confidence, a good social and relationship skill set, and a good general attitude. The individual needs to have a certain level of expectations and responsibilities placed on her in order for her to work towards goals, thus allowing or affording her the opportunity to have positive outcomes (Donnon & Hammond, 2007:452; Schoon, 2006:33). The warmth and compassion of the community will create a positive and safe environment for the individual to navigate towards the resources available to her (Boyden & Mann, 2005:7; Ungar *et al*., 2008:2).

3.3.2.4 Culture

According to Li and Karakowsky (2001:501), culture includes the rich legacy of a specific group of people's knowledge, experiences, convictions, principles, outlook, understandings, hierarchies, faith, time and universal concepts, roles, and understandings of the nature of possessions. Culture affects the way we form networks and how we rate these networks. Culture also places dictates which skills and activities should be valued. In most cultures religion and values are central to how culture is expressed (Gunnestad, 2006:2). According to O'Dougherty Wright and Masten (2005:30); and Crawford, O'Dougherty Wright and Masten (2005:356), protective resources are often rooted in culture.

An individual's culture helps her understand where she comes from. Being part of **religious organisations** gives an individual a sense of belonging (McMurray *et al.,* 2008:302). It encourages **cultural awareness** which enables her to have an understanding of and interest in other cultures and ultimately leads to respect other beliefs. Individuals then develop a life philosophy and self-betterment (Ungar & Liebenberg, 2005:218). Depending on the culture it can also offer the opportunity to become part of a **support group**. The individual feels accepted, can practise traditions and develop cultural beliefs, and also feel a part of something outside of families and school environment.

As noted above, s**piritual or religious beliefs and practices** are central to culture (Peres, Moreira-Almeidda, Nasello & Koenig, 2007:346). Spirituality is powerfully linked to people's longing to understand life and make meaning of it, both in the present and the hereafter. Religion provides a cultural framework for interpreting and coping with traumatic events (Peres *et al*., 2007:347). For example, certain religions emphasise the importance of the Ten Commandments, as they provide guidelines for everyday conduct and moral values, which encourage a life lived with integrity, the practice of forgiveness, empathy, altruism, kindness and love. Other processes by which religion and spirituality may also provide resilience are attachment relationships, social support, personal growth and development and transformational opportunities. Crawford *et al*. (2005:358) state that attachment relationships can be seen as **relationships with the divine**; **marital relationships and family cohesion**; **pro-social peers** and **pro-social mentors**. They also conclude that **social support** refers to a sense of community belonging; rituals for birth, marriage, death and burial; prayers for the at-risk, the traveller, the bereaved; visiting the sick; providing food in troubled times; counselling; support groups; political sanctuary and protection from persecution.

It can be stated that religious practices potentially encourage personal growth. For example, prayer; mediation; liturgy and music of worship, celebration, comfort; reinforcement of family values and rules; provision of meaning and a philosophy of life; acceptance of God's will; and conversion all potentially provide

opportunities for people to grow and even to become transformed (Crawford *et al.,* 2005:358).

Culture has a tremendous amount of power in the religion it dictates, the roles it deems important and the skills and activities it promotes. It creates a sense of belonging and purpose for the people in the culture, and it generally dictates how the cultural population should incorporate and interpret traumatic events (McMurray *et al*., 2008:302). Empathy, forgiveness, kindness and love are important factors in a culture and can be learned by the individual within that culture (Peres *et al.,* 2007:347). These factors relate to some individual traits that play a role in the resilience process. In summary, knowledge, experiences, beliefs, values and attitudes that culture brings with it, can have a great effect in the process of resilience.

3.4 CONCLUSION

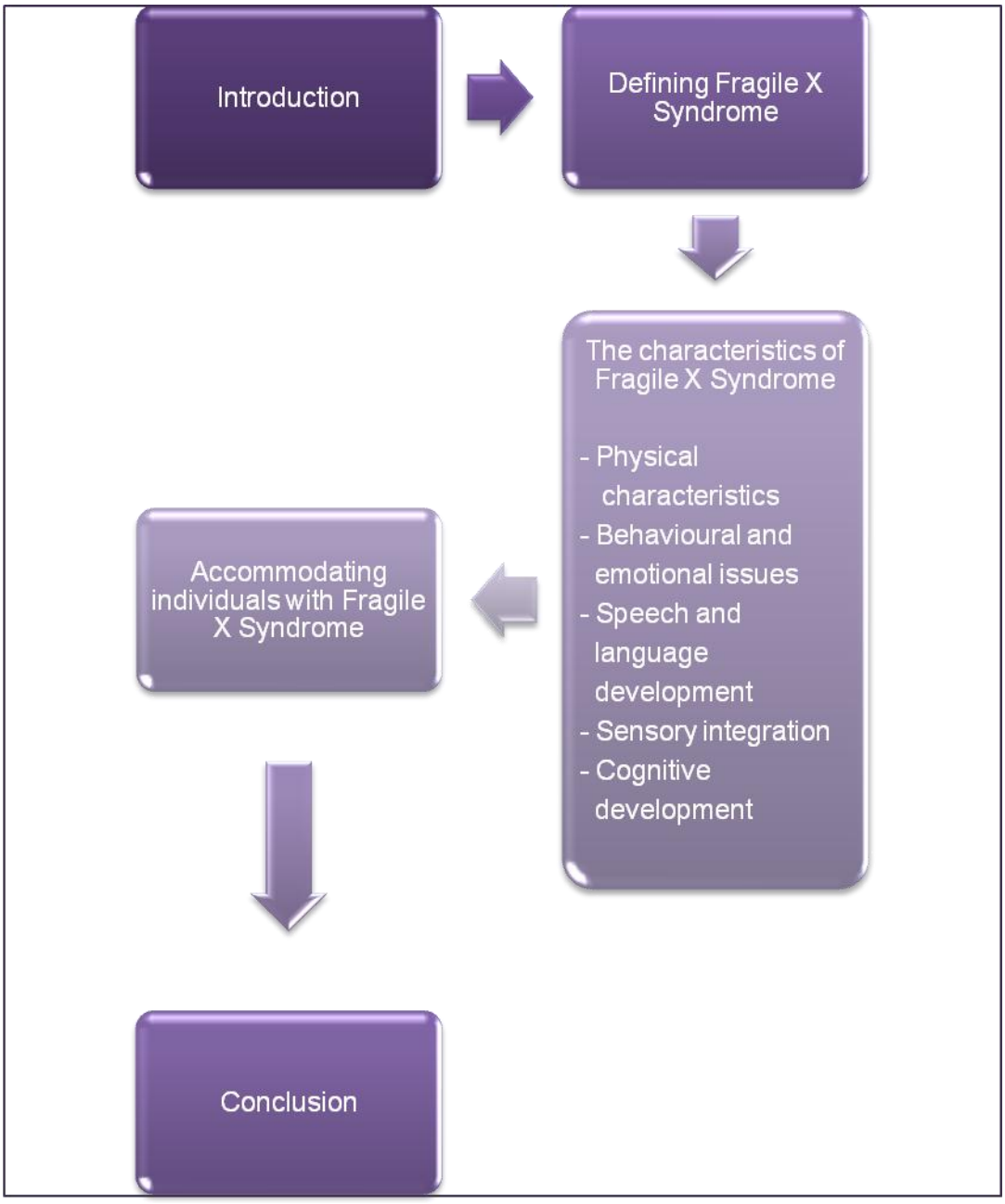
The intention of this chapter was to provide an understanding of resilience. Resilience was once thought of as only a personal trait within an individual. This concept has undergone changes and is now seen as a process, involving individual traits but also familial, environmental and cultural resources. In other words, resilience is encouraged by internal (the individual) and external (the family, environment and culture) resources. In order to acquire resilience, the individual's environment needs to make protective resources available, and furthermore the individual needs to be able to navigate towards these resources, making use of her internal resources (Ungar *et al*., 2008:2). Therefore resilience is seen as a bi-directional process (Lerner, 2006:40; Luthar *et al.,* 2000:543; Schoon & Bynner, 2003:22).

As stated previously, the risk factor that was chosen in this study is Fragile X Syndrome. The next chapter will concentrate on the definition and the risks that individuals diagnosed with Fragile X Syndrome face.

CHAPTER THREE

THE PHENOMENON OF FEMALES WITH FULL MUTATION FRAGILE X SYNDROME

Figure 3.1: Overview of chapter three



4.1 INTRODUCTION

Fragile X Syndrome has probably been around since man came into being. It has been found to occur in all ethnic and racial groups around the world. It was not recognised as a syndrome at all until recently. People with Fragile X Syndrome were diagnosed with autism, Tourette syndrome, Sotos syndrome, Prader-Willi syndrome, or X-linked mental retardation. Even today, some individuals with Fragile X Syndrome are undiagnosed. Fragile X Syndrome has been overlooked all these years, because the characteristics of Fragile X Syndrome are so diverse (Ashley-Koch, 2003:39; Hagerman, 2000:28; Harris-Schmidt & Fast, 2004:13).

No two individuals with Fragile X Syndrome are the same. Even when they do display the same characteristics, there may be huge differences in the degree to which they display them and the extent to which they affect the individual's ability to function (Harris-Schmidt & Fast, 2004:13; Saunders, 2000:11). Even so, there are specific characteristics that are associated with Fragile X Syndrome, some of which will be displayed by a significant number of individuals and many which will be recognised by those who are familiar with people who have the syndrome (Orloff, 2008:67; Roley, 2004:1; Saunders, 2000:11).

Children with Fragile X Syndrome are like every other child. They are human beings who happen to have some differences. Nevertheless, in explaining how Fragile X Syndrome can affect individuals, it helps to look at males and females separately. This is because some effects of Fragile X Syndrome often differ significantly between the sexes. However, females can have the same types of symptoms as males (Hagerman, 2000:11). This chapter will focus on the phenomena of females with Fragile X Syndrome and the impact of this syndrome on a female's life.

4.2 DEFINING FRAGILE X SYNDROME

Fragile X Syndrome is an inherited (genetic) condition. It is seen as the most common inherited cause of mental impairment. Individuals who have no apparent

signs of this genetic condition can pass it on in a family. This condition leads to a wide range of mental impairment, from mild learning disabilities to severe mental retardation. Fragile X Syndrome is caused by a change in a single gene, the "FMR1" gene. FMR1 stands for "Fragile X Mental Retardation 1" and is located in the region of the Fragile X site. (Anon, 2007a:1; Ashley-Koch, 2003:39; Barry, 2007:387; Braden, 1996:3; Finucane *et al*., 2002:5; FRAXA, 2008:1; Genetics Home Reference, 2007:1; Hagerman, 2000:9; Hagerman, 2002:7; Hagerman & Hagerman, 2002:30; Harris-Schmidt & Fast, 2004:9; Jewell, 2008:2; National Fragile X Foundation, 2007:1; Orloff, 2008:67; Reiss & Hall, 2007:663; Sherman, 2003:55; Wallis, 2008:47).

In order to try and understand Fragile X Syndrome, it is important to first understand how human genes and chromosomes play a part in this condition. Every human cell is made up of 46 chromosomes, or 23 pairs of chromosomes. These chromosomes in turn are comprised of genetic material, called as DNA. DNA is necessary to produce proteins which ensure growth, development and bodily as well as cognitive features in the human body. The first 22 pairs of chromosomes are identical in males and females. Only the last pair of chromosomes, namely the sex chromosomes (X and Y) differs. The sex chromosones determine gender. Males have one X chromosome and one Y chromosome, whereas females have two X chromosomes. Fragile X Syndrome is caused by a change or mutation in a gene called the FMR1 (Fragile X Mental Retardation 1 gene). This gene is found on the X chromosome and is thought to play an important role in the development of the brain. The change in the FMR1 gene is an expansion of a sequence of Cytosine-Guanine-Guanine (CGG) repeats. Everyone has an FMR1 gene and there should be approximately 5 to 50 CGG repeats. However, the number of CGG repeats in individuals with Fragile X Syndrome is much more, 200 or more. This is called full mutation (Anon, 2007a:1; Hagerman, 2000:9; Hagerman & Hagerman, 2002:3, Harris-Schmidt & Fast, 2004:12 & 118; Quercia, 2002:1366).

Males are more severely affected by Fragile X Syndrome because they have only one X chromosome. Females have two X chromosomes. Only one X

chromosome is affected by Fragile X Syndrome and therefore the undamaged X chromosome compensates for the chromosome which is affected. This means that females with full mutation usually have milder symptoms than males with a full mutation, due to the fact that males only have one X chromosome and so no FMR1 protein is produced. Therefore the symptoms found among females are typically less pronounced (Anon, 2007a:1; Ashley-Koch, 2003:39, 41; Barry, 2007:387; Hagerman, 2000:9; Hagerman & Hagerman, 2002:3, Harris-Schmidt & Fast, 2004:12 & 118; Quercia, 2002:1366).

As stated before, every individual is unique and this also applies to individuals with Fragile X Syndrome. There is no typical example of an individual with Fragile X Syndrome, as they all have different developmental strengths and weaknesses. This makes it very difficult to distinguish the impact of Fragile X Syndrome on individuals (Hagerman, 2000:207). The following section will give an overview of the most typical symptoms or characteristics of children diagnosed with Fragile X Syndrome. Even though there is such a difference in the severity between males and females with full mutation, literature often only concentrates on the male characteristics due to fact that females have the same symptoms as males, just less severe.

4.3 THE CHARACTERISTICS OF FRAGILE X SYNDROME

This section will generally discuss the impacts that are found in individuals diagnosed with the full mutation of Fragile X Syndrome. There are different aspects that should be considered when discussing how Fragile X Syndrome affects an individual. These are developmental issues, emotional and behavioural issues, social development, and sensory development/integration (Harris-Schmidt & Fast, 2004:19). Physical characteristics will also be discussed.

4.3.1 Physical characteristics

Some children with Fragile X Syndrome, especially females, are physically just like any other child. Others do have some physical differences, but these

physical differences may not always be obvious. Those females who do show noticeable physical differences often have the same types of symptoms as males. Therefore, physical characteristics that can be found in both sexes will be discussed in this section.

Children with Fragile X Syndrome might have lost connective tissue (Reiss & Hall, 2007:663). Connective tissue refers to tissue found throughout our bodies, which binds and supports the body (Foster, 2003:1), for example, ligaments, tendons, and skin. Due to loose connective tissue, physical differences like unusually flexible or hyper-extensible finger joints and double-jointed fingers, as well as flat feet (no arch in the foot) are found (Anon, 2007a:1; Hagerman, 2002:16,21; Harris-Schmidt & Fast, 2004:25; Jewel, 2008:7). Individuals with Fragile X Syndrome may also have ears that are larger and wider than usual due to the loose connective tissue (Hagerman, 2002:8; Harris-Schmidt & Fast, 2004:15; Jewel, 2008:7). The skin of people with Fragile X Syndrome is often also very soft. This is especially noticeable on the hands (Hagerman, 2000:13-14; Hagerman, 2002:22).

Hypotonia is also very common in children with Fragile X Syndrome. Hypotonia refers to low muscle tone (Hagerman, 2000:13-14). These children often have low muscle tone that is decreased in the torso area, especially when they are younger. This might make it hard for young children to sit and can even delay walking. It can also affect joint stability, fine and gross motor coordination, and sensory integration. For example, when joint stability is affected, the joints are prohibited from doing their job, so the child might struggle with certain physical movements, like walking. Fine motor coordination can and is typically affected by Fragile X Syndrome and can be referred to as the small muscle movement which often occurs in the fingers. This can make writing, tying shoe laces, and even getting dressed a challenging activity and obviously has negative implications for schooling and socialising (Hagerman, 2000:13-14; Hagerman, 2002:7:34; Reiss & Hall, 2007:663). Gross motor coordination can and is also typically affected by Fragile X Syndrome. Gross motor coordination is seen as movements that come from large muscle groups. These skills involve movements such as walking,

running, and jumping. Gross motor skills affect balance and motor planning. If children do not possess reasonable gross motor skills, they often struggle with the fine motor skills that are important for formal schoolwork. For example, if a learner cannot maintain upper body support, her writing will be affected (Logsdon, 2009:1). Sensory integration (discussed in 3.3.4) refers to the brain's ability to correctly process information brought in by the senses. An example of this in children with Fragile X Syndrome is that they do not like to be touched and are easily distracted (Hagerman, 2000:13-14; Hagerman, 2002:7:34; Reiss & Hall, 2007:663).

Individuals with Fragile X Syndrome can have a wide range of visual impairments. This can include nearsightedness, farsightedness, amblyopia (vision loss from lazy eye), strabismus (crossed eye), astigmatism (blurred vision caused by irregularities in the shape of the cornea) and nystagmus (jerking of the eyes back and forth (Hagerman, 2000:13; Hagerman, 2002:18).

It is also known that some of these individuals often have high and to some extent a narrow palate in the roof of the mouth. In some cases these children are also more likely to have a cleft palate, this being a split in the roof of the mouth. Some children with a cleft palate can develop problems such as speech and hearing difficulties, sinus and ear infections, or complications that can result in surgery to correct the cleft palate (Anon, 2007b:1; Biavati, 2006:1). These individuals tend to have larger heads than other children as well as broader foreheads (Hagerman, 2000:13; Hagerman, 2002:9).

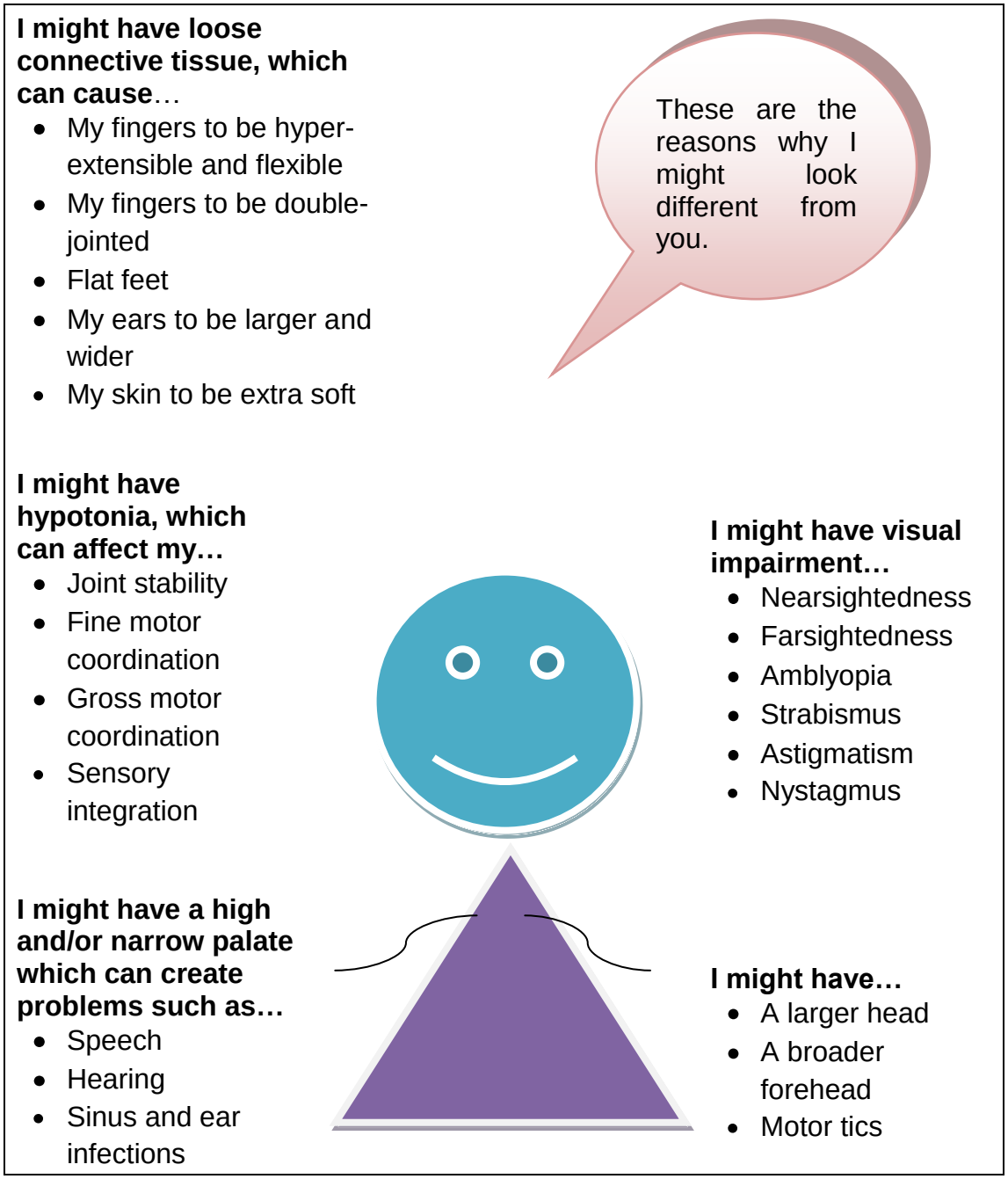
Research has shown that approximately 10 to 20 percent of individuals with Fragile X Syndrome have motor tics. Motor tics are jerky movements that generally affect the face, arms or legs. An example of this is repetitive eye-blinking (Hagerman, 2002:8, 16-22, 34; Harris-Schmidt & Fast, 2004:15, 20-25).

Children with Fragile X Syndrome often develop ear infections. It has been found that early ear infections can cause dysfunctional auditory input and therefore affect language development. This can also play a part in their balance (Harris-Schmidt & Fast, 2004:43; Stackhouse, 2004:3).

They have extensive spatial difficulties. This can result in difficulties with learning, reading, math skills, and puzzles as well as their general body orientation. This can then influence their gross and fine motor abilities, as discussed previously (Harris-Schmidt & Fast, 2004:43; Stackhouse, 2004:3).

It is therefore clear that the physical characteristics of Fragile X Syndrome as discussed above can be found in anybody, be it someone diagnosed with Fragile X Syndrome or not. Therefore, apart from the DNA test, there is no clear physical indicator or characteristic that can determine if an individual has Fragile X Syndrome (Harris-Schmidt & Fast, 2004:19).

Figure 3.2: Summary of physical characteristics



4.3.2 Behavioural and emotional Issues

The characteristics that will follow are very commonly found in individuals with Fragile X Syndrome, but some of these characteristics can also be found in individuals who do not have Fragile X Syndrome, as noted previously. Most of the behavioural and emotional issues discussed below are found in females with

Fragile X Syndrome. Typically, behavioural and emotional characteristics of people with Fragile X Syndrome include a great amount of anxiety, hyperactivity or attention deficit, and tantrums (Anon, 2007a:1; Harris-Schmidt & Fast, 2004:79).

According to Hagerman (2002:63), anxiety is the most prevalent feature in females with Fragile X Syndrome. Anxiety refers to the overwhelming sense of apprehension and fear. In other words, anxiety refers to the fearful anticipation of a possible future threat rather than to a fear of something tangible (such as being afraid of snakes) (Gerzon, 1997:13; Helgoe, Wilhelm & Kommor, 2005:4; Rachman, 2004:3). Anxiety is seen as a normal human emotion that can be experienced by all human beings at times. However, too much anxiety can interfere with healthy living (Helgoe *et al.,* 2005:4; Merrell, 2008:7; Rachman, 2004:3; Tyrer, 1999:1).

Females with Fragile X Syndrome typically have much more anxiety than males. Anxiety can cause severe panic attacks and directly affects daily functioning (Hagerman, 2000:22; Hagerman, 2002:63). Females often develop fear of the situations or environment in which the anxiety was experienced, and the need to avoid any similar experiences in the future. Braden (2002:450) states that females often fluctuate between flight-or-fight responses whenever they become anxious. In other words, when the individual becomes anxious, she wants to leave or escape the environment in which the anxiety is experienced (flight-response). An example of this might be that when an individual with Fragile X Syndrome is complimented, she will either turn or walk away from the person giving the compliment or simply “freeze”. She will probably say nothing, or will not make any eye contact or give any kind of response in return. Many individuals with Fragile X Syndrome have great difficulty in making direct eye contact with others for more than a few seconds. They typically feel overwhelmed and the reason for this may be because direct eye contact involves too much visual information for them to process. The flight-response might also be due to insecurity about how to respond when put on the spot. More consistently, the result might be verbal and/or physical abuse (fight-response). An example of a

fight response might be when an individual with Fragile X Syndrome is faced with walking in to a store where she might know someone. She can become anxious about whom she will see, and how to handle the situation. She could refuse to enter the store, and her reaction could result in physical abuse towards her loved ones by pulling their hair or slapping them. This is often also combined with verbal abuse, saying things like “I hate you”, or swearing (Braden, 2002:450-451; Hagerman, 2000:21).

Individuals with Fragile X Syndrome have a strong desire to socially interact with others. However, anxiety, hyperactivity, impulsiveness and even a short attention span make it difficult for females with Fragile X Syndrome to socialise. Females often become secluded and this ultimately results in depression (Hagerman, 2000:21-22; Reiss & Hall, 2007:664-665).

Their hyperactivity and attention deficit may also result in excessive motion, difficulty staying still, which all can contribute to difficulty staying focused and attending (Braden, 2004b:1). Understandably, their inability to focus or to remain sedentary will have negative impacts on socialisation and on progress in school.

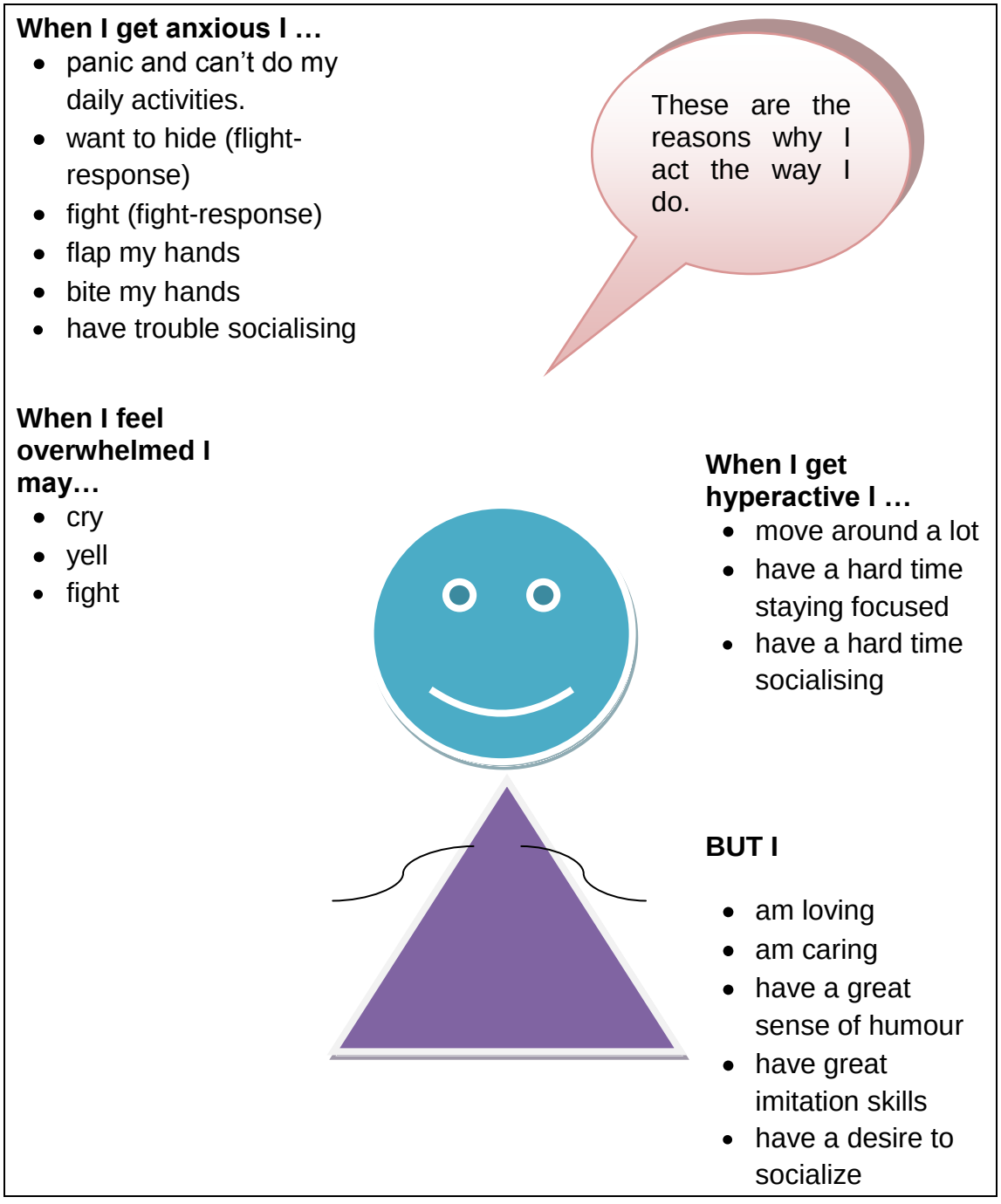
Another example of typical Fragile X Syndrome behaviour includes hand flapping and hand biting. Children with Fragile X Syndrome often flap or bite their hands when they become excited or anxious. The reason they do this might be to calm themselves or to give the brain a clear stimulus to focus on when they are overwhelmed (Hagerman, 2000:21).

Children with Fragile X Syndrome also have many tantrums. It is important to understand that this does not make them “bad” children. The reason for their behavioural outbursts might simply be due to them feeling overwhelmed by sights and sounds in their environment. A way in which children with Fragile X Syndrome react to this overstimulation is to cry, yell or thrash (Braden, 2004b:3; Hagerman, 2000:21; Orloff, 2008:68). Hagerman (2000:20) and Stackhouse (2004:2) believe that these behaviours are the result of sensory integration difficulties. Sensory integration will be discussed later on in this chapter.

Individuals with Fragile X Syndrome also have many positive behavioural characteristics. They are described as loving, caring, and having a great sense of humour. They also have excellent imitation skills and as stated before, even though they might be shy (due to anxiety), they have a strong desire to socially interact with others (Braden, 2002:445; Hagerman, 2000:24; Harris-Schmidt & Fast, 2004:80).

In summary, females with full mutation generally have emotional and behavioural issues due to anxiety, hyperactivity and overstimulation, as depicted in Figure 3.2 below (Anon, 2007a:1; Braden, 2002:450-451 & 445; Braden, 2004b:1 & 3; Hagerman, 2000:20-22 & 24; Hagerman, 2002:63; Harris-Schmidt & Fast, 2004:79-80; Orloff, 2008:68; Reiss & Hall, 2007:664-665; Stackhouse, 2004:2).

Figure 3.3: Summary of emotional and behavioural issues



4.3.3 Speech and language development

Females with Fragile X Syndrome seldom have pronounced difficulties with speech and language. In most cases their vocabulary and grammar skills are age appropriate, and this facilitates learning to read and write. However, their social

anxiety and shyness may get in the way of communicating. In other words, although their speech and language development is generally adequate to facilitate communication, behavioural issues can obstruct communication. Communication is also made more difficult because of the reasons discussed below.

Pragmatics is an area of weakness for females with Fragile X Syndrome, and therefore having a conversation with others is a difficult experience for females with Fragile X Syndrome. Pragmatics refers to the arrangement of words and phrases in order for them to make sense (Abbeduto, Brady, & Kover, 2007:40). For example, the individual might say something inappropriate, she might talk about unrelated things, tell stories in a disorganised way, and/or have little variety in language use. She may find it difficult to express herself. In my experience of living with an individual diagnosed with Fragile X Syndrome, a typical conversation would be as follows:

Table 3.1: Example of a typical conversation with an individual diagnosed with Fragile X Syndrome

Self:	*"What is your role in this year's school play?"*
Participant:	*"I wore a purple dress in freshman year."*
Self:	*"Lucy, what is your role in this year's school play?"*
Participant:	*"This is my last play. Next year I'm going to help backstage. This is my last play."*
Self:	*"The name of your play this year is 'Oklahoma' right?"*
Participant:	*"Yeah."*
Self:	*"What is your role again? Who are you playing?"*
Participant:	*"Umm, umm, I'm Vivian"*

When the female with Fragile X Syndrome is put on the spot, anxiety often arises and the individual does not give the appropriate feedback. Due to these problems the individual may experience lower social acceptance. Peers may avoid having a conversation with the individual, in part because peers might find it hard to

understand her and so social interaction with the individual with Fragile X Syndrome becomes difficult (Bennetto & Pennington, 2002:233; Hagerman, 2000:18; Scharfenaker, 2004:6).

Individuals with Fragile X Syndrome also tend to perseverate when they speak. In other words, they are inclined to repeat the same words, phrases and sentences. This is very common in children with Fragile X Syndrome. An example of perseveration can be that the individual with Fragile X Syndrome might ask a question many times, even after the answer has been given.

Table 3.2: Example of a typical conversation with an individual diagnosed with Fragile X Syndrome

Participant:	*"What did you do yesterday?"*
Self:	*"I met up with Genn and we went shopping at Old Orchard."*
Participant:	*"What did you buy?"*
Self:	*"I bought a dress and a pair of shoes. What did you do?"*
Participant:	*"Not much. What did you do yesterday?"*
Self:	*"I went shopping."*

This behaviour may bother people who do not understand that this is a typical feature of individuals with Fragile X Syndrome (Hagerman, 2000:22; Scharfenaker, 2004:6).

4.3.4 Sensory integration

Sensory integration refers to our ability to take in, sort out, and make meaningful use of information received from our senses (i.e. via sight, hearing, taste, smell, touch, and movement). Sensory integration is how we organise sensory input to make sense of the information we receive, and how we organise our movements or verbal reactions in response to what we have taken in and made meaning of (Hagerman, 2008:3).

Females as well as males with Fragile X Syndrome have difficulty interpreting information absorbed through their sensory systems (Braden, 1996:39). They are sensitive to sound, light, touch, and texture. Sensory issues may affect every other area of development for individuals with Fragile X Syndrome (Harris-Schmidt & Fast, 2004:39). It can interfere with speech/language, behaviour and cognitive development. It is therefore important to understand how it integrates with overall functioning (Braden, 1996:39).

Individuals with Fragile X Syndrome have trouble dealing with sound in their environment. They are unable to filter out unimportant sounds like the humming of a light fixture. At times it seems as if they can hear things that are miles away. Noisy crowds or high pitched noises, like for example the school bell may be too much for these easily over-stimulated children to deal with, especially if it is unexpected (Braden, 1996:40-41; Hagerman, 2000:19-20). I have noticed while observing an individual with Fragile X Syndrome, that whenever the school bell is about to ring, she will cover her ears and try to block out the noise of the bell.

These individuals might also be sensitive to certain light settings, for example fluorescent lights and their constant hum and flicker. Other visual information might also be overwhelming, like bulletin boards or walls with a lot of information or pictures on them. Again they do not know how to filter out the important sights from the unimportant. They might feel overwhelmed by flashing lights or at settings where a lot of activities are going on at once. In these situations they typically respond by yelling or hitting. Understandably, when individuals with Fragile X Syndrome are over-stimulated by visual and auditory stimuli in their environment, they will have difficulty concentrating (Braden, 1996:40; Hagerman, 2000:19-20; Harris-Schmidt & Fast, 2004:40).

Individuals with Fragile X Syndrome often do not like to be touched, tickled or cuddled (Saunders, 2000:13). However, it is interesting to note that deep pressure seems to be more acceptable as it is a form of comfort for them. An individual may for example wear two pairs of socks in order to provide a feeling of greater pressure and this gives them a feeling of security. In my experience

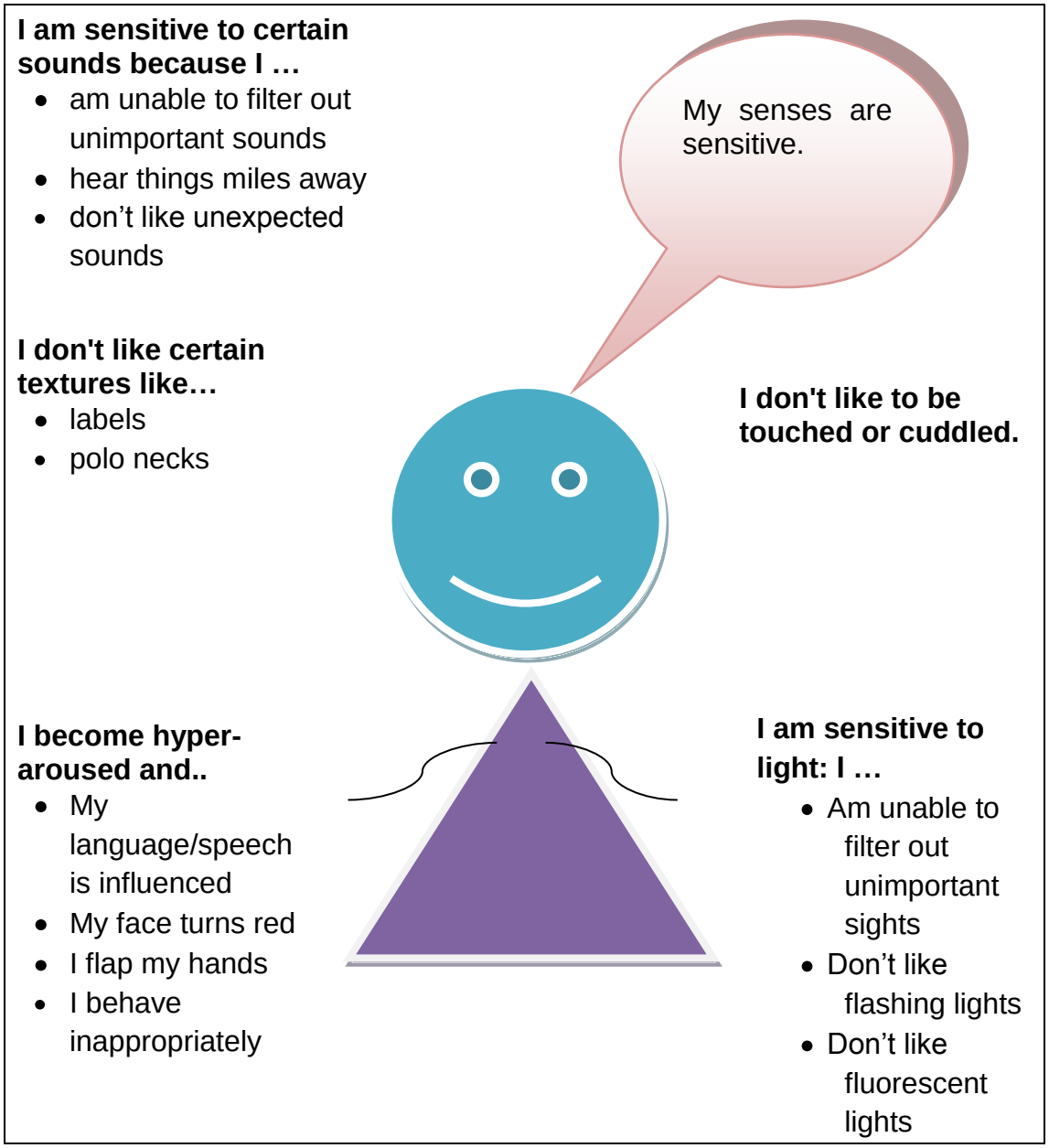
while living with an individual diagnosed with Fragile X Syndrome, I noticed that the individual would fasten a belt very tightly around her waist to make her feel tight and secure. She might have been doing this instinctively to compensate for her low muscle tone.

