Copyright and Citation Considerations for This Thesis/Dissertation

o Attribution — You must give appropriate credit, provide a link to the license, and indicate if changes were made. You may do so in any reasonable manner, but not in any way that suggests the licensor endorses you or your use.

o NonCommercial — You may not use the material for commercial purposes.

o ShareAlike — If you remix, transform, or build upon the material, you must distribute your contributions under the same license as the original.

How to cite this thesis
SUPPORTING A LEARNER
WITH CAUDAL REGRESSION SYNDROME
IN A SPECIAL NEEDS SCHOOL

By
MEGAN JAYNE EDMONDS

MINI-DISSERTATION
Submitted in partial fulfilment of the requirements for the degree
MAGISTER EDUCATIONIS
in
EDUCATIONAL PSYCHOLOGY
in the
FACULTY OF EDUCATION
at the
UNIVERSITY OF JOHANNESBURG

SUPERVISOR: Mrs JV Fourie

OCTOBER 2015
The case of Jo-Anne¹, a fourteen-year old girl with caudal regression syndrome, is presented in this study. Below is an artefact created by Jo-Anne in order for her to share her experiences of being disabled.

---

¹ Jo-Anne is pseudonym used to protect the identity of the individual discussed in this case
DECLARATION

I, MEGAN JAYNE EDMONDS, hereby declare that this study is my original work and that I adhered to the correct referencing and in the stipulated guidelines from the Ethics Board of the University of Johannesburg.

M. J. Edmonds
DEDICATION

This study is dedicated to Jo-Anne\textsuperscript{2}, without whom this study would not have been possible. I hope that the content accurately depicts her experiences and needs. I wish for others to become aware of this condition and acknowledge the support required for individuals with caudal regression syndrome.

\textsuperscript{2} Jo-Anne is a pseudonym, which has been selected to protect the identity of the individual in this study.
ACKNOWLEDGMENTS

I would like to acknowledge and express my sincere gratitude to the following people in assisting and guiding me to the completion of this study:

Firstly to my supervisor, Mrs Jean Fourie, for her continued support, constructive criticism and guidance.

Secondly to my husband, Chyle, for his continuous support and faith in me, for his understanding and sacrifices made during the course of this study.

Thirdly, to my parents for their continuous support and belief in my abilities.

Lastly, to Dr Tarryn Kingon, for taking time to work with me and explain the intricacies of spinal function and caudal regression.
ABSTRACT

Caudal regression syndrome (CRS) is a rare spinal condition affecting a small portion of learners with physical disabilities. Due to the rarity of this condition, there is limited research into the associated social-emotional and academic support needs. The case of Jo-Anne, a fourteen-year-old girl with CRS, has been used in this study to investigate the physical, academic, and social-emotional support needs associated with CRS. An in-depth exploration into the symptoms of CRS (five different types), treatment and prognosis was conducted using a literature review. The literature review also allowed for an investigation into the role of inclusive education and special schools in South Africa. Bronfenbrenner’s bioecological model for human development was highlighted to show the importance of systems and the effect of systemic factors on an individual with a disability. Bronfenbrenner’s model has been adapted in this study in order to create the ice-cream cone model for case conceptualisation. This model allows for a visual representation of how the domains of support needs, case history and systemic factors all interact affecting the well-being of the disabled individual. In order to collect data, interviews were conducted with relevant role players in Jo-Anne’s life, as well as using data from an artefact and photographs. Analysis of the data led to the emergence of three themes, domains of support needs, additional compounding factors, and systemic factors. The three domains of support needs, specifically physical, social-emotional and academic, are all interrelated. Furthermore, the physical symptoms lead to physical support needs as well as social-emotional and academic support needs. The specific support needs in the three domains that were identified include a need for mobility, catheterisation, identity and self-concept development, support to assist feelings of “fitting in”, especially in an able-bodied society, and academic support to improve concentration and understanding. The data showed that the support needs did not originate solely from caudal regression syndrome. The support needs also stem from factors such as the current life stage, family influence and background, school influence, and comorbid diagnoses, which in this case, are specifically ADHD and the presence of a cleft palate. The exploration of this case has shown that in order to fully understand the support needs of a condition such as CRS, additional factors have to be taken into account and therefore, support need to be reviewed for each individual case.

Jo-Anne is a pseudonym that has been selected in order to protect the anonymity of the individual.
TABLE OF CONTENTS

DECLARATION ii
DEDICATION iii
ACKNOWLEDGEMENTS iv
ABSTRACT v

CHAPTER 1: ORIENTATION TO THE RESEARCH

1.1 INTRODUCTION 1
1.2 BACKGROUND, RELEVANCE AND MOTIVATION FOR THE STUDY 2
1.3 ORIENTATION AND STATEMENT OF THE PROBLEM 4
1.4 RESEARCH QUESTION 4
1.5 AIM OF THE STUDY 5
1.6 RESEARCH ASSUMPTIONS 5
1.7 CONCEPT CLARIFICATION 6
1.7.1 Caudal regression syndrome 6
1.7.2 Foster mother 6
1.7.3 Special School 7
1.8 PROGRESSION OF RESEARCH REPORT 7
1.9 CHAPTER SUMMARY 8

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION 9
2.2 CAUDAL REGRESSION SYNDROME 10
2.2.1 Aetiology and Types 12
2.2.2 Symptoms or Characteristics 15
2.2.3 General treatment and care 17
2.2.4 Accommodations required in the school environment 20
2.2.5 Prognosis 21
2.3 INCLUSIVE EDUCATION 22
### 2.4 ADAPTING THE BIO-ECOLOGICAL MODEL ON HUMAN DEVELOPMENT TO VISUALLY REPRESENT HISTORICAL CASE INFORMATION

**2.4.1 Bronfenbrenner’s model of child development**

**2.4.2 Adaptation of bio-ecological model to form an ‘ice-cream cone’**

### 2.5 ROLE OF THE EDUCATIONAL PSYCHOLOGIST

### 2.6 CHAPTER SUMMARY

---

### CHAPTER 3: RESEARCH DESIGN AND METHODS

**3.1 INTRODUCTION**

**3.2 RESEARCH PARADIGM**

**3.3 CASE STUDY RESEARCH DESIGN**

**3.4 CASE SELECTION**

**3.5 THE RESEARCHER**

**3.6 DATA COLLECTION METHODS**

3.6.1 Interviews

3.6.2 Documents and Artefacts

**3.7 DATA PROCESSING AND ANALYSIS**

**3.8 MEASURES TO ENSURE TRUSTWORTHINESS**

**3.9 ETHICAL CONSIDERATIONS**

**3.10 CHAPTER SUMMARY**

---

### CHAPTER 4: DATA PRESENTATION, ANALYSIS AND INTERPRETATION OF THE FINDINGS

**4.1 INTRODUCTION**

**4.2 PRESENTATION AND OVERVIEW OF FINDINGS**

**4.3 THEME 1: DOMAINS OF SUPPORT NEEDS**

4.3.1 Literature discussion for theme 1: The domains of support needs

**4.4 THEME 2: ADDITIONAL COMPOUNDING FACTORS**

4.4.1 Literature discussion for theme 2: Additional compounding factors

**4.5 THEME 3: SYSTEMIC FACTORS**

4.5.1 Literature discussion for theme 3: Systemic factors

**4.6 CHAPTER SUMMARY**
CHAPTER 5: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION 82
5.2 OVERVIEW OF THE RESEARCH 82
5.3 THE FINDINGS IN LIGHT OF THE RESEARCH QUESTION 83
5.4 STRENGTHS OF THE STUDY 84
5.5 LIMITATIONS OF THE STUDY 84
5.6 RECOMMENDATIONS 85
5.7 CONCLUDING REMARKS 88

REFERENCES 89
# LIST OF APPENDICES

## APPENDIX A: ETHICAL DOCUMENTATION

<table>
<thead>
<tr>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethical clearance letter from the University of Johannesburg</td>
<td>100</td>
</tr>
<tr>
<td>Plagiarism evaluation from TurnIt In</td>
<td>101</td>
</tr>
<tr>
<td>Signed affidavit</td>
<td>102</td>
</tr>
<tr>
<td>GDE Research approval letter</td>
<td>103</td>
</tr>
</tbody>
</table>

## APPENDIX B: EXCERPTS FROM INTERVIEW TRANSCRIPTS AND FIELD NOTES

<table>
<thead>
<tr>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excerpt from interview with Jo-Anne</td>
<td>106</td>
</tr>
<tr>
<td>Excerpt from interview with Bronwyn</td>
<td>107</td>
</tr>
<tr>
<td>Excerpt from interview with Laura</td>
<td>108</td>
</tr>
<tr>
<td>Excerpt from interview with Natasha</td>
<td>109</td>
</tr>
<tr>
<td>Excerpt from interview with Fred</td>
<td>110</td>
</tr>
<tr>
<td>Excerpt from field notes for Jo-Anne 2</td>
<td>111</td>
</tr>
</tbody>
</table>

## APPENDIX C: ARTEFACT AND VISUAL DOCUMENTS

<table>
<thead>
<tr>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copy of Jo-Anne’s artefact</td>
<td>113</td>
</tr>
<tr>
<td>Visual documents: photographs of the school’s physical environment</td>
<td>114</td>
</tr>
</tbody>
</table>

## APPENDIX D: EVIDENCE OF DATA ANALYSIS

<table>
<thead>
<tr>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table showing issues arising from preliminary data analysis</td>
<td>117</td>
</tr>
<tr>
<td>Table of themes, codes and relevant data</td>
<td>119</td>
</tr>
<tr>
<td>Example of the member checking documents sent to participants</td>
<td>122</td>
</tr>
</tbody>
</table>
### LIST OF FIGURES AND TABLES

#### Figure 2.1
An example of a typically developed spine

#### Figure 2.2
An example of a typically formed spinal cord into the pelvis

#### Figure 2.3
An example of a typically developed pelvis

#### Figure 2.4
Examples of spinal cords with CRS types I and II

#### Figure 2.5
Examples of spinal cords with CRS types III, IV and V

#### Figure 2.6
Examples of flexion contractures and meningo(myelo)cele as seen in CRS

#### Figure 2.7
Bronfenbrenner’s bio-ecological model

#### Figure 2.8
Representation of the bio-ecological model as an ice-cream cone

#### Figure 4.1
Themes that emerged from the findings

#### Figure 4.2
Jo-Anne’s case history visually represented as the cone of the ice-cream

#### Figure 4.3
Summary of the findings visually represented using the ice-cone model

#### Table 3.1
Interview guide

#### Table 4.1
Abbreviations used in data presentation

#### Table 4.2
Summary of Gibson’s model of disability identity development
   (Adapted from Gibson, 2006; and Myers, Laux, and Murdock, 2011)

#### Table 5.1
Themes arising from the study with defining statements
# GLOSSARY OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD</td>
<td>Attention Deficit Hyperactivity Disorder</td>
</tr>
<tr>
<td>CRS</td>
<td>Caudal Regression Syndrome</td>
</tr>
<tr>
<td>FAS</td>
<td>Foetal Alcohol Syndrome</td>
</tr>
<tr>
<td>HOD</td>
<td>Head of Department</td>
</tr>
<tr>
<td>ISACRSA</td>
<td>International Sacral Agenesis/ Caudal Regression Association</td>
</tr>
<tr>
<td>ISP</td>
<td>Individual Support Plan</td>
</tr>
<tr>
<td>IQMS</td>
<td>Integrated Quality Management System</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
</tr>
<tr>
<td>SIAS</td>
<td>Screening, Identification, Assessment, and Support</td>
</tr>
</tbody>
</table>
CHAPTER 1

ORIENTATION TO THE RESEARCH

1.1 INTRODUCTION

According to policies put in place by the Department of Basic Education, education in South Africa should be provided in an inclusive manner, whereby all learners have their support needs met in order to benefit from the learning environment (Department of Education, 2001). In cases where a high level of support is required, learners should be provided for in special schools where there is specialised knowledge regarding their needs and where quality care can be provided (Department of Basic Education, 2014). Therefore, in a special school for learners with physical disabilities, it would be imperative for the educators and support staff to have an understanding of the conditions their learners may have and the support needs related to these unique conditions.

Some of the conditions experienced by learners in such an environment may be relatively rare and for this reason, school staff may have limited knowledge on the support needs of these rare conditions such as caudal regression syndrome (CRS). Based on the research conducted on this condition by various authors, such as Boulas (2009), Cuevas (1995), and Gillis, Bader, and Boyd (2013), much of the focus has been medical. For this reason, there is limited information on the emotional, social and academic support needs associated with this condition. This study will investigate the support needs experienced by Jo-Anne, a fourteen year-old girl with this condition, who is currently in a special school for learners with physical disabilities.

This introductory chapter seeks to contextualise the problem and orientate the reader towards the study and the research question. In order to provide the context of the study, the background of the research will be discussed, as well as placing this information within the context of inclusive education in South Africa. The motivation for this study will be argued by considering the lack of knowledge around the support needs of individuals of CRS while also considering a case of CRS from a special school for learners with physical disabilities. Following this discussion, the problem statement will be presented, which leads to the formation of the problem statement.

---

Jo-Anne is a pseudonym, which has been selected to protect the identity of the individual in this study.
research question and a clarification of the study’s aims. Furthermore, the assumptions of the researcher regarding the study will be discussed and some important concepts relevant to the study will be clarified. Finally, a summation of the progression for the reporting of this study will be provided.

1.2 BACKGROUND, RELEVANCE, AND MOTIVATION FOR THE STUDY

The inclusive education policy of South Africa requires that there should be a collaborative effort between all stakeholders so that the school environment can be adapted in order to accommodate learners. The type of specialised support and resources required in each case will be determined by considering the level of support that is needed (Department of Basic Education, 2014; Department of Education, 2001). In some cases, the barrier experienced by the learner will require a low level of support and therefore, a mainstream school could be adapted in order to provide adequate support. However, in other cases, the level of support may be so high that specialised teaching, as well as a range of specific resources is required; this is often the case for learners with physical disabilities.

In a school for learners with physical disabilities, specialised knowledge of the disability is required in order to provide accurate support. Often physiotherapists or occupational therapists are needed. There is regularly a range of conditions found in such a schooling environment and it is necessary to have an understanding of each condition that is encountered. Having this type of knowledge can be difficult when the condition is rare.

Caudal regression syndrome (CRS) is a rare disability occurring in approximately 1 in 50 000 to 1 in 100 000 births (Odent, 2010). According to Jadav, Gandhi, Somi, and Desai (2012), this condition can be described as a spectrum of abnormalities characterised by a lack of development and malformations of the lumbar and/or sacral parts of the spine. Such developmental disturbances in the spinal formation lead to physical difficulties, including leg deformities and problems with the internal and reproductive organs (ISACRA, 2013; Jadav, Ghandi, Soni, & Desai, 2012).

Some of the associated physical implications include difficulties with elimination control, often requiring catheterisation, various surgeries, and can cause kidney problems. In severe cases, CRS can lead to clubbed feet, cleft palate and paralysis from the waist down (Wilmshurst, Kelly, & Borzyskowski, 1999; Willey & Bemel, 2007). The various abnormalities associated
with this condition are discussed in further detail in chapter two, as well as the five different types of CRS.

Very often individuals with CRS will use wheelchairs, even if they do not suffer from paralysis. This is because the spinal abnormalities experienced, as well as the tightening of the muscles around the pelvis, lead to difficulties with walking (Sen & Patel, 2007). For this reason Rogers (2001), president of ISACRA who has CRS, stresses the importance of adapting the school’s physical environment to accommodate learners with CRS, because small stature that requires height adjustments of furniture, as well as to accommodate a wheelchair.

Due to the rarity of the condition, many doctors have very little knowledge of CRS and have had little experience working with individuals with the condition (ISACRA, 2013). If medical practitioners have such little knowledge of this condition, it is likely very few professionals involved in education have any knowledge and experience in working with children with this rare disability and therefore, there may be a lack in adequate support for these learners within the school environment. This motivates the relevance of conducting a study into the support needs of a learner with CRS within a school for learners with physical disabilities.

While there is much information on what CRS is, its cause, and the physical implications, there has been very limited research into the educational and social-emotional implications related to this rare spectrum of abnormalities. However, if one considers the associated physical abnormalities it is possible to see there is also a need for emotional support. When bladder difficulties, incontinence and catheterisation are experienced, emotional difficulties can cause the individual to experience stigmatisation and low self-esteem (Filce & LaVergne, 2011; Wilmshurst, Kelly, & Borzyskowski, 1999). It is possible for similar responses to develop in response to the physical abnormalities associated with the condition. Likewise, support may be needed, as research conducted by Persson and Ryden (2006) has found that the perceptions a person has regarding their disability is directly related to the individual’s ability to cope with their disability. Therefore, it is likely that children with CRS will need emotional support in order to perceive this syndrome in a positive light and develop the necessary coping skills. Furthermore, academic support will be needed as the condition causes frequent absences from school and from the classroom due to catheterisation, adaptations for physical activities may be needed, as well as giving home tasks and adjusting assessments (Filce & LaVergne, 2011).
It is evident that there is much research into the physical support needs of individuals with CRS, as seen in the works of Boulas (2009), Cuevas (1995), and Gillis, Bader, and Boyd (2013) among others. However, there is very little information available regarding the social-emotional and academic support needs for a learner with CRS. Therefore, what support can be implemented for these learners in special needs schools?

1.3 ORIENTATION AND STATEMENT OF THE PROBLEM

In 2013, as a student registered counsellor, I worked with Jo-Anne, who has CRS. She is a fourteen-year old learner at a special school for physically disabled learners. Jo-Anne’s condition was noted at birth but because of poor care during infancy, she only began receiving treatment and surgical interventions after the age of two.

During the time that I was working with Jo-Anne, I investigated CRS in order to identify any specific emotional and academic needs she may have. It was during this time that I realised the limited research into the aspect of CRS. This caused me to consider the emotional, academic, and social support needs of an individual with this condition.

Due to the limited amount of research regarding the cognitive, social-emotional, and academic needs of this condition, as a future educational psychologist, it is necessary to understand these aspects of the condition in order to provide accurate and appropriate support when working with an individual with this condition, within a special school environment. Therefore, a case study into the support needs of Jo-Anne could assist educational psychologists in future work with others who have this condition. Additionally, the findings could assist the special needs school in this study in providing appropriate accommodation, adaptations and interventions for Jo-Anne and similar learners.

1.4 RESEARCH QUESTION

The above discussion regarding the background and motivation for the study has led to the construction of the research question for this study, namely:

“What support is needed for learners with caudal regression syndrome (CRS) in a special needs school?”
The focus for this case study was targeted at the knowledge and understanding of staff at the school regarding Jo-Anne’s condition, and how they use this knowledge to best support her.

1.5 AIMS OF THE STUDY

The aim of this study was to explore and describe the support needs of a learner with CRS in a special school, as well as making recommendations regarding the support needs of the learner. This aim will be achieved through the following sub-aims:

- To conduct a literature review of the different physical abnormalities and types of CRS, specifically considering the relation of this literature to the case. This information would also guide me, as the researcher, to better relate the research from this case to other settings and individuals.
- To investigate the views of Jo-Anne’s educators, therapists, mother and herself in order to appreciate their understanding of the condition and support requirements.
- To attempt to gain insight into the support needs Jo-Anne has, in relation to the condition and in what ways her foster mother, therapists and educators have been able to provide support.
- Finally, to develop guidelines for supporting learners with CRS in schools.

1.6 RESEARCH ASSUMPTIONS

For the purposes of this study, there are a few assumptions that have been identified. The data collected may reveal that adequate support is being provided to meet the needs of Jo-Anne because the school is for learners with physical disabilities. Therefore, the educators, management, and therapists should have an understanding of the general support needs of learners with disabilities, such as making accommodations for wheelchairs, adjusting the curriculum where necessary, for example, physical education, as well as having an understanding of what is involved in catheterisation. This assumption is based on the fact that the Education White Paper Six (Department of Education, 2001), and the Screening, Identification, Assessment, and Support ([SIAS], Department of Basic Education, 2014) documents both state that special schools are designed for learners who require a high level of support and this should be provided in an environment where the staff in the school have specialised knowledge and training in order to provide adequate support. Therefore, I would
assume that the school in this study is meeting some of Jo-Anne’s support needs, as the staff should have specialised knowledge and training around disability.

However, due to the rarity of CRS, it is also assumed that although information on more common disabilities, such as cerebral palsy and multiple sclerosis, is readily available, as well as having experience supporting learners with these disabilities, the same cannot be said for CRS. Therefore, the school may be providing some forms of support; however, they may not be meeting all of Jo-Anne’s support needs due to a lack of knowledge and experience with her disability, CRS.

1.7 CONCEPT CLARIFICATION

In order to better understand the focus of this study, as well as the information that will be presented throughout, there are concepts that first need to be clarified. This section will clarify how certain terms, such as special schools, will be used in terms of this study.

1.7.1 Caudal regression syndrome

Caudal regression syndrome (CRS) is a rare condition affecting the formation of the vertebrae in the spinal column. In this condition, the spinal column is formed with an absence of some of the vertebrae in the lumbar and sacrum (Gillis, Bader, & Boyd, 2013; Jadav, Gandhi, Soni, & Desai, 2012). There are five different types of this condition and the spinal malformations differ with each type, affecting the severity of the condition, as well as having an impact on the individual’s range of movement (Jadav, Gandhi, Soni, & Desai, 2012; Sen & Patel, 2007). The literature review of this study will discuss all five types of the condition. However, throughout the discussion in this report, the term caudal regression syndrome will refer specifically to type III, as this is Jo-Anne’s type.

1.7.2 Foster mother

According to South African legislation, foster care is the placement of a child in the care of a suitable person who is not the parent or guardian. This placement is temporary and the child remains in the care of the foster parent for as long as the court order indicates. Once this order has lapsed, the court order is reviewed and can be extended (South African Government, 2015).
Jo-Anne lived with her foster mother, Bronwyn⁵, and had been in foster care for 12 years at the time of the study. Throughout the discussion in this report, the term foster mother, mother, and mom will be used interchangeably to refer to Bronwyn, Jo-Anne’s foster mother. When reference is made to Jo-Anne’s biological mother, the terms birth mother or biological mother will be used.

1.7.3 Special school

According to the Education White Paper Six (Department of Education, 2001), special schools are schools dedicated to providing a high-intensive level of educational support to learners in need of such requirements. Within a specialised site, such as special schools, there should be an availability of the range, nature, and adequate level of support (Department of Basic Education, 2015). In this study, the term special school refers specifically to a special school that caters for learners with physical disabilities.

1.8 PROGRESSION OF RESEARCH REPORT

The chapters will be arranged as follows:

Chapter one aims to present the background and rationale for the study. It also seeks to explore and explain the aims of study, as well as providing an overview of the research design and methods of data collection and analysis. The assumptions held by the researcher are also identified.

Chapter two provides a theoretical framework that includes a detailed discussion of the literature consulted and reviewed for the study. The purpose is to form a sound theoretical base in order to ground the investigation.

Chapter three provides details of the research design and methodology, which focuses on an in-depth case study. The methods of data collection and analysis will be clarified for the reader. The chapter ends by evaluating the ethical measures taken, as well as reviewing the trustworthiness of the study.

---

⁵ Bronwyn is a pseudonym, which has been selected to protect the identity of the individual in this study
**Chapter four** presents a detailed description of the case and subsequent findings in order to answer the research question. This is illustrated in a qualitative narrative, where the views of the participants are discussed by exploring their views regarding the support needs of Jo-Anne, and how these needs are met.

**Chapter five** has the purpose of concluding the enquiry by discussing the findings of the study as well as the limitations and recommendations for schools, parents, and for future research within a similar context.

**1.9 CHAPTER SUMMARY**

This chapter aimed to clarify and orientate the study by contextualising the research. Background information was first provided, which was related to the current framework of inclusive education in South Africa, as well to CRS. The motivation for the study was discussed, specifically considering the necessity for more information on the support needs of CRS, as well as how working with Jo-Anne allowed the researcher to identify this need.

This was followed by a discussion of the problem statement and the formation of the research question, specifically, “What support is needed for learners with caudal regression syndrome (CRS) in a special needs school?” Once the research question was discussed, the aims of the study were indicated and this was followed with a discussion of the researcher assumptions. The chapter concluded with an outline of the progression for the report.

