

UNDERSTANDING AN INVISIBLE DISABILITY


CHIARI I MALFORMATION

By

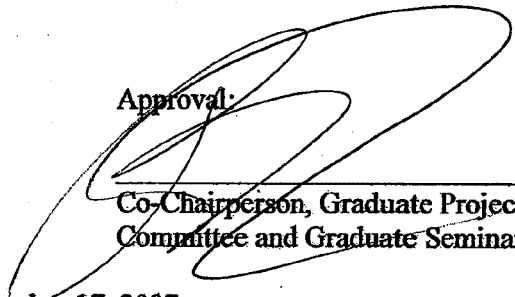
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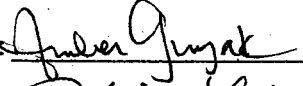
  
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## Dedication

I would like to dedicate this final project to my wonderful family who has stood by my side during my journey:

To my dear husband, Matt, I thank you for your patience, your never-ending support and for all of the sleepless nights spent editing this final project.

To my precious son who has been my constant reminder that it is important to take breaks and play. Without play, our lives lack happiness. Thank you, Graham, for reminding me to play.

To my baby girl who is not much of a baby anymore. I began this master's program right after you were born four and a half years ago. Your daily smiles and hugs were just what I needed to keep me going. Thank you, Grace, for your daily dose of sunshine.

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Running head: Understanding Chiari I Malformation

Understanding an Invisible Disability

Chiari I Malformation

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### Abstract

Through an extensive literature review, symptoms commonly associated with Chiari I Malformation (Chiari) that have the potential to obstruct a student's ability to succeed in an educational environment are identified. To study how these symptoms affect students, twenty-two persons with Chiari were asked to respond to thirty open-ended questions. Responses to the written questionnaire provide insight into the challenges facing students with Chiari and may assist educators in their efforts to develop appropriate modifications and accommodations in Individual Education Plans or Section 504 plans.

## Understanding an Invisible Disability: Chiari I Malformation

### CHAPTER I

#### INTRODUCTION

How do schools service students for a disability that is unknown to not only those in the educational field, but those in the medical field too? Prior to the enactment of the Individuals with Disabilities Education Act of 1997 (IDEA), many disabled children were prevented from having successful educational experiences in regular school programs because their disabilities were undetected. For many with disabilities, much has changed since the enactment of this act. However, children with unique or rare disabilities that are not fully understood, or even recognized, by the medical and educational communities, continue to face an uphill battle to obtain proper services that will allow them to succeed in school. Children with Chiari (pronounced Kee-AR'-ee) I Malformations (CMI or Chiari) and their families frequently fall into this category and face unique challenges that must be overcome to ensure that these children are able to maximize their educational opportunities.

Chiari I Malformation is a neurological disorder which afflicts approximately 1 in 1,000 people, causing debilitating headaches, neck pain, weakness and numbness in the limbs, balance problems, visual disturbances, and a host of other symptoms (C & S Patient Education Foundation, 2005). Symptoms present during infancy, but they may also delay until adolescence or adulthood (National Organization for Rare Disorders (NORD), 2005). “Most people with Chiari look and act normal until fatigue sets in, they overdo it physically, or they experience pressure changes” (Curtacci, 2006).

Students with this condition, like all students, are entitled to a free and appropriate education. *Appropriate* is defined as educational services designed to meet the individual education needs of students with a disability as adequately as the needs of nondisabled students are met (Office of Civil Rights, 1999). An Individualized Education Plan (IEP) or Section 504 Plan will ensure that students with Chiari I Malformation receive appropriate accommodations and modifications so that their educational needs are, in fact, met as adequately as nondisabled students. In order to do so, however, parents, educators, doctors, and students must first understand what Chiari is, how it affects a particular student in a classroom environment, and how non-extraordinary measures can be taken to meet the student's individual educational needs.

#### Statement of the Problem

Research reveals that individuals diagnosed with Chiari face physical and cognitive difficulties that are often unnoticed or misunderstood. These individuals struggle with obtaining the proper treatment and medical care because their symptoms are difficult for others to see and understand. As a result of this, students with Chiari may be deprived of services that meet their individual educational needs as adequately as those provided to nondisabled students.

#### Purpose of the Study

The purpose of this study is to examine, in detail, symptoms commonly associated with Chiari to determine whether they affect a student's educational experience and if so, what accommodations and modifications are needed to maximize these students' educational opportunities. This examination will be based on questionnaires of students