It has also been found that certain fabrics and types of clothing can bother individuals with Fragile X Syndrome (Braden, 1996:39). The labels sewn into the back of clothes might be irritating to them. Poloneck shirts also seem to bother these individuals, even if someone around them is wearing them (Braden, 1996:38-39; Hagerman, 2000:19-20; Harris-Schmidt, 2008:1; Harris-Schmidt & Fast, 2004:15 & 40; Stackhouse, 2004:4).

It is often found that behavioural outbursts occur when individuals with Fragile X Syndrome become hyper-aroused or anxious. Hyper-arousal can also affect the development of speech and language. There are also areas in which the child with Fragile X Syndrome does not seem to receive enough stimulus feedback. Signs of hyper-arousal or anxiety are reddening of the face and increased hand flapping (Harris-Schmidt & Fast, 2004:41). This might be a way to increase the information to the brain or simply to shut out overstimulation or simply to deal with anxiety.

In summary, an individual with Fragile X Syndrome often has sensory integration difficulties related to sound, light, touch and texture, as depicted in Figure 3.4 below (Braden, 1996:38-40; Harris-Schmidt, 2008:1; Harris-Schmidt & Fast, 2004:15 & 39-41; Stackhouse, 2004:4).

Figure 3.4: Summary of sensory integration issues



4.3.5 Cognitive Development

Cognitive development refers to overall intelligence that involves acquiring information, critical thinking, problem-solving, conceptual understanding and information processing and also attention or organisational skills (Emmons & Anderson, 2005:51). Cognitive difficulties, together with behavioural and neuropsychological difficulties, have been found to characterise Fragile X

Syndrome (Jewell, 2008:3). Research has found that 70% of females with Fragile X Syndrome have IQ levels lower than 85 and 30% of females with Fragile X Syndrome have IQ levels above 85. Even though their overall IQ might be lower than average, they still have strengths and weaknesses, as discussed below (Epstein, Riley & Sobesky, 2002:341; Harris-Schmidt, 2008:1; Reiss & Hall, 2007:665).

As discussed previously, females with Fragile X Syndrome may have attention problems. Attention refers to the ability to focus on something and keep that focus over time (Kozma & Stock, 1993:12). In order to learn, individuals need to pay attention to what they see, hear, and feel, and be able to shift their attention easily from one thing to another when necessary. It has been found that individuals with mental impairment often have attention problems (Kozma & Stock, 1993:12-14) and they may be easily distracted, impulsive and hyperactive. Their learning may therefore be affected negatively because they are unable to concentrate for a certain amount of time (Harris-Schmidt & Fast, 2004:33; Phelan, 1993:33-34). As cognitive development refers to thinking, problem-solving, conceptual understanding and information processing, it can be said that attention problems could directly impact on writing of tests and learning among individuals with Fragile X Syndrome (Harris-Schmidt, 2008:1).

As noted, females with Fragile X Syndrome have perceptual problems. Perception refers to the process of being aware of or understanding sensory information (Emmons & Anderson, 2005:51). Therefore perceptual problems can be referred to as having trouble understanding or making meaning of the information obtained through the senses (Baroff & Olley, 1999:189; Emmons & Anderson, 2005:51). For example, children with Fragile X Syndrome often have auditory discrimination difficulties. This can be connected to the history of recurrent ear infections. They may be unable to hear the difference among sounds. This can make reading as well as spelling difficult as they struggle to match sounds to letters (Harris-Schmidt & Fast, 2004:33; Saunders, 2000:13).

Perceptual difficulties often influence language and communication, and adaptive development. Communication skills and language of individuals with Fragile X Syndrome are very often not age appropriate, and therefore often affect their ability to learn and acquire skills such as receptive language, expressive language, articulation, and pragmatics (Emmons & Anderson, 2005:51). Having difficulty with adaptive development refers to having trouble in learning or acquiring the skills necessary for daily living and learning through play, such as meeting personal needs, social responsibilities, or participation in developmentally appropriate situations (Emmons & Anderson, 2005:52). Adaptive development can be seen as development which is age appropriate and allows the individual to adapt to her environment. Because of often limited cognitive development and emotional, sensory and physical barriers females with Fragile X Syndrome often struggle to fully adapt to certain living and learning environments and consequently do not learn as affectively as necessary.

Research has often shown that long-term memory is a strength found in individuals with Fragile X Syndrome. They may have difficulty with short-term memory but once the information has been stored in long-term memory, it can easily be retrieved. They easily remember people, directions and dates (Braden, 2004a:2; Hagerman, 2008:3; Harris-Schmidt & Fast, 2004:33).

Females with full mutation have significant difficulty in the area of arithmetic. It is seen as the most common learning disability found in females with Fragile X Syndrome. Mathematics involve abstract reasoning and it has been found that Fragile X Syndrome impairs abstract reasoning (Hagerman, 2000:18; Reiss & Hall, 2007:665; Saunders, 2000:9). Symbolic processing may also be an area of weakness for children with Fragile X Syndrome. Concrete facts may be learned relatively easy, but more abstract concepts are difficult for them to grasp. They do not connect meaning to the facts which they are storing in memory. If questions are reworded or presented differently, they may therefore not be able to respond. They have difficulty generalising that which they have learned to new settings, which means that adaptive development may be limited (Harris-Schmidt

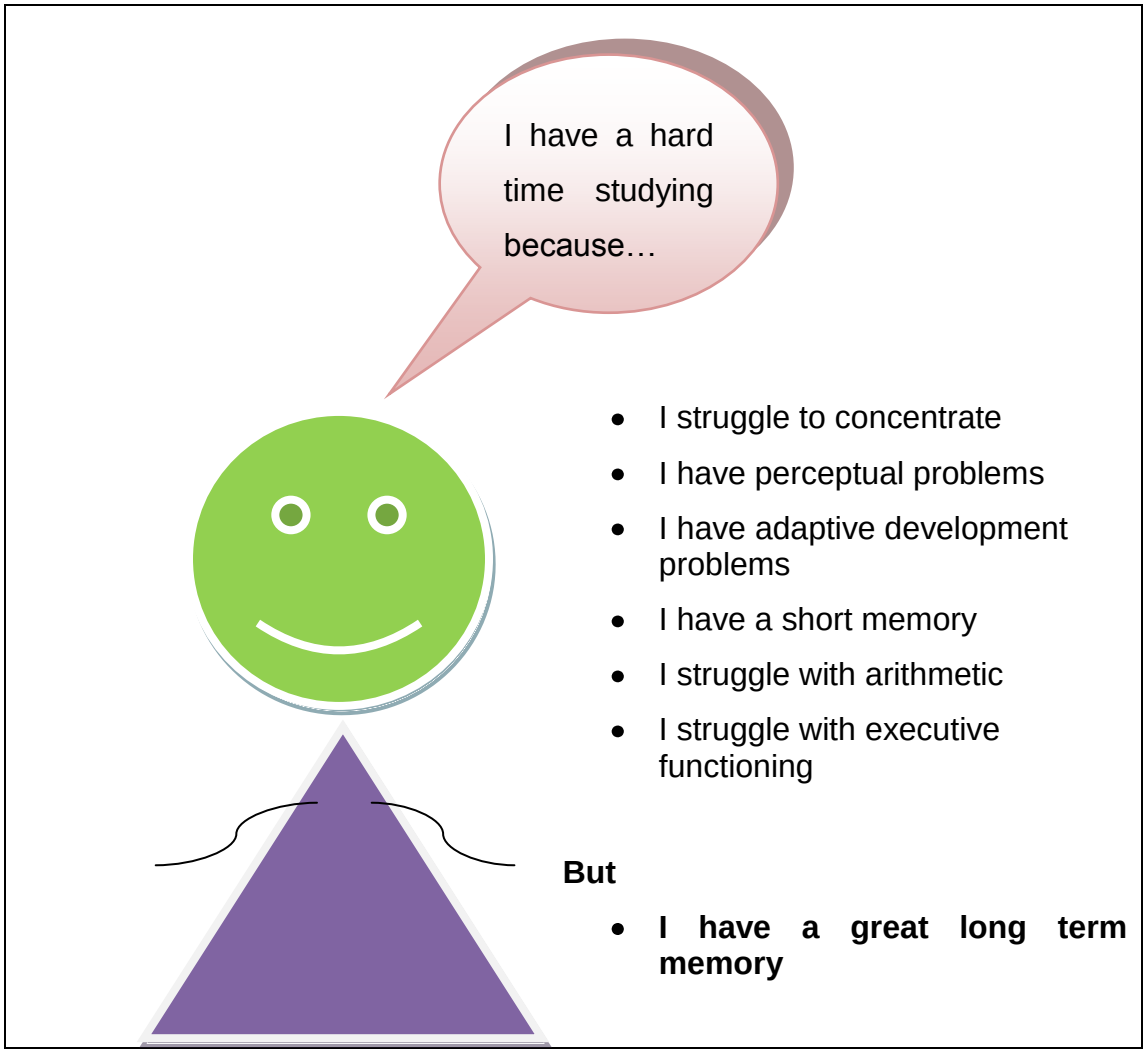
& Fast, 2004:33-34). Poor abstract reasoning is a typical feature of individuals with limited cognitive ability (Kozma & Stock, 1993:15)

Hagerman (2002:235) states that one of the most consistent neuropsychological functions in studies of females with Fragile X Syndrome, is a specific deficit in executive functioning. According to Cooper-Kahn and Dietzel (2008:1), executive functioning refers to a set of cognitive processes that involves managing yourself and your resources in order to accomplish a goal. It is the ability to plan, attend, sustain effort, create problem-solving strategies, use feedback, self-monitor and shift responses. In other words, it refers to the ability to make and execute a plan. Executive functioning also requires flexibility in problem-solving (Braden, 2000:264; Braden, 2002:436; Braden, 2004a:2; Hagerman, 2002:235; Harris-Schmidt and Fast, 2004:34; Kutscher, 2005:43; Reiss & Hall, 2007:665). Braden (2002:436) states that it is not unusual to watch a child with Fragile X Syndrome struggle when attempting to begin a task, typically because of limited executive functioning which means the child will be unsure how to plan the task, where to start, what to do next, which information to attend to and so on.

Living with an individual diagnosed with Fragile X Syndrome, I noticed certain features of executive functioning that she struggled with. It was often difficult for her to make decisions, for example deciding what to order at a restaurant. She also had a hard time keeping track of time. For example taking a bath expected to last no longer than twenty minutes, often took an hour or longer. She seemed to have very little concept of how long it would take her to do something, in other words she had very little concept of time and this impacted poorly on her ability to plan.

In summary, although females with full mutation have higher IQ levels than males, Fragile X Syndrome still affects their cognitive development in many ways. Their biggest struggles relate to abstract reasoning and formulating and executing a plan. Long-term memory is a strength within these individuals and should be used effectively in academic settings to increase their knowledge and to give them an opportunity to experience a sense of success.

Figure 3.5: Summary of cognitive development difficulties



4.4 ACCOMMODATING INDIVIDUALS WITH FRAGILE X SYNDROME

In the United States of America, school legislation encourages the inclusion of learners with disabilities with those who are developing normally (Hagerman & Hagerman, 2002:435). However, their inclusion is often facilitated by supportive resources and assistance in their more challenging subjects, such as a teacher assistant to facilitate participation and learning (Hagerman & Hagerman, 2002:435).

The USA's school systems offer learners a variety of services, such as speech-language services, occupational therapy, and behavioural interventions. The

speech-language pathologist coordinates a variety of academic and life skills activities, such as making phone calls, job interviews, and asking a friend to a movie. Occupational therapists and behaviour disorder specialists help to design calming techniques. The occupational therapist also helps with physical development issues, such as awareness in space, balance, gross and fine motor skills (Harris-Schmidt & Fast, 2004:104).

During high school a lot of emphasis is placed on vocational training. These work and training options often include placement in the local community. Job coaches such as special education teachers, vocational teachers, or speech-language pathologists, accompany students to employment settings to help with expectations of the job and to foster skills for success in that position (Harris-Schmidt & Fast, 2004:103).

As individuals with Fragile X Syndrome struggle with transitions, an unfamiliar situation often causes anxiety. Therefore, it has been found that giving an individual with Fragile X Syndrome a schedule ahead of time will help reduce the anxiety tremendously. A good example would be that of a visual schedule containing photographs and/or pictures so that the individual could see it beforehand (Hagerman & Hagerman, 2002:433: Harris-Schmidt & Fast, 2004:101). Schools that include these learners try to ease transitions.

Individuals with Fragile X Syndrome often try to avoid noisy and crowded environments. Some individuals can be desensitised by attending parts of the events in which they may feel anxious, such as lunchtime in the cafeteria and concerts. However, it is important to realise that some individuals with Fragile X Syndrome might never become comfortable in these environments (Hagerman & Hagerman, 2002:435).

Individuals with Fragile X Syndrome can make tremendous progress if the correct therapy, teaching and strategies are followed.

4.5 CONCLUSION

Throughout this chapter it was evident that many of the different characteristics, be it physical, behavioural, sensory, language/speech or cognitive, are interrelated. Many of the physical characteristics of individuals with Fragile X Syndrome affect their cognitive, speech and language, and behavioural development. Sensory issues affect their cognitive, speech/language, behavioural and physical development, and so forth. Therefore it is important to look at all the factors that impact individuals diagnosed with Fragile X Syndrome to gain a complete understanding of each individual's abilities, disabilities, and how they influence her life.

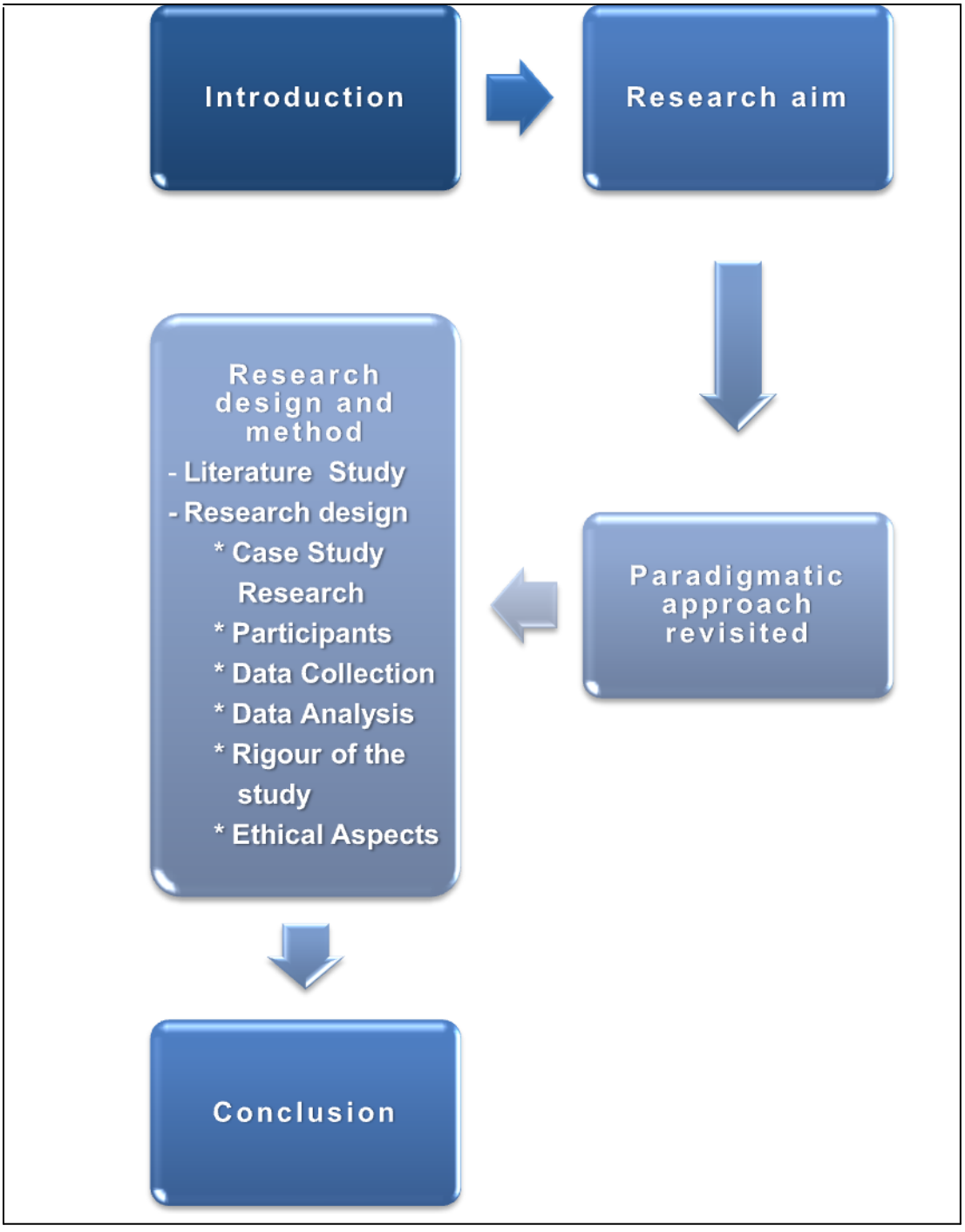
Despite the overwhelming negative impacts associated with Fragile X Syndrome, there are many positive aspects, including that individuals diagnosed with Fragile X Syndrome are very caring and loving people, have a great sense of humour, has a strong desire to socialize, great imitation and memory skills. However, the impacts these individuals experience made me believe that Fragile X Syndrome is a context of risk and for this reason I was wondering about the processes or resources that might facilitate resilient coping.

The next chapter will concentrate on the research design of the study**,** in other words the aims, objectives and methods of research.

CHAPTER FOUR

RESEARCH DESIGN AND METHOD

Figure 4.1: Overview of Chapter Four



5.1 INTRODUCTION

This chapter will represent the research methodology that was used in undertaking this study. I will explain why such methods were chosen, the steps I followed to collect the information and how it helped me to reach the aims of the study. I will also explain the ethical aspects and steps followed to ensure rigour.

5.2 RESEARCH AIM

The aim of this study was to explore what contributes to resilience in females diagnosed with Fragile X Syndrome.

The aim is then further sub-divided into sub-aims namely:

- To conduct a literature study on resilience;
- to conduct a literature study on Fragile X Syndrome;
- to conduct an empirical study to determine what might encourage resilience in females diagnosed with Fragile X Syndrome;
- to provide recommendations for parents and communities to encourage resilient functioning among females diagnosed with Fragile X Syndrome.

5.3 PARADIGMATIC APPROACH REVISITED

As noted in 1.5, I approached my study from an interpretivist perspective (Nieuwenhuis, 2007a:58-60). The interpretivist perspective can be understood as a perspective that tries to understand a phenomenon through the meanings that people assign to them (Nieuwenhuis, 2007a:59). As noted in 1.5, the interpretivist paradigm means that I am interpreting what the participants are telling me, but I also realise and understand that what they are telling me is their own interpretation of reality. This perspective locates my work in the post-modern realm, because I am not concerned with generating facts (Lincoln & Denzin, 2000:1059-1060; Vidich & Lyman, 2000:59).

I also noted in 1.5 that my interpretation might be influenced by the assumptions that I hold about resilience (see 1.5 for a list of these assumptions) and by my role as one of the participants' live-in caregiver. I was vigilant not to let my assumptions or lived experience colour how I made meaning. I spoke regularly to a psychologist with extensive experience in Fragile X Syndrome about my observations and emerging findings so that she could debrief me and limit bias (Creswell, 2009:192).

As also discussed in 1.5, my interpretation was informed by my choosing to take a transformative approach (Mertens, 2009). Because I experienced Lucy (the primary participant to whom I was a caregiver) as resilient, I became aware that females with Fragile X Syndrome also have 'strengths' (Mertens, 2009:18) and so I became curious about what influenced her resilient strength. Because I wanted to transform the traditional deficit perspective of females with Fragile X Syndrome (see Chapter Two) I chose a transformative approach (Mertens, 2009), but was careful to keep my eyes and ears open for evidence to the contrary.

5.4 RESEARCH DESIGN AND METHOD

The study was conducted in two phases, namely:

- A literature study, and
- Empirical research.

The procedure used in each phase is noted below.

5.4.1 Literature study

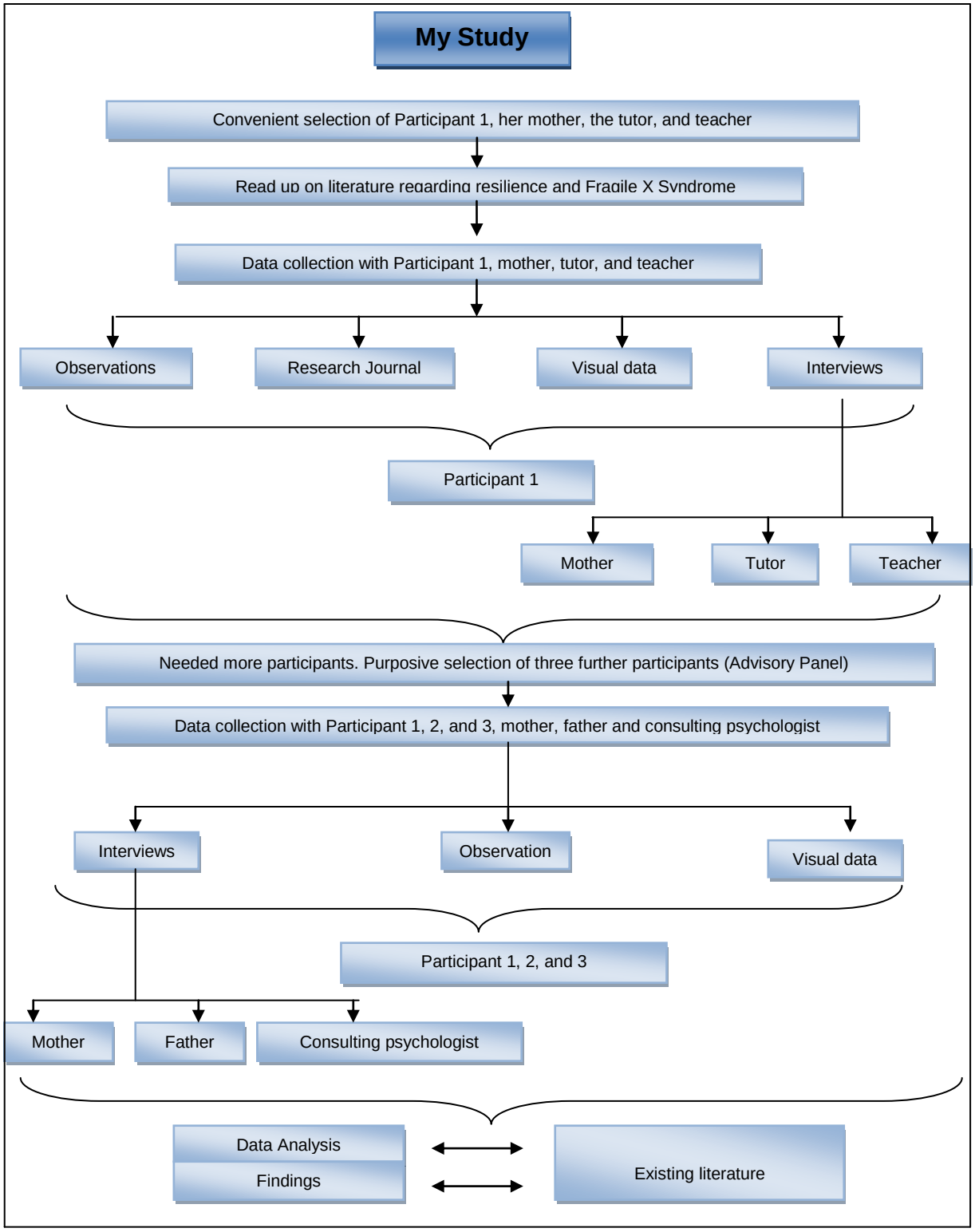
Reference books, educational journals and online resources (as summarised in Table 1.1) were reviewed and consulted to obtain relevant information on the phenomenon of resilience, and the impacts of Fragile X Syndrome on females. Relevant theories and various authors' views were analysed and interpreted. In reviewing these sources I noted that none focused on resilience in the presence

of Fragile X Syndrome, thereby motivating my study. This literature review helped me to better understand the nature of resilience in general, and the impacts of Fragile X Syndrome on female lives. I was then able to form my interview questions according to the information I found in the literature and also to make meaning of the data collected. The results of the literature research are documented in Chapter Two and Chapter Three.

5.4.2 Research design

In Figure 4.2 below, I provide an overview of the research process.

Figure 4.2: Research process



As stated previously, the main focus of my study was to explore what contributes to resilience in females diagnosed with Fragile X Syndrome and therefore a qualitative research approach was followed.

Qualitative research refers to a process that allows researchers to increase their understanding of the phenomenon under study by collecting, analysing and interpreting information (Henning *et al.,* 2004:5; Leedy & Ormrod, 2005:2). Qualitative research concentrates on understanding and describing human experiences (Fade, 2003:13; Fossey, Harvey, McDermott & Davidson, 2002:717; Leedy & Ormrod, 2005:94; Merriam, 1998:6; Nieuwenhuis, 2007a:51). People are believed to have their own assumptions, intentions, attitudes, beliefs and values (Nieuwenhuis, 2007a:55). The qualitative researcher therefore relies on the views of participants to better understand the phenomenon in question (Creswell, 2005:39; Nieuwenhuis, 2007a:50; Tan, Stokes & Shaw, 2009:169). Therefore I followed an interpretive approach (*Cf*. 4.3).

According to Merriam (1998:6), the most important characteristic in qualitative research refers to the fact that the phenomenon of interest should be understood from the participants' perspectives. As noted previously (see 1.5), the researcher is seen as the instrument of research, that is, the researcher is the one who collects and analyses the data obtained (Henning *et al.,* 2004:10; Merriam, 1998:6). In order for the researcher to understand the phenomenon from the participants' perspective, the researcher has to spend a great amount of time in their natural setting. The researcher physically goes to the site (home, school), in order to observe the participants' behaviour and to gather data that will help her understand the phenomenon better (Creswell, 2003:181; Merriam, 1998:6). In my study I collected and analysed the data that were collected from the primary and secondary participants (*Cf*. Figure 4.2). These data included interviews, observations, and visual material. I lived with the first participant (Lucy) for twenty months and was able to interact with her on a day-to-day basis. I interacted with Participants 2, 3, and 4 (Melissa, Cindy and Kelly) on three different occasions (see Figure 4.2).

The emphasis of qualitative research is on quality and depth of the information gathered (Nieuwenhuis, 2007a:51). Qualitative research is very descriptive, and makes use of words and pictures rather than numbers (as in the case of quantitative research) to describe the phenomenon (Merriam, 1998:6). The advantage of qualitative research is that is seeks a wide understanding of the entire situation and therefore presents more in-depth and comprehensive information about the phenomenon. One disadvantage is that it is difficult to verify the reliability and validity of the approaches and information obtained. It is also difficult to prevent or identify the researcher's induced bias (Key, 1997). Because of the known criticism, I commented on my assumptions related to the topic in 4.3 and also in Chapter One (*Cf*. 1.5) and I worked hard to heighten the trustworthiness of the research process and gathered data (see Section 4.3.2.5 later in this chapter).

Different types of qualitative research strategies can be found in the research literature (Leedy & Ormrod, 2005:135; Merriam, 1998:11; Nieuwenhuis, 2007b:70). Four common qualitative research designs are summarised in Table 4.1, as identified by Leedy and Ormrod (2005:144); Merriam (1998:12); and Nieuwenhuis (2007b:70-77):

Table 4.1: A summary of the different types of qualitative research designs

Case study	Refers to understanding one or more person, programme, event, group or community. The case study approach can further be divided into a disciplinary approach, overall intent approach, and multiple case studies approach.
Ethnography	Refers to understanding and describing the culture of a group by means of their behaviour.
Phenomenological study	Refers to understanding a phenomenon experienced by the participant/s in the study.
Grounded Theory Study	Refers to developing a new theory from the data that was collected in the natural setting.

As stated in Chapter One, I followed a multiple case study (Merriam, 1998:40) approach. This approach is discussed in detail below.

5.4.2.1 Case study research

Case studies refer to an in-depth study that focuses on understanding and collecting detailed information about a particular individual or more individuals, programme, event, activity, topic or process for a defined period of time (Creswell, 2003:15; Creswell, 2005;439; Leedy & Ormrod, 2005:135; Lindegger, 2006:460-461; Nieuwenhuis, 2007b:75; Simons, 2009:21). Merriam (1998:19) states that "the interest is in process rather than outcome, in context rather than a specific variable, in discovery rather than confirmation". Rather than concentrating on what should be found and confirming what has already been found, the study concentrates on how the outcomes were reached and also tries to discover new information and ideas. This was important in this study because I did not try to prove what has already been found in the resilience related literature, but tried to determine what contributes to resilience in females with Fragile X Syndrome.

Merriam (1998:27) emphasises the fact that the phenomenon being studied should be intrinsically bounded in order for it to be a case. She states that the boundedness can be assessed by asking "how finite the data collection would be". In other words, what is the limit to the number of people that will be interviewed, or is there a specific amount of time for observations (Lincoln & Guba, 1985:28). In this study there was a limit to the number of people that were studied. I studied four primary participants, and therefore four bounded cases. The cases were bounded in time too. My observation of and interaction with Lucy was from February 2008 to September 2009. My observation of and interaction with Melissa, Cindy and Kelly was from July 2008 to May 2009. The significant adults from whom data were collected are seen as the secondary participants as they helped me understand the four bounded cases.

As indicated above, I included four primary participants, which means I conducted a multiple case study. Multiple case studies refer to the study of

several cases that provide insight into an issue or theme (Creswell, 2005:440). According to Lindegger (2006:461); Merriam (1998:41-42) and Simons (2009:23-24) case studies consist of both strengths and limitations. The strengths and limitations as stated by them are summarised in Table 4.2:

Table 4.2: Summary of the strengths and limitations of case studies

Strengths	Limitations
The phenomenon under study is studied in detail.	The subjectivity of the researcher can influence the results.
Different viewpoints and perspectives can be explored and documented.	The study can take up a lot of time and money.
It is useful for exploring and offers insight into the phenomenon.	The study can be too detailed.
It is flexible. No specific method needs to be used and there is no set amount of time to be spent on the study.	The researcher can easily oversimplify or exaggerate the situation, and therefore give a distorted understanding of the findings of the study.
The participants are active in the research process.	The readers of the study might generalise too easily.
Behaviour found in similar settings can be predicted, without actually observing the setting.	The study can be limited with regard to sensitivity and integrity due to the researcher's inexperience.
Due to the fact that it is "real life", the descriptions of the study are seen as rich and holistic.	Ethics and trustworthiness - The reader and researcher should be aware of being biased.

I have noted the limitations to using case studies. However, I tried my best to decrease these limitations by following certain guidelines to improve the trustworthiness of the results. I engaged in self-reflection throughout the study to ensure that subjectivity did not influence my results. There was also a time limit to the study as I was only allowed a two-year time frame in the United States of America. I also made use of peer debriefing to ensure the information was not biased, member checks, and triangulation (see 4.3.2.5).

In order to conduct qualitative case studies, a number of steps have to be carefully followed. Table 4.3 below sets out the five steps I followed as discussed by Creswell (2005:451); and Leedy and Ormrod (2005:136):

Table 4.3: Steps in conducting a case study

Steps	Case Study Procedures	Example of how it was done in the study
1	State your intent, the design, how it relates to your research problem.	My intentions were to develop an in-depth understanding of what contributes to resilience in females diagnosed with Fragile X Syndrome. I chose to use multiple case studies. My aim was not only to understand the phenomenon, but also to be able to give recommendations to parents, teachers and other professionals so that they could encourage resilient functioning among other females diagnosed with Fragile X Syndrome. A multiple case study was well suited to providing such an in-depth understanding.

2	Plan to receive approval and gain access to study sites and participants	Approval was obtained from the institutional review board of North-West Universtiy to conduct the study **(NWU0003-08-A2).** Three of my participants were chosen by an Advisory Panel (*Cf*. 1.6.2.2). This panel also helped me access Melissa, Cindy and Kelly. The research was conducted ethically (i.e. I received the participants' permission to work with them (*Cf*. 4.4.2.6).
3	Collect data	Various forms of data collection were used. I made use of interviews, observations, a journal, and visual materials (*Cf*. Figure 4.2)
4	Analyse and interpret the data	I listened attentively to the participants during the interviews in order to ensure my research questions were answered. After I had conducted the interviews, I transcribed them and read through them until I was familiar with the content. I then coded the interviews according to my research questions. Later, I grouped the codes into groups to formulate themes. I also made observations and collected visual material, and kept record of these observations by means of a reflection journal (Richardson, 2000:941; Merriam, 2002:13). I then analysed the journal, observations, and visual material in the same way as the interviews and triangulated (Nieuwenhuis, 2007c:113) these with the interview data. I coded each data set for themes that shed light on resilience. I then compared and grouped or triangulated similar themes across the data sets.
5	Write and report the research	My findings are discussed in Chapter Five.

5.4.2.2 Participants

When I started this study, I was employed by a family in Chicago, Illinois, in the United States of America, as a live-in carer for their daughter, Lucy. Lucy was 16 years of age when I arrived and had been diagnosed with full mutation Fragile X Syndrome when she was six years old. I had not heard of Fragile X Syndrome until I met Lucy and her family and was very interested to learn more about learning more about the syndrome. I was fascinated by her ability to cope so well, even though she was considered to be mentally impaired. I wanted to find out what made her resilient, despite her having to face so many adversities on a day-to-day basis. Living with this family seemed like the perfect opportunity to do so.

I studied the literature on resilience and decided to conduct a single case study based on the case of Lucy, to find out what made her resilient (although I did later change this to a multiple case study, as stated above). Convenience sampling therefore took place (Henning *et al.,* 2004:71; Merriam, 1998:63). Convenience sampling refers to selecting participants based on time, money, location and availability of participants (Merriam, 1998:63).

However, as stated by Merriam (1998:63), convenience sampling is not very credible. I then realised that studying only Lucy was not enough to make this study trustworthy, and so I decided to back up my observations by adding additional participants. Although I did not live with them, I interviewed them and interacted with them on more than one occasion. The selection criteria for the additional participants included the following:

- They had to be females between the ages of 16 and 30 years.[2]
- They had to have been diagnosed with full mutation Fragile X Syndrome;

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[2] I hoped that the participants would be similar to Lucy in age, but I could not access any such participants. Therefore I accepted this age range.

- They had to be identified by an Advisory Panel as resilient.

Therefore, purposive sampling (Maree & Pietersen, 2007:178) was added to supplement my initial convenience sample. Purposive sampling refers to a technique where the researcher selects participants from whom the most can be learned (Merriam, 1998:61). As stated before, the three participants were identified by an Advisory Panel. The use of an informed Advisory Panel is advised and modelled by Ungar *et al*. (2008:291). An Advisory Panel refers to members of the community who have access to and knowledge of local young people who are resilient despite difficult lives (in this case, females who had been diagnosed with Fragile X Syndrome and who nevertheless were resilient). The Advisory Panel consisted of three individuals who were members of the Fragile X community, and therefore had access to and also knowledge of females who had been diagnosed with Fragile X Syndrome. These members comprised of a consulting psychologist (expert in Fragile X Syndrome), a teacher, a parent, and myself (the researcher). I met with the Advisory Panel in order to discuss how they understood and defined resilience. Their definitions were as follows:

Table 4.4: Advisory Panel members' definitions of resilience

Advisory Panel Member 1	The ability to "bounce back"/adapt/keep trying when things don't work out, when you don't get the result you hoped for, or when you fail to achieve what you set out to do. It's the motivation and drive to keep going.
Advisory Panel Member 2	Resilience is a quality of courage and toughness; more subtle than the former, more refined than the latter. It is perseverance without the drudgery, endurance without the pain. It threads its way through all these things, but does so without much notice; ever confident of its status as a handmaiden to strength. Like tempered steel, what

	makes someone resilient is their passage through fire; their ability to endure the heat while respecting its elemental power, thus emerging from adversity as a stronger and more durable person. It is both an instinct and a learned trait, but above all it is fundamentally rooted in flexibility and a sober acceptance of risk.
Advisory Panel Member 3	Their resilience has to do with their ability to problem solve during novel or unpredictable situations. They seem to be able to apply emotional stamina when they need to. They also have the ability to retry things they had problems with which is unusual for many females with a full mutation.

I explained how I understood and defined resilience (Ungar *et al*., 2008) and then, following debate, we agreed on a definition of resilience. This definition is as follows:

Resilience does not only involve an individual's adaptation skills, but is a process between the individual, her relationships in the family, community, and culture. The individual must have overcome the risk of Fragile X Syndrome and demonstrated positive adaptation even though she might be faced with significant adversity such as Fragile X Syndrome (Masten, 2001:228; Masten & Reed, 2005:75-77).

Indicators of positive adaptations in the case of Fragile X Syndrome were named as follows:

- Independence.
- Ability to problem solve.
- Being able to apply emotional stamina when needed.

- The ability to retry things with which they had problems (which is unusual for many females with a full mutation).
- Ability to ask for help.

The Advisory Panel then identified three[3] participants fitting this definition. The three chosen participants were all Caucasian (white), young adults, living in Madison, Wisconsin, United States of America. They all came from the same family.

Members of the Advisory Panel initially contacted the participants' parents to explain to them what my study was about and to ask them if they would allow me to meet with their children. Once the parents gave the Advisory Panel their permission, the members of the Advisory Panel provided me with e-mail addresses of the parents of the participants so that I could contact them. I asked the parents in advance if they would allow me to conduct a study with their children, to prepare the girls and to lessen their anxiety. I wanted the parents to broach the subject of my study on resilience with their children. I also gave them an outline of the questions in advance so that they would be familiar with what would be expected of them in order to decrease their anxiety, and also so that they had time to think about the questions. It has been found that if Fragile X Syndrome individuals are provided with a structured plan in advance, they have less anxiety (Harris-Schmidt & Fast, 2004:104).

I realised that I might be biased in my opinion of Lucy as resilient. She was well-known to the AP and so I asked them to comment on how well she matched their definition of resilience. they were unanimous in their confidence that she was resilient.