In the next chapter, a literature review will be presented. In this review, CRS will be discussed in detail in order to gain a better understanding about the condition’s types, symptoms, and prognosis. This chapter will also discuss the relevance of inclusive education, the role of the educational psychologist, as well as an explanation of Bronfenbrenner’s bioecological model on human development.
CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

Caudal regression syndrome (CRS) is a rare condition affecting the formation of the vertebrae in the spinal column. This in turn affects the spinal nerves and the range of movement the individual has, as well as leading to a variety of comorbid symptoms influencing the skeletal structure and the internal organs of the child.

It is important to have a clear understanding of the condition in order to understand the case discussed in this study, which is specifically looking at the support needs of a fourteen-year old female learner, Jo-Anne, with CRS, attending a special school. A literature review is needed to conceptualise the study and to assist in the understanding of the background of the study, as well as to analyse data appropriately. This understanding will ultimately assist in strengthening the argument within the study.

The first part of the literature review focusses on CRS. This discussion describes the condition in medical terms, as well as enhancing an understanding of this condition by comparing the spinal structures associated with this condition to a typically developed spine. The associated symptoms and characteristics are discussed, as well as the types of CRS and the causes associated with this condition. The treatment, care and the prognosis of this condition is discussed in terms of the different domains of functioning, specifically, cognitive, social-emotional and academic functioning.

However, this literature review not only focusses on literature relating to CRS, but also considers inclusive education in South Africa and the role that this will play in supporting and accommodating a learner with this syndrome.

A framework for discussing the case in this study is explored, namely the bioecological model for human development. This model is adapted to create an ice-cream cone, visually representing Jo-Anne’s development and support needs. This model focusses not only on conceptualising a case in terms of its context and systems but also considers the different

---

6 Jo-Anne is a pseudonym, which has been selected to protect the identity of the individual in this study.
domains of functioning. Therefore, in order to understand the influence of context, it is necessary to understand Bronfenbrenner’s bioecological model. This discussion introduces the different systemic levels, and shows how these are interrelated to one another and most importantly, indicates the relevance of these systems to caudal regression syndrome.

This chapter is concluded by considering the relevance and the role of an educational psychologist in providing support when working with clients that have a rare medical condition such as caudal regression syndrome.

2.2 CAUDAL REGRESSION SYNDROME

CRS also termed caudal dysplasia, sacral agenesis, lumbar sacral agenesis, caudal regression sequence or sacral regression (USA Social Security Administration, 2014) is a spectrum of abnormalities. It generally involves the abnormal development of the sacrum and lower lumbar vertebrae of the spine, as well as causing a range of other malformations to develop in the individual (Jadav, Gandhi, Soni, & Desai, 2012). Odent (2010) states that this congenital syndrome is rare, occurring in approximately 1 in 50 000 to 1 in 100 000 births. The prognosis and the impact on daily functioning will vary depending on the type, cause, symptoms, and severity of the condition. Due to these variances, the support needs of each individual with this condition will be different (Odent, 2010).

In order to better understand CRS, its various types, as well as the symptoms and characteristics, one first needs to have an understanding of the human spine. The spinal cord is part of the central nervous system. It has the function of controlling the sensation, autonomic responses, and motor control of the individual, by relaying information to and from the brain and the remainder of the central nervous systems through the spinal nerves (Nogradi & Vrbova, 2013).

The spinal cord and spinal nerves are protected by the bone structure that forms the vertebral column, which is made of five parts. Working from the top of the spine (Figure 2.1), the first section of vertebrae is the cervical spine made up of seven vertebrae. Next is the thoracic sections made up of twelve vertebrae. The thoracic section is followed by the lumbar section, which contains five vertebrae. Next is the sacrum that contains five vertebrae and finally, the coccyx, the tail bone, made up of four vertebrae. The lumbar, sacrum and coccyx are each made up of separate vertebrae that have been fused together. The sacrum has passages for the spinal
nerves to pass through, allowing the nerves to spread into the pelvis and legs. The lumbar section of the spine supports majority of the trunk’s weight (Johns Hopkins Medicine, n.d; Taylor, 2014).

![Spine Diagram](http://brentbrookbush.com/spine-and-trunk-muscles/)

**Figure 2.1. An example of a typically developed spine**

As can be seen in Figure 2.2, the spinal cord runs down the body directly into the pelvis, and the pelvis has the function of supporting the spinal column and protecting the abdominal organs. Johns Hopkins Medicine (n.d) describes the pelvis as a basin shaped structure that is made up of three pelvic bones; these are also the hipbones. These bones are the ilium, which is the broad flaring section of the pelvis that one is able to feel when placing their hands on their hips, the pubis, which is the lower front part of the pelvis, and the ischium, which is the part of the pelvis that forms the hip joint (Figure 2.3). The sacral bones flow into the pelvis, and the coccygeal bones are contained in between the left and right ilia bones (Figures 2.2 and 2.3).

The spinal cord and the pelvis is an intricate system made up of bones, nerves, soft tissue, and muscles. All aspects of this system work together to not only transmit information through the central nervous system but to also allow movement in the body and legs. This can allow one to consider the vast implications of a syndrome such as CRS, when a part or parts of this intricate system are no longer present in the body. With this understanding of the spine, a discussion on the types, causes, symptoms, treatment, and prognosis of CRS will follow.
Figure 2.2. An example of a typically formed spinal cord into the pelvis

Figure 2.3. An example of a typically developed pelvis

2.2.1 Aetiology and types

(a) Aetiology

The cause of CRS is commonly associated with diabetes in the mother during gestation, as this increases the risk for various congenital anomalies associated with this syndrome (Jadav, Gandhi, Soni, & Desai, 2012). It has been found that the incidence is 200 times more likely when maternal diabetes is present (Odent, 2010). It has also been found that environmental factors can also play a role in the condition. Such environmental factors include alcohol abuse, retinoic acid (a nutrient needed to help cells grow and develop, especially as an embryo), hypoxia (which is a lack of oxygen), and an imbalance of amino acids (News-medical.net,
2014; Nord, 2013). Odent (2010) states that a multifactorial aetiology should be considered, this would include considering vascular hypoperfusion and a genetic predisposition.

It has also been found that a genetic basis of the condition can be linked to a mutation in the ‘HLXB9 homeobox gene on chromosome 7’ (Jadav, Gandhi, Soni, & Desai, 2012, p. 130). The homeobox gene is known to play a role in the regulation of human embryonic development. When mutated, the gene is unable to encode the nuclear protein HB9 leading to a lack of functioning in the gene (Gillis, Bader, & Boyd, 2013). Other research suggests that a mutation of the VANGL1 gene, located on chromosome 1, is associated with the syndrome and this mutation would be inherited as an autosomal dominant trait from an affected parent (NORD, 2013).

The syndrome is known to occur at around the fourth week of gestation when there has been an insult to the caudal eminence, leading to failure of canalisations and retrogressive differentiation, leading to partial or complete sacral agenesis (Jadav, Gandhi, Soni, & Desai, 2012). In more severe cases, the condition can be identified during the first trimester; however, further magnetic resonance imaging (MRI) scans will need to be conducted on the new born in order to determine the extent of the condition and the associated malformations. Research suggests that the incidence is the same between males and females, and siblings are rarely affected (Jadav, Gandhi, Soni, & Desai, 2012; Odent, 2010).

In terms of this study, the development of the condition is largely attributed to maternal alcohol abuse throughout the pregnancy and there is no known maternal diabetes. Jo-Anne’s condition was not identified during pregnancy, as her biological mother did not go for regular sonar scans and did not have regular visits to a clinic during the pregnancy. Therefore, the condition was first noticed at Jo-Anne’s birth.

(b) Types of Caudal regression

Research into CRS, conducted by Renshaw, has led to five different types being identified. Type I (Figure 2.4) involves total or partial sacral agenesis, which is unilateral (Sen & Patel, 2007). Therefore, the child will be born with the sacral vertebrae or with a partial absence of the sacral vertebrae on only one side of the spinal column.

Type II (Figure 2.4) would present with variable lumbar and total sacral agenesis and has the ilia articulating with the sides of the lowest vertebra (Sen & Patel, 2007). With this type, the
individual would have a total absence of the sacrum, with or without the absence of some of the lumbar vertebrae. The remaining vertebrae, either in the lumbar or thoracic sections, would be resting on top of the hipbone (ilia articulating). Due to the missing vertebrae, there is no support for the nerves contained in that area of the spinal cord. Therefore, one would be able to see a sack of soft tissue protruding from the lower back of the individual, called a meningocele (Gillis, Bader, & Boyd, 2013). Cuevas (1995) discusses that this is the most common form of CRS.

**Figure 2.4. Examples of spinal cords with CRS types I and II**

Type III has variable lumbar and total sacral agenesis with the caudal end plate of the lowest vertebrae resting above a fused ilia or an iliac amphiarthrosis (Sen & Patel, 2007). Similar to type II, in this type there is no sacrum with partial or full loss of the lumbar spine. However, in this case, the hipbones may be fused together at the back of the pelvis; the caudal end plate (end of the spine) will rest on top of the hipbones. If there is no fusion of the hipbones, an amphiarthrosis occurs, which is when the caudal plate creates a ‘fake joint’ with the hipbone. In either case, the fusion of the ilia will restrict the movement of the individual, as the range of movement in the pelvic area becomes limited.

Jo-Anne presents with this type of CRS and has no sacrum, and only a very small segment of her lumbar vertebrae is present. Jo-Anne’s last fully formed vertebrae before her pelvis is the L1 vertebrae, which can be seen in Figure 2.1. According to Jo-Anne’s foster mother, between her pelvis and the L1 lumbar vertebrae is a non-descript bony mass and then her pelvis is relatively typical. This disconnection between the spinal column and her pelvis has caused Jo-Anne to have limited leg movement and therefore, she presents with paralysis. Jo-Anne has limited sensation in her upper legs.
Type IV involves the fusion of soft tissues of both the lower limbs (Sen & Patel, 2007). In this type, the fusion seen in type III is coupled with the fusion of the muscle and tissue in the hips and pelvis, causing an increased level of restricted movement. Type V is also known as ‘sirenomella’ or ‘mermaid syndrome’, where the child is born with a single femur and tibia (Sen & Patel, 2007). In this case, there is extreme fusion of tissue and bone in the pelvis and legs, causing the legs to fuse into one, giving the appearance of a mermaid’s tail.

![Figure 2.5. Examples of spinal cords with CRS types III, IV, and V](http://boneandspine.com/sacral-agenesis/)

### 2.2.2 Symptoms or characteristics

Research conducted into CRS indicated various irregularities would indicate CRS and the presence of such irregularities would vary between cases. Some of these irregularities include:

- A range of orthopaedic anomalies such as deformities of the feet, flexion contracture of the knees and hips (Figure 2.6), which is the tightening of the muscles into a bent or flexed position giving the appearance of ‘frogs legs’; dislocated hips, deformed pelvis, or missing ribs (Sen & Patel, 2007).
- Congenital heart defects and midline facial cleft (Sen & Patel, 2007).
- Partial agenesis of the lumbosacral spine, which is the absence of segments of the lumbar spine or a fractional absence of the sacrum that can affect the motor and sensory functioning of the body as well as causing there to be no bladder and bowel control (Cuevas, 1995).
• Imperforate anus, which occurs when there is no opening at the end of the digestive tract where the anus is found (Seattle Children’s Hospital, 2014).

• Atypical formation of the external genitalia (Jadav, Gandhi, Soni, & Desai, 2012).

• Central nervous system malformations including meningocele (sack of spinal fluid), meningomyelocele (which is a sack containing spinal nerves, shown in Figure 2.6) and spina bifida occulta (Boulas, 2009).

• Respiratory problems may arise due to the abnormal shape and size of the chest and lung volumes may be altered due to the absent thoracic bones, scoliosis, and short torso (Boulas, 2009).

• Bilateral renal aplasia, which is the most profound form of renal agenesis, characterised by the complete absence of kidney development causing there to be an absence of renal functioning leading to pulmonary hypoplasia (Schreuder, 2014).

• Increased incidences of ectopic kidneys, where the kidneys are located above, below, or opposite their usual position, and pulmonary hypoplasia leading to Potter sequence, which is the incomplete development of lung tissue causing respiratory problems making up part of a constellation of abnormalities including facial, skin, and limb abnormalities. This condition is often fatal to new-born infants (Chin, 2014; NKUDIC, 2011; Weerakkody, Stanislavsky, & Knipe, 2005).

More noticeable features suggesting CRS are shortened trunk due to the missing segments in the spine, narrow hips and poor development of the gluteal muscles known as hypoplastic gluteal muscles, and a shallow intergluteal cleft, which is a shorter groove between the buttocks extending from under the sacrum to the perineum. Some individuals may also present as having severe lower limb paralysis, as well as having a clubbed foot and contracture of the knee joints (Jadav, Gandhi, Soni, & Desai, 2012; Naidich, et al., 2009; Sen & Patel, 2007; Sullivan, Brooks, & Breen, 2014).

In many cases, individuals with CRS may experience a combined sensory-motor paralysis, a slight or partial paralysis, with motor deficits dominating the other symptoms associated with this condition. Thus, the level of motor deficit is generally higher than the level of sensory deficit. One is able to see that sacral spinal sensations can remain even in the most severe cases when paralysis occurs (Jadav, Gandhi, Soni, & Desai, 2012). In other words, the individual may still experience the sensations created by the nerves despite the missing vertebrae since the spinal nerves are still present.
Jo-Anne’s symptoms include lower limb paralysis due to the partial absence of the lumbar spine and full sacral agenesis. Despite being paralysed, Jo-Anne has retained some sensation in her lower limbs. Jo-Anne has bladder and bowel malformations that have been surgically treated and she will require the use of a catheter for the remainder of her life. Jo-Anne also presents with hip flexion contracture in her left hip. She is beginning to develop arthritis in her left hip where the bone has been operated on. Jo-Anne has both a hard and soft cleft palate, although this can be a symptom of CRS in rare cases, her foster mother and doctors feel that her cleft palate is related to exposure to alcohol in utero and is not a symptom of CRS.

**2.2.3 General treatment and care**

It is important to remember that the CRS itself is an irreversible condition and the treatment provided to individuals and their families is supportive with the aim of targeting the symptoms and related difficulties as they arise (Boulas, 2009). In order to adequately treat symptoms and provide support as needed, a multidisciplinary team of professionals will be required.

(a) Medical treatment and care

The individual symptoms and characteristics of the condition will generally determine the treatment that is needed in each case. Depending on the symptoms experienced, individuals may require surgeries to treat the various physical malformations experienced, such as urological and cardiac abnormalities.

Within a multidisciplinary team, the medical specialists involved in the case could include paediatricians, neurosurgeons, neurologists, urologists, orthopaedic surgeons, cardiologists, kidney specialists as well as physical and occupational therapists. Early intervention is key to
ensuring that individuals with CRS reach their full potential, therefore a vital member of the team is the neonatal nurse in terms of providing the initial care to the infant (Boulas, 2009; NORD, 2013).

It is common for individuals with neurogenic bladder and other renal malformations to experience frequent urinary tract infections, as well progressive damage to the renal area. Some patients may benefit from long-term catheterisation, however preserving renal function as much as possible is considered important. A colostomy will be required for cases where there is a closed or imperforate anus, other children may be required to use nappies due to their bladder and bowel difficulties (Boulas, 2009; Rogers, 2011; U.S.A Social Security Administration, 2014).

The type of orthopaedic malformations, such as severe flexion contracture of the joints, as well as the degree to which spinal segments are not present, may cause the individual to be in a wheelchair, because the individual may be unable to walk or stand.

The medical treatment Jo-Anne has had to improve her CRS symptoms include a surgical procedure known as osteotomy, which is a procedure where bone is cut around a damaged joint in order to improve movement (Healthwise, 2014). Jo-Anne underwent this produce in 2006 to improve the flexion contracture in her left hip, the surgery aimed to manipulate her left hip, knee, and ankle in order to create a more comfortable seated position for Jo-Anne when she is in her wheelchair. Jo-Anne experienced difficulties with poor wound healing in her hip, and further debridement surgeries were required. Debridement is a surgical procedure used to remove dead tissue and any contamination that are preventing a wound from healing due to preventing a good supply of blood in the wounded area (Baylor, Scott, & White Health, 2013). In 2007, Jo-Anne had abdominal surgery to allow for independent bladder and bowel management. Since this surgery, Jo-Anne requires a catheter, which she manages independently.

(b) Social-emotional treatment and care

Although medical care is vital to the individual with CRS, it is important not to neglect the fact that both the individual with CRS and the family will require support in order to cope with this condition. For this reason, social workers and psychologists should form part of the multidisciplinary team, and support to the family should begin as soon as the condition is diagnosed during pregnancy (Boulas, 2009; NORD, 2013).
As stated, the neonatal nurse has a vital role in terms of providing initial support to families. Specifically, these nurses help the family understand what to expect after the birth and what to expect of the care the infant will need in the future, as well as the implication of the specific malformations and abnormalities (Boulas, 2009).

It has been found that children with bladder and bowel dysfunctions, such as those seen in CRS cases, will be affected physiologically and psychologically. Research conducted by Filce and Lavergne (2011) indicate that support is needed for the affected individual as well as their family in various ways. Firstly, support is needed to assist in diminishing the stigma attached to these dysfunctions. It has also been found that due to the severity and chronic nature of these conditions, the child’s ability to participate in certain school activities may be negatively impacted, such as swimming for a child that struggles with incontinence. The emotional distress and anxiety caused by bladder and bowel dysfunctions can lead to decreased school performance (Filce & LaVergne, 2011). This effect on school performance is most likely due to the fact that anxiety negatively affects memory function and this has a negative effect on the ability of the child to reach his or her cognitive potential (Mazzone et al., 2007).

Research into physical disabilities has indicated that an individual’s quality of life is directly linked to the perception the individual has of their disability and personal possibilities. Therefore, the coping strategies of the individual would play an important role in the way in which they perceive their disability (Persson & Ryden, 2006). A study on the themes of effective coping with a physical disability, conducted by Persson and Ryden (2006), indicate that one’s perception of his or her disability and perceived quality of life is related to where the individual falls on two continuums, specifically acknowledgment of reality versus creation of hope and trust in oneself versus trust in others. Within these two continuums, the disabled individual will need to work through various tasks, specifically engaging in problem-reducing actions, experiencing a change in one’s values, issues around social trust and self-trust and finally minimising the feelings of threat that are related to the disability. Accordingly, coping and perceived quality of life would be experienced when there is a balance between feelings of hope while also acknowledging the reality of the situations, and their limitations, as well as experiencing a balance between trust in oneself and others in terms of being accepted and supported (Persson & Ryden, 2006).

Therefore, it could be argued that an individual with CRS may require psychological interventions to change the perceptions they have of the condition in order to potentially
improve coping strategies. It could also be beneficial to assist individuals with CRS in finding others with this condition or with similar conditions so that they can provide support to one another. Although the condition is rare, it might be possible to create such a support group through social media networks. Examples of such support networks include Facebook, where there is small CRS community that spreads information and offers support, and the ISACRA website, which provides links to various blogs (ISACRA, 2013). The focus of this study was on identifying the support needs of Jo-Anne, specifically the social-emotional needs.

2.2.4 Accommodations required in the school environment

Children with CRS generally present with no cognitive delays or intellectual impairments, however, school supports are required, and this will necessitate the co-operation of the multidisciplinary team. Some learners may be small in stature, with a small trunk, due to the missing spinal segments. These learners will need assistance reaching basins and tables, and adjustments, such as small steps by the basin, will be required. Some learners may be in a wheelchair due to their spinal deficits and orthopaedic abnormalities, and the school will need to be wheelchair friendly. Creating such an environment involves more than having ramps, there should be enough space in the classroom for the learner to manoeuvre his or her chair, enough space to be able to access the bathrooms, and alternative activities during physical education will be required. Learners who are paralysed and have sensation in their legs may require intervention and support from the physical therapists when writing exams, as they can experience pain in their legs.

Bladder difficulties are often neurogenic in nature, which is specifically related to difficulties with bladder control as opposed to a loss of sensation in the bladder (Jakobsen, Holm-Bentzen, & Hald, 1985). Individuals with neurogenic bladder difficulties either have an overactive bladder, causing little control in urination and a suffer urge to urination causing incontinence. Alternatively, individuals may have an underactive bladder, which occurs when the bladder does not empty properly, creating pressure in the bladder causing the surrounding muscles to become weakened leading to leakage of urine after going to the bathroom (Cleveland Clinic Foundation, 2012).

Based on these difficulties associated with bladder control, some learners will require assistance to change nappies, empty colostomy bags, and to ensure clean catheterisation in order to prevent infection. In such cases, the school might need to allow the learner to come to
school with a helper in order to provide assistance, unless the school has nursing staff available to assist the child. Other accommodations would include ensuring the individual has spare clothes at school in case of soiling (Filce & LaVergne, 2011; Odent, 2010; Rogers, 2011). These learners will require more and longer bathroom breaks than their peers because of their bladder and bowel difficulties, which will result in large amounts of class time being missed (Filce & LaVergne, 2011).

Finally, some learners with CRS may experience a higher rate of absenteeism due to doctor and therapy appointments and requiring time off for surgical procedures (Filce & LaVergne, 2011). Teachers will need to implement a system to ensure learners are able to catch up on missing work, have extensions for assignments should they fail to submit because of medical related issues, and be able to write tests that they may have missed when absent.

2.2.5 Prognosis

Since CRS has a spectrum of symptoms and severity, the prognosis of the condition will vary between individuals (NORD, 2013).

(a) Physical

The five different types of CRS not only vary according to symptoms and severity, they also vary in terms of prognosis with type I and II being associated with the best prognosis. This is because both these types generally have a more stable midline spinal column because of spinal absences being unilateral. Therefore, with orthopaedic intervention they may be able to walk. However, the presence of a meningocele reduces the likelihood of the individual being able to walk. Types III, IV, and V are frequently associated with neonatal death because of cardiac, respiratory, and renal complications. These deaths generally occur within the first 28 days. In cases where the infant survives, a variety of neurological, orthopaedic, and renal interventions will be required (Boulas, 2009; USA Social Security Administration, 2014).

(b) Cognitive and social-emotional

Most research conducted on CRS has indicated that in the majority of cases individuals will have no cognitive difficulties (Boulas, 2009; Rogers, 2011). However, individuals with CRS may experience decreased academic progress because of the frequent absenteeism associated with the condition. Missing instruction time and opportunities for learning leads to inadequate
levels of knowledge and a decreased understanding of academic content (Filce & LaVergne, 2011).

Literature shows that there is little evidence of social-emotional difficulties associated with the syndrome itself. However, the symptoms and medical conditions associated with the condition may affect the social-emotional functioning of the individual. Specifically, the way in which the individual is able to cope with their physical disability will have a direct influence on their perceptions of their disability, affecting the quality of life experienced by the disabled person (Persson & Ryden, 2006) and in turn the prognosis of the condition. Similarly, Filce and LaVergne (2011) indicate that the effect of having chronic bowel or bladder problems might cause increasing levels of anxiety related to their condition and around being accepted by their peers, and they might experience a decreased self-image and lower self-esteem. Therefore, one is able to see that the factors related to the psychosocial prognosis of CRS will stem from the associated symptoms such as paralysis, limb deformities, and bladder and bowel dysfunction.

2.3 INCLUSIVE EDUCATION

The Education White Paper Six embraces equality, respects human rights, and recognises the diverse needs of learners in this country and seeks to ensure that all learners despite disability, background, class, gender and race are able to access quality education (Department of Education, 2001; Engelbrecht, 2006). This policy moves away from a system of organising schools based on the categorisation of disabilities. It aims to provide education for disabled learners based on the intensity of support needed to meet their unique needs and abilities. It also includes strategies in order to identify learners with disabilities, and how they will be supported and incorporated into full-service schools, as well as to provide the necessary interventions to assist educators in coping with the diverse needs (Department of Education, 2001). The screening, identification, assessment, and support (SIAS) strategy has been developed and implemented to assist schools to reach the goals identified in the Education White Paper Six (Department of Basic Education, 2014).

Inclusion is not the same as the process of integration. Integration is based more on the medical model and focusses on assessing and diagnosing in order to provide treatment to allow learners to ‘fit in’, therefore placing an emphasis on changing the learner (Department of Education, 2001; Engelbrecht, 2006). In contrast, inclusion recognises that all learners are different and support should be provided to all learners in a manner that meets the unique needs and abilities
of all learners. From an inclusion perspective, the environment should change to support the learner (Department of Education, 2001).

It is important to consider that the inclusive education policy moves away from the medical model of the past, where children were labelled and categorised in order for them to receive an intervention that was curative in nature and not supportive. The view today is one that is more systemic and considers the influence environmental and contextual factors have on learning and behavioural difficulties, as opposed to only viewing the difficulty as being a biological predisposition within the child (Lomofsky & Lazarus, 2001). Such environmental factors can be found in the family, school, the broader education system, as well as the social, economic and political context.

Specific contextual factors that have been found to influence the learning and behaviour of children includes poverty, alcohol and drug abuse, violence, sexuality, lack of access to medical care, the HIV/AIDS pandemic and exposures to political violence (Donald, Lazarus, & Lolwana, 2012; Engelbrecht, 2006; Lomofsky & Lazarus, 2001).

The inclusive education policy of South Africa encompasses providing support to all learners experiencing barriers to learning, not only to learners with a physical disability, intellectual impairment, or condition that can be medically diagnosed or labelled. Support will also include those who are experiencing barriers because of their context, such as poverty.

It should be noted that there is a role for special schools in the inclusive education system. According to the Department of Education’s White Paper Six (2001), special schools are required for those learners who require such an intense level of support that they would not be able to cope in a mainstream environment. The staff working in such settings should have specialised skills and training for supporting the learners in their care, and therefore, it is the role of special schools to act as resource centres, sharing their skills and knowledge with other schools, especially full-service schools.

The SIAS process developed by the Department of Basic Education (2014), aims to facilitate the provision of a range of support programmes, services, personnel, and resources for special and ordinary schools. The focus is on the range, nature, and level of support programmes that are provided, rather than having a focus on each individual learner. Therefore, highly specialised support resources and facilities required for learners with high support needs can be provided at one site, such as special schools.
The special school in this study is one such school providing highly specialised support for learners with physical disabilities who will require a high level of support for their disability. The school is wheel-chair friendly and has on-site physiotherapists and occupational therapists to provide support and care to the learners, as well as having a small nursing staff to provide medication and medical support when needed. According to the policy laid out in the Education White Paper Six, the assumption is that in a school such as this the curriculum is flexible in order to support and accommodate all learners. The school environment is accessible to all learners and the educators, therapists and school management teams all have appropriate knowledge on not only the curriculum but also on the disabilities they encounter and the types of supports required (Department of Education, 2001).

Therefore, this study will be considering the support needs of a condition as rare as CRS and how these needs are met within a special school for physically disabled learners. However, in considering the support needs of a learner with CRS, a systemic and holistic view of the case is needed. The bio-ecological model on human development (Bronfenbrenner, 2005) has been explored and adapted to discuss the case in this study.

2.4 ADAPTING THE BIO-ECOLOGICAL MODEL ON HUMAN DEVELOPMENT TO VISUALLY REPRESENT HISTORICAL CASE INFORMATION

The bio-ecological model for human development considers development to be a phenomenon of continuity and change in the bio-psychological characteristics of human beings, which extends throughout the life course and across generations (Bronfenbrenner, 2005). Therefore, this model allows one to consider the influence various systems, including time, have on the development and experiences of a child. As was seen in the policies of inclusive education, contextual factors play a large role in the educational experiences of a child. Similarly, contextual factors influence all aspects of individual functioning.

For this study, an ice-cream cone model will be used to represent the historical information relating to Jo-Anne’s life visually, including her developmental history and her different domains of functioning. This visual representation will also allow me to consider the impact of the different systems, as discussed in the bio-ecological model, on Jo-Anne’s development. Therefore, an understanding of Bronfenbrenner’s model is necessary in order to understand the case presented in this study and the role of the various systems.
2.4.1 Bronfenbrenner’s model of child development

Bronfenbrenner (2005) notes that the “characteristics of a person at a given time in his or her life are a joint function of the characteristics of the person and of the environment over the course of that person’s life up to that point in time” (p. 108). Accordingly, Donald, Lazarus, and Lolwana (2012) discuss that when considering the development of a child, Bronfenbrenner identified four interacting dimensions that are central to developmental processes. These dimensions are person factors such as temperament, process factors such as family interactions, contexts, and time. The interactions between the person and process factors affect what is known as proximal interactions, which are face-to-face interactions and interactions occurring in long-term relationships such as those seen in the family. By understanding the proximal interactions experienced by the child, information on the reciprocal influences seen in the family, school, and greater community can be gathered. The personal, process, and interaction factors are all affected by time as the child changes and develops.

The four factors interact within the various interrelated contexts or systems that are part of the child’s life (Figure 2.7). The first of these interrelated systems is the microsystem, which is made up of the interpersonal relations experienced between the individual and their systems that they are part of daily life; these systems include the family, peers, and school. These systems contain other individuals with distinctive characteristics in terms of temperament, personality, and belief systems (Bronfenbrenner, 2005; Swart & Pettipher, 2005). In relation to this study, the microsystems of the individual will affect the type of care they receive in the home or school; the disability itself will affect the interactions between the individual and others within the microsystems.

The second level of systems is that of the mesosystems, which are considered the processes taking place between two or more microsystems containing the developing individual in question (Bronfenbrenner, 2005). Therefore, what happens in one microsystem will have an effect on the child’s functioning in another microsystem (Donald, Lazarus, & Lolwana, 2012). In terms of this study, an example of this interaction is the information the mother gives to the school regarding CRS and Jo-Anne’s needs. This will have some effect on the understanding she receives at school.

The third level of systems is termed the exosystem, which are systems that the child may not directly be a part of but they influence the child because of the effect they have on the
microsystems. Examples of exosystems include the education system, the health services, the media, community organisations, and the parents’ place of work (Bronfenbrenner, 2005; Swart & Pettipher, 2005). Once again, when considering this model in relation to the study, the media’s way of portraying disabilities can affect the way in which a child is accepted by his or her peers. Similarly, a lack of health care services in the community could place a strain on the ability of the parents to care for the child or may affect the quality of life for the learner.

The fourth and final level of systems is the macrosystem. These systems are the dominant economic and social structures, as well as the values, beliefs, and religious or cultural practices that influence all other social structures, thus causing them to be an overarching set of systems. Examples of such practices and beliefs include democracy, feminism, and principles inherent in a particular faith, as well as the economic factors such as an economic depression (Bronfenbrenner, 2005; Donald, Lazarus, & Lolwana, 2012; Swart & Pettipher, 2005).

The chronosystem is not a level of systems but is rather seen as running through all four levels and considers developmental timeframes. This system allows one to consider the effect of prior life events, either singly or sequentially, on later events. These timeframes influence all systems, as well as influencing the individual development of the child (Bronfenbrenner, 2005; Swart & Pettipher, 2005). A child with CRS will progress through the stages of development differently to a typically developing child, however they will still develop and change over time, and this will affect their disability as well as understanding of their condition and coping skills.

After considering the work of Bronfenbrenner, one is able to see the importance of considering a case of CRS systemically, as all the levels of systems are intertwined to affect the treatment, understanding and acceptance, prognosis, and quality of life of the life associated with each individual case. Therefore, in this study, the history and current context of Jo-Anne will be considered.
2.4.2 Adaptation of bio-ecological model to form an ‘ice-cream cone’ model

Applying the bio-ecological model, allows one to consider all aspects of the individual’s context as well as his or her history. This information can be visually represented using an ice-cream cone. The ice-cream cone, shown in figure 2.8, also allows one the opportunity to consider all domains of functioning and to consider information gathered from a variety of sources.
Figure 2.8. Representation of the bio-ecological model as an ice-cream cone

As seen in the bio-ecological model, the chronological system is vital. One way in which information on the chronological system is gathered, is from taking a detailed history including the development history, types of treatment and interventions required, family situation, information on behaviour and academic functioning, and experiences relating to the school, home and community (Sattler & Hoge, 2006). In this study, the background information is used to consider the physical and medical developmental history of the child to better understand how CRS has affected the physical development and health of Jo-Anne. The information gathered on the family, emotional development, peer, school, and community interactions would help the researcher understand how CRS has affected the emotional and social functioning of Jo-Anne, as well as understanding any effect on academic and learning skills. As is shown in Figure 2.8, the background information of the case makes up the cone of the ice-cream.

In order to consider the functioning of a child, and in the case of this study to consider the support needs, all domains of functioning need to be investigated and understood. These different domains are cognitive, physical, academic, and psychosocial, and can be represented as the different flavoured scoops of ice cream, with the cherry on top being the research question (Figure 2.8), which is the support needs of a fourteen-year old learner with CRS. Foxcroft and Roodt (2009) discuss that gathering information from a range of sources and considering all domains allows for a richer understanding of the case. Therefore, information needs to be collected from multiple sources in order to better understand the needs of the learner, in this case, as well as to understand the needs in terms of the different domains.

Making use of the ice-cream cone model allows one to see how the information gathered can affect more than one domain. For instance, incontinence is a physical condition therefore, affecting the physical domain but can affect academics as well, as extra time might be needed out of class, leading to missed instructions. It might also affect the psychosocial domain, as the learner may feel self-conscious about the condition and this may decrease confidence and self-esteem.

A final consideration is that a good understanding of the literature is vital in order to conceptualise the research problem (Henning, 2004). In the case of this study, the literature can also be grouped in the different domains, as was done when considering prognosis and
treatment, as this enhances the flavour and depth of each scoop of ice cream and further aids to the understanding of the needs of each domain.

2.5 ROLE OF THE EDUCATIONAL PSYCHOLOGIST

Although CRS is a medical condition, there is still a large role for the educational psychologist to play in supporting a learner with this condition. According to the Health Professions Council of South Africa, (HPCSA, 2011) the scope of an educational psychologist involves providing intervention in order to optimise human functioning in learning and development, as well as assisting in the development of policies and designing and managing educationally-based programmes with the goal of enhancing learning and development.

Therefore, in terms of a syndrome such as CRS, the educational psychologist needs to have a sound awareness of the support needs associated with this condition so that the appropriate interventions can be implemented in order to support these learners in the best way possible. An educational psychologist may also have to work in conjunction with the school-based support team to develop policies and programmes that support disabled learners. Such policies may include how to handle issues around catheterisation and the use of colostomy bags, alternative activities for physical education and concessions when the disability may slow down performance. The educational psychologist may also take on a ‘case manager’ role to ensure the appropriate supports have been implemented and to monitor the progress of the learner and adjust the intervention plan as needed.

Finally, the scope of practice also states that educational psychologists should be involved in research within the field of learning and development (HPCSA, 2011). Therefore, researching the support needs of a condition as rare as CRS, informs future work with these learners in the school environment.

2.6 CHAPTER SUMMARY

The literature put forward in this chapter focussed on information about caudal regression syndrome, its characteristics and symptoms, the five different types, the cause as well as the treatment and prognosis of this condition. This discussion gave an outline of CRS, the common symptoms as well as the malformations and abnormalities commonly associated with the condition. Of these symptoms, the most relevant to the study are full sacral agenesis and partial lumbar agenesis causing paralysis, hip flexion contractures, and bladder and bowel difficulties
as these are experienced by Jo-Anne. The discussion also looked at the different types of CRS, of these types Jo-Anne lives with Type II. This section ended with a discussion focusing on the prognosis and treatment.

The chapter then provided information on the role of inclusive education in South Africa and the influence this policy will have in terms of supporting a learner with caudal regression syndrome. Included in this section, was information on the SIAS document to indicate the levels of support, and where a special school for physically disabled learners fits into the levels and inclusive education policy.

This was followed by a discussion of a framework for conceptualising the case, specifically adapting Bronfenbrenner’s bio-ecological model for development to form an ice-cream cone to conceptualise the case and the case history visually. This model allows the researcher to consider the influence of the context, as well as considering the influence that caudal regression syndrome has on the different domains of functioning, and how these domains are interrelated.

Finally, the chapter ended with a discussion regarding the role of the educational psychologist in terms of providing support and intervention. The focus of this section is on the role of the educational psychologist in relation to what is stated in the HPCSA’s scope of practice and how this would affect work done with a client having CRS.

The next chapter will provide a detailed discussion into the interpretivist research paradigm and case study research design, as well as provide a discussion into the methods of data collection and analysis. The chapter will end by providing information into the trustworthiness of the study and ethical considerations.
CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

When beginning the study, it was important that the paradigm and research design selected correspond with one another, as well as with the researcher’s worldview and skill set. Once a paradigm and research design had been selected, the data collection and analysis techniques also needed to be an appropriate match to the purpose of the study, as well as to the paradigm and design.

This chapter will show the reader that a qualitative study, rooted in an interpretivist paradigm, was an appropriate match to the identified research problem, as well as to the worldview and skill set of the researcher. A discussion on the relevance of the case study research design will also be presented, during which the significance of the case study design within the interpretivist paradigm will be indicated, as well as providing a clear definition of this research design. The role of the researcher in a qualitative case study will be indicated, as well as discussing how the case for this study was selected. The data collection techniques will then be clearly discussed, by indicating how interviews, visual documents, and artefacts were used in the study. The research participants and their biographical details will be clearly stated in order to show their relevance to the study.

During the discussion, a detailed description of the data analysis process is provided and details as to how trustworthiness of the study was ensured are provided by explaining the use of the three principles of data collection discussed by Yin (2012) as well as member checking and audit trails. Finally, the importance of working ethically and the different ethical considerations that were required throughout the study are discussed.

3.2 RESEARCH PARADIGM

It is important to consider if the selected paradigm and research design corresponds with the worldview, personality, and skill sets of the researcher. Therefore, as the researcher, I would be required to have a sound understanding of the philosophical foundation that forms the basis for each research paradigm in order to make an informed research decision (Merriam, 2009).
For this study, I aimed to identify the support needs of Jo-Anne⁷, a learner with caudal regression syndrome (CRS) attending a school for learners with physical disabilities, and therefore, I was concerned with investigating Jo-Anne’s lived experience. I believed that the objective of this study corresponded with the underlying goal of qualitative research discussed by Merriam (2009), which states that qualitative research aims to understand how people interpret and make meaning of their experiences, as well as how they construct their world.

Furthermore, this study corresponds with my personal worldview and skill set because of an interest in the field of education, with a special focus in disabilities and special needs education, including the support needs of these learners. For this reason, this study is assisting me to expand my understanding of the support needs required for individuals with CRS. As a future educational psychologist, I am also interested in the lived experiences of individuals, how they make meaning of their experiences, as well as the coping skills they utilised. It is felt that this focus guides my professional development and is a fit with the qualitative research paradigm. Creswell (2009) discusses that qualitative research has an inductive form of data analysis through which themes are identified and used to interpret the views of the participants in order to give a holistic account of the experience or phenomenon under investigation. The work completed in my research methodology modules has allowed me to develop the skills required for the data collection analysis and interpretation in this study.

This study has an emphasis on the lived experiences within a specific context and the interpretation of such experiences. Specifically, Jo-Anne’s, a learner with CRS, experiences and how these experiences, located within the context of her school environment, indicate her specific support needs. Therefore, this emphasis suggests that this study is situated in an interpretivist research paradigm (Creswell, 2009; Henning, 2004). Interpretivist research aims to collect data in order to describe, understand, and interpret an experience or phenomenon, as it is perceived by each individual. Since reality is context bound, the data collected is based on the reflections of each participant (Merriam, 2009; O’Reilly & Kiyimba, 2015). Therefore, using these reflections I was striving to construct a shared meaning by considering the views of the various participants within this study.

---

⁷ Jo-Anne is a pseudonym that has been selected to protect the identity of the individual in this case
The interpretivist paradigm is applicable to the study, as the experience of Jo-Anne at school is to be understood from the various perspectives of her educator, therapist, school management, from Jo-Anne herself, and her mother, in order to discover a shared understanding of her support needs in relation to her CRS diagnosis. Since individuals make meaning of their experiences based on their history, the culture, and social perspectives (Creswell, 2009), all of the participants will have a different view and experience of CRS, and it is my task, as the researcher, to put all these experiences together and identify common themes in order to construct meaning and form a conclusion.

3.3 CASE STUDY RESEARCH DESIGN

For this study, a case study design (Yin, 2012) was used. When selecting a research design it is necessary for the design to be a suitable match to the qualitative and interpretivist paradigms. The case study design was appropriate, as it allowed me the opportunity to enter into an in-depth exploration of one individual within a clearly identified bounded system (Creswell, 2013; Creswell, 2009). Since this case study aims to gain insight and understanding into the experiences of one individual, this study is specifically an intrinsic case study (Flick, 2015).

This design allowed data to be gathered from multiple sources, which created a rich description of the case (Creswell, 2013). This correlates with Creswell’s (2009) discussion that highlights the importance of interpreting the views of multiple participants in order to give a holistic account of the experience (Creswell, 2009). Furthermore, the case study design corresponds with the interpretivist paradigm, which strives to describe, understand, and interpret an experience with the understanding that reality is context bound (Merriam, 2009).

A second consideration when selecting a design is, whether or not the design is a fit with the phenomenon in question. I was interested in identifying Jo-Anne’s specific support needs. This was achieved by listening to the views of various role players in Jo-Anne’s life in order to understand and interpret their experiences. I also considered that each participant’s reality was context bound; their context influenced their understanding and experiences.

Merriam (2009) emphasises that one of the most significant features of the case study design is the bounded system, which creates a clearly defined object to study. A bounded system should be an “integrated system focussing on specifics rather than generalities” (Simons, 2009, p. 4). The bounded system, object of study for this case was Jo-Anne, a fourteen-year old girl.
with CRS. It is possible to see that this case has more specifics than generalities, as the CRS in itself is a rare and unique condition. The context of the case was also unique to each participant as is the context of a school for learners with physical disabilities. The progression and effect of the syndrome on Jo-Anne was influenced by her personal history and development, causing her presentation of the syndrome to be distinctive.

A case study design is suitable when researching the identified case has a heuristic value, conducting the study can lead to increased insight and understanding into the experience, or create a new way of viewing the experience (Merriam, 2009). In terms of this study, it was my hope to increase understanding of CRS by gaining insight into the different support needs an individual with this condition may have. By conducting this study, professionals working with CRS in a school environment may think and act differently towards individuals with this condition by striving to identify and meet specific support needs for each individual.

3.4 CASE SELECTION

In 2014, as a student registered counsellor, I first learned of Jo-Anne and her rare condition during the marks discussion at the beginning of the third term. During these meetings, each learner in the school is discussed in terms of academic progress, therapeutic progress, as well as any special needs or concerns. During the term three discussion, it was mentioned that the educators had concerns about Jo-Anne, as she appeared to be struggling with expressing her feelings and managing her anger and for this reason, counselling was recommended.

During the counselling process, I was able to meet with Jo-Anne’s foster mother, Bronwyn8, who is also an occupational therapist working with physically disabled children. During the initial meeting with Bronwyn, I was able to gather detailed information on Jo-Anne’s condition and her history. Since I had never heard of CRS, I began investigating this condition. While investigating, I wanted to gather more information that would clarify the condition, but I was also particularly interested in how a lack of care by her biological parents affected the development and prognosis of Jo-Anne’s condition.

During the investigation for Jo-Anne’s counselling intervention, I began looking for information regarding the emotional needs of individuals with CRS. During this time, I began

---

88 Bronwyn is a pseudonym that has been selected to protect the identity of the participant.
to realise that there has been very little research conducted into the psychosocial and academic support needs of individuals with CRS. Due to the detailed background information already gathered on Jo-Anne, I decided her case would be suitable to conduct a case study in order to investigate her specific support needs.

3.5 THE RESEARCHER

Merriam (2009) states, that all forms of qualitative research, including case studies, requires that the researcher should become “the primary instrument for data collection and analysis” (p. 15). Therefore, during this study I became the primary instrument for collecting data using interviews and a collection of a creative artefacts produced by Jo-Anne. It was also important that I worked with the research participants in a collaborative manner so that they felt empowered during the research process (Creswell, 2009).

It has been found that researcher responsiveness and adaptability, as well understanding of verbal and non-verbal communication, are valuable aspects of having the researcher as the primary data collection instrument (Merriam, 2009). During my interactions with the participants, it was necessary to be responsive and be able to adapt as required during the interviews. It was also necessary to pay attention to both the verbal responses and the non-verbal communication, as this added to the data collected and allowed me to gauge the comfort of the participants during the interview process.

It was important to for me to consider the presence and influence of personal assumptions on the questions asked during the interview process (Henning, 2004). Therefore, when posing questions to the interviewees, I made a conscious effort to ask questions in an unbiased manner (Yin, 2012). Henning (2004) urges researchers to monitor how assumptions and biases may influence the data collection process, as well as data interpretation, while Merriam (2009) further discusses the importance of considering the context of the interview during the interpretation process.

As the researcher, it was vital to consider any biases or assumptions I may have had, such views could include showing pity for Jo-Anne due to her disability or assuming school staff is not equipped to support a learner with a rare condition. These could lead to the participants feeling uncomfortable or attacked during the interview process, or could cause incorrect interpretation of the data collected.
Any form of qualitative research requires that the researcher work in a collaborative manner with the research participants (Henning, 2004). In order to develop a relationship that allows for collaboration, it was important that there was a sense of trust developed between the participants and myself, especially Jo-Anne, as she had to share sensitive details of her experiences with me (Wengraf, 2001). Therefore, working in an unbiased manner and approaching the participants in a sincere style facilitated the development of a trusting relationship and enabled collaboration between myself and the research participants.

### 3.6 DATA COLLECTION METHODS

During this qualitative study, the objective was to understand more about a specific phenomenon. Therefore, the data collection methods needed to be selected in such a way that data could be gathered from a variety of sources (Henning, 2004) in order to gain a rich understanding of the phenomenon.

The type of data collected in a qualitative study differs from the data required for a quantitative study. In this study, data was collected through words, by looking specifically at direct quotations, excerpts, or passages from participants’ interviews (Merriam, 2009). From the techniques listed by Merriam (2009) and Creswell (2013), interviews and the use of documents were selected for this study. According to Merriam (2009), documents include the use of physical and visual artefacts, and in this study, both were used.

This study made use of semi-structured interviews and the use of documents and artefacts, specifically photographs and a written document created by Jo-Anne. These techniques are suitable for the study, as they are appropriate qualitative techniques, and both Yin (2012) and Creswell (2013) mention these techniques are appropriate tools for gathering data.

The use of interviews allowed the participants the opportunity to answer questions, share their experiences with CRS, and identify the support needs associated with the condition. The use of the artefact also allowed Jo-Anne to engage with her feelings associated with CRS on a deeper level and to share information on her experiences and support needs in a more creative manner, which is a match with her creative and artistic personality. These sources were able to provide the necessary data in order to determine Jo-Anne’s support needs. The use of interviews and artefacts in this study will be discussed in further detail below.
3.6.1 Interviews

Participants for this study were identified and selected due to the fact that are part of Jo-Anne’s daily life either at school or at home. These interactions with Jo-Anne gives the participants frequent opportunities to observe and take note of Jo-Anne’s condition and her support needs. Furthermore the staff at the school also have a large amount of knowledge and experience with physical disabilities and this may have a positive influence one their understanding of Jo-Anne’s needs, thus making them valuable sources of information for this study.

Interviews as a technique were selected as it allowed me to gather information about the participants’ individual feelings and experiences that could not be easily observed (Flick, 2015; Merriam, 2009). Formal in-depth, semi-structured interviews were conducted with Jo-Anne, her foster mother, educator, head of department, and school physiotherapist. In-depth semi-structured interviews were selected as they allowed me to plan open-ended questions in order to give some structure to the interview, while allowing there to be an improvised conversational quality (Wengraf, 2001). The open-ended nature of the questions allows the interviewee the freedom to share their views and opinions, while also fostering a sense of collaboration between interviewer and interviewee (Cohen & Crabtree, 2006; Wengraf, 2001). All these factors interacted and allowed me to gain in-depth insight (Wengraf, 2001) into the participants’ experiences with CRS, and their understanding of the associated support needs.

Interviews were conducted in one-to-one settings and were video recorded to allow for accurate records of the data. Additional hand written notes were made during the interview process to record some personal thoughts or to note observations that stuck out to me such as gestures (Creswell, 2009). Observation can be used as a tool for gathering additional information during settings such as during an interview (Henning, 2004). Selection of the questions for each participant also had to be carefully considered to allow the interview to have a relaxed conversational atmosphere but also to give it direction and purpose (Merriam, 2009).