I therefore explored four cases, which means that I had four primary participants. I also interviewed some of the significant adults in their lives, including parents,

[3] Only three participants were recruited, as it was difficult to find participants.

their consulting psychologist (expert in Fragile X Syndrome), and teachers (tutors) to provide me with a richer understanding.

5.4.2.2.1 Background of primary participants

The first participant (Lucy) was 16 years of age when the study was conducted. She was Caucasian and lived in Chicago, Illinois, United States of America, with her parents. She was the second of two children. She had an older brother, who did not have Fragile X Syndrome. She was diagnosed with full mutation Fragile X Syndrome when she was six years old. She attended mainstream schooling until the end of the seventh grade. During this time she had a one-on-one assistant. After seventh grade she transferred to a school for special needs children. She was exposed to numerous supportive resources, such as occupational therapy, speech therapy, tutors, live-in care, and social groups.

The second participant (Melissa) was a 23-year old, Caucasian female. She lived in Madison, Wisconsin, United States of America, with her parents and three sisters. She was the youngest of four girls all of whom had been diagnosed with Fragile X Syndrome. She was 12 years old when she was diagnosed with full mutation Fragile X Syndrome. She attended mainstream schooling, but was in the special needs class in the mainstream school. She was able to have extra classes, such as reading classes, during the summer (their long vacation); special education teachers; counsellors; and an individual education programme (IEP).

The third participant (Cindy) was a 26-year old, Caucasian female. She also lived in Madison, Wisconsin, United States of America, with her parents and three sisters. She was the second participant's older sister. She was diagnosed with full mutation Fragile X Syndrome when she was 14 years of age. She attended mainstream schooling throughout the first to twelfth grade. She then attended a college where she completed a Certified Nursing Assistant course but was unemployed at the time of the interview. The resources she was exposed to also included extra classes, such as reading classes, during the summer (their long vacation); special education teachers; and counsellors.

The fourth participant (Kelly) was a 29-year old, Caucasian female. She also lived in Madison, Wisconsin, United States of America, with her parents and three sisters. She was the eldest of four girls. She was only diagnosed with Fragile X Syndrome when she was 17 years old. She attended a mainstream school, and then went to college to become a qualified kindergarten assistant. She is currently still working at the same kindergarten and enjoys it very much. The resources she was exposed to included extra classes, such as reading classes during the summer (their long vacation), and counsellors.

Their barriers due to Fragile X Syndronme are summarised in Table 4.5 below.

Table 4.5: Summary of barriers

PARTICIPANTS	SCHOOLING	PHYSICAL BARRIERS	EMOTIONAL AND BEHAVIOURAL BARRIERS	SPEECH AND LANGUAGE	SENSORY INTEGRATION ISSUES	CURRENT POSITION
LUCY	Special needs school	• Loose connective tissue • Hypotonia • Visual impairment • Motor tics	• Anxiety • ADHD • Hand flapping and biting	• Pragmatics • Perseveration	• Sensitive to certain sounds • Dislike certain textures • Hyper-aroused • Sensitive to light	• At school • Lives with parents
MELISSA	Mainstream (in special needs class)	• Loose connective tissue • Hypotonia	• Anxiety • ADHD	• Abstract language	• Hyper-aroused • Dislike certain textures	• Employed • Lives with parents
CINDY	Mainstream with assistance	• Loose connective tissue • Hypotonia	• Anxiety • ADHD • Depression	• Abstract language	• Hyper-aroused	• Un-employed • Lives with parents
KELLY	Mainstream with assistance	• Loose connective tissue • Hupotonia	• Anxiety • ADHD	• Abstract language	• Hyper-aroused	• Employed • Lives with parents

5.4.2.2.2 Background of secondary participants

To understand my primary participants more fully, I interviewed adults who were integrally involved in their lives. This was partly necessitated by the difficulty I had in gathering verbal information from the primary participants. As discussed in Chapter Three, individuals with Fragile X Syndrome have speech and language difficulties (Abbeduto *et al.*, 2007:37). To overcome this challenge I augmented their interviews with observational data and visual data and I interviewed involved adults. These included:

- **Lucy's mother**

She was a Caucasian woman, and had been diagnosed as a carrier of Fragile X Syndrome. She was a board member of the National Fragile X Foundation in the United States of America. She was therefore very active in the Fragile X Community and had devoted her time to finding ways to help individuals like her daughter, who had been diagnosed with Fragile X Syndrome. Ever since the day her daughter was diagnosed with Fragile X Syndrome, she had been trying to expose her daughter to as many different kinds of resources as she could find.

- **Lucy's teacher**

She was Caucasian, a special education teacher, and an assistant teacher in Lucy's mainstream, first grade class, there specifically to assist Lucy (one-on-one). She maintained a close friendship with Lucy through all these years. They met on a weekly basis (every Sunday) when they went out to lunch.

- **Lucy's tutor**

She was a Caucasian, Montessori-trained teacher who had been working with Lucy for about three years. The most important thing she did with or for Lucy was to mediate with the school on Lucy's behalf. She understood Lucy and Fragile X Syndrome and was open to different learning styles. She actively tried to stay aware of different types of programmes, books, and activities and shared what she thought would work with the teachers. They e-mailed one another about what Lucy was doing in class, what they could do to help her with things she did

not understand and in which areas Lucy could do more. Doing homework with Lucy helped her stay in touch with what Lucy was doing in her classes. She helped Lucy's parents by keeping them informed about what was occurring academically.

- **Father of Melissa, Cindy and Kelly**

He was a Caucasian male, and father of four females who had all been diagnosed with full mutation Fragile X Syndrome. He worked as a Chief Financial Officer, but at the time of our meeting owned his own business. He was also a board member of the National Fragile X Foundation, and was therefore very much involved in the Fragile X Community.

- **Mother of Melissa, Cindy and Kelly**

She was a Caucasian female, and mother of four girls diagnosed with full mutation Fragile X Syndrome. She was diagnosed as a carrier of Fragile X Syndrome. She was a housewife, and being at home was therefore able to pay more attention to her children.

- **Consulting psychologist to Melissa, Cindy and Kelly**

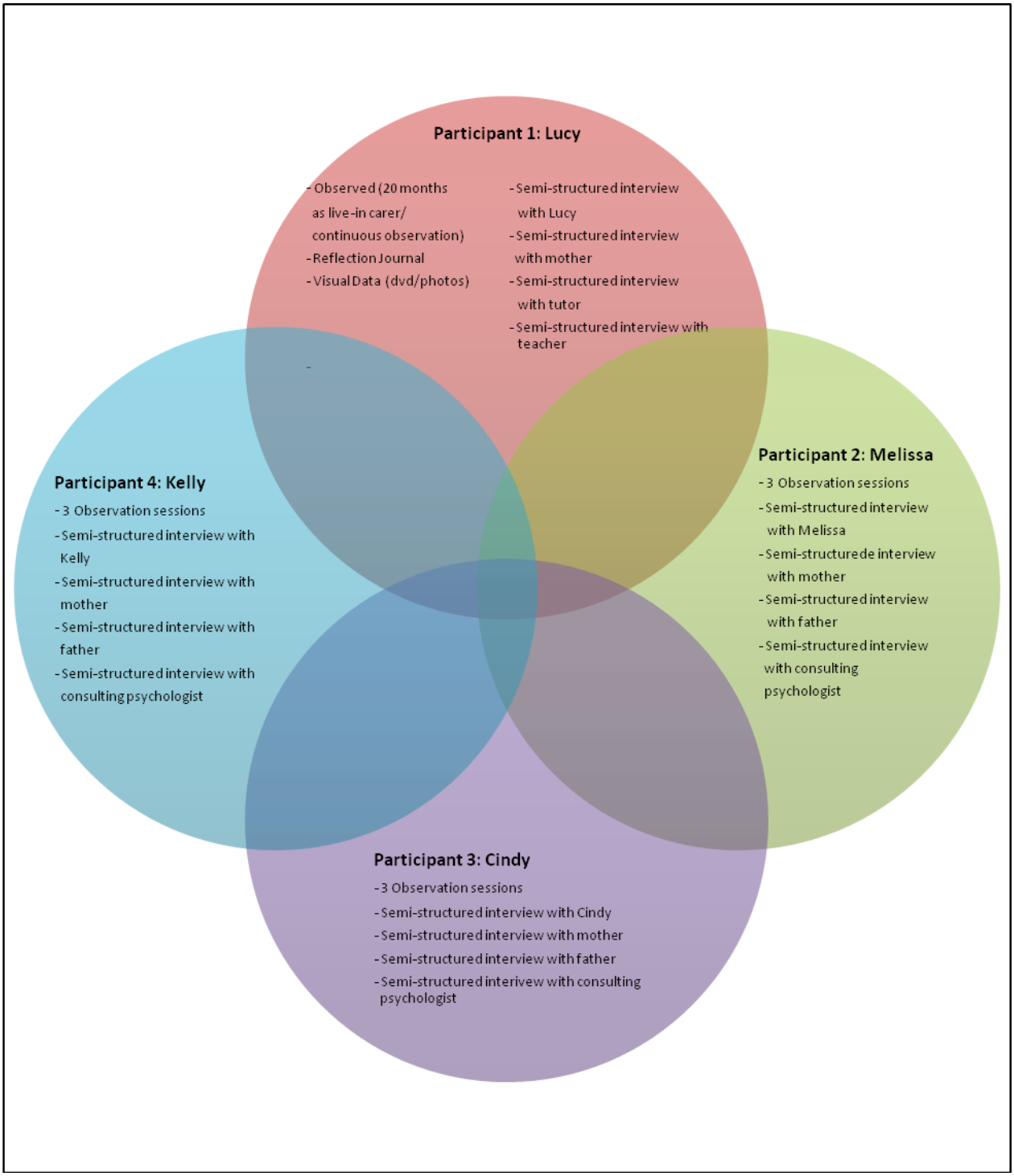
She was Caucasian, an expert in Fragile X Syndrome and a licensed psychologist, with a clinical practice specialising in children and adolescents. She was a former teacher with experience in teaching general and special education. She has written and published numerous articles related to education and behaviour management strategies, techniques, and interventions. She frequently consulted with parents, therapists, educators, and medical staff about effective treatments for Fragile X Syndrome and Autistic individuals. She had known Melissa, Cindy and Kelly (Participant 2, 3, and 4) for approximately six years.

5.4.2.3 Data collection

Case studies make use of a variety of methods or techniques to collect data (Creswell, 2003:15; Creswell, 2005:439; Nieuwenhuis, 2007b:76; Simons, 2009:21). These techniques can include observations, interviews, documentation reviews, and/or audiovisual material (Leedy & Ormrod, 2005:135; Merriam,

1998:155; Nieuwenhuis, 2007b:76). In this study I made use of semi-structured interviews, simple observations, a research journal, and visual material. In Figure 4.3 a visual summary is given of the participants and the techniques I used to collect data from each primary participant.

Figure 4.3: Summary of the primary participants and data collection techniques used



Due to the fact that I was living with Lucy (Participant 1) and her family, I was able to interact with her on a day-to-day basis and therefore collect more data than with the other participants. I conducted informal interviews, made simple observations, wrote a research journal, and also collected visual data (such as videos and photographs). I was also able to interview her mother, a teacher, and tutor.

I had three observation sessions with Melissa, Cindy and Kelly (Participants 2, 3 and 4) respectively, during which I was able to make videos and observation notes. I met them at the National Fragile X Conference in St. Louis in 2008, then again at a National Fragile X Foundation party, and once at their home in Madison. I was also able to interview their parents, and a psychologist who had known and worked with them for approximately six years.

Appointments were made by phone and e-mail to conduct the interviews face-to-face. One interview was done with each of the adults and additional information that was needed to clarify interview data was obtained through e-mails, phone calls and informal conversations. This all took place in the United States of America.

The data collecting techniques that were used in the study as summarised in Figure 4.3 are discussed in detail below.

5.4.2.3.1 Interviews

According to Merriam (1998:91), interviewing in qualitative research can be an excellent way to help understand the phenomenon that is under study. Interviews can be defined as a conversation between the researcher and participant/s, in which the researcher asks questions in order to collect data and to learn more about how the participant views and understands her experiences, ideas, and beliefs (Nieuwenhuis, 2007b:87).

The aim of an interview is to obtain rich and descriptive data. It can be a valuable source of information if used correctly (Nieuwenhuis, 2007b:87). In order to

successfully conduct interviews and get the most out of an interview, the following should be done (Kelly, 2006:299; Nieuwenhuis, 2007b:88):

- Find a participant who is best qualified to ensure that you obtain the required information;
- clearly state the aim of the interview so that the participant understands what is expected of her;
- collect rich and descriptive data;
- ask open-ended questions;
- include a variety of questions;
- listen, and do not dominate;
- take note of the participant's non-verbal communication.

I tried my best to comply with the above guidelines. However, because of the speech difficulties of the primary participants (Braden, 1996:10), standard interviewing procedures were difficult. In the interviews with the primary participants I often asked leading and closed questions (Merriam, 1998:79). The reason for this is that individuals with Fragile X Syndrome often avoid or have difficulty interacting socially. The participants often had a hard time expressing their feelings, thoughts and beliefs (Abbeduto *et al.,* 2007:37; Fidler, Philofsky & Hepburn, 2007:51). Therefore, in order to obtain answers from the participants, I often had to lead them. This posed limitations on the data collected from them in interview form as it was often initiated by me, the interviewer, and therefore the credibility of the information can be questioned. This is part of the reason why I included secondary participants and collected observational and visual data.

Interviews also have certain general advantages and limitations. These advantages and limitations as stated by Creswell (2003:186) are summarised in Table 4.6 below.

Table 4.6: Summary of the advantages and limitations of interviews

Advantages	Limitations
Interviews are useful when participants cannot be directly observed.	The gathered information is filtered through the views of the researcher.
Participants can provide historical information.	The interview does not take place in the natural setting
The researcher has control over the line of questioning.	Researcher's presence may bias the responses of the participants.

I dealt with the above limitations by making use of an independent coder to confirm what I found when the interviews were coded; and also by using observations, a research journal, and visual material together with the interviews conducted, to back up my conclusions.

Creswell (2003:186) identifies three ways in which interviews can be conducted, namely face-to-face, by telephone, and group interviews. The interviews that I conducted in this study were done face-to-face.

According to Nieuwenhuis (2007b:87), interviews can furthermore be divided into three types:

- Open-ended

Open-ended interviews are conducted in the form of a conversation. The intention of the interview is for the researcher to, together with the participant, explore the participant's views, ideas, beliefs and attitudes.

- Semi-structured

Semi-structured interviews are used by the researcher in order to confirm data arising from other data sources. The questions that the participants are expected

to answer have already been determined, but can occasionally be probed by the researcher.

- Structured

Structured interviews are usually developed in advance. This type of interview is often used in multiple case studies, in order to ensure that the interviews are consistent.

The interviews conducted with the four primary participants were semi-structured (Merriam, 1998:74). As noted above, I found that the participants often had trouble expressing their thoughts, feelings and views and therefore this type of interview allowed me to gather more information from the participants. The interviews were based on the following central question: “Tell me how you cope with life even though you have been diagnosed with Fragile X Syndrome.” However, I did not conduct a formal interview with Lucy (Participant 1), but had short informal conversations with her as she had more trouble expressing herself and communicating than the other three primary participants.

I used semi-structured interviews (Leedy & Ormrod, 2005:139; Merriam, 1998:75) to gather data from the secondary participants. The questions were set prior to the interviews being conducted and were based on current ecosystemic theories of resilience (Ungar, 2008a:22-23; Masten & Reed, 2005: 83; Schoon & Bynner, 2003:24). The questions to the parents and other professionals were based on the following questions:

- How does FXS impact on participant’s (I used her name) life?
- What mitigates/buffers/softens these impacts (protective factors)?
- What in the participant personally helps to buffer the impacts of FXS?
- What in the participant’s family helps to buffer the impacts of FXS
- What in the participant’s school helps to buffer the impacts of FXS?
- What in the participant’s friends helps to buffer the impacts of FXS?
- What in the participant’s community helps to buffer the impacts of FXS?

- What in the participant's culture helps to buffer the impacts of FXS?

I probed their responses by asking for examples or for deeper information. The interviews were recorded and transcribed word for word. Examples of interviews with a primary as well as a secondary participant are included in Addendum B and the rest of the interviews are available on request.

5.4.2.3.2 Observations documented as field notes

Observations can be defined as a process that involves recording data without necessarily questioning or communicating with the participant (Nieuwenhuis, 2007b:84). It is an intentionally unstructured, free-flowing activity in which the researcher uses her senses and intuition in order to gain better understanding of the phenomenon under study (Leedy & Ormrod, 2005:145; Nieuwenhuis, 2007b:84).

Kidder (quoted by Merriam, 1998:94-95), states that observations should include the following criteria:

- There should be a purpose for observing.
- The observations should be planned deliberately.
- The observations should be recorded systematically.
- The observations should be checked in order to ensure validity and reliability.

I made use of simple observations (Burns, 2000:408). I observed Lucy on a day-to-day basis as I was a live-in carer for her and focused on how she coped with everyday struggles and what helped her to cope with these struggles. As for Melissa, Cindy and Kelly (Participant 2, 3 & 4), I was only able to observe them on three occasions, due to the fact that they lived three hours away in a different state from me (the researcher). I was able to observe them at the National Fragile X Foundation Conference in 2008, at their home in Wisconsin, and at a social event.

I interacted with the primary participants (Kelly, 2006:310) informally and was able to observe their behaviour as it occurred in their natural setting (Mertens,

2005:382). By observing the primary participants, I was able to notice things that had become routine to these participants and I could also understand the context better (Merriam, 1998:95). Aspects that were not or could not necessarily be found or seen during the interviews, because the participants could not express certain things or talk about them, could be noticed during the observations (Merriam, 1998:96). I was able to observe what the setting was like, the characteristics of the participants, how they interacted and what they were doing, and also how my role affected them (Merriam, 1998:97-98). I noticed how Melissa, Cindy and Kelly interacted with others at parties and how they controlled their social anxiety when around others. I was also able to observe them interacting with their family at home. I could observe Lucy on a day-to-day basis and could therefore notice more about her reactions in different settings (such as school, home, and community). I was also able to observe how she interacted with her family and extended family, and how her family and community influenced her ability to cope with adversity.

After interacting with the primary participants, I noted down what I had observed (Kelly, 2006:310), and transferred my written notes to a computer (Bogdan & Biklen, 2007:118). However, I often had to rely on memory to recall the sessions observed (Merriam, 1998:104). I had decided to do this as it might have made the participants nervous or anxious if I continuously made notes. This however was a limitation as I could not always remember the events as precisely as I would have if I had made notes during the observation sessions.

Creswell (2003:186); and Leedy and Ormrod (2005:145) mention some advantages and limitations to observations. These are summarised below in Table 4.7:

Table 4.7: Summary of the advantages and limitations of observations

Advantages	Limitations
Researcher has a firsthand experience with the participants.	The researcher can be considered “intrusive”.
Researcher can record information that might have become routine to the participant.	Information that the participants might consider “private” might be observed.
Data can be recorded as it is revealed.	The researcher might not have the necessary skills to be a good observer.
The participant might be uncomfortable discussing certain topics. Through observations these topics might be explored.	The participant’s behaviour may be altered due to the observer being present.
The behaviour patterns that are observed can later be used as reference point in interviews.	

I dealt with the above limitations by participating with the primary participants as a friend, and not as an authority figure (Bogdan & Biklen, 2007:95). The primary participants were therefore able to act more naturally in front me. They trusted me and I assured them that I would not record events they did not want me to, as well as aspects that would place them in a negative light. I was able to use the

observations together with the interviews to substantiate what was found (Merriam, 1998:96).

5.4.2.3.3 Research Journal

During my observations of Lucy, I kept reflective records by means of a journal (Richardson, 2000:941). The purpose of keeping a journal was to learn more about Lucy, and to enable me to remember certain details about her and the activities she encountered (Merriam, 1998:119; Merriam, 2002:13). Due to the fact that I was able to observe Lucy more than the other three primary participants (Melissa, Cindy and Kelly) because I was a live-in carer, I was able to compile a journal of the observations made.

I found that Lucy often modified her behaviour by talking about unrelated things and also role-playing (pretending to be somebody else) when I interviewed her, and therefore this form of collecting data allowed me to record different kinds of activities that took place in her natural setting. The content of my research journal usually included notes about events that took place (Burns, 2000:440). I also realised that I had emotional reactions to the participant and therefore made use of reflection to ensure credibility. My reflection notes included actively questioning, raising issues with others (such as Lucy's mother) to confirm what I had observed and my understanding of my observations.

The research journal therefore served as a back-up to the findings from the interviews and the observations, and thus enhanced the findings' trustworthiness (Nieuwenhuis, 2007c:113).

5.4.2.3.4 Visual data collection

I also collected visual data such as photographs and videos of the primary participants and their environment (Bogdan & Biklen, 2007:141). I tried to capture events and situations that depicted the participants coping with everyday struggles. It provided visual evidence of how and what helped the participants cope with their everyday struggles. I also tried to capture some of the resources that were available to the participants (*Cf.* Addendum E). However, I collected

more photographs and videos of Lucy and her environment and resources, as I spent more time with her. These situations were also more accessible as I was a live-in carer for her.

I used the photographs and videos together with the interviews, observations, and research journal to back up my findings and thus add to the trustworthiness of the study (Kelly, 2006:287; Merriam, 1998:204; Mertens, 2005:426).

5.4.2.3.5 Data collection process

The process of data collection was lengthy, as summarised in Table 4.8 below:

Table 4.8: Summary of the data collecting process

Participant 1	Participant 2, 3 and 4
Moved in with participant (January 2008)	Met at the 2008 National Fragile X Conference in St Louis, MI., United States of America.
Explained goal of study to her and her parents (January 2008)	I observed and made notes during the conference as I was very interested in learning about Fragile X Syndrome and my attention was drawn to the three sisters with Fragile X Syndrome and how well they seemed to cope with things that Participant 1 often struggled with.
Gained their permission to conduct study. I noted in my Research Journal that she was excited to participate.	In January 2009, I realised that I needed to back up what I had determined from the data collected from Participant 1.

Participant 1	Participant 2, 3 and 4
Recorded observations on a regular basis (see excerpt from research journal - Addendum C)	In February 2009 I asked the Advisory Panel to refer me to additional participants.
Started collecting visual material (videos and photographs)	A member of the Advisory Panel e-mailed the parents of Melissa, Cindy and Kelly's to inform them about my study and interest in interviewing and observing their children.
Interviewed Lucy (August 6, 2008)	The Advisory Panel provided me with the e-mail address of the parents.
Transcribed interview	I e-mailed the parents at the end of February 2009 to gain their permission and to set up dates to meet with them and their children.
Observation	March 8, 2009 I visited their house to conduct an interview with each participant and then their parents and also to observe the participants during this time.
Collected visual material	Interview with mother (March 8, 2009)
Second interview with Participant 1 (September 20, 2008)	Interview with father (March 8, 2009)
Transcribed interview	Noted my observations of the participants
Observation (add to Research Journal)	Transcribed the interviews with the participants

Participant 1	Participant 2, 3 and 4
Collected visual material	Transcribed the interviews with the participants' parents
Interview with tutor (September 23, 2008)	Observed at a party (July 2009)
Transcribed interview	Noted my observations made at the party
Observation (add to Research Journal)	Collected visual material
Collected visual material	Interview with consulting psychologist
Interviewed mom (October 12, 2008)	Transcribe interview with consulting psychologist
Transcribed interview	
Observation (add to Research Journal)	
Collect visual material	
Interviewed teacher (November 1, 2008)	
Transcribed interview	
Observation (add to Research Journal)	
Collected visual material	

The above summary records the basic events in the data collection process.

5.4.2.4 Data analysis

Data analysis refers to the process of making meaning out of the data gathered by the researcher (Bogdan & Biklen, 2007:159; Merriam, 1998:178). This process involves "consolidation, reduction, and interpretation" of what the participants said and what was observed by the researcher (Merriam, 1998:178). The process of data analysis therefore involves working with the data, organising the data, coding the data, selecting themes from the codes and then searching for patterns (Bogdan & Biklen, 2007:159).

I made use of inductive qualitative analysis to organise, code and categorise the data which were collected in the study (Henning *et al.,* 2004:104-109; Leedy & Ormrod, 2005:32; Lincoln & Guba, 1985:202; Maree & Van der Westhuizen, 2007:37; Nieuwenhuis, 2007c:99 & 107). Inductive analysis can be defined as a process for "making sense" of data (Lincoln & Guba, 1985:202). It is a method that can be used to achieve descriptive generalisations or to give or arrive at an explanation (De Vaus, 2001:263). The use of inductive qualitative analysis allowed me to observe the primary participants, and to come to a conclusion about the population from which they came (Leedy & Ormrod, 2005:32)

Data analysis in a case study typically involves the following steps (Leedy & Ormrod, 2005:136; Merriam, 1998:181-182; Nieuwenhuis, 2007c:103-113) as discussed in Table 4.9:

Table 4.9: Steps in data analysis

Steps	Steps of data analysis	Adapted to this study
1	Select the data that will be analysed.	I used interviews, observations, and visual material that were gathered in the study.

2	Coding the data	As stated before, I made use of multiple case studies. In multiple case studies two stages of analysis take place, namely within-case and cross-case analysis (Merriam, 1998:194; Mertens, 2005:421). Firstly, within-case analysis was performed whereby the data of the each single case study was analysed. I read through every interview a number of times. Initially I only looked for potentially relevant information about the individual's personal attributes that may have helped her to cope resiliently. Then I looked for potentially relevant information about the participant' familial resources that might help her to cope resiliently. The next couple of times I looked for potentially relevant information about the participant's community that may have helped her to cope resiliently. Finally, I looked for potentially relevant information about the individual's culture in order to determine what helped her to cope resiliently. While reading through the transcribed interview, I jotted down the interesting or potentially relevant information. I then used codes to label these grouped statements that originated from the data. In other words, this open coding was an inductive process which allowed me to choose codes according to what the information meant to me (*Cf*. Addendum B). For example, when a participant described her teacher as supportive,

		I used the code: “supportive teacher”. I did not have a predetermined set of codes (Nieuwenhuis, 2007c:107), but my knowledge of related literature (*Cf*. Chapter Two and Chapter Three) influenced the codes that were chosen. I repeated this process for all the interviews. Then I compared the codes across all interviews: I made use of the constant comparative method (Merriam, 1998:18; 159). I also used the observation notes, research journal and visual material to support what was found in the interviews. I followed the same steps as stated above to look for different codes in the observation notes, research journal and visual material.
3	Categorise and select themes	After the analysis of each case was completed, a cross-case analysis was performed. The themes collected from each individual case were put together to see which themes were similar/different and to then build a general explanation that fits across the individual cases (Merriam, 1998:195).
4	Structure the data analysed	I went a step further by using axial coding to make sense of what contributed to the resilience of individuals diagnosed with Fragile X Syndrome (*Cf*. Addendum B). This means that I grouped my initial codes to form themes that could allow an understanding of what

		protective resources encouraged resilience in females coping with Fragile X Syndrome, thereby developing more sophisticated descriptions and more powerful explanations (Merriam, 1998:195). After working through all the interviews, I went back over the comments I had recorded and tried to group them together. I also used the observation notes/reflection journal and visual material to support what has been found in the interviews.
5	Interpret your data	During this step, I tried to connect what had been found in the data to that which was stated in the relevant literature, and also to see what new understandings were found.

Even though the steps as stated in Table 4.8 above were followed, it is important to remember that data analysis is an ongoing process. The process consists of noticing, collecting, and reflecting (Nieuwenhuis, 2007c:100), which means I observed and noticed important information. I then collected the valuable information and assigned codes to it, reflected on it and then coded it according to themes. It was an iterative process.

According to Merriam (1998:207), the use of different data sources can enhance the reliability and internal validity of the study. This is also known as triangulation (as discussed in section 4.3.2.6). I made use of multiple data sources, such as interviews, observations, and visual data. The use of these different data collection techniques enabled me to gain more understanding, added richness to the descriptions and also verified the findings (Simons, 2009:130). I also made use of an independent coder (Nieuwenhuis, 2007b:80), in order to justify the

themes that I had found while analysing the interviews (Creswell, 2003:196). I backed it up with the observations and visual data that were collected.

5.4.2.5 Rigour of the study

According to Lincoln and Guba (1985:991) credibility, applicability, dependability and confirmability are considered the key criteria for trustworthiness. In addition I triangulated (Kelly, 2006:287; Merriam, 1998:204; Mertens, 2005:426) multiple sources of data. These criteria are discussed below.

- **Credibility**

Credibility refers to being able to accurately describe reality (Hoepfl, 2006:12; Mertens, 2009:194; Van der Riet & Durrheim, 2006:90). In order to ensure credibility the following criteria were met:

  - Prolonged engagement: I spent enough time with the participants in order to reach a state of saturation. I spent time with Lucy every day for 20 months as I was a live-in carer for her. As for the other three participants, I met with them once at a National Fragile X Conference where they did speeches and once where I met them at their home to conduct interviews.
  - Peer debriefing: I discussed the research process and findings with impartial colleagues, an expert in Fragile X Syndrome (a psychologist) and my supervisor.
  - Progressive subjectivity: I engaged in self-reflection throughout the study. I made note of initial hypotheses and feelings and revisited them throughout the study (Mertens, 2009:194).
  - Member checks: I checked the believability of the results with both the primary and secondary participants by asking them if what I understood from what they had told me was correct (Lincoln & Guba, 1985:309; Mertens, 2009:195).

- **Applicability**

Applicability refers to the ability to generalise findings across different settings (Hoepfl, 2006:13; Mertens, 2009:195-196; Van der Riet & Durrheim, 2006:91). It refers to the researcher's ability to provide enough detail so that the reader is able to relate the findings to his or her own situation. Therefore, I provided sufficient detail on the background information of the participants (*Cf*. 4.4.2.2.2), and I also tried to make it clear that they were challenged by the risk of Fragile X Syndrome. I also provided sufficient detail regarding the findings (*Cf*. relevant parts of Chapter Five) in order to ensure transferability across different environments.

- **Dependability**

Dependability can be defined as the ability to track and document changes occurring during the study (Mertens, 2005:257; Mertens, 2009:196; Van der Riet & Durrheim, 2006:93). It refers to the degree to which the reader can be convinced that the findings in my study did indeed occur as I stated. In order to ensure dependability the following measures were used:

  - Logical reasoning and interpretation were applied, based on the literature review (*Cf*. Chapter Two and Chapter Three);
  - I also included direct quotations (*Cf*. Chapter Five), as well as examples of a transcribed interview (Addendum B), observation notes (Addendum C and D), and visual material (Cf. Chapter Five/Adddendum E);
  - The rationale for my choice of methods was clearly stated (*Cf*. 4.4) (Niemann, Niemann, Brazelle, Van Staden, Heyns, & De Wet, 2000:284-285).

- **Confirmability**

Mertens (2009:196) defines confimability as "the degree to which the researcher makes judgments about the meaning of results, and the extent to which those judgments might influence the results". The data that were obtained from the interviews, observations, research journal, and visual data were used to support

the research findings, by providing proof that the themes that were reported were not figments of my imagination or influenced by me (Mertens, 2009:196), and therefore the influence of my judgment as researcher was minimised (Mertens, 2005:257). The information I found in the interviews was confirmed by making use of the observations and visual data collected. I also checked with my study leader to ensure that I was being objective in my interpretation of data. I also asked an independent coder to confirm my conclusions (Nieuwenhuis, 2007b:80). She had knowledge of Fragile X Syndrome and agree with the definition of resilience as mentioned in section 4.4.2.2.

- **Triangulation**

Triangulation can be defined as multiple sources of data collected with the hope that it will all support a specific hypothesis or theory (Leedy & Ormrod, 2005:99). I triangulated the data obtained from multiple sources (see Figure 4.3) during the interpretation of what might contribute to individuals with Fragile X Syndrome coping resiliently. Nieuwenhuis (2007c:113) states that the use of different sources can help you check your findings. For example, the interviews conducted were backed up by the observations and visual material collected. Nieuwenhuis (2007c:113) states that if these different sources point to the same conclusion, the results will be more trustworthy. As illustrated in Chapter Five, my findings could be triangulated.

5.4.2.6 Ethical aspects

Every study should adhere to certain ethical aspects (Strydom, 2005:63). I received ethical clearance from the North-West University (NWU-0003-08-A2) to conduct my study. The ethical aspects that were followed are discussed below.

- **Avoidance of harm**

This refers to avoiding harm to the participants, physically and/or emotionally (Strydom, 2005:58). The participants were never harmed in either a physical or emotional manner. In most instances, they were keen to participate, especially once they got to know me.

- **Informed consent**

Informed consent implies that all possible or adequate information on the goal of the investigation, the procedures which will be followed during the investigation, the possible advantages, disadvantages and dangers to which the participants may be exposed, as well as the credibility of the researcher have to be disclosed to potential participants and their legal representative (Strydom, 2005:59; Henning *et al.,* 2004:73).

The participants were given accurate and complete information about what the study entailed and what would be expected of them to ensure that they were able to make a voluntary decision about taking part in the study. I firstly provided the parents of the primary participants with the necessary information and asked them to explain to their children what the study entailed to ensure that they understood better. I then explained to them in my own words what the study was about and what would be expected of them. I tried to keep the terminology as simple as possible, while explaining to ensure that they understood. The reason for doing so was the language barriers that existed with the primary participants. I then asked if they had any questions and if there was anything or any part that they were unsure of, so that I could explain it again.

I then provided them with informed consent forms that contained all the necessary information for them to sign (see Addendum A). I also explained what the form contained in simpler language, as some of them might not have understood because of the language barriers. The participants were also made aware that their participation would be voluntary and that they could withdraw from the investigation any time they wished to do so. The participants were also given adequate opportunity to ask questions before the study started, and also during the investigation (Strydom, 2005:60).

- **Deception of participants**

This refers to deliberately misrepresenting facts in order to make another person believe what is not true, thereby violating the respect to which every person is entitled. Deception occurs when the researcher intentionally misleads subjects by

way of written or verbal instructions, the actions of other people, or certain aspects of the setting (Strydom, 2005:60).

In order to ensure that deception did not take place, I was honest about the goal of the study. I also took care to explain in simple language and to check the primary participants' understanding because of their language barriers. The goal of the study was to find out what made the primary participants cope resiliently with the adversities they encountered, being diagnosed with Fragile X Syndrome. What would be expected of the participants was also explained openly to them openly. I would interview them and ask them questions that would try to find out how they cope. I would observe them in their natural setting to see what made them resilient. I also pointed out that visual data such as photos and video clips would be used to back up what I was observing. I also explained to them the emotions, such as uneasiness, that they might go through, if they remembered previous experiences that were unpleasant.

- **Violation of privacy**

The right to privacy is the individual's right to decide when, where, to whom, and to what extent her attitudes, beliefs, and behaviour will be revealed (Strydom, 2005:61).

None of the participants' real names were used. I assured them that their names would not be used in order that they would not be easily identified. Nevertheless, they were happy to pose for photographs and to be videoed. I also assured them that if there was information they wished not to share, I would not include that in the study. I explained to them that they did not have to answer the questions that I would ask them during the study, but that the more questions they were able to answer, the better the results of the study would be.

- **Release or publication of the findings**

This refers to the findings of the study (Strydom, 2005:65). The findings from this study are reported in this dissertation (*Cf*. Chapter Five). I tried to make sure that my report is as clear as possible and contains all the information necessary for

readers to understand what I have written. I tried to be objective and unambiguous. I avoided plagiarism and therefore gave recognition to all sources consulted. I also stated my study's limitations and challenges (*Cf*. Chapter Six).

- **Debriefing of participants**

Debriefing refers to sessions during which the participants get the opportunity, after the study, to work through their experience and its aftermath (Strydom, 2005:66). The participants were asked if they were feeling sad or depressed after talking to me about negative memories or experiences that might have arisen from the study. There were no such feelings. I then thanked them for participating.

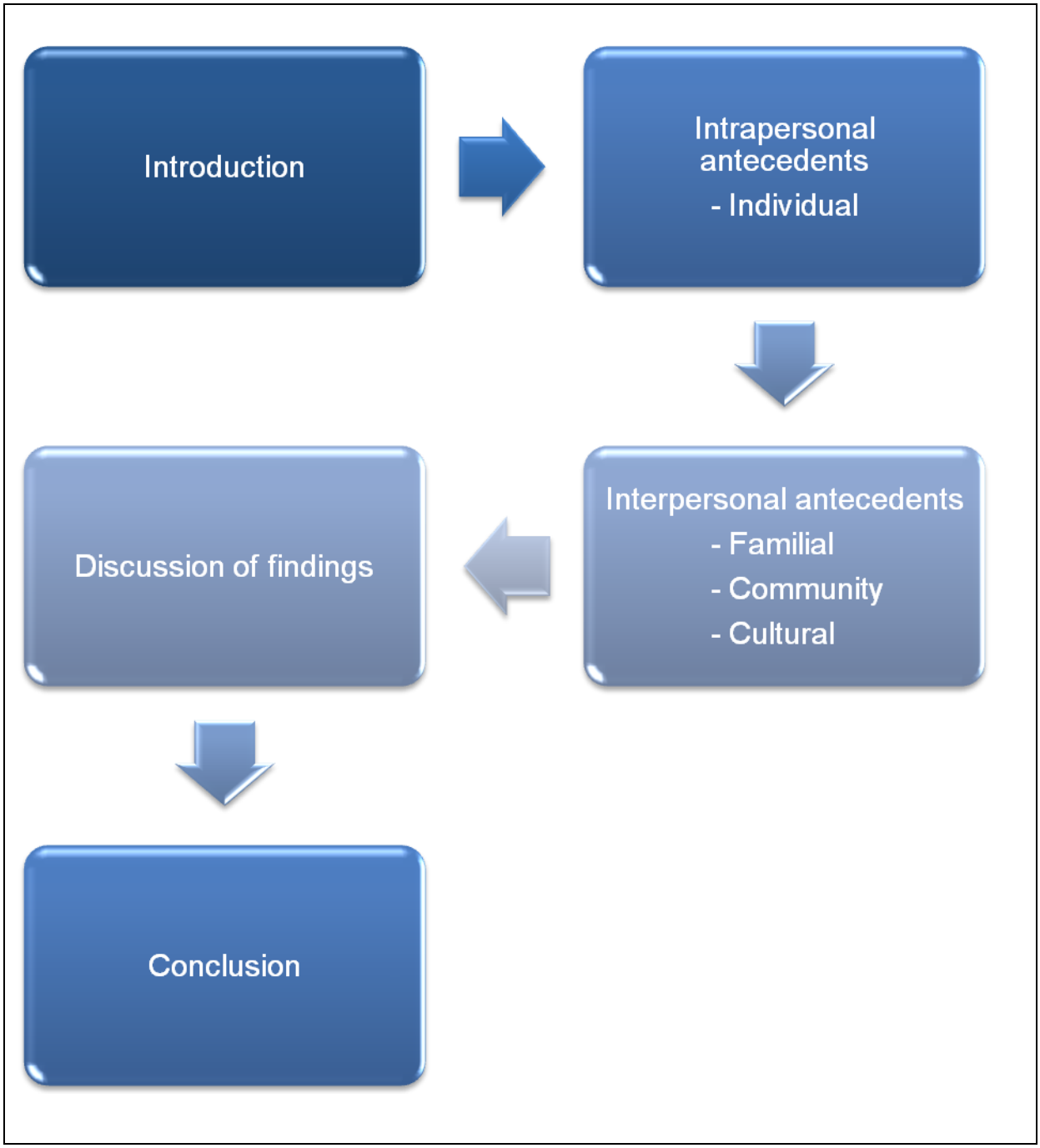
5.5 CONCLUSION

In this chapter the aims, objectives and methods of research I used were outlined. In order for me to reach these aims and objectives, I conducted interviews with four participants who were selected by an Advisory Panel. I also interviewed their parents, teachers, tutors and psychologist. The next chapter will concentrate on the data that were collected and analysed in order to represent the research results.