Questions were developed in order to elicit the data required to answer the research questions, identifying the support needs of a fourteen-year old girl with CRS. Merriam (2009) suggests that when developing questions, the wording should reflect the worldview of the interviewee; it should avoid technical jargon, and should make sense to the interviewee. Table 3.1 shows the interview guide, which contains a variety of question types including feeling, experience, and behaviour questions, opinion and value questions, and knowledge questions (Merriam,
It was also important that the questions were posed in such a way that they allowed for a dialogue between myself and the participants, while also allowing participants the opportunity to share their views freely (Flick, 2015).

**Table 3.1. Interview guide**

<table>
<thead>
<tr>
<th>A.</th>
<th>Jo-Anne, learner with CRS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What is your understanding of CRS?</td>
</tr>
<tr>
<td>2.</td>
<td>What are your thoughts and feelings in relation to CRS?</td>
</tr>
<tr>
<td>3.</td>
<td>What have your experiences been at school?</td>
</tr>
<tr>
<td>4.</td>
<td>What would you describe as your needs in terms of CRS?</td>
</tr>
<tr>
<td>5.</td>
<td>How do you feel the school meets these needs?</td>
</tr>
<tr>
<td>6.</td>
<td>Describe ways in which you feel your needs could be better met?</td>
</tr>
<tr>
<td>7.</td>
<td>In what ways does having CRS affect your emotional well-being, social self, academic life, and physical well-being?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B.</th>
<th>Jo-Anne’s foster mother</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What is your understanding of CRS?</td>
</tr>
<tr>
<td>2.</td>
<td>What are your thoughts and feelings in relation to CRS?</td>
</tr>
<tr>
<td>3.</td>
<td>What have your experiences been with Jo-Anne at school?</td>
</tr>
<tr>
<td>4.</td>
<td>What would you describe as Jo-Anne’s needs in terms of CRS?</td>
</tr>
<tr>
<td>5.</td>
<td>How do you feel the school meets those needs?</td>
</tr>
<tr>
<td>6.</td>
<td>Describe ways in which you feel these needs can be better met.</td>
</tr>
<tr>
<td>7.</td>
<td>In what ways do you feel CRS has affected Jo-Anne’s emotional well-being, social self, academic life, and physical well-being?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C.</th>
<th>Jo-Anne’s school physical therapist, head of department, and educators</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What is your understanding of Jo-Anne’s condition, CRS?</td>
</tr>
<tr>
<td>2.</td>
<td>What thoughts and feelings does this condition evoke in you?</td>
</tr>
<tr>
<td>3.</td>
<td>Are you aware of any unique needs Jo-Anne has?</td>
</tr>
<tr>
<td>4.</td>
<td>How do you feel the school is able to meet those needs?</td>
</tr>
<tr>
<td>5.</td>
<td>How do you feel you, as a physio/HOD/educator, are able to meet those needs?</td>
</tr>
<tr>
<td>6.</td>
<td>In what ways do you feel you could provide better support or meet her needs in a better manner?</td>
</tr>
<tr>
<td>7.</td>
<td>How do you feel the school would be able to provide better support?</td>
</tr>
<tr>
<td>8.</td>
<td>In what ways do you feel CRS has affected Jo-Anne’s emotional well-being, social self, academic life, and physical well-being?</td>
</tr>
</tbody>
</table>

Jo-Anne is a fourteen-year old female learner in Grade 7, at a special school in Johannesburg. She has type III CRS and has lower limb paralysis with some sensation in her legs, and she requires the use of a catheter. Jo-Anne’s foster mother, Bronwyn, is a forty-seven year old female and she has been Jo-Anne’s foster mother since she was two years and five months old. Bronwyn is a qualified occupational therapist who had been practicing for twenty-four years and had twenty years’ experience with spinal cord difficulties and wheel chairs. She first met Jo-Anne at the place of safety when Jo-Anne was two years old. Bronwyn was asked by the place of safety to assist Jo-Anne become more mobile.
Fred, the Head of Department (HOD) for Jo-Anne’s phase, is a sixty-four year old Afrikaans male. He is a qualified educator who had been teaching for forty years. He had been teaching at Jo-Anne’s school for thirty years, prior to which he had been at a clinical school for children with extreme behavioural difficulties. At the start of 2015, Jo-Anne moved into Fred’s phase and at the time of the study, he had been teaching her for nine months. Natasha, Jo-Anne’s educator, is a twenty-eight year old Afrikaans female who is a qualified teacher. Natasha had been teaching for six years and she had been teaching at Jo-Anne’s special school for her entire teaching career. At the time of the study, she had been teaching Jo-Anne for four years.

The final research participant was Jo-Anne’s school physiotherapist. Laura is a fifty-three year old Afrikaans female who is a qualified physiotherapist, who had been practicing for twenty-seven years. During this time, she had worked with families at the mines and had been working at Jo-Anne’s special school for thirteen years. Prior to moving to the school, Laura had worked with children in small amounts but when she made the move to the school, her focus shifted solely to children and physical disability. At the time of the study, Laura had been working with Jo-Anne for four years.

There are various advantages to using semi-structured interviews. Specifically this form of interviewing allows the researcher to probe during the interviews while also allowing the interviewees the opportunity to share personal views and interpretations (Flick, 2015; Stake, 2010). The open-ended questions allow the interviewees to share information spontaneously and to discuss a topic in greater depth than would have been possible with a questionnaire or more structured closed-ended questions (Flick, 2015; Stake, 2010).

One factor that is considered disadvantageous when using interviews is that they cannot be neutral tools for data collection because the researcher conducts the interviews and the researchers’ interests direct the conversation (O’Reilly & Kiyimba, 2015). Therefore, it was important for me to ensure clarity and be upfront about my intentions regarding the purpose for the interview. O’Reilly and Kiyimba (2015) also urge researchers to be clear about what the theoretical framework states about the role of the researcher during the interview process. In terms of interpretivist framework, I had to phrase questions in an open manner that allowed interviewees the opportunity to share their own understanding about CRS, as well as their experiences related to this condition (Merriam, 2009).
3.6.2 Documents and artefacts

Documents and artefacts can be valuable sources of information and have been found to be relevant to most case study investigations (Henning, 2004; Yin, 2012). These items can include private documentation such as diaries and medical records, photographs, and physical artefacts, and these items are able to corroborate and augment the data gathered from the interviews (Henning, 2004; Yin, 2012). In this study, both physical artefacts in the form of creative writing, and visual documents in the form of photographs, were used to substantiate findings from the interviews regarding the needs of Jo-Anne.

(a) Physical artefact

Yin (2012) states that artefacts can include a piece of creative writing, since Jo-Anne is a creative and artistic young lady it was beneficial to give her the opportunity to create an artistic artefact of her choice to represent her experiences. This led to a deeper understanding of her experiences and needs, which enhanced the quality of data the researcher was able to gather. Jo-Anne was to do a piece of creative writing, shown in Appendix C. The piece was a short passage on Jo-Anne’s experiences and feelings around being disabled. She felt that this passage would be a letter that she could share with other disabled children, as she never had anyone to give her guidance or to share their experiences.

Allowing Jo-Anne the opportunity to create an artefact for the study had the advantage of allowing for more active participation in the study (Rule & John, 2011). This form of data collection also allows the participant to have more control over the message that is being shared and this can minimise some of the disadvantageous control the researcher has when collecting data (Rule & John, 2011). Furthermore, the piece of writing Jo-Anne created allowed me to gain greater insight into her lived experiences (Richards & Morse, 2013).

Personal artefacts, such as Jo-Anne’s creative writing, have the disadvantage of being highly subjective and the participants can be selective about what feelings they choose to share (Merriam, 2009). This makes this form of data collection unreliable if used as the only source of information. In this study, I triangulated the information gathered from the interviews, Jo-Anne’s artefacts, and the photographs in order to draw conclusions.
(b) Visual documents

Merriam (2009) states that visual documents, such as photographs, are included in the list of documents that can be used when collecting data. The photographs used in this study were generated photographs (Merriam, 2009), in that they were taken by the researcher for the purposes of this study. The aim of the photographs was to capture details of Jo-Anne’s physical environment at school.

These photographs, attached in Appendix C, allowed me to gather data on the support structures put in place in the school environment for disabled learners, particularly learners in wheelchairs. This data allowed me to consider Jo-Anne’s support needs as an individual with CRS who uses a wheelchair in all aspects of life. The use of the photographs allowed me to capture this evidence visually, in a manner that is more meaningful than trying to describe the school setting verbally. It was important to ensure that the photographs’ data was triangulated with the other data collected in order to ensure the data was reliable (Merriam, 2009).

During the data collection, I endeavoured to follow Yin’s (2012) three principles of data collection, specifically making use of multiple sources of evidence, creating a case study database, and maintaining a clear chain of evidence. These principles assisted me to ensure data was collected in a thorough and reliable manner, which will be discussed in more detail later in this chapter. Once all the data was gathered through the interview process, and the artefacts and documents had been collected, the data had to be processed and analysed. A discussion of the analysis process will follow.

3.7 DATA PROCESSING AND ANALYSIS

Collecting and analysing data during a qualitative study is an ongoing process, whereby data may be collected and analysed simultaneously. This is because data analysis begins at the start of the first interview where insights start to emerge and are developed and refined as more data is collected and analysed (Merriam, 2009). During the data gathering procedure, I was simultaneously involved in a process of preliminary data analysis, and once all the data was collected, was able to start analysing the data using thematic content analysis techniques (Creswell, 2009; Grbich, 2007).

The process of data analysis for this study involved preparing and organising the data by creating transcripts and preparing photographs of the environment and Jo-Anne’s artefact. Data
was then examined and categorised according to codes. The codes were then condensed and
tabulated to allow final interpretations to be formed and themes to be identified so that the
findings could be presented and discussed in this research paper (Creswell, 2013; Yin, 2012).

During the process of preliminary data analysis, which is an ongoing process that takes place
each time data is collected (Grbich, 2007), I was able to begin preparing and organising the
data. This procedure involved summarising the main points identified from the interviews,
document, or artefact, as well as what issues require some follow-up questioning or reading
(Grbich, 2007). During and shortly after the interview, I was able to record information that
struck me as important or information that created a question in the back of my mind that
required further investigation. The preliminary analysis ended with the formation of a summary
of all initial findings (Grbich, 2007). This process is similar to initial analytic strategies
proposed by Creswell (2013), whereby ideas are ‘sketched’ in the researchers mind by making
use of field notes and then summarising field notes. Both processes described by Creswell
(2013) and Grbich (2007) allowed me to identify any areas where further investigation is
required before beginning the formal thematic content analysis. During the stages of initial data
analysis, researchers may find it beneficial to begin to formulate metaphors or begin to analysis
the purpose of specific words used by the participants (Creswell, 2013; Grbich, 2007). The
issues arising from the preliminary data analysis have been summarised in a table attached in
Appendix D.

Once the interviews had been completed, the conversations were transcribed verbatim in order
to create a set of raw data. I was then able to begin thematic content analysis (Creswell, 2009).
Thematic content analysis is the “process of segmentation, categorisation, and relinking of
aspects of the database prior to the final interpretation” (Grbich, 2007, p. 16). According to this
explanation, I had to analyse the raw data from interview transcripts and artefacts in order to
code the data. Related codes were grouped together to create themes. The themes were used to
interpret the data and allowed the researcher to draw the conclusions for the study (Creswell,
2009; Stake, 1995).

During the thematic content analysis procedure, I analysed the data from the interviews and
photographs by adapting the Creswell’s (2009) steps of data analysis.
1. I began by reading all the transcripts, looking carefully at the visual data, and made notes of ideas that came to mind. These thoughts were added to the notes created during the preliminary analysis of the data.

2. I then carefully read each transcript with a focus on thinking deeper into what the information is telling me by considering the underlying meaning.

3. These thoughts were then grouped into codes by considering the main topics, unique topics, and additional topics. I then created a table with these initial codes at the headings (attached in Appendix D). By this step, I had ten codes.

4. I then went back to the transcripts, visual data, and identified segments of the text that could be assigned a particular code. This code name was recorded in the margin near the applicable segment. At this stage, I used the block and file approach, whereby segments are highlighted and labelled according to a code or topic.

5. I then began grouping the ten codes into similar themes and was able to create three themes.

6. The keywords from the data were then placed into the table next to the appropriate codes and overall theme.

7. Data was revised and if necessary, themes were changed or regrouped. The final table showing the codes, themes, and data keywords is shown in Appendix D.

These data analysis techniques were suitable for this study as they are identified by Creswell (2013) and Grbich (2007), as well researched methods of qualitative data analysis. Creswell (2009) states that case study research requires a detailed description of the setting as well as an analysis of the data in order to identify themes. Using both the preliminary techniques and thematic content analysis allowed me to provide a description of the setting, biographical details of the participants, and identify themes as required for case study research.

Furthermore, because these techniques allowed me to compile a detailed description of the case by identifying themes and grouping them in a meaningful manner, I was able to form naturalistic generalisations and apply what has been learnt to similar cases and settings (Creswell, 2013), where support for CRS individuals may be needed.

3.8 MEASURES TO ENSURE TRUSTWORTHINESS

It is vital that all research is conducted in a manner that is trustworthy and reliable, indicating that the research was conducted in a thorough and ethical manner (Merriam, 2009).
Trustworthiness within qualitative studies implies that the researcher checks for accuracy of findings, as well as ensuring the selected approach is consistent across different researchers and different research projects (Creswell, 2013).

Merriam (2009) emphasises that the trustworthiness of the study should be considered from the time that the study conceptualised, throughout the data collection, analysis, interpretation, and discussion of the findings.

I was able to ensure the trustworthiness and reliability of the data gathered by following the three data collection principles. First, I ensured the use of multiple sources of evidence, by making use of interviews, artefacts, and visual documents (Yin, 2012). Gathering data from multiple sources allowed the triangulation of findings. Triangulating data is a process that gave me the opportunity to reach conclusions with increased confidence. Since triangulation is possible by the use of various sources, it allows for a richer description of the case to be developed (Remenyi, 2012; Yin, 2012).

Secondly, I compiled a case study database that ensured the raw data was organised and available for inspection (Yin, 2012). Data from the database was then incorporated into the discussion of the findings in this report. Keeping all the data together in a database assisted in strengthening the reliability of the study, as it is an indicator of evidence-base practice, as well as researcher transparency (Yin, 2012). This data base was created through the use of transcripts, additional handwritten notes, photographs and artefacts.

I also made use of member checking. During this process, the research participants were able to check a summary of their views that was compiled from the raw data, they could then determine if the data was an accurate representation of their views and opinions; this was especially important when analysing and interpreting Jo-Anne’s personal artefact (Kanuka, 2010; Stake, 1995). An example of this document is attached in Appendix D.

Finally, the third principle required that I maintained a clear chain of evidence, this allows the readers of this paper to “follow the derivation of any evidence from the research questions to the ultimate case study conclusions” (Yin, 2012, p. 122). Keeping a chain of evidence ensures that no information was lost during the course of the study and ensures all information receives appropriate attention and evaluation. Part of maintaining a chain of evidence was creating an audit trail. This allowed me to provide detailed records of each aspect of the research process such as interviews, transcripts, photographic evidence, initial coding, and conceptualisations.
of findings (Merriam, 2009). Merriam (2009) also emphasises that this record should include reflections of problems encountered during the research process, how these problems were resolved, questions or thoughts the researcher worked through, and reflections indicating the decision-making processes the researcher utilised. As discussed previously, I made use of thematic content analysis. By engaging with the data in this manner, I created another way in which I was able to ensure trustworthiness of the findings (Creswell, 2009).

All of the factors discussed were combined to ensure that all aspects of this study were carried out in a manner that protected the trustworthiness and validity of this study. I also had to ensure working in an ethical manner, as no findings could be considered trustworthy if the study was not conducted in an ethical manner. A discussion on ethical considerations will follow.

3.9 ETHICAL CONSIDERATIONS

It is vital that as a researcher, I followed guidelines and policies to ensure ethical practice and conduct. Creswell (2009) indicates that ethical research practices should begin as early as the identification of the research problem, as the problem should be beneficial or meaningful to others and not only to the research. I felt that the need to identify the support needs of individuals with CRS is beneficial to Jo-Anne, as it could lead to her receiving increased support at school. This study could also be beneficial to others with CRS, who may receive increased support because of the study.

According to the regulations put in place by the Faculty of Education’s Ethics Committee at the University of Johannesburg, once the research problem and purpose of the study had been identified, it was necessary for me to obtain institutional approval from the university; this approval is attached in Appendix A. Once I had received approval from the university, I then needed to get institutional approval from the Department of Education, this approval letter is attached in Appendix A. After this, I obtained consent from Jo-Anne’s school, where the school principal gave permission by signing the ethics document for informed consent.

In order to follow the guidelines of the Faculty of Education’s Ethics Committee, once approval had been granted from the various institutions, I was required to get informed consent from all participants before I was able to begin collecting data. Henning (2004) states that informed consent requires that the participants have a clear understanding about the purpose of the study, what will be involved in the interview process, how their artefacts will be used, and how will
their privacy be maintained. In addition, what will happen with the recordings and data after it is collected, and how will support be provided if the participants felt it was necessary in the event the interview process caused discomfort.

Once the process has been explained to the participant, a letter of consent needs to be signed. For minors, such as is the case with Jo-Anne, she had to give her assent but the researcher also required the consent of her foster mother in accordance with the Faculty of Education’s Ethics Committee’s guidelines.

For this study, I ensured that all participants had a clear understanding of what the interview process would entail, how the data would be stored, what the purpose of the study was, and that pseudonyms would be used to protect the identity of the participants. I also ensured that Jo-Anne gave her assent and that her foster mother consented to the research process.

When collecting data, it was important that I was honest with the participants during each aspect of the data collection and interviewing process. I also had to be respectful to the rights and vulnerabilities of the participants (Creswell, 2013). It was especially important to be respectful of Jo-Anne and her experiences around her disability. During the interview process, it was important that I interacted with the participants in a manner that allowed them to feel accepted and free from judgement. As well as this, I also had to be aware of any biases I may carry and not let these influence the data collection process (Henning, 2004; Yin, 2012). A final ethical consideration to be aware of when collecting data, was that Jo-Anne’s artistic artefact was something personal and acted as an extension of her feelings and experiences. Therefore, it was vital that I treated this artefact with respect and care (Henning, 2004). This was achieved by allowing Jo-Anne the opportunity to explain the meaning behind her creation fully, to ensure the researcher did not misinterpret her feelings.

When analysing the data and making interpretations, it was important that I worked with the data in an objective manner, free from personal bias and without siding with the views of the participants (Creswell, 2013). I used pseudonyms when reporting the research findings in order to protect the privacy of the participants, and ensured that data was kept in a secure place. I also considered all the data that had been collected as opposed to only considering aspects that I may have found preferential (Merriam, 2009).

When writing up the research findings, I ensured working in an ethical manner by not plagiarising and acknowledging the sources and literature that was consulted throughout the
research process. I will also endeavour to keep all collected data and evidence in a secure space for a period of two years (Creswell, 2009).

By working in an ethical manner and conducting research in a thorough and evidence-based manner using various sources, allowed me to gather data that can be triangulated and used to form a thick description of the study.

3.10 CHAPTER SUMMARY

This chapter indicated to the reader that a qualitative study rooted in an interpretivist paradigm was an appropriate match to the identified research problem, because this paradigm allowed me the opportunity to triangulate data collected from different sources and to interpret this data to draw conclusions relating to Jo-Anne’s support needs. The study will also lead to increased insight and understanding into experiences and needs of individuals with CRS, which is a goal of case study research. The manner through which this case was identified and selected for research was discussed by indicating that there was a gap in literature regarding the psychosocial support needs of individuals with CRS.

The researcher is the main instrument for collecting and interpreting the data for a qualitative case study, and this required me to work collaboratively with the participants, as well as to strive to work in a manner that is objective and free from bias. The data collection techniques, specifically the use of in-depth semi-structured interviews, visual documents, and a handmade artefact by Jo-Anne were discussed. The details of the research participants and their relevance to the study were provided by sharing the biographical details of each participant. The data analysis process was clearly explained by indicating the preliminary analysis process, as well as the steps involved in thematic content analysis by looking specifically at the coding and categorisation of data.

Details as to how trustworthiness of the study was ensured is provided by explaining the use of the three principles of data collection discussed by Yin (2012), specifically using multiple sources of evidence, developing a database, and maintaining a trail of evidence, as well as discussing the use of member checking and audit trails. Finally, the importance of working ethically and the different ethical considerations that were required throughout the study was discussed by making specific reference to selecting a research problem, gaining institution approval and informed consent, ethical considerations during the data collection and analysis
process, as well as the importance of reporting on the study and storing data in an ethical manner.

The next chapter will highlight the findings for this study by discussing the three main themes and their respective subthemes.
CHAPTER 4
DATA PRESENTATION, ANALYSIS, AND INTERPRETATION OF THE FINDINGS

4.1 INTRODUCTION

The aim of this study was to investigate the support needs of Jo-Anne\(^9\), a fourteen-year old grade seven learner with CRS. During the data collection process, the support needs in the academic, social-emotional, and physical domains were explored, as well as other influences on these support needs and the school’s ability to meet these needs.

As discussed in chapter three, data was collected using interviews, an artefact created by Jo-Anne, and through photographs of the school’s physical environment. A detailed description of the data collection and analysis methods was also provided in chapter three.

Chapter four presents the themes and findings of the study. The conclusions of the study are supported by direct quotes made by the research participants during the interviews, as well through the quotes from Jo-Anne’s artefacts, and the visual evidence from photographs of the school premises. All the findings were then related to current literature, further supporting the findings and finally the findings were related to the ice-cone model for case conceptualisation.

4.2 PRESENTATION AND OVERVIEW OF FINDINGS

The main themes that emerged from the thematic content analysis (Creswell, 2009) of the data are outlined below in Figure 4.1. All three themes are interlinked and influence one another. This makes the ice-cream cone model applicable when discussing the case, as this model lends itself to best highlighting this interrelatedness. These themes as well as the subthemes are discussed in detail during this chapter.

Throughout the chapter, the findings in each theme are supported with evidence taken from the interviews and artefacts. When referencing to the data, abbreviations will be used to indicate the data source and location in the documents. Table 4.1 provides a key for the codes used

\(^9\) Jo-Anne is pseudonym that has been selected to protect the identity of the individual
when data is being used during the discussion. The numbers following the abbreviated letters indicate line location in the transcription.

**Figure 4.1. Themes that emerged from the findings**

**Table 4.1. Abbreviations used in data presentation**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Document</th>
</tr>
</thead>
<tbody>
<tr>
<td>IJ</td>
<td>Transcribed interview with Jo-Anne</td>
</tr>
<tr>
<td>IB</td>
<td>Transcribed interview with Bronwyn (foster mother)</td>
</tr>
<tr>
<td>IN</td>
<td>Transcribed interview with Natasha (educator)</td>
</tr>
<tr>
<td>IL</td>
<td>Transcribed interview with Laura (physiotherapist)</td>
</tr>
<tr>
<td>IF</td>
<td>Transcribed interview with Fred (head of department)</td>
</tr>
<tr>
<td>FNJ1</td>
<td>Field notes for interview with Jo-Anne 1</td>
</tr>
<tr>
<td>FNJ2</td>
<td>Field notes for interview with Jo-Anne 2</td>
</tr>
<tr>
<td>AJ</td>
<td>Artefact created by Jo-Anne</td>
</tr>
<tr>
<td>PS1</td>
<td>Photograph set 1</td>
</tr>
<tr>
<td>PS1</td>
<td>Photograph set 2</td>
</tr>
<tr>
<td>PS3</td>
<td>Photograph set 3</td>
</tr>
<tr>
<td>PS4</td>
<td>Photograph set 4</td>
</tr>
</tbody>
</table>

---

\(^{10}\) Pseudonyms have been selected to protect the identity of each participant
In order to understand Jo-Anne’s experiences and the data discussed throughout the themes, it is crucial to have further insight into her history. Figure 4.2 presented below presents Jo-Anne’s case history.

**Newborn & Infancy:**
- Jo-Anne was given very little treatment and care for her disabilities. She was neglected as an infant and was mostly left unattended in her cot. Her older sibling tried his best to care for her and feed her.

**Prenatal and Birth:**
- No prenatal care, biological mother drank and potentially used drugs throughout the pregnancy. Due to lack of prenatal, condition not identified through scans.
- Disability and cleft palate first observed at birth, 29/09/2000

**Toddler:**
- At age 2 Jo-Anne was taken to a place of safety. At this stage she was severely underdeveloped and undernourished. She had reached very few developmental milestones and was unable to speak or communicate due to untreated cleft palate and she was not mobile at all due to the CRS. Jo-Anne also had frequent infections in her sinus passages due to her cleft palate.
- At age 2.5 years Jo-Anne was taken into foster care with Bronwyn

**Childhood:**
- Cleft palate surgeries: age 4, 5 and 8
- Age 6: Surgery on left leg, osteotomy and manipulation of hip, knee and ankle. Numerous follow up surgeries needed for debridement’s due to poor wound healing
- Age 7: abdominal surgery to allow for independent bladder and bowel functioning
- Age 7 started grade 1 at a mainstream school for able bodied learners, repeated grade 1.
- Grade 4, age 11, moved to new special school as mainstream could no longer accommodate wheelchair

**Adolescence:**
- Age 14 moved to grade 7, high school
- Age 15 got braces and glass
- Grade 7: experienced difficulties coping with the many changes at school
- Has had difficult encounters with biological family

**Figure 4.2.** Jo-Anne’s case history visually represented as the cone of the ice-cream
4.3 THEME 1: DOMAINS OF SUPPORT NEEDS

Jo-Anne’s support needs can be separated into three domains, specifically physical support needs, social-emotional needs and academic needs. These needs are all closely interrelated and affect each other, and are strongly related to the overall level of support required for CRS. Findings in this theme also indicate that the physical symptoms and support needs strongly affect the other domains.

(a) Physical symptoms and support needs

Evidence from the interviews indicated that Jo-Anne’s symptoms associated with CRS include incomplete spinal development with no sacrum, and disconnection of the bone and nerves between the spinal cord and pelvis, causing Jo-Anne to meet the characteristics for CRS Type III. Jo-Anne’s incomplete spinal development has led to her having lower limb paralysis as well as a much smaller torso and underdeveloped legs:

“She has basically no sacrum, and she has a total disconnect between the lowest vertebrae that works and the pelvis” IB [7-9].

“But hers has that she’s a ‘para’... So, it’s basically a Type 3” IB [18 & 19].

“Spinal Cord until T10, on the MRI one could see at T10 it had a – it’s got a – the cord is like that but it is at an angle, at T10 is where it ends. And then she’s got normal bones up until L1, so L1 is the last fully formed bone, that’s a recognisable bone like it should be, then there’s a gap and then there’s a bony mass, it’s a nondescript, and then a relatively normal pelvis” IB [42-47].

“It means I’m shorter than other people and people my age” IJ [56-57].

“The lower half of her body hasn’t developed and she’s restricted” IB [392-393].

These symptoms have led to independent physical mobility becoming the main focus in terms of her physical support needs:

“The main problem for her at the moment is the fact that she cannot emulate, she can’t walk, she can’t get around if she is not in a wheelchair” IL [242-243].

“At the end of the day, the treatment is about making her as independent as possible and making her as functional as possible” IL [49-50].
“Her physical needs are more easy to identify because she needs the support of the wheelchair” IB [195-196].

Jo-Anne also presents with other physical symptoms characteristic of CRS, these symptoms include bladder and bowel difficulties, which have led to a need for a catheter:

“It’s also impacted her bladder and bowel, which she manages very well now, but it has been an issue and it will always be because she does catheterise” IB [398-400].

“Bathing and toileting is fine but she has a catheter, which she is able to manage by herself” FNJI [70-71].

The final physical symptom Jo-Anne presents with is a flexion contracture in her left hip. This creates a need for physiotherapy, particularly being seated in the wheelchair for extended periods of time leads to leg pains:

“It’s (pain) actually very common in wheelchair users, but most people don’t experience it as pain, they experience it as ‘discomfort’ and they get spasms and things, because she’s got sensation she gets with more pain” IB [67-69].

“I go to physio, but sometimes I get a leg ache and then I have to do exercises” IJ [214-215].

“Jo-Anne gets pains in her leg from sitting in her wheelchair for too long... The pain is worse in her left leg, where she cannot straighten that leg fully” FNJI [108-109 & 111-112].

The above findings have shown that Jo-Anne’s main physical support needs are independent mobility both in and out of a wheelchair, catheterisation to manage her bladder difficulties, and pain management strategies for her hip flexion contracture. Currently, all of her support needs are being met and are stable.

(b) Social-emotional support needs

Social and emotional needs are strongly linked to one another, as well as being strongly influenced by Jo-Anne’s physical symptoms. It became clear from the interviews with the different participants that Jo-Anne’s physical symptoms create social-emotional support needs related to self-esteem and identity development:
“There are also issues to deal with in terms of self-image and you know, the wheelchair, bladder, and bowel issues” IB [136-137].

“At the moment, she has quite good control of her bladder and bowel, there is not big issues, but when she was younger there were some issues. And again I think that makes it very hard to fit into a social group” IL [302305].

“The catheter can be embarrassing and so Jo-Anne keeps it a secret in case she is teased” FNJ1 [71-72].

“Sometimes you feel ashamed because you can’t walk and you feel like you can’t do anything except sit around in your wheelchair” AJ [2-5].

“Her condition can lead to her doubting her abilities and Jo-Anne feels self-conscious about her legs because they are so thin” FNJ1 [79-80].

It is also possible to see that these social-emotional needs associated with her physical symptoms further compound the social and emotional difficulties commonly experienced in adolescence:

“I think it does because it (CRS) relates to her self-image, but also just going into a teenager there’s so many changes and she – it does have an impact” IB [433-435]

From the interviews and from Jo-Anne’s artefact, it became evident that for Jo-Anne ‘fitting in’ socially is an area of concern. The feelings she experiences of not fitting in are associated with her disability:

“I try and fit in with my friends... It’s a bit hard, but easy at sometimes” IJ [4 & 6].

“It (CRS) makes me feel a bit upset sometimes because I can’t really fit in with the kids my age because they think I am ten years old” IJ [62-64].

However, staff at the school observe Jo-Anne as a learner who fits in well with other learners and appears to have very few difficulties when interacting socially:

“Just observations it seems like she fits in very well, she’s the type of person that makes friends across social barriers, and across disability barriers and so on” IL [110-112].

“Socially I think things are going better now” IF [72]
The social-emotional support needs seen in Jo-Anne’s case can be seen as common to individuals who are physically disabled and experience similar physical support needs and are therefore not unique to CRS itself:

“A lot of her emotional and social needs aren’t linked to caudal regression itself, that this is what a lot of disabled kids would go through” IL [354-356].

The views of the participants also indicated that the social-emotional needs are not as easily identified as the physical support needs:

“Also physical stuff you can see, I mean you can walk pass and see, oh, but you sit very badly in this wheelchair, or the footplates are too low, or whatever. You can’t always see into somebody’s mind, how do they feel?” IL [345-349].

“Jo is at the moment, this very moment very emotional, but as I said she ‘hides’ it very well” IN [31-32].

It was also evident that Jo-Anne experiences difficulty managing stress and change, and this creates a need for emotional support during such times:

“But I think the greatest impact is more stress from the world, various stresses, because she has been – at times, this term she’s been very down” IB [435-437].

“She just goes into this frozen mode, everything shuts down, and whenever there is change that she can’t cope with” IB [445-446].

The social-emotional needs experienced by Jo-Anne, fluctuate and are affected by many factors, some associated with her disability, and some associated with adolescence and identity development:

“She goes through phases when she becomes quite insecure in who she is, and who she is willing to present herself as, and then she doesn’t even want to – she doesn’t want to face the world, when other times she embraces the world. So she sort of really goes through – and it’s phases of trying to get to grips with her, ‘who’ is she, and trying to understand herself” IB [202-207].

“I know that must be at times humiliating and difficult… especially as she is growing up. I think if you as a young girl, she would start to think about relationships and the
seriousness of relationships... and wanting to get married, having a boyfriend, getting engaged, having babies. All of that must be really hard and she is at the age where some of that starts to come into play” IL [309-316].

“I think also as a girl it is going to get harder for her, because you know all girls want to look pretty, and so I think it is going to get harder for her as she is getting older now” IN [90-92].

Due to Jo-Anne’s delayed development in early childhood, she is both cognitively and emotionally immature for her age, and she is functioning at a level two years below her chronological age:

“Yes, because she’s 14 but she’s not actually, she’s really 12. And that’s why she is two years behind in school and she actually fits in” IB [239-240].

Jo-Anne’s social-emotional needs can be considered common to various disabilities not unique to CRS itself. Many of Jo-Anne’s needs in this domain are associated with her physical symptoms, specifically not being able to walk and her need for a catheter. Another support need is associated with feelings of fitting in and this can be associated with her adolescent stage of development, as well as being linked to having a disability causing her to feel different. It is also felt that Jo-Anne’s social-emotional needs tend to fluctuate.

(c) Academic support needs

The data revealed that Jo-Anne has various academic support needs. She is aware of some of her needs and areas where she requires more support. These difficulties are specifically problems with concentrating, understanding the work and instructions, and difficulties experienced with mathematics:

“I need help with work sometimes at school, it’s frustrating... I don’t always understand it” IJ [130-313 &135].

“Jo-Anne feels that if she understood better and she was able to work faster she would feel more positive about school and her abilities” FNJ1 [104-106].

“Focussing her attention and understanding work is difficult, and working out sums in maths is not easy” FNJ1 [106-107].
The interview with Jo-Anne’s foster mother, Bronwyn, indicated that she had observed similar difficulties and support needs:

“She battles at school, she has to work very, very hard to just – to manage, and if she’s doing well then she is getting 62% and 70% with hard work, it doesn’t just come” IB [579-581].

The analysis of the data revealed that having a physical disability has affected Jo-Anne’s academic life in two instances. Firstly, having a disability has been choice limiting in terms of school selection and secondly, physical symptoms, such as pain, affecting her concentration and performance in the classroom:

“Now, from a physical point of view there are influences on academics, and so from a physical point of view the fact that she has got some functional limitations I think has an influence in her academics. She couldn’t go to any school in the world she wanted to go to” IL [410-413].

“It is choice limiting unfortunately, and that is just being in a wheelchair and having a speech impediment is choice limiting” IL [438-440].

“Having pain, and her pain is not nearly to that point... but if you are in pain it is very difficult to concentrate” IL [427-430].

The social-emotional domain also affects the academic support needs of Jo-Anne. It was often observed that when her need for emotional support increased so did her need for academic support:

“There are times when Jo-Anne will tell herself she cannot do well at school because of her disability” FNJ1 [102-103].

“This past term she wasn’t working as she used to. Homework not done, book not here, things that she doesn’t usually do... But I don’t think that it is much of a problem with her physical disability than it is with the emotional stuff that is going on” IN [175-179].

“I picked up that there was something wrong with Jo, she really wasn’t motivated, not really keen to do her work because there was some problems at home that her foster parent told me” IF [44-46].
“But as soon as anything goes wrong in her life the thing that gets hit is the academics” IB [583-584].

Various systemic factors also have influenced Jo-Anne’s academic performance and need for support. Such factors include the influence of having ADHD and a speech impediment, and the influence of her background and biological family:

“Then also I think her speech impediment I think has an influence on her academic support needs, and also her academic performance because whether it is difficult for you to speak or difficult for other people to understand you” IL [421-424].

“Yes, the lack of development and lack of stimulation, plus the ADD with the foetal alcohol syndrome is more – that’s really affected her” IB [559-560].

The academic support needs of Jo-Anne are related to various factors that do not necessarily stem from having CRS. The data showed that her academic support needs are strongly influenced by her speech impediment, as well as by her social-emotional needs. It was also found that Jo-Anne’s past and her biological family have had a strong influence on her academic needs.

(d) Level of support required

Observations from Jo-Anne’s teachers indicate that she appears to cope well with her disability and she is easily supported in the classroom:

“With Jo specifically it is (meeting her needs) not difficult” IN [67].

“In that class there’s really a big variety of disabilities and I don’t think she is in a position where she really needs an assistant maybe, no, I think she copes well enough at this stage” IF [63-65].

Evidence from Laura, Jo-Anne’s physiotherapist, suggests that currently, her physical symptoms are stable and she requires very little further physical support. Rather her current support strategies should be monitored and maintained:

“Because now she is at the point where, to a certain extent, it is going to be stable” IL [185-186].
“At this stage where Jo is, her physical support needs, there isn’t a lot that she doesn’t have, as a matter of fact I can’t think of anything that she doesn’t have right at the moment” IL [201-204].

As was seen in the discussion around the three domains, many of the support needs experienced by Jo-Anne are common to various disabilities and this did create less of a challenge when understanding and treating her physical symptoms:

“As time went on and I treated Jo, the focus shifted more towards her needs particularly, in spite of whatever her disability is” IL [7-8].

“As I said earlier, you would find parallels between a couple of different conditions” IL [55-56].

“From the physical therapy point of view her support needs is not that unique, because it is based on function and how functionally independent she is” IL [61-63].

A final finding in terms of the level of support Jo-Anne requires is that support needs are fluid and can change over time:

“I think when you’re smaller you have more social needs, to make friends you know, etcetera. I think as you grow up, especially for a girl, as you grow up you know, am I sexy? How can I be sexy if my legs are – just physical appearance?” IL [325-328].

“She gets a little bit ashamed of her body sometimes... whereas when she was younger it was not issue at all” IB [546-548].

The data revealed that the level of support Jo-Anne requires is not considered severe, as many of her needs are currently being met and her physical symptoms are stable. The fact that Jo-Anne’s symptoms are not unique to CRS has meant that her support needs and managing her needs was a more manageable task, since her symptoms were not rare, despite the rarity of the condition.

4.3.1 Literature discussion for theme 1: The domains of support needs

(a) Physical symptoms and support needs

As discussed, Jo-Anne presents with type III CRS, which has variable lumbar and total sacral agenesis. This causes the last developed vertebrae, which in Jo-Anne’s case is a mass of bone,
to rest on top of the ilia, hipbones (Sen & Patel, 2007). Furthermore, this spinal development leads to restricted movement in the pelvis (Sen & Patel, 2007) and in Jo-Anne’s case, this has led to paralysis. According to Cuevas (1995), Jadav, Gandhi, Soni, and Desai (2012), and Sen and Patel (2007), Jo-Anne’s hip flexion contracture, lower limb paralysis, a shortened trunk, and the bladder and bowel difficulties associated with missing spinal segments are symptoms characteristic of CRS.

The physical support needs Jo-Anne experiences because of her symptoms are consistent with the literature findings regarding the support needs of individuals with CRS and paralysed individuals. Such support needs include catheterisation, use of a wheelchair, and physiotherapy in order to manage the pain and difficulties associated with the hip flexion contracture. Further, it is suggested that an osteotomy, a surgical procedure Jo-Anne has undergone, is beneficial in treating severe contractures (Altaf, Hakel, Sivaraman, & Noorden, 2008; Rogers, 2011).

Research has also shown that increasing mobility and general independence is a priority when treating children with motor disabilities such as CRS (Butler, 2009). By not assisting these children to increase their mobility, children may develop ‘learned helplessness’ due to repeated failure to experience mastery over situations. These children are more likely to experience negative effects on psychological developments, as well as decreased social function and participation (Butler, 2009; and Richardson, n.d). Furthermore, Butler (2009) discusses that a lack of mobility will also lead to delays in perceptual, spatial development. Therefore, not treating this physical need of mobility would increase the social-emotional, academic, and physical support needs experienced by a paralysed child.

(b) Social-emotional support needs

The social-emotional support needs will be discussed using Gibson’s model (2006) of disability identity development, summarised in Table 4.2. Within this model, individuals with disabilities will move through three stages of identity development. As has been seen in this case, support needs are fluid and similarly, disabled individuals will not progress through the three stages in a linear fashion. Different situations and life stages may increase the social-emotional support needs of an individual and this in turn creates a need to work through some of the challenges associated with a previous stage of identity development (Gibson, 2006; Myers, Laux, & Murdock 2011).
Table 4.2. Summary of Gibson’s model of disability identity development (Adapted from Gibson, 2006; and Myers, Laux and Murdock, 2011)

<table>
<thead>
<tr>
<th>STAGE 1: PASSIVE AWARENESS</th>
<th>STAGE 2: REALISATION</th>
<th>STAGE 3: ACCEPTANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Starts in early childhood, can</td>
<td>Adolescence/early adulthood</td>
<td>Adulthood</td>
</tr>
<tr>
<td>continue into adulthood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to recognise disability</td>
<td>Attempt to recognise relationship with society</td>
<td>View selves as equal to able-bodied individuals. Develop a disabled identity</td>
</tr>
<tr>
<td>- No role model of disability</td>
<td>- Begins to see self as having a disability</td>
<td>- Shift in focus from ‘being different’ is seen as negative</td>
</tr>
<tr>
<td>- Medical needs are not met</td>
<td>- Self-hate and anger</td>
<td>- Begins to view self as relevant, ‘not less than’</td>
</tr>
<tr>
<td>- Taught to deny aspects of disability</td>
<td>- Concerned with how others perceive self</td>
<td>- Involves self in disability advocacy and activism</td>
</tr>
<tr>
<td>- Disability is the ‘silent family member’</td>
<td>- Concerned with appearance</td>
<td>- Integrates self into majority of the ‘able-bodied world’</td>
</tr>
<tr>
<td>- Co-dependency</td>
<td>- ‘Superhero’ complex</td>
<td></td>
</tr>
<tr>
<td>- Avoid direct attention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Will not associate with other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>disabled individuals</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

These challenges and stages of development are common to individuals with a variety of disabilities (Myers, Laux, & Murdock, 2011) and are not unique to CRS, correlating with the views that Jo-Anne’s social-emotional needs are common to many learners in her school environment. By considering the data and Gibson’s model, it can be seen that Jo-Anne is currently in stage two, realisation. In this stage, Jo-Anne is concerned with her appearance, she is aware of her disability, and at times feels the need to put on a ‘superhero’ persona.

Ego-related stressors have been found to be highly related to an increase in distress associated with being disabled, such stressors include feelings of inadequacy, helplessness, worthlessness, shame, and guilt. These feelings were reported to cause people to view their disability as a handicap and this leads to a pessimistic and helpless mind-set (Pande & TeWari, 2011). Furthermore, it was found that in disabled females, self-esteem is strongly dependent on body-esteem and this could largely be attributed to standards created by society in terms of female beauty (Taleporos & McCabe, 2002). Taleporos and McCabe (2002) discuss that for disabled individuals, body-esteem is closely associated with overall psychological well-being. This association was not as prevalent in able-bodied groups. Therefore, psychological interventions targeted at meeting social-emotional support needs of disabled individuals should also focus on issues around developing self-esteem.
This correlates with findings in this study that self-esteem and identity are support needs experienced by Jo-Anne currently, and that these factors are directly affected by her disability and will affect her ability to cope. These needs are further related to Jo-Anne’s stage of development in Gibson’s model, specifically stage two.

Having a lack of mobility can lead to smaller social networks, restricted social function, fewer friends, and appearing less socially desirable by peers (Richardson, n.d; Butler, 2008). As was discussed, Jo-Anne often has concerns around fitting in with her peers and being accepted, and this is often associated with her feelings around being paralysed. As discussed in chapter two, having bladder and bowel conditions and requiring the use of a catheter can often lead to various social-emotional needs. These children are often secretive about their conditions due to fear of stigma, embarrassment, and social rejection (Filce & Lavergne, 2011), as has been seen with Jo-Anne, who prefers to keep this aspect of her condition private.

Gibson (2006) discusses that society plays a vital role in determining how accepted disabled individuals feel. Often individuals with disabilities experience victimisation and internalise the perceptions held by society that they are ‘less than’ able-bodied individuals. Therefore, the attitudes and responses from society can greatly affect the feelings disabled individuals have about their physical symptoms, such as being in a wheelchair or having a catheter. Negative experiences or feelings of victimisation will therefore affect the social-emotional support needs of an individual, as it increases the challenges they need to overcome. In this case, any negative experiences Jo-Anne has when interacting in the able-bodied mainstream society will affect how able she is to overcome the challenges in the realisation stage of Gibson’s model. This will in turn affect Jo-Anne’s ability to fully progress to the third and final stage of acceptance in Gibson’s model.

(c) Academic support needs

The DSM-5 (American Psychiatric Association, 2013) indicates that children with ADHD present with difficulties focusing attention due to distractibility, as well as difficulties with impulsivity and difficulty sustaining attention. Research indicates that children with a diagnosis of ADHD often present with language problems and this results in difficulties with central auditory processing skills (Riccig & Hynd, 1996). These auditory processing difficulties often include problems with short-term memory, following instructions, listening in environments with distractions, missing details when required to listen for information, and a slower
processing speed. Difficulties such as these would then lead to a lack of understanding the classroom setting (Greathead, n.d). Therefore, it is possible to see why Jo-Anne experiences problems with concentrating and understanding information heard in class.

The data revealed that Jo-Anne experiences a decline in academic performance during periods where she experiences emotional difficulties. Research conducted by Wolff Heller, Alberto, and Meagher (1996) indicates that having a physical disability can negatively affect psychological factors such as motivation and self-concept, and this can have undesirable effects on academic performance. Specifically the way in which an individual reacts towards having a disability will affect their motivation to learn (Wolff Heller, Alberto, & Meagher, 1996); therefore assisting children to accept and cope with their disability may lead to increased motivation in the classroom. Poor self-concept because of a disability may lead to feelings of inferiority, which could lead to self-doubt and self-defeating thoughts relating to academic ability (Wolff Heller, Alberto, & Meagher, 1996). Therefore, the negative emotions associated with the disability itself could negatively affect academic performance.

Jo-Anne has also experienced other emotional difficulties not directly linked to her disability. It has been found that all emotional experiences consist of physiological, behavioural and cognitive response (Darling-Hammond, Orcutt, Strobel, Kirsch, Lit, & Martin, n.d). These different responses would interfere with many aspects of life, such as school performance. Negative emotions such as anger, anxiety, and sadness can distract children in learning situations (Darling-Hammond, et al., n.d).

Research has also found that emotions have an effect on working memory, particularly during periods of high anxiety. When a child is anxious, a large part of the working memory is focussed on the awareness of fears and concerns and this leaves less space for processing information during periods of learning (McPherson, 2011). From the literature discussed, it is possible to see that Jo-Anne’s social-emotional state can have a negative effect on her academic performance due to various reasons.

The experience of pain because of a physical disability, such as the painful sensations Jo-Anne experiences in her legs, can affect concentration in the classroom (Wolff Heller, Alberto, & Meagher, 1996). Pain can be related to the task, in the sense that some aspect of the task is creating pain in a muscle or joint due to the physical demands, or pain is unrelated to the task, such as the leg pains experienced by Jo-Anne. In the classroom setting activities may
need to be adjusted once the source of the pain is identified (Wolff Heller, Alberto, & Meagher, 1996). In this case, Jo-Anne may need to be given time to leave her wheelchair for a few moments in order to relieve her pain. Strategies such as these are important, because children are unable to attend to their academic tasks when they are in pain (Wolff Heller, Alberto, & Meagher, 1996).

The Australian Human Rights Commission (n.d) have found that there are not enough facilities available to meet the needs of the disabled community and this often means children with physical disabilities have limited choices when looking for school placements with many schools unable or unwilling to make the necessary accommodations. Similarly, Human Rights Watch (2015) has found that in South Africa, it is estimated that half-a-million disabled children do not have access to schools despite the country’s inclusive education policies.

Gibson (2006) discusses that part of the reason society lacks adequate supports and accommodations for physically disabled individuals is due to the past medical paradigms, which maintained that disabled individuals should make adjustments in order to fit into able-bodied society. Despite the fact that paradigms are shifting to more inclusive, person-centred models, there is still a long way to go to create a society that is fully inclusive and accommodating for disabled individuals. Figure 4.2, which summarise Jo-Anne’s history, shows that Jo-Anne’s disability has created barriers in terms of her school, as she had to change schools due to a lack of wheelchair accessibility.

**d) Level of support required**

The data revealed that in terms of Jo-Anne’s physical needs she is currently in a place where her physical support needs are met and stable. Part of the reason for this stability in terms of physical support is because she has an effective support system. When providing support in order to meet mobility needs, it has been found that a system of interventions and supports is needed, such as wheelchairs. The system should be as functional and energy efficient as possible so that the individual is able to use the supports in order to reach their full mobility potential (Butler, 2008). In Jo-Anne’s case, she is able to mobilise out of her wheelchair by using her arms but she also has an electric wheelchair for school and a manual wheelchair for home use.