CHAPTER FIVE

RESULTS OF EMPIRICAL RESEARCH

Figure 5.1: Overview of Chapter Five



6.1 INTRODUCTION

In this chapter I give an overview of the findings of my study. After analysis of the interviews, field notes, visual data and research journal, a number of themes emerged. The themes were clustered into two categories, namely intrapersonal and interpersonal antecedents. Each of these is discussed below.

6.2 INTRAPERSONAL ANTECEDENTS

Intrapersonal antecedents refer to the protective resources found within a person herself (*Cf*. Chapter Two). Within this category twelve themes emerged, all of which are discussed below. I begin each theme with a brief definition for the sake for clarity.

6.2.1 Self-determination

Self-determination refers to an individual's ability to make independent decisions, to set goals, independently attempt to accomplish these goals, independently evaluate her performance, and make adjustments based on the goal progress (Murray, 2003:23). According to Murray (2003:23) and Richardson (2002:310), one of the most promising abilities that can affect the outcome of resilience is related to the concept of self-determination (see 2.3.2.1).

One of the themes that emerged throughout the collected data and seemed to encourage resilience was self-determination. During my interaction with Lucy as her live-in carer, I observed that she struggled to walk down stairs. She had been able to do so independently up to the age of six. Her mother told me that suddenly one day Lucy wasn't able to do so any longer. Professionals told her mother that this was due to visual perception difficulties that developed as she grew older. During an informal interview with Lucy, I asked her about walking down the stairs independently and she answered: "*I will do it again*." (Interview 1, line 56). I also noted in my research journal that she was trying to walk down some steps by herself without holding on to me, but holding on to the wall and rail instead (Research Journal – July 8/10/11, 2008; Photo 5.1; Video clip 5.1).

Photo 5.1: Walking down the stairs independently, with determination

During an interview with Kelly, I asked her what advice she would give somebody who had the same diagnosis as her and therefore might be experiencing the same struggles. She answered: "*The determination in yourself that when you put your mind to something you can get it accomplished*" (Interview 8, lines 123-124). Her mother also stated: "*Kelly just kinda sticks her head in it and goes after what she wants to do*" (Interview 9, lines 24-25). Kelly's father stated: "*Kelly early on just had this determination to do things*" (Interview 10, lines 39-40). Kelly's psychologist also confirmed this by her comment on how Kelly was determined to succeed and finish her degree: "*She had to take one class over in order to graduate with an associate's degree*" (Interview 13, lines 7-8). Kelly also stated during a presentation at the National Fragile X Conference that she was determined to graduate from college, even though it would take her two years to do so (Video Clip 5.2). Self-determination can therefore be seen as a protective resources that promotes resilience.

6.2.2 Ability to ask for help

The ability to ask for help or support from others is seen as another protective factor (Kitano & Lewis, 2005:202). Seeking help from others can help reduce interpersonal conflict in individuals' lives. This all helps reduce stress (Greene & Conrad, 2002:36; Mills and Dombeck, 2005:1; Scott, 2006:1; Theron, 2004:319; Ungar, 2008b:227; Yates *et al.,* 2003:252).

During an informal interview with Lucy, I asked her a question and she replied by saying: "*Ummm, what do you mean?*" (Interview 1, line 36). She was not sure what was expected from her and was able to ask for clarity. Later in the interview she also asked me if I would be able to help her to explain to her boyfriend what exactly Fragile X Syndrome was: "If *you could help me explain it to him*" (Interview 1, line 218). Therefore I concluded that she was capable of asking for help when needed.

Lucy's mother also confirmed the fact that Lucy was able to ask for help when needed: "Lucy is very aware they (teachers and students) work together as a team. So if she wanted to know something she knows she can approach the teacher and it's pretty cohesive" (Interview 4, lines 220-221).

I also noted in my research journal that Lucy was able to ask her mom for help when she needed it:

> "*Lucy has missed some PE classes (physical education) due to the amount of travelling we've done. Marks are deducted from her final mark for every class she missed. This made her very upset because she likes to get good grades (her family is quite competitive). So she asked her mom to please call her PE teacher and ask him how they are going to solve this problem. He agreed on her coming in every morning before school until all the lost time was made up*." (Research Journal – May 1, 2009).

Cindy's consulting psychologist related a very interesting incident that confronted Cindy during an independent travel to England:

"*It is especially curious, however, that when she is motivated, she is able to travel to another country completely alone and on one occasion was detained in London due to an answer with the custom's officer. She was able to advocate for help and called her friend who was waiting for her and was able to overcome the situation."* (Interview 12, lines 24-28).

Cindy was capable of staying calm and calling her friend, which shows that she could be assertive when necessary.

Cindy's ability to ask for help was later confirmed by her father. He commented that she was able to ask for help during a time where she struggled with a class at college: "*She got home, she said, 'Dad, you know, I'm trying to get through this class down at MATC Community College. Do you mind calling up the person in the office there and talking about what I've got and how they can help me?*'" (Interview 10, lines 71-74).

It is therefore clear that my participants' ability to ask for assistance helps them to cope more resiliently with everyday struggles.

6.2.3 Tenacity

Tenacity refers to the ability to maintain performance even under stress, keeping your emotions under control and staying positive (Elkin, 2009:1; Theron, 2008:217). Tenacity is seen as a great quality to possess in difficult times as it helps individuals stay motivated and positive (Elkin, 2009:1; Lee & Tay-Koay, 2008:241; Schoon, 2006:29; Theron, 2004:319; Theron, 2008:217).

During my time as Lucy's live-in carer, I observed that she was anxious about going to the local grocery store in her hometown. I asked her mother the reason for this and she told me that Lucy once had a bad experience at the grocery store. Someone working at the store had come up to her unexpectedly, insisted on talking to her and that made her feel uncomfortable. My observation of her reluctance to go to the store confirmed this. During my informal interview with Lucy, I asked her about the incident at the grocery store and why she had not been back to the store. She said: "*I went there with Machelina, and I tried*."

(Interview 2, line 66). I then tried to find out from Lucy exactly why she didn't like going to the store and she replied: "*When I tried it, it was okay. But now I really wanna try when it's like quieter*" (Interview 2, line 68). Even though she had not been back to the store in years, when confronted, Lucy told me that she would like to go back there. In this way I found her to be no quitter, and therefore tenacious.

I also recorded the following in my research journal on June 15, 2009:

> "*The other night we went to Love's Yoghurt. It is always an issue to go in there, because she is anxious about seeing somebody she might know and having to face them. She loves socialising but at same time has so much anxiety. She and I were alone. And we had to take home some yoghurt for her dad. So I told her that we would buy it once we were done having our yoghurt so that it wouldn't melt. Once we were ready to go I asked her to go and buy the yoghurt, so that she could be independent, get some experience doing things like this by herself. Anyway, she was excited to go do it. I noticed that she liked to feel in charge and capable of doing things. Once she got back she told me that the man behind the counter didn't understand her. So I asked her to tell me what she did to help him understand her and she told me that she kept repeating herself and eventually showed him (the size of the container) she wanted. She had a hard time telling him the size she wanted*."

Lucy was able to keep trying to explain to the man what she wanted even though he did not understand. This clearly showed me that she was tenacious.

Lucy's teacher also confirmed that Lucy was tenacious by stating the following: "*Anxiety feels awful. It feels physically awful. My heart goes out to her and I think she's got tremendous courage, you know, that she gets through the day the way she does. She does things you know, that a lesser human being couldn't do. She's amazing*." (Interview 5, lines 205-208).

During an interview with Kelly, I asked her what her friends had done for her to help her cope during difficult times. She replied that she did not have many "*bad*

days" (Interview 8, line 70) when she really needed friends to help her cope. She reported that when she did indeed experience difficult times she would talk to herself and encourage herself to move beyond it: "*It's not too bad. I just tell myself to get over it."* (Interview 8, lines 70-71). I therefore found her to be able to stay positive and keep her emotions under control, and thereby demonstrated tenacity.

6.2.4 Social inclination

Social inclination refers to individuals having a desire to socially interact with others. Individuals who have a desire to socialise are more likely to become socially competent. Individuals who are socially competent and who are able to develop and sustain relationships with others are more likely to have positive outcomes (Murray, 2003:23; Theron, 2004:319). Relationships with supportive individuals enables adolescents during difficult times because these individuals can be relied on to offer support (Boyden & Mann, 2005:7; Killian, 2004:43; Masten & Powell, 2003:13; Siqueira & Diaz, 2004:151).

During my observations of Lucy I noticed on numerous occasions that she had a desire to interact with others socially and enjoyed doing so. On April 5, 2008 I noted the following in my research journal:

> *"She absolutely loved talking to everybody, young and old, about their lives, their children. She is so interested in other people's lives. She is such a social butterfly. If only she didn't have so much anxiety. But I noticed that once she's used to a person, she just loves talking to them."*

On May 23, 2008, I noted in my research journal: "She had a really good time today. She loved interacting with the other kids." On May 10, 2009 I recorded:

> *"Tonight was her prom. She looked absolutely gorgeous. We took lots of photos. There was a pre-prom party at Catherin's house. Catherin is a year older than Lucy and is currently dating the boy Lucy has had a crush on for so long. So her mom and I were quite nervous about that, not knowing what she would do. The pre-prom was really nice. All the high school kids were*

there. There were things to eat and drink and everybody took a lot of photos. Lucy was such a social butterfly. She wanted to talk to everybody and give everybody a hug, and also take photos with everybody."

Photo 5.2: Lucy socializing with friends before her prom[4]

During my informal interview with Lucy she stated the following: "*Like Mike for instance. I know him. And I really, I really like getting to know him a little bit more 'cause I don't get to see him that much."* (Interview 1, lines 120-121). I was able to conclude from Lucy's statement that she liked to interact with her peers and had a positive attitude towards socialisation. She seemed willing to socialise, even though females with Fragile X Syndrome often face a lot of social anxiety (Hagerman, 2000:21-22; Reiss & Hall, 2007:664-665).

Lucy's mother confirmed thiis: "...*and she is very social*." (Interview 4, line 21). Lucy's tutor also stated the following: "*Oh, she was so happy to be sitting with other kids.*" (Interview 5, lines 462-463).

During my observations of Melissa, Cindy and Kelly, I also noticed that they were all very outgoing and loved to interact with others. Even though they experienced

[4] In photos where I only received verbal permission from people pictured to take and use the photograph. I have minimised their recognisability.

a lot of anxiety, they still had a desire to interact with others and were able to overcome a lot of their anxiety (Observation – July 29, 2008). Melissa, Cindy and Kelly's consulting psychologist stated that both Melissa and Cindy were very outgoing: Melissa - "*Melissa is very outgoing and loves people.*" (Interview 11, line 27); Cindy - "*She is very good with older people; she is outgoing with people…*" (Interview 12, lines 20-21).

Melissa, Cindy and Kelly's father was also of the opinion that they enjoyed communicating with others: "*I mean, the kids will pick up the phone and ... I would say Kelly and Melissa are really the bigger talkers*". (Interview 10, lines 91-92).

Photo 5.3: Melissa, Cindy, and Lucy interacting with my sister and I

Even though females with Fragile X Syndrome often experience a great amount of social anxiety (Hagerman, 2000:21-22; Reiss & Hall, 2007:664-665), these participants had a strong desire to socialise with others. Even though the participants were not necessarily socially competent, their desire to socialise can be seen as a potential protective resource. This desire to socialise allows and also encourages them to build connections and relationships with others, which can improve their social skills and possibly increase their social competence

6.2.5 Self-knowledge

Self-knowledge can be defined as having the knowledge of one's own beliefs, desires, and sensations (Stanford Encyclopaedia of Philosophy, 2003). According to Wicks (quoted by Borchard, 2009:1), individuals who have a good sense of self-knowledge also tend to possess personal discipline and self-management, which are essential to resilience. Lewis (1990:277-297) also states that self-knowledge plays an important role in the social development of individuals.

During the interviews with Lucy, Melissa, Cindy and Kelly, I found that they were all able to express their feelings, and also to recognise their strengths and/or limitations. On the day of the scheduled interview with Cindy, she at first did not want to talk to me at all, but after a few hours (during which I spent time with her family) she said that she was willing to talk. Throughout the interview she was able to identify her strengths and limitations, as well as her likes and dislikes. I was also able to conclude from her answers that she had a great sense of self-awareness. Some of the comments she made during the interview were as follows:

> "*It's freaking cold, but I love it cold. I sleep better when I'm cold. Yeah, usually I have the fan going when I sleep. I sleep better when I'm cold*." (Interview 7, lines 10-12).

Later in the interview she commented:

> "*I'm a saver, not a spender*." (Interview 7, line 109).

Furthermore she stated:

> "*I'm not religious. And I really don't give a crap about religion. I really don't care about it.*" (Interview 7, lines 142-143).... "*Cause I wouldn't. I never do. I don't lead on. Nope. Never had, never will*." (Interview 7, line 186).

Cindy's consulting psychologist confirmed this conclusion about her self-awareness by stating that Cindy was able to talk about bad experiences: "*Cindy reported that her high school experiences were negative.*" (Interview 12, line 37).

Kelly was also able to express what she liked and what her struggles had been. The day I interviewed Kelly, I observed that she was wearing an American football shirt and that her room was decorated according to her favourite sports team. When she and I sat down to begin the interview, she was able to tell me that she enjoyed sports: "*I like going to football and basketball games*." (Interview 8, line 3). Even though this was not one of the research questions, her answer to my question about what kind of sport she likes enabled me to conclude that she was aware of what she liked and therefore had a sense of self-awareness.

Later on during the interview she was also able to state what her struggles were: "*It would always take me a long time to do my homework. I'd dawdle a lot and just take my time and then as it got later at night I'd dawdle on and get it done*." (Interview 8, lines 23-25). During the National Fragile X Conference in 2008, Kelly was asked to address the conference on her life as a female living with Fragile X Syndrome. I recorded parts of this presentation. During the presentation she also was able to describe her struggles and what had helped her to overcome them (see video clip 5.3). Kelly's consulting psychologists also stated that Kelly was able to express her feelings about her attendance at a Catholic school being a difficult experience: "*Later she told me it was very difficult and she wished she had attended public school*". (Interview 13, lines 55-56).

Lucy also demonstrated self-knowledge. I noted that she knew that she might become anxious and she wanted those close to her to know what she might do when she got anxious: "*While we were having dinner she said to me, 'Did you tell her?' I said, 'What?' 'What I'm gonna do if I feel anxious.'"* (Research Journal – June 25, 2009). I also noted that whenever her father started to worry about things and made them known, she would tell him that it was making her more anxious: "St*op creating anxiety, Father.*" (Research Journal – August 23, 2008). Lucy's ability to know she would become anxious, assisted her to ask for help. Therefore, her self-knowledge helped her to be assertive.

During an informal interview with Lucy I asked her if there was anything she struggled with in school. She was able to state that she had difficulties in her

science class: "*Ummm like.., like when Mr. Kirk gives me hard work in Science."* (Interview 1, line 42). Therefore Lucy's self-knowledge included knowledge of her weaknesses, as in the case with Cindy as stated above.

I found that the participants' ability to state their beliefs, strength, and weaknesses also helped them to ask for help when needed, and therefore they were able to discuss their feelings and thus receive help and build relationships with others.

6.2.6 Academic progress

It has been found that individuals who make academic progress and have higher intelligence may be more likely to possess effective information-processing and problem-solving skills, which enables them to contend with the stresses and challenges they experience (Fergusson & Horwood, 2003:132; Murray, 2003:23; Oliver *et al.,* 2006:4; Owens & Shaw, 2003:272; Vanderbilt-Adriance & Shaw, 2008:33).

During an interview with Lucy's mother she stated twice that Lucy was a very intelligent individual: "Y*ou know, we see her as, as being a very sharp little girl*." (Interview 4, lines 161-162); "*She really is a smart girl*." (Interview 4, line 329). Lucy's teacher also told this fascinating story, from which it is clear that Lucy is quick to think and intelligent:

> *"Oh oh, this was kinda funny. When we were in first grade umm, those were two years of tremendous growth for her. Once she got on the medication for the ADHD she was able to physically sit and concentrate and focus and oh everything changed then. When she would get frustrated, she always hated math, you know. We made her sit there, you know, and I would make her sit there. We would always try to make it as interesting as possible. We got manipulatives out. When she got frustrated she would lean over and pinch me. So I would say, 'There's no pinching, that is not allowed.' But that was how she kinda let out her frustrations. And that was because we didn't allow any yelling or screaming or hitting.*

So I told her, 'You don't pinch, you don't touch anybody.' She was complying to a degree, but sometimes she got overwhelmed with her frustrations. So one day we were doing math and I'm stretching the time she had to sit there and do it and it was hot and you know, I was tired. It was after lunch. She had had it. So we were doing math and she leaned over. Oh oh, and the background to this is, every 30 to 45 minutes to an hour we would stretch out and we would take a walk, we would take a walk to the nurse's office. We had this wonderful nurse. And we would go down there and chat with her. I would get my blood pressure checked because during that time I was having issues with blood pressure. So we used that as a break to go down to the nurse. I would get my blood pressure checked then we would talk about health issues. You know it was the way to do it. So we ended up doing this for a couple of months, so one day in math she has had it. I mean I could tell she was getting ready to blow. But the whole idea was to extend her time before she would blow. So she leaned over and she pinched me and I just looked at her and I looked down at her what she was doing, and I just looked at her and she said, 'I'm just checking your blood pressure'.

So I said, 'Okay, thank you very much. How does it look?' and she said, 'it's fine,' and I mean she's first grade, first grade. So I thought, oh God this is fabulous. She's got a sense of humour; she's quicker than a bunny rabbit. I said that is tremendous. That shows us so much of the potential inside of her." (Interview 5, lines 396-429).

This excerpt clearly demonstrated Lucy's ability to intelligently think of an answer when confronted. Throughout her school career, Lucy made steady academic progress.

Melissa, Cindy and Kelly all attended colleges where they were able to obtain a certificate or a diploma. Cindy completed her Certified Nursing Assistant course (Interview 7, line 117; Interview 10, lines 63-64), and Kelly her degree in Early Childhood Development (video clip 5.4). Even though Lucy, Kelly, Cindy and Melissa had some cognitive difficulties due to their having been diagnosed with

Fragile X Syndrome, they were found to have made academic progress in the midst of their cognitive difficulties.

I also found that Lucy and Cindy were computer literate. Computer literacy relates to effective use of computers and technology. It can also refer to a person's comfort level using a computer (Lombardi, 1983:72-73). Computer literacy can help increase the independence of individuals with disabilities (Bradley & Poppen, 2003; Gagliardi, Mazzarini, Papa, Guili & Marcellini, 2008:16; Nahm & Resnick, 2001:258). It can assist the ability to hold attention, help with social interaction, learning and written language (Harris-Schmidt & Fast, 2004:115).

Cindy stated the following during our interview: "*I have a friend, but she lives too far away. We talk by e-mail*." (Interview 7, line 55). During an informal interview with Lucy, she stated that she used "*You tube"* (Interview 1, line 197). I also noted the following in my research journal:

> "*Lucy is so good with the computer. I opened a Facebook account for her today. She is so excited and invited so many people to be her friends.*" (Research Journal – April 25, 2008).

Cindy and Lucy's ability to use a computer, therefore allowed them to increase their independence and communicate with others (Gagliardi *et al.,* 2008:16). Their literacy suggested ability to progress technologically.

6.2.7 Humour

Humour refers to the quality to be amusing, or a state of mind (Chapman & Foot, 1996:78-79). It is a very broad term, and refers to what people say or do that is perceived as funny, or makes others laugh. It can also be seen as a mental process that involves creating and perceiving amusing stimulus (Martin, 2007:5). It has been found that humour can lessen the impact of trauma, and improves an individual's mood. It allows an individual to see the comical in that which is tragic and feel relieved (Benard, 2003:27; Glicken, 2006:235; Kaplan & Owens,

2004:83; Masten & Reed, 2005:83; Siqueira & Diaz, 2004:151; Ungar, 2008b:227; Willoughby *et al.,* 2003:95-95).

It has been found that individuals with Fragile X Syndrome are seen as having a good sense of humour (Cf. Chapter Three) (Braden, 2002:445; Hagerman, 2000:24; Harris-Schmidt & Fast, 2004:80). The females on whom the study was based often showed their sense of humour during the data collection process.

At the National Fragile X Conference in 2008, I recorded video clips of Melissa and Kelly during their presentation. They both projected their sense of humour on this occasion. Melissa joked about the number of years it took her to complete high school (Video Clip 5.5), and Kelly was able to laugh about the car accidents she has had (Video Clip 5.6). Even though these experiences were difficult for them they were able to laugh about them.

During an interview with Melissa, she was able to talk and laugh, and even joke about the fact that she had a hard time reading social cues: "*Let's see, umm, with my family I can kind of tell, 'cause I know them. But outside the family, it's like, you'd have to buy me a book (laughs). Give me something, yeah.*" (Interview 6, lines 246-248). During an interview with Kelly, she explained that it was hard for her to socially interact with people she did not know well, but explained that she had realised that it could be overcome: "*And then, just getting over the fact that nobody bites (laughs). You know, it's not that bad*." (Interview 8, lines 40-41).

Cindy also demonstrated a good sense of humour during an interview with her even though she came across as very defensive: "*I love the cooking channel, but me, I like the microwave. If it can go in the microwave why the hell dirty a pan (laughing). I know it sounds hilarious but...*" (Interview 7, lines 28-29). She also stated that she used humour to help a friend through difficult times: "*Depends on what it is. I'll make a joke.*" (Interview 7, line 64).

During my observations of Lucy, I was able to come to the conclusion that she was funny and also had a good sense of humour. I mentioned this on numerous occasions in my research journal (Research journal – January 24, 2008; May 13, 2008). During individual interviews wtih them, Lucy's mother, teacher, as well as

her tutor confirmed that Lucy had a good sense of humour (Interview 4, line 120; Interview 5, lines 427-428; Interview 3, lines 91-92).

Photo 5.4: Lucy and friends imitating 'Goofy', showing her sense of humour

6.2.8 Sunny temperament

Temperament can be defined as the 'how' of behaviour, in other words, how an individual handles a situation (Spender *et al.,* 2001:50). An easy, outgoing temperament helps mitigate the effects of stress. An individual with an easy, outgoing temperament is capable of fitting into routine and is flexible (Atkinson *et al.,* 2009:142; Boyden & Mann, 2005:6; Kaplan & Owens, 2004:81; Kim Cohen *et al.,* 2004:653; Masten & Reed, 2005:83; Richardson, 2002:306; Schoon, 2006:79).

Lucy's teacher emphasised what an attractive or likeable person Lucy is:

> "*And you know, people really do like her. She got, she's got, a huge, you know community of support. And when, when she laughs and smiles, she's so engaging. When she's pleasant, there's nobody more pleasant than her. And I think that is her greatest asset. She's a wonderful person. She's so blessed with a sunny disposition. Her personality will take her very far*." (Interview 5, lines 563-367).

This statement was confirmed by Lucy's mother: "*Now part of it we were really lucky, 'cause she was really cute, and you know really cute and sweet, Little Miss Sunshine, and so she was a likeable person as opposed to the kids that can be very, very difficult*." (Interview 4, lines 209- 212).

Kelly's consulting psychologist also stated that the fact that Kelly was well-mannered made her more acceptable to and liked by others: "*She does care about others and has been taught good manners and being polite makes her more acceptable in public places and with a variety of people"* (Interview 13, lines 44-46).

So, Lucy and Kelly's sunny temperaments made them more attractive to others. Their ability to be cheerful also enabled them to not only concentrate on the negative but to stay positive and thus become more resilient.

6.2.9 Empathy for others

Empathy for others refers to the ability to be of assistance to others and to be aware of other people's feelings, thoughts or attitudes (Brooks & Goldstein, 2003:74).

An individual who has empathy for others often connects with them, therefore builds friendships and can become more resilient (Brooks & Goldstein, 2004:12; Donnon & Hammond, 2007:452; Mills & Dombeck, 2007:1; Ungar, 2008b:227).

I noted in my research journal, on numerous occasions that Lucy had a lot of empathy for others:

> "*It was so funny to see what a good 'baby sitter' Lucy is. She was totally in control. When Duane or Edward or any other kid went the wrong way or went off by themselves, she would be the one to say, 'No, where are you going? Come back here! Let's stick together'. She is so responsible. And whenever somebody needed help, she was all too willing to help them out.*" (Research Journal – May 23, 2008).

Later in my research journal I noted:

"*She kept asking me today how Giana was. Around 8-10 times. She always wants to know how other people are. She is so caring*." (Research Journal – September 1, 2008).

I also added:

"Today I called my parents. And like usual, I was crying, missing them so much. Lucy saw me. She is very nosy. She found me crying. She was so sweet. She kept telling me, 'It's Okay. Don't worry. I love you. I'm here for you.' And she hugged me. She is so sweet." (Research Journal – February 21, 2009).

Lucy's teacher remarked that Lucy cared a lot for other people: "*She's got more heart than ten adults or people I know. And that's what I love about her. She's got a lot of heart and she's got a lot of strength. And I think that pulls her through. That allows her, given the right circumstances to advance and to make progress*." (Interview 5, lines 389-392). Lucy's mother also stated that Lucy liked to help others: "*And then of course she is also just such a kind person. Umm, she is very generous. She likes to help people*." (Interview 4, lines 347-348).

Photo 5.5: Lucy helping out a friend, showing empathy

The day I interviewed Melissa I commented in my observation notes how she showed empathy towards me:

> "*At some point throughout the day, during informal interaction with her and her family, I commented on how much I enjoyed a cup of coffee. Later that morning I was busy with an interview with the girls' father when all of a sudden there was a knock on the door. It was Melissa with a cup of coffee just for me. She is so sweet.*" (Observation – March 9, 2009).

My observation of Melissa's empathy for others was confirmed by her father during an interview with him:

> "*I think for somebody like Melissa, Melissa is a person who's very accepting of help and she's very sensitive about personal relationships. So even like her umm high school teacher, she'll say, 'Oh I wonder how Angie Paddington is doing. I wonder how her son is doing'. So she, she, she, cares a lot about other people and she needs to feel close to other people."* (Interview 10, lines 45-49).

Cindy also showed empathy for others during an interview with her. I asked her to tell me more about what she studied after school. She told me that she studied to be a certified nursing assistant and stated: "Y*ou work with older people*." (Interview 7, line 126). I then told her how wonderful that sounded and she replied: "*Yeah, cause they can't do it themselves*." (Interview 7, line 134).

Cindy's consulting psychologist confirmed this by stating; *"She is very good with older people." (Interview 12, lines 20-21);* and: "*When she had a job at a retail shop, she enjoyed going to work and advising others about fashion. She liked being helpful and assisting customers."* (Interview 12, lines 54-56).

Kelly's consulting psychologist also commented that Kelly had empathy for others: "*She does care about others*." (Interview 13, line 44). Kelly's father spoke about how caring Kelly was of her sisters:

"*And it's like whenever Janet*[5] *gets a ride home from somebody else and they don't get home for a while, there's always risk that she's out drinking with them and it's you know, Kelly gets so concerned. She's like 'Dad, when she comes home late like this, she's been drinking a lot of times. I'm afraid she's probably out there drinking'".* (Interview 10, lines 119-124).

They demonstrated that they cared for others and were aware of other people's feelings. This also enabled them to be more attractive to others and I found that this made them feel good about themselves.

6.2.10 Role-play/fantasy

This refers to a person pretending to be someone else than who she really is (Ginsburg & Jablow, 2006:63; Smilansky, 1998:5). Literature shows that role-play or fantasy helps individuals deal with personal problems or upsetting emotions, helps to reassure themselves, be spontaneous, and releases creative energy (Ginsburg & Jablow, 2006:63:160; Morales, 2008:8).

During my interaction with Lucy on a day-to-day basis, it became very clear to me that she often tried to escape reality by means of role-play and fantasy. In my research journal I noted:

> *"Lucy absolutely LOVES acting. This year's school play is coming up. They will be doing High School Musical. She absolutely loves High School Musical. We listen to High School Musical in the car every day. She knows every song's words by heart. She makes me sing Troy's parts (the boy) and she is Gabriella (the girl). Anyways, so she is so, so excited about the play. She will be trying out for the play this week and she's hoping to get the part of Gabriella."* (Research Journal – April 22, 2008).

I later wrote further:

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[5] Janet is the fourth sister.

"*She talks to herself in the bathroom. She spends a lot of time in the bathroom and then you hear her talk to herself, pretending to talk to people at school and sometimes even celebrities. Today I asked her who she's talking to and she said, 'Nobody, just myself', and I asked her why and she replied 'I'm practising.*'" (Research journal – May 5, 2008).

I also noticed the following:

"*She often goes into the basement and sings. She stands in front of a portrait in which she can see her reflection and then sings and acts her heart out*." (Research Journal – June 16, 2008).

Photo 5.6: Lucy and a friend role-playing

Lucy's mother also commented that Lucy enjoyed theatre: "*She's very good in theatre umm."* (Interview 4, line 121). To me it seemed as if she was able to escape the real world and live in the imaginary world that she created for herself (see Video Clip 5.7).

Interestingly, during an interview with Melissa's consulting psychologist she commented that Melissa enjoyed drama and music and that it allowed her to escape reality: "*Melissa is somewhat dramatic in nature and loves drama and music, because she can pretend or maybe even hide behind the pretending to be someone else.*" (Interview 11, lines 32-34).

Lucy and Melissa often pretended to be someone else. I concluded that this helped them to deal with certain difficult situations and to escape from reality

when things became too difficult to deal with. This is seen as a positive as females with Fragile X Syndrome often experience high amounts of anxiety and then end up being emotionally paralysed (as stated above). By allowing themselves to be taken out of the situation and take on the role of somebody else has helped them to cope with their anxiety and thus increased resilience.

6.2.11 Peacefulness and privacy

Peacefulness refers to a state that is calm, or an absence of mental stress or anxiety (Raatma & Murphy, 2000:5). Peaceful people treat others with kindness and find good things in everyday life (Raatma & Murphy, 2000:5). According to WNCD (1977:916) privacy is defined as 'the quality or state of being apart from company or observation, a place of seclusion'.

Lucy had a negative experience at a local grocery store, as mentioned earlier under the sub-heading Tenacity. She had not been back at the store since that incidence. She told me that she would go to the store during more quiet times: "*I don't like it when there are people. I like it when it is really quiet*." (Interview 2, line 47). She could articulate her preference for peacefulness.

This was also confirmed during my observations of Lucy. I noted in my research journal that she preferred to go to places in the community, such as restaurants, if it was peaceful and quiet: "*She prefers going to places that are quieter and less crowded. It is always an issue to decide where to go out to dinner with her*." (Research Journal - September 22, 2008). While this may be related to females with Fragile X Syndrome experiencing sensory overload (see 3.3.4) she mostly preferred contexts that were calm.

My observation of Melissa, Cindy and Kelly was that they enjoyed their privacy and peacefulness. Their home was located in a quiet and safe neighbourhood, and each had her own room (Observation – 9 March 2009). Cindy projected on numerous occasions that she enjoyed her privacy:

> "*No, I don't even share my feelings with my own parents*." (Interview 7, line 47)... "'*Cause I don't. Never will. I've kept it in so long, so I'm used to it*."

(Interview 7, line 57). "*Depends what it is. I'll make a joke. I keep it all inside. Been doing it for years. I do!*" (Interview 7, lines 64-65).

Later in the interview, she stated the following: "*It depends. I don't tell her much*." (Interview 7, line 178).

Kelly also commented on how nice and peaceful it was when she could lie the children down to sleep at the day-care where she works: "*The issues that they have, sometimes just walking away from them for a minute or two, doing something else. I don't know, or I don't know. It's always peaceful when you can put them down for that nap."* (Interview 8, lines 77-80).

As stated before, females with Fragile X Syndrome often experience anxiety and this can directly affect their daily functioning (Hagerman, 2000:22; Hagerman, 2002:63). I found that when the participants were anxious they often secluded themselves from others and/or the situation. This seclusion allowed them to deal with the anxiety, become more relaxed and enabled them to face others or the situation again.

6.2.12 Imperviousness

Imperviousness can be defined as 'not capable of being damaged or harmed' (Merriam-Webster Online Dictionary, 2009). In other words, it can be defined as an individual's state of mind where she is often unaffected by negative experiences, for example negative remarks from her peers.

I noticed, especially during my interaction with Lucy, that very often she did not fully understand social cues, and therefore was not always aware when others were making fun of her, or trying to hurt her feelings. Lucy's mother made the comment that Lucy was not always aware of when others were making fun of her:

> *"I think she knows a lot of social cues. I think she knows when people, or to some extent, I think she knows when people are mad at her or something. I don't think she always gets when people are making fun of her. So some of those non-verbal languages, I don't think she picks up on those social cues.*

But the real obvious ones I think she probably gets. Like if somebody meant to harm her, I think she would know, you know that type of thing." (Interview 4, lines 132-137).

I also noted during my observation that she did not realise when one of her peers was trying to be hurtful towards her:

"Lucy acted like she was Miss Darbus (High School Musical – her role) today during lunch break. Ian told her to "shut up". She told him to shut up back. He apparently told her that he hated her glasses and that she was gay. Later that evening in the bath she told me that she and Kyle (her boyfriend) and Justin and I are all gay. She obviously has no idea what that word means." (Research Journal – July 8, 2008).

Melissa also stated during an interview with her that she found it difficult to read social cues:

"Like me, I cannot for the life of me read body language. I cannot tell when someone is telling a joke or teasing, umm you know umm... let's see. I cannot for the life of me read social cues, umm I don't know what category you put that under..." (Interview 6, lines 227-230).

Even though the fact that Melissa could not read social cues that well and that it can be seen as a negative, Melissa's consulting psychologist also stated that this was a positive as Melissa was not aware of all the rejection from her peers: *"She misread some of the interaction of her peers which served as a protection from some of the ridicule she experienced."* (Interview 11, lines 28-30).

Melissa and Lucy therefore often did not fully understand social cues. They were not always aware that their peers were making fun of them or teasing them. This imperviousness, in other words, not being affected by these negative experiences, allowed them to not get hurt by what was said or done to them by others.

6.3 INTERPERSONAL ANTECEDENTS

Interpersonal antecedents refer to the protective resources found within a person's ecology (*Cf*. Chapter Two), namely her family, community, and culture. Within this category five themes emerged. Each of these themes is discussed below. I begin each theme with a brief definition for the sake of clarity.

6.3.1 Familial protective resources

As stated in Chapter Two, research on family characteristics has shown that families are the primary source of emotional support promoting resilience (Hjemdal, 2007:307; Murray, 2003:23). Five themes emerged in this section, namely

- Supportive family members;
- parental encouragement and high expectations;
- parental insight;
- love and acceptance; and
- family quality time and shared activities.

6.3.1.1 Supportive family members

One of the resilience-promoting processes that emerged throughout the study was the continuous support from family members, such as parents, siblings, and also extended family members. Research has shown that having a family member be supportive will make the individual feel that she has someone she can trust and who will be there for her (Schoon, 2006:31).

- **Parents and extended family**

According to Murray (2003:23), children's outcome status can be influenced by the emotional support and responsive relationships demonstrated by parents. The child's academic, social, behavioural, and emotional skills can be promoted (Murray, 2003:23; Schoon, 2006:145; Schoon & Bynner, 2003:24; Siqueira & Diaz, 2004:152; Ungar, 2008b:227).

In my research journal I noted how Lucy's parents showed their support after Lucy's annual school play. To Lucy the school play was a very important event and she spent many hours rehearsing and preparing for the event. Therefore it was comforting to see her parents be so supportive of her:

> *"After the show, the parents (including Lucy's parents) stood outside with flowers and gifts. Everybody was so proud, and the Americans aren't afraid of telling and showing their children how proud they are of them."* (Research Journal – 13 May, 2008).

During an informal interview, Lucy also commented that her parents had supported and helped her when she was having a difficult time in her science class. When I asked her what exactly her parents did to support her she replied: "*They have talked to my science teacher.*" (Interview 1, line 71). I noted in my research journal that Lucy reported having trouble in her science class. Her mother then made an appointment with the teacher in order to discuss what was bothering Lucy and to then ultimately find solutions to these problems:

> *"Lucy has been complaining for the last two weeks about her science class. She told her mother and I that 'it's too difficult' and that she does not understand anything. Her mother made an appointment with the science teacher and they discussed what they thought was the problem. They concluded that Lucy will now be meeting with her science teacher every Monday morning before school (to discuss what they will be doing the week to come) and also Friday afternoons after school (to discuss what was done the past week."* (Research Journal – October 23, 2008).

Lucy's mother often arranged therapy for Lucy. Lucy told me: *"She sent me to my paediatrician. She actually sent me to a therapist. She sent me to an occupational therapist. And, and I was helped all my life. And I got help.*" (Interview 2, lines 80-81). I then asked her what the therapist did that helped her and she answered: *"She told me to do like breath exercises. And these mind exercises*." (Interview 2, line 83). I concluded that Lucy thought therapy was enabling. In Photograph 5.7 Lucy can be seen cooperating with her therapist.