Support needs in all domains are fluid and may change over time. Physical support needs, particularly relating to mobility, are likely to change with age. Contractures may lead to bone
deformity, or arthritis leading to an increase in pain (Butler, 2008). Jo-Anne currently has the start of arthritis in her hip due to the flexion contracture. It is likely she will experience more pain as she ages. In terms of social-emotional needs, Gibson (2006) indicates that there is a level of fluidity when moving through the stages of identity development and emotional difficulties can cause setbacks in this progression. Jo-Anne’s history indicates that the difficulties with her biological family can lead to such emotional difficulties and as shown previously, such emotional difficulties will lead to fluctuations in terms of her academic support needs.

The data revealed that although Jo-Anne’s diagnosis is rare, her symptoms and needs are common to many disorders, and this has made it easier to meet her support needs in the various domains. The work of Gibson (2006) has shown that the difficulties around identity development are seen in most disabled individuals. Similarly, the emotional difficulties Jo-Anne experienced regarding her bladder difficulties are not unique to CRS and can be generalised to other conditions with bladder difficulties. Other conditions leading to bladder difficulties can include Crohn’s disease, Down syndrome, cerebral palsy, and spina bifida (Botha & Kruger, 2005; Filce & Lavergne, 2011, Smith & Kruger, 2005).

From the above discussion, it is possible to see that the three domains are interlinked and therefore influence one another. Providing adequate support in one domain would have a positive ripple effect on the remaining two domains. However, adequate support in one domain does not imply that there would cease to be a need for support in the other domains. The level of support required may vary amongst the domains. The symptoms and support needs Jo-Anne experiences are neither rare nor unique despite the rarity of CRS, because many of these symptoms and support needs are common to many disabilities.

4.4 THEME 2: ADDITIONAL COMPOUNDING FACTORS

The compounding factors are divided into two main categories. Firstly, Jo-Anne’s ability to cope and the tools that she uses to manage her disability and secondly, her comorbid diagnosis that affects her condition and support needs. Both of these categories affect the domains of support needs as well as the level of support that Jo-Anne requires. These categories are also affected by the various systemic factors discussed in theme three, contextual factors.
(a) Coping strategies

During the data collection process, it became evident that the learners provide a great deal of emotional support to one another within the school setting:

“On break you can sit with your friends and your friends can help you express anything, like you can – if class was frustrating and then on break is the time when you can complain to your friends and ask them if they agree with you” IJ [231-234].

“I think they (the learners) support each other more than what they get support – a lot of the kids from home or from school. I think they rely on the support from their peers” IB [385-387].

Analysis of the data indicated that Jo-Anne has developed strategies in order to cope better with the emotional difficulties she experiences in relation to her disability and other challenges she experiences:

“I draw, I paint, I create things... It helps me express my feelings.” IJ [281 & 284].

“But she found that people could understand too much of what was going on inside her, so she preferred the poems because they are a bit more abstract, it doesn’t let people as close” IB [287-289].

“These feelings (feeling different) have changed because she has come to realise the only thing that is different between herself and her friends is the fact that she cannot walk” FNJ2 [21-23].

“Jo-Anne feels that sometimes it can be fun having CRS because she can run around on her hands and this is something other people cannot do. She also surprises people by doing things they assume she will not be able to do” FNJ1 [114-117].

Jo-Anne has also found ways to cope with her physical needs. These include discovering alternative ways to mobilise, managing her own catheterisation, and trying to manage the pain in her legs when she cannot go to the physiotherapist immediately:

“At breaks she will get out of her chair and move around on her hands. She can run very fast on her hands” FNJ1 [68-69].
“Jo-Anne gets pains in her leg from sitting in her wheelchair for too long, especially during exams. Getting out her chair and moving freely helps” FNJ1 [108-109].

“She’s able to swim, she swims very well and there she’s got freedom when she’s not in a wheelchair” IB [393-395].

“And then it’s also impacted her bladder and bowel which she manages very well now” IB [399-400].

“She’s very mobile. Yes, she is in a wheelchair but you know, I don’t know if you’ve seen her walk on her hands before... she is like super strong. She can do pull-ups, she can walk on her hands as I’ve said, handstands” IN [5-10].

“She is also like a little monkey. If she is not in her wheelchair she can – she’s got enough strength in her arms and her trunk to be able to sort of crawl, or her version of crawl around” IL [254-255].

The above discussion revealed that Jo-Anne has developed various strategies in order to cope with her disability. The learners at Jo-Anne’s school support one another in order to manage their challenges. Jo-Anne also engages in creative and expressive arts activities as a way to manage her social-emotional needs, as well as finding alternative ways to mobilise out of her wheelchair as a way of coping with her mobility needs.

(b) Comorbid factors

From the interview with Bronwyn, it was noted that Jo-Anne’s CRS condition developed due to poor prenatal care. Jo-Anne’s birth mother drank throughout her pregnancy and it is felt that the CRS developed because of the alcohol and poor nutrition:

“And then, a little bit of the frustration with the biological parents because one of your – there is no direct cause or things with caudal regression, but there is a very high incidence amongst diabetic mothers, and with the diet of alcohol and drugs you are not – your food is not optimal so you’re going to get the same presentation” IB [84-88].

Jo-Anne also has a cleft palate and it is evident that this is strongly related to foetal alcohol syndrome (FAS) and not a symptom of the CRS (Mersch & Shiel, 2014). Similarly, she has attention deficit hyperactivity disorder (ADHD), which is also because of the FAS (Breecher, 1999):
“She has ADD, she’s Attention Deficit Disorder not with hyperactivity, and then the cleft palate and those are very much – that’s related to the foetal alcohol” IB [93-95].

Both the ADHD and the cleft palate have had an impact on Jo-Anne’s physical, academic, and social-emotional support needs:

“Jo-Anne’s speech is not clear and this makes her frustrated as the children cannot always understand her” FNJ1 [74-75].

“There is quite a good chance that they’ll need to do some jaw surgery because her cleft palate, it means her upper jaw is smaller than her low jaw” IB [419-421].

“Looking from the outside, I would say that if you have a speech impediment you do easily need support just to not feel that you’re inadequate, people can’t understand you, people are making fun of you” IL [298-300].

“Then also I think her speech impediment, I think has an influence on her academic support needs, and also her academic performance because whether it is difficult for you to speak or difficult for other people to understand you” IL [421-424].

“She has become so anxious because she can’t finish anything, and hasn’t been able to focus at school” IB [571-573].

“The lack of development and lack of stimulation, plus the ADD with the foetal alcohol syndrome is more – that’s really affected her (academics)” IB [559-560].

Jo-Anne has two comorbid diagnoses, which are related to having FAS and do not stem from her diagnosis of CRS. These comorbid diagnoses are namely, ADHD, the inattentive type, and a cleft palate. These comorbid diagnoses have an influence on all three domains of support needs, physical, social-emotional, and academic.

4.4.1 Literature discussion for theme 2: Additional compounding factors

(a) Coping strategies

Jo-Anne has developed various coping strategies, one of which is the support she gets from her peers at school who are also disabled. Peer support can include a range of activities including informal conversations between peers with similar experiences (Department of Human Services, 2014). An important aspect of peer support is that it is based on mutual and
empathetic understanding of the situation. It has been found that when people identify with others, who they perceive to have similar feelings or experiences, a deep connection is made. These peer relationships allow individuals to freely interact without the constraints of a ‘client-expert’ relationship (Mead, Hilton, & Curtis, 2001).

Additionally, Jo-Anne has developed other strategies that assist her in coping with some of the emotional difficulties she experiences. Art therapy can lead to improvement in all domains of functioning for physically disabled individuals. Specifically art therapy can help to alleviate the difficult emotions associated with the disability, can assist during the recovery from surgery, or provide an emotional outlet for difficult life stages and transitions. Art therapy activities include activities such as music therapy, literary therapy, use of the visual arts, and performing arts (SAACA, 2014). Jo-Anne finds creating poems, painting, and drawing to be therapeutic and she especially makes use of these mediums to cope with social-emotional stressors specifically associated with her biological family and her feelings of being different.

The efficiency with which a disabled individual is able to manage the additional demands having a disability creates will determine how effective the coping strategies are (Pande & Tewari, 2011). The coping ability is strongly related to perceptions of the disability as well as views of personal possibilities (Persson & Ryden, 2006). When Jo-Anne is in a positive frame of mind and is able to view aspects of her disability and her abilities positively, she will be able to cope better.

(b) Additional comorbid factors

The data gathered and her history (Figure 4.2) show that Jo-Anne has FAS due to maternal drinking. It is felt that her comorbid conditions are largely related to the FAS as well as a lack of care as an infant. FAS is a birth defect caused by a mother consuming large amounts of alcohol during pregnancy. The condition can lead to facial and neural abnormalities, malformations in other organ systems, and a slowed growth rate (NICUS, n.d). The consumption of alcohol interferes with maternal nutrition by leading to reduced food intake as well as preventing the metabolism of the B vitamins, vitamins A and C, zinc, iron, calcium, and magnesium (NICUS, n.d).

It has been found that foetal alcohol exposure can contribute to the development of ADHD and it is common for children with FAS to first be diagnosed with ADHD before the FAS is identified (Breecher, 1999; Rovet, Greenbaum, & Kodituwakku, 2009). Furthermore, studies
have found that rat pups exposed to alcohol experience a fifty percent decrease in dopamine activity, indicating that FAS affects the same neural pathways as seen in children with ADHD (Breecher, 1999). Therefore, Jo-Anne has additional academic support needs due to her ADHD diagnosis resulting from FAS.

According to the National Institutes of Health (2008), research found that women who drink five or more drinks at a time during pregnancy are more than twice as likely as non-drinkers to give birth to a child with a cleft lip, with or without a cleft palate. This condition needs to be treated surgically as early as possible, as having a cleft palate can lead to feeding difficulties and severe ear infections that could lead to hearing loss (Cleft Palate Foundation, 2007; Naqarajan, Savitha, & Subramaniyan, 2009). Because Jo-Anne’s cleft palate was only treated after the age of two when she went into foster care, she suffered with chronic ear infections and was chronically underweight because of neglect and difficulties feeding due to the opening between the nasal cavity and mouth.

A cleft palate can influence the self-perception of a child and this will play a pivotal role in influencing self-esteem (Bryan, 2012; De Sousa, Devare, & Ghanshani, 2009). Children may also experience difficulties with psychological adjustment and increased behavioural problems as they are often teased and are unhappy with their facial appearance (De Sousa, Devare & Ghanshani, 2009).

Cleft palates often lead to delayed expressive language development because they acquire sounds at a slower rate. However, after reparative surgery, normal speech generally develops between ages of three and five (Naqarajan, Savitha, & Subramaniyan, 2009). Jo-Anne’s speech was further delayed because her palate was treated only after the age of two. Children with cleft palates also often experience neuropsychological deficits and academic difficulties, specifically problems with reading and memory, and an increased incidence of learning disabilities. Children often have speech difficulties and poor articulation due to malformations in the palate (Bryan, 2012; Mersch & Shiel, 2014). The cleft palate increases Jo-Anne’s social-emotional support needs due to the emotional difficulties, as well as social difficulties associated with poor articulation, the frustration around not being understood, and potentially being teased. Therefore, having a cleft palate increases Jo-Anne’s social-emotional and academic support needs, as well as creating physical needs in early childhood.
This discussion showed that Jo-Anne’s comorbid diagnoses have both stemmed from FAS and poor prenatal care, and these diagnoses increase the support needs in all three domains. The coping strategies as well as the support network she has developed with her peers assist Jo-Anne to manage the stresses and difficulties associated with her primary diagnosis of CRS and the comorbid conditions, better.

4.5 THEME 3: SYSTEMIC FACTORS

The systemic factors in this case have affected the development and prognosis of both Jo-Anne’s primary and comorbid diagnoses, as well as how her support needs have been met. The systemic factors that were identified during the data analysis included contextual factors, such as Jo-Anne’s history and family context; the support needs that are met at school and ways in which the school can improve in meeting support needs. When considering Bronfenbrenner’s bioecological model on human development (Bronfenbrenner, 2005), it is possible to see that these contextual factors are found in the microsystems of the family and the school, as well as within the exosystem of Jo-Anne’s community.

(a) Contextual factors

Jo-Anne’s biological family has had a great impact on the development of her CRS and the conditions associated with FAS. Additionally, her biological family continue to affect her support needs in the three domains:

“She wasn’t really working and focusing on other things, and at first I thought it was boys because girls are like this at that stage. And then her mother told me ‘no’ that it is about her biological family and that they are having a lot of issues with them” IN [36-40].

“I think academically I don’t know if the disability has influenced it a lot, I think at this stage it is more background” IF [225-226].

“And I know it is not easy for her always, because there is always that second family” IL [112-113].

“I don’t think her emotional needs can be separated. The rarity of her diagnosis with her socio-economic background, not of her of any person can be separated. So I know some of her emotional needs are due to her background” IL [288-291].
“She started off with spending basically two years in a cot, and so when she – at two she started at zero, so she’s lost two years, and she’s always been about two years behind development… by the age of two, no speech, no nothing. So it really, it did have an influence there in terms of it delayed the development, and then also there had been a couple of setbacks along the way when we have contact with biological parents” IB [115-123].

Throughout the data analysis, it became clear that Jo-Anne’s life stage, adolescence, has a great effect on her social-emotional development and support needs:

“You know, girls are girls, when they get to the teenage stage it is just boys, boys, boys” IN [114-115].

“It just has its extra influences when she’s now in puberty, there are also issues to deal with in terms of self-image and you know, the wheelchair, bladder and bowel issues, and then also the whole issue of children” IB [135-138].

The interviews indicated that the support of a family can be vital in ensuring support needs are met in all three domains. In Jo-Anne’s case, it is clear her foster mother has provided excellent support in order to ensure her support needs are met:

“Bronwyn being as supportive as she is, the fact that Jo has got different wheelchairs for different functions, the fact that she has the motorised wheelchair” IL [78-80].

“Bronwyn certainly is an advantage with her, because between having the physio and the OT, and having access to the best possible mobility aids and adjunctive therapies, or not therapies but activities” IL [139-141].

Various contextual factors specifically family influence, support and care and the individual life stage impact the physical, social-emotional and academic support needs of the individual as well as their coping strategies.

(b) School meeting support needs

The interviews indicated that the school offers a variety of support services for the learners:

“Well, they have all the therapies that she needs” IN [47]
I think it provides a lot, look, you yourself know that we do have all the different therapies here, which can cover most of those things” IF [98-99].

“The school has most of the services in theory she needs… the school has got the academic side and staff who certainly can deal with her needs there… So, the school has physiotherapists or offer physiotherapy services and OT… There is the speech therapy service that has been offered… There is a – the school does offer a psychology service, the school has access to – the school also offers nursing services. The school has access to social services” IL [123-150].

Evidence from the interviews and from the photographs taken of the school suggests that the school is physically accessible for wheelchair users:

“It is easily accessible to her. The classrooms are easy to get to, the classrooms inside are easy to move in. She can get to the sports field, she can get to therapy” IN [47-5294]0].

“But you have all the therapies, you have a very good sports programme, you have a very good cultural programme. You can go on the stage and dance in your wheelchair because there are lots of other kids that also do it and you’re not going to be labelled” IL [456-459].

“It’s (the school) fully accessible, there’s OT and physio and that has been good” IB [226-227].

The school has wheelchair ramps to allow wheelchair users access to the different levels [PS1].

All the rooms in the school have double door access to create enough room for wheelchairs to enter [PS2 and PS3].

The bathroom has an open stall with a chair and screen in order to allow wheelchair users the space to move from the wheelchair to the toilet seat, as well as to have enough space to catheterise [PS4].
The school is an environment that provides a feeling of ‘security’, as it is a school for learners with physical disabilities:

“At a school like ours, it is protected and every other child is dealing with some issue, whereas if you go out in the world you may end up being the only person in a fifty floor office block that has any kind of physical disabilities” IL [334-337].

Bronwyn, Jo-Anne’s foster mother, feels that the school adequately meets Jo-Anne’s physical needs:

“But they – on the physical side to me, they’re really do (meet Jo-Anne’s needs)” IB [308-309].

Evidence from the interviews with Jo-Anne’s educators indicated that the school provides educator training on some more common disabilities in order to provide support in class:

“I don’t think we did it this year but we did have it by the end of last year, some meetings where we went through all the different disabilities and unfortunately, I think this one wasn’t part of it, this type of disability” IF [119-122].

The physiotherapists offer physical support in order to meet physical support needs, which in turn can meet some academic support needs:

“So, then the support needs has an influence on the academics is actually to make sure that she is comfortable and the pain is as little as possible, or that medication or hot-packs, or a special cushion” IL [431-433].

In the classroom, the educators attempt to support learners by focussing on learner strengths and monitoring the understanding of the learners in the classroom:

“I try in the class to treat everyone you know according to what their capabilities are, not their disabilities” IF [39-41].

“I think in the class, that in most of the subjects, that they have, they should get enough support there” IF [102-104].

“Sometimes the teacher would ask me if I “understand” what’s going on” IJ [213-214].
The above discussion has shown that the school provides support to the learners in many ways. The school offers a range of therapies and the environment is physically accessible. The staff receive some training on more common disabilities and the physiotherapists assist to manage pain and physical difficulties in the learners which improves learning and centration.

(c) Support needs where school can improve

There appears to be a lack in educator knowledge on different disabilities, including CRS:

“We usually just read up on a lot of conditions if it really affects the child badly so that you know how to handle that child, but I mean if they are coping so well” IN [15-17].

“Unfortunately, I don’t know very much (about CRS) I’m sorry to say” IF [4].

“And teaching the teachers also what to… and then they think, okay, let’s make the adjustments for their ‘physical’ disability, because that you can see and it is much easier to actually plan that” IB [330-334].

The data revealed that despite the fact that the educators felt the support provided was adequate, there are challenges associated with the being in government setting:

“At the moment, there is no speech therapy because we are waiting for another speech therapist, which I do think she needs as well” IN [42-43].

“One of the big problems with the school setting, which is a government supported structure, is that one does have potentially staff shortages and overwhelming workload, and that impacts on the ability to meet a specific single child with all their support needs” [150-153].

“Sometimes needs can be better met by either outside consultations or a combination of outside and at school consultations, because unfortunately, the school is there for 200 odd children and just not for one person” IL [225-227].

It was also felt that the emotional support provided for the learners and their parents at the school could be increased:

“I don’t think on an emotional side. They’ve got kids in their class as well who have conditions that are very much progressive, and it’s glossed over so that, you know, nobody notices” IB [309-311].
“I think many of the parents don’t actually understand their kids’ disabilities. I’m glad we have a parents meeting once a term, and I often find that I end up chatting to parents while I’m waiting for a teacher, and find that they’re actually out of their depth” IB [357-360].

The various interviews indicated that there might be a need to monitor the quality of teaching and ensure it is standardised:

“There might be one or two little hiccups here and there, we all know that all the teachers are not the same, they don’t teach the same” IF [104-105].

“The teacher doesn’t explain the work, then – and sometimes we don’t remember we had homework, then we have failed in it the next day, but we didn’t know we had to do work” IJ [157-159].

There is a need for improved communication from the school to home, especially in terms of extra murals as lack of communication led to Jo-Anne being unable to participate:

“Yes, but I don’t know what’s been going on because this year it was hard for me to participate, because some days my mother couldn’t get off work... And they only tell us at the end of the day if there is something going on after school” IJ [267-275].

“But (sport) not accessible for a day scholar, because they change the times at the last minute” IB [294-295].

Despite the various ways in which the school supports the learners, there are aspects where support can be improved. There is a need for more educator training around the different disabilities and the implication for the classroom as well as ensuring that the quality of teaching is more standardised. Additionally improved communication between the school and home is required and more intensive emotional support can be provided to parents and learners. Finally the staff have to balance the financial and staffing constraints associated with being in a government school.
4.5.1 Literature discussion for theme 3: Systemic factors

(a) Contextual factors

The data indicated that Jo-Anne’s current life stage of adolescence is influenced by having a disability and affects the three domains of support needs. Adolescence is a time where there are profound physical, cognitive, and social-emotional changes (Rittenmeyer & Huffman, 2003). Physically, young teens enter puberty and with it, issues around sexuality emerge. Cognitively, intellectual interests begin to expand, capacity for abstract thinking increases, and there is an increased ability for deeper moral thinking. Finally, in terms of social-emotional development, there are difficulties with developing a sense of identity, a tendency for moodiness, intense emotional experiences, and a need to test boundaries. Teenagers are greatly influenced by their peers and often distance themselves from their parents (BCCP, 2008).

Having a disability increases the complexities associated with this life stage and the effect can be seen in the physical, cognitive, and social-emotional domains. In the physical domain, issues may develop such as difficulties with body image, pubertal complications, and height and weight problems because of the condition (Yeo & Sawyer, 2005). In Jo-Anne’s case, height and sexuality are particular issues. It has also been seen that teenagers with chronic conditions, experience a sense of alienation from their peers and high levels of frustration associated with managing the condition. There is also an increased likelihood for mental illness, specifically anxiety, depression, behavioural problems, and decreased school performance (Yeo & Sawyer, 2005). Currently, Jo-Anne does not appear at risk for a mental disorder such as depression or anxiety. However, her social-emotional needs should be monitored to ensure she receives adequate support in the future in order to minimise the risk of such disorders, especially due to the emotional strain the influence of her biological family creates.

Finally, chronic conditions, such as Jo-Anne’s, can lead to chronic absenteeism and poor school performance (Yeo & Sawyer, 2005). Presently, Jo-Anne is not at risk for frequent absenteeism as her physical symptoms are stable and she does not require further surgeries, this could change in the future since support needs and symptoms change over time.

Development is a process that occurs through the interaction of biological and environmental processes and the family has one of the most profound impacts on a child’s development (Harden, 2004). Parents have a significant influence on personality and emotional development, as well as behaviour. The support provided by caregivers and stability within the
family setting will set the foundations for the healthy childhood development. Secure attachment with caregivers that fosters feelings of warmth, support, emotional involvement, and nurturance will lead to the development of positive outcomes. This form of environment will predict the child’s future emotional development (Harden, 2004; Moges & Weber, 2014). The family can also have a negative impact on childhood development. Childhood neglect and maltreatment can have adverse effects on brain development, cognitive and language skills, and social-emotional functioning (Harden, 2004).

This case shows the positive and negative influence the family can have on development. The poor prenatal care and neglect by Jo-Anne’s biological parents has had a negative influence on her physical and cognitive development, since this lack of care led to the development of her CRS and ADHD. Jo-Anne was born with a cleft palate that formed due to poor prenatal care, and she currently experiences difficulties with articulation. Surgery in infancy could possibly have reduced these difficulties; however, this could not be clearly determined since it has been found that some articulation problems may persist even after early interventions due to the physical structure of the palate. After surgery, some children, such as Jo-Anne, may still have a nasal quality to their speech (Cleft Palate Foundation, 2007).

The deficits discussed above have in turn had a negative effect on Jo-Anne’s social-emotional self. Her recent negative interactions with her biological parents have also had a damaging effect on her social-emotional self, leading to poor academic performance. Conversely, Jo-Anne’s foster mother has shown the positive influence a stable family environment can have on meeting the various support needs in the academic, physical, and social-emotional domains.

(b) School meeting support needs

Current inclusive thinking pushes for environments to become more accommodating of individuals with disabilities as opposed to disabled individuals being required to adapt to the environment (Gibson, 2006). In South Africa, the Education White Paper Six (Department of Education, 2001) states that schools need to minimise barriers to learning so that participation of all learners can be maximised. This includes participation in extra-curricular activities and not only academic activities. The policy also states that support needs be provided at different levels in order to adequately meet the needs of each individual child. The SIAS process discussed in chapter two showed that support levels range from low to high and individuals
requiring a high level of support may require a range of therapies, small class sizes, and specialised teaching (Department of Basic Education, 2014).

The data indicates that Jo-Anne’s special school offers specialised services for physically disabled learners. This is especially done through the provision of physiotherapy, occupational therapy, speech therapy, psychological services, and nursing services. The necessary physical accommodations have been made by making the school wheelchair accessible and allows for the participation in sporting activities. The school also offers training to educators on some common physical disabilities, increasing their specialised knowledge. Being in a school with other disabled individuals, such as Jo-Anne’s, allows learners the opportunity to minimise their feelings of being different. However, it does also decrease chances to interact with more diverse group of individuals (Rittenmeyer & Huffman, 2003).