Photo 5.7: Lucy at occupational therapy

Lucy's mother also spoke about all the therapy Lucy had received:

> "*And if she got the therapy to do it, she would have been able to learn to crawl, umm you know, not too far delayed. And some of the activities and social interactions with kids would have been there at an early age when they were crawling around playing with toys, interacting, and she was just sitting there in one place. Umm so, you know, that's one of the reasons that I personally feel early intervention is so important. Even though there might not be a cure for Fragile X, they can identify this condition at birth, they can work with these kids at a very early age so that they don't have these delays and you can keep them as much on a normal track of umm a, a normal developmental track as possible. I think that's the best opportunities for an outcome because if something like social (skills) is not delayed there you know just each step can... The more normal you make it the better. But anyway, so Lucy was doing occupational therapy and physical therapy for a very long time. She eventually was able to step over curbs, to maybe climb up a swimming ladder, to step you know on one foot, to jump a little bit and to*

walk up and down stairs independently alternating feet. That was at about six years old that she could do that. At about twelve she stopped being, she started having problems again and specifically going down the stairs. Umm so she now needs... she marks time, you know what that is? She steps down with one foot one step and then the other foot on the same step. Umm which is a regression in terms of ability and she is also uncomfortable doing it while somebody is holding her hand, a lot of insecurity. And when I talked to an occupational therapist who really knew about Fragile X and neurologists they were not surprised." (Interview 4, lines 49-71*).*

Lucy's mother was therefore supportive as she arranged for Lucy to receive therapy and thus become more resilient.

Melissa reported that her parents were supportive and encouraging during difficult experiences. When asked what they had done for her, her reply reflected that they took time to advise her and be there for her: *"Umm, that's a good question. Uh well, you know, just, you, be the bigger person and, and umm just try to not let it upset you and they were on my side sort of.* (Interview 6, lines 117-119).

Melissa, Cindy and Kelly's consulting psychologist confirmed this when asked what their parents had done to help them cope in difficult times: *"Melissa's family is very supportive*." (Interview 11, line 36)... "*She (Melissa) was supported by her immediate and extended family members."* (Interview 11, lines 37-38).

When asked what has helped Cindy she stated: *"Cindy's family and extended family are very supportive and attempt to include her in family events and vacations*." (Interview 12, lines 31-32).

Later she said the following about Kelly: "*Kelly also has a very strong relationship with her maternal grandparents and aunts and uncles who she calls frequently and even travels to see them."* (Interview 13, lines 24-26).

Melissa, Cindy and Kelly's mother stated that she and her husband always tried to be supportive and encouraging towards their daughters and to look at the

positives rather than the negatives: "*I think just the way Michael (their father) is, Michael and I are. You know, like it's, it's never been you know, 'you have to get this grade', you know. It's like, "do your best'*." (Interview 9, lines 71-72). She also stated that Melissa, Cindy and Kelly had a supportive extended family: "... *they can call anybody in my family at any time, and not be self-conscious about it*." (Interview 9, lines 91-92).

Lucy's mother stated how fortunate they were to be able to have such a supportive extended family:

> "*You hear so many stories of families being unsupported. So fortunately that is not the situation here and I know that. I feel that it is also just a feeling for us that if anything happened to us, there are people that would take care of Lucy and that she will not be alone."* (Interview 4, lines 168-171).

She also stated that Lucy was fortunate and aware that her immediate and extended family was there to support her: "*She knows that she can call anybody if she needs anything*." (Interview 4, lines 313-314).

Lucy's tutor commented that Lucy seemed to have a close relationship with her grandparents and that they seemed to be supportive:

> "*She talks real positively about her grandparents. So I think they have a real kind of extended family that's really involved and as she ages, you know, that's gonna be more important, 'cause I don't know if she'll ever live independently*." (Interview 3, lines 216-219).

The support from extended family and parents therefore allowed Lucy, Melissa, Cindy and Kelly to feel wanted and loved. Their support has also been found to be a reassurance.

- **Siblings**

It has been found that siblings play an important role in the social, emotional, behavioural and cognitive development of children and adolescents (Hetherington & Elmore, 2003:182; Kretschmer & Pike, 2009:581; Yates & Masten, 2004:525).

I asked Melissa how her sisters had helped her cope during difficult times. She answered as follows:

> *"Yeah, we pretty much went through similar stuff. Different scenarios but, you know...[They] Just try to be on my side. Not the other person's side. That's helped a lot."* (Interview 6, lines 123-124; 128).

Therefore it can be seen that, according to Melissa, her sisters were a support system for her. During an interview with Melissa's consulting psychologist she stated that Melissa depended on her sisters to get around: *"Melissa does not drive, so she depends on her sisters for rides."* (Interview 11, line 55).

The consulting psychologist concurred that Kelly often relied on support from her sisters: "*Her sisters have provided her with the support she needs to feel included."* (Interview 13, lines 23-24).

Melissa, Cindy and Kelly's mother also confirmed that having each other as sisters offered them support:

> *"You know in a way I think it's been good 'cause they've been there for each other. If they'd had friends, chances are they wouldn't have all had friends and so the ones who did would have been left out, you know. So I don't know how deep they get with each other. There's time when they will say something and it's like, you know they've been talking, you know that they're more in tune with each other than what they lead on to be. I think they know each other pretty darn well."* (Interview 9, lines 61-67).

Melissa, Cindy and Kelly's father spoke of how supportive the sisters were of one another:

> *"Oh I think it has helped tremendously, because they help each other. If there was just one of them, Terisa and I would be the only ones there to help them and it's like we're not there all the time. And it's like you know they're their own advocates for each other when they're as a group, you know. I think they problem-solve together, they look out for each other. Even like last night, Terisa and I were at some friends' house for dinner and umm Kelly*

called and said, 'Dad, its six o'clock. Janet is not home yet. She got done with work at four'. And it's like whenever Janet gets a ride home from somebody else and they don't get home for a while, there's always risk that she's out drinking with them and it's you know, Kelly gets so concerned... So it's like, 'thanks for worrying about her and you know we're, just call me when she gets home' and things like that. So it's like they do think about each other and they worry about each other and they umm, you know they do, you know help each other out. You know, Kelly will go to Janet and be like, Janet, you work at 7 tomorrow you better go to bed pretty soon. You know, so they are really looking out for each other and you know they fight sometimes, like sisters do but, but umm I think it is umm ah, you know, I haven't thought about it, but if we had one child with Fragile X, it probably would be very different, you know." (Interview 10, lines 113-132).

So, it is clear to see that Melissa, Cindy and Kelly's relationship with each other (as siblings) enabled them to cope more resiliently with difficult situations. Their parents seem to think that their having Fragile X Syndrome in common strengthened the sibling bond.

6.3.1.2 Parental encouragement and high expectations

It has been found that individuals who are offered care, support, high expectations and encouragement from within the family are more likely to manage stress in their lives (Ungar *et al.,* 2008:1-2; Ungar & Liebenberg, 2005:218; Winslow *et al.*, 2005:338). Encouragement enables individuals to feel worthy, capable of contributing and motivated to succeed (O'Dougherty Wright & Masten, 2005:24). It has also been found that when parents expect high standards of moral behaviour, their children tend to develop resilience. The child develops an understanding that even though she might fail, she can bounce back and try again.

Kelly told me that her parents were very encouraging, also regarding socialising with friends: "*I would just say offering as much encouragement, and saying, you know, 'You'd have fun if you went out with friends and just hanged out'."*

(Interview 8, lines 45-46). Kelly's consulting psychologists reported that Kelly's parents were very encouraging and had high expectations of her to succeed: "*Her family has always expected her to try hard and to succeed*." (Interview 13, lines 31-32); "... *and also lots of encouragement from her immediate family and extended family members*." (Interview 13, lines 82-83).

Melissa, Cindy and Kelly's father spoke about how he and his wife were always encouraging towards their children and that they always expected them to give their best, even though they had been diagnosed with Fragile X Syndrome:

> *"And I think they receive, umm they receive quite a bit of encouragement at home and then they also umm receive a certain amount of expectation that they're gonna work hard too, you know. We don't really umm kind of let them off the hook because they're different. I mean, they you know they still you know have an obligation to themselves to be the best they can be in whatever they do and somehow that kind of translates, they know that."* (Interview 10, lines 77-82).

Melissa, Cindy and Kelly's mother stated during an interview with her that she and her husband always encouraged their daughters to do their best:

> "*I think just the way Michael is, Michael and I are. You know, like it's, it's never been you know, 'You have to get this grade' you know. It's like, 'Do your best'."* (Interview 9, lines 71-72).

Lucy reported during an informal interview that she once was afraid of dogs: *"Ummm… I'm afraid of dogs."* (Interview 2, line 75). I also noted this in my research journal:

> *"Some of the girls who have worked with Lucy before have told me how scared she is of dogs. Her mom was able to help by getting Lucy a dog of her own. At first she was very scared of the dog. I was not here to observe this, but her mother has told me about this numerous times. She now is so comfortable with the dog. He's licking her in her face and licking her feet. She*

loves getting home from school and telling the dog, 'Come kiss my tender toes'." (Research Journal – April 15, 2008).

Lucy's mom had high expectations for Lucy. She realised that Lucy's fear of dogs was to some extent holding her back from living a normal life. Lucy's mother decided to get a dog of their own, so that Lucy could get use to her own dog and then she would not be as afraid of other dogs. She expected Lucy to adapt.

Photo 5.8: Lucy showing that she has overcome her fear of dogs, thanks to her mother's continuous encouragement and high expectations for her to overcome her fear.

6.3.1.3 Parental understanding

Parental understanding refers to parents having an awareness of their child's ability and what it implies, but also being aware of what the child is capable of doing (Watson, 2008:168), and showing interest and monitoring their child's activities (Reese, Kroesen & Gallimore, 2000:320). Parents that show interest,

understanding and monitor their child's activities have been found to play an important role in resilience (Reese *et al.,* 2000:320; Schoon & Bynner, 2003:24).

From my continuous observation of Lucy over a period of 20 months I noticed that her parents demonstrated a good understanding of their child. On August 6, 2008 I made notes in my research journal about Lucy's mother preparing her daughter to go off to summer camp. I noticed that Lucy needed her mother to make plans for her and that her mother often had to help her carry them out, as written below:

> *"It's the night before Lucy leaves for camp. Lucy's mother has packed everything Lucy could possibly need. There is no way that Lucy will be struggling. ☺ Lucy has a lot of anxiety about going away. She'll be gone for 10 days. Her mother printed some envelopes with people's names and addresses on, to whom Lucy can write. This seems to help with some of the anxiety. Lucy, her mom and I talked about who she can write to and what she could tell them. Even though she has so much anxiety, she is so excited. It's hard to explain, but even though Lucy at some point is begging her mom not to allow her to go, she is also expecting her mom to MAKE her go. It seems like she needs someone to "push" her to go. That somehow helps with the anxiety."* (Research Journal – August 6, 2008).

On January 13, 2009 I noted in my research journal how Lucy's mother was able to use a technique (role-play/fantasy – *Cf*. 5.2.10) to help Lucy to not demonstrate negative behaviour:

> *"They are doing homework, mom and daughter. She has to make a speech. She is very close to throwing a tantrum or should I rather say she is hyper-aroused. So her mother did a great job to change the situation by saying that she (her mom) is Zack Efron from High School Musical. Her mood changed completely and she was able to do what needed to be done. Lucy loves to pretend, and live in her fantasy world."* (Research Journal – January 13, 2009).

On February 11, 2009 I noted the following:

> *"Lucy likes reading these specific books for school. It's a series. Anyways, today there were three books she hasn't read and her mother told her to choose one. The one was about the Titanic. Her mother then said that she shouldn't read that book because she wouldn't like it. Lucy then of course wanted to and her mother said that she would not allow her to. And that was the end of that. At first I couldn't understand why she wouldn't allow her to read it and then after a minute or two I clicked why she said that. Lucy has a lot of anxiety about things. As a family they like to travel a lot and they have gone on cruise ships numerous times and they enjoy doing that. If Lucy read the book and then saw the movie she would never ever want to go on a cruise ship again. Lucy's mother is so smart. She knows exactly what to look out for. Smart, smart woman!"* (Research journal – February 11, 2009).

It can therefore be seen from these three excerpts from my research journal that Lucy's mother was involved in her daughter's life, she showed interest and monitored her child's activities. Lucy's mother's understanding of her child was also confirmed during an interview with Lucy's teacher as well as her tutor. Her tutor confirmed that Lucy's mother understood her child, what she was capable of and what she struggled with. She also stated that Lucy's parents were up to date with the latest techniques and research:

> *"And I do think Lucy's mother in some ways with her worrying does have a really good handle on stuff. I think she kinda knows how Lucy learns. I think more so than maybe other parents and so I think like even with the math, she's pretty realistic about like... she needs real life skills. She needs to be able you know, budgeting and work on money things. So I think in that sense you know, she's pretty, you know that she's pretty good knowing about how she learns. And they've been to all these conventions and so they are into like the, excuse me, 'the newest techniques and research' and that I think really helps."* (Interview 3, lines 121-129).

Therefore, it can be seen that parental insight is not automatic, but these parents had learned how to support their child.

Lucy's mother told me the following:

> *"Okay, let's see. Because of it (Fragile X Syndrome), Lucy has tremendous amount of anxiety. Umm, even in situations that she would enjoy, she has a lot of anxiety and sometimes it prevents her from going someplace. Umm, transitions can be kind of difficult, but again if you know what you're doing and you can give her a heads up, it helps a lot."* (Interview 4, lines 3-7).

Melissa, Cindy and Kelly's mother stated that they did extra work with the girls during their summer vacation time in order to try and improve their academics:

> *"You know and we always did tutoring in the summer. So they would keep up with the reading and stuff like that and you know we, you know, stuff, we just normally thought that we should be working on with them."* (Interview 9, lines 123-125).

I therefore concluded that Melissa, Cindy and Kelly's mother understood that her children had a difficult time in school and tried to decrease the difficulties (such as reading) that they experienced by getting them help.

- **Parents as advocates**

Melissa, Cindy and Kelly's parents both stated during individual interviews that they wrote to the girls' school to ask for help once the girls were diagnosed. Their mother stated:

> *"Well, when Kelly was a freshman and we found out about Fragile X, Michael wrote a note to the school and said, 'You know, we just found out our daughters have this Fragile X'."* (Interview 9, lines 109-111).

Their father later stated:

> *"But then once we got the diagnosis we did write to the faculty a letter and just kind of umm you know, just kind of let them know that the big mystery had been unlocked. That there's a real diagnosis for what was going on with our kids and that, umm you know. I kinda played back to them what the written mission of the school was, which was helping the individual child to*

develop to the best of their potential. So we really just asked them, please be true to the mission for our kids. They're not the same as everybody else, but the mission of the school is still the same." (Interview 10, lines 162-169).

Lucy's mother also stated that she and her husband had made others aware of Lucy's disabilities and had asked a disability specialist to come and talk at Lucy's school:

"One of the things we did at a very early age, is that we had somebody come into the school who did the disability awareness type of thing." (Interview 4, lines 178-179).

By being aware of the individual's abilities and disabilities, the family can provide information and access to knowledge about the disabilities and abilities of the individual. The family is also able to steer the individual away from wasteful or dangerous abilities (Bayat, 2007:702; Siqueira & Diaz, 2004:152; Watson, 2008:173).

Lucy's teacher also mentioned how Lucy's mother had asked a disability specialist to come to the school and talk to the teachers and students about Lucy's disabilities: "*And she was working with a disability awareness specialist. Carmen Gordon. Wonderful, professional human being."* (Interview 5, lines 56-58).

The parents were found to seem to understand their children and know what their children were capable of and what not. This is important as it helped them to work on things that the girls might struggle with or to motivate or build the girls' self-confidence regarding that which they were capable of doing. By understanding their children and Fragile X Syndrome they were also able to be advocates in their children's lives, and could seek help on their children's behalf.

6.3.1.4 Love and acceptance

Love in this case refers to family members showing love, care, concern, and interest in the individual's life (Silberberg, 2001:54). It is also helpful having a family that provides a nurturing, caring and loving home environment (Donnon &

Hammond, 2007:452; Ungar & Liebenberg, 2005:218; Winslow *et al.,* 2005:24). Masten and Reed (2005:85); and Ungar and Liebenberg (2005:219) emphasise the fact that resilience is encouraged when an individual feels welcome and relaxed in all her living surroundings.

Acceptance means showing respect, appreciation and understanding for each other's individuality and uniqueness (Silberberg, 2001:54). Acceptance is a strength when family members acknowledge, value and tolerate each other's differences, and when the members allow each other space (Donnon & Hammond, 2007;452; Masten & Reed, 2005:83; Silberberg, 2001:54; Ungar & Liebenberg, 2005:218; Winslow *et al.,* 2005:24).

I noted in my research journal:

> *"It is very interesting and comforting to see how accepting Lucy's family is of her. I can tell that it is difficult for her parents to see her struggle with certain things. But they really go out of their way to make life easier for her. They are aware of her struggles and they have accepted her. I can really tell that they love her unconditionally. She loves her parents and her home. Home is where she feels safe and loved."* (Research Journal – 5 February 2008).

My observations were confirmed by Lucy's mother and tutor during interviews. Lucy's tutor stated that Lucy's family was very accepting of and loving towards her: "*But they seem to do a lot as a family and they are very accepting and loving of their family and they would almost do anything you know. So you know that is a real positive thing*." (Interview 3, lines 213-216). Lucy's mother also stated that the family had accepted Lucy's disability: "*Okay, umm, I think one of the biggest things is, at least where we are at now, I think her family accepts the disability.*" (Interview 4, lines 148-149).

Melissa, Cindy and Kelly's consulting psychologist stated that their parents showed them a lot of love and acceptance:

> *"She was supported by her immediate and extended family members and was again coddled to some extent by her maternal grandparents. This*

allowed her to feel especially loved and appreciated." (Interview 11, lines 37-40).

"Kelly has a very kind and loving family." (Interview 13, line 22).

Melissa, Cindy and Kelly's father stated that he thought an environment where his children felt loved and accepted was very important for them to be able to cope: "*How do we get them in environments where they're gonna be loved and accepted for who they are*." (Interview 10, lines 50-51).

So, the fact that Lucy, Melissa, Cindy and Kelly were accepted, loved and liked their homes (as expressed in their interviews) allowed them to feel wanted, loved and cared for and consequently to feel safe. The families also spent a lot of time together and this caused the children to feel loved and accepted. It also helped them to improve their social skills, as they were able to socialise with family members. They felt a sense of belonging in the family as they could also share in activities.

6.3.1.5 Family quality time and shared activities

Quality time refers to spending productive time with family members, sharing values, beliefs and morals (Silberberg, 2001:54). By spending quality time together as family, individuals feels a sense of belonging. Developing a sense of belonging is also seen as a potential protective resource (Fergusson & Lynskey, 1996:289; Kim-Cohen, 2007:277; Ginsburg & Jablow, 2006:112). Family activities refer to rituals and doing activities like sports, playing games, hobbies, etc (Silberberg, 2001:54). Family connections are enhanced by establishing family activities (Ginsburg & Jablow, 2006:118-119).

Kelly's consulting psychologist commented that Kelly, Cindy and Melissa took many trips with their family and also shared similar interests:

"*They have taken trips together and share many interests*." (Interview 13, lines 26-27); "*Kelly feels the attachment and wants to continue many of the family traditions and interests. For example, they share interests in college and professional football which provides opportunities to attend games*

together and to discuss the season and particular games and scores." (Interview 13, lines 27-31).

Cindy's consulting psychologist, told how Cindy's family always tried to include her in their family activities even though she enjoyed being alone when she had periods of depression:

"*Cindy's family is close and even though she may be depressed, they will stay engaged with her and not allow her to hide from their influence. They will continue to insist that she participate in some of the family plans and reunions."* (Interview 12, lines 59-61).

Melissa, Cindy and Kelly's mother commented that they often took part in family activities such as celebrating birthdays and having dinner together:

"*Well, we do try to do, we do a lot with my family, you know. Not so much with Michael's family, but umm. Birthdays my parents come or you know my brother or sisters come you know."* (Interview 9, lines 89-91); *"Michael and I tried to do a lot, you know like having family dinners."* (Interview 9, lines 95-96).

I noted in my research journal that Lucy's family also spent a lot of time together as family:

"We got back from a three week vacation in Israel on the 2nd of January. Lucy's whole family from her dad's side went on the trip together with their synagogue. Lucy enjoyed it very much. It was hard at times because there are a lot of cats, especially around Jerusalem, and Lucy has a lot of fear and anxiety around cats and dogs. And the days were long and busy. But I think it really helped her to cope with all her anxiety, the fact that she had her cousins and other family members there. She loves spending time with them and wanted to do whatever they were doing. It was a nice experience for her." (Research Journal – January 5, 2009).

Photo 5.9: Lucy with her family and extended family spending quality time together as a family during a trip to Israel

Lucy's mother stated that they did indeed spend quality time together as a family: *"We get together as a family and friends and have dinner together."* (Interview 4, lines 315-316). This was also confirmed by Lucy's tutor: *"But they seem to do a lot as a family*." (Interview 3, lines 213-214).

By spending quality time together as a family my female participants were able to build relationships with their family members and feel part of the family.

6.3.2 Community Resources

As stated in Chapter Two, supportive relationships with family and non-parental adults are not the only resources that protect adolescents from adversity, but also factors in the community (Boyden & Mann, 2005:7). My findings regarding the role that the community played in the resilience of the participants with whom my study was done, are discussed below. Four sub-themes emerged, namely:

- Supportive schools;
- peer support;

- professional community, and
- enlightened, well-resourced community.

6.3.2.1 Supportive school

Within this theme the sub-themes of accommodating special needs at school, supportive teachers, and parent-teacher communication emerged. I will discuss these sub-themes later on.

Supportive schools encourage resilience when they support their students with the necessary resources, for example special programmes, counsellors, well-trained and well-compensated teachers. The school also provides information, advice and experience to help ensure positive post-school outcomes (Schoon, 2006:33). According to Johnson and Lazarus (2008:29), schools that consist of effective resources have been found to experience less problems with students faced with adversities. This might be due to the fact that they offer more support to these students. Having high expectations at school have also shown that children have higher levels of academic success. Furthermore, giving students responsible roles within the school have also been shown to heighten resilience (Schoon, 2006:33).

In general, Lucy's mother stated that Lucy's elementary school was very supportive: "*Umm, school - there has been people that have been so supportive of her in school."* (Interview 4, lines 177-178). She also told how the school worked together as a team to help ensure Lucy's success and that the school also had a positive attitude:

> *"Anyway, so school just in general, the kids and the teachers were very supportive of her. The, they were a real team, because there were some key players that, I think the teachers really invested in her. So there was just this attitude that people were wanting to work together as a team, for Lucy."* (Interview 4, lines 206-209).

Lucy's teacher commented that, even though Lucy sometimes demonstrated inappropriate behaviour during her time in elementary school, the school had set

standards and they expected her to comply with and strive towards achieving these standards, such as appropriate behaviour:

> "*Cause Lucy had gone home and complained that she was going to have to share, and she didn't want to share. Now this is the second year of her being in first grade so, you know, we are requiring some level of maturity. And we require that she complies with reasonable rules and regulations."* (Interview 5, lines 113-117).

By having positive expectations and requiring compliance, the school supported Lucy toward socially appropriate behaviour.

I also noted in my research journal that the school organised special events for those with social anxiety to interact with their peers:

> "*I just dropped Lucy off at the local mainstream high school. The school has these activities that the kids with special needs kids do with other normal developing kids their age. Today they will be having lunch together and play basketball, next week they will go and play bowling. Lucy loves this. She knows many of the mainstream kids as she went to school with them during first grade up to seventh grade. According to her mom and teacher, these kids were very nice to her and she still calls them and writes to them over Facebook.*" (Research Journal – April 20, 2009).

These special activities supported Lucy to fit in, as did the reasonable expectations outlined above.

Melissa, Cindy and Kelly's father also spoke positively about how supportive Melissa's school had been:

> "*So some of the teachers were not quite as understanding but in the broad scheme of things the school was very supportive. Now Melissa went to the public school and was in the special education programme. There we had heard so many horror stories from other parents on how the school does anything they can to deny your kids. So we were prepared to you know, have a difficult, you know, time with the school and the first time we had a meeting*

*with them, they had a whole room of people there. And they were all about, 'Hmm how can we qualify Melissa for the greatest services we possibly could?' And it's like whenever we would have a meeting at the school, the vice-president of the school would come, the guidance counsellor would come. They all took a personal interest in Melissa and her success and, you know, we think our kids are wonderful and have special gifts and things and they ought to be loved by a lot of people, but still, when you're the vice-principal of a school that has 2000 kids, who do you have the time to care about? You don't have the time to care about everybody individually, so when you come to our meeting and show up, you demonstrate that you really do know our daughter. You know it's just, it's just very, very helpful. So it's like the environment they're in, whether it's work or school, it's just so important to their success.***"** (Interview 10, lines 175-192).

It would therefore seem that for Lucy, Melissa, school experiences seemed to be supportive, which allowed them to cope more resiliently with their challenges.

- **Accommodating special needs at school**

During my interaction with Lucy I noticed that her school was very supportive. They provided her with counsellors, well-trained teachers, an individual educational programme (IEP), therapy (such as occupational therapy and speech therapy), and special programmes.

I noted in my research journal that her school accommodated her needs in many practical ways*:*

"Today Lucy's mother and I went to Lucy's school. The teachers and parents had a meeting with the school district. During this time they discussed Lucy's IEP (Individual Education Programme) to see if she is up to date and what more they can do to help. Lucy's mother let me sit in on the meeting. It was really interesting. I was very surprised to see how much the school district cares and what they are willing to do to help Lucy succeed. I also found out from Lucy's mother afterwards that the school district pays Lucy's school fees every year in order for her to be in the special needs school (it is very

expensive), also her transport, even though they don't use it." (Research Journal – April 8, 2008).

I later noted the following:

> *"Today a consulting psychologist came to Lucy's school where she observed Lucy in the classroom and then afterwards had a meeting with the teachers and Lucy's parents on how she will learn best and what should be done to improve learning. I got to sit in too. The school was very complying and seemed eager to listen to what the consulting psychologist had to say to help improve Lucy's learning."* (Research Journal – September 8, 2008).

In other words, I observed that part of accommodating her needs was involving experts and providing spaces for therapies (see the photographs in 5.10 below).

Photo 5.10: Lucy's school offering occupational therapy

I found it very interesting to see during my observations and interactions with Lucy, her family and the Fragile X Community, that the American school district was very supportive. Lucy's mother said the following about the help they received from the school and school district:

> *"We've had a lot of support from the school district as being helpful. Umm and, and pretty much doing what is in her best interest, as opposed to trying to save money or get her out of the way and then we ended up coming to a special needs school with the support of our school district. Umm in terms of them covering the expenses, which is really great and umm the teachers, they are really, you know are really geared towards kids with different needs, and so, even though things are not perfect there, umm, they overall*

recognise every student there has needs and so Lucy is very aware they work together as a team." (Interview 4, lines 213-220).

Lucy's teacher explained that Lucy was able to learn to read by means of a special reading programme:

"There was a specific programme, where it was just memorisation of words. You would learn one word at a time. And that word was used repeatedly in a sentence and you would see it in different places. So it was sight memorisation, one word at a time. She couldn't do phonics. There was no sounding letters out. You know, that that was beyond her. So this reading programme, it was called EDMARK. It is spelled E-d-m-a-r-k. It had tabling of maybe 500 words, so that's the programme we used all the way through secondary school. And I used it with her. I was the one who was trained with it. Not that it was that difficult, but umm we did that from first grade up until she left fifth grade. Up until she left school, so that was terrific. That was how she learned how to read was sight memorisation of words." (Interview 5, lines 88-98).

From the above, I concluded that Lucy's needs were well-accommodated during her time at a mainstream school. However, later she was moved to a special needs school as her parents felt that it was the best thing to do for her academically. The school assured them that they would be included in parent-district-teacher meetings and collaboration with professionals would take place.

Lucy's tutor spoke about how special education had improved Lucy's performance:

"Well, I think there is such a community there (Lucy's high school). Just in terms of being with kids that are kind of like you. And being able to have a leadership role. If she was in a local public school, I mean I don't think she'll be secretary of the student council. So the opportunity she has to do those things, I think is really, really important. And I think a school like that does a lot from a social perspective. I'm not sure how much the special needs school has done for her academically, to be honest, and I think Lucy's

mother would agree with that. I'm not really sure. I think there's a whole lot more they can do. I think her consulting psychologist would agree with that too... That you know that there is a whole lot more they can do in the social venue of really facilitating social connections, especially at lunch and helping her orchestrates things." (Interview 3, lines 139-148).

During my interaction with Melissa, Cindy and Kelly, they also told me how their mainstream school accommodated them during their school years and how it had helped them cope during difficult times at school. One thing that emerged prominently during my interviews with them, was the Learning Resource Centre that was made available to them by the school.

Melissa explained to me how the Individual Educational Programme (IEP) and Learning Resource Centre (LRC) had helped her during her school years:

"Because you know, I couldn't finish the tests on time, and there was like this IEP, that is a legal backing up to say that I have extra time. And she was like, you go to this you know to the LRC (Learning Resource Centre) and you finish that test." (Interview 6, lines 99-101).

She also spoke about a special programme called Students with Disabilities (SWD):

"Well, umm at my high school there was a, ah, ah SWD, Students with Disabilities programme where you know... That's what the case managers are for and there, they have um classes that SWD can take instead of being in regular classes and that made it a lot easier for me. I was comfortable there." (Interview 6, lines 157-160).

Melissa's consulting psychologist also confirmed that the special education services and IEP had helped her cope during difficult times in school:

"Melissa's ability to access special education services made a big impact in her educational process. She was also provided with a transition plan which gave her a job coach as well as additional years to be educated after her

peers graduated. She is still employed at the same job and finds it rewarding to be employed as an adult." (Interview 11, lines 42-46).

She also stated:

"*She also was afforded an IEP which helped provide her with accommodation and reduced expectations which helped reduce her performance anxiety. On occasion, Melissa would get so frightened that she was literally unable to speak and actually stuttered periodically. The smaller group size and special education services provided some protection.*" (Interview 11, lines 20-25).

Kelly also said that the LRC buffered some of the troubles she had experienced academically:

"*One thing that helped a lot in high school, after we got diagnosed was, was this LRC, this Learning Resource Centre that they had at school and they umm would help break down projects. Even like long-term projects, 'cause that was a problem in school too, umm was to get those done. 'Cause I would wait until the last minute to get them done. And instead they taught me how to do a little bit at a time and then you don't have to worry about it, then it's all done."* (Interview 8, lines 50-56).

This once again was confirmed by Melissa, Cindy and Kelly's parents. Regarding the LRC, their father spoke about how supportive the school had been before the girls were diagnosed and also after the diagnosis:

"Yeah, umm you know, the main thing that the schools did is uh, was supporting the kids academically as much as they could. Umm, when our kids got diagnosed, you know Kelly, Kelly and Cindy would already be in high school, they would have been struggling mightily and the school tried to provide them with help. They had a learning resources centre which is a place they go to take tests and get extra help and they were pretty good about doing that." (Interview 10, lines 157-162).

Their mother said:

"The school had kind of a support system where they had a resource centre and they were able to go in and have an extended period for tests, if you needed the test read to you, you could get it read to you, you know." (Interview 9, lines 111-114).

So, the experiences of Lucy and of Melissa, Cindy and Kelly suggest that their schools' readiness to accommodate their special needs in varying ways supported them towards coping more resiliently with their challenges.

- **Supportive teachers[6]**

According to Schoon (2006:33), teachers often influence their students' feelings about their personal abilities. Therefore it can be concluded that if the teacher's feelings are positive towards the students, the outcomes demonstrated by the students will more than likely be positive (Murray, 2003:11; Schoon, 2003:24; Ungar, 2008b:227). As noted in Chapter Two, teachers are often instrumental in encouraging resilience (Donnon & Hammond, 2007:452; Murray, 2003:24; Ungar & Liebenberg, 2005:218).

During an informal interview with Lucy I asked her what her teachers had done for her at school when she was having a difficult time, and she replied: "*By leaving boys alone.*" (Interview 1, line 76). I then encouraged her to tell me what exactly the teacher did during this time (acting appropriately around the opposite sex). She replied by saying: "*Wait*." (Interview 1, line 95). I concluded from her answer that the school modelled coping skills, and therefore was seen as supportive. This was also confirmed by my observations:

"Lucy's been having a hard time at school socially. She likes this boy and has been following him around and trying really hard to make conversation. The boy has been getting irritated and has been rude to her. Lucy has been coming home upset almost every day. So her mom realised what the problem is and has called the school to see what they can do to help. Lucy's

[6] In this section I am referring to both mainstream and also special education teachers.

mother has asked them to make sure there is a social worker or teacher present during lunch period that would help facilitate during the social period and help model appropriate social skills." (Research Journal – April 11, 2008).

The teachers responded to this request and modelled and taught her appropriate behaviour, which facilitated better relationships with her peers, which is integral to resilience.

There were other examples of teachers being supportive: In my research journal I noted how the teachers supported the children (at the special school) during a school play:

"*There were some parts where Lucy forgot some of her lines. But the teachers had it all covered. There was a teacher sitting in front of the stage helping them in case they forgot their lines. It was such an experience seeing the kids take part like this*." (Research Journal – May 13, 2008).

Lucy's mother also commented how supportive the teachers were of Lucy (at both the mainstream and also the special needs school). She also commented that this helped the other children to be more supportive and accepting of Lucy:

"I think that the teachers in school saw the things that Lucy could do and there was so much she couldn't do, that I think they focused on, 'Oh my God, look what Lucy did today!' And it was so minor compared to where the other kids were at. But they were watching and helping her accomplish, and because of that created a very high self-esteem and it made school a very pleasant thing for her. It transformed it to the other kids, you know they, they saw what Lucy had accomplished and they were proud of her, of what she could do as opposed to what she couldn't do. So I think that helped a lot." (Interview 4, lines 197-209).

Later in the interview, she explained further:

"umm the teachers (special education teachers), they are really, you know are really geared towards kids with different needs and so even though

things are not perfect there, umm, they overall recognise every student there has needs, and so Lucy is very aware that they work together as a team. So if she wanted to know something she knows she can approach the teacher and it's pretty cohesive." (Interview 4, lines 217-221).

Photo 5.11: Lucy with her favourite teacher after their school play

Lucy's teacher also described how the teachers' support helped Lucy succeed. The school suggested that Lucy should repeat first grade. However, Lucy's mother was very concerned about doing so as she felt that Lucy had developed a support group with the children in her class and was worried about the other children moving on to the next grade and Lucy staying behind. The teacher assured Lucy's mother that it was best for her child to repeat first grade and that she would create another support group for Lucy with the new first graders. Her supportive stance is clear in the following excerpt from an interview with her:

"So we said, we'll create another support group with the other (children), in the next class. That's our job to do that. You trust us (i.e. the teachers). She needs to repeat first grade, so that she can learn how to read, she can read the letters, she can learn the numbers and have some of the basics, because if you just move along now she will not be able to sit in any of the classes because she won't have any of the background." (Interview 5, lines 68-73).

Lucy's teacher furthermore spoke about how encouraging and patient the teachers were towards Lucy and also her parents. She told how Lucy was expected to share things at school and that she had a hard time doing so. Lucy had gone home and told her mother that she did not want to share with her friends. Lucy's teacher tried to explain to Lucy's mother that it was important for Lucy to learn how to share. Lucy's teacher related that she had said:

> *"'We're gonna work with her. She needs to do this. She can do this. We'll model it for her. She will be one of the last ones to go (to share her candy with the other children)... She needs to do this. She needs to learn how to do this. Sharing is an important part of her social development'."* (Interview 5, lines 127-134).

The teachers (both mainstream and special education teachers) demonstrated skills (i.e. to share) and expected Lucy to practise these skills. They understood that sharing with others was difficult for her to do, but they also realised that sharing was an important skill that she had to learn and insisted on her doing so.

Kelly stated the following: "*I had nice teachers for the most part."* (Interview 8, line 50). Melissa's consulting psychologist told how supportive Melissa's teachers were and that they were advocates of reform, and therefore were in favour of her success: "*Melissa had several Special Education teachers and a counsellor who were advocates and supported her during difficult times.*" (Interview 11, lines 19-20). Melissa, Cindy and Kelly's father also told how supportive many teachers were:

> *"But, you know, across the broad spectrum of teachers one would run into, you know there were some... I'm thinking the most important aspect, their teachers really cared, but some teachers have just been teachers for too long and they get to the point where they are kind of cynical about their job and you know. So some of the teachers were not quite as understanding, but in the broad scheme of things the school was very supportive."* (Interview 10, lines 171-177).

However, as indicated in this excerpt, supportive teachers were not a general phenomenon. In other words, not all the teachers interacting with these girls were specifically supportive of them. Even though only some teachers were supportive, those who were supportive still had an impact on Melissa, Cindy and Kelly's school years and made a difference for the positive.

- **Parent-teacher communication**

Parent-teacher communication refers to having consistent communication between the parents and teachers or school (Murray, 2003:22). School-parent communication can be seen as a potential protective resource as the school and parent interact to positively influence the development of the at-risk individual's educational achievement and to encourage resilience (Murray, 2003:22; Schoon, 2006:31).

As noted previously in this chapter, Lucy earlier commented on how parent-teacher communication had helped her cope during difficult situations: "*They have talked to my science teacher.*" (Interview 1, line 71).

During my observations I was able to notice another incident where parent-teacher communication made a difference in Lucy's coping with difficult situations:

> *"Lucy has had a hard time acting appropriately around a boy she liked. Her parents brought this to the teacher's attention and the teachers assisted where necessary to help her act appropriately. This means that she was able to tell her parents that she was having a hard time acting appropriately around the boy. Her parents were able to talk to the school, so that they could assist. The teachers assisted Lucy to ensure more appropriate behaviour."* (Research Journal – August 7, 2008).

Lucy's ability to tell her parents about the problems she was experiencing therefore allowed her parents to then talk to the teachers. This in turn allowed the teachers to be more supportive towards Lucy and to help her portray appropriate behaviour.

Melissa also said that she was able to talk to her teacher and then know that her teacher and parents would communicate about difficulties and successes:

> "*Well, like when I was working on a project, she would e-mail my mom or if I didn't know how to tell my mom something, I'd tell her and she'd kinda tell my mom and umm you know, what I umm know couldn't tell my mom.*" (Interview 6, lines 180-182).

In other words, for Melissa parent-teacher communication was initiated by her teacher and this communication helped to ease parent-child communication.

6.3.2.2 Peer support

Peer support refers to relationships with peers that offer emotional comfort, experiences of trust, a sense of belonging, love, caring, and compassion (Ungar *et al.,* 2008:7). Support from peers and peer acceptance can also enhance children's resilience. Positive peer relationships enable children to experiment, develop positive attitudes, skills and values, learn how to share and help others. These then all correlate with individual protective resources such as competence, building relationships with others, empathy, and feeling they are part of a group. The child is able to build confidence. This all helps build resilience (Boyden & Mann, 2005:8; Schoon, 2006:81; Ungar, 2005:316).