(c) Support needs where the school can improve

The above discussion showed that it is important for educators in a special school setting to have specialised knowledge on the needs of the learners (Department of Basic Education, 2014; Department of Education, 2001). Learners with physical impairments have been found to have unique educational needs. This in turn requires educators to have specialised knowledge about these impairments in order to appropriately meet the unique needs of the learners (Wolff Heller & Swinehart-Jones, 2003). In this study, it is clear that there is a need for educators at Jo-Anne’s school to have more knowledge on her condition.

The data revealed that there are inconsistencies in the quality of teaching among the different educators at Jo-Anne’s school. The department of basic education has developed an Integrated Quality Management System (IQMS) for educators in order to monitor and enhance the quality of educators, as well as to identify areas in which support or further development is required (Department of Basic Education, 2009). This system should be used in schools such as Jo-Anne’s, to identify areas where the learning experience can be enhanced.

Parenting a child with a disability can be challenging and the school has an important role to play in providing support for these parents. Parents raising a disabled child often experience poorer physical and psychological health and a negative affect (Ha, Greenberg, & Mailick Seltzer, 2011). Additionally, parents often need a great deal of information regarding their child’s disability, possible grants, social services, medical treatments, and available therapies
(NICHCY, 2014). This type of emotional support and education is something that has been identified as lacking for the parents at Jo-Anne’s school.

Communication between the school and parents is another way to improve parent support as well as increasing support for learners, having a partnership between the school and home leads to improved learning for the child. Frequent communication helps ensure that both the school and home are aware of the unique needs of the learners and therefore, support children’s overall development in a more effective manner (Comer & Haynes, 1997). Communication between home and school is something identified as lacking at Jo-Anne’s school, especially as poor communication makes extra mural activities less accessible to some learners, including Jo-Anne.

Good partnerships between the school, family, and community lead to improvements in academic achievement, self-esteem, school attendance and social behaviour. Such partnerships should view parents and school staff as equal role players and clear measurable goals should be set. It is also likely that such positive changes will cause parents and teachers to experience a greater sense of satisfaction when reflecting on the child’s school experience. It is also recommended that districts become involved in school-parent partnerships to increase the sustainability and strength of such partnerships (Epstein & Shledon, 2006; Lemmer, 2007). In a special school environment, this study has shown that parent-school partnerships are imperative in allowing for open communication between the school and home, as well as ensuring the various learner support needs are being met.

A final need that was identified in the data was the need for further emotional support for the learners. The work of Gibson (2006), Pande and TeWari (2011), and Persson and Ryden (2006) discussed in the previous themes, have shown the importance of emotional support for children with physical disabilities and the important role emotional health plays in coping and quality of life.

This third and final theme has shown the influence different microsystems and exosystems have on the progression of Jo-Anne’s condition, and the influence these factors have on her support needs. Figure 4.2 shows how the various factors presented throughout the three themes are all interrelated and that all of these factors have a role to play in the presentation and needs of Jo-Anne’s condition. This figure visually presents the information using the ice-cream cone model as well as the influence of the systems within this model.
4.6 CHAPTER SUMMARY

This chapter discussed the findings of this study by linking pertinent data with relevant literature. These findings were grouped into three themes, namely the domains of support needs, additional compounding factors, and systemic factors. The themes were discussed using the ice-cream model for case conceptualisation, while also relating this information to the systemic influences discussed in Bronfenbrenner’s bioecological model on human development. This discussion showed how the themes are interrelated, affecting one another, meaning that a change in one theme leads to a change in another, all of which affecting Jo-Anne and her support needs.

Chapter five will now present the final discussion of this case as well as the limitations of the study and final recommendations.
CHAPTER 5

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter, a summary of the study will be given. The answers to the research question will be stated as well as providing recommendations for future research based on the findings of this study. The strengths and limitations of this study will also be explored. Finally, the researcher will consider the contribution this study will make to the field of inclusive education, specifically in special school settings, as well as considering that this study will add to current research on CRS.

5.2 OVERVIEW OF THE RESEARCH

The main aim of this research study was to explore the support needs of a fourteen-year old girl with CRS, in a special school for the physically disabled. During the discussion of the background of the case in chapter one, the need for this study was identified due to the limited information available on the social-emotional and academic support needs of someone with CRS. CRS is a rare condition that affects the formation of the spinal cord causing an absence of some or all of the vertebrae in the sacrum and lumbar areas.

A theoretical framework was developed using a literature review on chapter 2. This theoretical framework allowed the researcher to explore CRS in detail by looking at the causes, the different types, common symptoms and characteristics, and long-term prognosis. The literature review also allowed for an exploration of the inclusive education paradigm in South Africa and the relevance this paradigm has on the case. The literature concluded with a discussion of Bronfenbrenner’s bioecological model on human development, and this how model could be adapted in order to create the ice-cream cone model for case conceptualisation, which was used to organise and discuss the findings of this study.

Data was collected using in-depth semi-structured interviews, photographs of the school’s built environment, and from an artefact created by Jo-Anne. Using thematic content analysis, the process data analysis revealed three main interrelated themes: domains of support needs, additional compounding factors, and systemic factors.
The implications of each of the themes are discussed later in this chapter when recommendations are made. These recommendations will highlight how the findings of this study can contribute to the literature in the field of CRS, especially by adding to the literature available on the social-emotional and academic support needs.

5.3 THE FINDINGS IN LIGHT OF THE RESEARCH QUESTION

The research questions for this study was, “What support is needed for learners with caudal regression syndrome (CRS) in a special school?”

As stated in chapter four, three themes emerged from the data analysis, these themes are listed below in Table 5.1. Each theme is paired with a brief defining statement in order to show the researcher’s understanding of each theme in relation to this study.

Table 5.1. Themes arising from the study with defining statements

<table>
<thead>
<tr>
<th>Domains of support needs</th>
<th>Specific domains are physical, social-emotional, and academic. This theme also considers Jo-Anne’s CRS symptoms and the level of support required.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional compounding factors</td>
<td>Factors creating additional support needs, specifically comorbid diagnoses and factors minimising support needs, specifically coping skills and strategies.</td>
</tr>
<tr>
<td>Systemic factors</td>
<td>Micro- and exosystemic influences on the condition and support needs, either leading to increased support needs or decreased support needs through adequate provision of support.</td>
</tr>
</tbody>
</table>

From these themes, it is possible to answer the research question for this study. Jo-Anne has various support needs in all three domains, physical, social-emotional, and academic. These support needs include the need for mobility, a catheter, and pain management, support with identity development and self-image, and academic support to increase her ability to concentrate and understand. However, the themes of additional compounding factors and systemic factors show that is it not possible to separate Jo-Anne’s support needs into those exclusively associated with CRS. Rather, Jo-Anne’s support needs not only stem from her disability but are also strongly linked to her comorbid conditions, specifically ADHD and a cleft palate. It is also not possible to separate factors such as family and school from an analysis of support needs. Therefore, in order to fully conceptualise Jo-Anne’s support needs and those of other individuals with CRS it is vital to consider all other factors, such as the family
background, comorbid conditions, school environment, and developmental stage, since these factors affect the person and in turn affect the support needs associated with having CRS.

5.4 STRENGTHS OF THE STUDY

This study has shown the physical benefits of special schools catering specifically for children with physical disabilities. Being in such an environment allows learners to have full physical access to the school’s built environment, as well as full access to extra mural and sporting activities. This school environment also allows for adequate physical support from a team of specialised occupational- and physiotherapists.

Since this study was a single case study, it allowed for a rich understanding of Jo-Anne’s experiences to be developed because it allowed for a detailed exploration of Jo-Anne’s support needs. This has also led to the understanding that support needs have to be viewed by considering an individual holistically, and the needs associated with a condition such as CRS cannot be separated from other individual factors such as family background, school environment, life stages and comorbid conditions. Therefore, this can lead to new ways of viewing learners with disabilities and considering how best to provide support, as it will require professionals, such as educators and therapists, to have an understanding of the disability itself, knowledge on the influence of life stages and an awareness of the learner’s context in order to devise an adequate support strategy.

Jo-Anne was willing to share her experiences with the researcher and those around her, and this has allowed us the privilege of researching and exploring CRS and Jo-Anne’s experiences. This provided a glimpse into what living with such a rare condition is like, and how difficult the world of having a disability can be. During this study, I was also fortunate enough to have been able to obtain detailed in-depth data, not only from Jo-Anne but also from the many willing and caring participants who openly shared their experiences of working with Jo-Anne and their understanding of her condition and support needs.

5.5 LIMITATIONS OF THE STUDY

Time played a large role in the data collection process of this study. Finding time to conduct the interviews was a challenge, as both Jo-Anne, her mother, and the school’s staff have busy timetables. It is felt that some of the interviews were conducted quite quickly due to the
schedules of the participants and longer interviews could possibly have led to richer data being gathered. Additionally, I had to complete this study within a limited period, which restricted the time available for data collection. This narrowed the amount of data that could be collected as only her current educators and therapists were interviewed, and although her background has been considered, the data only reflects eighteen months of Jo-Anne’s life and how her history has affected her current functioning. Should there have been more time available to conduct this study, data could have been collected from additional sources such as past educators and therapists as well as her doctors.

Although Jo-Anne has had short psychological interventions through the form of counselling, she has not had any intensive therapeutic intervention with a psychologist. It is felt that should Jo-Anne have had such an intervention, the data gathered from a psychologist could have had allowed for a richer description of the social-emotional needs Jo-Anne experiences and this could be an area for further study in the future. However, despite this limitation, the information gathered from Jo-Anne, her mother, educators and physiotherapist did lead to adequate understanding of Jo-Anne’s social-emotional needs.

5.6 RECOMMENDATIONS

This section will provide suggestions for further research while also making recommendations regarding methods to provide support for learners with CRS and other physical disabilities in a special school environment.

(a) Suggestions for future research

This study considered the support needs of Jo-Anne, a girl with CRS. Despite her early neglect and lack of care, she currently lives with a foster mother who has shown exceptional support and care in ensuring that all of Jo-Anne’s support needs are met as far as possible. The financial status of this family has in part assisted in meeting Jo-Anne’s support needs. It would be interesting to compare the support needs and coping skills of a child with CRS in Jo-Anne’s socio-economic group with a child in a lower socio-economic group. Such a study would shed light on the role family support and resources play in terms of identifying and meeting support needs, as well as in the development of effective coping skills. It would also give insight into the type of resilience individuals with disabilities may develop based on the type of supports they experience.
An additional area for future research is further in-depth research into the social-emotional support needs of individuals with CRS. Although this study identified some social-emotional needs, I believe this is just the tip of the iceberg in terms of understanding the complexities of social-emotional development for individuals with physical disabilities. This study has shown the profound effect having a disability has on social-emotional development and in order to support disabled clients adequately in terms of mental health, it is vital to have a sound understanding of the social-emotional needs experienced by this community.

Research into the systemic and societal feelings towards the disabled community and the effects on support needs and coping skills of disabled individuals would also be valuable. Societal and systemic research of this nature would give insight into how the broader community may be able to provide support to individuals with physical disabilities, as well as creating an understanding as to how the community could add to the support needs of a disabled person.

A longitudinal study that follows Jo-Anne into adulthood is also recommended, as this would give better insight into how support needs change throughout the life stages, based on the different environmental, developmental, physical, emotional, and social demands. This type of study would also indicate where and how support needs are met in later life when Jo-Anne has left the schooling environment, which provides support to many of her needs. As well as showing the effect of leaving the safety of being in an environment specifically for disabled individuals that possibly minimised her feelings of being different.

(b) Recommendations for special schools catering to physically disabled learners

This study showed that there is a gap in knowledge in Jo-Anne’s school in terms of the understanding different disabilities. The therapists in the school have almost expert knowledge in the disabilities they are treating; however, the educators appeared to have a lack of specialised knowledge in terms of the various disabilities and their effect on learning. In a special school, understanding the diagnosis will have important repercussions in the classroom, as it will give insight into the social-emotional and cognitive limitations of each learner. This knowledge will also assist educators in making appropriate classroom accommodations based on physical needs, and knowledge on the disability should guide the development of Individual Support Plans (ISP). It is strongly recommended that educators receive assistance to increase their knowledge on a child’s disability through training and information sharing with therapists and medical professionals, as this plays a vital role in the learning experience of the
The development of ISP’s can be used to document information on the disability such as necessary physical supports, common social-emotional and cognitive needs and long-term prognosis. This document can follow the learner through the different grades and phases and can be used to assist teachers in understanding the child and how best to provide support.

It is recommended that schools should provide support and psycho-education to parents and caregivers. Sadly, many parents in South Africa will have limited understanding around their child’s condition due to language barriers or lack of education. Parents may be in denial about their child’s condition or have feelings of shame and guilt. The school can be a valuable source of support and education for parents offering parent support groups and informative talks at parents’ days. The school is often a source for parents to be matched with appropriate social service workers in order to get support, such as assistance to apply for grants.

This study has shown the important role families play in helping disabled children cope with their disability. However, when parents are unsure about the diagnosis or experience difficulty accepting the diagnosis, the disabled child is not going to receive the family support needed in order to develop coping skills. Therefore, the school has an important role to play in supporting and educating parents in order to support learners.

The district can become involved in assisting schools to provide support and guidance for parents through the provision of resources such as posters, video-clips, and human resources by linking schools with relevant support organisations like the association for the physically disabled. The district could also assist in meeting the support needs of disabled learners by providing guidance and training on how to adapt the curriculum appropriately and how to implement differentiated teaching methods in a classroom with diverse needs and abilities.

A final recommendation is that the wider community, surrounding special schools, should be invited to visit the school and interact with the learners. This could help to foster a supportive community environment for disabled learners by increasing the knowledge and understanding the community has towards individuals with a disability. This lack of knowledge creates stigma and fear when interacting with those who are disabled, while also increasing the experience of being different and lesser, which is often felt by the disabled community.
5.7 CONCLUDING REMARKS

This study explored the support needs of Jo-Anne, a fourteen-year old girl with caudal regression syndrome. The way in which her needs were met in her special school environment was also explored and this led to the identification of areas where further support could be provided.

The role of additional factors, such as comorbid diagnoses, family and the school environment, play in the identification and presentation of support needs was identified and this became an integral factor in understanding Jo-Anne’s support needs. Although there were limitations identified in this study, it is felt that the data gathered was an accurate representation of Jo-Anne’s experiences. It can be concluded that Jo-Anne has various physical, social-emotional, and academic support but these needs have developed out of an interaction between many factors and are not only the result of having caudal regression syndrome.

I am grateful to Jo-Anne and her foster mom for allowing me the opportunity to use Jo-Anne’s experiences to generate a better understanding of caudal regression. It is my hope that this study has been an accurate and respectful representation of Jo-Anne’s case and that this study will lead to increased knowledge around this rare condition.

This research has also been a journey of personal growth and development. I have learnt that to always value the important role context plays in all aspects of life and that no feature of a person can be looked at and understood in isolation, as there are so many factors playing a role in determine the functioning, development, and needs of the individual. This study has also caused to me to consider how valuable my health and physical ability is, I often take for granted, and how lucky I am to have never had to experience even one day in the world of a disabled individual.

To conclude this study, I would like to share my admiration for Jo-Anne and the resilience and inner strength she portrays. She is such an inspiration to me and many others. She has truly taken all the difficulties life has thrown at her in her stride. I will be forever grateful that she allowed me to share her story through this study.
REFERENCES


Department of Basic Education. (2014). Policy on screening, identification, assessment and support. Pretoria: Department of Basic Education.


96


APPENDIX A: ETHICAL DOCUMENTATION

Ethical clearance letter from the University of Johannesburg

Example of ethics document used to gain participant consent and assent

Plagiarism evaluation from TurnIt In

Signed affidavit

GDE Research approval letter
ETHICAL CLEARANCE LETTER FROM THE UNIVERSITY OF JOHANNESBURG

Dear MJ Edmonds

Ethical Clearance Number: 2014-047

Re: The support needs of a learner with Caudal Regression Syndrome in a special needs school.

Ethical clearance for this study is granted subject to the following conditions:

- If there are major revisions to the research proposal based on recommendations from the Faculty Higher Degrees Committee, a new application for ethical clearance must be submitted.
- If the research question changes significantly so as to alter the nature of the study, it remains the duty of the student to submit a new application.
- It remains the student's responsibility to ensure that all ethical forms and documents related to the research are kept in a safe and secure facility and are available on demand.
- Please quote the reference number above in all future communications and documents.

The Faculty of Education Research Ethics Committee has decided to

☑ Grant ethical clearance for the proposed research.
☐ Provisionally grant ethical clearance for the proposed research
☐ Recommend revision and resubmission of the ethical clearance documents

Sincerely,

[Signature]

Prof Geoffrey Lautenbach
Chair: FACULTY OF EDUCATION RESEARCH ETHICS COMMITTEE
11 August 2014
PLAGIARISM EVALUATION FROM TURNIT IN

Minor dissertation

2% SIMILARITY INDEX  2% INTERNET SOURCES  1% PUBLICATIONS  1% STUDENT PAPERS

1. Submitted to Central Queensland University 1%
2. ecp.eu <1%
3. medicalmantra.com <1%
5. uir.unisa.ac.za <1%
6. libserv5.tut.ac.za 7780 <1%
7. www.lbima.org <1%
8. www.se-cure.ch <1%
9. www.mern.ca
SIGNED AFFADAVIT

Annexure A

AFFIDAVIT: MASTER’S AND DOCTORAL STUDENTS TO WHOM IT MAY CONCERN

This serves to confirm that I, Megan Tuyk Edmonds

ID Number: 8112500071-81
(Full Name(s) and Surname)

Student number: 250516825

Qualification: MEd Psychology

Faculty: Education

Hereewith declare that my academic work is in line with the Plagiarism Policy of the University of Johannesburg which I am familiar with. I further declare that the work presented in the minor dissertation (or corresponding work) is authentic and original unless clearly indicated otherwise and in such instances full references to the source(s) acknowledged and I do not pretend to receive any credit for such acknowledged quotations, and that there is no copyright infringement in my work. I declare that no unethical research practices were used or material gained through dishonesty. I understand that plagiarism is a serious offence and that should I contravene the Plagiarism Policy notwithstanding signing this affidavit, I may be found guilty of a serious criminal offence (perjury) that would amongst other consequences compel the UJ to inform all other tertiary institutions of the offence and to issue a corresponding certificate of reprehensible academic conduct to whomever requests such a certificate from the institution.

Signed at Brackenhub on this 30th day of November 2015.

Signature

Print name: Megan Tuyk Edmonds

STAMP COMMISSIONER OF OATHS

Affidavit certified by a Commissioner of Oaths

This affidavit conforms with the requirements of the JUSTICES OF THE PEACE AND COMMISSIONERS OF OATHS ACT 16 of 1963 and the applicable Regulations published in the GG NAR 1258 of 21 July 1972, GN 803 of 16 July 1998, GN 105 of 2 February 2001 as amended.

Bracken Gardens COUNTER
30 Nov 2015
2
1452

[Stamp]
GDE RESEARCH APPROVAL LETTER

Date: 17 April 2015
Validity of Research Approval: 17 April 2015 to 2 October 2015
Name of Researcher: Edmonds M.J.
Address of Researcher: 68 Van Bergen Street; Brackenhurst; Alberton; 4118
Telephone / Fax Number/s: 072 296 0161
Email address: megedmonds87@gmail.com
Research Topic: Support needs of a learner with Caudal Regression Syndrome in a special needs school
Number and type of schools: ONE LSEN school
District/s/HO: Johannesburg East

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved. A separate copy of this letter must be presented to the Principal, SGB and the relevant District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted. However participation is VOLUNTARY.

The following conditions apply to GDE research. The researcher has agreed to and may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

CONDITIONS FOR CONDUCTING RESEARCH IN GDE

1. The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter;
2. A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB);

[Signature]
2015/04/20

Office of the Director: Knowledge Management and Research
9th Floor, 111 Commissioner Street, Johannesburg, 2001
P.O. Box 7710, Johannesburg, 2000 Tel: (011) 355 0506
Email: David.Makhado@gauteng.gov.za
Website: www.education.gpg.gov.za
3. A letter/document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned;

4. The Researcher will make every effort obtain the goodwill and cooperation of all the GDE officials, principals, SGBs, teachers and learners involved. Participation is voluntary and additional remuneration will not be paid;

5. Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal and/or Director must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage;

6. Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year;

7. Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education;

8. It is the researcher’s responsibility to obtain written parental consent and learner;

9. The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources;

10. The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations;

11. On completion of the study the researcher must supply the Director: Education Research and Knowledge Management with one Hard Cover, an electronic copy and a Research Summary of the completed Research Report;

12. The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned; and

13. Should the researcher have been involved with research at a school and/or a district/head office level, the Director and school concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

Dr David Makhado

Director: Education Research and Knowledge Management

DATE: 20/04/20
APPENDIX B: EXCERPTS FROM INTERVIEW TRANSCRIPTS AND FIELD NOTES

Excerpt from interview with Jo-Anne
Excerpt from interview with Bronwyn
Excerpt from interview with Laura
Excerpt from interview with Natasha
Excerpt from interview with Fred
Excerpt from field notes for Jo-Anne 2

11 Pseudonyms have been used in the interview transcripts to protect the identity of the participants
EXCERPT FROM INTERVIEW WITH JO-ANNE

Megan: Okay alright, okay, so if we had to say, you need – you want some more support with school stuff, okay, and then you don’t have a lot of other needs at school, so you don’t have a lot of physical needs or emotional needs. So how do you think the school is helping you meet these needs?

Jo-Anne: Sometimes the teacher would ask me if I “understand” what’s going on, and I go to physio, but sometimes I get a leg ache and then I have to exercises. Mam Laura is just a little bit overboard, she pulls my leg a bit too much.

Megan: Oh, so she can sometimes be a bit –

Jo-Anne: Violent.

Megan: Okay, so for the physical stuff the school helps by having physio?

Jo-Anne: Yes.

Megan: And did you – I know you’re not having OT now, but did you like having OT? Did you think it helped?

Jo-Anne: Yes.

Megan: What things did it help you with?

Jo-Anne: Sometimes I’ll work on computers, you do maths and sometimes they would ask me questions, if I need help at home or anything.

Megan: Okay and do you feel – in what ways do you feel the school provides some social support?

Jo-Anne: No, I don’t know that one – on break you can sit with your friends and your friends can help you express anything like you can – if class was frustrating and then on break is the time when you can complain to your friends and ask them if they agree with you and things like that.

Megan: Okay, so the main thing the school does for social support is that you get to have break time with your friends?

Jo-Anne: Yes.

Megan: Do they do other social things or fun things at school?

Jo-Anne: Some – we do have fun days at the beginning of the year.

Megan: Okay and how is the fun day?

Jo-Anne: It’s active and busy, as we’re – you’re swimming and athletics.

Megan: Okay, so it’s a nice active day with your friends.

Jo-Anne: And then also every second year we have a concert or a show.

Megan: Okay.

Jo-Anne: In grade five we had a concert, and I think this term we going to have a talent show or something.
EXCERPT FROM INTERVIEW WITH BRONWYN

Megan: Okay and then she also mentioned to me that she gets “pains” in her joints if she sits for long, is that quite common or –
Bronwyn: It’s actually very common in wheelchair users, but most people don’t experience it as pain, they experience it as ‘discomfort’ and they get spasms and things, because she’s got sensation she gets with more pain
Megan: Yes.
Bronwyn: She also has a little bit of arthritis in the hip where they operated, there is a bit more pain there than there should be.
Megan: Okay.
Bronwyn: So Physio – when it gets – if it gets bad then physio helps, but they say it is not interfering at all, it’s fine.
Megan: Okay.
Bronwyn: When she was younger she used to have gnawing pain in her leg all the time, but it’s not there anymore.
Megan: Okay and what kind of thoughts or feelings does the caudal regression bring up in you?
Bronwyn: To me it’s just, it’s a fact, and when people say, but oh, you must do this and you must do this so that she can walk. She can’t, she’s got – there’s no connection between the pelvis and spine, so it’s not a possibility. And then a little bit of the frustration with the biological parents because one of your – there is no direct cause or things with caudal regression, but there is a very high incidence amongst diabetic mothers, and with the diet of alcohol and drugs you are not – you food is not optimal so you’re going to get the same presentation. And some of her issues at school, her cleft palate are all related to the foetal alcohol syndrome, but you do sometimes get cleft palate with caudal regression, but rarely, it’s more likely to have issues with kidneys and other things.
Megan: Ja.
Bronwyn: Whereas she does have – she has ADD, she’s Attention Deficit Disorder not with hyperactivity, and then the cleft palate and those are very much – that’s related to the fetal alcohol. So it’s just a – not an anger with her mother, just the frustration that she didn’t realise and she didn’t even know that she – you know, just went into it.
Megan: Ja.
Bronwyn: My feeling is, this is what you’ve got, whatever you can do with what you’ve got that’s what you build on and you go ahead.
Megan: Yes.
Bronwyn: But also because using a wheelchair, in my line of work in my circles that I move in is not an abnormality.
EXCERPT FROM INTERVIEW WITH LAURA

Megan: How do you feel as a school, so not necessarily just the physio section, if you had to give your opinion of entire team, how do you feel that you’re able to meet the various support needs that Jo has? Or do you think it is adequately able to meet the different needs?