During my observations of Lucy I noted that she had a lot of peer support and that this helped her accomplish more. For example, she came home from camp being able to tie her own shoelaces:

> *"She came home from camp today! And she was able to tie her shoelaces!!!! WHAT AN ACCOMPLISHMENT!!! I've tried to teach her, her mom tried to teach her. And here she comes home, doing it by herself. PERFECTLY! Lucy's mother and I discussed this accomplishment and concluded that it must have been the influence of the other kids at camp! How fantastic. I can't wait to see what she'll be able to do next time she comes home from camp!!* ☺ ☺ ☺" (Research Journal – August 17, 2008).

Photo 5.12: Lucy tying her own shoe laces

I also concluded that peer support played a role in her resilience from the following statements she made during an informal interview. I asked her what her friends has done for her during difficult times. She answered that a boy had once helped her deal with her fear of dogs:

> *"Ummm… (pause)… Okay… (pause)... it was, I am.. ummm… When I was a freshman, he was a junior, he helped me with Huron (Lucy's dog) actually."* (Interview 1, lines 106-107).

I asked her how he had helped her and she replied: "*By like, he like put his hand on top. He like petted it first. And then he hold Huron and then I hold the leash, and then.. and then he really helped."* (Interview 1, lines 113-114). Again I noticed how peer support has helped Lucy overcome some fears:

> *"Today we met up with some of Lucy's friends. They are four sisters between the age of 13 and 22. Three out of the four sisters have been diagnosed with full mutation Fragile X Syndrome. What an interesting day it was. These girls are awesome! They are each other's best friends. They love Lucy and the five girls just got along so well. We met them for lunch and after lunch we went shopping a bit. Today, Lucy went down the escalator for the first time. Her mother and I couldn't believe what we were seeing. The girls each hooked their arm in hers and they went down the escalator, no issues! It's amazing what peer pressure can do."* (Research Journal – February 14, 2009).

Photo 5.13: Lucy and her four friends shopping together

Lucy's tutor was also of the opinion that having friends with the same disabilities as herself had made Lucy connect more with these peers:

> *"Well, I think, yeah, well, I think having friends that have the same disability, you know, that she's had for a long time, umm probably helps and you know there is kind of a community and connectiveness there."* (Interview 3, lines 167-169).

I also asked Kelly what her friends has done to help her cope and she replied: "*I don't know, just getting me out of the house. And like doing things. Like going to the movies or to dinner.*" (Interview 8, lines 64-65).

I concluded that these friends had encouraged socialisation. Kelly's father stated:

> *"Kelly just kinda sticks her head in it and goes after what she wants to do. You know, she's never been, she's you know, she's always had like one friend or somebody, you know. And now she's got this lady who has a day-care out of her house, and umm so she's got a friend, they go to the movies."* (Interview 9, lines 24-28).

Melissa's consulting psychologist stated that the fact that Melissa's peers had similar learning difficulties has made it easier for her to connect with them on a social level:

> "*Melissa has several friends she made in high school. These friends have similar learning differences (difficulties) and relate to her on a similar cognitive level. This has been a good thing for her as she has been successful with her friends in social venues.*" (Interview 11, lines 48-50).

Cindy's father stated that Cindy's friend who had also been diagnosed with Fragile X Syndrome was someone with whom Cindy could be herself:

> "*So it's like when Cindy goes to visit this girlfriend of hers over in London, you know umm, I guess they've seen each other 4 times in their life but they met at a conference and it's like, it's just something that I think Cindy can be herself with. This person she can be as silly as she wants to be because she's not being judged, she's just being who she is. And umm, and Cindy can just kinda be herself."* (Interview 10, lines 26-31).

Melissa also spoke positively about a social group with which she was involved:

> *"I'm in a social group. It's me, my friend Jessie, she's the same age as me, there is this girl Elizabeth, she's in high school and this girl Alana, she's ah she adopted. She's from Russia. Umm and there's umm, let's see, Sarah, Jenny, another Jenny and umm anyway, we meet every Monday and uh we do a bunch of different stuff."* (Interview 6, lines 204-207).

Melissa was therefore able to interact with others in a controlled environment and seemed to feel a sense of belonging: *"So it's my one thing a week, you know, where I can like you know, you know, do whatever, have fun."* (Interview 6, lines 221-222). Melissa's consulting psychologist confirmed this:

> *"She also has a social skills coach who runs a group with Melissa and her friends from school. They go into the community and engage in social interactive activities. This gives her a wonderful resource and much to look forward to."* (Interview 11, lines 51-53).

From the above excerpts it emerged that the main source of peer support for Lucy, Melissa, Cindy and Kelly was their friends who were also disabled. Although Lucy went to camp with peers who were not all disabled, and although

Huron, her dog (not disabled), helped her, her true friends were disabled young people. It seems then that for my participants peer support which brought about change and facilitated new learning, came from individuals and groups who were not disabled (llike Lucy tying her shoelaces after camp) and peer support which provided companionship and friendship was more likely to come from those who were disabled.

6.3.2.3 Professional community

Within the theme of having access to a professional community, multiple sub-themes emerged, namely diagnosis and medication, therapy, and professionals doubling as mentors.

- **Diagnosis and Medication**

The Webster's New Collegiate Dictionary (1977:313) defines diagnosis as 'the art or act of identifying a disease from its signs and symptoms'. It has been stated that many people with learning difficulties experience failure early in life. Receiving a diagnosis will help the individual to get the necessary help in order to progress. It will also help the individual to understand what her capabilities are (Lachiewicz & Mirrett, 2000:236-237; Willoughby *et al.,* 2003:94-95). The WNCD (1977:714) defines medication as 'something that treats or prevents or alleviates the symptoms of disease'. Brooks and Goldstein (2002b:126) state that 'a pill is not a substitute for an available, caring parent, a set of friends, a competent teacher, or successful life experiences. However it can be effective in reducing symptoms and adverse consequences children face'.

Kelly was only diagnosed with Fragile X Syndrome once she had completed high school. During an interview she stated that eventually getting diagnosed had been positive, due to the fact that she now understood why certain things were difficult and she was then able to take medication:

> *"Okay, umm (sigh) let's see, before I was diagnosed, it would always take me a long time to do my homework. I'd dawdle a lot and just take my time and then as it got later at night I'd get it done. Umm, but after being diagnosed it*

got easier. I mean you were able to, I mean I was able to umm understand why it was so hard and with the right medication it made a difference.... Being on the right medication helped." (Interview 8, lines 23-27; 40).

Melissa, Cindy and Kelly's consulting psychologist also confirmed that the diagnosis and receiving the right medication had helped the girls cope more resiliently:

"Melissa attended a public high school and had the benefit of having a diagnosis before she entered high school." (Interview 11, lines 9-10).

"*Cindy has been medicated for anxiety and mood liability. The medication seems to be effective."* (Interview 12, lines 15-16).

Melissa, Cindy and Kelly's father stated:

"Umm but I do think that umm some of these, some of these medications have helped the kids too. When Cindy got through her educational programme for CNA (Certified Nursing Assistant), umm it took her three times to get through the class. And in the past Cindy would have tried something, failed and really just kind of beat herself up about it. And not gone out and tried again, but she really stuck with this thing. Part of it I think is she started taking a medication called ABILIFY, which has really helped her a lot and umm I would say the last couple of months she has been a little more sensitive than she was a few months earlier. But after she started taking his drug, when she, she used to be so deathly afraid of anybody knowing she was different in any way, he got home, she said, 'Dad you know, I'm trying to get through this class down at the community college. Do you mind calling up the person in the office there and talking about what I've got and how they can help me?' And it was like so night and day different from Cindy, afraid that someone would find out that something was different about her. So, so I think, so I think medications can really help umm get them through, but yeah." (Interview 10, lines 62-77).

As for Lucy, her teacher explained that medication had helped Lucy to perform better academically:

> *"But finally they were convinced to put her on some medication. She was like a different child. She came back in January after she's been on if for about a week or two and you could see the change. She was able to sit. She was calmer. She was focused. So the second half of first grade she started to pick some of the stuff up because now she was able to concentrate." ... "I think once she got medication for the ADHD, that allowed her to sit down and really be able to learn. Up until then we were just, she was not able to sit, she was not able to focus, she was not able to concentrate. She was one of those kids who medication was essential for her to take."* (Interview 5, lines 39-43; 500-503).

Thus it can be seen that being on the right medication helped Kelly, Cindy, Melissa and Lucy to perform better, be it academically and/or socially.

- **Professionals doubling as mentors**

A mentor can be defined as a trusted counsellor or guider (WNCD, 1977:718). When individuals are supported by their community, they get a sense of belonging – mentors and role-models, such as teachers, therapists, and counsellors, can often encourage belonging and positive growth when they form a support system for adolescents (Masten & Reed, 2005:83). If an individual feels supported and part of the community it is easier to ask for help, guidance and support (Masten & Reed, 2005:83; Ungar, 2008b:227).

During an interview with Melissa she frequently spoke of her relationship with her case manager. A case manager can be defined as someone that is assigned to identify resources that will help reduce stress in an individual's life, but also to link these resources so that the needs are met (Ambrosino, Ambrosino, Emeritus & Emeritus, 2008:141). She described her case manager as a friend, a second mother, and someone whom had been very supportive, as illustrated in the three excerpts below:

"Umm, well, I had a case manager, umm who I'm good friends with umm, you know. She's helped me through different situations." (Interview 6, lines 46-47).

Later in the interviewed she further stated: *"Well, my case manager was like a second mom to me."* (Interview 6, line 164). She furthermore said:

"Umm, she picked me up from work once and we went to a Mexican uh restaurant and we uh you know had um we had some tacos or something like that and we got talking and you know you know. I would call her on the phone and you know, and talk and you know, stuff like that, every once in a while. She has been a tremendous help to me." (Interview 6, lines 172-176).

There were other professionals who played a mentoring role: Melissa's father told how fortunate they were to have professionals such as a consulting psychologist who had been supportive and provided professional help and mentorship for their children:

"I mean we've got you know great friends and resources and people like their consulting psychologist you know who helps us out more than she knows." (Interview 10, lines 274-275).

Photo 5.14: Lucy, Melissa, and Cindy together with their consulting psychologist, my sister and I

Another source of mentors was camp counsellors. I noted in my research journal that Lucy had a counsellor at a camp that she attended and that the presense of this counsellor made Lucy feel more at ease about going away to camp:

> *"One of the counsellors who was there knows Lucy and vice versa. She was making jokes with Lucy and has a very positive, outgoing personality. Just what Lucy likes so that should be fun. To me it seemed like she felt much more at ease about going to camp now than before."* (Research Journal – June 9, 2008).

So, professionals such as counsellors, consulting psychologists, and case managers helped Lucy, Kelly, Cindy, and Melissa to cope more resiliently with their challenges by being mentors to them.

6.3.2.4 Enlightened, well-resourced community

This refers to a community having accessible resources available, allowing an individual to feel that she belongs within the community (Schoon, 2006:81). By being socially involved within the community, individuals develop a sense of belonging and security (Wong & Lee, 2005:316). This sense of belonging encourages individuals to navigate towards the community for guidance and support when facing adversity (Boyden & Mann, 2005:7; Schoon, 2006:81; Ungar, 2005:316). According to Murray (2003:22) and Ungar (2008b:227), having an opportunity to access resources in the community has been found to be a potential protective resources.

Lucy's teacher stated that Lucy was well-known in her community, and therefore able to get around more easily: *"Well I think probably that people know her, hopefully or she goes to the same places and you know she has a familiarity with that."* (Interview 3, lines 188-189). The fact that she was well-known in her community allowed her to be more comfortable going out into the community.

Lucy's tutor commented that the community was very supportive of Lucy and her disabilities: *"And you know, because people really do like her. She got, she's got,*

a huge, you know community of support. And when, when she laughs and smiles, she's so engaging." (Interview 5, lines 563-565).

Lucy's mother also commented on what their community had to offer:

> *"We live in a great community. I really think we are very lucky. It's beautiful, it's safe and there is so much that the community offers her. It's kinda quiet and yet there is a lot going on. If she wasn't so scared of going out, you know the anxiety, she could go shopping by herself, she could walk to the store, and also, Lucy is well-known throughout the community. People know her, you know. If it's either from school, or the synagogue. And she is familiar with her surroundings and so that kinda lessens the anxiety about going places cause she already knows the situation.*
>
> *Our community also offers a lot of activities for those with disabilities. They have this programme that you can join if you have a disability and they organise activities for you to do fun things with others. Like bowling, or laser tag or stuff like that. And also, the community is great about providing jobs for those with learning disabilities. You can work at the pharmacy, the grocery store, packing the grocery bags. Lucy actually worked at the library one summer. Umm, she would organise the books. And she also had a job coach with her, to kinda watch and help her. You know so that is great experience for them and they feel a part of the community and as if they are offering something. Lucy is actually talking about finding a job this summer. So it's something she looks forward to and wants to do. It is a positive experience*." (Interview 4, lines 266-283).

Even though Lucy had a lot of anxiety about going out in the community and also a fear of dogs, I noted in my research journal that she took part in the Independence Day Parade:

> *"Lucy took part in 2 parades today for Independence Day. She at first didn't want to go, but with encouragement she decided to go. She did great. She acted like head cheerleader. She shouted really loud and enjoyed handing out stickers. There were a lot of people and a lot of dogs. She handled*

herself really well. There were no incidences with any dogs." (Research Journal – July 4, 2008).

Photo 5.15: Lucy taking part in the Independence Day Parade

I also later noted the following:

"Lucy has to take religious classes at her synagogue in order for her to be confirmed in the Jewish religion. So every Wednesday evening at 6 they have class. She is very excited about going every week. But then a few hours before the class she starts doubting if she should or can go. This is her way of dealing with the anxiety. She has a lot of social anxiety, even though she knows most of the people who will be there. So today Lucy's mom called the Rabbi and asked what can be done to help Lucy, so that she can be confirmed but that will help her to cope with her anxiety. The Rabbi was very supportive and told Lucy's mother that Lucy can do an individual study. He will help her, but she can do it on her own time at home. And if she feels that she would like to come to class at a later stage she's welcome to." (Research Journal – September 28, 2008).

I therefore concluded that even though Lucy had anxiety about many things, she still wanted to take part in community activities, because there she had a sense of belonging. In her case, her community accepted her as an integral part of their neighbourhood and supported her.

- **Accessible resources**

I noted in my research journal how the community had different things to offer persons with different disabilities:

> *"Lucy's mother took us (Lucy, her brother and I) to a place called Lamb's farm today. It is a place that they have created for those with special needs. Adults with special needs work on the farm, either at the restaurant, or in the pet shop, or little souvenir shops. They look after the animals and so forth. It is really nice. These individuals can also live on the farm. There are houses/dorms for them."* (Research Journal – August 21, 2008).

It can therefore be seen that the community offered safe and well-resourced living areas and also created work opportunities for individuals with disabilities, which would be available to Lucy after she completed high school.

Lucy's tutor stated that Lucy lived in a well-established community that offered many resources and opportunities. Although she was ambivalent about the pressure the community placed on youth, she was positive about its resources and safety:

> *"Because they consider this area the North Shore. I think it is very, I mean there is a lot of money. You know, everybody thinks their kid is kinda like... It's just a hard place to be even average. In some ways it's nice, 'cause everything is nice but even think about that with my kids, you know, would I've been better to stay in the city where I was. It's just hard. A lot of people have a lot of things and everybody is doing things and going places. So I think in some ways its good cause there's a lot of opportunities and it is safe... You know, so if she had to go like. If we're gonna start doing this banking thing, you could chat with people and you know she could go and she wouldn't be totally be taken advantage of and she'll be safe. So that's the positive thing."* (Interview 3, lines 192- 201).

I found Lucy's community to be a wealthy and safe community, and this allowed her to be exposed to many opportunities and resources. Due to the fact that it

was a safe community it allowed her to easily access these resources and act independently.

In my research journal I noted that Lucy often went away to camp. Camp is a traditional community-based opportunity for American youth. Camping was a good way for her to make new friends and get to know more people in her community:

> *"Tonight we went to the camp meeting where Lucy got to meet some of the kids that will be going with her to the camp and also the camp organisers and counsellors. All the kids in the group have some sort of disability, but at camp there will also be mainstream kids. She seems excited."* (Research Journal – June 9, 2008).

Photo 5.16: Lucy with her camp counsellors

Another resource available to Lucy was an accessible gym and personal trainer:

> *"Lucy is training with a personal trainer now, every Tuesday. He is trying to help her lose some weight. She has done some amazing things with him. She has balance issues, but she climbs the pull-up machine like somebody who does it every day. According to her trainer that is hard for many people and here she does it so easy. I'm not sure why, but my suspicion is because she wants to impress Justin and some of the other boys who she knows in the gym."* (Research Journal – March 2, 2009).

Being exposed to the gym and having a personal trainer has allowed Lucy to get out into the community more and interact with others. This has also allowed her to improve her physical well-being.

Photo 5.17: Lucy working on her balance with her personal trainer

The parents of the participants also stated that being involved in the Fragile X Community had helped them as a family to feel socially embedded. Lucy's mother stated that becoming part of the Fragile X Community had helped them as a family to deal with the challenges they faced having a child with disabilities and, more importantly, helped them to feel part of a group:

> *"Probably others thought I was the most realistic, umm but a lot of it that was good for us was being involved in the National Fragile X Foundation. And I*

felt that we are lucky that we have a kid with disabilities, that we are able to do that. I think that is a tremendous support thing for anybody that has a kid with a disability, to find some - either if they can find it within the same disability or if it's just within the school district, if there's a parent-teacher, special teacher-parent organisation or something so that you can meet other parents and be able to bounce things off of them and umm you know to just sort of be in a group that way." (Interview 4, lines 151-159).

Photo 5.18: Lucy together with some of the leading researchers in Fragile X Syndrome Movement

Lucy's teacher confirmed this by stating the following:

"So I think them getting involved in the Fragile X movement has helped Lucy all the way to know, to allow people to say it, the disability she has, to say it out loud, to get involved and for other people to become educated about it. And to become more relaxed about her disability." (Interview 5, lines 447-450).

Melissa, Cindy and Kelly's father also spoke about his participation in the National Fragile X Foundation:

"You know, my wife and I have always wanted to ah, kinda do whatever we could to help. And in some ways it's a little bit selfish on our part to spend

time with people like you, because we like to recruit people to the cause I mean, there are, this National Fragile X Foundation that I am on the board and Lucy's parents are on the board for. For the last probably 10 years umm they've give $2500 scholarships out 6/7 a year for umm college age kids to kinda work on a research project for Fragile X and it's like so many of those people who got involved when they were in college in a research project, today are like important researchers in the area of Fragile X, so anyway." (Interview 10, lines 1- 9).

So, participation within the Fragile X Syndrome community allowed Lucy, Kelly, Cindy and Melissa as well as their families to feel embedded within this community. It also allowed them to learn more about the syndrome.

- **Opportunities for employment**

I also noticed that obtaining work helped the participants in my study (Lucy, Kelly, Cindy, and Melissa) to feel socially embedded and therefore to persevere. Kelly's consulting psychologists stated:

"Kelly prides herself on the jobs she has been able to secure and the successes she has had there. Unfortunately, she is best suited to work in smaller, family-owned day care centres and those types of centres are at risk to close down or need to provide less hours to her. That has caused her to have a chequered work record. Recently when she was unemployed and looking for work, she reported being depressed and feeling less confident. She is very good with young children who seem to accept her even with her Fragile X Syndrome. She also feels needed and this is critical to her self-esteem." (Interview 13, lines 70-77).

Melissa, Cindy and Kelly's father also commented on how obtaining a professional job had been a positive experience for the girls:

"*How do we get them in environments where they're gonna be loved and accepted for who they are? And so, I think Melissa's work environment and*

umm where uh, she's formed some of these relationships that's really helped her persevere." (Interview 10, lines 50-53).

Lucy's mother commented how her part-time work at the library helped her grow, as mentioned earlier in this chapter.

Therefore in summary, it is clear to see that protective resources (like supportive schools; peer support; professional community; and enlightened, well-resourced community) within the community have also played an important role in encouraging resilience in the participants in my study.

6.3.3 Cultural Resources

As stated in Chapter Two, culture plays an important part in resilience (O'Dougherty Wright & Masten, 2005:30; Crawford *et al*., 2005:356). Below I will discuss my findings regarding the role that culture played in the resilience of the participants with whom my study was done. One sub-theme emerged, namely religious activities.

6.3.3.1 Religious activities

Religious activities refer to the affiliation with a religious organisation and taking part in activities and gatherings (Ungar, 2008b:227). Religious beliefs and practices are important components of almost all cultures (Peres *et al.*, 2007:346). Religious frameworks are practices that may have an important influence on how people interpret and cope with traumatic events (Boyden & Mann, 2005:8; Peres *et al.*, 2007:347).

During an interview with Kelly she described how she, together with her school, would go to church and pray. Kelly attended a Catholic school and this was an activity they did on a weekly basis: "*I went to Catholic school. You know, they would, there would be mass once a week where we'll pray*." (Interview 8, lines 113-115).

This was also confirmed by Kelly's consulting psychologist. She furthermore stated that Kelly's strong belief system helped Kelly to cope with difficult experiences: "*She has a strong faith and prays regularly, asking God for help and*

guidance in her life." (Interview 13, lines 41-42). Kelly furthermore stated that she also believed in God and heaven: "*I mean, I believe in God, I go to church but not as often as I should. I believe in heaven. That we'll all go there when we pass on."* (Interview 8, lines 112-113).

During an interview with Melissa she stated the following:

> *"You know there are some church songs that I like, like the Christmas songs. Umm like 'On eagles' wings'. O love that song, umm, 'joyful joyful we adore Thee'. You know it's kinda like it, the song they make it like a picture of heaven, you know."* (Interview 6, lines 265-268).

I concluded that both Kelly and Melissa found it comforting to know that there is a heaven, and that they'll be going to heaven after death.

Lucy's mother spoke of how Lucy enjoyed taking part in Jewish activities, such as songs and prayers: *"Whenever we celebrate the Jewish holidays, she just loves to participate. She knows all the prayers and songs in Hebrew and English."* (Interview 4, lines 301-302). She also stated that Lucy took part in different activities at the family's synagogue, such as camps and religious classes: *"She feels accepted and loved there. She goes on camps with the temple. She is now busy with her confirmation classes. She loves taking part in that."* (Interview 4, lines 304-306).

Lucy's teacher also spoke about Lucy attending religious camps and classes:

> *"Yeah, the synagogue has made her part of their community. She's in their Religious Ed class. She's in the confirmation class there. She goes to their camps. Umm, attends the weekend camp. Last year she went to a camp and I remembered being shocked. And Lucy's mother was shocked that she went."* (Interview 5, lines 553-556).

On another occasion, Lucy's tutor stated that there is a sense of family within the Jewish culture (Lucy's family are reformed Jews):

> *"I have other clients that are Jewish too. I think it's a very - I think there's a real sense of family within the Jewish culture. That I don't see as much in other cultures maybe."* (Interview 3, lines 210-213).

Lucy's mother also confirmed that Lucy has been accepted and loved at the family's temple: *"She also enjoys going to the synagogue. We have a great rabbi. They all really accept and love her at the temple. She feels accepted and loved there."* (Interview 4, lines 303-304).

I also noted the following in my research journal:

> "*Lucy's family have a great synagogue. All the kids Lucy's age are being confirmed. They have class every Wednesday evening. The Rabbi has given Lucy the opportunity to either come to class with the other kids, or to do a individual study at home in order to finish the requirements and then be confirmed*." (Research Journal – July 8, 2009).

Later in my research journal I noted:

> "*Tonight was Lucy's confirmation night. We all went to their synagogue - her parents, grandparents, uncle and aunt. Lucy had to read a piece that was expected from her. And she did GREAT!! No mistakes. Unbelievable! She did so, so well. It was awesome! I'm so proud of her! You wouldn't have known that she had any disability. The synagogue has also been great. They organised that the kids all walk into the synagogue with a friend. This was great because Lucy was able to hold onto somebody when they walked up the stairs. (Lucy was the only one with significant disabilities)*." (Research Journal - July 17, 2009).

Photo 5.19: Lucy at her confirmation ceremony

Lucy being so involved in religious activities and gatherings helped her to develop a sense of belonging in the synagogue community. A sense of belonging refers to feeling that you are a part of something outside of your family and school environment (Ungar, 2008b:227). Being part of religious organisations gives adolescents a sense of belonging. It encourages cultural awareness which enables them to have an understanding and interest in other cultures and ultimately leads to the respecting of other beliefs (Ungar, 2008b:227; Ungar & Liebenberg, 2005:218).

Melissa, Cindy and Kelly's mother also stated during an interview that their family celebrated Christmas and Easter, and the girls attended services, and therefore saw this as part of their culture: "*Easter and Christmas and stuff they do*." (Interview 9, line 159).

Lucy's mother spoke in a similar vein:

> *"We celebrate the holidays together as a family. All the traditions, you know, like Passover. We get together as a family and friends and have dinner together and read the Torah parts. Everybody gets a turn to read. It is just a great time to get together and celebrate. I think, umm, I think it's just fun and she really, really enjoys it."* (Interview 4, lines 314-318).

Photo 5.20: Lucy lighting a candle during a Hanukah ceremony

I noted the following in my research journal:

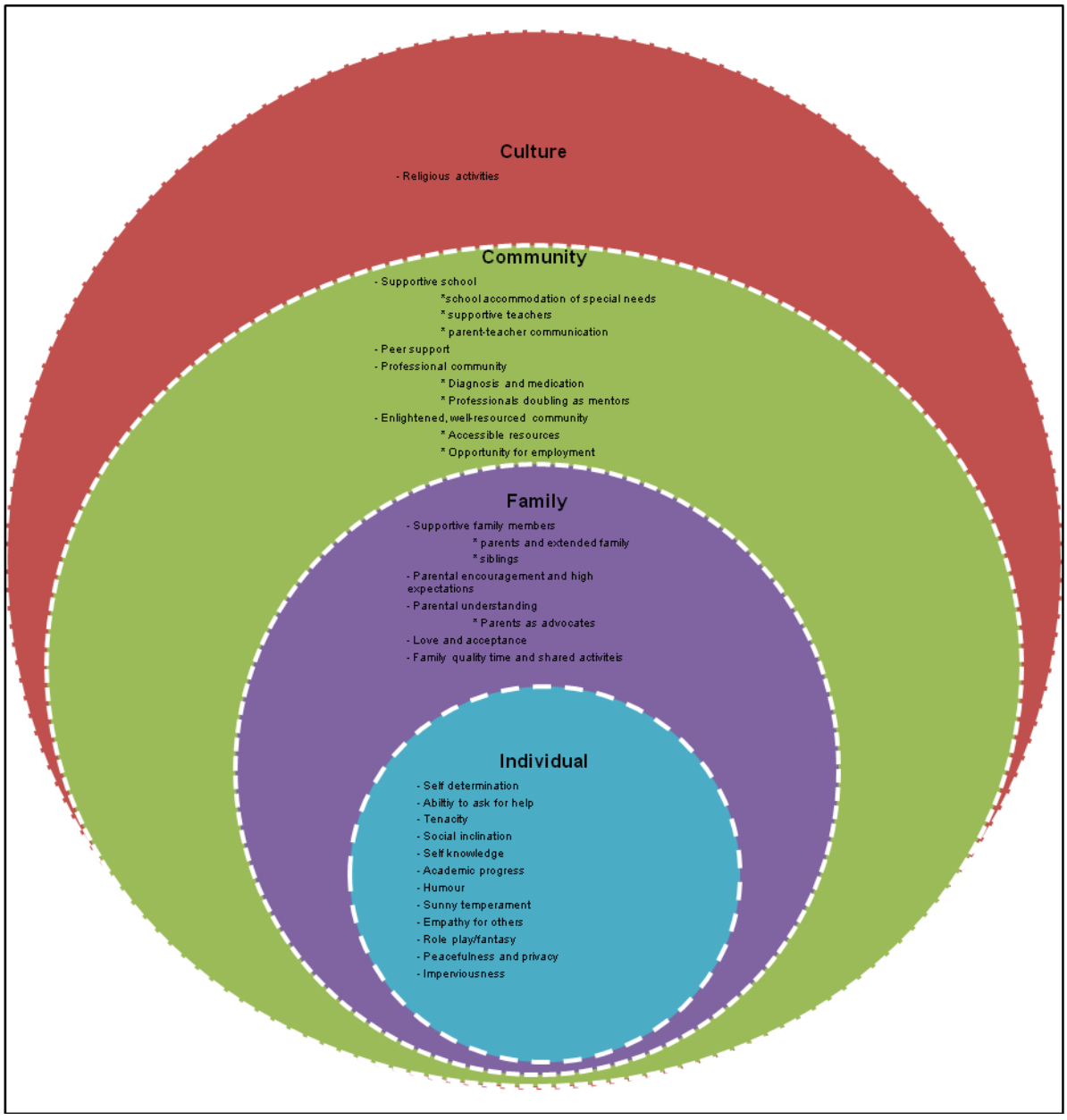
"Lucy's family on her dad's side are very close. They always get together for Jewish holidays and birthdays and accomplishments. Tonight we went to Lucy's grandfather and grandmother's house for the holidays. We all sat around two big tables. Lucy's father's side of the family were all there. Kids and everything. It was very interesting. They all had a time to read a portion that Lucy's father and brother prepared (they rewrote a part of the Torah). Every person who was there had the opportunity to read a piece. And so did Lucy. Oh she loves it! She is so proud to be Jewish. And every time there was a prayer (often in Hebrew) she said it out loud with her dad. This was very impressive. It is clear that she has done this for a couple of years now and that she takes pride in it. This was a great experience. And once again I realise how much potential this young lady has." (Research Journal – May 26, 2008).

It can therefore be seen that taking part in religious and cultural activities allowed Lucy, Kelly, Cindy and Melissa to learn about their culture and religions and consequently they were able to join organisations within the community and develop a sense of belonging within these organisations.

6.4 DISCUSSION OF FINDINGS

A review of my findings reveals that resilience in my female participants with Fragile X Syndrome was encouraged by intra- and interpersonal resources (*Cf*. Figure 5.2 below). The intrapersonal themes include individual protective resources and the interpersonal themes include familial, community and cultural protective resources, as summarised in Figure 5.2 below:

Figure 5.2: Summary of findings



A review of current literature on resilience indicates that these intrapersonal and interpersonal themes (*Cf*. Figure 5.2) are well-known. Studies with resilient youth in other contexts of risk have shown that the following intrapersonal themes encourage resilience in youth who are at risk:

According to a study by Murray (2003:23), (specifically disabled youth) and Thomas and Menamparampil (2005:336) (specifically youth affected by violence), **self-determination** is seen as one of the most promising protective resources that can affect resilience. Lewis (1990:277-297) and Showers and Boyce (2008:521-534) reported that **self-knowledge** has also been found to encourage resilience in youth in general. Likewise, the **ability to ask for help** – this is supported by the work of Ungar (2008b:227) and also Theron (2004:319) (specifically youth with learning difficulties). In previous studies with at-risk youth (specifically adolescents with learning difficulties [Theron, 2004:319; Theron, 2008:217]) **tenacity** was reported to encourage resilience. **Imperviousness** has been noted to help youth to withstand and rebound from adversities, as noted by Luthar and Cicchetti (2000:857-858).

In a previous study with at-risk youth (specifically disabled youth [Murray, 2003:23]), an **easy and outgoing temperament** was also reported to support resilience. My findings correlate with Raatma and Murphy (2000:5), who report that **peacefulness and privacy** help promote resilience in individuals faced with difficult circumstances. In a study by Ungar (2008b:227) (specifically among youth with exposure to community violence, institutionalisation, mental health problems [depression, violence, drug abuse], social dislocation [immigration or forced migration], homelessness, poverty, exposure to political turmoil, and war), **humour** was found to encourage resilience. Demonstrating **empathy for others** as a source of resilience is further supported by the work of Ungar (2008b:227).

As stated in my findings, the participants in my study also demonstrated a **desire to socialise**. This motivated them to form relationships with others, and thus become more socially competent. This finding corroborates studies by Murray (2003:23) (specifically disabled youth), and Theron (2004:319) (specifically

adolescents with learning difficulties), that indicate that youth who are socially competent and able to develop and sustain relationships with others are more likely to have resilient outcomes when faced with adversity.

Role-play (i.e. the capacity to indulge in fantasy) was also reported as a protective resource by Morales (2008:8), (specifically learners in early childhood education). Finally, even though the primary participants in my study had some cognitive difficulties, they still made clear **academic progress**. Studies (specifically with disabled youth [Murray, 2003:23; Oliver *et al*., (2006:4]) have reported that working towards improving the cognitive and academic abilities of youth with disabilities can affect their long-term outcomes positively and are therefore seen as a resilience-promoting resource.

In other words, the above shows that the intrapersonal resilience-promoting resources noted in my study were reported in previous resilience studies with cohort of youth placed at risk by circumstances other than Fragile X Syndrome. The one possible difference may relate to imperviousness. It is possible that my participants' capacity not to be negatively affected by social taunts, related to the barriers of their disability. In this sense, their disability ironically offered some protection.

The same (i.e. previous documentation) is true of interpersonal resources: **Supportive family members** were reported to encourage resilience, as found by Thomas and Menamparampil (2005:334) (specifically youth affected by violence); and Bernard and Este (2005:444-445) (specifically young African-Canadian males affected by racism). This finding is also supported by Murray (2003:23) (specifically disabled youth) and Ungar (2008b:227) (specifically among youth exposed to community violence, institutionalisation, mental health problems [depression, violence, drug abuse], social dislocation [immigration or forced migration], homelessness, poverty, exposure to political turmoil, and war).

Parental encouragement and high expectations from parents were also reported to be protective resources that encouraged resilience as reported by Ungar and Liebenberg (2005:218) and Ungar *et al.,* (2008:1-2) (specifically in

youth who experienced family breakdown, poverty, cultural disintegration, multiple relocations, being a child in care, drug and alcohol addictions, discrimination based on race, gender, or sexual orientation, and mental illness, their own or that of their parents).

Furthermore, **parental understanding** as protective resources is supported by the work of Fergusson and Zimmerman (2005:399-419) (specifically relating to substance use, violent behaviour and sexual risk behaviour in adolescents). Families demonstrating **love and acceptance** is a theme that correlates with findings from Ungar and Liebenberg (2005:218) (youth from different cultures placed at risk by personal and environmental risks). Lastly, within the family, **quality time and shared activities** were found to be another protective resource previously reported by Fergusson and Lynskey (1996:289) (adolescents experiencing family adversity) and Kim-Cohen (2007:277).

In previous studies with at-risk youth, protective resources within the community were also reported to encourage resilience. These included **supportive schools** (Johnson & Lazarus, 2008:29); **peer support** (Boyden & Mann, 2005:8 [specifically among adolescents faced with poverty, armed conflict, forced migration, family problems, environmental degradation and exploitation]; Van Teefelen, Bitar and Al-Habash, 2005:429 [specifically youth affected by psychological stressors]); **professional community** (Bernard & Este, 2005:449 [youth affected by racism]; Boyden & Mann, 2005:8; [specifically among adolescents faced with poverty, armed conflict, forced migration, family problems, environmental degradation and exploitation]; and Willoughby *et al.,* 2003:94-95 [individuals faced with disabilities]); and an **enlightened, well-resourced community** (Ungar, 2008b:227) (specifically among youth exposed to community violence, institutionalisation, mental health problems [depression, violence, drug abuse], social dislocation [immigration or forced migration], homelessness, poverty, exposure to political turmoil, and war).

Previous studies have also reported that faith and religion encourage resilience (Thomas & Menamparampil, 2005:334-335 [specifically youth affected by

violence]). **Activities within their religion** (Boyden & Mann, 2005:8 [specifically among adolescents faced with poverty, armed conflict, forced migration, family problems, environmental degradation and exploitation]; Peres *et al.*, 2007:347 [specifically trauma victims]) have been found to create a sense of belonging for individuals.

In summary, my findings have mostly been noted in previous studies. However, when I review literature on Fragile X Syndrome, my study makes a contribution to theory because even though the themes that emerged in my study have been connected to resilience in general, these themes can now be linked directly to resilience in females with Fragile X Syndrome. A few studies with females with Fragile X Syndrome have reported positive traits (Braden, 2002:445; Hagerman, 2000:24; Harris-Schmidt & Fast, 2004:80), but these were not explicitly linked to resilience. My contribution therefore lies in the fact that I have identified that resources traditionally associated with resilience characterised my participants (i.e. females with Fragile X Syndrome) as well. Historically, females with Fragile X Syndrome were considered vulnerable (Abbeduto *et al.,* 2007:37; Dahl, Goonewardena, Malmgren, Gustavson, Holmgren, Seemanova, Anneren, Flood & Pettersson, 1989:304-309; Orloff, 2008:67). My study therefore transforms (Mertens, 2009) this stereotype and in so doing encourages communities, educators and parents to work together with individuals who have Fragile X Syndrome to encourage their resilience.

A further contribution lies therein that my findings support more recent understandings of resilience as an ecosystemically embedded phenomenon that is encouraged by young people navigating towards resilience-promoting resources and by the ecologies of these young people responding and supporting these efforts (Ungar *et al*., 2008:2) My findings illustrate that in females with Fragile X Syndrome, resilience is nurtured by individual resources (i.e. self-determination; ability to ask for help; tenacity; social inclination; academic progress; humour; sunny temperament; empathy for others; role play/fantasy; peacefulness and privacy; imperviousness), familial resources (i.e. supportive family members; parental encouragement and high expectations;

parental understanding; love and acceptance; family quality time and shared activities), community resources (i.e. supportive school; peer support; professional community; enlightened, well-resourced community), and cultural resources (i.e. religious activities).

All of these resources contributed to my participants' resilience, rather than only one of them. This fits into a more recent understanding of resilience as ecosystemic (Lerner, 2006:40; Ungar *et al*., 2008:2). For example, Lucy's honesty with her parents about her difficulty with science gave her mother the opportunity to assist her, but at the same time her mother and her teacher were willing to respond to Lucy's predicament. Her resilience was encouraged by her own resources which enabled her to speak up and by familial and community resources. There are other similar examples. Cindy didn't like anybody to know that she was different. Once she started taking the right medication she was able to tell her father that she was having a hard time in class and suggested that he call someone at the school to assist her with extra help. So, her resilience was encouraged by receiving the right medication, her own resources which then enabled her to speak up and by familial and community resources - her pathway to resilience was a collaborative effort, as in the case with Lucy above.

Another example relates to a time where Kelly showed empathy for her sister. Her sister enjoyed going out after work and didn't always let her family know. One night Kelly called up her father to tell him that her sister wasn't home yet. Her father was then able to reassure her and to seek help to go look for her sister. Again Kelly's resilience was encouraged by her empathy for others and her ability to ask for help, and also by familial and community resources.

Because my findings support the idea that resilience is not linked to either inter- or intrapersonal resources, but needs both the individual and her ecology to work together towards encouraging resilience (Ungar, 2008a:22-23), I purposefully used fragmented lines in Figure 5.2 to illustrate that resilience is nurtured by this bi-directional, ecologically embedded transactions (Lerner, 2006:40).