Laura: I think the school has most of the services in theory she needs. Unfortunately one of the problems at her school is that in theory and in practical it is not always the same thing. For instance maybe in Jo’s condition it would have been a good idea to have more hydrotherapy sessions, something like that, and in the end have to just – I mean you can only do what you can do. And what you can do for that person is sort of dependent on what you have to do for other people, but the school has got the academic side and staff who certainly can deal with her needs there, I think – and although I’m not very sure about the academic background, I think any needs there should theoretically be able to be met by the school. So the school has physiotherapists or offer physio therapy services and OT which from a physical and functional point of view should be able to meet all her needs.

And I – Jo is very lucky that she has a foster mom that really does a lot, because if Jo was still in a bad socio economic background things probably would have been a lot worse, especially with her specified group of disabilities maybe would lead to her – the condition deteriorating, but being with Bronwyn certainly is an advantage with her, because between having the physio and the OT, and having access to the best possible mobility aids and adjunctive therapies, or not therapies but activities, ja, I hardly think there are any sort of physical functional needs that cannot be met. As I say, thank God for Bronwyn, because otherwise it may not have been adequate what the school can provide. There is the speech therapy service that has been offered and I’m not quite sure how well will speech therapy with a repaired cleft palate work. I know there’s a stage where everything that could be done is done and I will presume Jo is now there. There is a – the school does offer a psychology service, the school has access to – the school also offers nursing services. The school has access to social services. One of the big problems with the school setting, which is a government supported structure, is that one does have potentially staff shortages and overwhelming workload and that impacts on the ability to meet a specific single child with all their support needs. So in theory since she started here all her needs should have been able to be met. In practice unfortunately that is dependent on the staffing issues and workload issues.
EXCERPT FROM INTERVIEW WITH NATASHA

Megan: Okay, what is your understanding of Jo’s condition, the caudal regression syndrome?
Natasha: I know she doesn’t have the use of her legs, and that it is from her spine that it comes from, but I have to say that she is a very, how can I put it? Her condition doesn’t affect her very much, she’s very mobile. Yes, she is in a wheelchair but you know, I don’t know if you’ve seen her walk on her hands before.
Megan: I haven’t, but she has told me.
Natasha: Ja, she is — that girl is amazing, she is like super strong. She can do pull-ups, she can walk on her hands as I’ve said, handstands all of those things. So her disability doesn’t affect her very much. I know she also has a speech problem, I don’t know if it is part of the disability that she has, or if it is a separate thing.
Megan: Ja.
Natasha: We usually just read up on a lot of conditions if it really affects the child badly so that you know how to handle that child, but I mean if they are coping so well, ja.
Megan: Ja, okay. So basically with her condition is that she doesn’t have the use of her legs and that her spinal cord isn’t fully developed. So if you had to look at her and look at her condition as a whole, does it bring up any thoughts or feelings inside of you that could be positive or negative?
Natasha: I just think it is very admirable what she does and how she copes with her condition. I don’t think a lot of people would have coped with it that well, and she — I don’t know if she hides very well, but she never shows any negative signs of her condition.
Megan: Okay. Are you aware of any unique support needs that Jo has? And they can be any kind of support needs, so related to academic or her physical development, or emotions, anything where you have identified she requires support.
Natasha: I have heard from her mother the other day, at the parents meeting she told me that Jo is at the moment, this very moment very emotional, but as I said she “hides” it very well.
Megan: Ja.
Natasha: I didn’t even notice that. And I said to her mother as well, she must tell me because then I can help her. I noticed last term that she wasn’t working which was very odd because she always works. She wasn’t really working and focusing on other things, and at first I thought it was boys because girls are like this at that stage. And then her mother told me “no” that it is about her biological family and that they are having a lot of issues with them. So ja, as far as I know she is seeing some or other psychologist or counsellor or something at the moment. She didn’t really elaborate, and then the other therapy I think she gets physio. At the moment there is no speech therapy because we are waiting for another speech therapist, which I do think she needs as well.
EXCERPT FROM INTERVIEW WITH FRED

Megan: So for you as a teacher would you say having a sound understanding of their diagnosis would impact how you work with them in the class, or does it not really play a huge role?

Fred: No it does definitely. You have to be aware of what the problems are and as any teacher should do you should plan around that to be able to help them cope in class as well with what their problems are. Ja, so in that class there’s really a big variety of disabilities and I don’t think she is in a position where she really needs assistance maybe, no, I think she copes well enough at this stage as long as everything goes fine then –

Megan: Yes, not too many changes.

Fred: Ja, because that can be a big problem.

Megan: Okay and just from your short time working with Jo, because I know it has only been these two and bit terms, have you seen any unique support needs that she has? And it can be in any aspect, so physically, emotionally, socially and academically.

Fred: Ja look, socially I think things are going better now as I’ve said. Academically I think she’s on par at the moment, I don’t know if she needs, as I’ve said you know like some children needs an assistant, I don’t think she needs that, I think she is strong enough to cope with that. Socially again it depends on what is happening at home. I think that has got a big influence.

Megan: Ja.

Fred: But socially I think at the moment she’s going up, she is improving really. What was the other one I can’t remember what it is?

Megan: Emotionally.

Fred: Emotionally, ja, I think emotionally she might need a bit of support. In class she’s – I don’t know if she is scared of me or whatever, she shouldn’t be, but she’s quite quiet you know, she only really reacts if you address her personally. I think she might need some support for things that have happened in her life and whatever to deal with it a bit more. I really think so, that’s my point of view.

Megan: And do you think that has more to do with her background, and that her background has been troubled than with her diagnosis?

Fred: Ja, that’s an interesting question. I think it might be more on the background, that’s the way I would see it, ja, more and more on the background. I personally don’t know, you know, I’m not a medical person and how the disability itself what influence that can have. So I don’t think I want to give comment on that really.

Megan: So in terms of her whole range of support needs, so her physical, her emotional and her social, how do you feel the school is able to meet those needs?

Fred: I think it provides a lot, look, you yourself knows that we do have all the different therapies here which can cover most of those things. I can’t remember, she’s not in the hostel?

Megan: Uh-uh.

Fred: No. So ja, I think in the class I hope so, that in most of the subjects – sorry, that she – that they have they should get enough support there. There might be one or two little hiccups here and there, we all know that all the teachers are not the same, they don’t teach the same.
Jo-Anne was asked to create an artefact to share her experiences of having CRS. She chose to do some creative writing. Jo-Anne was unsure about where to begin, I suggested she think about what she would want people to know about herself and her condition.

Jo-Anne’s experience around creating her artefact
Jo-Anne felt that writing the story let her feel like she was being herself. She wanted to story to have a positive feeling. The story is directed at someone who is disabled, these are the things she would want someone else to know.

What she shared in the story are things that she has learnt “along the way”, no one has ever shared things similar to this with Jo-Anne.

Jo-Anne’s thoughts on whether or not it is difficult to put herself in a positive frame of mind
It can be difficult sometimes, especially during times when there is a lot of noise as this is overwhelming.

Situations that cause Jo-Anne to feel different or “not normal”
Jo-Anne shared that she has felt this way around some of her friends in the past. These feelings have changed because she has come to realise the only thing that is different between herself and her friends is the fact that she cannot walk.

The importance of keeping busy and begin active
Jo-Anne’s likes to keep busy and active because these activities are fun and relaxing. It does not matter if she is good at these activities, Jo-Anne participates for the enjoyment and to be with her friends.

Jo-Anne’s views on not being able to walk
There isn’t really a difference between being in a wheelchair and her friends who are able to walk.

However not being able to walk has been difficult for Jo-Anne and it is sometimes difficult to be positive about this aspect of her disability. This is especially because she wants to be able to run like the other children. But at school if her friends play a running game she will join in using her wheelchair.

When Jo-Anne was younger she felt some shame around not being able to walk. When she was at her old school because it was a school for able-bodied people, At her previous school she felt different.

How Jo-Anne would handle stations where people make her feel different
When Jo-Anne feels different she would try to explain to people that they have upset her and that have been rude to her.

She would prefer not to explain to people what her disability is about or how she feels about being in a wheelchair.

Form of self-expression
Positive focus on having a disability
Possible need for guidance from other disabled individuals
Not always easy to stay positive
Situations that cause her to feel abnormal
Positive understanding of her disability helped feelings of inadequacy
Keeping busy & being active helps with stress
Emotional and social needs due to paralysed, including difficulty with social participation
Learnt to participate in different ways (using upper body)
Acceptance of environment impacts emotional need due to disability
Prefers to keep feelings about disability private
APPENDIX C: ARTEFACT AND VISUAL DOCUMENTS

Copy of Jo-Anne’s artefact

Visual documents: photographs of the school’s physical environment
My story on being disabled

Hi today, I am going to tell you about having a disability is normal to me but sometimes, you feel ashamed because you can’t walk and you feel like you can’t do anything except sit around in your wheelchair. NO! You are normal, trust me. I am also disabled but that doesn’t stop me. I can do a lot of activities, dancing, cooking, being active keeps the worrying and stress off my mind. And so can you. We are all different but unique. I am a 14-year-old girl who understands some of your other friends, who can walk, make you feel sad, but forget about them; you are more able than them.
VISUAL DOCUMENTS: PHOTOGRAPHS OF THE SCHOOL’S PHYSICAL ENVIRONMENT

Wheelchair ramps making the school wheelchair accessible

Double doors create enough width for wheelchairs to pass through
Swinging double doors creating easy access for wheelchair users in the bathroom

Bathroom with screen and chair to create space for wheelchair and catheterisation
APPENDIX D: EVIDENCE OF DATA ANALYSIS

Table showing issues arising from preliminary data analysis
Table of themes, codes and relevant data
Example of the member checking documents sent to participants
TABLE SHOWING ISSUES ARISING FROM PRELIMINARY DATA ANALYSIS

<table>
<thead>
<tr>
<th>Interview with Jo-Anne</th>
<th>Interview with Bronwyn (Foster mother)</th>
<th>Interview with Laura (school physio)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before beginning the interview, I explained the purpose of the interview and the study. I went through the ethics document with Jo-Anne and her foster mother, Bronwyn. The ethics document was signed by Jo-Anne and Bronwyn. The interview was conducted at the offices of Bronwyn.</td>
<td>Before beginning the interview, I explained the purpose of the interview and the study. I went through the ethics document with Bronwyn. The ethics document was signed by Bronwyn. The interview was conducted at the offices of Bronwyn.</td>
<td>Before beginning the interview, I explained the purpose of the interview and the study. I went through the ethics document with Laura. The ethics document was signed by Laura. The interview was conducted at the school in physiotherapy department.</td>
</tr>
<tr>
<td>• Issues around being different and fitting in</td>
<td>• Impact on physical structure of body, incomplete spinal development and small torso</td>
<td>• Compounding factors cannot be separated from the diagnosis such as background and socio-economics</td>
</tr>
<tr>
<td>• Impact on physical structure of body, incomplete spinal development and small torso</td>
<td>• Additional factors influencing development of disability (Foetal alcohol syndrome, early neglect, adoption and attention deficit disorder)</td>
<td>• Importance of parental involvement</td>
</tr>
<tr>
<td>• Disability causing an ‘upset’ feeling</td>
<td>• Speech delays</td>
<td>• Although the disorder is unique, the symptoms are not unique and can be seen in various disorders</td>
</tr>
<tr>
<td>• Difficulties with understanding in class</td>
<td>• Influence of life stages-adolescence</td>
<td>• Physical disabilities are choice limiting- impacting school selection, social life and career choice</td>
</tr>
<tr>
<td>• Issues around managing temper</td>
<td>• Issues around identity development</td>
<td>• Limitations of a government school in terms of resources influencing support (socio-economics of macro-system)</td>
</tr>
<tr>
<td>• Importance of being able to express and release emotions</td>
<td>• Issues around self-esteem and insecurities</td>
<td>• Physical elements influence emotional support needs-feelings around colostomy and catheters, being in a wheelchair and speech impediments</td>
</tr>
<tr>
<td>• Importance of having an active lifestyles</td>
<td>• Disability limits life choices such as school selection</td>
<td>• Physical factors influence social support needs in terms of romantic relationships</td>
</tr>
<tr>
<td>• Issues around having a catheter-embarrassment</td>
<td>• Issues around interactions with mainstream society</td>
<td>• Support needs may change according to life stages</td>
</tr>
<tr>
<td>• Issues around being wheelchair bound and physical restrictions</td>
<td>• Influence and role of educators</td>
<td>• Influence of context and background in forming friendships</td>
</tr>
<tr>
<td>• Physical pain in legs</td>
<td>• Need to express emotions</td>
<td>• School offers numerous support services- speech therapy, physio, OT, nursing services and psychological services</td>
</tr>
<tr>
<td>• Cleft palate impacting speech</td>
<td>• Need for physical support which is met through physiotherapy</td>
<td>• Issues around being in a protected special needs</td>
</tr>
<tr>
<td>• Influence of the environment and context on experiences and coping</td>
<td>• Lack of emotional support within the school</td>
<td></td>
</tr>
<tr>
<td>• Issues around self-esteem and self-defeating thoughts</td>
<td>• Influence of environment and context on social self</td>
<td></td>
</tr>
<tr>
<td>• Influence of life stages-adolescence</td>
<td>• Issues around catheterisation and bladder and bowel functioning</td>
<td></td>
</tr>
<tr>
<td>• Mobile despite being paralysed</td>
<td>• Issues around physical restrictions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Numerous surgeries</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Issues around stress and managing stress and change</td>
<td></td>
</tr>
</tbody>
</table>
### Interview with Fred (Head of Department)
Before beginning the interview, I explained the purpose of the interview and the study. I went through the ethics document with Fred. The ethics document was signed by Fred. The interview was conducted at the school in Fred’s office.

- The focus in classroom is ability/asset based
- Unsure of the condition
- Understanding the diagnosis of a learner is important for teachers to have for planning purposes
- School offers various support services
- H.O.D guides and supports educators in order to ensure learners are supported
- School offers training to educators on common disabilities
- Issues around lacking parental involvement impacting learner support
- Emotional impact of disability depends on ability to cope with disability
- Social support needs may be linked to the impact of disability on future capabilities
- Issues around moving from sheltered environment to mainstream society- adjustment generally good
- Background and family context impact academic performance
- Influence of life stages- adolescence

### Interview with Natasha (educator)
Before beginning the interview, I explained the purpose of the interview and the study. I went through the ethics document with Natasha. The ethics document was signed by Natasha. The interview was conducted at the school in a spare office.

- Mobile despite being paralysed
- Strong upper body
- Educators research conditions less if child is coping well
- Emotions can impact academic performance
- School provides support in terms of different therapies
- School is wheelchair accessible
- Jo-Anne copes well and has a positive outlook
- Issues around body image and self-esteem
- Issues around boys, dating and relationships (life stage) and the impact of having a disability
- Issues around peer pressure
- Issues around a lacking father figure
- Should cope well in mainstream society
- Impact of home environment and family context in terms of support and coping skills

### Issues arising from Jo-Anne’s artefact and discussion
Before beginning the session, Jo-Anne was given a choice of different creative mediums. She chose to do some creative writing. The instruction was to create something showing her experiences or what she wants others to know.

- Overall positive outlook on disability
- Issues around feeling different
- Issues around being unable to walk and being in a wheelchair
- Feelings of shame, being less than or not normal
- Importance of being active
- Importance of spending time with friends
- Focus on strengths and abilities
- Disability can make a person unique
- Need for people to understand the experiences of the disabled
- Upper body strength
### TABLE OF THEMES, CODES AND RELEVANT DATA

<table>
<thead>
<tr>
<th>THEMES (TO BE DISCUSSED IN ICE-CREAM CONE)</th>
<th>SUB-THemes</th>
<th>SUPPORTING DATA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical symptoms and support needs</strong></td>
<td>Physical symptoms and needs may change over time</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symptom:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Symptoms individually are not unique to condition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Incomplete spinal development (no sacrum, disconnect between spine and pelvis)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Paralysed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Small torso</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficulty balancing on knees</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hip flexion contracture</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bladder and bowel difficulties</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Underdeveloped lower body (less muscle tone)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Partial sensation in legs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Needs:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Easier to identify than other needs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Needs not unique to condition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Needs and condition appear stable</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Catheter</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Surgeries for bladder &amp; bowel, palate and contracture</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Legs pains especially in contracture</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focus on independent functioning and mobility</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Paralysed therefore mobility and wheelchair are a need</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Previous needs: splints and braces</td>
<td></td>
</tr>
<tr>
<td><strong>Social and emotional support needs</strong></td>
<td>Emotional and social needs more difficult to identify</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Issues around fitting in and a need for acceptance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Issues around seeming younger because of body</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Managing anger</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Feelings of being different</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Impact of physical symptoms &amp; appearance on social self &amp; self-image &amp; self-esteem, ability to participate socially, forming romantic relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Feeling unwanted, environment influences self-image</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Need to have someone to share similar experiences</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficult to be positive at times</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shame associated with being paralysed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Keeps feelings surrounding disability private</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Coping with change</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appears to socially cope well</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional support needs linked to ability to cope with disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disability can impact future social potential</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unsure of quality of social interactions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional &amp; social needs related to cleft palate &amp; bladder bowel issues</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social and emotional needs change over time, may become more prevalent than physical needs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social and emotional needs not unique to CRS</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social factors such as wearing a dress when in a wheelchair</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficulty coping with negative emotions and change (become introverted), at times she struggles emotional difficulty experienced</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Previously needed speech therapy in order to communicate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Socially immature due to neglect</td>
<td></td>
</tr>
</tbody>
</table>
| Academic support needs | Difficulties understanding  
| | Coping with academic challenges  
| | Difficulty working quickly  
| | Concentration  
| | Maths difficulties  
| | Emotional needs impact academic needs  
| | Appears to be ‘average’ academically (Fred)  
| | Various factors impact academic ability  
| | Physical disability impacts academics in that it is choice limiting  
| | Comorbid factors impact academic needs (speech impediment)  
| | Physical symptoms (pain) influence concentration  
| | Family influences academic progress and support  
| | Cognitively immature due to neglect  
| | Stress associated with need to concentrate and perform academically |

| Level of support required | Appears to cope well  
| | Does not need a lot of physical assistance  
| | Condition is rare but physical symptoms common to many disabilities  
| | Condition is easily managed in class |

| COMPUNDING FACTORS | Coping strategies | Friends, learners offer support to one another  
| | Emotional coping strategies (time alone, creative activities, writing stories and poems, break time with friends)  
| | Strong upper body used to mobilise, able to swim  
| | Get out of chair when pain is bad  
| | Positive attitude & focus on what is unique about Jo-Anne  
| | Keeping busy and being active  
| | Appears to cope well, not a ‘push over’  
| | Catheterise herself |

| Co-morbid factors | Cleft palate and influence on speech, potential future surgery  
| | Foetal alcohol syndrome  
| | ADHD |

| Contextual factors | Life stage: adolescence, moving to high school  
| | Influence of biological family: negative impact on social & emotional needs  
| | Influence of foster family: meets support needs (wheelchair), support assists coping, having emotional needs met, creating opportunities for social interactions and providing academic support  
| | Influence of early neglect, poor prenatal care & poor maternal nutrition  
| | Friendships influencing emotional needs  
| | School environment influences social interactions and peers choices, influence of cultural variety, difficulty with socialising due to demographics  
| | Background and family history influences academic ability, friendship selection,  
| | Socio-economics status influences how needs are met  
| | Multiple influences on emotional needs  
| | Influence of personality |

| School meeting support needs | Training to increase staff knowledge for common disabilities and dependent on how learner appears to cope  
| | Various Support services offered: OT, physio, nurses, social services, speech therapy & psychologist  
| | Emotional & physical needs met (Jo)  
| | School meets physical needs (Bronwyn)  
| | Group physio offered when needs decrease  
| | Physio’s needed to treat physical symptom in order to ease academic performance  
| | Educators should provide adequate academic support (Fred) |
| SYSTEMIC FACTORS | Some educators try to clarify issues around sexuality  
School support is adequate (Fred)  
Educators monitor understanding  
Extra murals & sports offered  
Related to individual staff knowledge, experience & skill (school physio independently researched condition, own experience assisted treatment)  
Active fun days  
Art group offered for emotional release  
Strengths based focus in the classroom |
|---|---|
| Support need the school is unable to meet/improve | Lack of training to increase staff knowledge on CRS & other conditions, this knowledge is important  
Need to increase educator empathy  
Need for improved emotional support  
Educators not always aware of learner coping and emotional functioning  
Need to monitor quality of teaching  
Improved communication between home & school  
Need for educator involvement in sports  
Coping strategies not always possible in class (during tests etc.)  
Need to educate parents for academic support  
Need to offer education and support to parents regarding conditions  
Always ways to practically improve support given learner support may need to be supplemented outside of school  
Limitations & constraints of a government school setting  
School is physically accessible but has other limitations (subject choice)  
Need for a new speech therapist  
Educators need more support in class  
Need to prepare learners for integration in mainstream society  
Lack of physical accommodations in classroom for upper body disability |
| Environmental acceptance | Jo is a member of accepting social & sports environments  
Negative side to small special environment (sheltered, limited choices)  
Environmental acceptance impacts feelings of ‘fitting in’  
Some environments make her feel ‘abnormal’  
Special school environment is supportive  
Mainstream environments may not be as accepting as school  
Disabilities are choice limiting  
Environments need to be physically accessible  
Family is fully embedded in a supportive community and community of disabled individuals- allowed for ‘typical life experiences’  
Different communities offer different levels of acceptance |
EXAMPLE OF THE MEMBER CHECKING DOCUMENTS SENT TO PARTICIPANTS

Member checking document for Bronwyn’s interview

The interview was conducted between myself and Bronwyn on 6 July 2015. Before beginning the interview, I explained the purpose of the interview and the study. I went through the ethics document with Bronwyn and the ethics document was signed. The interview was conducted at the offices of Bronwyn.

From Bronwyn’s interview I was able to extract the following information that is relevant to this study.

1. CRS has impacted the physical structure of Jo-Anne’s body, specifically her spine which is not fully developed with no sacrum and this has caused Jo-Anne’s torso to be relatively small. This has also led to Jo-Anne being paralysed but with some sensation in her legs.
2. Additional factors have influenced the course and development of the disability, such as foetal alcohol syndrome, early childhood neglect, being adopted and ADD.
3. Jo-Anne experienced delayed speech development related to neglect and a cleft palate.
4. Life stages, specifically adolescence, impact Jo-Anne’s experiences and feelings associated with her disability.
5. Being disabled complicates issues associated with identity development, self-esteem and insecurities associated with body image.
6. Having a disability has limited the life choices for Jo-Anne such as school selection.
7. Being in a special school, which is a sheltered environment, may hinder Jo-Anne’s ability to cope in mainstream society later in life.
8. The school does not implement strategies to support learners with the above integration into mainstream society.
9. Educators have an important role in supporting disabled learners in school emotionally not only academically.
10. Disabled individuals, especially disabled teenagers including Jo-Anne, need a way to express emotions.
11. Need for physical support which is met at school with physiotherapy.
12. There is a lack in the provision of emotional support in the school and parental education and support.
13. The environment strongly influences the social development of the individual.
14. Jo-Anne is able to manage her catheter but this has taken time, there can be emotional difficulties associated with the use of the catheter.
15. Physical restrictions can be difficult hurdles to overcome.
16. Managing stress and coping with unexpected changes can be difficult for Jo-Anne.
17. Jo-Anne’s academic ability is influenced more by her background and ADD than by CRS.

I, __________________________________, agree/ do not agree with the information presented in this document.

☐ I feel that it accurately reflects my thoughts, feelings and experiences.
☐ I feel that it does not accurately reflect my thoughts, feelings and experiences.

In order to make this document an accurate representation of my views I would like the following changes to be made (use an additional page if necessary):

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

Signed (participant): ______________________  Date: ______________