Finally, my findings make a contribution to theory because they refine how one of the previously noted protective resources work for females with Fragile X Syndrome. In this regard, I refer to peer support. Although reported previously as a resilience-promoting resource, I found that my Fragile X Syndrome participants' main source of support was from peers who were also disabled. Previous studies have not specified that peer support comes from peers with similar difficulties. This refinement can therefore be seen as a contribution to the theory of what encourages resilience in females with Fragile X Syndrome.

6.5 RECOMMENDATIONS

The above findings are also valuable because they can potentially inform how families and communities can enable females with Fragile X Syndrome to be resilient.

6.5.1 Recommendations for families

Families can enable females with Fragile X Syndrome to be more resilient by being supportive and encouraging (Donnon & Hammond, 2007:452; Ungar & Liebenberg, 2005:218). Even though individuals with Fragile X Syndrome can struggle to express their feelings (Bennetto & Pennington, 2002:233; Hagerman, 2000:18; Scharfenaker, 2004:6), parents should be patient and encourage the female to state her strengths, weaknesses and needs. When she does so, be willing to listen and then seek appropriate help if needed. Parents need to have realistically high expectations for the female with Fragile X Syndrome (Donnon & Hammond, 2007:452; Ungar & Liebenberg, 2005:218).

Parents and families can also help a female with Fragile X Syndrome socially. Spend quality time together as a family and include family activities (Fergusson & Lynskey, 1996:289; Kim-Cohen, 2007:277). This is a good time for the female with Fragile X Syndrome to interact with her family and also to learn social skills. Encourage her to socialise with peers, even if a parent has to be the facilitator.

Most importantly, make her feel loved and accepted as part of the family (Ungar & Liebenberg, 2005:219).

Also ensure that she takes part in religious and cultural activities, such as religious organisations (Boyden & Mann, 2005:8; Ungar, 2008b:227).

Educate the family about Fragile X Syndrome so that they can be more supportive and understanding. Also, be advocates for the female with Fragile X Syndrome when necessary. In other words, be willing to seek help on her behalf. In this regard, the examples of Lucy's, Melissa's, Cindy's and Kelly's parents who were actively involved in the Fragile X community and who went out of their way to educate their extended family and community can be used as a powerful incentive of what parents can do in this regard.

Allow the female with Fragile X Syndrome to take part in role play and fantasy (Ginsburg & Jablow, 2006:63; 160; Morales, 2008:8). When sensing her anxiety, allow her to remove herself from the setting for a while to allow the anxiety to abate.

It is also important to realise that the female with Fragile X Syndrome might not reach the academic standard of a female in mainstream. However, concentrate on making progress. Set goals that she should be able to work towards, but that will also ensure success (Winslow *et al.,* 2005:338).

6.5.2 Recommendations for communities

Communities can enable females with Fragile X Syndrome to be more resilient by ensuring that schools are supportive (Johnson & Lazarus, 2008:19-20; Schoon, 2006:14), and that professional help and resources are available (Masten & Reed, 2005:83; McMurray *et al.,* 2008:302).

Schools can be supportive by ensuring that they can accommodate the requirements of children with special needs. These accommodations could include special needs teachers, extra classes, resources centres within the school, and individual education programmes.

The professional community also plays a role in the resilience of the female with Fragile X Syndrome. It is important that the female receive the correct diagnosis and therefore the right medication. Also, by receiving the correct diagnosis, the female with Fragile X Syndrome will be able to receive the correct therapy, such as occupational therapy. Mentors within the community can also be resources that will enable resilience in the female with Fragile X Syndrome. Mentors such as case managers, one-on-one teachers, social workers and job coaches have been found to be an asset in these females' lives.

The above recommendations might be easier in the American context as schools there are well-resourced. Actions can be taken by schools to promote a well-resourced school, as stated by Donald, Lazarus and Lolwana (2007:128-129). With specific reference to girls with Fragile X Syndrome (or similar disabilities) this might include:

- The school should create and promote a supportive, non-discriminatory culture, so that the commitment to support individuals with disability towards resilience is clearly reflected.
- There should be a sense of ownership, belonging and control between members of the school, which in turn will elevate development within themselves.
- The school should set goals for its curriculum development strategies that reflect the vision and values to support individuals with disabilities.
- The curriculum needs to be evaluated to review the effectiveness of the school's practices in promoting well-being, competence, and confidence in all students with disabilities.
- In order for the school to be well-resourced and supportive of students with disabilities, management and leaders in the school should organise relevant technical support (i.e. learning support), set appropriately inclusive structures and procedures in place, and model and facilitate school practices that are inclusive and supportive. It would be so

beneficial if schools in South Africa could include resources like those referred to by my participants (e.g. individual educational programmes, special programmes (like Students with Disabilities), case managers and learning resources centres).

- The school needs to empower all members of the school community and encourage active, non-discriminatory participation to support students with disabilities.
- Members of the school community also need to engage within their social context in order to promote supportive strategies for students with disabilities.

Teachers can also enable females with Fragile X Syndrome to be more resilient by being supportive. This means understanding the female's abilities as well as disabilities, thereby catering for and facilitating her needs. Parent-teacher communication is also important.

Communities should also ensure that they have resources available for females with Fragile X Syndrome. These could include recreation centres, cultural organisations or institutes, camps, social activities (organised by the community), and opportunities for employment.

6.5.3 Interactivity of resources

It is important for families and communities to remember that they must encourage females with Fragile X Syndrome to develop personal resources that will encourage them to navigate towards and negotiate for resilience-promoting resources. At the same time, families and communities also need to make resources available (Donald *et al*., 2007:131; Ungar *et al.,* 2008:1).

Families should encourage females diagnosed with Fragile X Syndrome to state their strengths, weaknesses and needs (as stated in 5.3.1). This will allow their families to then be aware of their needs and make negotiation for resources possible. At the same time resources within the community should be available in order for the females diagnosed with Fragile X Syndrome to navigate towards

these resilience-promoting resources, such as therapy or medication. In other words, the recommendations provided must be integrated. For example:

Families can encourage females with Fragile X Syndrome to set goals (as stated in 5.3.1). These goals could refer to academic goals. However, it is important to remember that goals can only be reached if they are clearly set out by the parents and school. Furthermore, the school should be supportive and provide the necessary resources (such as special education teachers) to help the individuals succeed. The school needs to bbe backed up by professionals and researchers in the community. Regular conferences (like the one illustrated in my video data) that includes individuals with Fragile X Syndrome, their parents, teachers and therapists are important to enable all stakeholders.

In summary, as illustrated in the cases of Lucy, Melissa, Cindy and Kelly, resilience in the face of Fragile X Syndrome can be encouraged when families, communities (professionals, residents, teachers, peers, employers, religious leaders), community structures (schools, religious organisations) and the individual with Fragile X Syndrome collaborate. Thus, the chief recommendation flowing from my findings is that families and communities must work with females with Fragile X Syndrome in practical, ongoing ways to encourage resilience.

6.6 CONCLUSION

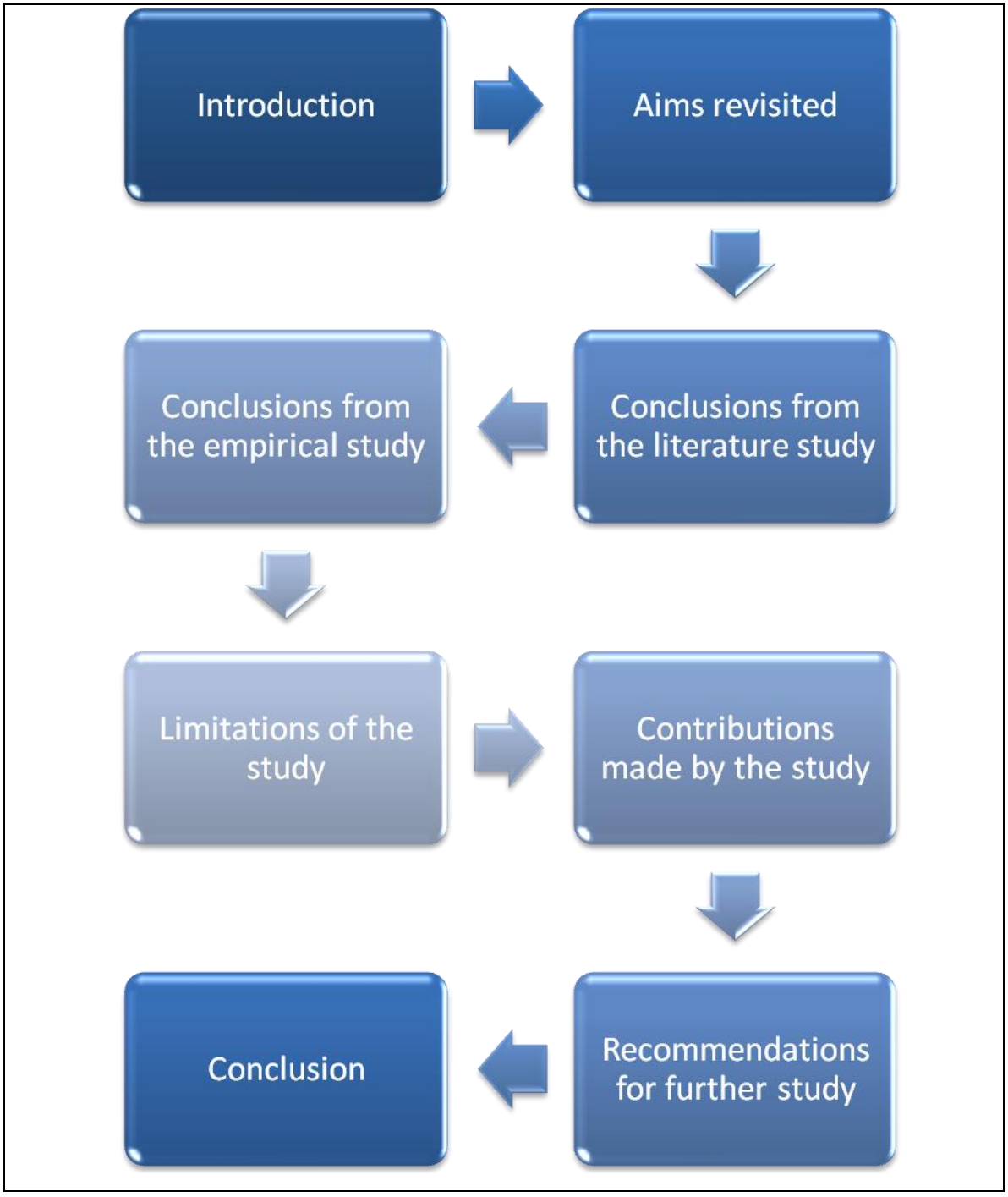
The value of the above findings lies in the fact that we can and should see females with Fragile X Syndrome in a more positive light. I focused on what resources help encourage resilience in the lives of the selected participants. Even though they might face numerous difficulties in their everyday lives, there are multiple resources that can be concentrated on and facilitated in order to help females diagnosed with Fragile X Syndrome cope resiliently with their struggles. Concentrating on and facilitating these protective resources in their lives can thus help other females with Fragile X Syndrome to become more resilient individuals who experience success and positive outcomes.

In the next chapter I will summarise the literature and empirical study, state the limitations of my study and provide recommendations for further study.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

Figure 6.1: Overview of Chapter Six



7.1 INTRODUCTION

The problem that I investigated in this study was: What factors contribute to resilience in females diagnosed with Fragile X Syndrome? Through my experience as a live-in carer for a female with Fragile X Syndrome, I found it interesting that she always had a sense of humour and self-determination (often associated with resilience), even though she faced so many adversities because of her disabilities. Her family and teachers also described her as resilient. This made me curious to explore what encouraged females with Fragile X Syndrome to cope resiliently. I then conducted a literature and empirical study to explore the antecedents that promote resilience in females diagnosed with Fragile X Syndrome. The literature study and empirical study undertaken, are summarised below. I also realised that my study had limitations. In this chapter I therefore also state these limitations and make recommendations for further study.

7.2 AIMS REVISITED

The aim of my study was to explore what contributes to resilience in females diagnosed with Fragile X Syndrome. In order to determine if my aim was reached or not, I revisited my sub-aims. Table 6.1 summarises the aims of my study, and also states whether or not my aims were achieved.

Table 6.1: Aims governing this study

Aims	Achievement
A literature study on resilience.	A thorough literature study was conducted to give relevant information on the phenomenon of resilience, in order to clarify all that is incorporated in the process and outcome of resilience. This literature study was documented

	in Chapter Two.
A literature study on Fragile X Syndrome.	A thorough literature study was conducted to give relevant information on the impact of Fragile X Syndrome on females. This literature study was documented in Chapter Three.
An empirical study to determine what might encourage resilience in females diagnosed with Fragile X Syndrome.	I observed and recorded my observations in a research journal. I also conducted informal interviews and collected visual data (such as photographs and video clips). I realised that one primary participant was not enough to determine what might encourage resilience in females diagnosed with Fragile X Syndrome. An Advisory Panel then identified three other primary participants as resilient, in order to determine what protective resources were contributing to their resilience. I also interviewed the three participants, made observations and collected visual data. The study also included secondary participants, these being the primary participants' involved adults (teachers, tutors, consulting psychologists and parents). I also

	conducted interviews with the secondary participants to gain a better understanding of the primary participants' ability to cope resiliently in the midst of adversity. The interviews from the primary participants and their involved adults were coded using a process of inductive content analysis to identify the antecedents of the participants' resilience. The coding was influenced by current resilience theories. I also coded my observations, notes in my research journal and visual data that had been collected, and used it in triangulation with the interviews. The emerging findings were documented in Chapter Five. These findings summarise what appeared to encourage resilience among my participants.
Providing recommendations for parents, and communities to encourage resilient functioning among females diagnosed with Fragile X Syndrome.	Based on the findings of my study, I provide guidelines to communities and parents on how they can help females diagnosed with Fragile X Syndrome to cope more resiliently with the adversities they face. These guidelines are documented in Chapter Five (see 5.5).

Table 6.1 clearly shows that the aims of my study were achieved. Therefore, if my sub-aims were achieved, my aim to explore what contributes to resilience in females diagnosed with Fragile X Syndrome was also achieved.

7.3 CONCLUSIONS FROM THE LITERATURE STUDY

The literature study was documented in Chapter Two and Chapter Three. Chapter Two focused on the nature of resilience and Chapter Three focused on the phenomenon of females diagnosed with Fragile X Syndrome and the impact of this syndrome on the individuals' lives.

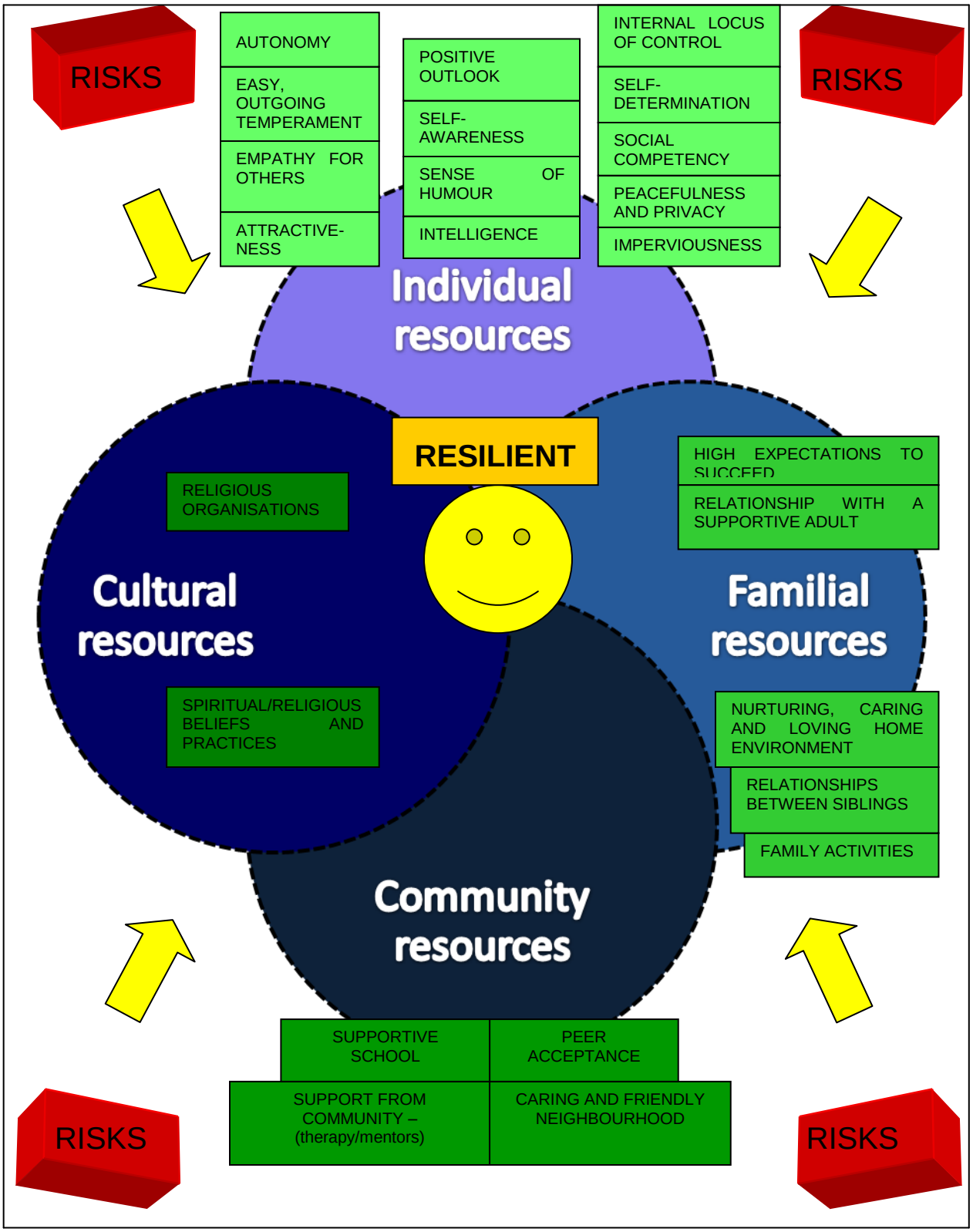
7.3.1 The nature of resilience

Resilience can be defined as a dynamic process, characterised by good outcomes in the midst of serious threats to development (Luthar *et al.,* 2000:543; Masten, 2001:228; Masten & Reed, 2005:77; Schoon & Bynner, 2003:22).

Throughout the literature study various protective resources (found in the individual, her family, community and culture) were identified that can assist individuals in coping resiliently with adversities they might face. In summary, resilience is seen as a dynamic, positive developmental process between individuals, their environments, culture, psychological and physiological processes (Benard, 1999:270; Boyden & Mann, 2005:9; Cameron *et al.*, 2007:285; Evans and Prilleltensky, 2005:407; Hjemdal, 2007:306; Kim-Cohen, 2007:272; Koller & Lisboa, 2007:342; Lee & Tay-Koay, 2008:241; Schoon, 2006:6; Siqueira & Diaz, 2004:150; Ungar, 2005:xxviii). These processes are encouraged by the interaction of resources within the individual's ecosystem and so resilience can be described as an ecologically embedded bi-directional process (Lerner, 2006:40). In other words, to be resilient an individual under stress should be able and willing to access health promoting resources and functions in an ecology that makes such resources available (Cameron *et al.,* 2007:288). I purposefully used fragmented lines in Figure 6.2 below to illustrate that resilience is nurtured by this bi-directional, ecologically embedded

transactions (Lerner, 2006: 40). In Figure 6.2 I graphically summarise the resources that contribute to resilience.

Figure 6.2: Resilience depends on interaction between inter- and intrapersonal resources



7.3.2 Fragile X Syndrome from a risk perspective

Risks can be defined as the internal (intrapersonal) and external (interpersonal) characteristics, traits and experiences that increase the likelihood that individuals will manifest negative or non-resilient developmental outcomes (Armstrong *et al.,* 2005:276; Boyden & Mann, 2005:6; Mash & Wolfe, 2005:17; Masten & Powell, 2003:7; Murray, 2003:21; Schoon, 2006:5; Seidman & Pedersen, 2003:318; Theron, 2006:201; Theron, 2008:216).

Numerous intrapersonal and interpersonal risk factors that threaten resilient outcomes can be identified. However, my study focused on the risks inherent to Fragile X Syndrome. Intrapersonal risk factors associated with Fragile X Syndrome include antisocial behaviour, intellectual development disabilities, behaviour and emotional problems, physical problems, speech and language development issues and sensory integration issues (Harris-Schmidt & Fast, 2004:19). Possible interpersonal risk factors associated with Fragile X Syndrome - include poor parental supervision, poor family attachment, inadequate schools, peer rejection, community instability and low community attachment (Kim-Cohen, 2007:272; Siquiera & Diaz, 2006:150; Thomilson, 2004:384-387).

As mentioned in Chapter Two, for resilience to occur an individual needs to be at-risk. In other words, an individual cannot be resilient if she has not experienced any risk (Armstrong *et al.,* 2005:275; Luthar *et al.,* 2000:543; Oswald *et al.*, 2003:50; Vanderbijl-Adriance & Shaw, 2008:31). My review of the many risks associated with Fragile X Syndrome allowed me to conclude that a diagnosis of Fragile X Syndrome would place the individual at risk for non-resilient outcomes.

7.4 CONCLUSIONS FROM THE EMPIRICAL STUDY

My study consisted of four cases, that is, I followed a multiple case study design (Merriam, 1998:40). I made use of semi-structured interviews (Merriam, 1998:75) and observations (Leedy & Ormrod, 2005:145; Merriam, 1998:94-96;

Nieuwenhuis, 2007b:84) when collecting data from Melissa, Cindy and Kelly (Participants 2, 3 and 4). I was also able to collect visual data, such as photographs and video clips (Bogdan & Biklen, 2007:141). With Lucy (Participant 1) I also made use of semi-structured interviews (Merriam, 1998:75) and observations (Leedy & Ormrod, 2005:145; Merriam, 1998:94-96; Nieuwenhuis, 2007b:84). However, with Lucy the observations I made were recorded in a research journal, due to the fact that I was able to observe her most days (as I was a live-in carer for her) (Richardson, 2000:941). I also collected visual data (Bogdan & Biklen, 2007:141) such as photographs and video clips of Lucy. The secondary participants (parents, teachers, tutors, and consulting psychologists) were also interviewed and again I made use of semi-structured interviews (Merriam, 1998:75).

The data that were collected focused on understanding the antecedents of the resilient functioning of my participants, all of whom were diagnosed with Fragile X Syndrome. I used inductive qualitative analysis to analyse my data (Henning *et al.,* 2004:104-109; Leedy & Ormrod, 2005:32; Lincoln & Guba, 1985:202; Maree & Van der Westhuizen, 2007:37; Nieuwenhuis, 2007c:99 & 107). This enabled me to suggest that my participants' resilience was encouraged by individual, familial, community and cultural protective resources. Table 6.2 summarises the individual protective processes that were identified as antecedents of resilience.

Table 6.2: Summary individual protective processes of empirical study

Protective Individual Processes	More than 2 participants	Previous resilience studies	Previous FXS studies	Not noted in previous resilience studies	Not noted in previous FXS studies
Self-determination	☺	☺	☺		
Ability to ask for help	☺	☺			☺

Protective Individual Processes	More than 2 participants	Previous resilience studies	Previous FXS studies	Not noted in previous resilience studies	Not noted in previous FXS studies
Tenacity	☺	☺			☺
Social inclination	☺	☺	☺		
Self-knowledge	☺	☺			☺
Academic progress	☺	☺	☺		
Humour	☺	☺	☺		
Sunny temperament	☺	☺	☺		
Empathy for others	☺	☺	☺		
Role-play/fantasy	☺	☺	☺		
Peacefulness and privacy	☺	☺	☺		
Imperviousness	☺	☺			☺

As Table 6.2 illustrates, the individual protective processes that were identified in my empirical study were reported in previous studies. Even literature on Fragile X Syndrome reported that individuals diagnosed with Fragile X Syndrome have many of these characteristics. However, resilience and Fragile X Syndrome have never been overtly connected. In this sense, I make a contribution to theory in showing that typical resilience-promoting resources are true for the Fragile X Syndrome participants in my study (*Cf*. 5.4)

Table 6.3 summarises the familial protective processes that were identified as antecedents of resilience.

Table 6.3: Summary of familial protective resources of empirical study

Protective Familial Resources	More than 2 participants	Previous resilience studies	Previous FXS studies	Not noted in previous resilience studies	Not noted in previous FXS studies
Supportive family members • Parents and extended family • Siblings	☺ ☺	☺ ☺			☺ ☺
Parental encouragement and high expectations	☺	☺			☺
Parental understanding • Parents as advocates	☺	☺			☺
Love and acceptance	☺	☺			☺
Family quality time and shared activities	☺	☺			☺

Even though all the familial protective resources that emerged in my empirical study were noted in previous resilience studies, none of these protective factors were related to resilience in females diagnosed with Fragile X Syndrome. Again, my contribution lies in the fact that I found that typical resilience-promoting resources are also true for the Fragile X Syndrome participants in my study (*Cf*. 5.4)

Table 6.4 summarises the community protective processes that were identified as antecedents of resilience.

Table 6.4: Summary of community protective resources of empirical study

Protective Community resources	More than 2 participants	Previous resilience studies	Previous FXS studies	Not noted in previous resilience studies	Not noted in previous FXS studies
Supportive school: • School accommodation of special needs • Supportive teachers • Parent teacher communication	☺ ☺ ☺	☺ ☺ ☺	☺ ☺		☺
Peer support	☺	☺			☺
Professional community: • Diagnosis and medication • Professionals doubling as mentors	☺ ☺	☺ ☺	☺		☺
Enlightened, well-resourced community: • Accessible resources • Opportunities for	☺ ☺	☺ ☺	☺		☺

employment					

As stated in Chapter Five, peer support was noted in previous resilience studies. However, I found that the main source of peer support for the Fragile X Syndrome participants in my study were peers who were also disabled, and this can therefore be seen as a contribution to theory.

Table 6.5 summarises the cultural protective processes that were identified as antecedents of resilience.

Table 6.5: Summary of cultural protective resources of empirical study

Protective Cultural Resources	More than 2	Previous resilience studies	Previous FXS studies	Not noted in previous resilience studies	Not noted in previous FXS studies
Religious activities	☺	☺			☺

Even though religious activities as a protective resource were noted in previous resilience studies, this theme has not been related to resilience in females diagnosed with Fragile X Syndrome. Therefore, my contribution lies in the fact that religious activities as a resilience-promoting resource is also true for the Fragile X Syndrome participants in my study (Cf. 5.4).

Table 6.2, 6.3, 6.4, and 6.5 therefore clearly illustrate that most of the factors noted by the participants in my study as contributing to their resilience were identified as resilience-promoting in previous studies, as discussed in my findings in 5.4. As stated in Chapter Five, although the themes that emerged in my study were previously reported in resilience studies, these themes can now be linked directly to resilience in females diagnosed with Fragile X Syndrome. A further contribution is that my findings illustrate that resilience is nurtured by individual, familial, community and cultural protective resources. In other words, resilience is seen as ecosystemic (Lerner, 2006:40; Ungar *et al*., 2008:2). Resilience is thus

not linked only to inter- or intrapersonal protective resources but also relies on both to work together.

Peer support was previously reported as a resilience-promoting resource, but in my study I noticed that the main source of peer support came from peers who were also disabled. This is therefore seen as a contribution to theory of what encourages resilience in females diagnosed with Fragile X Syndrome. Furthermore, my study transforms (Mertens, 2009:18) how we see females diagnosed with Fragile X Syndrome. This transformation allows and encourages communities and families to work together towards resilience in females diagnosed with Fragile X Syndrome.

7.5 LIMITATIONS OF THE STUDY

The following limitations were identified:

- I engaged with four primary participants only. I am aware that the findings cannot be generalised to all females with Fragile X Syndrome. My participants probably had varying degrees of Fragile X Syndrome (as noted in Chapter Four and Table 4.5). It is possible that this influenced their resilience. It is also possible that females with more visible Fragile X Syndrom symptoms, may have been more vulnerable.
- My study also only concentrated on the resilient functioning in females diagnosed with Fragile X Syndrome, and not males.
- The primary participants in my study were not the same age. Their differing ages means that individually they may have had more or less life experience which could have influenced how they described the antecedents of their resilience.
- My participants were only Caucasian Americans. It is therefore possible that the findings cannot be transferred to other females diagnosed with Fragile X Syndrome from other cultural groups.

- Melissa, Cindy and Kelly (Participant 2, 3, and 4) came from the same family. This can be seen as a possible limitation as their experiences and strategies to cope resiliently might be similar.
- The participants all came from well-resourced communities. This can be seen as a limitation as they were exposed to more resources than others and consequently could possibly be more resilient than individuals from poorly resourced communities.
- My participants came from families in which their parents were highly motivated to support them and to negotiate support for them. It is possible that females without supportive parents may have been much more vulnerable.
- As stated in Chapter Three, females with Fragile X Syndrome often find conversations with others difficult due to pragmatics. Consequently there was a communication barrier at times and interviews might not have been the best data collection process to use with these individuals. I tried to make up for this by adding a reflection journal, taking photographs, and interviewing multiple secondary participants, but the communication barrier remains a limitation all the same.
- I was a live-in carer for Lucy (Participant 1). My close relationship might therefore have made my observations biased. I did however attempt to address this by gathering data from secondary participants in her life and by asking my study leader and a psychologist to regularly act as a peer debriefer (Creswell, 2009:192).

7.6 CONTRIBUTIONS MADE BY THE STUDY

My study makes the following contributions:

- The antecedents of resilience that encourage some females diagnosed with Fragile X Syndrome were explored. This fills the gap in current literature and provides insight into the process of resilience for females with Fragile X

Syndrome. Because I described my participants in great detail, it should be possible for other researchers/students to determine how transferable (Creswell, 2009:192-193) my findings are to females diagnosed with Fragile X Syndrome they might know or who are under research with them.

- I contribute to the emerging understanding of resilience as ecologically embedded phenomenon (*Cf*. 5.4). I noticed and reported that all of the resources that emerged in my study contributed to my participants' resilience and not just one of the resources. In other words, my findings emphasise that resilience results when individuals and their ecologies collaborate to promote resilience (Lerner, 2006:40).
- My study also contributes to theory, in that it suggests a new profile, or a new understanding of Fragile X Syndrome and resilience. (*Cf*. 5.4). My study emphasises that females diagnosed with Fragile X Syndrome should not be seen as just vulnerable. I concentrated on the positives and therefore transformed (Mertens, 2009:18) this stereotype and suggest that females diagnosed with Fragile X Syndrome can be seen as, and supported towards, functioning resiliently.
- My study also refines how one of the previously noted protective resources (namely peer support) operates for females diagnosed with Fragile X Syndrome. My case studies illustrate that peer support is protective when it comes from similarly disabled peers (*Cf*. 5.4).
- By being made aware of these resilience-promoting processes, my study contributes to practice in that guidelines can be given to families and communities of those females diagnosed with Fragile X Syndrome for them to work together to encourage these females to cope resiliently.

7.7 RECOMMENDATIONS FOR FURTHER STUDY

My study was not without limitations (*Cf*. 6.5). I therefore trust that this will encourage other researchers to continue with further studies such as:

- A larger study that explores the antecedents of resilience among resilient females with Fragile X Syndrome, including a larger number of females diagnosed with Fragile X Syndrome and participants from all cultural groups coping resiliently with Fragile X Syndrome. Future studies should explore resilience among individuals who are more visibly disabled.
- A study that includes males diagnosed with Fragile X Syndrome and not only females.
- A study that explores the antecedents of resilience among individuals diagnosed with Fragile X Syndrome who are similar in age.
- A study where the participants do not come from the same family, and where participants have less supportive parents.
- A study with participants who do not come from well-resourced communities, are not exposed to as many resources or do not have as many resources available.
- A study that does not make use of interviews as a way of collecting data, as interviews might not be the most effective technique of collecting data from the Fragile X Syndrome population. For example, making use only of observations and visual data.
- A study where the relationship between the researcher and participants is not as personal as in the case of my close relationship with Lucy.

7.8 CONCLUSION

I was very fortunate to have been introduced to Fragile X Syndrome. Throughout my stay with Lucy and her family I became very interested in what made this young woman so full of life and exuberant, even though she faced so many risks. I found with the participants in my study that resilience is indeed not a personality trait, but relies on the dynamic interaction between individual, familial, community and cultural protective resources (Donnon & Hammond, 2007:451; Heath *et al.,*

2008:40). My study therefore contributes to the growing understanding of resilience as an ecosystemic construct (Lerner, 2006:40; Ungar *et al*., 2008:2).

Also, my interpretation encourages a transformation of how females diagnosed with Fragile X Syndrome are conceptualised (Mertens, 2009:18). My study focused on finding the positive features within the challenging experiences of females living with Fragile X Syndrome (Mertens, 2009:25). They can therefore be viewed in a positive light, as individuals who can be resilient, and not merely as victims (Mertens, 2009:10). This positive view does not negate their many challenges (anxiety, limited cognitive ability, hyperarousal and so on) but it encourages communities, families adn professionals not to stereotype them and to collaborate to further their potential for resilience.

I conclude my study with a poem dedicated to Lucy. She has been an inspiration to me. It is because of her that I developed such an interest in Fragile X Syndrome. She has shown me that no matter how difficult life may be, there is always a reason to get up, try again and keep smiling. In summary, she taught me the meaning of resilience.

To Lucy

I’m not a poet, and I know it.

But about you, I want to write.

The first day I met you,

I couldn’t help but love you.

You made me laugh, you cared and you shared.

At times you felt anxious and shy,

But still you went out and gave it a try.

You’re always laughing

And it keeps me thinking.

How can it be?

They say you should learn from me.

But yet, I’ve learned so much more from YOU.

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ADDENDUM A

- LETTER OF INFORMATION (PRIMARY PARTICIPANTS)
- INFORMED CONSENT FORM (PRIMARY PARTICIPANTS)
- LETTER OF INFORMATION (SECONDARY PARTICIPANT)
- INFORMED CONSENT FORM (SECONDARY PARTICIPANTS)

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

24 February 2009

Information about *RESILIENCE IN THE PRESENCE OF FRAGILE X SYNDROME* study

You are invited to participate in a study to help understand the impact of Fragile X Syndrome on the life of female diagnosed with this syndrome and to understand the factors and/or processes that support them to do well despite the risks of Fragile X Syndrome. To participate, you must be a female that has been diagnosed with Fragile X Syndrome, between 15 - 28 years old, be coping well with the difficulties you face, and must have a parent or guardian who can also consent to your participation in the study. The research will occur in the city and region of Chicago, Illinois, United States of America.

Chantel Fourie is the student-researcher conducting the research. Prof Linda Theron at the North-West University will be Chantel Fourie's supervisor and project leader. You can contact Chantel Fourie at any time for further information. Chantel Fourie will interview and observe you at a time and place convenient to you.

What you will be asked to do: The study will involve three parts:

Part 1: You will meet the student-researcher (Chantel). She will talk to you informally and get to know you. She will observe you (in an informal setting) and collect visual data (such as videos and photographs) of you interacting with others and handling certain situations

Part 2: At a different time, the student-researcher will visit you again. You will be asked to talk about your life. You will be asked for your opinions on growing up, and about your community, your friends, your family, and other relationships that are important to you. In your interview, you may be asked to remember stressful times in your life, which may make you feel uncomfortable. A contact number will be provided after the study if you would like someone to talk to about your thoughts and feelings. The first meeting will take 30 minutes - 1 hour. Your conversation will be recorded. The researcher will also talk to your parents and teachers/consulting psychologists about you and what has helped you to cope resiliently.

Part 3: At another time, the researcher will return to make more observations. She will again observe how you interact with others, and handle yourself in different situations. She will als tell you how she interpreted what you said during the interview. You will be able to add to what she understood or explain to her if she misunderstood something.

Possible risks and benefits: Because you will be talking individually to the student-researcher, confidentiality is possible. Only your first name or a pseudonym (e.g. Participant X) will be used when referring to what you said, and we will keep specific details of where you come from confidential. If you agree, the researcher will include photos and videoclips of you when she makes her research findings public, but she will not add your names to these. Participation is completely voluntary and you can stop participating in the study at any time, without consequences. If you become concerned with anything you said, you can let us know, and your interviews, or parts of these, will be destroyed. You may ask any questions you have before, during, and after the study.

Only members of the research team will know your full name. The interview tapes and transcripts might be used by other researchers to understand how females cope with Fragile X Syndrome. The research data and

recordings will be kept for the foreseeable future (five years) in a secure location at North-West University. We will also ask you if you are interested in being contacted again in the future should the research continue.

The only time we will have to inform someone of your participation in the study and provide them with your full name is if you are at risk of being hurt by someone or hurting someone else. In that case, we will explain to you that we must get you help from someone like a social worker, psychologist or the police, but we will let you know we are doing this.

Questions/ Problems: If you have any questions or concerns before, during or after the study, please contact the student researcher or the research leader, using the contact information below.

Student-researcher	**Research leader**
Chantel Fourie 1086 Saxony Drive Highland Park, Illinois 60035, USA Telephone: (847) 828 9095 Email: chantel_fourie@yahoo.com	Prof Linda Theron School of Educational Sciences Vaal Triangle Campus, North-West University; Hendrik van Eck Boulevard Vanderbijlpark; 1911 Telephone: (016) 910 3076 Email: Linda.Theron@nwu.ac.za

For concerns about how this study is being conducted, you may also contact the Research Director (Educational Sciences, NWU): Prof JdeK Monteith at 10055738@nwu.ac.za or at 018 299 4780.

Thank you!

Chantel Fourie

NORTH-WEST UNIVERSITY
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NOORDWES-UNIVERSITEIT

VOLUNTARY Informed consent form

THE *RESILIENCE IN THE PRESENCE OF FRAGILE X SYNDROME* STUDY:

If you agree, please place an "X" in the 'yes' boxes to show that you understand and agree with each statement:

1. I understand the information about the study in the Information Letter. Any questions I had were answered.	**Yes, I understand**
2. I realize that participation is completely voluntary and that I can stop participating in the study at any time. If I am uncomfortable answering any question, I may choose not to answer.	**Yes, I understand**
3. I understand that my full name will not be used, nor will specific details of where I live be shared, when information from the interviews is used by researchers.	**Yes, I understand**

4. I understand that what I say may be quoted at great length in publications, presentations and the final report. If I become concerned with anything I said, I can ask for parts, or all, of what I said not to be quoted. I may also have deleted any parts of the interview I want deleted.	**Yes,** **I understand**
5. I understand that even if my parent or guardian consents to my taking part in the study, it is my decision whether I want to participate. If I do not wish to participate, or want to withdraw from the study at any time, my wishes will be respected without penalty. My parent's or guardian's consent does not make me have to participate.	**Yes,** **I understand**
6. I understand that if something troubles me while participating, the researcher will provide me with information about community resources (e.g. a local psychologist) that might help me. I understand that I will be responsible for the payment of such a professional in the event that I should follow-up the referral.	**Yes,** **I understand**
7. I understand that photographs and video clips of me might be used in this study. These photos will be used in the dissertation and research articles / chapters / conference papers that may be used world-wide. I give permission to use my photograph in these ways.	**Yes,** **I understand**

I agree to take part in this study.

_____ _____

(Research Participant's Signature) *(Date)*

I agree to allow my child to participate

_____ _____

(Parent or Guardian's Signature) *(Date)*

The study has been explained to the young person and this form signed voluntarily

_____ _____

(Researcher's Signature) (Date)

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
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24 February 2008

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You are invited to participate in a study to help understand the impact of Fragile X Syndrome on the life of female who have been diagnosed with this syndrome and to understand how females with Fragile X Syndrome cope. To participate, you must be a parent, caregiver, teacher or therapist of a female diagnosed with Fragile X Syndrome who is participating in the study. The research will occur in the city and region of Chicago, Illinois, United States of America.

Chantel Fourie is the student-researcher conducting the research. Prof Linda Theron at the North-West University is Chantel Fourie's supervisor and project leader. You can contact Chantel Fourie at any time for further information. Chantel Fourie will interview you at a time and place convenient to you.

What you will be asked to do: The study will involve two parts:

Part 1: You will meet with the student-researcher (Chantel). You will be asked to talk about the life of the female/s taking part in the study who have been diagnosed with Fragile X Syndrome. You will be asked for your opinions on her ability to cope with adversity, and also the role their family, friends, community and culture have played in their ability to cope resiliently. The meeting will take about 30 minutes – 1 hour. Your conversation will be recorded.

Part 2: At another time, the researcher will return to tell you how she interpreted what you said. You will be able to add to what she understood or explain to her if she misunderstood something. This meeting will take another 30 minutes - 1 hour and will also be recorded.

Possible risks and benefits: Because you will be talking individually to the student-researcher, confidentiality is possible. Only your first name or a pseudonym (e.g. Participant X) will be used when referring to what you said, and we will keep specific details of where you come from confidential. Participation is completely voluntary and you can stop participating in the study at any time, without consequences. If you become concerned with anything you said, you can let us know, and your interviews, or parts of these, will be destroyed. You may ask any questions you have before, during, and after the study.

Only members of the research team will know your full name. The interview tapes and transcripts might be used by other researchers to understand how females cope with Fragile X Syndrome. The research data and recordings will be kept for the foreseeable future (five years) in a secure location at North-West University. We will also ask you if you are interested in being contacted again in the future should the research continue.

Questions/ Problems: If you have any questions or concerns before, during or after the study, please contact the student researcher or the research leader, using the contact information below.

Student-researcher	**Research leader**
Chantel Fourie 1086 Saxony Drive Highland Park, Illinois 60035, USA Telephone: (847) 828 9095 Email: chantel_fourie@yahoo.com	Prof Linda Theron School of Educational Sciences Vaal Triangle Campus, North-West University; Hendrik van Eck Boulevard Vanderbijlpark; 1911

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For concerns about how this study is being conducted, you may also contact the Research Director (Educational Sciences, NWU): Prof JdeK Monteith at 10055738@nwu.ac.za or at 018 299 4780.

Thank you!

Chantel Fourie

VOLUNTARY Informed consent form

THE *RESILIENCE IN THE PRESENCE OF FRAGILE X SYNDROME* STUDY:

If you agree, please place an "X" in the 'yes' boxes to show that you understand and agree with each statement:

1. I understand the information about the study in the Information Letter. Any questions I had were answered.	**Yes, I understand**
2. I realize that participation is completely voluntary and that I can stop participating in the study at any time. If I am uncomfortable answering any question, I may choose not to answer.	**Yes, I understand**
3. I understand that my full name will not be used, nor will specific details of where I live be shared, when information from the interviews is used by researchers.	**Yes, I understand**
4. I understand that what I say may be quoted at great length in publications, presentations and the final report. If I become concerned with anything I said, I can ask for parts, or all, of	**Yes, I understand**

what I said not to be quoted. I may also have deleted any parts of the interview I want deleted.	
5. I understand that if I do not wish to participate, or want to withdraw from the study at any time, my wishes will be respected without penalty.	**Yes,** **I understand**
6. I understand that if something troubles me while participating, the researcher will provide me with information about community resources (e.g. a local psychologist) that might help me. I understand that I will be responsible for the payment of such a professional in the event that I should follow-up the referral.	**Yes,** **I understand**
7. I understand that photographs and video clips of me might be used in this study. These photos will be used in the dissertation and research articles / chapters / conference papers that may be used world-wide. I give permission to use my photograph in these ways.	**Yes,** **I understand**

I agree to take part in this study.

_____ _____

(Research Participant's Signature) *(Date)*

The study has been explained to the participating adult and this form signed voluntarily

_____ _____

(Researcher's Signature) (Date)

ADDENDUM B

INTERVIEW 1

Interviewee: Lucy (participant 1)

Date of interview: August 6, 2008

Place: Highland Park, Illinois, USA

The purpose of this study is to understand the impact of Fragile X Syndrome on the life of Lucy and to determine the antecedents that help her cope resiliently.

She is sitting on a chair next to me at the dining room table. She is very excited and starts flapping her hands (this usually occurs when she is very excited- over stimulated).

Remember I told you that I'm doing my paper for school.

Yes.

On Fragile X.

Yes.

Ok, so I'm gonna ask you a bunch of questions that I want you to answer for me.

Ok.

If you don't understand, I want you to ask me.

Ok (enthusiastic)

So in order for me to write my paper I have to interview a whole bunch of people, like your mom and dad, your brother, some of your teachers.. (Lucy interrupts).

Hays..

Yeah, Mr. Hays, Miss Silverberg, Linda Simard and so on. Ok, so let's start. Are you ready (hand flapping starts again)?

Yes.

Ok, have you ever heard of Fragile X?

Yes.

You have! Ok good. Do you know what it is?

It's my syndrome.

It's your syndrome, ok! Do you think the fact that you have FX makes you different from other people like your brother or me or Sarah or any other person?

Yeah..

How does it make you different? Can you think of something? Like maybe the way you walk, your balance or anxiety or (she interrupts)..

I'm exactly the same, but.. but.. I have a better… uhmm. Uhmm (pauses).. responsibility.

Ok, you are more responsible than other people. That is a good example. What else can you think of?

Ummmm.. (pauses)

What do you think makes you different from Sarah?

Ummmm.. she and I have different hair.

Ok. Apart from the way you look, are there things that you might struggle with that she might not struggle with because you have Fragile X and she doesn't?

She doesn't know that I have Fragile X.

Are there things in school that you struggle with that other people don't, like a specific subject?

Ummm.. what do you mean?

Like history or math or science?

Freshman year.

What did you struggle with in freshman year?

Ummm.. (she gives a nervous/embarrassed laugh)

Don't be nervous. It's ok. It's just you and I talking.

Ummm like.. like when Mr. Kirk give me hard work in Science.

Ok. So science was hard for you. How about math?

Math!! I've gotten use to.

Ok, so you think that you are ok with math?

Yeah.

How about the fact that you don't like to go to Sunset (the grocery store)? Why do you not want to go there?

Because.. because.. because.. cause.. they don't know that I have Fragile X and that like.. they don't know.

If they knew about Fragile X would you go there?

Yeah.

You would?

Yes. If they knew.

How about you walking down the stairs. Why do you not like to walk down the stairs?

I will do it again. I walked down the stairs until I was about 6 years old.

So how come you don't do it anymore you think?

I'm just getting use to it.

Do you think that you will be able to do it by yourself again?

Yeah.

Ok. Good.

I'm trying.

I know you are. You'll get there, I'm sure. Are there things you feel bad about, something you don't like about yourself?

I like everything about me.

Good! That's a great answer. You should! Are there things that your mom and dad have done to make you cope with Fragile X, in other words to help you. Things you struggle with like science or…(she interrupts again)

Yes .

What have they done?

They have talked to my science teacher.

Ok. So they have spoken to your teachers when you've had problems. How about your school? Have they helped you to cope with Fragile X?

Yes.

How have they helped you?

By leaving boys alone.

Ok. So leaving boys alone. Are you having trouble with the boys at school?

(Her sentences or statements are often repeated by the researcher to ensure she stays focused and remember what we are talking about.)

Yes.

How has Cove (your school) helped you?

This is my fourth year and ummm… (pauses)

How have they helped you cope with the boys at school?

Ummmm.. (giving a laugh/sigh)… by meeting them for the first time when I started cove.

Meeting who?

All the guys. I'm just getting used to them.

But how has your school helped you to not pay so much attention to the boys?

Ummm… I walk away.. (laughing)

Who told you to walk away?

I just do it myself.

Wasn't there somebody walking with you before. One of you teachers or someone?

Yes.

Ok. So they were walking with making sure that you don't do what?

Wait.

So that you don't wait for some of the boys?

No.

You never will again?

No.

Are there things that your friend do or can do…(interrupts again)

In the past?

Well, in the past and in the future. Let's first start with the past. Are there things that your friends did to help you cope… (interrupts again)

Freshman year.

Tell me about it.

Ummm… pause… ok… pause.. it was I am.. ummm… when I was a freshman, he was a junior, he helped me with Huron actually.

Oh he did? Because you were scared of dogs?

Yes. He helped me a lot.

What did he do?

He helped me pet him.

How?

By like, he like put his hand on top. He like petted it first. And then he hold Huron and then I hold the leash, and then.. and then he really helped.

That is great. So how about the future. How about your friends right now?

Now?

Yes. Things you are scared of. How are your friends helping you now?

Ummm.. they are really amazing. My friends. My friends from camp.

How have they helped you? Have they helped you make friends with other people?

Like Mike Early for instance. I know him. And I really, I really like getting to know him a little bit more cause I don't get to see him that much.

Ok. And how has he helped you?

He helped me because he was my friend and he knew about it.

And he understood.

Yeah!

How about the community? Do you know what the word community means?

No.

Let me re-phrase my question. Do you think that the people in Highland Park help you with coping with Fragile X?

Yes

How?

Like going to Stevo's place.

Like going to Steve's place. Is it because they know about Fragile X?

If you tell them about it.

Are they supportive.. do..(interrupts)

Yes.

They understand.

Yes.

They treat you the same as everybody else?

Yes.

Ok. How about your culture? And how about your religion. How about being Jewish. Do you think there are benefits from being Jewish?

Yeah, I love being Jewish.

Now say for example, Camp Chi. That was a Jewish camp right?

Yeah.

Ok. So did the people at camp know that you have Fragile X?

No.

They didn't?

No.

Nobody knew?

Nobody knew.

Do you think your mom might have told them?

Yes.

Ok. So they did know.

Yes. But none of my camp friends knew.

Did they treat you differently than others or were they all being really nice to you?

They were great friends.

Oh they were?

Yeah.

That's great. I'm so glad to hear that. Well, thanks Lucy. I appreciate you talking to me.

Anything else you wanna tell me?

You are amazing!

Anything else you want to tell me about Fragile X? Tell me anything!(this is her way of telling you she wants to talk more)

Is there anything you want to or can tell me about Fragile X?

Me!!! Ask me!! (tone of voice gets louder)

You want me to ask you more questions?

Yes. Anything.

You just love being interviewed, don't you?

Absolutely!

You don't want to stop.

No! (laughing) Ask me anything! Any celebrities you want to ask me?

Aaahh.. have you met any celebrities?

Ummm… I met Tom. Tom Chapin.

Wow!! Has he helped you with Fragile X at all?

Ummm.. he doesn't even know that I have it.

He doesn't?

No.

Ok. So you have been a fan of his for a long time, haven't you?

Yeah. For 11!

11 years? Wow!

He helped me.. he helps me by not being shy to people.

How did he do that? That's awesome!

Because I met his daughter.

How old was she?

I don't know.

How old were you?

Six. I met his daughter and and I didn't know who she was and now I am more brave.

You are braver? Great! What did she say to you?

She said hi and he told her that he knew that I was shy and umm, he really thought of me.

Did he introduce her to you?

No.

So how did you become friends?

Ummmm… you tube.

So do you ever speak to her?

I listen to her music.

So have you ever met her?

Ummm.. she waved to me.

Oh she did? When was this?

A couple of years ago.

What's her name?

Abigail.

Abigail Chapin?

Yes.

Wow!

I've met like a ton of celebrities myself. A lot of Nicolodian stars.

Oh really?

Yeah.

How cool.

Like Kealan, like Josh, and Amanda. Ummm, Amanda didn't know that I had Fragile X. None of My friends know and my boyfriend didn't know.

Does he know now?

Ummmm…. He doesn't.

Are you going to tell him?

If you could help me like explain it to him.

Ok. Well, let's pretend that I am Kyle. What would you say to him?

I have a special syndrome.

A special one huh? What is it called?

It is on my shirt.

What is it? Fragile X?

Nods (yes)

Wow! Ok, so what is Fragile X? I know it is your syndrome, but can you give me an explanation?

I…. have…. Friends.

Ok. But I also have friends. Does that mean I have Fragile X?

I have Doughy and Ethan.

Ok. Who is Doughy and Ethan? Do they have Fragile X?

Yes.

Ok. What makes you guys different from you? What makes Doughy and Ethan different?

They both have Fragile X like me.

So let's pretend I have the flu. How can you tell I have the flu?

Maybe because you have like a stuffy nose.

What else?

Fragile X to me is.. ummm.. (a 5 second pause) I get to see ummm the people.

What people?

In California.

Oh, you mean the researchers at Stanford?

Yeah.. and then like, the like, ummmm, ummm, you go to parties. And it's really fun.

Yeah, the parties are fun. But Kyle hasn't been to a party. What can you tell him about Fragile X?

I was diagnosed in March. And I wear glasses.

But how about your brother, he wears glasses. Does that mean that he has Fragile X?

Yeah, it does.

And how about my mom? She wears glasses. Does that mean that she has Fragile X?

My mom wears glasses.

Does she have Fragile X?

Yes.

Do you think only people with Fragile X wear glasses?

No, anybody can wear glasses.

So how else would you explain to Kyle?

I don't know?

Well Lucy, you have been a great help. Thank you so much allowing me to interview you. You did great!

Ha ha ha ha.. (laughing)

INTERVIEW 10

Interviewee: Michael

Position: Father of Kelly, Cindy and Melissa

Date: 9 March 2009

Place: Madison, WI. USA

He is the father of 4 girls that has been diagnosed with Fragile X Syndrome. He is also on the board of the National Fragile X Foundation.

You know, Terisa and I have always wanted to ah, kinda do whatever we could to help. And in some ways it's a little bit selfish on our part to spend time with people like you, because we like to recoup people to the cause I mean, there are, this National Fragile X Foundation that I am on the board and Lucy's parents are on the board for. For the last probably 10 years umm they've give $2500 travel ships out 6/7 a year for umm college age kids to kinda work on a research project for Fragile X and it's like so many of those people who got involved when they were in college in a research project, today are like important researchers in the area of Fragile X, so anyway.

I appreciate you all talking to me today. The focus of my study is to find out how females with Fragile X Syndrome cope with the difficulties they face. And what aspects play a part to decrease the negative outcomes they might experience. So if you could tell me, what are the struggles the girls have had to face because of Fragile X Syndrome?

I think it's really being able to make friends with other people and have social relationships. And I think it's painful for them and may even be more painful for us as parents than it is for them. Cause umm you know, when they were in the school environment some parts of the school environments are tough, because kids at the high school level, they can be can be kind of mean, you know, if they sense you are different or sense that you're weak. Umm but then post high school it's like when the kids don't really have a network of friends umm you know there has to be something more to their live than just kind of working, coming home, and watching TV, and uh, being kinda satisfied with daily living chores. So I think the hardest thing is, how do you really establish social relationships with people who are true friends? So it's like when Cindy goes to visit this girlfriend of hers over in London, you know umm, I guess they've seen each other 4 times in their live but they met at a conference and it's like, it's just something that I think Cindy can be

herself with. This person she can be as silly as she wants to be because she's not being judged, she's just being who she is. And umm, and Cindy can just kinda be herself. So I think that's uh, that's, that's real important for a relationship, but I think that's. Those I think are things that are the hardest, and these are things that I hope to work on with the kids is, how do you develop a network of friends, people that will really look out for them and care for them.

What within them personally have buffered these struggles?

Yeah, I think it's kind of umm, it's probably different for each one. Like umm, Kelly early on just had this determination to do things. You know, it's like, she's just decided she's gonna do something and then didn't really seem to be bothered by the noise going on around her. So some of the determination that she had to have to get through this 2 year school, there were a lot of obstacles there she was just very determined and put on blinders.

I think for somebody like Melissa, Melissa is a person who's very accepting of help and she's very sensitive about personal relationships. So even like her umm high school teacher, she'll say, "oh I wonder how Angie Paddington is doing. I wonder how her son is doing". So she, she, she, cares a lot about other people and she needs to feel close to other people and then and that's why this, umm our kids were sensitive to. How do we get them in environments where they're gonna be loved and accepted for who they are. And so, I think Melissa's work environment and umm where uh, she's formed some of these relationships that's really helped her persevere.

Our kids are just so prompt. I mean, if they have to do something or be somewhere at a certain time they're there 10 minutes early or they're there an half an hour early. So they are very disciplined about their commitments to work and things. So I think that is kind of a general trait that they all share.

Umm I think probably umm Cindy is the one that has the hardest time persevering and I think it's, my own assessment of it is that she's the one who is most sensitive about recognizing that she's different than other people and she hates being talked about like she's different than other people. So I think that kind of holds her back some. Umm but I do think that umm some of these, some of these medications have helped the kids too, when Cindy got through her educational programme for CAN, umm it took her three times to get through the class. And in the past Cindy would have tried something, failed and really just kind of beat herself up about it. And not gone out and tried again, but she really stuck with this thing. Part of it I think is she started taking a medication called Abilify, which has really helped her a lot and umm I would say the last couple of months she has been a little more sensitive than she was a few months earlier. But after she started taking his drug, when she, she used to be so deathly afraid of anybody knowing she was different in any way. She got home she said, "Dad you know, I'm trying to get through this class down at MATC Community College. Do you mind calling up the person in the office there and talking about what I've got and how they can help me?" And it was like so night and day different from Cindy, afraid that someone would find out that something was different about her. So, so I think, so I think medications can really help umm get them through, but yeah. And I think they receive, umm they receive quite a bit of encouragement at home and then they also umm receive a certain amount of expectation that they're gonna work hard too you know. We don't really umm kind of let them off the hook because they're different. I mean, they you know they still you know have an obligation to themselves to be the best they can be in whatever they do and somehow that kind of translates, they know that.

That's great. How do you think have family played a role in buffering the difficulties the girls have?

I think it's a, a family is important because it's one more element that lets them know that they're loved and they're accepted. Because they don't really umm get as much of that validation, because they lack social relationships outside of the family. But umm uh Terisa's family is very involved with the kids and very loving and you know. I mean the kids will pick up the phone and, more kind of I would say Kelly and Melissa are really the bigger talkers. Janet she's always busy working, and Cindy is a little more to herself, but it's like the other 2 they pick up the phone all the time calling, you know their aunt Kim or their grandma or grandpa. And so I think it just kind of let's them be themselves and they know that they are loved and accepted there. Umm you know, they don't really have too much contact with uh my side of the family. Ah umm you know, the families, we're kind of different. Terisa's folks umm Terisa's father, when he was young he was like a workaholic. He started his own businesses and he had phrases like "the greatest wealth is created between the 14th and 16th hour of the work day", you know. So he was always gone and always working but it's funny as, as they turned into grandparents and he's retired. I mean there's nothing more important to them than what's going on with the grandkids, and being with family you know and they're just wonderful, wonderful people. My folks are a little more like "we got exhausted raising 8 kids. These are your kids to raise now". And it's like they don't really say that but it's like they don't you know. Terisa's parents could sit down with our kids all day and just talk to them all day long. You know my parents aren't really like that.

Do you think having three sisters has helped the girls and how would you say have it helped?

Oh I think it has helped tremendously, because they help each other. If there was just one of them, Terisa and I would be the only ones there to help them and it's like we're not there all the time. And it's like you know

they're their own advocates for each other when they're as a group, you know. I think they problem solve together, they look out for each other. Even like last night Terisa and I were at some friends house for dinner and umm Kelly called and said "Dad, its 6 o'clock. Janet is not home het. She got done with work at 4". And it's like whenever Janet gets a ride home from somebody else and they don't get home for a while, there's always risk that she's out drinking with them and it's you know, Kelly gets so concerned. She's like "Dad, when she comes home late like this, she's been drinking a lot of times. I'm afraid she's probably out there drinking". So it's like, "Kelly, she might be or she may be not". You know you, "but thanks for worrying about her and you know we're, just call me when she gets home" and things like that. So it's like they do think about each other and they worry about each other and they umm, you know they do, you know help each other out. You know Kelly will go to Janet and be like, "Janet, you work at 7 tomorrow you better go to bed pretty soon". You know so they are really looking out for each other and you know they fight sometimes, like sisters do but, but umm I think it is umm ah, you know I haven't thought about it, but if we had one child with Fragile X, it probably would be very different, you know.

How would you say do they help each other with the struggles they face?

I think that they're really not at, umm a cognitive level of understanding around some of those things. I think they deal a lot of more kind of umm more kind of an experience of maybe they ran into or just kind of how they're feeling about things. I think there are limitations because of their cognitive profile in terms of their cognitive profile in terms of understanding things which would be common for anybody with a low cognitive profile and things like how do they relate to umm, what is money. Money is kind of an abstract concept. You know once Janet did start spending money which was a good thing you know she'd come home with some jewelry, and "Janet where'd you get that? Oh I got it at

the jewelry store". And then she's like making payments on jewelry and it's like I mean she's buying thousands of dollars of jewelry you know. And it's like it's great you know, she's rewarding herself for her work and stuff like that, but to her $200 and $2000 is the same thing. She doesn't really know I mean she, she signs up for payment plans even though she can write a check for it. She takes a certain amount of pride in paying her bills. But she's probably paying a ridiculous amount of insurance. So you know I think they get kind of you know, so there's some of these things that kinds of navigates their way through you know, like they don't really understand a lot of the details behind it. So.

Ok. How has the school supported the girls?

Yeah, umm you know the main thing that the schools did is uh, supporting the kids academically as much as they could. Umm, when our kids got diagnosed you know Kelly, Kelly and Cindy would already be in high school, they would have been struggling mightily and the school tried to provide them with help. They had a learning resources centre which is a place they go to take test and get extra help and they were good about doing that. But then once we got the diagnosis we did write to the faculty a letter and just kind of umm you know, just kind of let them know that they big mystery had been unlocked. That there's a real diagnosis for what was going on with our kids and that, umm you know. I kinda played back to them what the written mission of the school was, which was helping the individual child to develop to the best of their potential. So we really just asked them, please be true to the mission for our kids. They're not the same as everybody else, but the mission of the school is still the same. So you know, the guidance counsellors were particularly strong advocates for our kids and you now there are across the broad spectrum of teachers. But you know across the broad spectrum of teachers one would run into, you know there were some I thinking the most important aspect, their teachers really

cared, but some teachers have just been teachers for too long and they get to the point where they are kind of cynical about their job and you know. So some of the teachers were not quite as understanding but in the broad scheme of things the school was very supportive. Now Melissa went to the public school and was in the special education programme. There we had heard so many horror stories from other parents on how the school do anything they can to deny your kids. So we were prepared to you know have a different you know time with the school and the first time we had a meeting with them, they had a whole room of people there. And they were all about, "hmm how can we qualify Melissa for the greatest services we possibly could?" And it's like whenever we would have a meeting at the school, the vice president of the school would come the guidance counselour would come and it's like. They all took a personal interest in Melissa and her success and you know we think our kids are wonderful and have special gifts and things and they ought to be loved by a lot of people but still when you're the vice principal of a school that has 2000 kids, who do you have the time to care about. You don't have the time to care about everybody individually, so when you come to our meeting and show up, you demonstrate that you really do know our daughter. You know it's just, its just very, very helpful. So it's like the environment they're in, whether it's work or school it's just so important to their success. You now and I think it's probably also been you now helpful that you know that people with Fragile X, there's a broad range of functioning level. I think it was very helpful that our kids were at the higher end of functioning cause I think it made it umm, that much more possible for a broader group of people to care and help them. Umm so, so I think, we've been very blessed in that regard.

How has friends played a part in helping the girls cope with difficult situations they have faced?

I think it's very comforting to know that you have a friend and somebody you can talk to. But it's like yeah in, in, in terms of talking about personal issues, umm I don't really know who the kids talk to about that. You know and I think maybe umm Janet who you didn't get a chance to meet, she has a friend that at work who, she's probably early, early 40's. But they seem like they have the characteristics of true friendship where they talk about a lot of things like, making the story kind of longer is, Janet's friend Kelly at work had a twin sister Sharon. And umm a couple of years ago, Sharon dropped out of a heart attack and its like that was very hard for Janet and it's been very hard on Sharon's twin sister, Kelly who is umm friends with Janet now. But I think that they probably do talk about the real kind of issues, you know how they are feeling and what are they doing, umm Kelly umm and Kelly and Melissa, to the extent that they do have friends you know actually the people they might call friends it's really a wrong kind of social activity as opposed to umm you know any sort of a person connection to draw strength from. And I don't know why that is. I don't know if it's because umm, if just kind of umm you know I don't know what goes on in their heads, whether they just don't know what goes on in their heads, whether they just don't have anybody that they're close to or whether kind of kind of intellectually they don't you know kind of talk about things that bother them. So.

How about the community. Has the community done anything to buffer the struggles they face?

You know, not really. I mean in that sense, I don't know why we never really developed that aspect of it. That's probably one of the things when we talk about there's so many positive things about having each of them have 3 sisters that were affected, if we only had one child with Fragile X it would have probably been more natural for us to reach out to other communities that support, but so the kids don't really have umm

outreach into the community not through you know not through church not through special Olympics and not through things like that.

How has culture and religion played a part in their lives?

Yeah, I don't really think religion too much. Terisa and I both come from you know very ah catholic families that umm you know, our, our parents were very strong church goers and umm you know I attend church uh you know, a little bit more than Terisa does. Usually we'll both go together. The kids kind of umm stopped going to church a couple of years back, umm and it just started happening kind of gradually. I think that we weren't gonna be real disciplined about making them go if they didn't want to go. Umm since it was really just kind of going to church to a service once a week, it wasn't really like the uh community relations really developed around a church setting. So I think that that was probably hindsight missed opportunities because I think that umm church setting should be a very natural place for people to be allowed to be excepted and uh you now to find their role within the community. So but the you know that's something that Terisa and I will continue to give more thought to in terms of you know we start thinking of Kelly, she's 29. How did she get to be 29? Before we know it she's gonna be 39 you know. We love having the kids around but umm we've got to have more intentional strategies around how do they, how do they form the relationships and form the ability to be able to live more independently and feel real good about themselves doing it. So.

You guys have been awesome. Thank you so much for talking to me.

Well, good. I do think that our kids have been real resilient and I am amazed at some of the things that they achieved. And so it's always you know is the glass half full or is the glass half empty and I think the glass

is 2/3's full. Umm but it's, you know it's in some ways something new every day. I think we're getting into a period now where it will probably start to be umm you know it's always been a little and kind of a Fragile X family I think, there it's very natural for umm you know the mom or the children to feel a more sense of responsibility and burden you know in terms of how come our kids aren't like other kids are. As much as you can logically rationalize, why we're very blessed on so many things, it's umm uh you know it will still be hard for Terisa, when we're going to a wedding in june1st. One of our nieces and nephews are now getting married and on the one hand it will be a very celebratory family occasion but on the other hand it's kind of one more reminder to Terisa that you know, it might not happen for us. They would be umm, our kids would be great moms and they would be great partners in life, but we just haven't figured that out how to kinda make that happen. I mean cause in so many ways they are really of the kind of umm socially maturity level of somebody very young. So you know it's hard, but you know every day is a new day. I mean we've got you know great friends and resources and people like their consulting psychologist you know who helps us out more than she knows. And umm you know one of the reasons I stay involved in this National Fragile X Foundation board is that there are some really smart people who are working on a lot of these issues and I mean one of the person's on our board, Sirena Lowe, is working on issues around adulthood and intellectual disabilities umm and its ah just trying to create opportunities for them to develop as much as they want to develop and be as independent as they want to be and umm giving them the opportunities to develop the social relationships that's so important to all of us and you know so it's like there's, there's people working on really cool stuff whether it's basically research around medical things that will help the kids or whether it's about creating environments that will help them be more successful. So there's lots of positive role models on board. So we'll keep working on that stuff and umm you know and the kids are a joy to have around, but we're realizing that they're growing up too and we gotta try and help them a little bit more.

322

323 Thank you!!!

ADDENDUM C

REFLECTION JOURNAL OF LUCY (2008-2009)[7]

April 5, 2008

I have not written for the last two months. I'm not sure what I should be looking for. I have tried to read up on resilience and what I should look for. So hopefully what follows over the next few months will be more valid.

We are currently in Arizona. We are visiting Lucy's grandparents. They live here during the winter season. Tonight some of their family came over. All older cousins, third and fourth cousins. Lucy hasn't met any of them, but has asked her parents and grandparents about them the last couple of days. Tonight everybody was shocked about the fact that she knew so much about everybody. She knew more than some of the people knew about themselves. :) She absolutely loved talking to everybody, young and old, about their lives, their children. She is so interested in other people's lives. She is such a social butterfly. If only she didn't have so much anxiety. But I noticed that once she's used to a person, she just loves talking to them.

April 11, 2008

Lucy's been having a hard time at school socially. She likes this boy and has been following him around and trying really hard to make conversation. The boy has been getting irritated and has been rude to her. Lucy has been coming home upset almost every day. So her mom realized what the problem is and has called the school to see what they can do to help. Lucy's mother has asked them to make sure there is a social worker or teacher present during lunch period that would help facilitate during the social period and help model appropriate social skills.

May 23, 2008

Today we went to Great America/Six Flags with Lucy's school. This is an amusement park. Lucy is not one for scary roller coasters and such things, but we went because she wanted to be part of the rest of the high school. I volunteered to go with and help. They divided us into groups. It was the school's principle, myself, and six kids. It was so funny to see what a good "baby sitter" Lucy is. She was totally in control. When Dough or Ethan or any other kid went the wrong way or went off by themselves. She would be the one to say, "No, where are you going? Come back here! Let's stick together". She is so responsible. And whenever somebody needed help, she was all too willing to help them out.

[7] The rest of the Research Journal is available upon request.

She had a really good time today. She loved interacting with the other kids. I'm trying to help her with her social skills and events like these definitely help to practice these skills. She is improving day by day.

January 13, 2009

They are doing homework, mom and daughter. She has to say a speech. She is very close to throwing a tantrum or should I rather say hyperaroused. So Lynda did a great job to change the situation by saying that she is Zack Afron from High School Musical. Her mood changed completely. And she was able to do what needed to be done. Lucy loves to pretend, and live in her fantasy world.

May 1, 2009

Lucy has missed some PE classes (physical education) due to the amount of travelling we've done. Marks are deducted from her final mark for every class she missed. This made her very upset because she likes to get good grades (her family is quite competitive). So she asked her mom to please call Mr Batista, her PE teacher and ask him how they are going to solve this problem. He agreed on her coming in every morning before school until all the lost time was made up.

May 16, 2009

Today we went shopping her and I. When I met Lucy she wasn't much of a shopper. She is nervous about going to the mall and seeing people. But the more we've been doing it the better it's becoming. So today we went to the mall and she was telling me, "try this on, try that on. Oh that is so cute on you, get that". At first I couldn't believe what I was seeing and hearing and then I realised!!!! This is what the Rosanova girls were telling her the other day. Exactly what they were telling her. Peer pressure or should I say peer influence is a great thing. She has learned by example! AWESOME!!!!

May 18, 2009

Tonight Lucy and I went out with Sarah, a friend of Lucy's that goes to school with her. We went to Libby Loe. Libby Loe is a store where you go with a friend, they dress you up (makeup and hair) and then you get to shop in the store and model in the store. It's quite cute. But it's mostly for younger girls. Let's say up to the age of maybe 10 or 12.

However these two 16year old went and had a great time. They got all dressed up and felt like models or actresses. As we left the shop, people were looking at us all over the place. Lucy was wearing a Hannah Montana wig (blonde wig) and Sarah's hair were done up, on top of her head. They had make-up on and glitter all over the place. Anyways, so people were looking at us and the girls kept asking me why people were looking at us. I couldn't hurt their feelings and rip them out of their fantasy world, so I told them that people were looking at them because they were looking so beautiful. Oh and did that give them even more self confidence. They were "strutting" their stuff all the way through the mall.

I felt that I would rather build their self confidence than break it down.

ADDENDUM D

NATIONAL FRAGILE X CONFERENCE – July 28, 2008

I met Melissa, Cindy and Kelly for the first time today. I was amazed to see how well spoken, and confident they are. The three of them were asked to deliver a speech at the National Fragile X Conference.

They all gave excellent speeches and the people listening really enjoyed them. They were able to make jokes during their presentations and also to laugh about their mistakes and jokes.

Kelly was part of the adult panel, where as Cindy and Melissa were part of the female adolescent panel. Kelly was the only female in her panel. There were three other males about her age. She seemed to be able to interact with them and felt comfortable around them. They were all diagnosed with Fragile X Syndrome. As for Cindy and Melissa, there were two other girls in their panel. They also seemed to get along well with them. The one female was from Detroit and the other from New Zealand. This is great that the Fragile X Community is able to ensure connections between the girls from different culture.

They were able to state their strengths and weaknesses during their presentations. I thought this was great. Lucy often struggled to express her feelings, so this struck me as being a great quality to have, and can be seen as a protective resources.

I recorded their presentations (see visual material).

OBSERVATION NOTES – 9 MARCH 2009

MELISSA – PARTICIPANT 2

Melissa was the first to come greet when I arrived at their house today. She struck me as being very well mannered, kind and polite. She was very friendly too.

Melissa and her parents invited me to come into the living room. They live in a nice, big house. It was nicely furnished and spacious. Melissa, her father, and I sat in the living room, while Melissa's mother was cooking lunch in the kitchen.

Her sisters (Cindy and Kelly weren't around). I understood this as I had experience from Lucy, I realised that they were just shy and anxious about meeting me again.

Melissa's dad and I just sat and spoke, and she just seemed happy to be there, very content. Her dad then told her to go upstairs and call her sisters to come down to meet me. She was happy to do so. She went upstairs and came back down again after a few minutes. She told her father that Kelly would be down in a minute but that Cindy didn't want to come down.

A few seconds later, Kelly came down.

At some point throughout the day, during informal interaction with her and her family, I commented on how much I enjoyed a cup of coffee. Later that morning I was busy with an interview with the girls' father when all of a sudden there was a knock on the door. It was Melissa with a cup of coffee just for me. She is so sweet."

Melissa seems like a very outgoing and lively person. She is confident in herself and very caring of others.

CINDY – PARTICIPANT 3

Cindy came down stairs last. She had a book, pencil and ruler in her hand. I made a point of it to use this as an ice breaker later during our interview, if

necessary. This was interesting for me to see, as I have noticed during my time with Lucy, that when Fragile X Syndrome females are nervous or anxious about a situation they have something (in this case her word puzzles) to keep themselves busy with and use as an excuse if they did not want to interact with others immediately.

She greeted me politely, but with very little eye contact. She then carried on walking through to the kitchen where she stood with her mom.

Her father then told me some lovely stories about Cindy. He told me of how she finished her Certified Nursing Assistant diploma. He furthermore also told of how determined she was to finish, even though she had a difficult times during her studies. He also told me that she is currently looking for a job.

He also explained that he and his wife will be leaving for Italy in a week's time and how the girls will be on their own for eight weeks. The family has a home in Italy and often go there. I was amazed to hear that they leave the kids alone at home. This really struck me as an incredible achievement for Fragile X Syndrome females as Lucy's family was very worried about her being independent when she is older.

I really think that this is incredible that these girls are capable of looking after themselves for such a long period of time. Their parents have obviously done a great job at creating a sense of independence within the girls.

After speaking to Melissa, Kelly and their father, I felt the need to also talk with Cindy, in order for her to feel less anxious about talking with me. She was busy working on her word puzzles. I asked her about it and she told me how much she enjoys doing it. She also made sure to tell me that she finishes a book a day. She struck me as having a good amount of confidence. This could also just be part of the American culture.

During the interview with Melissa, Cindy knocked on the door and came into the room with four different kinds of sodas (soft drinks). She politely asked me if I would like one and gave me the option to choose which one I would like. These girls really are well mannered and empathetic. I felt that their parents have taught them well, how to handle guests and how to handle themselves appropriately.

KELLY – PARTICIPANT 4

Kelly was the oldest of four girls. She came down the stairs to where we were sitting in the family room, wearing a sports shirt (American football) . Later I used this as an ice breaker.

She also seemed like a really kind person. She greeted me politely and sat with Melissa, her father and myself. Kelly's father told me about her accomplishments and how proud he and her mother are of her. He also told of how determined she has been to finish school. I could tell from the expression on her face that she felt special, loved and appreciated by her family. She enjoyed hearing positive things about herself.

Her father also told me about her job, caring for younger children at a nursery school. Kelly just sat there looking down, and smiling.

She later told me that she really enjoy watching sport, such as football, baseball and basketball. She also decorated her bedroom accordingly. She seems to have a good sense of self-knowledge.

My observation of Melissa, Cindy and Kelly was that they enjoyed their privacy and peacefulness. Their home was located in a quiet and safe neighbourhood, and each had her own room

I also found it very interesting to see and hear that their parents only spoke positively about their children. Not once did they bring them down in front of me. I admired this, as I think this helps their self-confidence and self-esteem.

NATIONAL FRAGILE X FOUNDATION PARTY – May 3, 2009

There was a party to honour some of the people that have made a difference in the Fragile X Community, such as doctors, and researchers. There were many adolescents affected by Fragile X Syndrome. It was interesting to see that Melissa, Cindy and Kelly were able to interact with others so well. It was clear to see that there were connections between them and other attendees at the party.

Cindy actually met her best friend at a party like this. Her friend was also diagnosed with Fragile X Syndrome. This friend actually lives in England and they are still in contact.

Melissa, Cindy and Kelly were dressed well, and seemed to be wanting to fit in with the others.

Even though females with Fragile X Syndrome tend to have a lot of anxiety when it comes to socialising, it was clear to see that these girls had a great desire to want to socialise with others.

ADDENDUM E